An Exploration of Older People who 'Call Out' Repetitively in the Acute Hospital

Jessica Louise Beaver

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Abstract

Background

On acute Medicine for Older People hospital wards, staff often care for patients with cognitive impairment who ‘call out’ repetitively. This behaviour, combined with acute hospital admission and busy, unfamiliar staff, can cause serious effects on the quality of care provided for people who call out. Little is currently known about knowledge or beliefs surrounding this behaviour, and how hospital staff and carers respond to it.

Aim

The aim of this study was to explore calling out in the context of the acute hospital. This involved describing calling out, the people who display it (in hospital and after discharge), the way in which others react and respond to it, and people’s knowledge, beliefs, and experiences of calling out.

Method

An ethnographic case-series study was conducted across ten Medicine for Older People wards on two acute hospital sites. This utilised structured and unstructured observations of people who call out repetitively, and records of medical and nursing documentation. Baseline and ongoing measures of calling out, cognitive ability, activities of daily living, pain, depression, and behavioural and psychological symptoms of dementia were undertaken. Semi-structured interviews were conducted with patient participant’s relatives, and hospital staff members. Qualitative and quantitative data were analysed using inductive thematic analysis, and descriptive statistics.

Results

Thirty patient participants were recruited into the study. They scored highly for frequency and severity of calling out. They had poor mobility and functional ability, severe cognitive impairment, and were likely to have delirium. Most were in mild to moderate pain. Most displayed depression, agitation/aggression, anxiety, and apathy. Average length of stay was two and a half times more than for older patients in the United Kingdom in general. A third died within the three-month participation period. 55% of the remaining patient participants were readmitted into hospital. Patient participants were described or observed exhibiting other challenging behaviours alongside their calling out, such as physical aggression.

Calling out was considered by relatives and staff members to be often due to the presence of an unmet need. Many needs were identified, relating to medical and functional biological needs, mental distress, and social relationship needs. However, uninterpretable needs, and the concept of a patient participant having "no needs" also arose, causing staff to sometimes feel that no intervention was required.

Many interventions were observed or discussed by staff or relatives. These were pharmacological (analgesia and psychotropic medication, including sedation) and non-pharmacological (activity, verbal distraction, reassurance, re-orientation, physical comfort, and environment). Barriers to intervention included the context of the acute hospital, staff knowledge and attitudes, and availability of individual patient information.

Conclusions

These findings allow for the better understanding of the cognitive and functional abilities of people who call out repetitively within the acute hospital, and provide a detailed description of the 'problem' of calling out.

The study was feasible to conduct in terms of participation and retention rates; however, new or adapted measures for calling out are required, to be able to detect more subtle and immediate changes in calling out, should an intervention study be conducted.

Hospital care for patients who call out repetitively is complex. The unmet needs model is useful for cases where needs are straightforward to understand or interpret. However, it falls short in more complex cases; such as patient feelings of existential distress, impractical communications of need, or insufficient resources available to either discover or help with the need. Staff feelings of futility are theorised to be due to generative mechanisms of a want to protect professional identity and personal morality.

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List of Abbreviations

ADL	Activities of Daily Living
BI	Barthel ADL Index
BPSD	Behavioural and Psychological Symptoms of Dementia
CFAS	Cognitive Function and Ageing Studies
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
CMAI	Cohen-Mansfield Agitation Inventory
CMAI-D	Cohen-Mansfield Agitation Inventory- Daily
CQC	Care Quality Commission
CSDD	Cornell Scale for Depression in Dementia
DME	Department of Medicine for the Elderly
DRS-R-98	Delirium Rating Scale- Revised- 1998
DsD	Delirium superimposed on Dementia
FAB	Frontal Assessment Battery
FTLD	Frontotemporal Lobar Degeneration
HCOP	Healthcare of Older People
ICD	International Classification of Diseases
MDT	Multi-Disciplinary Team
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NPI	Neuropsychiatric Inventory
NPI-NH	Neuropsychiatric Inventory- Nursing Home Version
PAINAD	Pain Assessment IN Advanced Dementia
PAS	Pittsburgh Agitation Scale
PAS-AV	Pittsburgh Agitation Scale- Aberrant Vocalisations
PPI	Patient and Public Involvement
PWD	Person living With Dementia
WHO	World Health Organisation

Impact and Achievements

Invited Talks and Conference Presentations

"*An Exploration of Older Patients in the Hospital who 'Call Out' Repetitively*" at the 33rd International Conference of the Alzheimer's Disease International (ADI), McCormick Place, Chicago: USA, July 2018

"*Older Patients who 'Call Out' Repetitively in the Acute Hospital: A Focus on Palliative Care?*" at the Palliative Care Student Conference, The Orchards, University of Nottingham: England, June 2018

"*Older People who 'Call Out' Repetitively in the Acute Hospital*" at the CLAHRC 3-Minute Thesis Competition, Institute of Mental Health, Nottingham: England, June 2018

"*Older Patients who 'Call Out' Repetitively in the Acute Hospital: Towards a Useful Intervention*" at the British Geriatric Society Spring Meeting, Nottingham Conference Centre, Nottingham: England, April 2018

"*Repetitive Vocalisation in People with Dementia*" at the Palliative Care PPI Meeting, School of Health Sciences, Nottingham: England, June 2016

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Chapter 1

Introduction and Background

1.1 Introduction

The prevalence of dementia has increased steadily with the ageing population, and will continue to do so in the coming decades. Most people with dementia will exhibit behaviours that challenge (Jost and Grossberg, 1996) with calling out repetitively seen as one of the most disruptive (McMinn and Draper, 2012). People living with dementia are more likely to be admitted to the acute hospital, due to comorbidities, and susceptibility to infections and falls (Natalwala et al. 2008). They may have delirium complicating their dementia, causing further confusion and disorientation (Siddiqi et al. 2006). Hospitals can be distressing environments for people with dementia, and staff can find it difficult to care for patients who exhibit challenging behaviours, hindering the delivery of person-centred health care (Clissett et al. 2013). This thesis reports research on cognitively impaired older people who call out in the acute hospital. This chapter gives an overview of the background to the research; and describes dementia and delirium, behaviours that challenge, acute hospitals, and person-centred care. It will finish with a justification for completing this research, and an outline of the structure of the thesis.

1.2 Key Definitions

This section provides definitions required to understand some of the terms used in this thesis.

Acute care is a branch of health care where a patient receives short-term treatment for a severe injury or episode of illness, such as an urgent medical or psychiatric condition, or during recovery from surgery (Hirshon et al. 2013).

Whereas, a general hospital is a non-specialised health care institution, treating patients suffering from many kinds of disease and injury, but usually specifically excluding mental healthcare (Khan, 2012).

Behaviours that Challenge and Behavioural and Psychological Symptoms of Dementia (BPSD) [1] represent non-cognitive symptoms and behaviours occurring in people with dementia. These can include agitation, overactivity, restlessness or motor retardation, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes.

Calling out is a persistent and usually disruptive vocal noise-making behaviour (Doyle et al. 1997). It is recognised by clinicians in the United Kingdom as 'calling out' or 'shouting out'. Examples of calling out include persistently shouting 'Help me! Help me!' for a number of hours despite staff attempts to intervene, and constant vocalisations of the patients' stream of consciousness (Goldberg et al. 2014). It is also known as repetitive vocalisation, disruptive vocalisation or verbal agitation.

Cognitive impairment is a general term which describes difficulties with attention, concentration, memory, and problem solving (Barker and Board, 2012). It can refer to dementia, delirium, delirium superimposed on dementia (DsD), or any other condition that causes problems with a person's attention, concentration, and memory.

Delirium is an acute disorder of cognition and attention (Oh et al. 2017). It is usually reversible, comprising of a series of dysfunctions that may appear similar to dementia. These include cognitive, attentional, arousal, motor, sleep, perceptual, delusional and emotional disturbances (WHO ICD-10, 2016). *'Delirium Superimposed on Dementia' (DsD)* is a term for delirium occurring in people with underlying dementia (Fick and Foreman, 2002). Dementia is the strongest risk factor for delirium. Delirium occurs in half to two-thirds of people with dementia in the hospital (Siddiqui et al. 2006).

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[1] The nomenclature of 'BPSD' is controversial, as it attributes the behaviours to the dementia, rather than the environment, relationships and communication that the person experiences. Behaviours that challenge and BPSD can also be referred to as 'distressed' behaviour, or 'responsive' behaviours.

Dementia is a chronic and progressive neurological syndrome involving the deterioration of cognitive abilities such as memory, communication, and reasoning; affecting activities of daily living (WHO ICD-10, 2016). Dementia is diagnosed if symptoms persist for more than six months, and if there is no other explanation for the cognitive impairment.

Person-Centred Care is a philosophy of health care, built around the needs of the individual. It promotes the delivery of individualised care for patients, and is tailored to the patients' personal needs and preferences (Fazio et al. 2018).

1.3 Prevalence of Cognitive Impairment

There are over 850,000 people living with dementia in the United Kingdom. With demographic ageing, this will rise to around one million people by 2021 (Prince et al. 2014). One in three people who were born in 2015 are predicted to develop dementia in their lifetime (Lewis, 2015). In acute hospitals, delirium, dementia, and DsD presentation can be difficult to distinguish, and their problems and care needs are similar; leading to a proposal that in cases of medical emergency, they should all be considered together (Reynish et al. 2017). Occurrence of delirium is a risk factor for later onset of dementia (Davis et al. 2012); and a person with dementia is more likely to get delirium in the presence of precipitating factors (Witlox et al. 2010). Therefore, both dementia and delirium are independent risk factors for the development of the other. Duration of delirium lasts anywhere from a few hours to several months, and can last up to six months (Collier, 2012; Cole and McCusker, 2009). Delirium is present in around one-fifth of acute general hospital patients, and this rises to over one-third in acute hospital patients over the age of 80 (Ryan et al. 2013). Delirium can persist in up to 78% of cases at or beyond hospital discharge (Dasgupta and Hillier, 2010; Cole and McCusker, 2009). It has a number of 'predisposing' factors, such as alcohol misuse, being over the age of 75, and visual impairment. 'Precipitating' factors include dehydration, psychoactive drugs, and infection (Inouye, Westendorp, and Saczynski, 2014).

The most common subtype of dementia is Alzheimer's disease, which accounts for approximately 60-80% of people with dementia (Wilson et al. 2012;

CFAS Neuropathology group 2001). Other subtypes include Cerebrovascular dementia, dementia with Lewy Bodies (DLB), Frontotemporal lobar degeneration (FTLD), and Parkinson's Disease Dementia (PD). Combinations of dementia, known as 'mixed dementia' are increasingly being recognised as more common; with studies showing that around half of all people with dementia have pathological evidence of more than one type of dementia (Schneider et al. 2007; CFAS Neuropathology group, 2001). Severity of dementia can be identified as mild, moderate, or severe. Mild dementia indicates that the cognitive impairment is such that it limits functional activities; however, the person with dementia is able to live independently. In moderate dementia, the cognitive impairment inhibits functional activities, the person can retain familiar information; and support is needed to be able to live independently. Severe dementia causes the person to be unable to retain new information, and requires assistance for all activities of daily living. The person may be able to communicate only via sounds or single words (Waite et al. 2008).

1.4 Behaviours that Challenge

Challenging behaviours can affect up to 90% of people living with dementia, affecting relatives' ability to provide care and support in the community (Jost and Grossberg, 1996; Braun et al. 2018). The high prevalence of behaviours that challenge in people with cognitive impairment, and the difficulties caregivers face due to them, highlights the necessity to further investigate and understand them.

Calling out is one of the least well-understood behaviours in older people with cognitive impairment (Calvet and Clement, 2015), and one of the most challenging (Ridder et al. 2013; McMinn and Draper, 2012). Prevalence studies in nursing homes report very broad rates, varying from 10-52% (Cohen-Mansfield and Werner, 1995; Lai, 1999; McMinn and Draper, 2005); this large range is likely due to inconsistencies in definitions and severity criteria (Burgio et al. 2001; Lemay and Landreville, 2010). It is often placed under the umbrella term of 'agitation' (Bourbonnais and Ducharme, 2008). Agitation is a term endorsed by Cohen-Mansfield (Cohen-Mansfield and Martin; 2010), encompassing behaviours such as aggressive and non-aggressive physical behaviour (such as hitting or wandering), and aggressive and non-aggressive vocal behaviour (such as aggressive language or calling out).

People living with dementia are thought to call out primarily due to the presence of an unmet need (Algase et al. 1996). The need could be physical, social or emotional. In moderate to severe dementia, the person can find themselves unable to physically meet some of their own needs, and can lack the cognitive ability to communicate this need to another; therefore, their frustration and distress can be expressed by calling out.

1.5 The Acute Hospital

Almost all acute hospitals in the United Kingdom have specialised geriatric medicine wards (a variety of names are used, such as Medicine for the Elderly or Healthcare of the Older Person (HCOP) wards). These wards predominantly care for patients over the age of 80, with the most common reason for admission in England being falls (Hospital Episode Statistics, 2015). Older people occupy 68% of hospital beds (Imison, Ponteliakhoff and Thompson, 2012), around 50% of these people have cognitive impairment (Goldberg et al. 2014), and over 40% have dementia (Sampson et al. 2009).

People with cognitive impairment often have many functional problems, such as incontinence, or an inability to walk; alongside behavioural and psychological problems, such as delusions, hallucinations, or agitation (Goldberg et al. 2011). These problems can result in a high and unpredictable workload for staff when combined with staff shortages, and unsafe or non-adapted, noisy and unfamiliar environments (Nilsson, Rasmussen and Edvardsson, 2015). The communication difficulties that people with cognitive impairment face, exacerbate the problems associated with the assessment of symptoms, which can delay provision of treatment or alternative care. Staff sometimes possess little knowledge about the patient as an individual, their background, or their beliefs (Clissett et al. 2013) affecting their ability to provide adequate care (Hall and Hoy, 2012). Ward staff report they do not have the skills or knowledge to adequately care for patients who call out (Griffiths et al. 2014).

80% of those who stay in hospital for longer than two weeks are over the age of 65 (Poteliakhoff and Thompson, 2011). People with dementia are more likely than those without to be readmitted within three months (Draper et al. 2011). Around one-third of people admitted acutely to hospital over the age of 65 are in their last year of life (Clark et al. 2014). Many people living with dementia die in hospital, with the care they received being potentially sub-optimal (Sampson et al. 2006). Older people's acute hospital admissions have a palliative component, increasing the importance of providing good quality care and reducing unpleasant experiences (Goldberg and Harwood, 2013).

Calling out can negatively affect the person manifesting the behaviour, and anyone who is in close proximity to them (Calvet and Clement, 2015). A person calling out may be angry, upset, or attempting to vocalise a specific need (Algase et al. 1996). Calling out is associated with a general decrease in quality of life (Hurt et al. 2008) and poor outcomes (Dewing and Dijk, 2016). Care quality can rapidly deteriorate around the patient, with frustration, avoidance and overt disregard for their psychological (and sometimes physical) needs (Goldberg et al. 2014). Calling out and other behaviours that challenge can significantly increase the cost of care (Murman and Colenda, 2005), due to additional staffing, delayed discharges, and use of pharmaceuticals to control or suppress the behaviour. Many patients on a ward will be disturbed by calling out, especially at night. It may increase stress levels of other patients, disrupt their daily activities and sleeping pattern (Older People's Commissioner for Wales, 2011). Calling out could also produce feelings of anxiety or fear in other patients, be overwhelming or overstimulating, and could increase length of stay (Barton, Findlay and Blake, 2005). This negative patient-patient interaction raises an ethical question of which is more fair: to keep the individual calling out on a bay disturbing others, or to situate them in a side-room, in effect, containing the problem whilst putting the individual at risk of social isolation (Maben et al. 2015).

Staff report that they find it distressing or frustrating when a patient is calling out and they are unsure of what to do to prevent it. Staff may also take vocalisations personally, increasing feelings of frustration (Barton, Findlay and Blake, 2005), workplace dissatisfaction, stress and burnout (Cooper et al. 2018). A patient calling out could add to staff workload, as they may feel they are required to attend to the patient more often, giving them less time to see other patients under their care (Brodaty, Green and Koschera, 2003).

An inspection from the Care Quality Commission (CQC, 2014) reported the following:

> *We heard a person in their room shouting out and screaming in distress. The person residing in the room opposite told us "(the person) shouts and shouts – it goes on for hours and hours, they say she's lonely, well they should go to her shouldn't they." We entered the room of the distressed person who was tearing at their hair and saying "I want it all off me." Notes in the person's care plan recorded numerous occasions when they were heard shouting out and banging in distress.*

This type of report is damaging for public perceptions of the National Health Service (NHS) and its staff. Visitors and regulators may see calling out as an example of failure of the staff to adequately care for the patient. In the above text, loneliness was implied to be the perceived cause of the calling out; however, the description suggests distressing hallucinations, illustrating the uncertainty that can surround interpreting calling out.

1.6 Challenges of Person-Centred Care

Person-centred care has been widely adopted for many years in disciplines such as psychotherapy (Brooker, 2003). Kitwood (1988) first used the phrase in relation to caring for people with dementia. The idea was to promote holistic humanness and individual value (Edvardsson, Winblad, and Sandman, 2004). The four elements of person-centred care can be understood using the "V.I.P.S" framework, V: Value, valuing people with dementia and those who care for them; I: Individual, treating people as individuals; P: Perspective, looking at the world from the perspective of the person with dementia; S: Social, a positive social environment (Brooker and Latham, 2015). Person-centred care approaches underpin all definitions of good practice in dementia care (NICE, 2018).

Delivering person-centred care in the acute hospital can present challenges. Competing priorities and demands in a busy acute environment can restrict the level of person-centred care staff feel able to deliver, especially in the context of life-threatening physical illnesses, severe physical dependency, and an organisational focus on safety and rapid discharge. Hospital staff can view a patient admitted acutely as a 'set of problems' that are required to be fixed before getting to know the patient (Ross, Todd and Clarke, 2015). Care is reported to move from being people-centred, to task-focused, as staff struggle to get necessary jobs done in the time they have (Francis, 2013). This causes staff difficulty in making the most of every opportunity they have to achieve person-centred interactions, resulting in a negative impact upon the patient's sense of personhood (Clissett et al. 2013).

Personal profile documents have been developed in an attempt to support care adapted to personal identity, history, preferences and routines; and to reduce the difficulties faced when delivering person-centred care in healthcare settings. The 'This is Me' document is a tool developed jointly by the Alzheimer's Society and the Royal College of Nursing (Alzheimer's Society, 2017). It is a small booklet with prompts and spaces for a relative or carer to document personal details about the person with dementia. Many hospitals have developed their own booklet based on the 'This is me'. The document is described as providing a "snapshot" of the person with dementia, giving details about them as an individual; for example, their personal background, special needs, interests, likes, dislikes, and preferences. It is recommended that relatives communicate to staff if the person with dementia might get agitated if they are restricted from doing something they like to do, such as walking around the ward, or waking up early to have a cup of tea. This was developed to facilitate staff's delivery of person-centred care to patients that they may initially know little about.

Staff can particularly struggle to deliver person-centred care on acute hospitals where length of stay is short; as they have limited time to gain the necessary knowledge about the patient in order to provide individualised care (Grealish et al. 2018). When a person with dementia is exhibiting challenging behaviour, hospital and residential home staff alike have been found to avoid that person (Goldberg, 2014; Cooper et al. 2018). Moore et al. (2017) reported that sceptical, stereotypical attitudes from staff caused poor person-centred care. Not responding to requests will make the person feel devalued and isolated, overlooking the principles of person-centred care.

1.7 Justification for the Present Study

Calling out repetitively is a commonly occurring, distressing, and disruptive problem, often occurring in people living with dementia. People with dementia are more likely to be admitted into the acute hospital as an emergency, increasing the incidence of calling out in the acute hospital. The unfamiliar environment of the acute hospital can exacerbate the problem; as patients are often distressed, and staff rarely possess sufficient personal information about the patient in order to provide person-centred care. Little research has been conducted regarding calling out, especially in the acute hospital, and the behaviour remains misunderstood and challenging. To address this problem, calling out needs to be understood in more depth, to allow for the development of evidence-based solutions.

1.8 Overview of the Thesis

The purpose of this study is to explore calling out in the context of the acute hospital. This involves describing calling out and the people who display it in hospital and after discharge, the way in which others react and respond to it, and people's knowledge, beliefs, and experiences of calling out.

1.8.1 Aims and Study Design

The aims of this study are to:

- Characterise calling out as a behaviour, and the patients who call out.
- Understand the knowledge, beliefs, and experiences of hospital staff members, and relatives of patients who call out.
- Observe and record the ways in which others respond to or manage calling out in the acute hospital.
- Record what happens to patients who call out after they are discharged from hospital.

An ethnographic case-series study design was selected.

1.8.2 Structure of the Thesis

This chapter has provided an overview of the background to the research. Chapter Two systematically explores key research on calling out, and identifies the main gaps in the literature. Chapter Three justifies the study methodology, using principles from the philosophy of critical realism. Chapter Four describes the methods undertaken to recruit participants, and to collect and analyse the data. Chapters Five to Seven present the quantitative and qualitative findings of the study, separated into three sections: Characterisation, Needs, and Interventions. Chapter Eight presents an overall discussion of the three findings chapters in relation to previous literature, concluding with future directions for the research.

Chapter 2

Literature Review

2.1 Introduction

This chapter presents a scoping review on calling out in older people with cognitive impairment in health and social care settings. Within the review, the heterogeneity of terminology for calling out is discussed, as well as its consideration as a form of agitation. Theories explaining the cause of calling out are presented, alongside its natural history, typologies, current practice, and measurement. Reported interventions are outlined, both pharmacological and non-pharmacological. The chapter concludes by identifying gaps in the literature, and how the aims and objectives for the current study address some of these gaps.

2.2 Scoping Review Process

Calling out in people with cognitive impairment is a conceptually difficult topic, and a complex phenomenon, with multiple potential ways of investigating and researching it. Calling out has not been reviewed extensively, and little is established regarding definitions, causes, or interventions for the behaviour (Randall and Clissett, 2016). 'Gold standard' systematic reviews are difficult to produce where the literature has high levels of heterogeneity regarding methods, definitions, or measures (Campbell et al. 2018). They are also suitable for assessing the value of interventions. As this study is exploratory and about a phenomenon which has not been extensively researched in its own right, a scoping review allows for the inclusion of a wider variety of studies, especially those studies where the phenomena under consideration is not central to the study being reviewed. For research of this nature, scoping reviews have been advised, to map key concepts underpinning the subject, the core sources, and available evidence (Mays et al. 2001). A scoping review allows for the broadening of the topic area, investigating new ideas and lateral thinking (Dijkers, 2015). It is a more exploratory method, which allows deeper exploration of published literature (Popay et al. 2006). Scoping reviews are recommended by Arksey and O'Malley (2005) as a useful method of identifying gaps in the literature, as they help to draw conclusions regarding the overall state of research activity. The aim of this review is to examine what is known about calling out, how it has been researched, as well as to establish where there are gaps and absences in our understanding and in study designs. Calling out is physiological, but it also has social consequences, therefore it is also necessary to review qualitative studies that examine the meanings and interpretations of calling out.

The aim for this scoping review, was to deconstruct the existing literature on the phenomenon of calling out; to evaluate definitions of calling out, including its link with agitation, theories surrounding how and why the behaviour develops, and a summary of intervention attempts. This allowed for the identification of gaps in the literature, in order to inform the research question and aims.

A systematic review is generally seen as the 'best practice' method of conducting a literature review, due to their high level of rigour and transparency (van der Knaap et al. 2008). They are agreed to be the most robust, empirical, and focused type of review (Mallett et al. 2012). A non-systematic review does not give as comprehensive a statement about 'what works' (van der Knaap et al. 2008). However, the aim for this literature review was to examine the breadth of the data surrounding calling out, and not to narrow research down to interventions that work. Precautions can be taken to ensure that some of the 'gold standard' qualities of a systematic review can translate over to a scoping review. Arksey and O'Malley (2005) outline a methodological framework for conducting scoping reviews; underpinned by traditional systematic review methods, to ensure rigour and transparency. The five stages involve: 1. Identification of the research question; 2. Identification of relevant studies; 3. Selection of studies; 4. Charting the data; 5. Collating, summarising and reporting the results. Arksey and O'Malley advise that scoping reviews do not involve an assessment of the quality of included primary studies. Some reviewers argue quality assessments should take place, with around 22% of scoping reviews being published with some level of quality assessment, as minimal as reviewer opinions of 'low, medium and high' (Pham et al. 2014). It is argued that because the intent of scoping reviews is to present an overview of existing literature in a field of interest, all literature should be presented regardless of methodological quality; this is to present a more complete overview of all research in the field (Pham et al. 2014). Furthermore, Levac et al. 2010 state that there are a number of practical challenges associated with assessing the quality of a wide range of different study designs and the large volume of literature, such that a quality assessment within a scoping review may not provide much of value in comparison to a systematic review. The subsequent sections of this review will follow Arksey and O'Malley's scoping review framework.

2.2.1 Identification of the Research Question

Consistent with scoping review methodology, a broad research question was selected to facilitate the identification of research gaps, and enable a wide breadth of coverage (Arksey and O'Malley, 2005). This was:

What is known from the literature about calling out repetitively in older people with cognitive impairment? The question 'what is known' is not limited to interventions, but is broader and encompasses questions about perceptions of the phenomena; experiences of caring for patients with this condition; but also ways in which the condition might be measured, assessed, and recognised.

2.2.2 Identification of Relevant Studies

A number of large popular databases were searched, including Web of Science, BIOSIS, MEDLINE, OVID, PubMed, and SCOPUS; which identified over 3500 papers to examine initially. The systematic search was first conducted in March 2016, and then updated in May 2018. The numbers in the PRISMA diagram (Figure 2.1) represent the overall numbers of articles for both searches combined. The following database search was conducted, developed from the research question:

ALL FIELDS: (voca* OR verba* OR call*) AND TOPIC: (problem* OR disrupt* OR agitate* OR behav* OR BPSD OR repet*) AND TOPIC: (dement* OR alz* OR cognitive*)

2.2.3 Selection of Studies

Included studies could be about calling out as a single entity, or within a wider umbrella; such as agitation, behavioural and psychological symptoms of dementia (BPSD), or behaviours that challenge. Publications were included if there was sufficient focus placed on calling out that it was referred to separately and defined, or had an outcome measure or item relating to calling out. Both qualitative and quantitative studies were included. Reviews were excluded, however their reference lists were hand-searched, to capture relevant studies within them. Studies referring to 'verbal repetition' or 'verbal perseveration' were excluded, due to these being an unrelated phenomenon, with a different meaning. Verbal repetition or perseveration refer to repetitious responses, that are more widely associated with brain injury and disease (Bayles et al. 1985).

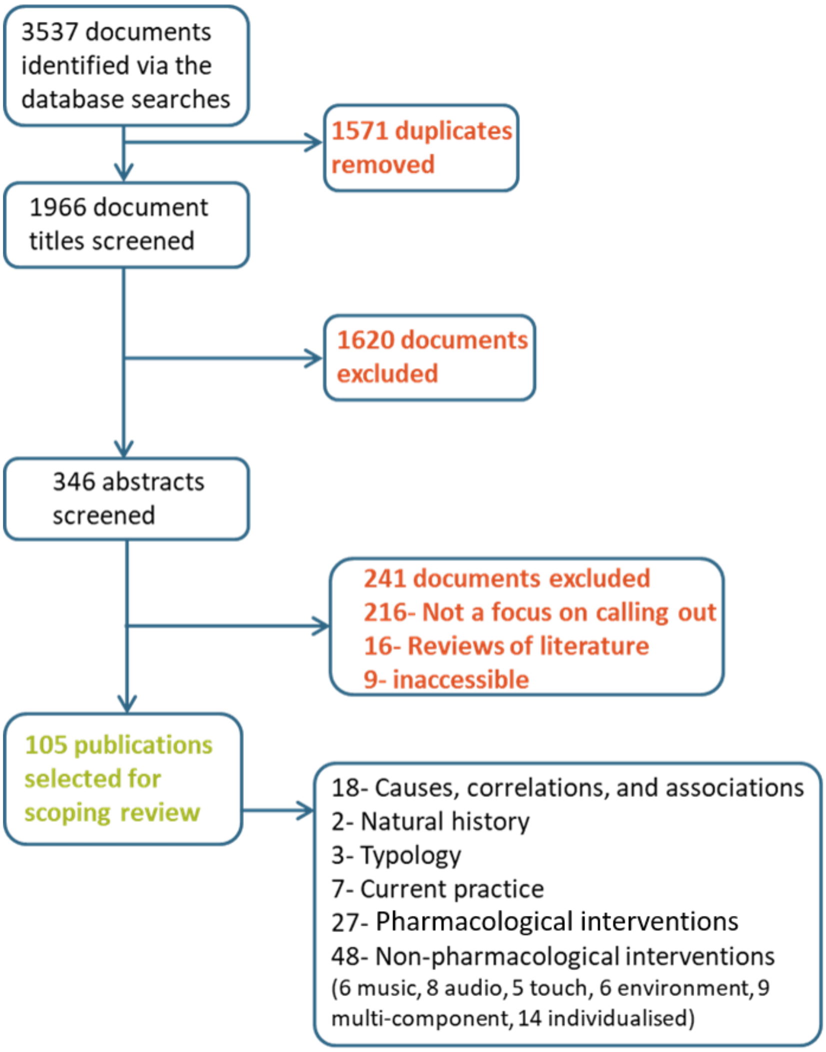

Figure 2.1: PRISMA diagram to display the inclusion and exclusion of studies for the scoping review

Based on the inclusion and exclusion criteria, 105 published studies were included in the scoping review. These publications have all been included within the scoping review with the aim of answering the literature review question: What is known from the literature about calling out repetitively in older people with cognitive impairment? These have been separated into types of study for ease of reporting. Categories for the scoping review include: 18 causes, correlations, and associations (any study that attempts to understand why people call out), two natural history (following the course of calling out with no manipulation), three typology (examinations of the behaviours that make up calling out), seven current practice (investigation of what currently happens in practice regarding calling out), and 27 pharmacological and 48 non-pharmacological interventions.

2.3 Descriptors

First, an examination of the descriptors used for calling out within the literature was investigated. Most studies did not refer to calling out as a single construct, often referring to it as an 'agitated' or 'challenging' behaviour (Figure 2.2). To investigate this further, the main descriptor for calling out across the included studies was recorded. This was to explore whether any agreement existed regarding what calling out should be called, and to search for the original source of definitions.

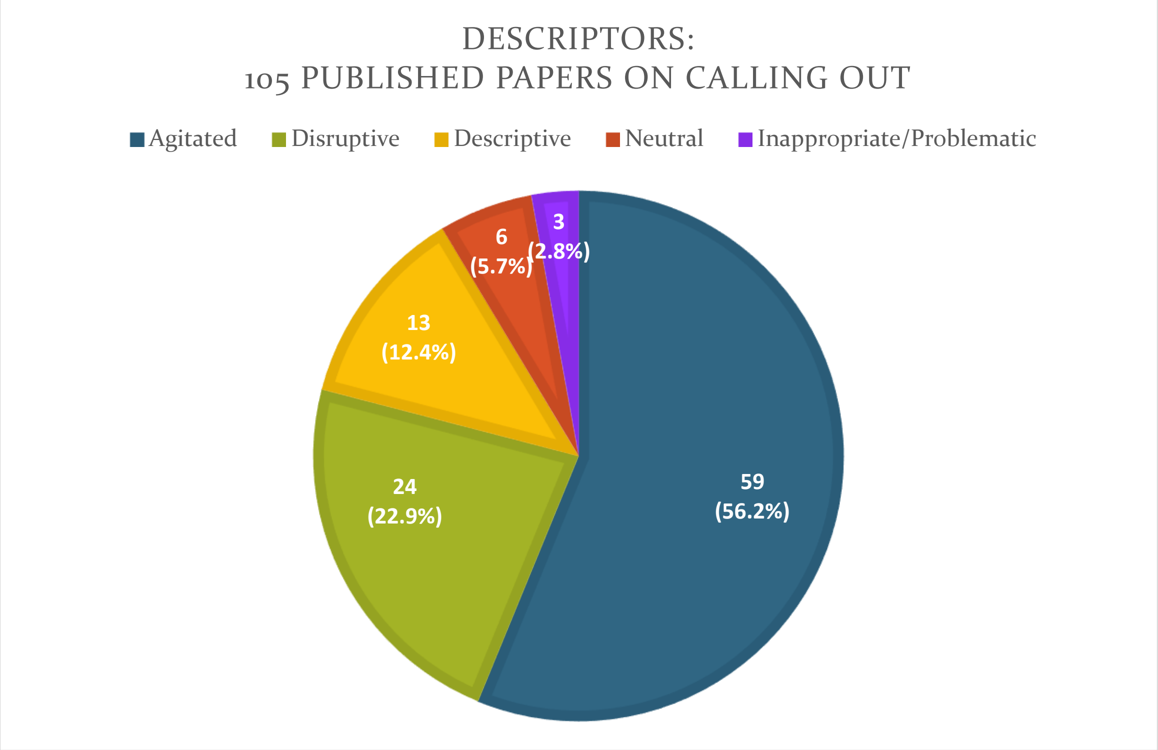

Figure 2.2: A pie chart to display descriptors used by published papers on calling out

Fifty-nine of the 105 (56.2%) included papers referred to calling out as being under the umbrella term of 'agitation' (verbal agitation, verbally agitated behaviour, and verbal and vocal agitation). Twenty-four (22.9%) of the papers identified calling out as a 'disruptive' behaviour (disruptive vocalisations, verbally disruptive behaviours, vocally disruptive behaviours, and repetitive disruptive vocalisations). Thirteen papers (12.4%) used descriptive language that may include words but may also include repetitive use of sounds (screaming, shouting, crying out, verbal outbursts and verbal aggression). Six (5.7%) used neutral terminology (repetitive vocalisations, vocalisation, and responsive behaviour). Three papers (2.8%) referred to calling out as a 'problematic' behaviour (inappropriate vocalisation, verbal inappropriate behaviours and problematic vocalisations).

This illustrates the heterogeneity of the terminology used for calling out. Twenty different terms or phrases were identified that referred to either calling out as a single construct, or within a wider collection of behaviours, such as agitation or BPSD. This can be problematic for researchers conducting reviews of published studies, as terms may be missed by literature searches. It also displays uncertainty and disagreement about what calling out as a behaviour actually is. It could also cause difficulties for caregivers of people who call out when searching for informed methods of managing the behaviour. Medical terminology should be neutral, so as to not place value-judgements on patients or their conditions (Scadding, 1988), however the existing literature on calling out often places assumptions or judgements on the behaviour, by using terms such as 'agitated' or 'disruptive'. Neutral terminology, such as 'repetitive vocalisations' only made up six of the 105 included studies; however, this can be seen to be medicalising the phenomenon, and may be considered to be 'jargon' (Dahm, 2011). The term 'calling out repetitively' is used in this thesis, in preference to these other terms, in an attempt to move away from jargon, and assumptive, emotive, or critical language.

2.4 Agitation

Most published papers refer to calling out as an aspect of 'agitated behaviour'. Many define agitation or agitated behaviours using a definition formulated by Cohen-Mansfield and Billig (1986) in a conceptual review of agitation. Cohen-Mansfield is heavily cited within the agitation and calling out literature, with the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991) popularly used as a measure of agitation in people with dementia (Beck et al. 2011; Davison, 2016; Deudon et al. 2009; Fox et al. 2012; Howard et al. 2007; Karel, 2016; Moyle et al. 2017; Ramadan et al. 1999; 2000; Rabinowitz et al. 2004; 2007; Shankle et al. 1995; Sust et al. 2015; Vermeiren et al. 2011). A review of agitated behaviours in older people (Spira and Edelstein, 2006) only included behaviours that were 'consistent with the definition of agitation provided by

Cohen-Mansfield and Billig (1986)', which highlights how widespread the definition is.

The Cohen-Mansfield and Billig (1986) paper was a literature review that identified 16 studies relating to agitation, and used them to define the concept as a whole. Table 2.1 displays the papers included in the Cohen-Mansfield and Billig (1986) review, and which of those refer to vocal behaviours.

TABLE 2.1 **REVIEW OF AGITATED BEHAVIOURS**

De Ajuriaguerra et al. (1963)	No mention of vocal activity
Beber (1965)	No mention of vocal activity
Chesrow et al. (1965)	No mention of vocal activity
Craig (1982)	No mention of vocal activity
Davis (1983)	'Screams' as a related syndrome
Fisher et al. (1983)	No mention of vocal activity
Gerz (1964)	'Over-talkativeness' as a related syndrome
Granacher (1982)	No mention of vocal activity
Huck (1982)	No mention of vocal activity
Miletto et al. (1963)	No mention of vocal activity
Mishara et al. (1973)	No mention of vocal activity
Petrie and Ban (1981)	No mention of vocal activity
Petrie (1983)	No mention of vocal activity
Taillefer et al. (1983)	No mention of vocal activity
Zarit et al. (1982)	'Asking repetitive questions' as a definition of behaviour
Zimmer et al. (1984)	'Disturbing to others: Verbally (noisy, abusive, etc.)' as a definition of behaviour

Table 2.1: Included studies in the Cohen-Mansfield and Billig (1986) review of agitated behaviours, and how many of those refer to vocal or verbal behaviours

Four of the 16 included papers mentioned vocal activity ('screams', 'over-talkativeness', 'asking repetitive questions', 'disturbing to others verbally (noisy, abusive, etc.)). Most focused on the motor aspects of 'agitated behaviour', such as 'wandering', or repetitive movements. Despite the minimal references to vocal behaviour in the review, agitation was operationally defined as:

> *"Inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual... Agitated behavior is always socially inappropriate, and can be manifested in three ways: (a) It may be abusive or aggressive toward self or others; (b) It may be appropriate behaviour performed with inappropriate frequency, such as constantly asking questions; or (c) It may be inappropriate according to social standards for the specific situation, as in putting on too many layers of clothes."*
>
> *Cohen-Mansfield and Billig (1986)*

Due to the popular use of this definition in the literature, calling out is usually considered to be a part of the manifestation of agitation. It may have been premature to label verbal or vocal activity as an agitated behaviour when little was known at the time of publication. Cohen-Mansfield and Billig (1986) stated that the literature was largely anecdotal; and that no studies regarding predisposing factors to agitation had been conducted. It was concluded that '*The current literature underscores the lack of research on agitation*' and that '*basic research needs to explore dimensions, definitions, and components of agitation*'. It is almost taken for granted that calling out is an expression of agitation, with little primary empirical evidence to support this.

The Cohen-Mansfield and Billig (1986) definition possesses some limitations for use in practice. Its use of vague and undefined terms such as 'inappropriate' or 'confusion' make it difficult to ascertain the exact behaviour being defined. It also does not address the internal mechanisms behind agitation, stating that the causation '*cannot be judged by an outside observer to result* *directly from the needs or confusion*' of the individual. Cassell (2004) states that '*Suffering is ultimately a personal matter- something whose presence and extent can only be known to the sufferer'* (-p.39); this makes outside observer judgement regarding this problematic, especially if the observed individual is experiencing dementia or delirium. Furthermore, if an individual is experiencing an unmet need, for example, to use the toilet, but cannot walk and there is no one to help them, this person would not fit under the definition of agitation, when they are likely to be feeling agitated.

Some research suggests that calling out should not be considered within the same behaviour construct as other behaviours that challenge. Factor analyses have been conducted of measures of agitation (Heeren et al. 2003; Rabinowitz et al. 2005) finding calling out to be separate from other behaviours such as wandering or physical aggression. Mintzer and Brawman-Mintzer (1996) conclude that different types of behaviour under the term 'agitation' each likely have a different aetiology and treatment. Agitation in dementia is often referred to as vague (Koder, 2018) and poorly defined (Chiu, 2015).

To summarise, calling out is poorly defined, and often placed under the umbrella term of 'agitation'. This is not necessarily justified; as there is little empirical evidence to suggest that calling out and other BPSD behaviours should be placed under the same category. A large number of terms have been used as descriptors, and calling out has been chosen for this thesis in an attempt to use a neutral term. Further descriptive work is required to characterise calling out to construct an operationalisable definition, and researchers should agree upon a descriptor for the behaviour.

2.5 Aetiology

There are three repeated overarching theories that explain the occurrence of calling out. These are the theory of unmet needs, behavioural conditioning, and biological symptoms of dementia.

2.5.1 The Theory of Unmet Needs

The main theory for the cause of calling out in people with cognitive impairment is the theory of 'unmet needs' (Miranda-Castillo et al. 2010). One version of this is the Need-Driven Dementia-Compromised Behaviour Model (NDDCB; Algase et al. 1996). The NDDCB suggests that calling out is a way for the person to express an unmet need, or their distress due to it. It posits that a mixture of ‘background’ and ‘proximal’ factors lead to calling out. Background factors involve characteristics of the person with cognitive impairment that are difficult to change, such as personality, cognitive impairment, or physical function. Proximal factors are more likely to fluctuate, and are easier to adapt, such as elements of the physical and social environment, medication, and personal basic needs such as hunger or the need to urinate. Background and proximal factors are assumed to work together to produce Need-Driven Behaviours (Figure 2.3). Therefore, a patient with a predisposing background factor, such as poor physical health or anxiety, may be more likely to call out whilst being bathed (a proximal factor) than a patient who does not possess a predisposing factor.

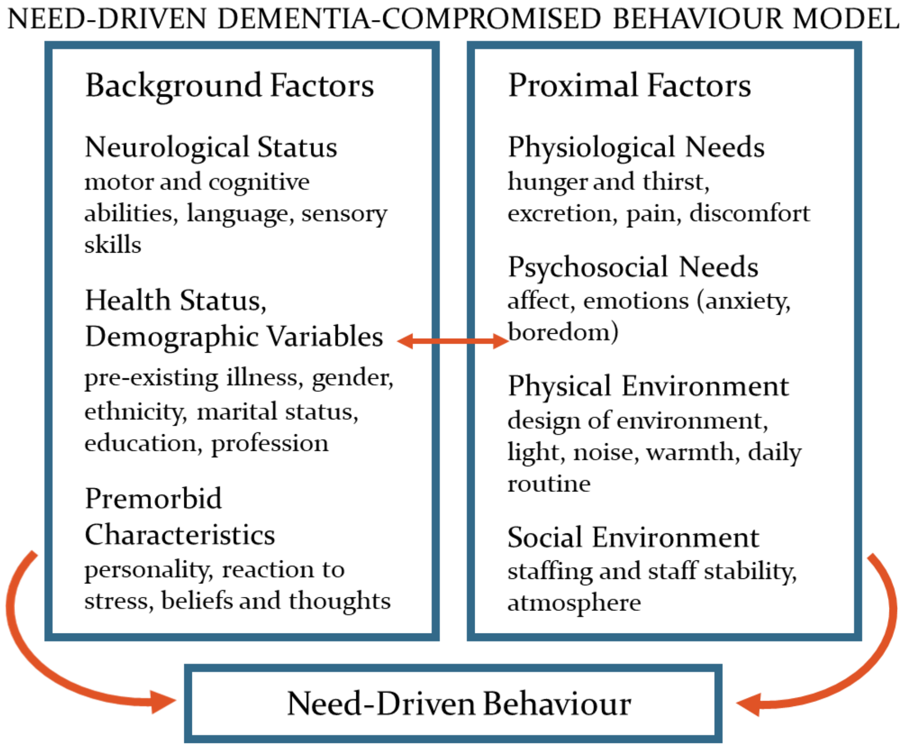

Figure 2.3: Algase et al.’s (1996) background and proximal factors working together to produce needs-driven behaviours

There are a number of variants of the unmet needs theory (Schölzel-Dorenbos et al. 2010; Miranda-Castillo et al. 2010; Cohen-Mansfield and Werner, 1995). However, the general theory remains the same, and is identified as the current best causal explanation for calling out (Livingston et al. 2014).

Kitwood (1997) considers the single all-encompassing psychological need for people with dementia is love; which is fulfilled via five fundamental needs: inclusion, attachment, comfort, identity, and occupation (Figure 2.4). Distress is said to result from a failure to meet these needs, or via the disregard of these needs through 'malignant social psychology' such as the carer ignoring overt distress, or invalidating their experiences.

Figure 2.4: A representation of the main psychological needs of a person with dementia as identified by Kitwood (1997)

2.5.2 Behavioural Conditioning

Behavioural conditioning, is where behaviour is 'learned' through a series of paired events, wherein one stimulus gives rise to another (Olson and Fazio, 2001). Behaviour is learned either by a rewarding event occurring after completing an action, causing the behaviour to be reinforced and repeated; or by the occurrence of an adverse event, causing future avoidance of the behaviour.

Spira and Edelstein (2006) reviewed intervention studies for agitation including calling out in dementia that were based on the behavioural operant conditioning approach. However, they conclude that many of the studies included in the review were poorly designed, and lacked adequate control groups, making findings uncertain (Spira and Edelstein, 2006). This raises questions about this explanation for the phenomenon.

2.5.3 Dementia

Calling out is more common in people with dementia than those without (Cariaga et al. 1991, Kolanowski et al. 2017), and has a higher prevalence in people with dementia who have more severe cognitive impairment (Cohen-Mansfield and Libin, 2005; Draper et al. 2000, Sloane et al. 1999; Hallberg and Norberg, 1990). Symptoms manifested in dementia, such as a lack of impulse control, social disinhibition, inability to communicate, or a lack of memory for when they last vocalised, may contribute to the behaviour.

However, not all people who call out have dementia. A study conducted by Cariaga et al. (1991) examined a sample of 147 participants over the age of 60 (76 who called out, 71 who did not) from two nursing homes in the USA. Calling out was of sufficient severity to require consideration within the resident's care plan. 59% of people in the calling out group had a diagnosis of dementia, and 37% who did not call out had a diagnosis of dementia. However, delirium was not documented in the study.

2.5.4 Individual Causes or Associations with Calling Out

A number of studies from the search identified possible causes for, or associations with calling out (Table 2.2). The most common were affect (Beck et al. 2011; Cankurturan, 2014; Cohen-Mansfield et al. 2012; Draper et al. 2000; Lemay and Landreville, 2010); pain or discomfort (Beck et al. 2011; Berastegui et al. 2017; Buffum et al. 2001; Sloane et al. 1997; Hallberg and Norberg, 1990; Pelletier and Landreville, 2007) lack of social interaction (Berastegui et al. 2017; Cohen-Mansfield et al. 2015; Draper et al. 2000) anxiety (Draper et al. 2000; Hallberg and Norberg, 1990; Lemay and Landreville, 2010); and severity of dementia (Buffum et al. 2001; Cohen-Mansfield and Libin, 2005; Draper et al. 2000).

Other factors included personality traits, health status, age, gender, loneliness, sensory loss/deprivation, poor functional ability, emotional distress in nursing staff, sleep, incontinence, co-morbid conditions, loss of autonomy, threats to integrity, reactions to the environment, automatic behaviour, and the lack of meaningful activity. This constitutes a wide range of factors with little overarching agreement across the studies. For example, Beck et al. (2011), and Cohen-Mansfield and Libin (2005) state female gender as an associated factor of calling out, however Proitsi et al. (2011) concluded the opposite.

Of the 18 included studies focusing on causes, correlations and associations, only one took place in a hospital setting, with the rest taking place in care or nursing homes. Vermeiren et al. (2011) measured glutamate (an enzyme found in excess in the brain of those with Alzheimer's Disease) within cerebrospinal fluid samples of people with dementia, and found that verbally agitated behaviour on the Cohen-Mansfield Agitation Inventory (CMAI) was negatively associated with the glutamate levels. Aside from this, there is a current lack of knowledge surrounding further potential causes for calling out within a hospital setting. It might be that a change in environment, especially an unfamiliar and stressful one like a hospital setting, as opposed to the more familiar care home settings, might be found to cause calling out.

There are many potential causes for calling out reported in the literature. Most of these causes support the unmet needs model of calling out (Algase et al. 1996). The person with dementia is unable to meet their needs, due to poor functional ability, and cannot express them to others in a socially appropriate way, due to their deteriorated cognitive functioning and communication ability. There is a lack of evidence for causes, correlations and associations for calling out within the context of the general hospital, with only one of the 18 included studies taking place in this setting.

Because definitions are very variable, and because the evidence about aetiology is theoretically derived, rather than empirically established, the review thus far shows that research about calling out repetitively lacks systematic empirical study.

TABLE 2.2 CAUSES, CORRELATIONS AND ASSOCIATIONS WITH CALLING OUT

Study	Type	Description	Findings
Beck et al. (2011)	Descriptive Study	Background and proximal data obtained through tests, interviews, and observations, set in nursing homes.	Using 'verbally agitated' on the Cohen-Mansfield Agitation Inventory (CMAI), the background factors of gender, agreeableness, general health status, and age were predictors, as were the proximal factors of affect and discomfort. No relationship found with temperature or humidity.
Berastegui et al. (2017)	Focus group	Focus group and brainstorming of triggers/aggravating shoutings by clinical professionals.	Five types of calling out: 1) physical/ moral pain, emotional reactions, 2) sensory loss, 3) social isolation, under-stimulation/hyper sensitivity, 4) reminiscences 5) re-emergence of painful memories/ loss of language skills.
Bourbonnais and Ducharme (2010)	Ethnography	7 triads, people with dementia calling out, informal caregiver, and formal caregiver.	Screams are a unique language that can be learned. Other influencing factors included respect for the person's wishes, needs, and personality, shifts in power relations within the triad.
Buffum et al. (2001)	Cross-sectional	33 nursing home residents assessed for severity of dementia, pain, discomfort, and agitation/calling out.	Significant relationship between agitation [including calling out] (CMAI) and discomfort (the Discomfort Scale); and agitation [including calling out] (CMAI) and severity of dementia (Global Deterioration Scale).
Cohen-Mansfield et al. (2012)	Comparison Study	Engagement, affect, and agitation/calling out/problem behavior was measured and direct observations were collected during stimulus presentation and control conditions.	No relationship between engagement and negative affect or agitated behavior [including calling out]. Positive relationship between agitated behavior [including calling out] and negative affect.
Cohen-Mansfield et al. (2015)	Descriptive Study	89 people with dementia who called out from nursing homes assessed by research assistants and nursing assistants for their unmet needs using multiple assessment tools.	Three unmet needs per resident identified on average, informants rated boredom/sensory deprivation, loneliness/need for social interaction, and need for meaningful activity as most prevalent.
Cohen-Mansfield and Libin (2005)	Observation	175 people with dementia from 11 nursing homes. Observations of the participants' behavior were conducted using the agitated behaviors mapping instrument.	Verbally agitated behaviors correlated with female gender, cognitive decline, poor performance of activities of daily living, impaired social functioning, and signs of depressed affect.
Draper et al. (2000)	Case-Control	25 people with dementia- Screaming Behavior Mapping Instrument, Cornell Scale for Depression in Dementia, Dementia Behavior Disturbance Scale, measures of cognition, functional capacity, social activities, and emotional reactions of nursing staff.	Calling out is associated with other disturbed behaviors, depression, anxiety, severe dementia, functional impairment, communication difficulties, and use of psychotropic medication, social isolation, and emotional distress in the nursing staff.

Hallberg and Norberg (1990)	Qualitative Interviews	17 experienced caregivers interviewed after listening to tape recordings of two patients calling out.	Seven categories of explanations: anxiety over abandonment, dissolution, loss of autonomy, threats to integrity, expression of bodily needs, reactions to disturbing environment, and automatic behaviour.
Howler (2011)	Qualitative Interviews	Biographical interviews conducted with nursing home staff.	Explanations for behaviour patterns including calling out divided into biographical central characters, institutional characteristics, and characteristics from nurses.
Leon et al. (2018)	Descriptive assessment	Four patients displaying inappropriate vocalisations, observations of environmental events correlated with inappropriate vocalisations	Predictive events included the presence of staff attention, the presence of divided attention (1.5m from the patient but attending to somebody else), and the absence of attention. Further, data for three of the four subjects indicated that attention was significantly more likely to follow occurrences of inappropriate vocalizations than to occur independent of them.
Liu et al. (2000)	Case Study	Elderly nursing home resident, case study assessing the cause of their calling out.	Acute arthritis, treatment of this underlying condition reduced calling out.
Lövheim et al. (2006)	Cross-Sectional	2017 resident's geriatric care - prescription records and observations made by care staff of BPSD including calling out among residents during the preceding week.	Aggressive, verbally disruptive and wandering behavior was independently associated with the use of antipsychotics.
Pelletier and Landreville (2007)	Cross-sectional correlation	Registered nurses provided data on forty-nine residents from three long-term facilities displaying agitation/calling out. Discomfort Scale, the Cohen-Mansfield Agitation Inventory, the ADL subscale of the Functional Autonomy Measurement System, and the Functional Assessment Staging.	Hierarchical multiple regression analyses controlling for residents' characteristics (sex, severity of dementia, and disability) show that discomfort explains a significant share of the variance in overall agitation (28%, $p < 0.001$), non-aggressive physical behavior (18%, $p < 0.01$) and verbally agitated behavior (30%, $p < 0.001$).
Proitsi et al. (2009)	Cohort study	Three cohorts comprising 957 people with dementia assessed using the Neuropsychiatric Inventory (NPI).	Male gender, longer disease duration, older age of onset, and psychosis associated with agitation including calling out on the NPI.
Sloane et al. (1997)	Consensus Meeting	Reports the results of a consensus meeting convened to provide guidelines for clinicians and recommendations for researchers.	Calling out arises in people with cognitive impairment and reflects underlying need or discomfort. Key to management is appropriate identification of all possible factors and development of an individualized treatment plan.
Vermeiren et al. (2011)	Cross-Sectional	297 hospitalised people with dementia, assessed behaviour, agitation and depression and took cerebrospinal fluid samples.	In frontotemporal dementia patients, glutamate levels were negatively correlated with CMAI cluster score "verbally agitated behavior".

Wyles (2016)	Observational	Direct observation of vocally disruptive behaviours, antecedents and consequences observed	Caregivers would benefit from specific training to equip themselves with a range of interventions to allow for the individual needs of residents and the changing nature of the calling out behaviour.

2.6 Natural History

Two studies were found that examined the manifestation of calling out over time with no experimental manipulation (Table 2.3). Both of these studies collected data over a six-month period, and both were conducted in nursing homes. It is important to observe what would happen with no intervention, to understand the effects an intervention may have, or even how necessary intervention is.

Sloane et al. (1999) in a study of people who displayed severe calling out, found that over six months, 24% of recruited people that were calling out had died. Of the surviving patients; 45% called out significantly less than when the study started, or had stopped entirely. This shows that with no intervention or manipulation, a reduction in calling out was discovered nonetheless, and highlights the importance of having a control group when conducting intervention research.

Voyer et al. (2015) found that behavioural and psychological symptoms of dementia (BPSD) lasted a mean of 2.3 months, with the category 'saying things that do not make sense' lasting the longest at 3.6 months. This again shows that calling out can reduce over time with no intervention or manipulation, however that it is still persistent relative to other BPSD.

Little is currently known about the natural history of calling out in nursing homes, and no natural history research has been conducted in an acute hospital. To effectively inform an intervention within an acute hospital setting, more knowledge is required about the nature of the calling out in this setting, in particular how long people call out for, and whether they continue upon discharge.

TABLE 2.3 NATURAL HISTORY OF CALLING OUT

Study	Type	Description	Findings
Sloane et al. (1999)	Longitudinal cohort	Describe severe calling out in nursing homes, patients clinical and behavioral characteristics, staff responses, treatments used, report on prognosis over 6m.	45% called out significantly less than at baseline, or had stopped entirely. Predictors= greater ADL dependence, hearing /vision problems, shorter length of stay, urinary incontinence, and use of a treatment other than one-on-one interventions. 23.4% died within 6 months.
Voyer et al. (2015)	Secondary Analysis	146 nursing home residents. Describe the course of each measured Behavioural and Psychological Symptom of Dementia (BPSD) over a period of 6m. Identify which BPSD were associated with antipsychotic drug use.	Results showed that BPSD including calling out lasted for an average of 2.3 months, and the BPSD 'saying things that do not make sense' had the longest duration, with 3.6 months.

2.7 Typology

Three publications (Burgio et al. 2001; Cohen-Mansfield and Werner, 1997; and Nagaratnam et al. 2003) were identified which focused on the typology or characterisation of calling out separately from agitation (Table 2.4).

Burgio et al. (2001) observed 68 nursing home residents with dementia displaying 'disruptive vocalisation' over a nine-month period. They identified a number of different types of calling out: word repetition, self-talk, screaming, moaning, crying, abusive language, singing outside of an organized activity, and gurgling. On average, residents called out 15 times per hour, with each episode of calling out lasting an average of 40 seconds[2].

Cohen-Mansfield and Werner (1997) assessed a typology of 'vocally disruptive behaviour'. This involved: 1. the type of sound (quality, content, and timing); 2. the purpose of the sound; 3. responses to the social or physical environment; and 4. level of disruptiveness. They suggested that types of repetitive vocalisations should be considered separately, as they did not correlate with one another (e.g. groaning, mumbling, yelling).

Nagaratnam et al. (2003) categorised the types of calling out into '(i) Persistent screaming, (ii) Perseverative vocalisation, (iii) Continuous chattering, muttering, singing or humming, and (iv) Swearing, grunting and bizarre noise-making'.

Typology studies place a focus on calling out being a disruptive and socially inappropriate behaviour. These appear to be defining characteristics of the 'problem' of calling out, as opposed to the apparent distress levels of the person exhibiting it (which would be more congruent with the notion that it is caused by an unmet need), which could be much more difficult to objectively define or measure in practice. None of the included studies focused on typology were conducted in an acute hospital setting, therefore they may not be applicable to the general hospital context.

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[2] An 'episode' was classified as any vocalisations with no more than 3 seconds of silence separating them from each other.

TABLE 2.4 TYPOLOGY OF CALLING OUT

Study	Type	Description	Findings
Burgio et al. (2001)	Observational	Observations of residents with dementia exhibiting disruptive vocalisation.	Residents exhibited an average of 15 occurrences of calling out per hour with an average duration per occurrence of 40 seconds. The most frequently occurring types of calling out were word repetition, self-talk, screaming, moaning, crying, abusive language, singing outside of an organized activity, and gurgling. More than one category could be recorded for each resident.
Cohen-Mansfield and Werner (1997)	Typology	Description of typology, interrater reliability, validation of typology.	Type of Sound: Quality (groan, yell, shriek, mumble, loud song, sigh, loud talk, chatter, howling, disruptive talk, inappropriate verbal, other) Content (non-verbal, verbal-nonsense, verbal-pain, verbal-complaints, verbal-help, verbal-specific requests, verbal-hallucinations, vocal complaining, ADL needs, other), Timing (constant, random, apparent pattern). Purpose of Sound: Requests for attention, expression of pain, emotional stress, self-stimulation, unknown. Response to the environment: Social environment (Talking to other persons, presence of others during toileting, bathing/ other ADLs, presence of people without interaction, other.) Physical environment (too hot/cold/bright/dark/noisy/crowded, and other) Level of disruptiveness (1: not at all disruptive – 5: extremely disruptive).
Nagaratnam et al. (2003)	Observational	Described 12 PWD displaying RV.	Categorised noise making into (i) persistent screaming, (ii) perseverative vocalization, (iii) continuous chattering, muttering, singing or humming, and (iv) swearing, grunting and bizarre noise making.

2.8 Current Practice

The literature in this section focused on what paid carers reported that they did in practice when a person in their care was calling out. These are distinct from intervention studies, as they examine what caregivers did in their environment, rather than being concerned with an intervention or adaptation from the researcher. All current practice research acknowledges the fact that staff/carers find calling out extremely challenging (Table 2.5).

Staff report a 'trial-and-error' approach to intervening with patients who call out repetitively (Inkley and Goldberg, 2016), and use medication (Landreville and Leblanc, 2010), attention or direct interaction (Van Camp et al. 2005; Landreville and Leblanc, 2010), and music (Van der Geer et al. 2009) as forms of intervention. Staff and carers feel they must spend a significant amount of time implementing interventions (Cassidy and Sheikh, 2002; Inkley and Goldberg, 2016), but struggle with minimal resources and inadequate staffing levels (Clifford and Doody, 2018; Inkley and Goldberg, 2016; Van der Geer et al. 2009). Staff have also been observed or reported to avoid or ignore patients who call out (Inkley and Goldberg, 2016; Van Camp et al. 2005). Cohen-Mansfield et al. (2016) found that only a small number of staff relied on information from family members prior to hospital admission, but that multidisciplinary teams (MDT's) are considered valuable.

In an acute hospital environment, one might argue that the requirement for effective care-planning to manage disruptive behaviours such as calling out should be paramount, however no study has reported that this exists. Only two of the papers discussed current practice in the context of an acute hospital setting, with one of those based in England (Inkley and Goldberg, 2016). This study lasted for just two weeks, therefore arguably did not gain a detailed account of calling out in the context of an acute hospital setting. However, the study found no systematic approach to care planning for people who call out in hospital, and a lack of training and support for nursing staff. The other hospital-based study (Cohen-Mansfield et al. 2012) involved a questionnaire, therefore relied on the accurate replies from respondents, when they might be inclined to report what they know they should do, as opposed to what they actually do.

TABLE 2.5 CURRENT PRACTICE REGARDING CALLING OUT

Study	Type	Description	Findings
Cassidy and Sheikh (2002)	Cross-Sectional	Observations conducted on a long-term care unit with 25 patients with BPSD including calling out.	Approx. 40% of staff time is spent implementing interventions and 'sundowning' has a significant effect on behaviour.
Clifford and Doody (2018)	Interviews	A qualitative descriptive study utilizing in- depth audio-recorded interviews of nine nurses, recruited from private and public care facilities.	Availability of staff, adequate time and financial restraints hinder nurses' ability to provide care when patients are displaying agitation including calling out. Access to ongoing education and being able to provide one- to-one care was valued as dementia- specific education changed nursing practice.
Cohen-Mansfield et al. (2012)	Qualitative	Questionnaire -physicians, psychologists and nurse practitioners-their approach to behaviour problems including calling out.	All relied on info from nursing staff/ assistants, and care team meetings in assessment; NPs more likely to consult with family members.
Inkley and Goldberg (2016)	Qualitative	Staff surveyed regarding their management strategies for verbal agitation.	Strategies included trial and error, distraction, engagement, reassurance, communication and familiarity. No systematic approach to care planning-lack of training, support on the ward, scarce resources.
Landreville and Leblanc (2010)	Qualitative	Acceptability ratings of direct interaction, risperidone differential reinforcement of incompatible behaviours, point of view of older people.	For nonaggressive vocalisations, direct interaction is the most acceptable intervention followed by differential reinforcement of incompatible behaviours and then administration of risperidone. For aggressive vocalisations, direct interaction and differential reinforcement of incompatible behaviours are more acceptable than risperidone.
Van Camp et al. (2005)	Overview	Descriptive analyses of disruptive behaviour including calling out exhibited by four older people in a nursing home and paid carers interactions.	Staff provided low levels of attention to residents overall. Three participants' disruptive behaviour neither increased nor decreased. For one participant, staff were more likely to remove their attention when they called out.

Van der Geer et al. (2009)	Secondary Analysis	Each interview focused on up to three psychogeriatric residents with verbal and vocal agitation. In total, 51 residents were discussed in the interviews.	Frequency of music, type, and degree of correspondence between the music being offered and the resident's preferences varied. Music is frequently played in nursing homes to people with dementia who call out. When offered to a group, music is not tailored to preferences of residents. When offered individually, musical preferences are generally taken into account.

2.9 Measurement

No validated measures were found in the literature search that assessed calling out as a single construct, separately from agitation or behaviours that challenge. Non-validated measures of calling out as a single construct in the literature included staff report (Davison et al. 2007) and observations of the number of vocalisations per minute (Beck et al. 2011). A report by Cohen-Mansfield and Martin (2010) reviewed all of the ways in which agitation can be measured (Figure 2.5), and many of these include calling out within the measure of agitation.

Many included studies within this scoping review utilise the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991), which appears to be the most popularly-used validated measure of calling out and perceived associated agitation (Beck et al. 2011; Davison et al. 2016; Deudon et al. 2009; Fox et al. 2012; Howard et al. 2007; Karel, 2016; Moyle et al. 2017; Ramadan et al. 1999; 2000; Rabinowitz et al. 2004; 2007; Shankle et al. 1995; Sust et al. 2015; Vermeiren et al. 2011). The CMAI measures agitation across three domains: aggressive behaviour, physically non-aggressive behaviour, and verbally agitated behaviour, with the verbally agitated behaviour items referring to calling out (Appendix A). It involves 29 items, and is scored based upon how frequently the behaviour occurs, from ‘never’, to ‘3+ times per hour’. It has been validated for use with nursing home residents, with high internal consistency and ‘marginally adequate’ interrater reliability (Finkel, Lyons and Anderson, 1992). Whilst it is popular within the literature, it only measures frequency of behaviours, and does not include a score for the severity of calling out, such as volume, content, or level of distress; nor does it track the nature of the calling-out.

The Pittsburgh Agitation Scale (PAS; Rosen et al. 1994) is a short measure, designed to be very quick and simple to use. It includes four items: aberrant vocalisation, motor agitation, aggressiveness, and resisting care (Appendix B). Interrater reliability and validity have been confirmed on a busy psychogeriatric inpatient unit, and a nursing home (Rosen et al. 1994). This tool measures the intensity of the behaviour, including volume and ability of caregiver to redirect; however, unlike the CMAI, it does not measure the frequency of calling out.

Assessment	# Items (estimated # tapping behavior problems)	Scale
Dementia Behavior Disturbance Scale (DBD) (Baumgarten, Becker, & Gauthier 1990)	28 (19)	5-pt frequency
Disruptive Behavior Scale (DBS) (Beck, 1997); (Chafetz et al., 1987)	45 (all)	presence/absence 9-point severity
	29 (21)	7-pt frequency
Cohen-Mansfield Agitation Inventory—nursing home version (CMAI) (Cohen-Mansfield, Marx, & Rosenthal, 1989)	29 (all)	7-pt frequency
Cohen-Mansfield Agitation Inventory—Community (CMAI-C) (Cohen-Mansfield et al., 1995)	36 (all)	7-pt frequency 7-pt disruptiveness
Cohen-Mansfield Agitation Inventory — Short form (CMAI-S) (Werner, Cohen-Mansfield, Koroknay, & Braun, 1994)	14 (all)	5-pt frequency
The Neuropsychiatric Inventory (NPI) (Leuchter et al., 1994)	83 (62)	4-pt frequency 3-pt severity 6-pt disruptiveness
Behavioral Syndromes Scale for Dementia (Devanand et al., 1992)	33 (all)	varies accd to item: 6 point severity, yes/no occurrence
Columbia University Scale for Psychopathology in Alzheimer's Disease (Devanand et al., 1992)	26 (5)	varies accd to item: yes/no, 2-pt severity 4-pt severity
Care Taker Obstreperous-Behavior Rating Scale (COBRA) (Drachman et al., 1992)	30 (all)	5-pt frequency 5-pt severity
Brief Agitation Rating Scale for Nursing Home Elderly (BARS) (Finkel, 1993)	10 (all)	7-pt frequency 7-point disruptiveness
Gottfries-Brane-Steen Scale (GBS) (Gottfries, Brane, Gullberg, & Steen, 1982)	29 (4)	7-pt severity
Behavior and Mood Disturbance Scale (BMD) (Greene, Smith, Gardiner, & Timbury, 1982)	34 (10)	5-pt frequency or severity
Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988)	19 (2)	3-pt severity
Dementia Behavior Scale (DBS) (Reding, Haycox, Wigforss, Brush, & Blass, 1984)	8 (1)	7-pt frequency
Multidimensional Observation Scale for Elderly Subjects (MOSES) (Fisman, Gordon, Feleki, Helmes, McDonald, & Dupre, 1988)	40 (10)	5-pt frequency
Neurobehavioral Rating Scale (NRS) (Levin, et al., 1987)	27 (4)	7-pt severity
Dementia Signs and Symptoms Scale (DSSS) (Loreck, Bylsma, & Folstein, 1994)	43 (29)	4-pt severity 4-pt frequency
Stockton Geriatric Rating Scale (SGRS) (Meer & Baker, 1966)	33 (8)	3-pt frequency

Figure 2.5: The ways in which agitation can be measured (Cohen-Mansfield and Martin, 2010)

Assessment	# Items (estimated # tapping behavior problems)	Scale
Dysfunctional Behavior Rating Instrument (DBRI) (Molloy, McIlroy, Guyatt, & Lever, 1991)	25 (19)	6-pt frequency
Functional Dementia Scale (FDS) (Moore, Bobula, Short, & Mischel, 1983)	20 (8)	4-pt frequency
Disruptive Behavior Rating Scale (DBRS) (Mungas, Weiler, Franzi, & Henry, 1989)	21 (all)	5-pt severity 3-pt distress to staff
Behavior Problem Checklist (BPC) (Niederehe, 1988)	52 (16)	5-pt frequency; 5-pt duration; 5-pt reaction
Brief Psychiatric Rating Scale (Overall & Gorham, 1962)	16 (5)	7-pt frequency
Rating Scale for Aggressive Behavior in the Elderly (Patel & Hope, 1992)	21 (19)	4-pt frequency
Global Assessment of Psychiatric Symptoms (GAPS) (Raskin & Crook, 1988)	19 (3)	5-pt severity
The Nursing Home Behavior Problem Scale (Ray, Taylor, Lichtenstein, & Meador, 1992)	29 (23)	5-pt frequency
Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (Reisberg et al., 1987)	25 (18)	4-pt severity
Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994)	4 (all)	varies; 5-pt severity for most
The Alzheimer's Disease Assessment Scale (ADAS) (Mohs, 1996)	21 (4)	5-pt severity
Ryden Aggression Scale (RAS) (Ryden, 1988)	25 (all aggression)	6-pt frequency
Sandoz Clinical Assessment-Geriatric (SCAG) (Shader, Harmatz, & Salzman, 1974)	19 (4)	7-pt severity
Overt Aggression Scale (OAS) (Silver & Yudofsky, 1991)	16 (all)	presence/absence (also, duration, timing and intervention items)
Behavioral and Emotional Activities Manifested in Dementia (BEAM-D) (Sinha et al., 1992)	16 (9)	5-pt combined severity and frequency
Dementia Mood Assessment Scale (DMAS) (Sunderland, Hill, Lawlor, & Molchan, 1988)	24 (2)	7-pt severity
Behavior Rating Scale for Dementia of CERAD (Tariot et al., 1995)	51 (17)	3-pt frequency
Revised Memory and Behavioral Problems Checklist (RMBPC) (Teri et al., 1992)	24 (10)	5-pt frequency 5-pt reaction
GIP: Observational Ward Behavioral Scale (Verstraten, 1988)	82 (about half)	4-pt frequency
Psychogeriatric Dependency Rating Scales (PGDRS) (Wilkinson & Graham-White, 1980)	26 (15)	3-pt frequency
Memory and Behavior Problems Checklist (MBPC) (Zarit & Zarit, 1983)	29 (11)	6-pt frequency 5-pt caregiver distress

Figure 2.5: The ways in which agitation can be measured (Cohen-Mansfield and Martin, 2010)

2.10 Interventions

There is currently little agreement regarding the management of calling out. Many popular dementia-nursing books include little or no information about how to manage calling out. Barton, Findlay and Blake (2005) summarise that pharmacotherapy (such as antidepressants or antipsychotics), behavioural interventions (such as staff training; or antecedent, behaviour, consequence (ABC) analysis), and adjunctive approaches (such as music or therapeutic touch therapy) have been reported in the literature. However; it is reported that the treatment of calling out currently requires a 'trial-and-error' approach (Barton, Findlay and Blake, 2005) and that there is not enough evidence base to make recommendations for practice (Randall and Clissett, 2016). For the purposes of this review, published interventions for calling out will be divided into 'pharmacological intervention studies' and 'non-pharmacological intervention studies'.

2.10.1 Pharmacological Interventions

Many pharmacological interventions have been trialled, and published results suggest that some drugs are effective (Table 2.6). Husebo et al. (2014) identified a large decrease in verbally agitated behaviours when introducing daily pain medication to 352 participants, despite the fact they did not appear to be in pain initially. Manfredi et al. (2003) also found significant reductions in calling out when using opioid medication as opposed to a placebo, but only in people over the age of 85, finding no significant difference for people aged 85 and under.

Kahraman et al. (2009) found that the largest improvement on the Pittsburgh Agitation Scale (PAS; Rosen et al. 1994) was of 'aberrant vocalisations' when using dronabinol (a man-made form of a natural substance in marijuana) to treat patients with dementia for agitation, aggression, and resistance to care.

In a small-scale study, Kopala and Honer (1997) found that risperidone (an antipsychotic), reduced 'persistent, purposeless vocalisations' to less than 20% of the initial baseline ratings in two case participants. This evidence could suggest that a cause of calling out might be related to symptoms of psychosis. In much larger successive studies following this, Rabinowitz et al. (2004; 2007) concluded that risperidone, produced significant effects in reducing 'repetitive sentences or questions' on the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991), and 'verbal outbursts' on the Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Reisberg et al. 1987). A randomised controlled trial being conducted by Howard et al. (2007) was suspended however, due to the United Kingdom Committee for Safety of Medicines recommending that risperidone and olanzapine not be used for the treatment of BPSD (Medicines and Healthcare products Regulatory Agency, 2004).

Porsteinsson et al. (2001) found improvements in Brief Psychiatric Rating Scale (BPRS) Agitation scores when using divalproex sodium (used to treat manic episodes associated with bipolar disorder, epilepsy, and migraine headaches) compared with a placebo, in 56 agitated people with dementia. However, a randomised controlled trial of 110 participants conducted by Tariot et al. (2005) found no improvement on the Brief Psychiatric Rating Scale (BPRS) Agitation factor when using divalproex sodium over six weeks.

Kim et al. (2000) trialled the use of citalopram, an antidepressant, in the reduction of calling out. They found that participants showed reduced levels of verbal agitation after the intervention, however there was no use of a control group. The experimental group involved only two participants, therefore there is a higher likelihood of the results of the study being due to chance.

Burns et al. (2011) in a randomised controlled trial of 114 people with Alzheimer's found no significant difference in the Pittsburgh Agitation Scale (PAS) between donepezil (Alzheimer's disease treatment), aromatherapy, and placebo use over a period of 12 weeks. This supported research by Howard et al. (2007), who also found no significant difference between donepezil and a placebo in 272 people over 12 weeks. Fox et al. (2012) studied 149 agitated people with Alzheimer's disease, and found no significant difference between memantine (Alzheimer's disease treatment) and placebo on the Cohen-Mansfield Agitation Inventory (CMAI) at six and 12 weeks.

Electroconvulsive therapy (ECT) involves controlled, electrically-induced seizures delivered to the brain. It has been reported to be successful in treating a wide range of mental disorders (Sinclair, 2019). Lau (2017) retrospectively examined five cases of patients who had previously called out, and found that their verbal agitation score significantly decreased after receiving ECT therapy. Sutor and Rasmussen (2008) also conducted a chart review of people who called out and were treated using ECT. Nine of the eleven participants showed an improvement, and in a follow-up of one year, re-admissions were also found to have decreased. Aksay et al. (2014) also reported positive effects from the use of ECT in severe pharmacotherapy-resistant agitation and calling out, and reported its use to be safe and effective. This suggests that whilst ECT is predominantly used for various treatment-resistant mental health disorders, it may also help to reduce calling out, or the negative emotions that cause it.

Some of the published study designs are weak, involving case studies with three or less participants (Amadeo, 1996; Bastiampillai et al. 2009; Fàzzari et al. 2015; Greve et al. 2016; Kim et al. 2000; Kopala and Honer, 1997; Roccaforte et al. 2000). There are a number of reports involving no control group, wherein the calling out could have resolved on its own in the same time. Antipsychotics could relieve psychosis or anxiety, and antidepressants could relieve anxiety or emotional lability. It is also likely that the sedative effects of psychoactive drugs play a role in the reduction of calling out.

Pharmacological intervention effectiveness could be explained using the unmet needs model, because if biological background factors such as anxiety or psychosis can be treated by medication, the patient may express their needs in a more 'socially acceptable' manner, or may not feel as distressed by their unmet needs.

However, whilst some of these studies support the use of drugs for reducing the occurrence of calling out, this form of treatment could reduce the patient's quality of life (Sivertsen et al. 2015), and increase the cost of care (Murman and Colenda, 2005). A study by Lövheim et al. (2006) also found that the choice of drug treatment is more related to the caregiver or their situation than the patient's symptoms. This could indicate that the person administering the drug treatment may not necessarily be working with the possibility of unmet need, and that pharmacological treatments, are more likely when the behaviour is treated as 'disruptive'. However, reducing strain in the carer might increase quality of care. Furthermore; research has indicated that overall effect sizes for antipsychotic drugs in the treatment of BPSD are low, and that the increased long-term risk of mortality in people with dementia outweighs the positive effects (Banerjee, 2009).

TABLE 2.6 PHARMACOLOGICAL INTERVENTIONS FOR CALLING OUT

Study	Type	Intervention	Findings
Aksay et al. (2014)	Case-Report	Use of electroconvulsive therapy for dementia-related agitation including calling out.	Significant clinical improvement- demonstrates the safe and effective use of electroconvulsive therapy in pharmacotherapy-resistant severe agitation in Alzheimer's disease.
Amadeo (1996)	Case-Series	Three patients therapeutic trial of the agent's progestagen acetate and luprolide acetate.	Verbal and physical aggression had ceased; activity disturbances such as agitation including calling out, pacing, and restlessness were markedly reduced.
Angelini et al. (2007)	Cohort Study	Measuring the improvement of BPSD including calling out with the use of atypical antipsychotics- risperidone (42.8%), olanzapine (31.3%), and quetiapine (25.9%).	Significant improvement of emotional and behavioural scales, five patients (15.6%) had extrapyramidal symptoms and 1 (3.1%) showed gynaecomastia.
Bastiampillai et al. (2009)	Case-Report	Clozapine used for a patient with agitation including calling out and thought disorder.	Hypersalivation as a result but less agitated, PRN medication no longer required and cognitive ability (MMSE) improved.
Burgio et al. (1992)	Cohort Study	Haloperidol or oxazepam, observations of frequency of behaviours per hour.	Modest reductions in disruptive vocalisations but not significant.
Burns et al. (2011)	RCT	Placebo medication and active aromatherapy; active medication and placebo aromatherapy or placebo of both.	There were no significant differences between aromatherapy, donepezil and placebo at week four and week 12, but importantly there were substantial improvements in all three groups with an 18% improvement in the Pittsburgh Agitation Scale [including calling out] and a 37% improvement in the Neuropsychiatric Inventory over 12 weeks.
Cruz et al. (2017)	Retrospective Study	Use of Buspirone for behavioural disturbances including calling out and verbal aggression.	68.6% of patients displaying verbal aggression or physical aggression responded to buspirone, with 41.8% being moderately to markedly improved using the Clinical Global Impression scale.
Fàzzari et al. (2015)	Case-Study	Case-study patient with agitation including calling out, maintenance electroconvulsive therapy for six months.	Behavioural control improved.
Fox et al. (2012)	RCT	Memantine versus placebo in 149 agitated people with Alzheimer's disease.	No significant difference between memantine and placebo using the CMAI [including calling out] at six or 12 weeks.
Greve et al. (2016)	Case-Study	Case study, one patient with agitation including calling out, trial of Prazosin.	Reduced agitation and aggression.

Howard et al. (2007)	Randomised parallel-group trial	272 agitated patients with dementia- donepezil compared with placebo. 12 week trial	No significant difference on the CMAI [including calling out] of donepezil compared with placebo
Husebo et al. (2014)	RCT	352 patients, daily pain treatment (acetaminophen, extended release morphine, buprenorphine transdermal patch, and/or pregabaline).	Verbally agitated behaviours showed the largest significant difference- responded the best to pain treatment for those agitated but not in apparent pain.
Kahraman et al. (2009)	Cross-Sectional	40 patients' charts diagnosed with dementia and treated with dronabinol for agitation, aggression, resistance to care and/or poor appetite.	Largest improvement on Pittsburgh Agitation Scale was of aberrant vocalisations [including calling out] (1.33 +/- 1.16).
Kim et al. (2000)	Case Study	Two cases verbal agitation, use of citalopram.	Case 1- considerable reduction in verbal agitation, case 2- approx 80% improvement in verbal agitation.
Kopala and Honer (1997)	Case Study	Two cases, persistent, purposeless vocalisations. An intrasubject on-off-on design was employed.	With risperidone treatment, the vocalizations diminished to less than 20% of baseline ratings.
Lau (2017)	Retrospective chart review	Electroconvulsive therapy for five patients with disruptive vocalisation	Verbal agitation score decreased from 6.8 to 2.3, with clinical and statistical significance.
Manfredi et al. (2003)	Repeated Measures Study	25 patients- opioid treatment for agitation including calling out vs. placebo.	Patients <85 years old -no significant differences in agitation level between placebo and opioid phases. Patients ≥85, agitation including calling out at end of opioid phase was significantly lower.
Porsteinsson et al. (2001)	Randomised study	56 agitated nursing home residents with dementia, using divalproex sodium versus placebo	Significant reduction in Brief Psychiatric Rating Scale Agitation [including calling out] scores for divalproex sodium versus placebo
Rabinowitz et al. (2007)	Retrospective	Post hoc exploratory analysis of data on 479 nursing-home patients from three 12-week, double-blind, placebo-controlled clinical trials.	CMAI- risperidone significantly more effective than placebo in treating repetitive sentences or questions. BEHAVE-AD, risperidone significantly more effective than placebo in treating verbal outbursts.
Rabinowitz et al. (2004)	Retrospective	Post hoc exploratory analysis of an integrated database from three randomized, controlled trials of risperidone versus placebo in treating 1150 nursing home residents with BPSD.	CMAI- risperidone significantly more effective in treating cursing or verbal aggression, repetitive sentences or questions, constant request for attention. BEHAVE-AD- risperidone significantly more effective in treating verbal outbursts and agitation.

Ramadan et al. (1999)	Case-Series	A before-and-after trial consisting of case series of 15 patients each followed for a period of four months. Use of paroxetine for agitation	All subjects = reduction in CMAI [including calling out] scores at end of first month of treatment with paroxetine. Further reduced at end of third month.
Ramadan et al. (2000)	Case-Series	Eight nursing home, seven community- oral doses of paroxetine.	All patients = reduction in CMAI [including calling out] scores at end of first month of treatment. Scores = further reduced in five patients at end of month three. Most patients tolerated paroxetine well.
Roccaforte et al. (2000)	Case Report	Patient with dementia in nursing home, constant disruptive vocalisations, treatment of electroconvulsive therapy.	By 5th treatment, disruptive vocalisations had completely stopped and had not returned over one year follow-up.
Shankle et al. (1995)	Cross-Sectional	12 patients, disruptive, aggressive, agitated were treated with low-dose propranolol monotherapy.	Subscales of the CMAI [including calling out] showed responders to have significant reductions in physical and verbal aggression/agitation and in pacing/wandering.
Sultzer et al. (1997)	RCT	28 agitated people with dementia assigned to trazodone or haloperidol.	More adverse effects in haloperidol group- Repetitive [calling out], verbally aggressive, and oppositional behaviors responded preferentially to trazodone. Symptoms of excessive motor activity and unwarranted accusations responded preferentially to haloperidol.
Sutor and Rasmussen (2008)	Case-Series	Chart review of agitated Alzheimer's disease patients treated with electroconvulsive therapy from 2001 to 2006.	9/11 = improvement or remission of agitated behavior including calling out. Hospitalizations 1 year after initial electroconvulsive therapy series decreased for all patients in the study.
Tariot et al. (2005)	RCT	Divalproex sodium in 110 agitated nursing home residents with Alzheimer's disease	No benefit of divalproex sodium for treatment for agitation including calling out in dementia at a mean dose of 800 mg/day over six weeks.

2.10.2 Non-Pharmacological Interventions

Literature identified regarding interventions for calling out have been categorised into six music, eight audio, five touch, six environmental, nine multi-component, and 14 individualised care plan intervention studies (Tables 2.7-2.12). Some were reported to be successful in reducing the rate, occurrence or severity of calling out (Bourgeois, 1997; Karlin et al. 2014; Woods et al. 2005), and some have shown weak (Buchanan and Fisher, 2002), or short-term (Vink et al. 2013) effects. Some of the studies reported uncertain results, such as small numbers of participants showing an improvement (Bedard and Landreville, 2011; Draper et al. 2003; Casby, 1994). Some found no significant reduction in calling out (Davison, 2016; Hawranik et al. 2008), and some even reported that a number of participants actually worsened after intervention (Miller et al. 2001; Garland et al. 2007; Edberg and Hallberg, 2001).

Casby (1994) conducted an intervention study focused on the use of music for three people who were agitated and calling out in a care home. Both classical music, and music of individual preference were played in phases, to find that two of the three participants decreased their calling out. This shows promising results, however with the very small sample size, the results may not be generalisable. In a larger-scale study, Cooke (2010) facilitated a live group music programme for 47 people in a care home who called out. No significant decrease in agitation, calling out, or anxiety was found for the participants, however an increase in verbal aggression was found. These studies highlight the unpredictable nature of the condition, as well as the unpredictability of possible interventions.

Lin et al. (2018) delivered 'white noise' to agitated people calling out living in dementia care centres. Ocean, rain, wind, and running water sounds were played; the control group received routine care. Based upon observations and questionnaires, the experimental group (28 participants) displayed significantly lower agitation than the control group (35 participants) after four weeks of receiving the intervention. There was no measure of the long-term effects of therapeutic white noise however. Cohen-Mansfield (1997) trialled three different audio interventions for people in a nursing home who called out repetitively. Videotapes of the persons' relative talking found a 56% reduction in calling out, live social interaction found a 46% reduction, and generalised music found a 31% reduction. A control group was included, in which no audio intervention was used, which found a 16% reduction in calling out. Results from this study suggest that a person calling out finds more comfort from social interaction with a person they know, rather than generalised audio intervention. This could infer that calling out is more likely to be caused by feelings of isolation or loneliness, as opposed to under-stimulation or boredom.

Woods et al. (2005) measured the effects of therapeutic touch on a number of behavioural symptoms of dementia, including calling out. The presence of therapeutic touch significantly decreased calling out, compared with placebo therapeutic touch (mimicked with no contact) and usual care. This study only measured the effects over a three-day period, however, and had around 20 participants in each group. Fu et al. (2013) utilised aromatherapy and hand massage in a study of 67 people residing in care homes who called out repetitively. Participants were either administered aromatherapy, aromatherapy and hand massage, or a placebo (which involved a plain water spray in place of essential oils) twice per day for six weeks. This study found no significant reduction in disruptive vocal behaviour for any of the groups. This shows that the presentation of calling out is variable, and that while some interventions might work for some people, sometimes, they won't necessarily work for all people, all of the time.

Environmental adaptation interventions generally showed overall positive effects. Harrison et al. (1990) in a case study of one person who called out repetitively, found that their repetitive vocalisations reduced when a dimmer light was used, and a lower volume. Mitchell et al. (2015), investigated the effects of a multisensory room on people who called out. This involved a room with tactile, auditory, and visual stimuli, all implemented with the aim of producing a calming and stimulating environment. The study found significant decreases on all subscales of the Pittsburgh Agitation Scale (PAS), including that of aberrant vocalisation, however levels of aggression did not significantly decrease.

Gozalo et al. (2014) delivered an educational program for staff members in nursing homes, aimed specifically at aggressive and agitated behaviours during bathing. It focused on improving communication techniques, the theory of unmet needs, person-centred care, and maximising comfort. Two hundred and forty people with dementia participated, and a significant reduction in the rate of verbally agitated behaviours was recorded. Although only tested during bathing, the principles of this study could be applied to more general situations in dementia care. Karel et al. (2016) also trained staff members working in community living centres and care home settings to manage challenging behaviours in veterans with dementia. The six-month training program included three components: 1) Identification of ABC's (Activators, behaviours, and consequences), 2) Identification of personally relevant and meaningful pleasant events, 3) Communication skills, including listening with respect, comforting, and redirection. In 71 agitated veterans with dementia, Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991) scores decreased significantly, with a reduction in symptoms of agitation.

Cohen-Mansfield et al. (2010) explored the effects of different types of stimuli presented to 111 mildly agitated nursing home residents with dementia. Effects were measured within three minutes of receiving the intervention. Stimuli included music, live social stimuli (a baby, a dog, or one-on-one socialising), simulated social stimuli (soft/robotic lifelike toys), self-identity (delivery of individualised activities based upon past occupation, hobbies or interests), work (such as stamping envelopes or folding towels) and manipulative (a stress-ball, fidget blanket, or jigsaw puzzle). Live social stimuli was found to be the most successful intervention in reducing total agitation, however all interventions were found to be more effective in reducing physical agitation than verbal. Therefore, physical agitation was suggested to be due to boredom, with verbal agitation due to other aetiologies such as loneliness, pain, or discomfort. This study did not investigate the effects of these interventions in people with severe agitation however.

Individualised interventions are the most popular and appear to be generally the most effective, however no specific type of intervention is largely superior to others. It is likely that contextual factors play a role in each individual trial, such as staff/ carer acceptance of the intervention.

Most of the included intervention studies are of poor design and quality. Some use staff report alone for measuring calling out (Davison, 2007; Fick et al.

2014; Yusupov and Galvin, 2014) despite the fact that there are validated standardised measures that include calling out within them (Cohen-Mansfield and Martin, 2010) which could have been used alongside staff report. Sample sizes are generally too small to show effects, for example Draper et al. (2003) report that 33% of the participants significantly benefitted from their intervention; however, there were only 18 participants in the study. Casby and Holm (1994) report positive effects from their intervention, however only two out of a total of three participants showed a reduced number of vocalisations over a series of ten-minute observation periods. Only four of the 50 included intervention studies conducted power analyses (Cooke, 2010; Fu et al. 2013; Hawranik et al. 2008; Remington, 2002), and one of these did not meet the requirements of the analysis (Hawranik et al. 2008). Many of the included intervention studies did not measure the long-term effects, or the practicality of delivering the interventions (Cohen-Mansfield et al. 2010; Lin et al. 2018; Woods et al. 2005)

There remains a distinct lack of research conducted regarding calling out as a separate behaviour in general hospitals. Of the included 48 non-pharmacological intervention studies within this scoping review, only one study was conducted in an acute hospital. Honda et al. (2016) introduced the multimodal intervention 'humanitude', which highlighted to hospital staff the importance of eye contact, verbal communication, and touch. The researchers measured participants agitated, aggressive, and calling out behaviours, and found that during the humanitude intervention, negative behaviours were dramatically and significantly reduced. It is likely that this intervention reduced feelings of distress in the participants, as it was seen as a form of comfort in an otherwise stressful environment.

Insufficient information about calling out is given in the existing intervention literature, meaning there is little theory behind why a certain intervention may work better than another. Many of the intervention studies have inadequate or no control groups, and most are underpowered. The fact that calling out has been found to decrease over time (Sloane et al. 1999) causes uncertainty regarding the effectiveness of non-pharmacological interventions.

TABLE 2.7 MUSIC INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Casby (1994)	Care home	Classical music and favourite music played presented in phases.	3	Significant decrease in calling out in 2 of the 3 participants.
Chang et al. (2010)	Care home	Background music played during lunchtime.	41	Significant reduction of physical and verbal aggressive behaviour with a one-week time lag.
Cooke (2010)	Care home	Live group music programme involving engaged song-singing and listening.	47	No significant decrease in agitation/calling out or anxiety, increase in verbal aggression over time.
Lin et al. (2011)	Nursing home	Group music intervention- 30 minutes twice per week for 12 weeks.	100	Verbally non-aggressive behaviour reduced throughout intervention and one month post-intervention, verbally aggressive behaviour only reduced at six weeks.
Ridder et al. (2013)	Nursing home	Six weeks individual music therapy versus six weeks standard care.	35	Agitation disruptiveness/calling out increased during standard care and decreased during music therapy.
Locke and Mudford (2010)	Care home	Case-study, music played through headphones.	1	Reduction in disruptive vocalisations.

TABLE 2.8 AUDIO INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Burgio (1996)	Nursing home	Environmental white noise audiotapes.	13	23% reduction in verbal agitation, tapes only used 51% of time.
Cohen-Mansfield (1997)	Nursing home	1. Videotape of family member talking, 2. In vivo social interaction 3. Music.	32	56% reduction of calling out in group 1, 46% in 2, and 31% in 3. Also a 16% reduction in the control group.
Garland et al. (2007)	Nursing home	Simulated family presence vs music, favourite music, family member talking on tape, and placebo (talking about gardening).	30	Responses varied widely, some reductions, some same, some became more verbally agitated.
Lin et al. (2018)	Care homes	White noise, including ocean, rain, wind and running water. 20 minutes a day for four weeks vs routine care	63	Agitated behaviour [including calling out] in experimental group improved significantly.
Miller et al. (2001)	Nursing home	Simulated presence therapy.	7	28 episodes (7 residents), significant decline in agitation/calling out level, six episodes (4 residents)- agitation stayed the same or worsened.
Runci et al. (2006)	Care homes	Language-relevant intervention, spoken in Italian or English.	3	One participant showed reduced verbally disruptive behaviour for Italian; one was same for both and one displayed verbally disruptive behaviour more for the Italian condition.
Struve et al. (2016)	Care facility	Intercessory prayer twice a day for 12 weeks	6	Four participants decreased disruptive behaviour/calling out, one increased, and one stayed the same
Van der Ploeg (2016)	Nursing homes	Skype versus landline telephone conversations with family members. Four 20-minute conversations over a two-week period, and then conditions were switched	9	Skype conversations lasted longer than landline telephone calls and mean agitation [including calling out] counts fell by 24.1 from baseline during Skype calls compared with 12.9 during standard calls. Neither difference proved statistically significant.

TABLE 2.9 TOUCH INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Fu et al. (2013)	Care homes	Aromatherapy (A) and hand massage (M), 3 groups A, A & M, and placebo (water spray) twice daily for six weeks.	67	No significant reduction in disruptive vocal behaviour for any group.
Hawranik et al. (2008)	Care home	RCT- therapeutic touch, simulated therapeutic touch, or usual care.	51	Physical non-aggressive behaviours significantly decreased however no difference for verbally agitated behaviours.
Moyle et al. (2017)	Care homes	PARO the robotic seal versus plush toy versus usual care.	415	Videos showed that PARO was more effective than usual care in improving agitation including calling out (3.33, 95% CI: 5.79-0.86, P = .008). When measured using the CMAI-SF, there was no difference between groups.
Woods et al. (2005)	Care homes	Therapeutic touch versus placebo therapeutic touch versus usual care.	57	Therapeutic touch significantly more effective at reducing behavioural symptoms of dementia [including calling out].
Yang et al. (2007)	Nursing home	Six-week acupressure treatment program.	20	Significantly lower agitation/calling out for acupressure.

TABLE 2.10 ENVIRONMENTAL INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Detweiler et al. (2008)	Care home	Wander garden, garden with lots of visual and tactile stimuli with a circular path.	34	Those who used the garden more displayed less agitated behaviour/calling out, however this was not significant, and physical incidents increased.
DeYoung et al. (2002)	Care home	Behaviour Management Unit-distraction, time-outs, activity diversion, getting to know patient, managing the environment.	32	Significant reduction in 'aggressive, agitated, or disruptive behaviours'.
Harrison et al. (1990)	Veterans ward	Bright light and noise intervention, differing light intensity along with differing levels of white noise volume.	1	Dimmer light and lower volume noise reliably decreased repetitive vocalisations.
Matthews et al. (1996)	Care home	Environmental manipulation, change from task-oriented approach to client-oriented approach.	33	Verbal agitation decreased, but other more infrequent agitated behaviours significantly increased.
Mitchell et al. (2015)	Geriatric psychiatric care unit	Multisensory room intervention, room with visual, tactile and auditory stimuli.	13	Significant decreases in all PAS subscales [including calling out] apart from the aggression subscale.
Sust et al. (2015)	Care homes	Daylight intervention, alternating basic illumination and intervention illumination.	60	CMAI scores [including calling out] increased with basic illumination and decreased with intervention.

TABLE 2.11 MULTICOMPONENT INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Buchanan and Fisher (2002)	Nursing home	Non-contingent reinforcement, reinforced behaviours of music and attention being presented based on fixed-time schedules	2	'Modest reduction' in disruptive vocalisation but not significant.
Davison et al. (2016)	Nursing home	Memory box, touch-sensitive computer screen incorporating personalised music, film clips, messages and photographs.	11	Reduction in anxiety and depression but not in CMAI [including calling out].
Gitlin et al. (2017)	Nursing homes	WeCareAdvisor™ provides a systematic approach to describe behaviors including calling out, investigate modifiable contributors, create treatment plans consisting of management tips tailored to symptom presentation, and evaluate effectiveness.	n/a	n/a (Protocol)
Gozalo et al. (2014)	Nursing home	Bathing without a Battle intervention, communication techniques, maximising comfort.	240	Significant reduction in verbally aggressive and agitated behaviours.
Honda et al. (2016)	Acute hospital	'Humanitude' A multimodal comprehensive care methodology, with eye contact, verbal communication, and touch.	3	The duration of aggressive behaviour including calling out of each patient during conventional care was 25.0%, 25.4%, and 66.3% and 0%, 0%, and 0.3% in Humanitude.
Karel (2016)	Nursing home	(a) Activators and Consequences that may reinforce or exacerbate the challenging Behaviors; (b) Pleasant Events: identifying and increasing personally relevant and meaningful pleasant events; and (c) Realistic Expectations and Communication Skills.	71	Significant reductions in CMAI [including calling out] scores (from 28.5 to 20.8)
Karlin et al. (2014)	Veterans nursing home	STAR-VA, an interdisciplinary behavioural intervention coordinated by Mental Health Providers completing specialized training.	64	Significant reductions in the frequency and severity of challenging dementia-related behaviours including calling out.
Remington (2002)	Nursing homes	Ten minutes of calming music, hand massage, both, or nothing.	68	Each intervention reduced agitation/calling out more than nothing, no benefit to combining interventions.
Vink et al. (2013)	Nursing homes	Music therapy versus recreational activities.	77	Both music therapy and recreational activities lead to a short-term decrease in agitation/calling out, but there was no additional beneficial effect of music therapy over general activities.

TABLE 2.12 INDIVIDUALISED INTERVENTIONS

Study	Setting	Intervention	Participants	Effect
Beck et al. (2002)	Nursing homes	Externally recruited nursing assistants helped patients with daily living activities	28	Baseline 'vocally agitated score' =50.53, after two months = 33.49
Bedard and Landreville (2011)	Care home	Individualized multicomponent intervention, addressing needs for comfort, social interaction and sensory stimulation.	26	Half of the participants (54%) improved their agitation/calling out during the intervention but only during treatment period.
Bourgeois (1997)	Community	Cue cards given to PWD including the answers to repetitive questions/requests.	14	Successful in reducing patient repetitions- long-term effects lasted for 16 weeks or more.
Cohen-Mansfield et al. (2010)	Nursing home	Presentation of: music, social stimuli, simulated social stimuli, and individualized stimuli based on the person's self-identity.	111	All reduced agitation including calling out but live social stimuli was most successful.
Cohen-Mansfield (2012)	Nursing home	Treatment Routes for Exploring Agitation (TREA), a method for individualising non-pharmacologic interventions.	125	Significant decline in verbal agitation.
Davison (2007)	Care homes	Personalised interventions based on meetings with the patient, focused on staff, the individual, or family.	31	Biggest reduction (suggested by staff) was verbally agitated behaviours.
Draper et al. (2003)	Nursing homes	Outreach service, a series of psychosocial interventions or medication recommended by a specialist team.	18	33% (six) patients showed visible improvement in verbally disruptive behaviour.
Deudon et al. (2009)	Nursing homes	Teaching input and clinical supervision for caregivers, supported by instructional cue cards, lasted for three months	272	On CMAI [including calling out], verbally non-aggressive behaviours fell by 0.47 in the experimental group compared with the control group which fell by 0.03
Edberg and Hallberg (2001)	Nursing home	Supervised implementation of individually planned care and systematic clinical supervision.	22	For the intervention group, vocal behaviours constantly present decreased- however, behaviours occurring in periods increased.

Fick et al. (2014)	Nursing home	Lollipop given when calling out displayed, average eight lollipops per day.	1	Effective daily for eight months. At the moments he used the lollipop he relaxed, mostly sat down in a chair and sometimes closed his eyes. Motor agitation decreased, his inner need to walk diminished and he stopped making repetitious noises and vocalizations.
Koder (2018)	n/a	Focuses on cognitive behaviour therapy as a valid framework in assessing and treating people with behavioural and psychological symptoms of dementia including calling out.	n/a	n/a
Palese et al. (2009)	Nursing homes	Nurses asked to keep diaries recording strategies and durations for each episode of disruptive vocalisation during allotted shift.	22	Managing disruptive vocalisation with multi-strategies reduces the duration of the disruptive vocalisation episode and increases the perceived effectiveness of management.
Teri et al. (2000)	Alzheimer's Disease Cooperative (ADC) study sites	Trained therapists taught behavioural management techniques for 11 weeks	41	Used ADCS-CGIC over 16 months. 20 participants repetitive vocalisations increased, eight didn't change, 13 decreased
Yusupov and Galvin (2014)	Community case report	The patient [who was calling out] was called to attention by calling her first name, then directed to take a deep breath and count to 10.	1	Reports of technique being beneficial, no analyses.

2.11 Summary of the Existing Literature

This scoping review identifies that the literature treats calling out as a form of agitation. This seems to stem from a seminal paper that makes significantly more references to 'wandering' than calling out (Cohen-Mansfield and Billig, 1986). Since this paper, there have been no studies to explore whether it is appropriate to conflate calling out with agitation. In other words there is little empirical evidence that conclusively establishes that people who call out are necessarily agitated. Calling out deserves to be treated as a distinct phenomenon suitable for study in its own right. If we do not fully understand a phenomenon being studied, it is best to examine it separately to avoid making potentially incorrect assumptions or conflating the nature of the behaviour. To imply calling out is 'agitated' assumes the emotions of the people exhibiting it, which may or may not be correct. Associating calling out with disruption, also assumes something about the behaviour that may also be hindering our understanding of the behaviour.

Intervention studies present trial-and-error attempts at reducing the occurrence, severity, or frequency of calling out. When presented together, effects appear to be mixed. Only one non-pharmacological intervention has been trialled previously in an acute hospital setting (Honda et al. 2016). The general hospital is a substantially different context to a long-term care residency; staff do not necessarily know the patient, and priorities are fixed on their acute illness and their discharge. The environment is busy, noisy, and unfamiliar to the patient; and patients are acutely ill, often with delirium superimposed on dementia, potentially triggering the onset of a multitude of physical, behavioural, and psychological problems.

Whilst there are a number of published studies in the literature, only two studies followed participants' journey longer term to evaluate the natural history of calling out. Sloane et al. (1999) reported that 66% of surviving patients called out less frequently after six months with no intervention, which adds further doubt to the effectiveness of included intervention studies that did not include a control group.

The definition of calling out is ambiguous and lacks scientific specificity with little grounding in empirical data. In order to develop and successfully implement an intervention, in-depth information must be known about the context in which the intervention is being delivered (Nilsen, 2015). What is required for an intervention in the acute hospital to be created and implemented is a description of calling out in the context of the hospital, how it develops, and its effects concerning the individual who is calling out as well as people in the proximity.

Overall, the assumption that calling out is directly related to agitation or other behaviours that challenge has not yet been justified in the literature. This causes the adopted definition to be inherently flawed, as it categorises the phenomenon using these assumptions. Little research has been conducted in the context of the acute hospital regarding calling out, with no existing research investigating the natural history of calling out in the acute hospital. Current intervention literature is inconclusive, and it might be that a lack of thorough knowledge and understanding about calling out and the contexts in which it is exhibited in is contributing to this. A piece of research that deconstructs what calling out is, how it manifests itself in the acute hospital setting, how caregivers currently manage it, and its natural history, is necessary to increase the chances of producing a more effective intervention.

2.12 The Research Question

Reviewing the existing literature has highlighted the necessity to return to the fundamentals of calling out. Too little is currently known and understood about calling out, especially how it presents itself in an acute hospital setting and its natural history. More must be known about the nature of calling out in the acute hospital, the beliefs surrounding it, and how people react or respond to it. The following research question was selected:

How does calling out present itself in the acute hospital and beyond discharge; what are the beliefs surrounding the behaviour, and how do others react or respond to it?

2.12.1 The Research Aims

To characterise calling out as a behaviour, and to characterise the patients who call out.

To observe and record the ways in which others respond to or manage calling out in the acute hospital.

To understand the knowledge, beliefs, and experiences of both hospital staff members and relatives of patients who call out.

To find out what happens to patients who call out after they are discharged from hospital.

Chapter Three

Research Methodology

3.1 Introduction

Chapters One and Two concluded that the literature lacks consensus on of the definition of calling out, how it manifests in an acute hospital setting, and its natural history. This chapter describes the study methodology selected to address the research question: How does calling out present itself in the acute hospital and beyond discharge, what are the beliefs surrounding the behaviour, and how do others react or respond to it? It begins by describing the epistemological challenges of undertaking health sciences research, and proposes the philosophical approach of critical realism as a solution. Critical realism was used to inform the study methodology, which included an ethnographic case-series. Chapter Four will then provide a detailed account of how these data collection approaches were performed in practice.

3.2 The Challenges of Health Sciences Research

Health sciences research focusses on the health of human beings. Healthcare is primarily governed by pathology; however, humans are not just physical beings, they are also social. Therefore, their experiences of illness and health care will be shaped not only by the physiological pathologies, but also the social context in which such pathology arises. A myriad of unobservable variables can influence human behaviour, and many of these will remain 'unknowable' (Plsek and Greenhalgh, 2001). Human beings are distinct from one another in their experiences, beliefs, and actions. They are part of, and interact with, a number of open and complex systems, that are continuously changing and adapting.

Social constructionism is a philosophical theory of knowledge; founded upon the principle that humans and society define reality (Leeds-Hurwitz, 2009). One example of a social construct is currency, as it would hold no value had societies not agreed that it should. Social Constructionists believe that there is no access to an external reality independent of our perceptions (Berger and Luckmann, 1966). Freidson (1970) argued that illness and disease are social constructions, as they are evaluative categories based upon social ideas of what is 'unacceptable' or 'undesirable':

> *When a physician diagnoses a human's condition as illness, he [sic] changes the man's [sic] behavior by diagnosis; a social state is added to a biophysiological state by assigning the meaning of illness to disease. It is in this sense that the physicians creates illness […] and that illness is […] analytically and empirically distinct from mere disease. (Freidson, 1970; p. 223)*

This suggests that there is social construction and human interpretation within all health sciences research, and to separate social construction from physiology would be to disregard the humanness of disease.

Dementia is fundamentally a biomedical phenomenon. Abnormalities in the brain of a person with dementia are observable and measurable, and in some instances can predict and explain the cognitive impairments they experience (Irving et al. 2018). Dementia does not exist independently from social construction, however. When a person is diagnosed with dementia, their status in society is negatively affected, due to the highly-placed value of independent functioning, cognitive skills, and ability to contribute economically within western society (Clare, 2002). This leads to stigma; which has a damaging impact upon help-seeking for dementia, alongside negative labelling which leads to discrimination in the health and workforce sectors (Phillipson et al. 2015).

Calling out is often seen as a challenging behaviour. Challenging behaviours are socially constructed, because the way in which we react to them, how we interpret them, and how we understand our own thoughts surrounding them influences how we understand the challenging behaviour (Brunero and Lamont, 2020). Calling out repetitively is a socially constructed 'problem', as it is often seen as a behaviour exhibited to attract the attention of others, and is received negatively by our social environment. It is different from dementia in that it is not something that can be medically diagnosed, however it produces observable effects that can be measured (such as volume). Calling out also has ‘truths’ that we cannot easily access, observe, or measure; such as the emotion of the person calling out, especially if they have severe communication problems due to dementia. This makes calling out a fitting problem for critical realism, as critical realist beliefs aid us in accessing unobservable meanings and social causation about a behaviour.

Most conditions or systems within health sciences research can be objectively identified and measured, but do not exist without social construction. Social constructions can influence the way in which biomedical conditions are viewed and responded to by society, and therefore they cannot be overlooked. An appropriate philosophy used within the health sciences must acknowledge that there are real, biological elements that exist independently of human interaction; but also that social constructions can affect the way in which we interpret, experience and respond to these biological elements.

3.3 Critical Realism

Critical realism is a philosophical perspective, which, unlike social constructionism, assumes that there is an external reality that exists independently of human perception (Porter et al. 2017). This means that critical realist ontology (the reality of the world) cannot be reduced to epistemology (our knowledge of reality), as human knowledge can only acquire a small part of a deeper and vaster reality (Fletcher, 2017). Some philosophers believe that reality is what can be perceived or demonstrated (positivists); some believe that there is no actual reality, and that all that exists is people’s interpretations of it (social constructionists). Critical realists draw on elements of both positions (Alvesson and Sköldberg, 2010). Human society is an ‘open system’ full of interwoven and complex systems or generative mechanisms, which interact together and separately (Bhaskar, 2013). A series of mediating and moderating variables are taking place in every situation or event (Sayer, 2000). This is combined with the fact that humans have free will to act in which way we please, and we may feel and act differently at certain times or occasions based upon our surrounding context, prior experiences, or emotions.

Critical realism seeks to ask why something happens as it does. This calls for the uncovering of 'structures' or 'generative mechanisms' within observations or data (McEvoy and Richards, 2003). For example, if we find that an intervention was successful in a particular study, we cannot assume it will work in the same way in a different context, as the world is an open and complex system (Edgley et al. 2014). Instead, what we must do is to attempt to identify the generative mechanisms that are acting to ensure the success of the intervention. For example, a group music intervention for people with dementia may only be successful due to the social dynamics within the group enhancing feelings of belonging.

For research concerning chronic illness, Williams (2001) states that a critical realist approach enables us to take the biological body into account, impaired or otherwise; consider the individual in relation to society; and reconsider beliefs surrounding identity, difference, and the ethics of care.

Bhaskar (2013) established the 'DREIC' approach to guide critical realist inquiry (Table 3.1). It sets out a framework for discovering 'real' generative mechanisms, which can help to produce theories about social systems.

Describe	Produce a description of the phenomenon in question
Retroduce	Imagine a mechanism which if it were true, would explain the phenomenon
Eliminate	Eliminate false mechanisms through further empirical analyses
Identify	Identify real mechanisms at work
Correct	Correct previous theories

Table 3.1: Bhaskar's (2013) 'DREIC' approach to guide critical realist inquiry

The approach lacks objective guidance on how to eliminate 'false' mechanisms, and it may be possible to construct arguments to support many different mechanisms (Isaksen, 2016). Kemptser and Parry (2014) suggest two methods for accepting or rejecting potential mechanisms. The first is to present the suggested mechanisms to respondents unconnected to the research, to seek disagreement or opposing opinions. The second is to publish the results and theories, allowing other researchers to test the proposed mechanism in other cases, whilst remaining aware of contextual differences.

Critical realism advocates the use of any method that is likely to enhance understanding of the complex pattern being investigated (Clark et al. 2008). Critical realist research can use qualitative, quantitative, or mixed methods to achieve this, and advocates using a variety of sources. It can involve an investigative approach that moves from quantitative methodology, to qualitative, and then back to quantitative, or vice versa (Clark, 2015).

3.4 Summary of Philosophical Underpinning

Critical realism is suitable for research within the health sciences, where phenomena often have a physical or biological basis, yet they occur within society, and are ultimately influenced by social constructions. It can be established in dementia research that the person's brain changes, but we also know that there is a social effect to this diagnosis, associated with social behaviour no longer seeming 'normal'. Calling out is also a critical realist issue, as it can be observed in itself and measured easily, however there are also undeniably hidden 'truths' or generative mechanisms which cause calling out to occur, such as the emotion or beliefs of the person calling out, as well as the possibility that the behaviours of those around them could be causal. This can be a hard phenomena to access, due to the high likelihood of communication problems in people with severe cognitive impairment.

I believe that there is something real which we can point to in relation to calling out, such as changes to the brain, or observable behaviour of calling out; and that there is also transitive knowledge associated with the meanings given to calling out, and the underlying causes of it. Therefore, I would like to study both the physiological and observable aspects of the calling out, but also the social impact and meanings given to the condition, because this shapes behaviour and experiences.

Critical realism allows for the pragmatic use of methods, and guides a constructive way of thinking. It can support the development of successful interventions, as the focus on generative mechanisms ensures applicability in different contexts, as opposed to standardised 'one size fits all' interventions, which were shown in Chapter Two to produce mixed and uncertain results. Critical realism can be operationalised using the 'DREIC' (Describe, retroduce, eliminate, identify, and correct) approach to uncovering generative mechanisms.

In summary, calling out is a behaviour related to dementia, and therefore has biological influences. However, calling out is also a socially constructed 'problem', as it only becomes a problem when a social group decides that it is. Therefore, both the positivist and the social constructionist elements located within the philosophy of critical realism are acknowledged. Critical realists maintain that research should use a variety of sources to obtain data, and must emphasise both the observable aspects of the phenomenon, and the social and physical environment or context in which it occurs, to explain why or how it occurs (the generative mechanisms). Based on these principles, an ethnographic case-series methodology was proposed.

3.5 Ethnography

Ethnography is the methodical investigation of people, cultures, and contexts. It translates from Greek as 'writing about people' (Madden, 2017), and concentrates on perceptions, interactions, and actions, with the aim of understanding the culture of a social group (Emerson et al. 2011). Ethnography is conducted through immersive observation of a setting, focusing on how the people within it carry out their lives and daily activities, and the things that they see as meaningful or important (Atkinson et al. 2001). LeCompte and Schensul (2010) identify six methodological characteristics of ethnographic research. These were: 1) direct participant observation 2) descriptive field notes 3) retrieval of multiple sources to confirm the data, or 'triangulation', 4) research conducted in unmanipulated, naturalistic settings, 5) long-term residence and total immersion in the field, 6) focus on small and bounded populations. LeCompte and Schensul (2010) suggest that ethnography should be used to define an unclear problem; to identify unknown or unidentified participants, populations, stakeholders, or boundaries of a population; explore factors associated with a problem to identify, understand, and address them; and to design measures that match the characteristics of the target population.

Madden (2017), contended that ethnography does not lead to neatly-bounded research, stating that the subject of enquiry (humans) is too ‘messy’ to permit this. The ethnographer must conduct the research in the most practical way, and not be bound by precise or strict methodological rules, but maintain the systematic collection and analysis of data in an internally consistent way. To produce a holistic portrayal, multi-method designs are often conducted. Whitehead (2004) suggested the addition of quantitative data alongside qualitative, to strengthen both internal and external validity of the data collected.

Ethnography is an ideal methodology for understanding environments, as it provides a picture of what happens (LeCompte, 2002). It is ideal for exploratory research due to its iterative approach, allowing the researcher to ‘hone in’ on emerging ideas. The purpose of ethnography is not to attempt to create generalizable data, but instead to consider the data in reference to the context of the situation; to uncover beliefs and experiences that can help to shape future research (Dewan, 2018).

The application of ethnography in healthcare settings has gained popularity, due to growing recognition of its value (Goodson and Vassar, 2011). Ethnography provides ability to identify and critique links between individual interactions, actions and social norms taking account of the context in which they are occurring (Savage, 2006).

Edwards et al. (2014) reported that critical realism offers a robust philosophical grounding for ethnographic research, with the understanding that critical realist ethnography should seek to explain rather than merely describe social phenomena. Ethnographic research uses similar methodological values to critical realism, such as data triangulation (LeCompte and Schensul, 2010) and the belief in methodological pragmatism (Madden, 2017). In the present study ethnography allows investigation of how others react or respond to calling out, people’s beliefs about the behaviour, and how calling out manifests itself and is perceived and responded to within the context of the acute hospital.

3.6 Case-Series Research

A case-series design follows a group of patients who have a similar diagnosis or condition, or who are undergoing the same procedure (Kooistra et al. 2009); it does not require a control group. Case-series involve up-close, in-depth, and detailed examinations of each subject of study, as well as the related contextual conditions. Case-series studies are considered the 'first line of evidence' for when there is little existing knowledge about a medical phenomenon, with a high sensitivity for detecting novelty (Vandenbroucke, 2001).

The initial protocol for this PhD was a cohort study. This is similar to a case-series design, however would have involved recruiting a much larger sample of patients, and comparing various measures with a large sample of patients who did or did not call out. The lack of existing literature surrounding people who call out in the acute hospital meant that there was insufficient knowledge to inform the development of a cohort study. Little prevalence data were found in the scoping review to provide estimates of sample sizes for a cohort study. Moreover, it was unclear how long calling out might persist during an admission, how it was interpreted, what made it 'problematic', and what family or professional care givers did about it. Case-series research could obtain more in-depth data per individual participant than cohort studies, and could incorporate additional methodologies within its design, such as the use of ethnography. This was in-line with critical realist philosophy (Easton, 2010).

3.7 The Chosen Study Methodology

The intent of a traditional or conventional ethnographic study is to determine how the culture works, rather than to understand an issue or problem using the case as a specific illustration (Creswell and Poth, 2017). A case-series methodology enhances the ability to focus on the specific individuals. I employed an ethnographic case-series study design; in order to achieve a comprehensive description of the individual people who call out, those around them caring for them, and an immersed exploration of the context. Structured and unstructured observations gave information on what people who call out actually did in practice. They also allowed for measurement of the types and duration of calling out. Interviews elicited relative and staff member views and beliefs about the condition of calling out, and what they did about it.

3.8 Summary of the Study Methodology

Critical realism has shaped the development of an ethnographic case-series study design. This aimed to provide a comprehensive insight into individual patients who call out repetitively, and to viably facilitate observations and interviews in this setting. Ethnographic methods influenced the research design, to effectively capture the context in which calling out is manifested.

Chapter Four

Research Methods

4.1 Introduction

Chapter Two previously identified the research gaps on calling out, revealed though a scoping review; it concluded that research was lacking in the acute hospital which characterised calling out and examined its natural history. Chapter Three established that critical realism was a useful approach to inform the research methods and analysis, using an ethnographic case-series study design.

This chapter describes the research methods for the study. Study sites and participants will be described, along with data collection and analysis processes, including the methods for identification and recruitment of participants. This study recruited a vulnerable patient group; therefore, a number of ethical considerations are described. A deliberation on the credibility of the data collection and analysis methods concludes the chapter.

4.2 Summary of the Method

An ethnographic case-series study of 30 cognitively impaired patients who called out repetitively was conducted across ten acute geriatric medical wards at two hospital Trusts. Structured and unstructured observations were undertaken of patients, their care, and their environments; and patient medical and nursing notes were examined. Follow-up was conducted 90 days from the date of admission. Healthcare professionals were interviewed about their knowledge, beliefs and practice of working with older, cognitively impaired patients who called out in an acute hospital setting. Relatives were also interviewed about the patient participant, their calling out and their care.

The design for this study was emergent, allowing for adaptation of methods, based upon the direction the data appeared to be taking. Whilst data analysis occurred simultaneously alongside data collection, a preliminary analysis phase was undertaken at a mid-point during data collection, and presented to a steering group of healthcare professionals and patient and public involvement (PPI) representatives. Data collection then recommenced following advice from the steering group allowing for adaptation of topic guides and refining of factors of interest.

Ethical approval for staff interviews was attained through the University of Nottingham's Faculty of Medicine and Health Sciences Research Ethics Committee (Ethics reference number: K14112016, IRAS project ID: 213039).

Ethical approval for the remainder of the protocol was attained through the NHS Health Research Authority Yorkshire and the Humber- Bradford Leeds Research Ethics Committee (REC Reference: 16/YH/0493, IRAS Project ID: 212966).

4.3 Participants

4.3.1 The hospital sites

Participants were recruited from acute hospital sites in two National Health Service (NHS) Trusts (Site One and Site Two). This involved ten wards caring specifically for older people, comprising 287 patient beds.

Data collection first began at site one for three months, before the team discussed the idea that a second site would be useful for the data collection, therefore approval was sought and attained for the addition of site two. This was in order to increase sampling variability, availability of participants, and to increase the protection of confidentiality. The two sites also had different approaches to the use of single rooms (usually referred to as 'side rooms') due to their layout, allowing for the critical comparison of these differences.

4.3.1.1 Site One

Data were collected from seven Healthcare of the Older Person (HCOP) wards within Site One (Figure 4.1). One of these wards was a medical and mental health unit, one a post-acute orthogeriatric ward, and the rest were acute general HCOP wards. The total number of beds across the wards during data collection was 215. The wards all had four multi-bed, single-sex bays, each holding six patients per bay. All wards had two to four ‘side rooms’. Side rooms would predominantly hold one patient, a small number held two. Use of side rooms was generally reserved for patients who needed to be separate from other patients due to infection control, or the patient was receiving end of life care, resulting in a need for increased privacy. Bays were all open and attached to the same corridor, therefore if it was noisy on one bay, the sound could easily be heard from the next.

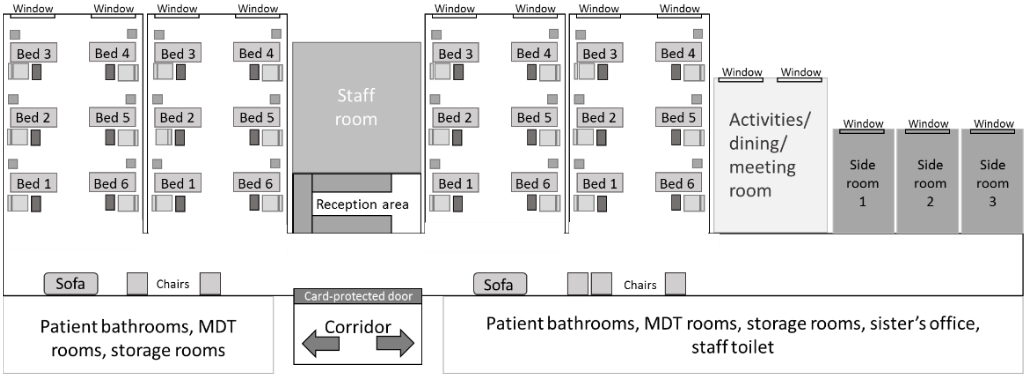


Figure 4.1: A diagram of a typical ward on Site One
MDT: multidisciplinary team

Visiting hours on these wards were from 11am until 8:30pm, which was three and a half hours longer than the majority of other wards at this site. All wards on Site One were locked at all times, requiring either staff card access, or visitor authorisation through an intercom system. A staff member would need to press a button behind the reception area to let visitors out.

4.3.1.2 Site Two

Data were collected over three Department of Medicine for the Elderly (DME) wards at Site Two (Figure 4.2). One of these wards was a specialist dementia ward, and two were acute general older persons’ wards, with a total of 72 beds. The wards all had three to four multi-bed single-sex bays, each holding four patients per bay. All wards had ten to 12 side rooms. Side rooms in Site Two were not restricted specifically to patients requiring infection control or privacy. The structure of these wards meant a higher proportion of patients were in a side room than at Site One. Bays were walled, with the ability to shut the door, however doors were rarely closed. Nonetheless, the bays were much quieter at Site Two than at Site One, due to the walls and the layout.

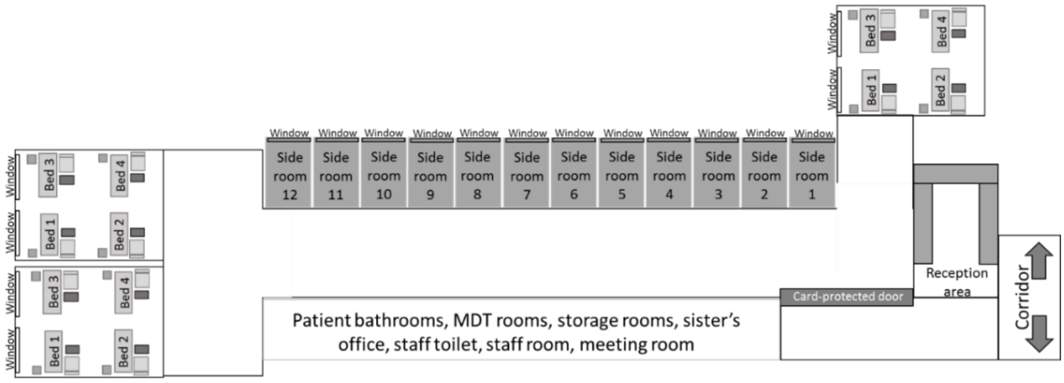


Figure 4.2: A diagram of a typical ward at Site Two
MDT: multidisciplinary team

Visiting hours were from 11:30am- 7pm. Wards on Site Two were less securely locked than on Site One, with a red or green light above the intercom system to display whether the door to the ward was locked or not. To leave the ward when locked, visitors would press a large green button by the door in order to unlock it. Occasionally, staff would tape a sheet of paper over the button in order to conceal the exit mechanism from patients who had been trying to leave.

4.3.2 The Steering Group

A steering group comprising five independent healthcare professionals with expertise in dementia (a physiotherapist, a physician, an occupational therapist, a specialist dementia nurse, and a consultant psychiatrist) and a Patient and Public Involvement (PPI) member met during data collection to discuss the development of themes for analysis. This was to allow for the emergent design of the study to develop.

4.3.3 Participant Eligibility

Patient participants were admitted as an unplanned (emergency) admission onto a study ward. Patients were selected based on an eligibility criteria. When multiple patients were available for recruitment, they were selected based upon the soonest availability of the personal consultee (family member from whom agreement to participate was sought).

4.3.3.1 Patient Participant Eligibility Criteria

Patients were deemed eligible to take part as a patient participant if they:

- Had been admitted onto a ward caring for older people on site one or site two.
- Were lacking mental capacity as assessed by the Mental Capacity Act (2005).
- Were cognitively impaired (Montreal Cognitive Assessment; MoCA <20/30; Nasreddine et al. 2005), or had a diagnosis of dementia or delirium in their medical notes.
- Were observed to have been calling out, identified by a score of 1-4 on the Pittsburgh Agitation Scale- Aberrant Vocalisations (PAS-AV; Rosen et al. 1994), (from “low volume, not disruptive in milieu, including crying” to “extremely loud screaming or yelling, highly disruptive, unable to redirect”).

Patients were excluded from the research study if they:

- Had a plan in place for discharge from the ward.
- Were thought by the clinical team or their family to be too unwell to participate in the study, especially if thought likely to die within a week.
- Had no family member willing and able to provide consultee agreement, and no staff member willing or able to provide nominated consultee agreement.

4.3.3.2 Relative Eligibility Criteria

Patient participants’ relatives were eligible to be interviewed if they gave verbal confirmation that they believed they knew the patient well enough to answer questions about the patient’s life before admission.

4.3.3.3 Staff Member Eligibility Criteria

Staff members were eligible to participate in the interview if they:

- Were paid staff working on an older person’s ward at either of the two sites.
- Routinely worked with older patients who call out.

Staff members were excluded if they:

- Were working on the ward on a temporary basis as agency staff, or if they were a student.
- Had been a member of the steering group.

4.3.4 The Sample Size

A sample size of 30 patient participants was chosen. This number is typically used in qualitative research to gain sufficient variability in a sample (Ritchie et al. 2003) alongside reducing the chances of missing factors of interest (DePaulo, 2000).

The initial intention during study development was to recruit one relative for each patient participant; however, some relatives were expected to have other commitments, and some patient participants were anticipated to have no immediate family. Therefore, the aim was to recruit as many relatives as possible, with a goal of 15. The staff member recruitment goal was also 15, to produce a total goal of 30 interviews. Due to the specific nature of the questions being asked in interviews, these sample sizes were expected to produce suitable variability, whilst remaining within my capacity limits as a lone researcher.

Data saturation is a contentious issue within qualitative research (O'Reilly and Parker, 2012), however to those who support the notion, it involves the belief that further recruitment of participants will provide nothing new for the research, as all possible beliefs around the topic of interest have been recorded (Fusch and Ness, 2015). This ensures the ability to replicate the study (Walker, 2012), thus increasing the reliability of the study. The decision of data saturation can be made via ongoing data analysis ascertaining that no new codes are being created, with the knowledge that no new additional information is being obtained (Guest et al. 2006). Due to differences in study designs, there is no fixed number of participants said to produce data saturation, with the main focus being on the depth of the data, as opposed to the size (Burmeister and Aitken, 2012). It is suggested however, that data saturation is quicker to achieve when the same questions are asked to all interview participants, to avoid a 'constantly moving target' (Guest et al. 2006).

Around two-thirds of the way through the data collection for each participant group, I began to realise that less new codes were being generated, with many new codes being similar to ones already listed (such as 'loneliness', and 'social isolation'). Therefore, I believe I reached data saturation by the end of the data collection in this study.

4.3.5 Recruitment

4.3.5.1 Patient Participant Recruitment

Prior to commencing data collection, I spoke to ward managers about involving their ward in the study, including the expected involvement of staff once a patient was recruited from the ward. All agreed to participate.

To identify participants, I visited the wards, and spoke to staff who were able to identify patients who called out. Eligibility of patients was assessed by confirming with staff that the patient had been calling out, then by asking if the patient was cognitively impaired; confirmed, if necessary, by checking medical case notes. Usually, I would observe the patient calling out during this interaction, and could confirm the score of 1-4 on the PAS-AV. If the patient was sleeping or not calling out at that time, staff were asked about the behaviours the patient had been exhibiting, and to describe the behaviour. Mental capacity was assessed by introducing myself to the patient, then describing the study whilst assessing their understanding, retention and use of information to make a decision, and ability to communicate the decision, following the requirements of the Mental Capacity Act (2005). A Capacity Assessment Form (Appendix C) was used to document the patient's capacity.

Upon confirming the eligibility of suggested patients, I would identify the nearest relative's contact details, which were usually provided in the nursing documentation. I would then introduce myself to the relative via telephone call, explain the study briefly, and that their relative had been recommended by staff. If the relative was happy to continue the conversation, I would ask them when they would next be coming in to see their relative, so that I could give them a Participant Information Sheet for Consultees (Appendix D) and answer any questions they have about the research. The aim was to get an information sheet to the relative as promptly as possible, therefore the form was sometimes emailed to the relative, or an envelope was given to the ward receptionist to give to the relative in cases where I would not be available. In these cases, a cover letter was included to introduce the information sheets (Appendix E). The most successful way of gaining agreement was through face-to-face contact.

The study was discussed with the relative, and they were asked if they had any further questions. If the relative did not know of any reason why the person with dementia would not have wanted to take part in the study, they were asked to sign the consultee advice forms (Appendix F). In cases where no relative was available, a staff member who knew the patient, and was not involved with the research, was asked if they knew of any reason why the patient would not want to take part in the research, or should otherwise be excluded. If they knew of no reason, they completed a consultee advice form.

Posters were displayed on the wards during observations (Appendix G). These notified patients, family and staff that an observational study was being conducted, with an invitation to notify myself (via provided telephone or email contact information) if they had concerns or did not want to be included. No concerns were raised.

Recruitment took place over 12 months. New patients were recruited on a time-point basis, generally 2-4 patients were actively involved at any one time, with a maximum of 6 (Figure 4.3). This was to ensure that enough time was spent observing each patient, to allow for contemporaneous in-depth data of each participant.

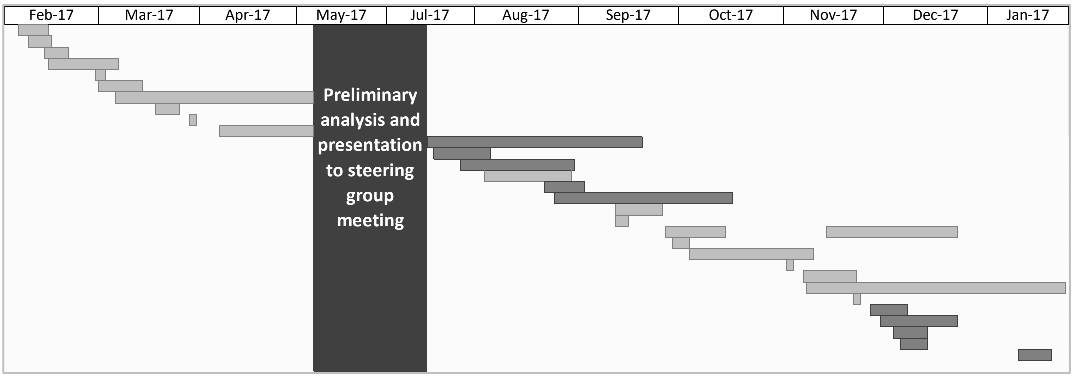


Figure 4.3: A chart to show the numbers of patients being observed at the sites at all time points during data collection
The light grey lines indicate participants who were recruited at site 1, and dark grey for site 2

4.3.5.2 Relative Recruitment

Patient participants' relatives were asked if they would like to take part in an interview about the patient participant, and given an information sheet (Appendix H). Two patient participants had no family members; therefore, 28 relatives were asked. Ten agreed to participate and signed a consent form (Appendix I); one of these declined to be audio recorded, therefore written notes were taken during the interview. Relatives declined to be interviewed due to being too busy (n=7), or the patient participant had either died or had a severe health decline, therefore they felt too upset, or did not feel it was appropriate to be interviewed due to their change in circumstance (n=6). Other reasons included a perceived lack of knowledge of the patient participant or their calling out (n=3), a relative being uncontactable after signing nominated consultee agreement (n=1). One family member was not interviewed as safeguarding concerns had been raised about his behaviour towards his mother, and a research interview was considered inappropriate whilst this investigation was ongoing.

4.3.5.3 Staff Member Recruitment

To recruit staff members, I would first introduce myself to the ward manager and explain that I would like to interview staff about their knowledge, experiences and beliefs of calling out. Staff members who worked regularly with patients who call out were recruited either by recommendations from other staff members, or via direct approach from myself. Staff were given an information sheet (Appendix J), and time to consider whether they wanted to be involved. If willing, they signed a consent form (Appendix K). They were also assured of their anonymity and it was made clear that they could withdraw at any point. Some ward managers would allow me the use of their office on the ward to interview staff members, therefore seven staff members were interviewed during their shift. Eight staff members were interviewed either in a staff room, meeting room, or a pre-booked room during their lunch break, or outside of their working hours.

4.4 Data Collection Process

Data collection ran from the 12th of January 2017, to the 23rd of January 2018, with final follow-ups completed by the 6th of March 2018 (Figure 4.4). There was a nine-week preliminary analysis phase within this period, from the 8th of

May 2017, to the 10th of July 2017, to allow for iterative analysis and steering group feedback, alongside ethical applications to extend the study to a second site.

After the first ten staff interviews, and the first ten patient participants had been recruited and discharged, the nine-week preliminary analysis and consultation phase began. Data collection for Site Two commenced on 10th July 2017 in which ten participants were recruited, and a further ten participants were recruited from Site One. All remaining staff interviews from 10th July 2017 were conducted with staff members at Site Two.

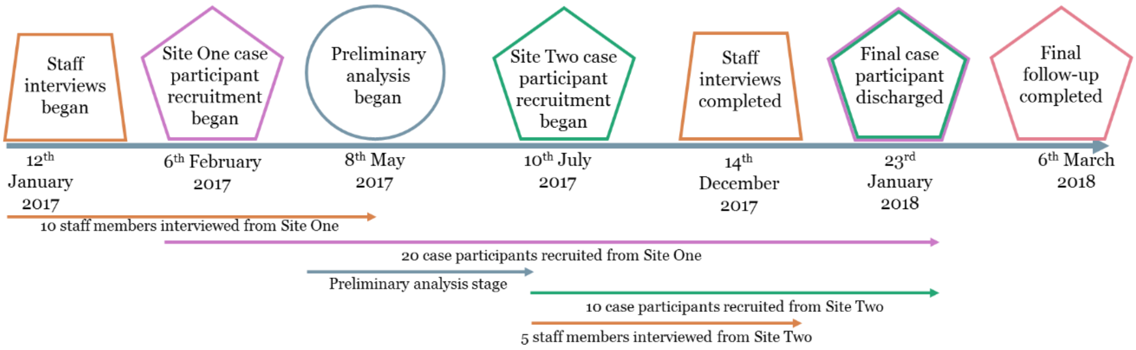


Figure 4.4: The study data collection process

4.4.1 Quantitative Measures

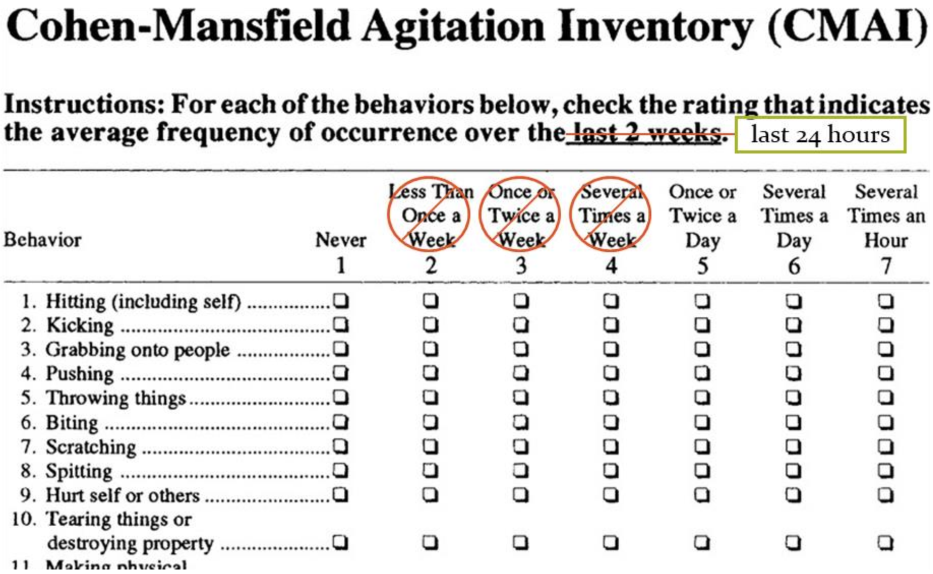
Quantitative data were collected from the patient participants within the first four days of recruitment. Some data were collected just once at baseline, and some every few days. Measures utilised patient participant report, staff or relative report, and researcher observation.

4.4.1.1 Calling Out

Measures of the severity and frequency of the calling out were recorded regularly throughout the patient participant's hospital stay. They were conducted alongside unstructured observations, and systematic scrutiny of nursing documentation. I observed patient participants every one to three days for the first two weeks from recruitment, and then every three to seven days for the remainder of their admission.

Cohen-Mansfield Agitation Inventory (CMAI)

The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991) is the most widely used measure of agitation (Levy et al. 2017). The CMAI involves 29 items relating to agitation, and assesses the frequency of these behaviours (Appendix A). Items for this measure are based on behaviours observed over the two weeks prior to the date of the test. For the purposes of this study, a daily time frame was used (asking if the behaviour had been observed in the previous 24 hours), in order to track changes across the admission. This is referred to as the CMAI-D. Item scores for the original CMAI range from ‘never’ to ‘several times an hour’. For the purpose of the CMAI-D, some of the mid-range ratings were removed, including ‘less than once a week’, ‘once or twice a week’, and ‘several times a week’. Therefore, for the daily measure, frequency ratings included ‘never’, ‘once or twice a day’, ‘several times a day’ and ‘several times an hour’ (Figure 4.5).



Cohen-Mansfield Agitation Inventory (CMAI)

Instructions: For each of the behaviors below, check the rating that indicates the average frequency of occurrence over the ~~last 2 weeks.~~ last 24 hours

Behavior	Never 1	~~Less Than Once a Week~~ 2	~~Once or Twice a Week~~ 3	~~Several Times a Week~~ 4	Once or Twice a Day 5	Several Times a Day 6	Several Times an Hour 7
1. Hitting (including self)	☐	☐	☐	☐	☐	☐	☐
2. Kicking	☐	☐	☐	☐	☐	☐	☐
3. Grabbing onto people	☐	☐	☐	☐	☐	☐	☐
4. Pushing	☐	☐	☐	☐	☐	☐	☐
5. Throwing things	☐	☐	☐	☐	☐	☐	☐
6. Biting	☐	☐	☐	☐	☐	☐	☐
7. Scratching	☐	☐	☐	☐	☐	☐	☐
8. Spitting	☐	☐	☐	☐	☐	☐	☐
9. Hurt self or others	☐	☐	☐	☐	☐	☐	☐
10. Tearing things or destroying property	☐	☐	☐	☐	☐	☐	☐
11. Making physical							

Figure 4.5: An image to show the original CMAI with the minor adaptations that were made for use in the study as a daily measure

The CMAI-D ratings were collated for each patient participant and a structured CMAI measure was completed based on the CMAI-D ratings for the period of the patient participants’ admission.

Pittsburgh Agitation Scale (PAS-AV)

The Pittsburgh Agitation Scale (PAS; Rosen et al. 1994) is a 4-item measure of agitation, which includes observations of ‘aberrant vocalisation’ (repetitive requests or complaints, nonverbal vocalisations, e.g. moaning, screaming), motor agitation (pacing, wandering, moving in chair), aggressiveness, and resisting care (Appendix B). For this study, only the ‘aberrant vocalisation' scores were recorded, in order to measure the severity of the calling out for each patient participant. Scores ranged from zero (not present) to four (extremely loud screaming or yelling, highly disruptive, unable to redirect).

4.4.1.2 Cognitive Ability

Patient participant's level of cognitive impairment, presence and severity of delirium, and manifestation of frontal executive dysfunction were measured. These scales aimed to characterise the severity and nature of the cognitive impairment.

Delirium Rating Scale-Revised-98 (DRS-R-98)

The Delirium Rating Scale-Revised-98 (DRS-R-98; Trzepacz et al. 2001) is a 16-item clinician-rated scale with a maximum total score of 46. It relies on having observed the patient for at least 2-4 hours. Severity items are rated on a scale of 0-3 (sleep-wake cycle disturbance; perceptual disturbances and hallucinations; delusions; lability of affect; language; thought process abnormalities; motor agitation/retardation; orientation; attention; short/long term memory; visuospatial ability). Diagnostic items are rated on a scale of 0-2 and 0-3 (temporal onset of symptoms; fluctuation of symptom severity; physical disorder). DRS-R-98 scores were documented on a score sheet (Appendix L). A cut-off score of 18 or more to indicate presence of delirium has been selected for the study, as this was found to have a sensitivity of 92%, and specificity of 95% (Trzepacz et al. 2001). Higher scores indicate more severe delirium. The DRS-R-98 has high inter-rater reliability, sensitivity, and specificity for detecting delirium in hospital populations (Meagher et al. 2007).

Frontal Assessment Battery (FAB)

The Frontal Assessment Battery (FAB; Dubois et al. 2000) is a short screening tool, used to assess frontal lobe functioning (Appendix M). It takes around 10 minutes to administer; and involves six subtests including: conceptualization, mental flexibility, motor programming, sensitivity to interference, inhibitory control, and environmental autonomy. These subtests assess fluency, abstraction, impulsivity and primitive reflexes. Subtests are scored from 0-3, dependent on how well the participant completes each task. The maximum score is 18. A score of 12 or less indicates frontal lobe deficit with a sensitivity of 77% and a specificity of 87% (Slachevsky et al. 2004).

Standardised Mini-Mental State Examination (sMMSE)

The Standardised Mini-Mental State Examination (sMMSE; Molloy and Standish, 1997) was selected as a test of global cognitive ability (Appendix N). It is a standardised version of the Mini-Mental State Examination (MMSE; Folstein, 1975), including more explicit instructions for administers, controlling better for inter-rater reliability.

The sMMSE and the Montreal Cognitive Assessment (MoCA; Nasreddine et al. 2005), are the two most commonly used tests of cognitive ability in the UK (Lawton et al. 2016). The MoCA is currently preferred over the SMMSE, due to the MoCA covering more cognitive domains, and being free to use. However, due to the likelihood of moderate to severe cognitive impairment in the population sample (Cohen-Mansfield and Libin, 2005; Draper, 2000), the sMMSE was used as participants were thought likely to find the MoCA too difficult to complete, resulting in missing or uninterpretable data.

4.4.1.3 Staff-Reported and Observational Measures

Barthel Index for Activities of Daily Living (BI)

The Barthel Activities of Daily Living (ADL) index (BI; Collin et al. 2009) is a carer-rated instrument; consisting of the patient's ability to complete ten routine activities, including eating, bathing, dressing, toileting, walking and continence (Appendix O). It is rated on amount of physical assistance required. Activities are scored from 0-2 or 3; a maximum score of 20 indicates complete independence and a score of zero indicated total dependence.

Pain Assessment in Advanced Dementia Scale (PAINAD)

The Pain Assessment in Advanced Dementia Scale (PAINAD; Warden et al. 2003) is a quick to administer observational tool for people with advanced dementia (Appendix P). It is appropriate for use in acute care settings (Hutchinson et al. 2006); it is valid and reliable (Costardi et al. 2007); and has good internal consistency (Costardi et al. 2007) and inter-rater reliability (Schuler et al. 2007). It is measured across five pain-indicating behaviours (breathing, negative vocalisation, facial expression, body language, and consolability) from 0-2. A score of zero indicates no pain; 1-3 indicates mild pain; 4-6, moderate pain; and 7-10, moderate to severe pain.

4.4.1.4 Family-Reported Measures

Cornell Scale for Depression in Dementia (CSDD)

The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, 1988) is a 19-item scale developed to assess signs and symptoms of major depression in people with cognitive impairment (Appendix Q). It is based on two semi-structured interviews with the patient and an informant, such as a close relative or carer. The scale is focused on five main indicators of major depression (1) mood-related signs (anxiety, sadness, lack of reactivity to pleasant events, irritability); (2) behavioural disturbances (agitation, multiple physical complaints, loss of interest); (3) physical signs (loss of appetite, weight loss, lack of energy); (4) cyclic functioning (diurnal variation of mood, difficulty falling asleep, multiple awakenings during sleep, early morning awakenings); and (5) ideational disturbances (suicide, poor self-esteem, pessimism, mood-congruent delusions). Items are rated from 0-2, dependent on severity. The final ratings of the CSDD items represent the rater's clinical impression, and the full test takes approximately 20 minutes to administer. Scores of 0-6 indicate no significant depressive symptoms, scores above 10 indicate probable major depression, and scores above 13 indicate definite major depression.

Neuropsychiatric Inventory- Nursing Home Version (NPI-NH)

The Neuropsychiatric Inventory (NPI) is the most commonly-used scale for measuring behavioural and psychological symptoms of dementia (Cankurtaran, 2014). The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001) is used to assess twelve behavioural domains (delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep and night-time behaviour change, appetite and eating change). Each domain is rated on frequency, severity, and occupational disruptiveness (Appendix R). The maximum score across all domains is 120, however domains can be considered individually. The nursing home version can be used in institutional settings, and applies equally in hospitals.

4.4.1.5 Clinical Data

A number of non-standardised measures were recorded from the patient participants. These included: prior diagnosis of dementia, length of stay, days spent calling out whilst in hospital, presence of hearing impairment, presence of visual impairment, and presence of itch, breathlessness or nausea (unpleasant symptoms that might provoke calling out).

4.4.1.6 Demographics

Patient participant's social and demographic details were collected from multidisciplinary case records, supplemented by questions to the patient and their carer. These included age, gender, country of birth, residence, and whether they lived independently or had a carer.

4.4.2 Conducting Observations

Both structured and unstructured observations of the patient participants were undertaken. Structured observations were always non-participant, with no active role played in the situations or events being documented. Unstructured observations utilised a mixture of participant and non-participant observation, including observations made during quantitative data collection.

4.4.2.1 Structured Observations

Structured observations lasted for two hours, with one participant observed per session. They took place at varying times of day, between 7am and 9pm, and on different days of the week. Initially, I used a structured observation sheet (Appendix S) which involved tallying specific types of calling out, based upon the typology of disruptive vocalisations by Cohen-Mansfield and Werner (1997). However, I found this was not capturing the full range of differences between vocal behaviours exhibited by patient participants. Therefore after the fourth patient participant, I adapted the structured observation sheet to allow for more description of the behaviours, and with space to record the content of the calling out. The data collected from this point onwards was more useful in describing the behaviours exhibited, and how others responded to it. Using the structured observation sheet (Appendix T), the location (such as in bed, sat at table), current activity of the patient (such as lying in bed, eating dinner), the lighting (such as bright sunshine outside, dimmed lighting with curtains drawn) and activity level (such as calm, quiet, busy with lots of visitors) of the bay or side room was recorded. The time was then recorded, and the first three-minute observation began. For three minutes every twenty minutes, I recorded whether the participant was calling out, everything they were saying, and responses from others. I also documented what the patient was doing, facial expressions, mood and what was happening around them (such as music, dinner time, visiting time, weather). I used a checklist and sat some distance from the patient (around 3-8 metres away). I found this more effective than sitting in the patient participant's bed space, as it caused them to be less likely to try to interact with me, making observations less overt. There were boxes on the observation sheet to allow space to note down the nature of the calling out, social stimulation, potential triggers, its effect on others, and additional notes.

4.4.2.2 Unstructured Observations/ Field Notes

Unstructured observations (field notes) were written upon every visit to the ward. This often initially involved recording my perceptions of the atmosphere on the ward at that time; for example, if there was music playing, lots of visitors and chatter, or staff appearing relaxed or stressed. The unstructured observation did not include using a checklist, but I recorded my thoughts and feelings about what I was seeing within the bays and the ward, and any conversations I had with the patient, staff or relatives. On occasion, I would sit with the patient participant, and occasionally interact with them; but most of the time, sat on a chair overlooking the whole bay to observe the patient participant from afar. The unstructured observations would continue for as long as I felt necessary; for example, if the patient participant was behind a curtain being changed and calling out, I would wait until after staff had finished, to see what happened when they stopped changing the patient participant. Furthermore, if a patient participant fell asleep and seemed settled, I would halt the observation, as nothing of interest for the research was happening. When a staff member had a conversation with me either about the ward environment, the patient participant, or patients who call out repetitively in general, a summary of the conversation was written down with the knowledge of the staff member.

Field notes were firstly hand-written on designated sheets of paper whilst on the ward (Appendix T). Field notes were typed up as soon after leaving the ward as possible, to allow for accurate expansion and additional detailing of what I observed. Whilst typing field notes, I would reflect upon what I thought this meant, my feelings or opinions surrounding what I had seen or heard, or any difficulties I had faced in doing what I had intended to do. These were later coded under nodes such as 'reflexivity' or 'feasibility' in NVivo, so that I could compare my thoughts across patient participants.

4.4.2.3 Nursing documentation

During data collection of the seventh patient participant, some particularly interesting extracts within the nursing documentation caught my attention, therefore I noted them down within the field notes. I realised this was useful in describing and understanding the behaviours exhibited by the patient participants when I was not present, alongside attaining more staff members' interpretations of the behaviours they were observing, and verifying staff accounts of the patient participant. From this point forward, medical and nursing documentation were systematically scrutinised throughout patient participants' admission for any references to agitation, calling out, challenging behaviour, or unusual or changed behaviour. Any entries that mentioned these points of interest were copied into field notes with the time and date that the medical or nursing note had been written. Notes were copied word for word, but only included extracts with the points of interest, alongside any intervention (or lack thereof) that was written in reference to it.

4.4.3 Conducting Interviews

Topic guides for interviews were developed prior to the commencement of data collection, with the view in mind that they would be open to change, due to the emergent nature of the study design.

4.4.3.1 Staff Member Interviews

Semi-structured interviews were conducted with 15 staff members (ten females and five males), across seven wards on Site One and Site Two. Staff were asked about their knowledge, beliefs and experiences of patients who call out. Immediately prior to the start of the interview, staff members were asked to confirm that they understood the information sheet and agreed to the interview being audio recorded. They were asked to give their job title, an estimate of how long they have worked clinically with older patients, and the number of hours they worked per week. Interviews were informed by a topic guide (Appendix V), but evolved according to answers staff members gave to questions, allowing me to explore staff members' ideas further. At the end of the interview, I asked staff members if there was anything they would like to add, ask, or clarify, so as to not miss anything of importance. Throughout the study, less of a focus was placed on prevalence and amount of pressure calling out repetitively places on staff members' workload, and became more focused on how much it affects staff and other people emotionally, together with their interpretations of what they thought was happening to the patient. It was useful to observe staff behaviour, and then speak to them in interviews, not about specific patients, but to explore some of their underpinning assumptions in respect of calling out.

4.4.3.2 Relative Interviews

Ten semi-structured interviews were conducted with 12 patient participants relatives (two interviews were conducted with two family members together). Topic guides for relatives focused on the patient participant's life (career, family, trauma), and their calling out (Appendix V); however similarly to the staff interviews, relative interviews would develop naturally, based upon the focus they placed on certain topics. Relatives were asked about their perceptions of the care the patient participant was receiving on the ward, and whether they thought there were any improvements that could be made. Relatives were also given a chance at the end of their interview to add, ask, or clarify anything they deemed important. I was mindful of the emotional tone of the interviews, and took them at a slower pace than the staff interviews.

4.4.4 Conducting Follow-Up Data Collection

Follow-up meetings were conducted with the relative who acted as consultee, by telephone, 90 days (+/- 5 days) from the date of the patient participants' admission. Prior to this telephone call, investigation into whether the patient participant had died was first conducted, in order to maintain the appropriate tone for the call. The telephone conversations lasted approximately 10 minutes. Follow-up telephone calls were not audio-recorded. Relatives were asked where the patient participant was currently residing, and if this was different to where they were before their admission. They were asked if the patient participant had been readmitted to hospital for any reason between the discharge date recorded in the study and the date of the telephone call. They were also asked if the patient participant was still calling out, and if so, to describe its frequency, severity and content. Again, at the end of the telephone call, I gave relatives the opportunity to add anything they might consider to be of importance.

4.5 Preliminary Analysis Phase

A preliminary analysis of the interview and case-series findings was conducted after 10/15 staff interviews, and when 10/30 patient participants had been recruited and discharged. This preliminary analysis was presented to the study supervisors and the study steering group.

Initial ideas and theories were introduced to the steering group in the form of a workbook (Appendix W), developed through supervision meetings. The workbook was sent electronically for members to read prior to the meeting. The workbook was then printed off ready for the session. In the four-hour session, members went through the ideas and discussed the themes. The main points for discussion included the definition of calling out, the concept of 'futility' amongst staff members, and 'relatives and carers' including the 'This is Me' document and its usefulness. The steering group discussed and debated the ideas and theories using their clinical and personal experiences.

4.6 Data Analysis

4.6.1 Quantitative Data Analysis

Quantitative data were stored on a password protected Microsoft Excel spreadsheet. In order to effectively describe and characterise the sample of patient participants, descriptive statistics were calculated. Means and standard deviations were calculated using Microsoft Excel, and displayed alongside frequency charts, created on Microsoft PowerPoint.

4.6.2 Qualitative Data Analysis

4.6.2.1 Input and Storage of Qualitative Data

Interviews were recorded on a digital audio recorder, and transcribed in clean verbatim (elimination of false starts and filler words) by a University of Nottingham-approved transcription company. Four of the interviews were transcribed by myself. Once interviews were transcribed, audio recordings were deleted from the digital audio recorder, however they were saved for auditing purposes in a password-protected folder on a university server. I individually listened to every audio-recording whilst reading the transcript, in order to ensure accuracy. Corrections were made where necessary.

Field notes were converted from hand-written format, to typed electronic versions. Extracts of medical and nursing documentation were written throughout the designated field note sheets (Appendix T) to provide context. Interview transcripts and field notes with nursing documentation were stored and managed in QSR International's NVivo 11. NVivo is a data analysis computer software package, specifically designed to manage rich text-based data, and facilitate deep levels of analysis across multimedia information. It ensures reliable back-up procedures for safety of stored data, and can be password protected to provide a high level of data protection. Structured observations were recorded all together in a Microsoft Excel spreadsheet in the form of a table. This was imported to NVivo for analysis in pdf format.

4.6.2.2 Iterative Analysis Process

Analysis was an iterative process occurring alongside and after data collection, allowing for interview topic guides to be edited, to pick-up and expand upon initial findings (Kerssens-van Drongelen, 2001). This was supplemented by three iterative processes; a reflexive diary, data analysis supervision meetings, and a steering group meeting. I kept an ongoing reflexive diary throughout the data collection period, which allowed me to identify my continuing and developing thought processes. These included the directions I thought the data might be heading, and things I thought might be important to pursue. My supervisors and I met on multiple occasions to discuss and compare the thematic analysis process collectively, throughout data collection. We discussed our interpretations of the data, and subjects that should be further investigated in subsequent interviews. The steering group provided an independent view on data interpretation; and their feedback helped me to develop further questions to ask both staff members and relatives in interviews, and during unstructured observations.

4.6.2.3 Thematic analysis

The process of thematic analysis followed the Braun and Clarke (2006) method. This is a widely used qualitative analysis method; which aims to identify, analyse, and report patterns within qualitative data. It allows for flexibility regarding the researcher's choice of theoretical framework. Braun and Clarke (2006) describe a six-stage approach in order to conduct a thematic analysis which ensures clarity and rigour. This includes: 1. the necessity for familiarisation of the data, 2. generation of initial codes, 3. searching for themes, 4. review of themes, 5. refining and naming the themes, and 6. the production of the report.

The first stage of familiarisation involves the researcher immersing oneself with the data. This began with the initial collection of the qualitative data, such as conducting the interview, or recording the field notes. The data were then re-examined through the inputting of the data. Qualitative data were then read and re-read. In the case of interviews, audio recordings were listened to whilst reading the written transcripts to check accuracy of typing.

The generation of initial codes is also referred to as 'open coding'. This stage involved the process of carefully reading through the qualitative data line by line, generating unlimited codes. Some extracts of text would have up to seven different codes simultaneously assigned to them, due to the overlapping of ideas and use of semantically similar words. Codes identified were specific, for example ‘radio playing’, with the view that broader themes, such as ‘music’ would be generated from these in the later stages.

Staff member and relative interviews were analysed individually, and then combined through the process of searching for overarching themes. There was an overlap between staff members and relatives on many of the theme topics, therefore data from both sets is presented together, in order to show where perspectives coincide, and where there are differences.

The process of searching for themes often involves a more visual process, of sorting generated codes into larger coinciding categories. For this study, this involved printing off the individual code names, which totalled over 400. These were cut out individually, and then sorted into piles with other codes that were similar. This process generated a number of potential themes, such as ‘verbal intervention’ which included codes such as ‘reassurance’, ‘verbal distraction’, ‘responding’, ‘communication’, and ‘reorientation’.

The review of themes involved extensive thought and deliberation into whether to combine or split certain themes, and generation of subthemes and sub topics. These were considered at theme and at coded level, to prevent misidentification of a code, and to ensure coherence between themes and codes. I presented potential themes with their allocated codes and examples of these to the supervisory team and discussed in detail to aid the reviewing process.

Themes were then refined and re-named based upon the reviewing process, and suitable names chosen. This is to ensure the name of the theme infers its meaning. A final thematic table is included at the end of each findings chapter.

4.6.3 Ethical issues regarding collection and analysis of data

4.6.3.1 Informed Consent

None of the patient participants in this study had capacity to give informed consent. This was due to the change to protocol requested by the Yorkshire and Humber - Bradford Leeds Research Ethics Committee approving the study that only patients who *lacked* mental capacity to consent were to be recruited as patient participants. They reasoned that this would avoid unnecessary distress and upset from such patients who may have the mental capacity to consent for themselves, but who may not have been aware of the fact they had been calling out.

I was committed to ensuring ongoing, continuing agreement to participate as involvement in the study progressed. This included during interviews and across observations.

4.6.3.2 Regaining Capacity

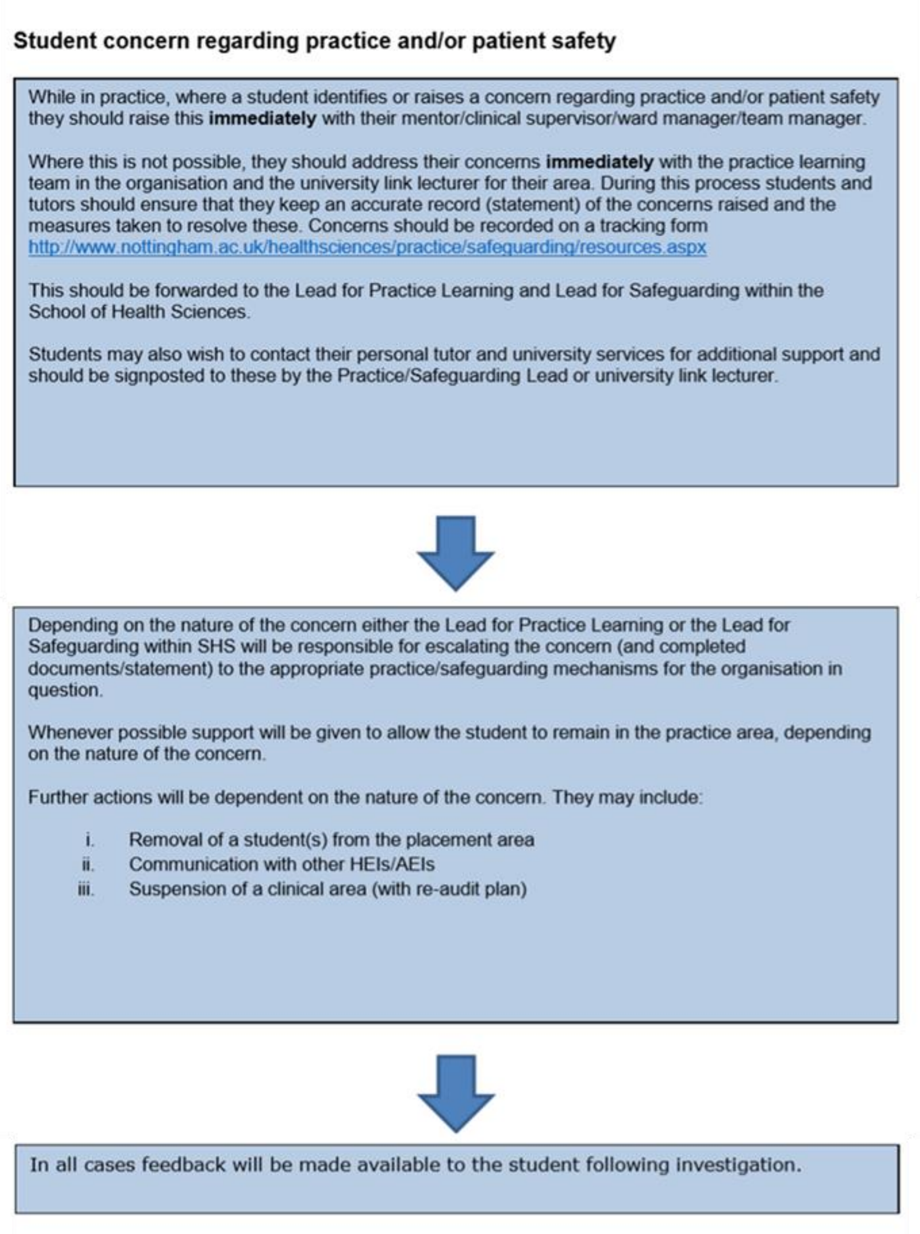
Some participants recruited to the study had delirium, or delirium superimposed on dementia (DsD). It was possible that these participants might regain capacity during the study. The Mental Capacity Act (2005) states that where a participant regains capacity, they should be fully informed about the study, and their consent must be sought to continue in it. A consent form for the choice of continuation or cessation of participating in the research study was created for potential cases in which the patient participant had regained mental capacity throughout their admission (Appendix X). Two participants were reassessed during their admission, due to the possibility of regained capacity, but neither person was found to have done so.

4.6.3.3 Observations

There were ethical concerns surrounding conducting observations of vulnerable participants who appeared to be in distress. To minimise distress, observations did not take place in bathrooms, or behind closed privacy curtains. It was agreed prior to data collection, that if a patient being observed appeared to be in distress primarily due to the fact they were being observed, then that observation would stop; however, this situation was not perceived to arise. Observations were to continue unless the patient participant was considered to be at immediate risk of physical harm. Two examples of this occurred during the structured and unstructured observations. In the first, a patient participant who was unsteady on her feet and needed 1:1 supervision with walking had begun to stand up from her chair without the staff member’s knowledge, therefore I notified the staff member, who then assisted. In the second instance, a patient participant was pulling a plate with hot gravy toward him, which I believed was about to fall off the table and onto his lap, so I again notified a staff member who had her back turned to the patient participant, and she quickly steadied the plate. By the end of the observation period, if I believed a patient had a need that had not been met, it was communicated to a staff member.

4.6.3.4 Safeguarding

The Care Act (2014) details types of abuse and how to recognise the signs of them (SCIE, 2014). The School of Health Sciences within the University of Nottingham have outlined their safeguarding escalation policy to raise and escalate concerns regarding practice and/or patient safety (Figure 4.6). On one occasion, a staff member was observed to be mocking a patient participant and imitated her calling out in front of her. I informed my main supervisor on the same day. It was decided that because the patient participant had moved to a different ward a few hours later and that no aspects of the patient participants' care had been affected then the safeguarding issue would not be escalated.



Student concern regarding practice and/or patient safety

While in practice, where a student identifies or raises a concern regarding practice and/or patient safety they should raise this **immediately** with their mentor/clinical supervisor/ward manager/team manager.

Where this is not possible, they should address their concerns **immediately** with the practice learning team in the organisation and the university link lecturer for their area. During this process students and tutors should ensure that they keep an accurate record (statement) of the concerns raised and the measures taken to resolve these. Concerns should be recorded on a tracking form http://www.nottingham.ac.uk/healthsciences/practice/safeguarding/resources.aspx

This should be forwarded to the Lead for Practice Learning and Lead for Safeguarding within the School of Health Sciences.

Students may also wish to contact their personal tutor and university services for additional support and should be signposted to these by the Practice/Safeguarding Lead or university link lecturer.

Depending on the nature of the concern either the Lead for Practice Learning or the Lead for Safeguarding within SHS will be responsible for escalating the concern (and completed documents/statement) to the appropriate practice/safeguarding mechanisms for the organisation in question.

Whenever possible support will be given to allow the student to remain in the practice area, depending on the nature of the concern.

Further actions will be dependent on the nature of the concern. They may include:

i. Removal of a student(s) from the placement area
ii. Communication with other HEIs/AEIs
iii. Suspension of a clinical area (with re-audit plan)

In all cases feedback will be made available to the student following investigation.

Figure 4.6: The study safeguarding escalation policy

A number of relative interviews were conducted either at the relatives' home or place of work. The University of Nottingham's Lone Working Policy was followed during these instances. This involves a designated university colleague being informed of the date, time and location in which the interview was to take place, and the expected amount of time this should take. If the designated colleague had not heard from the researcher by the predetermined time, and could not get in touch with the researcher, they were to escalate the situation. This circumstance did not occur.

4.6.3.5 Data Security

Participants' rights to privacy and informed consent were protected, adhering to the Data Protection Act, (1998). Generalised Data Protection Regulations (GDPR) were not in place at the time of this study. Access to the information were and will continue to be limited to the research team and any relevant regulatory authorities. All quantitative data were input and stored on a password-protected Microsoft Excel spreadsheet stored on a personal password-protected server within the University of Nottingham. Transcripts were stored as password-protected Microsoft Word documents, and stored and managed in password-protected QSR International's NVivo 11 qualitative data analysis software. NVivo Server-held data, including the study database, were held securely and password protected. Access was restricted by user identifiers and passwords (encrypted using one-way encryption). Information about the study in the participant's medical records and hospital notes were treated confidentially.

4.7 Reflexivity

Reflexivity in research is defined as an attempt to consider how the researcher is positioned in social, political, cultural and linguistic contexts, where it may impact upon the data collection, interpretation, or dissemination process (Alvesson, 2002). Its consideration can help to improve the rigour of a study, by modifying processes such as interviewing style (McNair, Taft, and Hegarty, 2008).

4.7.1 My Relationships and Roles in Research Settings

I came into the PhD process as a masters-level Psychology graduate, with no clinical or healthcare training. My only prior healthcare experience was as a volunteer in an acute service for dementia. This may have had both positive and negative impacts upon the research process. A positive aspect was that I had no preconceived ideas of what staff should and should not be doing. The two sites and the wards within them operated in different ways; and I did not enter data collection with an opinion of what the 'best' way might be. Had I been extensively trained to work clinically in a specific way, I might have judged individuals or organisations who worked differently to myself.

A further positive feature of not being a healthcare professional is that I believe both staff and relatives treated me as an ally. Staff felt they could open up to me easily, I did not expect such high levels of honesty and openness about their feelings and emotions. Relatives also felt they could easily raise any concerns they had about the care of their relative on the ward, or particular staff members they were unhappy with. On occasions, I was receiving opposing sides of a dispute from relatives and staff. This was overwhelming at times, but I also felt privileged to be experiencing both sides of the story, and happy that staff and relatives were equally comfortable to share these issues with me.

Although I had volunteered for a year on a hospital ward for older people with dementia, I felt I did not have adequate knowledge of the varying job roles on the wards, and what each staff member's role entailed. I found myself needing to research what each uniform colour, or different stripes on uniforms actually meant. A number of uniforms were different upon entering Site Two, therefore I felt I needed to learn again. This left me feeling slightly unconfident and unprepared at the commencement of data collection. Once I learnt how each ward was run and got to know the staff however, these feelings dissolved, and I quickly began to feel confident and in control of the data collection.

4.7.2 My preconceptions, prior experiences, and perspectives

I had worked as a 'mealtimes' volunteer in my previous work experience. I attended the ward between the hours of 4pm and 7pm, helped to bring teatime meals to the patients, and then sat and provided company to the patients who wanted it. During my volunteering experience, I spent most of my time speaking with patients, and did not form any friendships with staff. I believe I did not adopt any of the staff members beliefs surrounding their job or the patients during this time to influence my perspectives on this study.

Recognising that my prior experience as a volunteer may have influenced this study; I have tried to not over-emphasise volunteerism throughout this research, but have also not purposefully blocked it out. Volunteers were rarely observed throughout the data collection process, but when they were present during observations, volunteers were not overlooked.

4.8 Maximising Trustworthiness

Lincoln and Guba (1985), identify a number of methods that help to ensure the worth of qualitative research: credibility, transferability, dependability, and confirmability.

The credibility of research is the confidence in the 'truth' of the findings. To establish prolonged engagement, sufficient time was spent on the wards during observations in order to become effectively orientated to the context. I spoke with a wide range of staff members, of varying seniority, in order to gain trust. This allowed me to 'blend in' on the wards, with staff feeling comfortable enough in front of me to occasionally speak controversially about the patient participants, their relatives, or elements of their working environment. Triangulation enhances the credibility of qualitative data (Angen, 2000). I used multiple data sources throughout data collection, ensuring an in-depth and comprehensive account of the patient participants and their ward environment.

The transferability of qualitative data analysis refers to the level of 'thick description' of the data (Holloway, 1997). I sought to document detailed accounts of field experiences, and make explicit the cultural and social relationships within the context.

The dependability of data collection and analysis is determined by 'external audits', which can involve a process of preliminary findings being summarised to 'outsiders', or people not directly associated with the research (Lincoln and Guba, 1985). Feedback leads to additional data gathering, alongside further development of better articulated and stronger findings. The dependability of the research was enhanced primarily through the utilisation of the steering group meeting, but also through the presentation of the research findings to the delegates of the British Geriatrics Society (BGS) Spring Meeting 2018.

The use of external audits can also improve the confirmability of a qualitative research project (Lincoln and Guba, 1985). Alongside this, the researcher must be reflexive about their position in the research process, and how this will affect both collection and analysis of data. I achieved this by keeping a reflexive journal to aid recollection of thoughts and opinions surrounding reflexivity throughout the data collection process.

4.9 Research Methods Summary

An ethnographic case-series study was designed; with the goal of characterising calling out, understanding it in the context of the acute hospital, and identifying mechanisms that can explain varying outcomes surrounding hospital staffs actions and behaviours, and calling out itself.

In this chapter, the methods used for conducting the research have been described. The two study sites and the eligibility criteria of individual participants have been explained. The methods for acquiring quantitative and qualitative data have been detailed and rationalised, alongside the processes of identification, recruitment, and consultee agreement attainment. A number of ethical considerations were detailed, due to the involvement of a vulnerable population sample and setting. The importance of reflexivity is highlighted, and the chapter concludes with an outline of the care taken to maximise the trustworthiness of the data collection and analysis. The next chapters will present the quantitative and qualitative findings of the study.

Chapter Five

Characterisation

5.1 Introduction

This is the first of three chapters of study findings. This chapter focuses on describing the phenomena of calling out, and the people who call out. The development of categories and typologies for the presentation of the findings arose both from the thematic analysis, and from the scoping review conducted prior to the commencement of the data collection. This was to ensure that the findings from the study expanded upon the findings from the scoping review, and sought to address the gaps identified within the literature review. Quantitative findings are split into four categories: 1. Overview of patients (age, gender, and prior living arrangements); 2. Clinical data (reason for admission, dementia diagnosis, and length of stay); 3. Standardised assessments conducted at baseline (level of cognitive impairment, presence of pain, and physical ability); and 4. Follow-up measures (continuation of calling out, readmissions, and mortality). These findings are summarised in a table in Appendix Y. Within the qualitative findings, the identified types of calling out are presented, alongside frequency, duration, persistence, and volume. Staff members interpretations of patient participants feelings and emotions are described. The characterisation of patients who call out focuses on staff and relatives perceived association with socially problematic behaviour, cognitive impairment, and the decline in physical and mental health.

Pseudonyms have been assigned for each participant in the study. Where personal names have been used in interview or observation transcripts, these have also been pseudonymised to maintain confidentiality. This was chosen in opposition to anonymisation to retain the personal feeling of qualitative data, and to articulate and better express the flow of language used.

5.2 Characteristics of Participants

Of the 30 patient participants, 20 were female, and 10 were male. Their mean age was 82.1 years, with a range of 63-96. Most participants spoke English as their first language (27); with the remaining three predominantly speaking Greek, Polish or German. Before they were admitted into hospital; 18 (60%) lived at home. Six (20%) had no professional carers, three (10%) had visiting professional carers, and nine (30%) had a full-time, live-in carer. Twelve (40%) came into hospital from a care or nursing home.

The initial aim was to recruit patients as soon as possible after being admitted, in order to capture transient cases of calling out. However, accessing family members in a timely fashion proved in some cases to be impossible. Therefore, 12 patient participants were recruited within three days of their admission (zero to three days), and 18 were recruited more than three days after their admission (between four and 12 days). Of the 12 patient participants recruited within the three days, two stopped calling out before discharge or death (16.6%), and two died (16.6%). Of the 18 recruited between four and 12 days after their admission, two stopped calling out before discharge or death (11.1%), and eight died (44%).

Personal consultees (n=28) were sons or daughters (n=13), spouses (n=7), other family members, such as niece, brother, and cousin (n=5), and close family friends (n=3). Nominated consultees (n=2) were senior nursing staff members (ward managers or deputies) who had come into contact the most with the patient participant.

63% (19/30) of patient participants had a formal diagnosis of dementia documented in their medical notes. Types of dementia included vascular (5), Alzheimer's (4), and unspecified (10), which involved documentations such as 'advanced dementia'. One patient participant was diagnosed with delirium alone, and 17% (5/30) had diagnosed delirium superimposed on dementia (DsD). 33% (10/30) had no previously diagnosed dementia or delirium, but were described by nursing staff as cognitively impaired or confused (Figure 5.1).

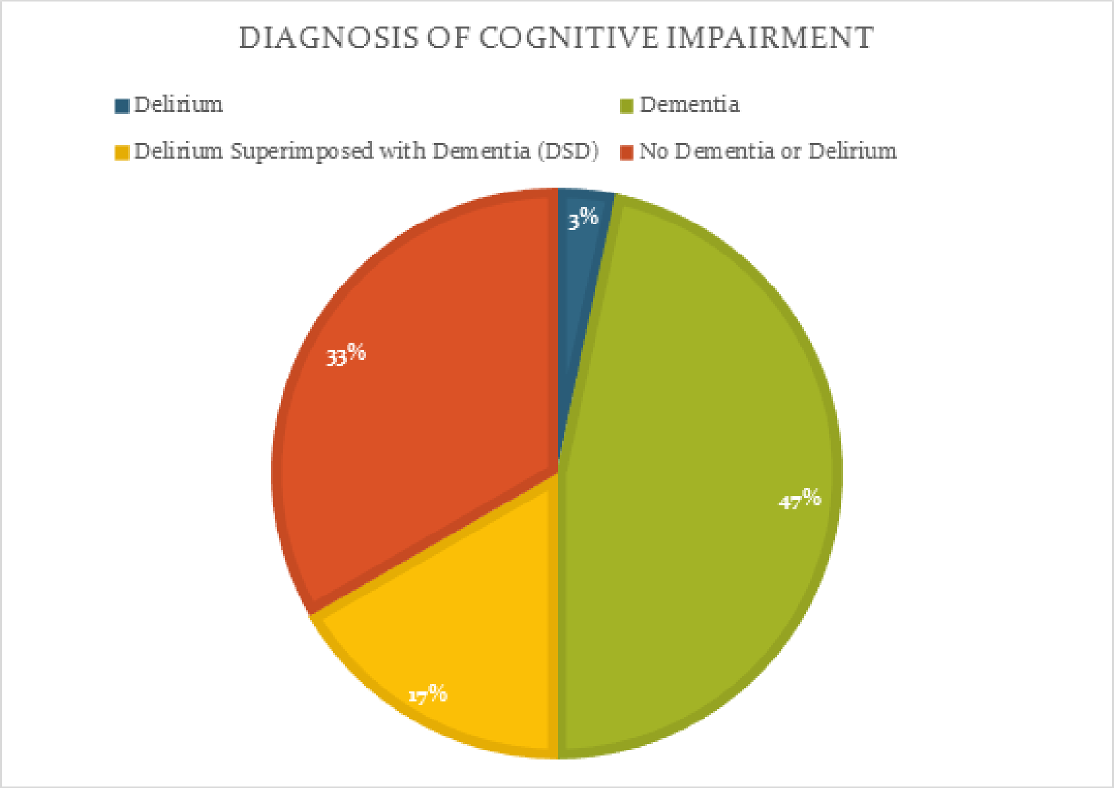


Figure 5.1: Patient participant's diagnosis of cognitive impairment

The most common reasons for admission were infections (13 patient participants, 43%) and falls (12 patient participants, 40%). Other reasons for admission were increased confusion (two patient participants, 6%), shortness of breath (one patient participant, 3%), aspiration (one patient participant, 3%) and abdominal pain (one patient participant, 3%). Some patient participants had multiple causes for their admission into hospital, in which case the primary cause was recorded.

Patient participants had a mean of more than three additional diseases or disorders recorded in their medical notes, alongside their primary reason for admission, and their cognitive impairment (Table 5.1).

Condition	Frequency
Recurrent falls	10 (33.3%)
Hypertension (high blood pressure)	8 (26.6%)
Chronic obstructive pulmonary disease	7 (23.3%)
Type 2 diabetes mellitus	6 (20%)
Stroke	6 (20%)
Chronic kidney disease	6 (20%)
Atrial fibrillation	5 (16.6%)
Depression	4 (13.3%)
Arthritis	4 (13.3%)
Heart Attack	4 (13.3%)
Anxiety	3 (10%)
Hypothyroidism	3 (10%)
Chronic back pain	3 (10%)
Epilepsy	3 (10%)
Chronic constipation	3 (10%)
Cancer	3 (10%)
Hip/ knee replacements	3 (10%)
Previous sepsis	2 (6.6%)
High cholesterol	2 (6.6%)

Table 5.1: Comorbidities of patient participants

Additional comorbidities found in just one patient participant per condition include: sleep apnoea, bipolar disorder, seizures, irritable bowel syndrome, permanent pacemaker, mouth ulcers, cellulitis, oesophageal ulcer, lymphodema, bronchitis, pulmonary edema, ventricular dysfunction, cataracts, peripheral vascular disease, macular degeneration, sciatica, aortic stenosis, hiatus hernia, mastectomy, ischemic heart disease and pneumonia.

Twelve of the 30 patient participants had a hearing impairment (40%), but only three of these (25%) used a hearing aid. Twenty had a visual impairment (66.6%), with 11 of these (55%) corrected with the use of spectacles.

Mean length of stay for the patient participants was 28.8 days, with a range of 6-90 days (Table 5.2).

Days	Frequency
1-10	8 (26.6%)
11-20	8 (26.6%)
21-30	4 (13.3%)
31-40	3 (10%)
41+	8 (26.6%)

Table 5.2: A table to show distribution of patient participant length of stay

5.2.1 Cognition

The standardised Mini-Mental State Examination (sMMSE; Molloy and Standish, 1997) is a test of global cognitive ability (Appendix N). It was conducted with 28 of the 30 patient participants, as two participants declined to be tested[3]. The mean score was 5.8/30 (standard deviation = 6.0). Scores ranged from 0-20/30; a score of 0-9/30 indicated severe cognitive impairment, and a score of 10-19/30 indicated moderate cognitive impairment. Most patient participants were found to be moderately (25%, n=7) to severely (71%, n=20) cognitively impaired. One patient participant scored 20/30.

The Frontal Assessment Battery (FAB; Dubois et al. 2000) is an assessment of executive functioning (Appendix M). Twenty-five of the 30 patient participants were tested using the FAB, four patient participants declined to answer the questions, and one was discharged prior to the test being conducted. The mean score on the FAB was 2.5/18 (standard deviation = 3.8) with a range of

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[3] When a participant declined to partake in a structured assessment, I would ensure the participant was not declining to participate in the whole study by asking the participant if they were still happy for me to observe them. The participant would confirm that they were, therefore they would remain as a participant within the study. Often, participants would deflect answering cognitive assessment questions. For example, one participant when asked what date, month, and year is was responded each time with "Oh I never worry about that". All participants confirmed that they were happy to continue in the study.

0-12/18. Using the suggested cut-off score of 12 or lower (Dubois et al. 2000), every participant tested was judged to be experiencing dysexecutive problems.

The Delirium Rating Scale (DRS-R-98; Trzepacz et al. 2001) is a screening test to assess the likelihood of a person having delirium (Appendix L). Twenty-seven of the 30 patient participants completed the DRS-R-98, one declined to participate in the test, and two were discharged prior to the test being conducted. The mean score was 24.2/46 (standard deviation = 6.1). Scores ranged from 16-41/46. A person is likely to have delirium if they score 18 or more; therefore 88% (24/27) patient participants tested likely to have delirium at the time of testing.

5.2.2 Calling Out

The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991) total score was calculated for each participant, which included a number of physical and vocal challenging behaviours (Appendix A). CMAI total scores ranged from 36-108/203, with a mean of 64.6/203. There are 29 items within the CMAI, the two most commonly occurring items amongst patient participants were 'verbally non-aggressive' items: 6) repetitive sentences/ questions and 5) constant unwarranted requests. All patient participants were measured using the CMAI, with no missing data.

Twenty-eight (93%) of the 30 patient participants tested were observed to score the maximum for at least one of the 29 items of the CMAI, with one patient participant scoring the highest possible score on nine items. The items with the highest number of maximum scores: item 6) Repetitive sentences/ questions (occurring in 26 participants), item 5) Constant unwarranted requests (occurring in 17 participants), and item 28) General restlessness (occurring in 13 participants).

The Pittsburgh Agitation Scale- Aberrant Vocalisations (PAS-AV; Rosen et al. 1994) was used to measure severity of calling out, including volume and ability of carers to redirect (Appendix B). Throughout the study, participants' PAS-AV scores ranged from 0-4/4. The mean score was 2.3/4, meaning that on average, patient participants fell between 'Louder than conversational, mildly disruptive, redirectional' and 'Loud, disruptive, difficult to redirect'.

The graph below (Figure 5.2) shows the percentage scores of each patient participant for both the CMAI and the PAS-AV. Percentage scores were used because the highest possible score on the CMAI is 196 whereas PAS-AV is 4.

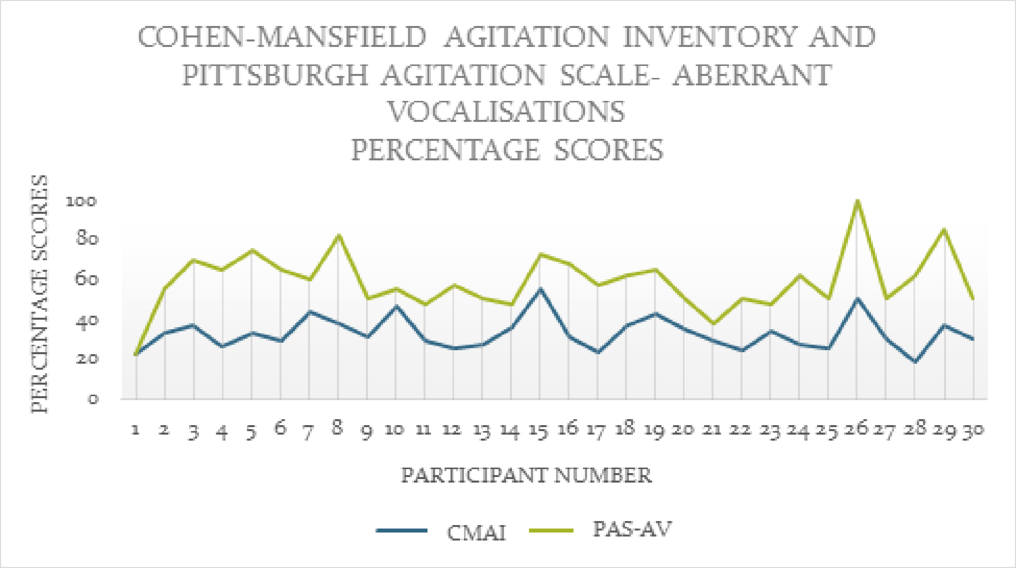

Figure 5.2: Percentage scores of each patient participant for both the CMAI and the PAS-AV

5.2.3 Behavioural and Psychological Symptoms

Scores on the Neuropsychiatric Inventory (NPI-NH; Wood et al. 2001; Appendix R), ranged between 13-54/144, with a mean of 28.3/144 (Standard deviation = 10.3). Participants scored highest for agitation/aggression, anxiety, apathy, and irritability (Figure 5.3).

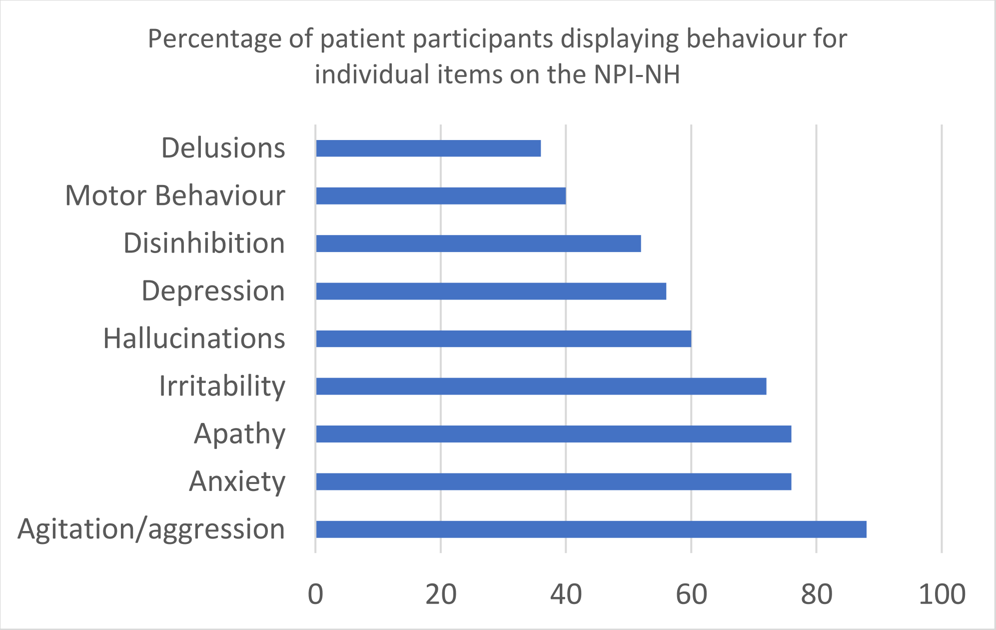

Figure 5.3: The percentage of patient participants who displayed the behaviours for individual items on the NPI-NH

The mean score on the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, 1988; Appendix Q), was 14.9/38 (standard deviation = 5.6, range = 2-25). Five patient participants were not tested on this measure due to relatives being unavailable. Eight of the 25 tested participants were rated as having a 'definite major depressive episode', twenty had a 'probable major depressive episode', five were unlikely to have depression

5.2.4 Pain

Observational pain scores using the Pain in Advanced Dementia scale (PAINAD; Warden et al. 2003; Appendix P) ranged from 'no pain' to 'severe pain'. Table 5.3 indicates that the majority of patient participants (79.9%) were determined to be in mild to moderate pain. No PAINAD data were missing.

Severity of Pain	Frequency
No pain	4 (13.3%)
Mild pain	11 (36.6%)
Moderate pain	13 (43.3%)
Severe pain	2 (6.6%)

Table 5.3: Distribution of pain scores using the PAINAD

5.2.5 Activities of Daily Living

The mean score on the Barthel Activities of Daily Living Index (BI; Collin et al. 2009; Appendix O) was 3.7/20 (standard deviation = 4.0), with a range of 0-13/20. A score of 20 indicates complete independence. Twenty-two of the patient participants scored between zero and five, indicating severe disability (Figure 5.4). Many patient participants had difficulty with drinking, swallowing, or sitting balance. No Barthel ADL data were missing.

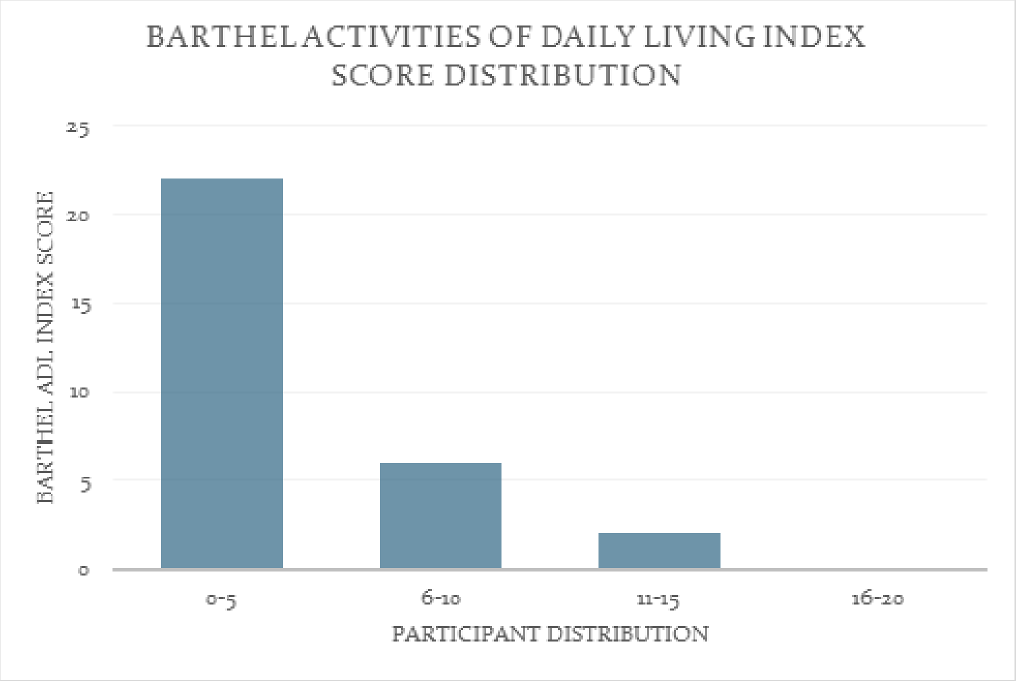

Figure 5.4: Score distribution of the Barthel ADL Index

5.2.6 Follow-up Data

All patient participants were followed-up via a phone call to a relative around 90 days from the date of admission, unless they died during their admission. 13 (43%) participants were discharged to the same place, or the same level of care as before their admission; six (20%) increased their dependence upon additional care, one patient participant was still in hospital at the follow-up date, and ten (33%) of the patient participants had died.

Of the patient participants who survived, 11 (55%) participants were reported to have continued to call out at the follow-up, and nine (45%) had ceased to call out. Eleven of the surviving participants (55%) were re-admitted into hospital. There was no association identified between continuation of calling out and re-admission.

5.3 Interview and Observation Descriptions of Calling Out

In this study, over 140 hours of unstructured observations and 50 hours of structured observations were conducted, alongside the interviews and standardised assessments. Over 550 extracts from nursing and medical documentation was recorded. 28 relatives were approached for interview, as two patient participants had no available relatives. 18 relatives declined to be interviewed for a number of reasons (they were too busy, they felt too upset about their relatives condition, they did not feel comfortable being interviewed) therefore ten relative interviews were conducted (Table 5.4).

Participant Number	Pseudonym	Relative Interviewed
PP101	Betty	-
PP102	Charles	Daughter and Wife
PP103	Martha	-
PP104	Raymond	-
PP105	Frances	-
PP106	Mildred	-
PP107	Antonio	-
PP108	Robert	-
PP109	Joan	-
PP110	Jessie	-
PP111	Florence	-
PP112	Carol	-
PP113	Beverly	-
PP114	Claudine	Daughter
PP115	Vincent	-
PP116	Judy	Daughter
PP117	Vivian	Husband
PP118	Lewis	-
PP119	Diane	Niece
PP120	Charlotte	-
PP121	Elaine	Cousin
PP122	Frank	-
PP123	Shirley	-
PP124	Agnes	Daughter
PP125	Ruth	Brother and Sister-in-Law
PP126	George	Wife
PP127	Evelyn	-
PP128	Joe	Daughter
PP129	Marjorie	-
PP130	Edward	-

Table 5.4: A table to show the patient participant pseudonyms, and relatives interviewed.

5.3.1 Presentation of Calling Out

This section presents the types of calling out that were identified through observations and interviews. The occurrence of calling out amongst the patient participants is described, including the incidence, frequency, persistence, and volume. The meanings and judgements that observers place on the behaviour are also discussed.

5.3.2 Types of Calling Out

Four types of calling out were identified: 1) repetition of a tangible need, 2) single word/phrase repetition, 3) semantic repetition (different words used but the same overall meaning), and 4) stream-of-thought vocalisation. Many participants displayed more than one of these types of calling out during observations.

5.3.2.1 Repetition of a Tangible Need

Often, patient participants repetitively called out a request or desire which was understandable within the context it was given. Staff were conceivably able to meet the need, and no interpretation was needed to attempt to understand the need being vocalised.

> *Vivian called "Dennis!" [husband] … "Can I have a drink please?"*
> *PP117, Structured Observation, Patient Participant 'Vivian'*

> *"Help me… somebody… help me… help me" *crying* "help me" *crying* "I'm cold"*
> *PP116, Structured Observation, Patient Participant 'Judy'*

> *Remains anxious and shouting out for help. Complained of a headache (…) paracetamol given (…) doctors informed of patient headache*
> *PP124, Nursing Documentation, Patient Participant 'Agnes'*

Recorded communications of tangible needs included asking for the toilet or a drink; or being in pain, too cold, or feeling uncomfortable. All patient participants communicated a tangible need on one or multiple occasions during their admission. Sometimes, this need would continue to be called out even after staff had attempted to meet the need.

The repetition of a tangible need has been defined as a type of calling out as it differs from that identified as 'normal' behaviour in the hospital. The participants who vocalised tangible needs did so with much higher frequency and urgency than those who were not identified as calling out repetitively. Other types of calling out were often interspersed with this type of calling out as well, such as the patient participant *'shouting out for help'* initially. Therefore, the behaviour exhibited by the participants appeared disinhibited.

5.3.2.2 Single Word/Phrase

Most patients had a word, or two-to-three-word phrase that they would call out, such as "help me!" or "mum!". It was usually very persistent; and in the more extreme cases, was almost constant, with some patient participants only pausing to sleep or eat

> *I went to the new ward to see how Raymond was doing, staff there said he has been "constantly calling out 'help!'"*
> *PP104, Field Notes, Patient Participant 'Raymond'*

> *"Help me Joe" -(x18) "Help me" "Help me Joe" -(x30)*
> *PP128, Structured Observation, Patient Participant 'Joe'*

Joe would persistently call "Help me, Joe", pause for one-to-two seconds, and then call it again. His daughter reported that Joe was talking to himself when he did this:

> *"But he'd say things like 'Yes, I think so, Joe', if he was making a decision, or changing the channel, 'No I don't think I want this on, Joe'. So that's how it started, him talking to himself a bit."*
> *PP128, Relative Interview, Daughter of Patient Participant 'Joe'*

Single word/phrase calling out was generally deemed to be the patient participant's 'typical' behaviour; staff members were often aware of this, and were very rarely observed to respond to this type of calling out.

5.3.2.3 Semantic Repetition

Semantic repetition involved patients having a recurring request that was not being met. Patient participants would repeat their request persistently, using different words and phrases:

> *"Please take me back to my bedroom, will you?" (…) "This isn't my house, get me home!", "Get me to my bedroom so I can take my pills."*
>
> *PP127, Field Notes, Patient Participant 'Evelyn'*

Requests were often based upon leaving the hospital, going home, or wanting to see/speak to a (sometimes deceased) family member. Therefore, these were usually conceivable needs that could not be met, due to impracticality, or impossibility. Elaine, was almost permanently anxious about money, bills, or paying staff for the work they were doing:

> *"If she's got anything on her mind, she won't let it drop until you've sorted it."*
>
> *PP121, Relative Interview, Cousin of Patient Participant 'Elaine'*

Sometimes, staff members would attempt to explain to the patient participants why their recurring requests could not be met. Patient participants would rarely accept staff member's rationale, adding to their distress:

> *An external staff member is talking to Shirley. She is trying to comfort Shirley, as she is currently upset. Shirley thinks her children are young and that she needs to leave the hospital so she can look after them. The staff member said "It's 10 o'clock, they'll be at school!" but Shirley is not accepting this- they have been going around in circles saying the same things for about 5 minutes, and Shirley is getting increasingly agitated, raising her voice every now and again.*
>
> *PP123, Field Notes, Patient Participant 'Shirley'*

Staff sometimes treated patient participant's vocalisations as rational; as though it must be an unmet need, even where the expressed need was not rational. Semantic vocalisations were problematic for staff, as patient participants appeared fixated on their expressed need, and they would very rarely appear to process a staff member's rational response before calling out the same thing again. Staff would often end up ignoring this type of calling out.

5.3.2.4 Stream-of-Thought

Stream-of-thought calling out involved continuous words or sounds which appeared to be spoken as soon as they came to mind. Specific words were not usually repeated consecutively, but could cycle in similar patterns of thought. Three types of stream-of thought calling out was identified; incomprehensible, hallucination-related, and decontextualized.

1. *Incomprehensible.* Continuous vocalisations that made little or no sense to the listener. It was extremely difficult to place any literal or contextual meaning on the vocalisations.

> *"I hope to goodness that you've found somebody out… why… and I mean this, I really do… this is why… I, Marjorie Taylor… have had to say… 1 word… I will find out… surely you know… 1, 2, 3, 4, FIIIVE! … I hope you're ready for this… and I mean this… I really do… there's only 1 word"*
>
> *PP129, Structured Observations, Patient Participant 'Marjorie'*

Incomprehensible stream-of-thought calling out was at no point judged by staff members to be based on the communication of a specific need. They would range from being clearly spoken (such as the above quotation), to being mumbled or slurred.

2. *Hallucination-related.* Continuous vocalisations that appeared to be responding to visual hallucinations. There was conceivable meaning behind the vocalisations and they made sense, but not in the environment in which they were situated.

> *Shirley appeared to be hallucinating this morning. As staff were walking past [she was] saying "there's another bus that's just gone by" continued to say that she was waiting for the bus to come by to pick her up.*
>
> *PP123, Nursing Documentation, Patient Participant 'Shirley'*

Patients who displayed hallucination-related stream-of-thought calling out did not appear to want staff/carer attention as a result of their calling out. They were focused on their hallucinations and would not often respond to staff members or relatives attempting to communicate with them.

3. *Decontextualised.* These vocalisations generally made sense in the environment they were in, and the sentences themselves made sense. However, the person vocalising would not be in conversation with another person. This could be described as the person loudly talking to themselves.

> *"All these old codgers looking out the window… all moaning saying things aren't what they used to be… and they're right"*
> *PP118, Structured Observation, Patient Participant 'Lewis'*

These patients did not appear to be hallucinating, and if engaged, could have a coherent and meaningful conversation.

Generally, stream-of-thought vocalisations were not often directed to any person in particular, the patient would often be staring straight ahead, or 'through' others. This could be due to a number of factors, such as reminiscing about a past situation and being unable to attend to the current environment, or they could be aiming their vocalisations at everyone in the environment, therefore not paying specific attention to any one person.

5.3.3 Occurrence

5.3.3.1 Prevalence

Wards would usually have between one and three patients who were calling out on a ward of 24-28 patients. Infrequently, wards could have as many as five or six patients who were calling out. On recruitment days, it was rare that a ward would have no potential patient participants, and there was not a single occasion during the data collection period in which there were no potential patient participants across a hospital site.

Despite this, many staff members held the opinion that calling out was rarer than that observed during recruitment and data collection:

> *"Somewhere between half and all the time there is somebody who is calling out to some degree"*
> *PP001, Staff Interview, Male, Consultant*

> *"I guess it's one of those things that can be a bit sporadic. It might not happen for a while, and then you might get two or three cases at once. But yes, I'd say most weeks there's somebody that calls out."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

However, some staff claimed calling out to be more common that this:

> *"There's always someone shouting you."*
>
> *PP008, Staff Interview, Male, Healthcare Assistant*

> *"I think on these wards, like here and next door, quite a few, and that's every day of the week."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

This shows conflicting opinions between staff members about how common calling out is in the acute hospital.

5.3.3.2 Frequency

The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991) demonstrated a ceiling effect, therefore it did not capture the high frequency of vocalisations observed, and provided little descriptive power for the sample. Structured and unstructured observations were used instead to illustrate the frequency of calling out.

During the two-hour structured observations, the maximum number of vocalisations within a three-minute period was recorded; the mean across all patient participants was 11 (range= 1-52). A 'vocalisation' was classed as an exclamation in the form of a single word or sentence without pause[4]. The highest number of vocalisations produced by a single participant within three minutes was Joe, with 52 vocalisations of "Help me, Joe". Joe would call out constantly in this way throughout his admission, pausing only to take breath, to eat or to sleep. Much like Joe, some patient participants would call out repetitively whenever

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[4] Stream-of-thought vocalisations were only counted as one 'vocalisation' during the three-minute structured observation period. This was the case for five patient participants.

they were awake, however some would call out less frequently. The patient participants could not be placed into distinctive categories regarding the frequency of the calling out, as this fluctuated regularly. However, eight patient participants called out almost constantly when awake, and would sometimes shout over the top of somebody trying to speak to them. Fifteen patient participants called out very regularly, and would generally only stop upon receiving verbal input from staff or relatives. The remaining seven patient participants called out intermittently, generally repetitively calling out a need that could be met. For most patient participants, there were reports in the nursing documentation or from relatives about previous 'constant' calling out.

5.3.3.3 Persistence/Transience

For patients who called out, not every day was the same regarding the frequency and persistence of their vocalisations. Some days, patient participants would be significantly 'quieter' or 'more settled' than usual.

Persistent

Figure 5.5 describes persistent calling out using the Pittsburgh Agitation Scale- Aberrant Vocalisations (PAS-AV; Rosen et al. 1994), in which a score of 0 indicates no vocalisation, and a score of 4 indicates "extremely loud screaming or yelling, highly disruptive, unable to redirect". Antonio called out every day from the start of his admission until he was discharged, and had continued to do so at follow up. Patients who persistently called out often fluctuated day-to-day on the PAS-AV.

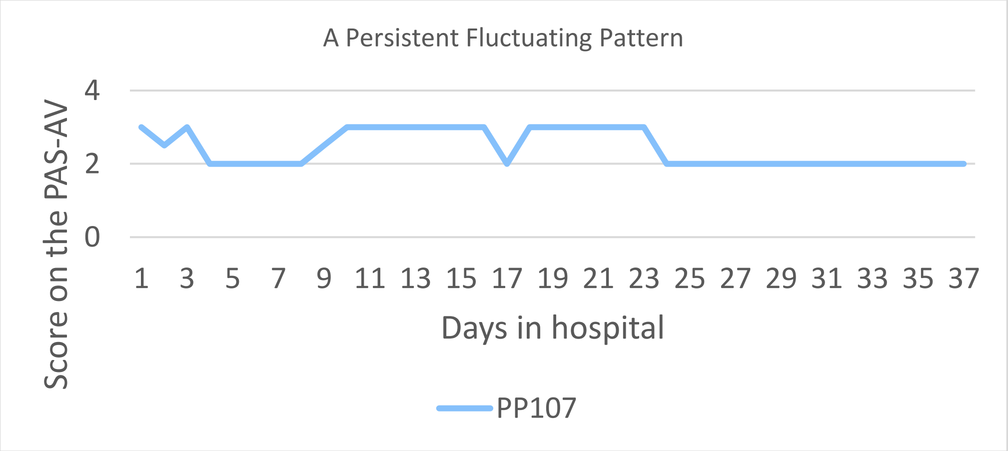


Figure 5.5: The persistent fluctuating calling out of Antonio based on the PAS-AV.

Nineteen of the 30 patient participants called out persistently throughout their admission, with daily fluctuations in the severity of their behaviour.

Fluctuations were sometimes reported to be caused by the patient participant staying awake throughout the night and sleeping more in the day, causing less instances of calling out during the day:

> *"When she's shouting out a lot and nobody's responding to her, she wears herself out, and the following day she's just asleep all the time and won't cooperate, and won't eat, won't drink, because she's too tired. She's wore herself out physically trying to get the help the day before and her body just can't cope with it so it shuts down and goes to sleep."*
>
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

Transient

Some patient participants would call out frequently at the start of admission, and then show a steady decline over time (Figure 5.6). They would not stop fully, but be more manageable due to the decreased volume and increased distractibility from their calling out.

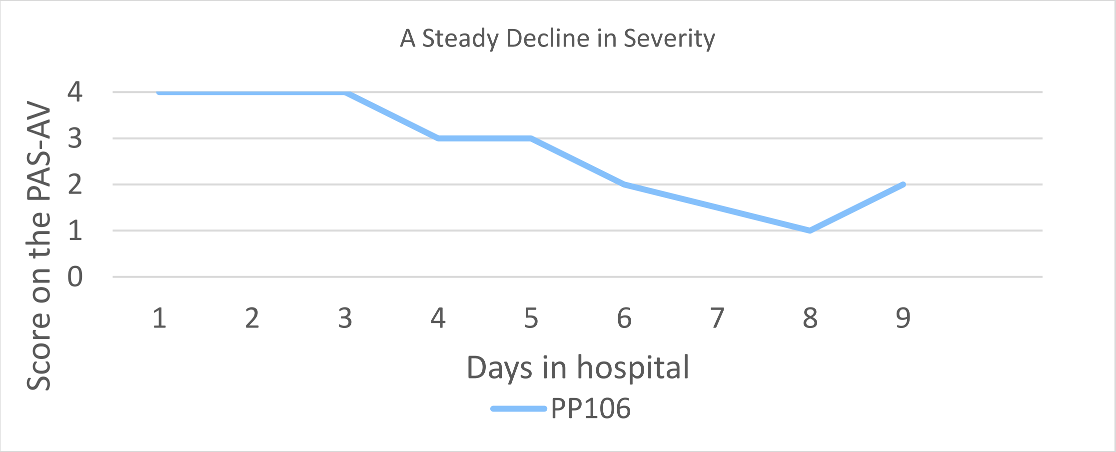


Figure 5.6: A steady decline in severity of calling out, based on Mildred's PAS-AV scores

Some staff members reported that some patients may call out for a few days, and then stop entirely.

> *"It often varies through the course of an admission, some people have periods when they're calling out and then stop, other people call out entirely through the admission"*
> *PP001, Staff Interview, Male, Consultant*

Figure 5.7 displays the PAS-AV scores of Martha, who called out for three days and then stopped on the fourth day while still in hospital.

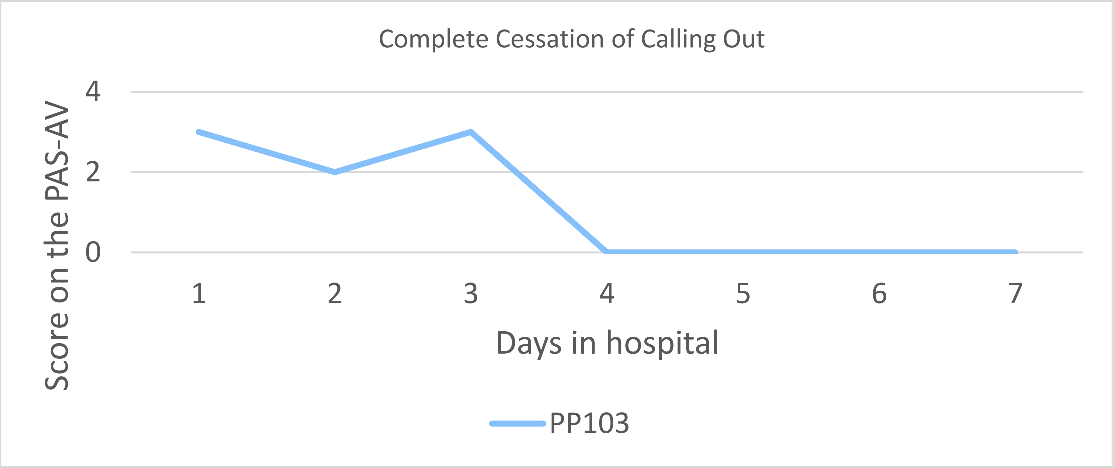


Figure 5.7: Complete cessation of Martha's calling out, based on the PAS-AV

Eleven of the 30 patient participants stopped or reduced their calling out before they were discharged. Two suggestions were raised for why patients may stop calling out. Some staff members suggested that delirium had caused the calling out, and once resolved, the calling out stopped. This was observed in five of the patient participants.

> *Staff on this new ward said [PP103] is being "lovely" […] They said she has not been calling out since she arrived on the ward, and it is likely she had delirium before.*
> *PP103, Field Notes, Patient Participant 'Martha'*

Another reason calling out stopped was a further decline in health, often suggesting fatigue.

> *A nurse is telling a consultant on ward round that Diane is much more settled today, she thinks it's because Diane has become more poorly. The consultant said: "So when you say 'settled', you don't mean better?" and the nurse said: "No, she's quieter because*

she's worn out, she was shouting out a lot yesterday."
PP119, Field Notes, Patient Participant 'Diane'

More daytime sleep meant less time to call out during the day, this was observed in six of the patient participants.

Overall, a number of differences were found in the frequency and severity of the patient participants. It is difficult to place patients who call out into specific categories, as they changed and fluctuated throughout their hospital admission. Both positive (recovery from delirium) and negative (a decline in health or energy) causes for transient calling out were suggested.

5.3.3.4 Volume

The volume of the calling out was not systematically measured, however dramatic differences in the way that patient participants called out was observed. Some patient participants were observed to be shouting at the loudest volume they could achieve:

Bellows at the top of her voice when she wants something.
PP119, Nursing Documentation, Patient Participant 'Diane'

He is very loud, and I could hear him clearly down the other end of the corridor despite the fact his door was closed.
PP126, Field Notes, Patient Participant 'George'

On the other hand, some patient participants were observed to whisper quietly under their breath with their eyes closed:

7:40am- Raymond seems to almost be saying "help" under his breath with every exhale.
PP104, Field Notes, Patient Participant 'Raymond'

A healthcare assistant is taking Mildred's temperature and blood pressure, Mildred is muttering quietly but continually under her breath.
PP106, Field Notes, Patient Participant 'Mildred'

These examples illustrate the extremes regarding calling out volume, however many intermediate volumes were observed between these levels. Occasionally, the behaviour could be described as ‘shouting’, other times, ‘loud talking’, and sometimes, ‘whispering’. This further emphasises the differences between calling out behaviours, and the difficulty in describing the behaviour.

5.3.4 Patient Differences

Differences between patient participants were observed to affect the amount of intervention they received from staff, including language barriers, sensory impairments, and a lack of patient motivation.

5.3.4.1 Language

People with dementia may lose their second language, and revert to their first (Tipping and Whiteside, 2015). Three of the patient participants had English as a second language, and would regularly attempt to communicate with staff and relatives in their first language. This was a problem for others who could not speak their language.

> *Antonio keeps talking to staff in Greek, and they keep reminding him to speak in English as they cannot speak Greek. Staff say he regularly fluctuates between Greek and English.*
>
> *PP107, Field Notes, Patient Participant ‘Antonio’*

> *“My only problem is when we first came in, she reverted back to German, and I can’t speak German so I was scuppered. And then before they decided to give her some fluid, she started to speak German again. And I’m thinking ‘mum, if you don’t speak English, I can’t understand you’. So, it was quite touch and go because I was really worried that she’d revert back to German and our communication would be over, unless I picked the language up extremely quickly.”*
>
> *PP114, Relative Interview, Daughter of Patient Participant ‘Claudine’*

Patient participants reverting back to their first language would sometimes have nobody available to speak to them, especially if family members also did not know the language, increasing the sense of isolation, and limiting potential interventions.

5.3.4.2 Sensory Impairment

Hearing

Difficulties with hearing could cause staff to be reluctant to interact with patient participants. The negative implications of patient hearing impairments manifested themselves in many ways.

> *The healthcare assistant came out of Judy's room and said to me "because she hasn't got a hearing aid, she shouts SO loud". He said it's difficult when caring for Judy, as she'll shout "you're hurting me" loudly, which he feels makes him look bad, so he tries to only go in to see her with another person.*
>
> *PP116, Field Notes, Patient Participant 'Judy'*

> *Constantly talking and singing, calling out "lady, I'm dead, I'm going to die" reassurance given frequently but difficult as very deaf.*
>
> *PP125, Nursing Documentation, Patient Participant 'Ruth'*

> *A healthcare assistant (HCA) is changing Agnes's bedsheets, she picked Agnes's hand up to take her hand off the bed without saying anything to her. The HCA isn't chatting, but Agnes can only hear if you talk loudly into her ear, and I think the HCA just wants to get her job done. After changing Agnes's bed, the HCA went immediately to change the next patient's bed and engaged in conversation with the other patient: "are you alright?... Your hair is nice and combed back... wow you have lots of pillows! ... shall I get you a blanket?"*
>
> *PP124, Structured Observation, Patient Participant 'Agnes'*

> *“Sometimes she has her glasses on, sometimes she has her hearing aid on, but not always. And whenever I visit, and I visit every day, I make sure that I put her glasses on, and I put her hearing aid in. But equally I take her hearing aid out because usually afternoons she’ll fall asleep, and I don’t want it lost. So, I put it in the box.”*
>
> *PP124, Relative Interview, Daughter of Patient Participant ‘Agnes’*

Staff were generally observed to interact less with patients experiencing hearing impairment. Agnes’s daughter reported removing Agnes’s hearing aid to avoid it getting lost, however this would also have impaired her hearing.

Eyesight

Poor eyesight was also found to hinder the ability to intervene with patients who call out. Many straightforward activity-based interventions rely on eyesight, such as most games, reading, writing, and television.

> *He has his eyes closed most of the time, maybe as he is registered blind in one eye and cannot see well in the other. I believe it is difficult to get his attention due to this.*
>
> *PP102, Field Notes, Patient Participant ‘Charles’*

> *“She’s limited with activities because her love is to write and read, and with her eyesight she can’t do that now. And that must be so frustrating for her.”*
>
> *PP119, Relative Interview, Niece of Patient Participant ‘Diane’*

Poor eyesight was also suggested to cause additional confusion, as patients could struggle to orient themselves.

5.3.4.3 Motivation

Patient participants often had little motivation to engage in therapeutic or pleasurable activities, causing difficulties for staff members and relatives trying to complete interventions.

> *Edward said to me "it's horrible, I just don't want to do anything" between drifting off to sleep.*
>
> *PP130, Field Notes, Patient Participant 'Edward'*

> *"The last month prior to going in hospital, it was as if she didn't want to know or do anything, the shutters seem to have come down."*
>
> *PP125, Relative Interview, Brother of Patient Participant 'Ruth'*

> *"By which time he had deteriorated in what he could do for himself or what he was prepared to do for himself, I'm not quite sure about that."*
>
> *PP128, Relative Interview, Daughter of Patient Participant 'Joe'*

A lack of motivation in the patient participants may have been due to a depressed mood, fatigue, physical illness, apathy due to dementia, or because they were nearing end of life. Staff members and relatives struggled to motivate patients when they were feeling this way.

As summarised by Agnes's daughter, many of the identified patient differences that hinder intervention can occur together, or even manifest themselves all at once.

> *"My mother has got macular degeneration so she doesn't see very well. She's hard of hearing, English is not her first language, she's in an unfamiliar situation and she's got a fractured pelvis. So, she's obviously distressed"*
>
> *PP124, Relative Interview, Daughter of Patient Participant 'Agnes'*

5.3.5 Perceived Emotion of People who Call Out

It is often difficult to ascertain a person's emotional state when they have communication impairments (Stanyon et al. 2016). Staff members and relatives often attempted to make assumptions regarding the emotions of the patient participants. Agitation and distress were commonly mentioned when discussing internal feelings or emotions.

5.3.5.1 Mental Agitation

Staff members spoke regularly about how they believed patient participants were feeling ‘agitated’ when they were calling out:

> *Diane is getting agitated this afternoon. Diane states she wants to go home today and declined her medication (…) Diane threw her ID band out of the window and [has been] hitting the foot stool board with her right foot. Diane is saying she does not care and wants to leave the hospital.*
>
> *PP119, Nursing Documentation, Patient Participant ‘Diane’*

> *“A lot of them are [agitated], they can be agitated through one thing or another.”*
>
> *PP009, Staff Interview, Female, Staff Nurse*

Staff believed patients who called out were mentally agitated for three reasons: 1. the patient’s physical behaviour, such as kicking or hitting; 2. verbal cues, such as stating they do not want to be in the hospital, or declining medication; or 3. through their medical condition, such as the knowledge that the patient might be experiencing pain. All of these factors, separately or combined, caused staff members to believe that patient participants were feeling agitated.

Some staff members stated that they believed patients who called out or displayed behaviours that challenge had been labelled as agitated:

> *“We've had people that get described as quite agitated and actually it's just they want to walk around. So, we let them walk around. And they're lovely.”*
>
> *PP002, Staff Interview, Male, Mental Health Nurse*

> *“It could just be singing and singing very loudly the same thing over and over again, that might not be agitated. It's just soothes them.”*
>
> *PP010, Staff Interview, Male, Consultant*

In these instances, staff members implied that others were labelling patients who called out as agitated, when the patient may not necessarily have been feeling internally agitated.

5.3.5.2 Distress

Reports of distress in the patient participants were commonly noted by myself, staff members and relatives:

> *She shouts and gestures a lot when in distress.*
> *PP111, Nursing Documentation, Patient Participant 'Florence'*

> *Vincent is putting his hand on his forehead and fidgeting with his face, hands, and cannula, he is extremely restless and appears distressed. He is still shouting out "eeerh" and patting and squeezing his legs.*
> *PP115, Field Notes, Patient Participant 'Vincent'*

> *Very distressed at times, not able to get comfortable when sitting in chair or lying in bed.*
> *PP124, Nursing Documentation, Patient Participant 'Agnes'*

> *"So, I wasn't overly concerned until the pulling of the clothing was happening, and the actual biting of oneself […] And just trying to understand how to make that better, to stop the anxiety and stop the upset."*
> *PP114, Relative Interview, Daughter of Patient Participant 'Claudine'*

A number of physical behaviours were displayed by patients believed to be in distress. These included holding their hands to their face, frowning and crying. A general indication of restlessness also contributed to the observation of distress, such as pulling at clothing or fidgeting. If a patient was calling out 'help!'

they were generally only considered to be feeling distressed if the indicative body-language accompanied the vocal behaviour.

Some staff members believed that generally, patients were feeling distressed when they were calling out:

> *"I'd say it was usually a symptom of feeling unhappy, or feeling distressed, or feeling lost, rather than feeling okay."*
> *PP006, Staff Interview, Female, Occupational Therapist*

> *"Calling out and distress, they're calling out because – well it's the same thing isn't it? If you're distressed you call out"*
> *PP004, Staff Interview, Female, Staff Nurse*

However, other staff members indicated that they did not always feel that a patient who called out was necessarily in distress:

> *"But sometimes, it's sort of a more contented muttering or singing, we had a gentleman who was singing Silent Night really rather persistently, of course you know that doesn't take long for that to upset people but it wasn't greatly distressed [...] I mean, singing Silent Night doesn't communicate any great unhappiness."*
> *PP001, Staff Interview, Male, Consultant*

> *"But people will call out and not be what you might call distressed. They just might be calling out. [...] You know, there's not necessarily any distress linked to it."*
> *PP002, Staff Interview, Male, Mental Health Nurse*

On one occasion, a staff member dismissed Vincent's (PP115) behaviour (described on page 134) as being 'habitual', however his facial expressions and body language indicated that he was in pain:

> *The consultant came and said to me that Vincent has a history of shouting out, so thinks that it is habitual. Vincent appears very*

> *distressed though- can distress be habitual?*
> *PP115, Field Notes, Patient Participant 'Vincent'*

It was often the content of the calling out, or the patient's body language that caused staff to identify patients as being in distress. Therefore, if these appeared to be neutral or relaxed, observers would not necessarily interpret this as distress:

> *[asked if they could easily tell if a patient who is calling out is feeling distressed]: "Yes, because I think the temperament changes, yes."*
> *PP012, Staff Interview, Female, Healthcare Assistant*

> *"Just because somebody's shouting out, it doesn't mean that there's something wrong necessarily. And just because somebody's not shouting out, it doesn't mean that they're OK. It's looking, trying to look at the body language of that person as well. And it's not always easy."*
> *PP013, Staff Interview, Female, Deputy Ward Manager*

Staff members who interpreted feelings of agitation or distress described similar outward appearances in patient participants for both. The labelling of both agitation and distress relied on further interpretations than simply the content of the calling out. They instead relied on motor cues, such as restlessness. In contrast, relatives would not refer to the patient participant as feeling 'agitated' and would focus more on the idea of the patient being 'anxious' or 'distressed'. There appeared to be more of a feeling of pity coming from relatives as opposed to staff members.

5.3.6 A Socially Problematic Behaviour

Staff members regularly reported that calling out repetitively is problematic within the social context of the acute hospital ward due to it being a collective environment shared by many people. This was observed and reported in interviews as: either related to emotionally-challenging content within the vocalisations; or associated physical challenges, such as aggression or wandering, and the disruptiveness of the calling out.

5.3.6.1 Verbally Challenging Content

The content of calling out was sometimes found to be challenging for staff members. This involved personal racism, sexual disinhibition, and verbally confrontational language:

> *A staff nurse told me about how Martha kept calling her a "black bitch" and wouldn't let the nurse administer her medication. She said Martha asked other staff members for the nurse to leave the building and she wouldn't take her medication unless she was not in the building.*
>
> *PP103, Field Notes, Patient Participant 'Martha'*

> *Asking to kiss staff [...] shouting out about naked women.*
>
> *PP108, Nursing Documentation, Patient Participant 'Robert'*

> *A male HCA [healthcare assistant] was taking Antonio to the toilet, and Antonio said to the HCA "I will get a knife and kill you, you bloody idiot".*
>
> *PP107, Nursing Documentation, Patient Participant 'Antonio'*

> *Telling staff she's going to "bite their faces off" and other vile things [...] shouting "shut up or I'll beat you up until you die".*
>
> *PP119, Nursing Documentation, Patient Participant 'Diane'*

These situations were relatively common, with a total of 13 of the 30 patient participants exhibiting emotionally-challenging calling out. Two patient participants (one male, one female) exhibited personal racism towards black staff members, usually involving derogatory language and profanities directed towards the staff member. Three patient participants (all males) used sexually disinhibited language, often involving the direct verbal pursuit of a specific staff member, or general use of sexual language. Thirteen patient participants (six males, seven females) used verbally confrontational language. This included verbal expressions of aggressive acts, such as threatening to hurt or kill somebody, alongside curse words directed at others. Verbally challenging content appeared to upset and distress some staff members; however, some would humour the behaviour of the patients.

> *A staff member reported that Antonio had told her they were going to get married in Cyprus tomorrow whilst laughing.*
> *PP107, Field Notes, Patient Participant 'Antonio'*

> *I asked a HCA how Diane had been, she said "Diane has been the apple of my eye" sarcastically, then laughed.*
> *PP119, Field Notes, Patient Participant 'Diane'*

5.3.6.2 Physically Challenging Behaviour

A number of physical behaviours were exhibited by patient participants that staff members found challenging. These have been categorised into staff-directed, and non-staff-directed. Staff-directed behaviours involved hitting, punching, kicking, throwing things, biting, and spitting at staff members, and resisting care using aggression directed at staff. Non-staff-directed behaviours involved trying to get to a different place, loudly banging on the table, removing clothes in public spaces, and self-harm, such as scratching until blood was drawn. Seventeen patient participants exhibited staff-directed physically challenging behaviours:

> *Attempted to assist with personal hygiene needs, very aggressive on interventions. Hitting, kicking, punching, spitting at members of staff.*
> *PP115, Nursing Documentation, Patient Participant 'Vincent'*

> *A nurse has entered George's room to dress him, as he had removed his clothing. George said "I'm freezing" to the nurse, and the nurse said "I'm not surprised!" A few moments later, she said "Don't bite, that's not nice… I don't bite you, do I?"*

> *PP126, Field Notes, Patient Participant 'George'*

> *"It's shouting, hitting, throwing things at you."*
> *PP012, Staff Interview, Female, Healthcare Assistant*

Often, staff-directed challenging behaviours were due to unwanted intervention from staff, causing physical resistance to care. However, George had bitten the staff member despite the fact he had implied he wanted help to get dressed.

Fourteen patient participants exhibited non-staff-directed physical behaviours:

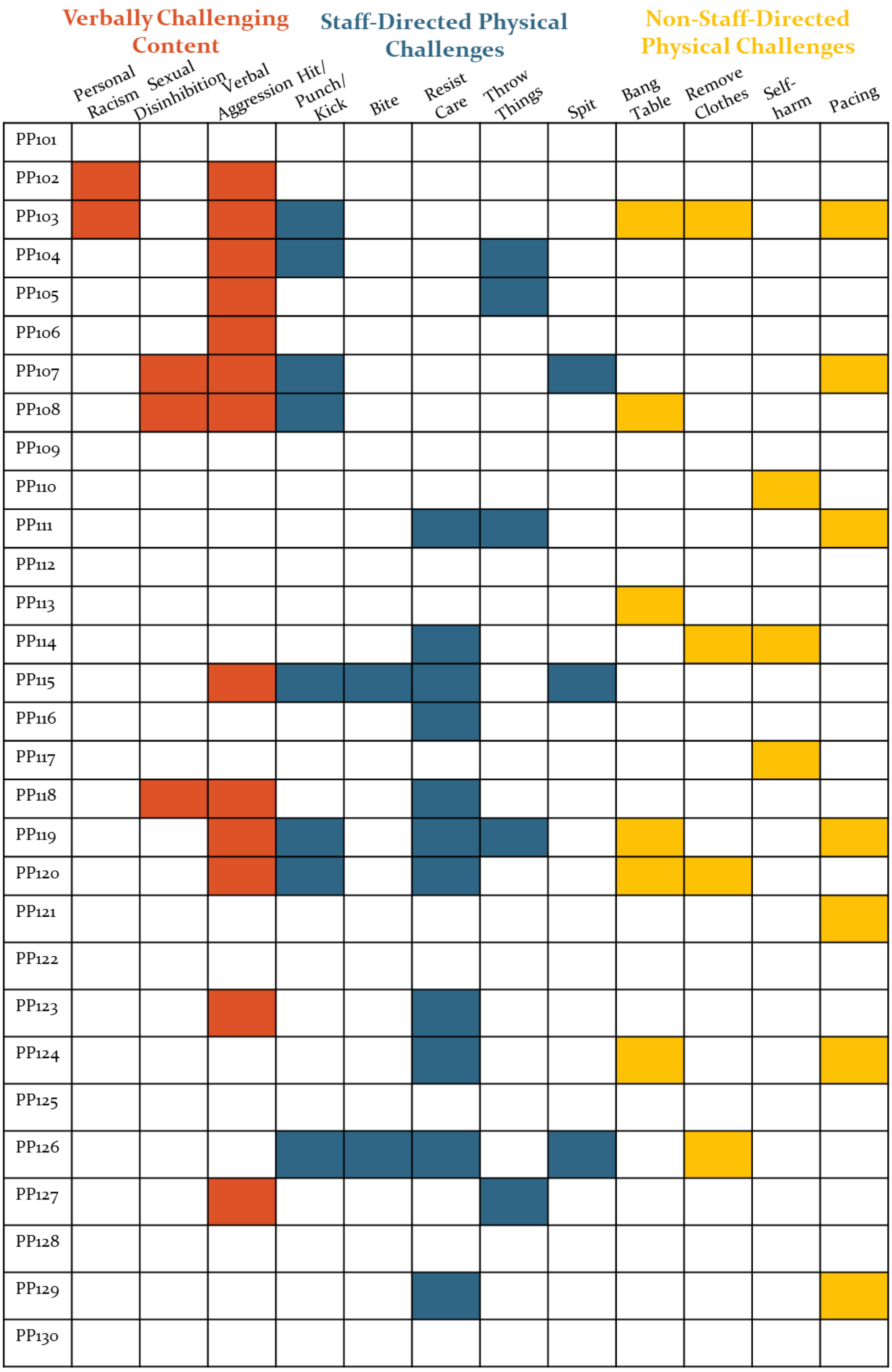
> *Patient was confused early morning, she got out of bed stripped, stood up and passed urine on the floor. After being cleaned, she was put back into bed and she slept.*
> *PP103, Nursing Documentation, Patient Participant 'Martha'*

> *Diane has also been kicking, knocking, and shaking her bedrails.*
> *PP119, Structured Observation, Patient Participant 'Diane'*

> *Marjorie has been extremely agitated and confused, she has not sit still constantly on the move, disturbing other patients in bay and removing their belongings.*
> *PP129, Nursing Documentation, Patient Participant 'Marjorie'*

Physically challenging behaviour overall was observed in 21 out of 30 patient participants (70%). The number of participants who displayed verbally challenging behaviour or physically challenging behaviour was 23 out of 30 (76.6%). Seven participants did not display any verbal or physical challenging behaviours (23.3%) additionally to calling out. The chart below (Figure 5.8) displays every additional challenging behaviour type displayed by each patient participant, displaying the overlap between different behaviour types.

It was noted that relatives did not willingly discuss details of challenging behaviours of patient participants, and would be relatively vague when discussing challenging behaviours of their relatives. When discussing their relatives challenging behaviours, they would often reinforce that this had not been their usual presentation throughout their life, and that it was a change due to their dementia. This was found in both interviews and in informal conversations.



	Verbally Challenging Content			Staff-Directed Physical Challenges					Non-Staff-Directed Physical Challenges			
	Personal Racism	Sexual Disinhibition	Verbal Aggression	Hit/ Punch/ Kick	Bite	Resist Care	Throw Things	Spit	Bang Table	Remove Clothes	Self-harm	Pacing
PP101												
PP102	🟥		🟥									
PP103	🟥		🟥	🟦					🟨	🟨		🟨
PP104			🟥	🟦			🟦					
PP105			🟥				🟦					
PP106			🟥									
PP107		🟥	🟥	🟦				🟦				🟨
PP108		🟥	🟥	🟦					🟨			
PP109												
PP110											🟨	
PP111						🟦	🟦					🟨
PP112												
PP113									🟨			
PP114						🟦				🟨	🟨	
PP115			🟥	🟦	🟦	🟦		🟦				
PP116						🟦						
PP117											🟨	
PP118		🟥	🟥			🟦						
PP119			🟥	🟦		🟦	🟦		🟨			🟨
PP120			🟥	🟦		🟦			🟨	🟨		
PP121												🟨
PP122												
PP123			🟥			🟦						
PP124						🟦			🟨			🟨
PP125												
PP126				🟦	🟦	🟦		🟦		🟨		
PP127			🟥				🟦					
PP128												
PP129						🟦						🟨
PP130												

Figure 5.8: The challenging behaviours exhibited by each patient participant

5.3.6.3 Disruption

When patient participants called out, they would generally disturb other patients on the bay that they were situated, particularly if the volume was louder than conversational. Many patient participants were observed to be distressing and disrupting others on the ward, primarily due to their repetitive calling out:

> *A patient in the bed next to Mildred was holding her head in her hands, and telling her visitor that she's "had to put up with this [the shouting] the whole time". She is now holding a teddy bear to her ear and grimacing- she is clearly affected by the calling out. The patient on the other side of Mildred also appears to be extremely distressed and looks as if she's crying as her face is clenched/wincing.*
>
> *PP106, Field Notes, Patient Participant 'Mildred'*

> *Spoke to the HCA [healthcare assistant] who said that the past few nights before, Jessie had been extremely loud and disruptive, and that the other patients on the bay all had very little sleep due to this, and had been very annoyed.*
>
> *PP110, Field Notes, Patient Participant 'Jessie'*

> *"When he shouted he used to wake other residents up."*
>
> *PP128, Relative Interview, Daughter of Patient Participant 'Joe'*

Disruption would occur day or night, although other patients would generally feel more disrupted and irritated by calling out when it occurred during the night, disturbing their sleep. Some patient participants were more disruptive in the day, some more at night, and some did not increase or decrease in level of disruptiveness. A number of patient participants were observed to be calling out extremely quietly on one or multiple occasions. The majority of patient participants were moderately to severely disruptive for others on the ward on at least one occasion during their admission.

5.3.6.4 Difficulty to Discharge

Some staff members discussed the difficulty in discharging patients who were known to have been calling out for an extended period of time, and were considered likely to not stop. Patient participant Diane- PP119 remained in hospital at the time of her follow up. The receptionist on the ward claimed that "*no-one will take her as she's just so difficult*". Similarly, Antonio- PP107 remained in hospital for 66 days before a care home was found for him, having been ready for discharge for over 50 days. A conversation with a staff member regarding Antonio highlighted that this was not a rare occurrence, and that care homes would state the patient would not 'get on well' with other residents at the care home as a reason to not accept a difficult-to-manage patient.

5.3.7 Decline in Physical and Mental Health

5.3.7.1 Physical Decline

Patient participants generally had very severe physical impairment, with a mean activities of daily living score (Barthel ADL Index) of 3.7/20. Relatives and staff members similarly believed patient participants often lacked the physical ability to meet their own needs. Many relatives reported a decline in physical health in the weeks leading up to the patient participant beginning to call out:

> *"And once he couldn't physically do [the things that interest him], it's a perpetual spiral downwards really."*
>
> *PP102, Relative Interview, Daughter of Patient Participant 'Charles'*

> *"Oh, she was coping. I mean she was feeding herself, keeping herself clean and her house clean. But I was noticing a steady decline."*
>
> *PP121, Relative Interview, Cousin of Patient Participant 'Elaine'*

Furthermore, some relatives suggested that the decline in physical health might have caused the patient participant to begin calling out:

> *"He's trying to control things. And is that because he can't control how he uses his hands, he can't control what he sees. The only*

> *thing left he can control is what comes out of his mouth."*
> *PP102, Relative Interviews, Daughter of Patient Participant 'Charles'*

> *"Maybe it's because she now is helpless and she can't do things for herself."*
> *PP124, Relative Interview, Daughter of Patient Participant 'Agnes'*

Relatives appeared to place more of a focus on a physical decline than staff. Likely due to the fact that this was a new occurrence for them, as opposed to hospital staff, who were more used to seeing poorly patients and did not see it as novel.

5.3.7.2 Cognitive Impairment

Staff members and relatives discussed the relationship between calling out and cognitive impairment. All staff reported that people who call out are confused, forgetful, and have impaired communications skills, and are likely to have dementia, delirium, or both.

Forgetfulness

> *Shirley's daughter has now left, so I went over to speak to Shirley. She was very upset that she'd been "dumped here" and was saying that no one knew she was here. She had no recollection of her daughter being there with her for over 2 hours, even when I reminded her.*
> *PP123, Field Notes, Patient Participant 'Shirley'*

> *"I'll go to them and see if I can help them. And then you probably help them in what they need, and they've forgotten, then they're asking you again."*
> *PP014, Staff Interview, Female, Staff Nurse*

Confusion

> *Shouting out about his father being missing for several years, asking staff/patients if they have seen him. Also stated him and his father are twins*
>
> *PP108, Nursing Documentation, Patient Participant 'Robert'*

> *"But the ones that shout are normally very confused."*
>
> *PP008, Staff Interview, Male, Healthcare Assistant*

Impaired Communication

> *Mildred has lost her speech/communication skills almost entirely- I have not heard her say anything at any point that makes sense to the context, or that indicates that she knows where she is or what is happening.*
>
> *PP106, Field Notes, Patient Participant 'Mildred'*

> *"There might be something they can't express. They might be wanting a drink but all they can say is help"*
>
> *PP014, Staff Interview, Female, Staff Nurse*

Lacking Decision-Making Capacity

> *"When [the kitchen staff] come around and ask what you might eat, might have a choice, I usually make the decision for her because I don't think she is capable of doing that now."*
>
> *PP117, Relative Interview, Husband of Patient Participant 'Vivian'*

These data highlight the difficulties associated with effectively communicating with people who call out, due to forgetfulness, confusion, impaired communication, and a lack of mental capacity.

There were many references to dementia or delirium found throughout the qualitative data from both staff and relatives:

> *"He's been calling since he first had his dementia"*
> *PP102, Relative Interview, Daughter of Patient Participant 'Charles'*

> *"You get some patients who have got the highly advanced dementia and they'll call out frequently."*
> *PP014, Staff Interview, Female, Staff Nurse*

> *Very agitated + delirious all night. Non-compliant with care + medication*
> *PP120, Nursing Documentation, Patient Participant 'Charlotte'*

> *"It could be delirium, they don't necessarily come in with dementia, but any kind of infection in elderly people will make them shout out"*
> *PP004, Staff Interview, Female, Staff Nurse*

5.3.7.3 Palliative Care

A large proportion of patient participants (10/30, 33.3%) died within a relatively short time period of three months. Alongside the high rate of readmissions in patient participants who survived, (11/19, 57.9%), this suggests that the majority were in very poor health when recruited into the study. Qualitative data also pointed towards the notion that people who call out can be very ill, and may be in the end stages of life:

> *The doctors have told Beverly's relative that Beverly may live for 2-3 more days, however her relative said she thinks that it may only be a day, with the way that Beverly appears currently.*
> *PP113, Field Notes, Patient Participant 'Beverly'*

> *Vincent's relatives are back by his bed- I spoke to the consultant and he said the O2 levels that Vincent had earlier, on paper, he*

> *should have died. His comorbidity means he's not fit for intervention, so at the moment it's a matter of administering the O2 and keeping Vincent comfortable.*
>
> *PP115, Field Notes, Patient Participant 'Vincent'*

Despite the quantitative findings in this study, no staff members suggested in interview that people who call out repetitively in the acute hospital are likely to be nearing the end of their life.

5.4 The Ward Environment

Sometimes, the wards were busy and 'chaotic'. A number of observational extracts were identified, which characterise the environment in the acute hospital.

> *The bay is very busy, cleaning staff are using ladders to take bedside curtains down and making a lot of noise. The ward feels extremely hectic. Lots of loud conversations are happening at the same time, and there are lots of additional sounds (banging and clattering, moving furniture) alongside the usual hospital ward sounds (telephones, beeping). I am feeling stressed and overwhelmed myself, and imagine the patients must be feeling the same. Joan is quietly vocalising and trying to take her blanket off, another patient is calling out for a commode, but no staff members are coming to her, they appear short-staffed. […] Joan is crying on and off and calling "please". One of the cleaners pointed at Joan and then said to the other cleaner "Look you upset her- what did I tell you about upsetting them?" whilst laughing.*
>
> *PP109, Field Notes, Patient Participant 'Joan'*

> *Claudine is currently lying with her eyes closed calling "help, help", "owwwwww, owwwwww", "help me!" (x6)- she's calling ever so slightly louder than I've heard her before- but she's being drowned out by the sound of workmen outside, and no nurses are near her. I think trees are being cut down just outside, as I can*

> *hear very loud chainsaws. It is a warm day, so the windows are open letting all of the sound in.*
>
> *PP114, Field Notes, Patient Participant 'Claudine'*

> *This bay is busy with patients requiring all kinds of needs. Whilst Agnes is calling out from her chair, another patient is stood at the foot of her bed folding and re-folding sheets, two patients are walking around the bay holding items that do not belong to them. One of these patients tried to take the folding lady's slippers whilst saying he was looking for the yellow pages, another lady tried to take the folding lady's sheets and they began to fight over them. Another patient is loudly banging her walking frame on the floor. Three of the patients in the bay have one or more visitors. Staff are handling this hectic situation amazingly well currently; they look positive, full of energy, and are smiling. A staff member gave extra sheets to the patients fighting so they had enough of their own sheets and stopped fighting, and distracted the patient 'stealing' the slippers by talking to him and walking him away from them. […] A staff member went over to the folding lady, who was about to pick some medical notes up from the nursing station. The patient told the staff member they were unorganised, and the nurse said 'oh I know' and pretended to organise them. A healthcare assistant bought the yellow pages man a book to read.*
>
> *PP124, Field Notes, Patient Participant 'Agnes'*

These extracts highlight the dynamic nature of this patient population, and how situations and behaviours could easily get 'out of control' if not managed appropriately. Events can occur to disrupt the ward that are beyond the control of the ward manager, such as loud external building works. The atmosphere of the ward can be dramatically affected by patient personality clashes or the prevention and control of infection, however the way in which staff manage these situations can determine if the situation becomes a positive or a negative experience.

Conversely, there were also occasions in which the wards had a peaceful and calm atmosphere.

> *The bay is peaceful, a radio is playing very quietly and a fan is by Florence's bed, on and pointing to her face- a healthcare assistant has come to feed Florence some breakfast, and a cleaner is wiping down a bed in the corner.*
>
> *PP111, Field Notes, Patient Participant 'Florence'*

> *Diane is sitting up in bed fully dressed, she was smiling when I walked in. A healthcare assistant is smiling and laughing with her. Music is playing, and Diane is moving her feet in time to the music. The ward feels calm and relaxing.*
>
> *PP119, Field Notes, Patient Participant 'Diane'*

A quiet ward, with soft music playing appeared to enhance the feeling of calm. Conversations between staff were often little more than a whisper at this time, making jokes about their attempts to maintain the 'sense of calm' for as long as possible.

5.5 Summary

Calling out, and the people who display it, have been characterised using quantitative and qualitative data. Quantitative data identified that patients in the acute hospital who call out repetitively are severely cognitively impaired, and are likely to have delirium and dementia. They have poor physical ability, a number of comorbid conditions, and could be close to the end of their life. They are likely to be in mild to moderate pain, and experiencing symptoms of depression. They often stay in hospital for a long time, and if they survive, are likely to be readmitted into hospital within a short space of time.

As Figure 5.9 displays, Calling out was presented in four types: 1. repetition of a tangible need, 2. single word/phrase repetition, 3. semantic repetition, and 4. stream-of-thought vocalisation (separated into incomprehensible, hallucination-related, and decontextualized). Patient participants could display multiple types of calling out throughout the day.

Participants could vocalise almost continuously, causing a substantial ceiling effect on the Cohen-Mansfield Agitation Index (CMAI; Cohen-Mansfield, 1991). Two levels of permanence of calling out were found. ‘Persistent’ patient participants called out for the entirety of their hospital admission, with temporal fluctuations. ‘Transient’ patient participants either reduced their calling out over time, or stopped after a number of days, due to resolution of delirium, or a severe decline in health, often resulting in death. Observer interpretations of calling out were examined. Restlessness was commonly associated with agitation and distress.

A characterisation of the type of patient who calls out was also outlined. Many patient participants exhibited socially problematic behaviours. Verbally challenging content involved personal racism, sexual disinhibition, and verbally confrontational language. Physically challenging behaviour involved staff-directed behaviours, such as hitting or biting staff, and non-staff-directed behaviours, such as banging on the table or trying to get out of bed. Staff and relatives reported forgetfulness, confusion, impaired communication and a lack of mental capacity in patients who call out. A high proportion of patient participants died during participation; however, staff did not perceive the likelihood of death in interviews.

Presentation of Calling Out

Types of Calling Out	Occurrence	Patient Differences	Perceived Emotion	Socially Problematic	Decline in Physical and Mental Health
Repetition of a tangible need Single Word/Phrase Semantic Repetition Stream-of-Thought	Prevalence Frequency Persistence/ Transience Volume	Language Sensory Impairment Motivation	Mental Agitation Distress	Verbally Challenging Content Physically Challenging Behaviour Disruption Difficulty to Change	Physical Decline Cognitive Impairment Palliative Care

Figure 5.9: A summary diagram of the qualitative findings regarding the presentation of calling out.

Chapter Six

Needs

6.1 Introduction

This chapter focuses on the reported or expressed perceived needs of the patient participants, identified via observations and interviews. Staff members and relatives implied that some needs take precedence over others. This was shown through either explicit statements that some needs were more ‘important’ or had to be prioritised, or by staff listing the order they would go through a needs assessment.

6.1.1 Cause versus Need

The terms ‘cause’ and ‘need’ are used interchangeably throughout this chapter, based on the assumption that the discovery of a cause indicates the patient’s need. For example, ‘pain’ may be a cause and not a need, however the presence of pain indicates the need for relief of pain. In this chapter, when a finding is introduced as a cause, it is assumed that the ‘need’ is for the treatment or meeting of the cause.

6.2 Staff Understanding of Unmet Needs

Almost all staff members during interview stated that the reason that patients call out was the result of an unmet need, or that they were communicating distress, agitation, or anxiety caused by the presence of an unmet need.

> *“The book answer is it’s communicating an unmet need”*
>
> *PP001, Staff Interview, Male, Consultant*

> *“I'd say it was usually a symptom of feeling unhappy, or feeling distressed, or feeling lost, rather than feeling okay.”*
> *PP006, Staff Interview, Female, Occupational Therapist*

Staff reported that they usually felt able to ascertain patient’s needs, and that most patients were able to communicate their needs*: “on the whole, most of them tend to know what they want” (PP009, Staff Interview, Female, Staff Nurse)*, and that meeting patients’ needs was achievable. However, if the patient could not verbalise their needs, staff reported that the situation became more uncertain, and identifying the unmet need was more difficult, necessitating the need for a “mental checklist” to discover what might be the cause.

> *“You run through sort of a bit of a mental checklist. What are they after? Do they want something to drink? [...] Do they want the toilet? Are they in pain?”*
> *PP001, Staff Interview, Male, Consultant*

> *“A lot of our patients have dementia, so they can’t always communicate, so you’re trying to find out if it is they’re hungry, are they in pain, if they’re constipated- its normally constipation and toileting that makes them shout out”*
> *PP004, Staff Interview, Female, Staff Nurse*

> *“So, it could be that they need a bed pan, it could be that they are wet, that they've been incontinent. It could be that the catheter bag hasn't been emptied, sometimes we find that [...] It could be that they want water, that they are dry. It might be pain.”*
> *PP010, Staff Interview, Male, Consultant*

This idea was often amongst the first to be introduced by staff; suggesting that in most cases staff feel able to work out what is wrong with a patient, help the patient, and then the ‘problem’ of the patient calling out goes away.

6.3 Biological Needs

Two types of biological needs were identified; 'medical' biological needs (needs requiring medical intervention), and 'functional' biological needs (needs which are regularly recurring, such as needing the toilet).

6.3.1 Medical Biological Needs

6.3.1.1 Infection

Infection is a common cause of delirium (Inouye, Westendorp, and Saczynski, 2014); therefore, staff would often refer to it as a cause of calling out. Infection was documented in the medical notes in 17/30 patient participants. Some patients had an infection recorded as their primary cause for admission, and some acquired an infection during their admission.

> *Less confused however repetitive vocalisation evident. Catheter specimen of urine results show UTI. Stat dose of fosfomycin [antibiotic] 3g administered.*
> *PP123, Nursing Documentation, Patient Participant 'Shirley'*

> *"It happens day or night. The only thing that I can really associate it with is when my mum's got a UTI [urinary tract infection]."*
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

> *"There again it can be through somebody who has picked up an infection, who's had an operation, which can cause delirium."*
> *PP011, Staff Interview, Female, Assistant Practitioner*

If the relative had previous experience of the patient participant calling out, they would often voice their suspicions of infection to staff. Many staff members would discuss infection as something they would regularly consider if a patient was calling out.

6.3.1.2 Pain

Pain was present in instances both related and unrelated to the patient's acute medical condition. This could be pain relating to arthritis, abdominal pain or headache, but could also be following an incident such as a fall.

> *Appeared to be in pain, agitated and screaming most of the time... PRN [as required] oramorph given as prescribed, settling for short periods of time.*
> *PP120, Field Notes, Patient Participant 'Charlotte'*

> *"So, is there something specifically medical like pain? So, we can deal with that"*
> *PP001, Staff Interview, Male, Consultant*

> *"Yeah, [they] can't say 'oh my leg's killing me', so they just scream out."*
> *PP008, Staff Interview, Male, Healthcare Assistant*

Staff indicated they could identify if a patient was in pain via verbal communication from the patient, or by non-verbal cues; such as screaming or groaning, facial expression or rolling around on the bed. It was implied that the short-term treatment of pain was simple, with the administration of an analgesic drug.

6.3.1.3 Discomfort

General discomfort, which may indicate presence of pain, was often noted by staff members.

> *Agnes keeps wanting to be re-adjusted, asking for the backrest to be raised and lowered. She says "that's lovely" immediately after changing position, but then wants re-adjustment again only a couple of minutes later.*
> *PP124, Field Notes, Patient Participant 'Agnes'*

> *“Sometimes they can shout out and you don’t realise that they’re uncomfortable”*
> *PP015, Staff Interview, Female, Healthcare Assistant*

When a patient participant called out to be repositioned, they would sometimes not stay comfortable for long, asking to be repositioned again only a short while later. Other times, the patient participant would settle and fall asleep after being repositioned.

6.3.1.4 Itch

Three of the 30 patient participants experienced episodes of itching. One patient participant’s itch was severe and lasted a number of days, caused her to draw blood through scratching, and was not responsive to medications or creams. It was occasionally implied by both staff and the patients that the intense itching was causing them distress and making them call out:

> *Jessie is vocalising constantly “bababa … waaaaayah … daaaa, oh dear… oh god… miss! nananana … oh dear god … I want to scraaaaatch!” The HCA [healthcare assistant] said “Don’t scratch Jessie, you’ll only make it worse.”*
> *PP110, Field Notes, Patient Participant ‘Jessie’*

> *A student nurse said Florence has just got to sleep after being very agitated- she was apparently scratching at her arms and being very loud, she has apparently had her second dose of midazolam*[5]
> *PP111, Field Notes, Patient Participant ‘Florence’*

---

[5] There was a national shortage of lorazepam at the time of the observations. Midazolam was being temporarily used as a replacement for parenteral use.

These extracts imply that the patient participants were experiencing distress due to their itch, coupled with their frustration at being unable to rectify the issue themselves.

6.3.1.5 Dehydration

Dehydration in older people can cause 'confusion' or delirium (Inouye Westendorp, and Saczynski, 2014). Both staff and relatives acknowledged dehydration or thirst as a potential cause for calling out.

> *"And one of the problems is that she hasn't been drinking enough, she's been very dehydrated."*
> *PP117, Relative Interview, Husband of Patient Participant 'Vivian'*

> *"But the medical staff had other things that they were treating him for, which we found out when he got in there, which I think also contributed to the shouting. That's why I asked you how he was shouting because definitely it had reduced once he'd had a whole load of liquid and fluids, fluid and antibiotics and things, when he was feeling better in himself. Still doing it but it had reduced somewhat."*
> *PP128, Relative Interview, Daughter of Patient Participant 'Joe'*

> *"Sometimes it's something as simple as making them a cup of tea. If they want a drink"*
> *PP015, Staff Interview, Female, Healthcare Assistant*

Joe-PP128's daughter placed more emphasis on the delivery of fluids aiding in the reduction of her father's calling out than antibiotics, implying she believed the dehydration to be the main cause for his calling out.

6.3.1.6 Constipation

The final medical biological need identified was constipation.

> *George's wife said that the cause of George's shouting is primarily due to the fact he cannot open his bowels by himself, so needs enemas to help him. She said that if he could have a regular weekly enema then it would likely help the shouting.*
>
> *Relative Interview [not audio recorded], Wife of Patient Participant 'George'*

> *Current presentation is due to infection + constipation.*
>
> *PP130, Nursing Documentation, Patient Participant 'Edward'*

> *"If they're constipated- its normally constipation and toileting that makes them shout out"*
>
> *PP004, Staff Interview, Female, Staff Nurse*

George-PP126 had extremely severe constipation, and had very rarely had a natural bowel movement over the years his wife had been caring for him. She felt certain it was constipation that primarily caused his calling out.

6.3.2 Functional Biological Needs

Functional biological needs were commonly identified as a cause of calling out. These involved needs that patients were unable to meet on their own due to physical impairments; therefore, would call out to communicate distress, or their need for help.

6.3.2.1 Going to the Toilet

Toileting was commonly presented by staff as a need that patients were regularly distressed by, and would call out because of. Some patients would need the toilet again only a short while after urinating or opening their bowels, making this an onerous need for staff to repeatedly tend to.

> *Robert is drinking lots of water, and whilst I have been here [15 minutes] he has urinated twice. Multiple times in between this, he has called out to say he needs to go again. He opened his bowels and urinated, then within 2 minutes of being changed, he called out to say he needed a wee.*
>
> *PP108, Field Notes, Patient Participant 'Robert'*

> *"When [the calling out] first started, which was all around going to the toilet, I think he was anxious then. Because he had an enlarged prostate, so when he wanted to go to the loo he'd got to go there and then. And so, if they weren't quick enough in coming to help him, then he did get a bit anxious."*
>
> *PP128, Relative Interview, Daughter of Patient Participant 'Joe'*

> *"We had somebody a while ago fixated on going to the toilet, I want to go to toilet, I want to go to toilet."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

It was sometimes suggested that calling out for the toilet was built upon longer-term manifestations of anxiety, or an indication of an underlying medical condition. Staff were observed to roll their eyes or sigh if a patient was repeatedly asking for the toilet.

6.3.2.2 Hunger

The feeling of hunger was regularly identified as a cause for calling out. It was often discussed by staff as something they would try if a patient was calling out.

> *"Usually because she wants a drink of water, or she's hungry."*
>
> *PP114, Relative Interview, Daughter of Patient Participant 'Claudine'*

> *"She was shouting for food (sandwiches)"*
> *PP111, Nursing Documentation, Patient Participant 'Florence'*

> *The nurse told me Agnes was disruptive last night, and this morning she was shouting loudly for a 'good hour', she had been shouting 'help me' and 'let me get on the bed'- she said Agnes shouted no matter what they did, she said that once Agnes had something to eat she calmed down.*
> *PP124, Field Notes, Patient Participant 'Agnes'*

Staff and relatives often indicated that relieving feelings of hunger was one of the 'simplest' needs a patient participant could have.

6.3.2.3 Temperature

Patient participants would occasionally communicate that they felt too hot or too cold.

> *Diane is currently shouting "colddddd.... Freezing colddddd". The healthcare assistant put a blanket over Diane.*
> *PP119, Field Notes, Patient Participant 'Diane'*

> *"You try making sure they're not too hot or not too cold, or make sure the sun is not shining in their eyes, or anything like that."*
> *PP006, Staff Interview, Female, Occupational Therapist*

Multiple actions for controlling temperature for patient participants were observed, including removal or addition of blankets or clothing, opening or closing windows, and the use of a pedestal or desk fan.

6.4 Mental Distress

Needs were communicated by patient participants that were indicative of mental distress, including depression, anxiety and psychosis. Mental distress needs were primarily treated using medication at both study sites.

6.4.1 Depression

There were many instances in which patient participants had been diagnosed with, or were believed to have depression, or were experiencing a depressed mood.

Low in mood, subjectively expressing wish to die + expressing hopelessness re: current situation.
PP125, Nursing Documentation, Patient Participant 'Ruth'

"Yeah the callings, it's changed in the way he does it, but he's been calling since he first had his dementia, first had his depression."
PP102, Relative Interview, Daughter of Patient Participant 'Charles'

Diane called "Can I have a bit of respect on this and have this radio off? I want it as quiet as possible on my last day on this earth". The nurse came to switch the radio off and told Diane she wasn't going to die today.
PP119, Structured Observation, Patient Participant 'Diane'

Negative thoughts were often focused on death. Some patient participants would often express the belief they were going to die imminently, or communicate a wish to die. These patient participants would call out about the topic of death, either seeking reassurance about their fears, or asking to die.

6.4.2 Anxiety

Staff and relatives expressed that anxious patients who called out required constant reassurance. Often, feelings of anxiety were attributed to either the hospital environment, or a change in environment. Some participants' anxiety would be focused on the need for a relative, and they would repetitively call out the relative's name.

> *Given midazolam for agitation as she was crying out- appeared more anxiety related than pain.*
> *PP114, Nursing Documentation, Patient Participant 'Claudine'*

> *Anxious at times, anxiety settles with explanations and reassurance.*
> *PP117, Nursing Documentation, Patient Participant 'Vivian'*

> *"I know that my mum has been saying 'please, please', (…) and I say to her 'what can I do', 'what can I do?' And she'll say nothing. So there is that anxiety"*
> *PP124, Relative Interview, Daughter of Patient Participant 'Agnes'*

6.4.3 Psychosis

Some patient participants experienced hallucinations or delusions, this could cause them to call out in response to their experiences.

> *After discovering Betty's delirium had resolved and she was no longer calling out, I chatted to Betty about the hallucinations she had been having when she was calling out. She reported she had been very confused, and had thought her pillow was a man who wanted to take her away and she hadn't known why.*
> *PP101, Field Notes, Patient Participant 'Betty'*

> *Appeared to be hallucinating this morning, as staff were walking past saying "there's another bus that's just gone by" continued to say that she was waiting for the bus to come by to pick her up. More settled this afternoon.*
> *PP123, Nursing Documentation, Patient Participant 'Shirley'*

> *"If somebody is very psychotic, if they're deluded or hallucinating and they're shouting at the delusions or hallucinations or answering to voices, you could imagine an antipsychotic drug might help"*
>
> *PP001, Staff Interview, Male, Consultant*

When a patient participant was responding to symptoms of psychosis, their calling out would often get louder, causing further disruption to others. When in psychosis, patient participants would have difficulty in attending to social interaction, as they would be focused on their hallucinations or delusions. This meant communication with these patient participants could be particularly problematic.

6.5 Social Relationship Needs

Patient participants displayed a number of behaviours that were identified as social relationship needs. These needs involved attachment, physical and emotional comfort, belonging, and identity.

6.5.1 Attachment

Some patient participants would call out for a specific person, which was usually a relative. Sometimes this would be a person who visited regularly during their admission, and sometimes it would be for a deceased relative, such as their mother or father.

> *I asked a healthcare assistant how Vivian has been today, she said Vivian has been very quiet with her calling out, and that she's usually calling for her husband. She said that now Vivian's husband is here "she has calmed right down", as "that's all she wants".*
>
> *PP117, Field Notes, Patient Participant 'Vivian'*

> *"All [Charles] wants to do is just sit, in my view, sit in a chair with my mum holding his hand. As soon as my mum would get up and go and do things in the kitchen, [he'd] shout her name, all the time*

> *to 'come back', and 'what are you doing', 'what are you doing', 'what are you doing?'"*
>
> *PP102, Relative Interview, Daughter of Patient Participant 'Charles'*

> *"There was one person who was calling out to their father, in her mind she was a young child, she had a doll next to her. She was calling out to her father saying that she was scared."*
>
> *PP010, Staff Interview, Male, Consultant*

Staff members would often suggest that calling out for a deceased relative meant that the patient had regressed to a child-like state, and was feeling fearful or anxious. Relatives frequently reported that the patient participant had increased their emotional dependence on them. Relatives reported difficulty in attending to patient participant's attachment needs, as they were often excessive, impractical or both; for example, wanting someone to be by their side at all times.

6.5.2 Physical contact

The need for physical contact, including hand-holding, hair-combing, and stroking was identified. Staff often spoke about tending to these needs only if they had the time.

> *"If she needs anything, even if it's only for somebody to hold her hand, she calls out."*
>
> *Relative Interview, Husband of Vivian- PP117*

> *"There was a patient on a ward not long ago, who it said on her board, 'If she's agitated, please comb her hair.' [a relative] must have written on her board. I had five minutes when I'm in between doing things and she was really really agitated, shouting and shouting. I just got her comb out and sat and combed her hair for five minutes. She was quiet for an hour after that."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

No patient participants were observed explicitly vocalising a need for physical contact; therefore, this was an implicitly-assumed need, related to anxiety or attachment. However, the need for physical contact could also have an emotional or symbolic meaning.

6.5.3 Belonging

The need for inclusion, or a feeling of belonging in the social environment was suggested. This was either through specific verbal interactions, or the physical proximity of the participant to others.

> *"It is crucial to my mum's recovery that she can be sociable."*
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

> *"Sometimes if somebody's shouting out a lot in the cubicle it's because they're wanting to know that somebody's close by, so if you move them into a bay then they don't shout as much."*
> *PP013, Staff Interview, Female, Deputy Ward Manager*

> *Antonio is close to a communal table and nurses sit and chat there, which might help him to feel included.*
> *PP107, Field Notes, Patient Participant 'Antonio'*

Staff members and relatives believed that feelings of isolation or loneliness could cause calling out; and that ensuring social belonging could counteract these. Enhancing a patients' feeling of belonging was reported to be as simple as placing them on a bay rather than in a side-room, so that they could observe other people in their environment.

6.5.4 Identity

Respect for patient participant's identity was considered important for some staff members, and a key aspect of person-centred care.

> *Today is Jessie's birthday, she has a balloon that says 'It's not the age, it's the attitude!' and 3 or 4 birthday cards. A staff nurse said*

> *"Jessie, when was your birthday?" Jessie said "today, [date], oh dear… oh lord", the staff member sang happy birthday to her, Jessie said "thank you miss".*
>
> *PP110, Field Notes, Patient Participant 'Jessie'*

> *"And another guy who has got dementia and he was fascinated with trains, so we got him some train books, things to try and occupy him"*
>
> *PP014, Staff Interview, Female, Staff Nurse*

> *Elaine is sitting up, fully dressed in her chair with her red lipstick on.*
>
> *PP121, Field Notes, Patient Participant 'Elaine'*

Staff believed that maintaining respect for individual patients' differences, backgrounds, and preferences may help to reduce feelings of agitation or distress. However, maintaining identity was reported to be problematic due to the hospital environment and care routines.

6.6 Uninterpretable Needs

Some patient participants expressed needs which were either unable to be understood or unable to be resolved.

> *"So, it's to find out a need, and if there is something that can be correctable, to correct that"*
>
> *PP010, Staff Interview, Male, Consultant*

It was commonly accepted by staff that sometimes needs were communicated but could not be met for various reasons. These included a lack of resources, and expressed needs that were suicidal, or did not make sense in the context they were communicated within.

6.6.1 Overwhelmed Resources

Some needs were expressed by patient participants that were easily understood; however, staff lacked the ability, time, or resources to meet the expressed need.

> *Beverly said she didn't feel right. I asked "In what way?" and Beverly said "I feel like… I want to walk" [Beverly is currently physically unable to walk without the support from two staff members]*
>
> *PP113, Field Notes, Patient Participant 'Beverly'*

> *Wanting to sit outside and have a cigarette.*
>
> *PP123, Nursing Documentation, Patient Participant 'Shirley'*

> *George is shouting "Help!… help!, help!… would you take me out? Help! Would you take me out!?" The volunteer said "I'd love to take you out, but I can't", George shouted "Help!".*
>
> *PP126, Structured Observation, Patient Participant 'George'*

These needs could plausibly have been fully or partially met for these patient participants; however, staff reported a lack of time to accomplish them. These needs were generally considered by staff to be lower priority than biological, psychological or social needs, as staff reported they would attend to biological needs first.

6.6.2 Suicidal Wishes

Some patient participants would vocalise their desire to die, which could be an indication of existential distress, frustration, or suffering.

> *Shouts out at times sometimes saying "I want to die".*
>
> *PP114, Nursing Documentation, Patient Participant 'Claudine'*

> *Low in mood, subjectively expressing wish to die.*
>
> *PP125, Nursing Documentation, Patient Participant 'Ruth'*

Staff generally appeared uncomfortable when suicidal wishes were communicated by patient participants. From observations patient participants who communicated suicidal wishes would often be ignored or have their expressed wish invalidated by staff telling them they did not mean it and do not really want to die.

6.6.3 Decontextualised Needs

Some needs communicated by patient participants made little sense when taking their context into account. These usually involved patient participants calling out for something they already had, or had recently received.

> *A staff member came in and asked if Raymond was okay, Raymond said "I want a shave", the staff member said "I've just shaved you Raymond!"*
>
> *PP104, Structured Observation, Patient Participant 'Raymond'*

> *Swearing and shouting to take his shoes off (patient was barefoot)*
>
> *PP108, Nursing Documentation, Patient Participant 'Robert'*

> *Vincent's relatives are here, Vincent is saying "can I have a drink, can I have a drink.... I want a drink" His cousin is holding a drink to his mouth and saying "I'm trying to give you a drink but you're pushing it away". She looks very teary and exasperated, Vincent is saying "Get me a drink please, I want a drink, I want a drink" whilst pushing the drink away that his cousin is holding. "I want a drink". His cousin said to me "He's saying he wants a drink but he doesn't".*
>
> *PP115, Field Notes, Patient Participant 'Vincent'*

Decontextualised communications of need were often met with an explanation from the staff member or relative that the patient had already received what they were calling out for. Rational explanations from staff were often poorly understood by the participant.

6.7 Futility

Alongside the belief that calling out indicated presence of unmet need, ward staff also held the view that sometimes, calling out was not associated with an unmet need.

> *Claudine is calling "help" loudly [...] The HCA [healthcare assistant] sitting watching the cohort bay [constant observation bay for patients at high risk of falling] said to me that Claudine calls out all the time, for no reason. She said there was "nothing staff could do" to stop her calling out and said "It's just how she is. She is who she is".*
>
> *PP114, Field Notes, Patient Participant 'Claudine'*

> *22.08.17, 3:50am- 'Pt [patient] was shouting all night no apparent reason. PRN meds ['as required' sedative medication] given as prescribed but poor result. Continued shouting reassured at several times but no result.*
>
> *PP116, Nursing Documentation, Patient Participant 'Judy'*

> *"And then you know even though the person is shouting they might just not want anything"*
>
> *PP007, Staff Interview, Male, Deputy Ward manager*

> *"Sometimes people just call out and it's just what they do (...) Just because somebody's shouting out, it doesn't mean that there's something wrong necessarily."*
>
> *PP013, Staff Interview, Female, Deputy Ward Manager*

Further exploration of the data were conducted to understand the rationale behind the concept of no (unmet) need. In practice, need was frequently observed to be almost impossible to assess, especially if a patient had severe cognitive impairment, as was often the case.

6.7.1 Rationalisations for Futility

There were multiple examples of situations in which carers attempted to rationalise the idea behind a patient calling out as having ‘no need’. These often appeared to be pre-determined interpretations of causes based on little assessment or evidence.

6.7.1.1 “It’s part of the dementia”

Staff used a diagnosis of dementia to rationalise why a patient participant could call out with no need.

> *“I don’t think that they can help it, some people. I think some people do just call out […] I think it’s part of the dementia process that it affects everybody in different ways”*
> *PP013, Staff Interview, Female, Deputy Ward Manager*

> *“It’s something they just do. I think that’s a part of the dementia.”*
> *PP015, Staff Interview, Female, Healthcare Assistant*

When reporting dementia to be the cause, calling out was regarded ‘habitual’ or inadvertent, suggesting the behaviour has no intentionality.

> *“I think it's mainly people from a care home, they have been doing it, doing it, doing it, and it's just there, so it's more psychological and it's more… habitual for them.”*
> *PP007, Staff Interview, Male, Deputy Ward manager*

> *“Because you do get the ones where they’re shouting out for attention then you get the genuine ones, my opinion, that have got dementia and they don’t know they’re doing it.”*
> *PP012, Staff Interview, Female, Healthcare Assistant*

Staff implied that dementia causes disinhibited calling out. They would sometimes focus on dementia as a cause for calling out, potentially disregarding the fact the patient may have an additional ‘real’ unmet need as well.

6.7.1.2 "It's a phase"

Staff and relatives implied that patient participants would call out for a while, and then stop for no apparent reason, and that it came in 'phases'.

> *"I think it's really difficult for the whole team because you don't know what the matter is. Often, it's like a phase, isn't it? And then an hour later they'll be fast asleep and fine."*
> *PP006, Staff Interview, Female, Occupational Therapist*

> *"Like today I've had a gentleman wanted to know what time's he going home, what time's he going home? So, we've changed the subject now. Now he's asking 'what's for tea, what's for tea?' So, you try and divert from one but it's not too long before they get fixated on something else"*
> *PP012, Staff Interview, Female, Healthcare Assistant*

> *Jessie's relative said that "every now and again" Jessie would "go off into her own little world". She would call out and then she'd "come back", as if it came in phases.*
> *PP110, Field Notes, Patient Participant 'Jessie'*

This implies a feeling that there is no specific cause for the calling out, and that if the staff member or family member did nothing, then the 'phase' could pass on its own.

6.7.1.3 "They like doing it"

Some staff suggested that calling out was a form of self-soothing or self-stimulating behaviour. They often reported calling out to be a form of 'comfort' for the patients.

> *"they might just not want anything. They're just calling because that's how they feel comfortable"*
> *PP007, Staff Interview, Male, Deputy Ward manager*

"But sometimes they just want to hear their own voice and I think that is the comfort they have, I suppose. They might not be just calling out they just might sing to themselves or the same thing repetitively over and over and over again."
PP010, Staff Interview, Male, Consultant

This idea was more frequent during situations in which the patient was not explicitly calling for 'help', for example, when the participant was counting or singing.

6.7.1.4 "Crying Wolf"

Staff and relatives discussed occasions in which they believed the patient calling out was 'crying wolf' in order to gain attention, rather than voicing a genuine need.

"So of course, while he was at home, we used to say to him, 'you like crying wolf, the more you [shout] the more people won't believe there's anything the matter with you'."
PP102, Relative Interview, Daughter of Patient Participant 'Charles'

"It's a bit kind of boy who cried wolf sometimes"
PP003, Staff Interview, Female, Junior Doctor

They believed the patient was making a specific request when they did not actually need it, increasing the likelihood of a subsequent genuine need getting overlooked.

After Judy had been calling out for a bed pan, the Healthcare Assistant came out of Judy's room with an empty bedpan, gestured to it and said "she'll do that every time" and laughed.
PP116, Field Notes, Patient Participant 'Judy'

The statement of 'she'll do that every time' shows the staff member believed Judy would call out for a bed pan again without needing one, which on this occasion transpired to be correct. The suggestion of 'crying wolf' implies that eventually, Judy may have shouted for a bed pan, but staff may then assume she did not need to go when she actually did, causing a genuine need to be overlooked.

6.7.1.5 "It's normal for them"

Staff implied that if a patient was calling out prior to admission, if it was their 'usual behaviour', they should simply tolerate it, and generally not attempt to discover unmet needs.

> *"If that's a normal thing for him then you have to accept it [...] he's just going to carry on. Although frustrated or not, you just have to carry on."*
>
> *PP007, Staff Interview, Male, Deputy Ward manager*

> *24.4.17 3:50am- Had a settled night within herself with the usual behaviour of presence of speech.*
>
> *PP110, Nursing Documentation, Patient Participant 'Jessie'*

> *The daughter told me that staff had asked if Joan was normally vocalising in this manner, she said "and I said yes, but that doesn't mean they can just ignore her, does it?".*
>
> *PP109, Field Notes, Patient Participant 'Joan'*

Staff members would not attempt to assess unmet needs if they believed that the behaviour was not 'new'. This gave some relatives a lack of confidence in whether staff were intervening and providing adequate care for the patient participant.

6.7.2 Learned Futility

The findings suggest that some staff learned to assume that intervention for calling out was futile, perpetuated by lack of time and resources, together with staff experiencing the complexity of working out what the need might be, and whether there is an unmet need at all. Staff reported either not knowing what to do for a patient who was calling out when they first started the job, or whether to intervene. They spoke of seeking advice from a more experienced member of staff who would often advise inaction.

> *"And I think being in HCOP for a while now, I think I've got that shield of knowing when to intervene, and when just to let it roll."*
> *PP003, Staff Interview, Female, Junior Doctor*

> *"[I] confused myself like 'oh my God what do I do? How do I stop this person from doing this? What's wrong with them?' Then obviously you'd go up to the nurse and they're busy and you're like 'what do I do?' Then because you're new they just fob you off with anything don't they? 'Just sit there and watch him he'll be all right' […] They're [nurses are] experienced, aren't they? They calm you down quite quick because there's no worry in their face or panic, 'it's just, it's the way they are, it's the condition'. That's normally what you get: 'they're unwell so this is what they are'"*
> *PP008, Staff Interview, Male, Healthcare Assistant*

> *"Yeah you can usually tell, separate them which ones are the full-on dementia and not quite sure or the ones who just, it's like when they're buzzing all the time and sometimes, they're doing it for attention or sometimes they're doing it because they don't know they're doing it. You soon get to learn."*
> *PP012, Staff Interview, Female, Healthcare Assistant*

Staff spoke of gaining the experience and knowledge to distinguish quickly between patients with and without needs. Staff implied that the more senior 'experienced' staff members taught them that some needs just cannot be met, and that they were better at their job because they could quickly identify whether or not intervention was necessary in their opinion.

6.7.3 Staff Response to Futility

Staff members sometimes reported an emotional reaction when a patient was calling out, yet they felt unable to do anything to reduce the behaviour or meet the possible unmet need.

> *"I find it distressing sometimes [...] especially when you've just spent quite a lot of time with them and you think you've consoled them and then they, they do it again."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

> *"If it's a patient calling out 'Help me, help me, help me,' or, 'Where am I? Where am I?' I find it really, really heartbreaking to just walk past them and ignore them."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

Staff could also be defensive about their lack of intervention with a patient who was calling out, and suggested that outsiders do not understand the complexity of calling out.

> *"If I had all the time in the world, I would talk to every patient, every day."*
>
> *PP005, Staff Interview, Female, Discharge Coordinator*

> *"It's like the gentleman today, I've had to make a comment [to people visiting another patient] that 'he doesn't want a drink really, he's just fixated on wanting a drink', because along the line, one of the patients relatives will come out and say 'that gentleman wants a drink'. And I sometimes think that they don't realise that's not the case. [...] I think that sometimes irritates me more, because they think we're not giving them the care that they require, and it's like no, that's not the case at all."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

They would regularly reiterate the level of training they had, and that they were good at their jobs, despite being extremely busy. Staff would often commend their team, stating that they were hard-working and competent.

> *"We tend to get people that are more difficult to physically manage, because we're the specialist ward and we've got mental health nurses on"*
> *PP002, Staff Interview, Male, Mental Health Nurse*

> *"There are days where it's extremely busy and you've just not got enough time specifically for that person, but you're trying to work round everybody if you like. So that's what makes it difficult. Especially if you know there's nothing you can do to help them."*
> *PP015, Staff Interview, Female, Healthcare Assistant*

> *"We're quite good at doing it where I work, therefore resolvable calling out doesn't get noticed as 'calling out', cause they're not calling out, cause we resolve it"*
> *PP001, Staff Interview, Male, Consultant*

Staff were aware that the notion of futility is not readily accepted by 'outsiders' such as visitors, therefore they often provided justifications for not intervening with a patient without being prompted. Staff were keen to defend themselves and their team as ethical and competent.

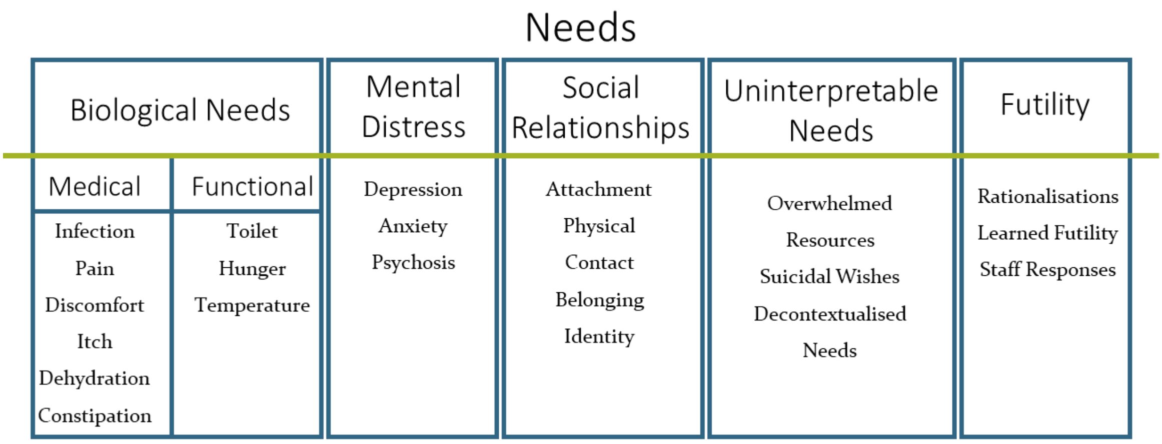
6.8 Summary

A large number of potential needs were identified during interviews (Figure 6.1). Biological needs were considered a high priority for intervention amongst staff. These included medical biological needs, such as treatment from infection or constipation; and functional biological needs, such as going to the toilet or hunger. Needs relating to mental distress were identified, involving the patient's feelings and emotions, or anxiety, psychosis, or depression. These needs where usually based upon emotions or social relationships. Relatives appeared to place more of a focus on mental distress needs

More complex interpretations of need were also discovered, which do not conform to the unmet needs model. These included needs considered incomprehensible, uninterpretable, or unmeetable primarily due to the participants misapprehension of reality, (such as requests to have their shoes removed when they were barefoot) or needs that were simply not possible to meet because of a lack of resources (such as wanting family members to be present, to go home or an expressed desire to walk, with not enough staff to support this). There were also cases in which the patient was determined by staff to have 'no need', and that calling out was due to other reasons unconnected to need, such as habitual behaviour. Staff were aware that others might not consider futility as a possibility for calling out, therefore often defended themselves and their team as moral and competent in their work.

Staff know about and appear to accept the unmet needs model, but did not appear to have a good framework for assessing needs. They also appeared to have other explanations than unmet need to understand the cause of calling out. In practice, competing demands made it difficult to deliver a comprehensive needs assessment, or to meet the more difficult to interpret or intangible needs. This led to inconsistent behaviour, and a culture of dismissing communicated needs as futile.

This chapter outlines how complex or futile the identification of an unmet need can be in patients with cognitive impairment who call out. Staff members have adopted collective short-cut heuristic thinking in order to counteract these difficulties.



Needs

Biological Needs		Mental Distress	Social Relationships	Uninterpretable Needs	Futility
Medical	Functional	Depression Anxiety Psychosis	Attachment Physical Contact Belonging Identity	Overwhelmed Resources Suicidal Wishes Decontextualised Needs	Rationalisations Learned Futility Staff Responses
Infection Pain Discomfort Itch Dehydration Constipation	Toilet Hunger Temperature				

Figure 6.1: A summary diagram of the needs identified in the study.

Chapter 7

Interventions

7.1 Introduction

This chapter focuses on interventions for calling out that were either observed or reported. The types of interventions are described and divided into pharmacological and non-pharmacological interventions. Non-pharmacological interventions varied in time taken to deliver, with interventions as simple as quick verbal reassurance to perceptions of distress. Some of the observed interventions appeared to be intentionally therapeutic, whereas others were considered by some to be less so. Some of the interventions also appeared to be more likely to be beneficial to other patients on the ward, rather than the person calling out.

The reported or observed facilitators and barriers to interventions are discussed in the second half of this chapter. These involve the acute hospital context, staff knowledge and attitudes, patient differences, and availability or otherwise of individual patient information. The chapter concludes with a summary of the two main sections.

7.2 Types of Intervention

7.2.1 Pharmacological Interventions

Medical interventions were common in the acute hospital setting as a method to try to reduce the frequency or severity of calling out. This was often as a treatment for a condition that was distressing for the participant and may be causing them to call out, such as pain. However, it could also be sedative medication to 'calm' the patient. The treatment of infection should also be noted as a form of intervention, however data regarding this is presented in Chapter 6.

This section is divided into two categories of medical intervention: analgesia, psychotropic medication, and sedation.

7.2.1.1 Analgesia

Medical alleviation of pain was identified as an intervention, when there was a belief that the patient was calling out as a result of pain. Analgesia was sometimes reported as effective in reducing calling out, and other times it would not. Staff reported in interviews that they would sometimes use analgesia, and monitor its effectiveness, when it was difficult to determine if the patient was in pain, and they were unsure of what else to do.

> *Appeared to be in pain, agitated and screaming most of the time... PRN oramorph [analgesic] given as prescribed, settling for short periods of time.*
>
> *PP120, Nursing Documentation, Patient Participant 'Charlotte'*

> *"I think with the patients confused; pain is a big problem. Because a lot of the time they're maybe shouting out but not showing any real [signs of] pain. And then when they have a painkiller they calm down, so obviously they needed it."*
>
> *PP008, Staff Interview, Male, Healthcare Assistant*

It was implied by staff that pain medication was given in a trial-and-error fashion for calling out, as presence of pain in people with cognitive impairment can be difficult to establish.

7.2.1.2 Psychotropic Medication

Psychotropic medication use was often based upon the assumption that the calling out was due to psychological or mental distress, such as anxiety or depression. Psychotropic medications were sometimes reported in nursing documentation and in interviews to be successful in reducing or ceasing calling out. However, there were also occasions in which they were described to be unsuccessful.

> *Betty had slept through the night, no vocalisations, no hallucinations. The night shift nurse mentioned she has been put*

> *on Risperidone [anti-psychotic drug], and that might be why.*
>
> *PP101, Field Notes, Patient Participant 'Betty'*

> *Frank normally becomes very anxious in the afternoon fearing that he is falling when sat still in bed (called: 'don't let me fall'). He does not readily respond to verbal reassurance as he is unable to retain the information. Frank is prescribed Trazodone [anti-depressant and anxiolytic] 50mg at 12pm [noon] to help minimise anxiety.*
>
> *PP122, Nursing Documentation, Patient Participant 'Frank'*

> *Pt alert, keeps shouting most of the time. Haloperidol [anti-psychotic] given to try and calm patient, however still awake and shouting.*
>
> *PP116, Nursing Documentation, Patient Participant 'Judy'*

Much of the time, the nursing documentation would not specify whether the administration of psychotropic medication had been successful or not. During unstructured observation, staff reported varied success rates. Staff reported being more wary of delivering psychotropic medications than analgesics.

Sedation

Sedation is used to produce a state of calm or sleep. The use of sedatives in older people is generally not recommended (Kouladjian et al. 2016), due to a higher risk of adverse outcomes; such as falls, or onset of delirium. Staff implied that they were reluctant to prescribe sedatives, and that they were avoided in practice, if the only 'challenging' behavioural symptom was calling out.

> *"We're very wary of sleeping tablets because, if you give people sleeping tablets and they get up in the night to the toilet they fall over, so there's a big area of risk there."*
>
> *PP001, Staff Interview, Male, Consultant*

"They just need talking to, they just need that extra time, instead of trying to sedate them."
PP003, Staff Interview, Female, Junior Doctor

However, use of sedation was observed and documented in this study as a method for intervening with a patient who was calling out.

Another staff member said that Antonio is 'calmer' today, and that the effects of the sedative may still be present.
PP107, Field Notes, Patient Participant 'Antonio'

She was very agitated at night midazolam given.
PP111, Nursing Documentation, Patient Participant 'Florence'

There are no mentions in the nursing notes of Carol shouting out or being agitated over the past couple of days, she is now regularly receiving midazolam.
PP112, Field Notes, Patient Participant 'Carol'

Staff reported in interviews that sedation was not used for calling out alone. Antonio and Florence were documented to exhibit physically challenging behaviour as well as calling out; yet it was unclear from the nursing documentation whether physically challenging behaviour as well as calling out had occurred prior to the administration of sedative medication. Carol and Claudine were on an end of life pathway, and had not been reported or observed to pose any risk to themselves or others due to physically challenging behaviour at any point during their admission. Sedation as an intervention appeared to be not as therapeutically-motivated as other forms of pharmacological intervention, and may be more likely to be seen as an intervention for the benefit of others on the ward as opposed to the person calling out.

7.2.2 Non-Pharmacological Interventions

A number of non-pharmacological interventions were identified through report and observation. These have been placed into four categories: activity, verbal, physical comfort, and environment.

7.2.2.1 Activity

Staff regularly discussed the usefulness of activity as an intervention, and expressed a wish for more time and resources to complete activities with the patients.

> *"I think I'd like to try more along the activities side of things. You know, like providing different stimulations and all the research that this is regarding stimulations and sensory stuff, I'd like to try more of that."*
> *PP013, Staff Interview, Female, Deputy Ward Manager*

> *An external staff member walked past with another, looked at the whiteboard next to Edward's door and said "oh look, ward xx activities, that's good, isn't it?" and laughed. The board says 'activities' at the top, and the days of the week down the side, apart from this, the board is completely blank and has been ever since I started collecting data on this ward.*
> *PP130, Field Notes, Patient Participant 'Edward'*

A ward that did not complete regular structured recreational activities with their patients was generally looked upon negatively by staff. Staff who worked on wards without activities often reported that they would like to do activities with their patients. Wards were considered by staff as 'better' for people with dementia if they had an 'activities room' with games and activities in, than a 'meeting room' with tables and chairs. Many types of activities were observed and discussed by staff and relatives throughout the study. These included games, music, touch, animals, television, tactile activity, and occupation.

7.2.2.2 Games

Staff members were observed playing or overseeing games with patients. Games were selected based on what was available on the ward, often dominoes or jigsaws. The games available on the wards usually required a low level of mental effort, so that patients with cognitive impairment could participate. Games usually took place around a communal table, either on the bay or in an activities room. Staff would often encourage patients to join in, so that there were three to four patients playing together.

> *Another patient has come to join in with dominoes, and a nurse came over to another patient: "Joy, would you like to come and join in playing dominoes?... are you sure?" The bay is warm, and there is a lot of chatter and laughter coming from the patients. Elaine looks calm, alert, and focused on the game.*
> *PP121, Field Notes, Patient Participant 'Elaine'*

> *"I think programmed activities is quite useful, getting people, getting them around a table, they really enjoy that, playing dominoes or drawing or things like that, if they're capable of doing that."*
> *PP010, Staff Interview, Male, Consultant*

> *"It's like today our activities coordinator was in there doing a memory game with them with cards and stuff, you know, with pictures of people, which they probably might not do on other wards."*
> *PP014, Staff Interview, Female, Staff Nurse*

Staff members appeared to enjoy playing games with the patients, and believed that the patients enjoyed them too. However, from observations it was noted that games were generally exclusively for patients with no more than moderate cognitive impairment as opposed to severe; and generally for patients who were not bed bound. Therefore, not all patients got the opportunity to play games as an activity. One patient participant, Elaine, was observed to be much calmer when playing a game of dominoes, which she had enjoyed regularly prior to her admission. However, she had performed much better on a number of quantitative measures than average for the study sample, with a Barthel Activities of Daily Living Index score of 12/20 (mean score across patient participants: 3.7/20); and a standardised Mini-Mental State Examination score of 19/30 (mean score across patient participants: 5.8/30), indicating mild to moderate cognitive impairment.

7.2.2.3 Music

Music was commonplace on the wards, and varied from a radio playing at a low level in the background, to live music performers visiting the ward. Music was not always regarded as an effective intervention; however, it was reported as easy to attempt.

> *Antonio is sitting on a sofa at the front of the bay with two volunteer musicians singing 'Tambourine Man' to him. One is singing and the other is playing a guitar, they have a box of percussion instruments at their feet for patients to join in.*
>
> *PP107, Field Notes, Patient Participant 'Antonio'*

> *"There's music going on to help calm people, and the person [staff member] who is there all the time on the bay."*
>
> *PP010, Staff Interview, Male, Consultant*

Sometimes the music would be tailored to the musical era of the patient demographic. On other occasions, current popular music would be playing. Once, a staff member turned a radio on next to a patient who had stated just before that they did not want music playing. This suggests that on occasion, the use of music as an intervention was more tailored towards others on the ward, as opposed to purely for the person calling out.

7.2.2.4 Television

Wards often owned a television that could be wheeled onto a bay or played in an activity room, which multiple patients could watch. Each bed area also had an individual television, however was operated on a 'pay as you go' basis, which not every patient participant was able to access. Some patients appeared to be less focused on their calling out when watching the television. Staff spoke favourably about using the television as an intervention, and suggested all patients attend to it well when it is used.

The television seems to keep Antonio somewhat distracted, with less calling out.
PP107, Field Notes, Patient Participant 'Antonio'

"We've got televisions, I'll tell you what, though, they work amazing. So, if you put something on that's old fashioned-y, they all just go, [mimed staring at a television] you know."
PP008, Staff Interview, Male, Healthcare Assistant

Televisions were considered problematic in some cases. This was generally due to symptoms of the patient participants' cognitive impairment, such as poor memory or attention; and also due to problems with hearing and/or eyesight, causing difficulties with attending to the television.

"He's fed up, there's nothing for him to do. He can't listen to the television, he can't see the television, he can't read, he can't write, he can't, there's nothing he can do."
PP102, Relative Interview, Daughter of Patient Participant 'Charles'

Relatives discussed how the patient participant could struggle to operate a television if left unattended, leaving them reluctant to leave the patient participants watching the television alone.

7.2.2.5 Tactile

Tactile interventions involved anything that patients were required to use their hands to interact with. A common tactile intervention was the use of 'twiddle muffs' (also referred to as 'fidget blankets'). These are squares or muffs of often hand-knitted fabric, with various touchable or movable embellishments attached; such as buttons, zips and unusual fabrics. They were reported to be useful in distracting patients from performing seemingly-agitated behaviours, such as scratching themselves excessively, or pulling out cannulas or catheters.

Carol has two fidget blankets by her bed. Her daughter had told me that Carol likes to use these, and that they calm her.
PP112, Field Notes, Patient Participant 'Carol'

> *There is a twiddle muff on the table by Evelyn. I asked the family about it, and they said that she had been trying to pull her cannula out, so the staff had put a twiddle muff over the cannula to distract her from pulling it out.*
>
> *PP127, Field Notes, Patient Participant 'Evelyn'*

Fidget blankets were not commonplace on every ward however, and relied upon charitable donations. Risk of cross-infection meant that patients could not share fidget blankets, therefore there was often a limited supply. Due to hospital infection policies, fidget blankets were not considered safely washable.

7.2.2.6 Occupation

Occupational activities could involve providing a patient with a 'job' to do or an activity to complete, such as folding laundry. It could also involve allowing a patient to do something staff might initially have tried to stop the patient from doing, such as walking around the ward, providing they were not at risk of harming themselves or others.

> *Yesterday, another patient broke a biro, as he was using it to try to twist screws on the nursing station; so a staff member got a screwdriver activity set for him from the activities room, after saying that they think the patient was a carpenter. He is using the set again today (they later discovered he had been a mechanic).*
>
> *PP124, Field Notes, Patient Participant 'Agnes'*

> *"It's like where the one guy was continually walking up and down, up and down, and he used to be a security guard. So, you can understand why they're behaving in a certain way."*
>
> *PP014, Staff Interview, Female, Staff Nurse*

Some occupational activities were considered to be generic activities that could be completed with most patients, such as activities on a tablet computer. Other occupational interventions were tailored to specific individual experiences or interests, such as the screwdriver set given to the man who used to work as a mechanic, or sheets given to a woman to fold who regularly washed clothes. It was reported in interviews and informally that allowing patient participants an occupation could cause them to be less likely to call out; either due to contentedness, or by being distracted from their vocalisations.

7.2.2.7 Animals

Relatives and staff members spoke of the use of animals as a form of intervention to help with the relaxation of distressed patients. Some wards would have regular, if brief, visits from a 'therapy dog', which patients could stroke and interact with if they wished. This was observed on Site one; on Site two it was reported in interviews that this "*used to*" occur.

> *A man has arrived with his 'therapy dog', a large, tan, shaggy-haired dog. The man is introducing patients to the dog, the patients look excited to see him.*
>
> *PP110, Field Notes, Patient Participant 'Jessie'*

> *"There were times when, I don't know if we still do or not, we used to get like an assistance dog, do you know the ones that come around and visit, we used to get one come around on a Monday. And those who saw it, you could see change in them once they recognised a dog, especially if they'd had a dog previously."*
>
> *PP015, Staff Interview, Female, Healthcare Assistant*

The presence of animals was generally thought an effective way to reduce calling out, however the effects of the intervention was considered short-lived. It was also an intervention that could not be performed easily on command. Wards that had a dog come to visit would receive a visit around once per week or less, and each patient would not get much time with the dog. Therefore, the presence of animals seems less practical for the acute hospital setting, and not something that could be relied upon as a sole intervention for calling out.

7.2.2.8 Verbal

Verbal interventions could include any constructive verbal response made to the person who was calling out. This could be made by staff, relatives, or other patients. This manifested in the forms of reassurance, verbal distraction, and reorientation.

Reassurance

Reassurance was regarded as any verbal interaction made as an attempt to comfort patients about their vocalised concerns. The terms 'reassurance given' or 'reassured' was used regularly in nursing documentation, with very little additional detail into what exactly was said, and whether it was effective in reducing or stopping the calling out.

> *Lewis said he wants to know what's happened to his dog, and added "my dog is a lovely little fella, with a heart as big as a bucket", the nurse told Lewis that his dog is being looked after in kennels and is safe.*
> *PP118, Field Notes, Patient Participant 'Lewis'*

> *Has been shouting most of the night reassurance given.*
> *PP116, Nursing Documentation, Patient Participant 'Judy'*

> *Calling out requiring reassurance, stating he feels scared, thinks he might fall out of bed.*
> *PP122, Nursing Documentation, Patient Participant 'Frank'*

From observations, staff would regularly approach a patient who was calling out and ask "what do you want?"/ "what do you need?"/ "what can I do for you?"/ "what's all this shouting for?" It seemed this was often the type of 'reassurance' staff would regularly report in the nursing notes. There were also occasions in which a patient appeared to require reassurance where it was not given:

> *A nurse entered the side room to give Judy her medication. The nurse rather abruptly said "tablet for you here" whilst putting the tablet in Judy's mouth, and then poured a liquid medication into Judy's mouth that Judy appeared to hate the taste of. Judy said "no, no, give me 5 or 10 minutes" and waved her hands to gesture 'no'. The nurse ignored this, and started attempting to put a nebuliser mask over Judy's mouth without explaining what it was, Judy appeared to be getting very distressed, and clearly did not want the mask on, pushing it away with her hands and grimacing. The nurse shrugged, said "I'll try again in a bit" and left the room.*
>
> *PP116, Field Notes, Patient Participant 'Judy'*

This extract highlights the fact that on occasion, verbal reassurance appeared to be perceived as a necessity when it was not actually provided. It could be argued that the term 'reassurance' may have become a 'buzzword' in nursing documentation, due to its common usage, with little evidential support of its actual use.

Verbal Distraction

Verbal distraction would generally involve a staff member asking the patient a question, or talking about something unrelated to the patients' vocalisations, in an attempt to steer them away from the topic of their expressed calling out.

> *She is still fixated on going home, and keeps asking if her husband is behind her, but it has become easier to distract her from her repetitive questions.*
>
> *PP127, Field Notes, Patient Participant 'Evelyn'*

> *"If they're not having that sort of thing, then it's a case of trying to get them focused on something else, talking about something else."*
>
> *PP009, Staff Interview, Female, Staff Nurse*

This had varying degrees of effectiveness due to the high level of confusion patient participants were experiencing. Patient participants often appeared ‘fixated’ in their calling out, and an attempt to distract from these would sometimes go unnoticed by the patient. Occasionally, an attempt to distract would result in frustration from the patient, potentially as the person responding was not listening to or validating their concerns.

Reorientation

Reorientation involved staff members or relatives reminding patient participants of their location, the time, the date, or their current activity. The idea was that this might help patients if their calling out appeared to be related to disorientation.

> *Sleep in short intervals. Calling/shouting when awake. Constant reorientation with very little effect. Shirley shouts mostly about giving instruction on how to catch the bus.*
> *PP123, Nursing Documentation, Patient Participant ‘Shirley’*

> *“If they're distressed, they're trying to climb out of the bed I will try and orientate them to time and place.”*
> *PP009, Staff Interview, Female, Staff Nurse*

> *“You just say to them where they are and ‘you’re in hospital, do you know where you are?’ ‘Yeah I’m at home’. ‘No, you’re not at home you’re in hospital’. Then five minutes later ‘I want to go home’, and then you’re into that repetitive cycle over and over and again.”*
> *PP014, Staff Interview, Female, Staff Nurse*

Attempts at reorientation were generally received unfavourably by patients, and staff interviews corroborated this. It was thought that when a patient was severely delirious, it was difficult to successfully reorient the person to time and/or place, and could consequently cause further distress for the patient. Staff sometimes considered it unwise to attempt to reorient a patient who was calling out as they would end up getting into a ‘repetitive cycle’. Therefore, the use of reorientation as an intervention was occasionally believed to be unhelpful.

7.2.2.9 Physical Comfort

Physical comfort could be delivered in the form of repositioning for comfort, or any level of touch not considered to be essential for the delivery of medical care. Staff members varied greatly with the levels of touch they used, some would only touch patients to deliver professional medical care, whereas others would embrace patients, hold their hand, or kiss them on the cheek. Physical comfort is presented in three sections: repositioning, affection, and pampering.

Repositioning

Repositioning was based upon the belief of staff that the patient was calling out due to being physically uncomfortable. The patient participants who were repositioned very regularly by staff usually had an underlying issue which was causing discomfort, such as constipation or pain; however, all immobile patients were required to be repositioned regularly for the prevention of pressure sores.

> *Constantly shouting ‘help me’ despite many attempts to reposition and make comfortable – possibly repetitive vocalisation that pt [patient] doesn’t realise she is doing?*
>
> *PP114, Nursing Documentation, Patient Participant ‘Claudine’*

> *Found pt [patient] in bed shouting++ reassured and assisted to reposition.*
>
> *PP126, Nursing Documentation, Patient Participant ‘George’*

The positive effects of repositioning were often short-lived, with patient participants calling out again very soon after being repositioned. Patients who were bedbound were repositioned regularly to prevent bed sores, but this was not considered an intervention for calling out.

Affection

Some staff members displayed physical affection towards the patient participants, such as stroking or holding their hand. From observations, patient participants would appear to receive physical affection positively.

> *"Nice deep breaths, Vincent, you're doing really well". Vincent's O2 [saturation] has now increased from 77% to 82% and he looks calmer. He has fallen asleep as the healthcare assistant is trying another finger to check his oxygen levels and it's fallen again- she is stroking his arm.*
> *PP115, Field Notes, Patient Participant 'Vincent'*

> *The patient next to Diane has hidden some cake under her pillow for dinner later. The healthcare assistant found the cake and said "you're so funny" to the patient whilst laughing, the patient is laughing too, but looks confused, the healthcare assistant said "give us a kiss" and kissed the patient on the cheek.*
> *PP119, Field Notes, Patient Participant 'Diane'*

> *"Sometimes you hold their hand and talk to them, just for them to know that you are there and you are talking to them."*
> *PP007, Staff Interview, Male, Deputy Ward manager*

Some staff members reported being less comfortable with displays of affection. Generally, most staff members appeared comfortable with stroking or holding the hands of the patients, with only a small few engaging in embracing patients or kissing them on the cheek.

Pampering

Female staff members reported in interviews and were observed conducting 'pampering' activities with patients, including nail painting and hair styling. It was suggested that these types of activities would produce a relaxing and positive effect for both parties.

> *A cleaner had finished her duties, so had begun curling a patient's hair and chatting to her. I spoke to her after about it, and she said she loves chatting with the patients and it makes her feel good.*
> *PP110, Field Notes, Patient Participant 'Jessie'*

> *Sometimes, the carers have painted her nails, which is quite a nice activity for them to be doing while they're chatting to her.*
> *PP125, Relative Interview, Brother of Patient Participant 'Ruth'*

Pampering activities were only considered an option if staff had completed every job they were required to do. Due to the often hectic nature of the wards, pampering activities were only rarely observed or reported.

7.2.3 Environment

Some interventions involved adapting or changing something in the environment for the patient participant, with the belief that an aspect of the environment was causing distress for the patient. This included cohort nursing, single (side) rooms, and general layout changes.

7.2.3.1 Cohort Nursing

Cohort nursing usually refers to an area within a hospital or ward which is dedicated purely to patients with a specific illness, disease, or set of symptoms. This has proven helpful in preventing the spread of disease, and to keep disease contained (Cepeda et al. 2005). However, the term 'cohort' was used commonly in this context to mean the grouping of people who exhibited challenging behaviour. This was usually patients who were regarded to be a high risk of falls, and were attempting to get out of their bed or chair; therefore, needed to be watched closely, to reduce the chance of a fall. It was also used more generally for patients displaying various types of challenging behaviour, including calling out.

> *Pt [patient] moved to cohort bay as requires cohort nursing, verbally aggressive at times.*
> *PP119, Nursing Documentation, Patient Participant 'Diane'*

> *"We have a cohort bay for patients like that [who call out repetitively], you're running behind time all the time because you've got to sit and calm them down, reassure, move on, and its- throughout the day."*
>
> *PP004, Staff Interview, Female, Staff Nurse*

> *"Sometimes they put them together because they think they're safer together."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

Whilst cohort nursing was not defined explicitly as an intervention for the patients, it was thought of as a way of managing the ward. It was considered easier to keep watch of an entire bay, as opposed to individual patients on separate bays. It was also reported to be a method to keep other patients (who did not call out) less disturbed by the noise. Cohort nursing bays were often considered to be much more demanding to work on than the other bays. This form of intervention appeared to be utilised in order to alleviate the negative effects of calling out for the other patients on the ward, as opposed to necessarily improving care for the person calling out.

7.2.3.2 Single Rooms

Whilst single (side) rooms were primarily used for infection control, privacy purposes, or end of life care; they were also considered by some staff members as a method for reducing calling out. This was either by providing a low-stimulus environment for the patient, if they thought that the environment was overstimulating, or to provide respite for the other patients on the ward.

> *"There would be a rationale for isolating people. I think the idea of a side room as a low-stimulus environment, there is less noise, there is less distraction, there is less activity, which may help."*
>
> *PP001, Staff Interview, Male, Consultant*

> *"Having that side room for someone who's calling out, it's probably a good thing in a way, because you get to reorient them*

> *in their way, so you can turn the light off when you want, or you can have it on."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

> *"You'll get somebody who shouts in a side room. Then they put them in a bay and sometimes they're no better. Then all they're doing then is keeping all the other three people up, and we had an experience of that not too long ago where that patient kept the other three up."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

It was regularly observed that a patient participant calling out on a bay would appear to be disturbing the other patients. Other patients were observed grimacing, or making negative comments to others about the noise. However, some staff and relatives saw side room use as unfavourable, due to increased isolation.

> *"I've been trying for approximately three weeks now to get my mum out of a side room and get her into a bay with other people. So that my mum has at least got people walking round that she can see as reassurance."*
>
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

> *"Sometimes if somebody's shouting out a lot in the cubicle [side room] it's because they're wanting to know that somebody's close by, so if you move them into a bay then they don't shout as much."*
>
> *PP013, Staff Interview, Female, Deputy Ward Manager*

Generally, the use of side rooms as an intervention was suggested to be assessed on a case-by-case basis. In practice however, accommodation in a bay or side room was generally focused upon what was available, or medically or socially appropriate at the time.

7.2.4 Types of Intervention: Summary

Both pharmacological and non-pharmacological interventions were identified. Pharmacological interventions involved: treatment of pain via analgesia, treatment of mental distress via psychotropic drugs and sedative medication used to calm the patient. A wide range of non-pharmacological interventions were discussed or observed (Table 7.1). When intervening with patient participants, staff members would firstly attend to any evident unmet physical needs communicated by the patients either verbally or non-verbally. When staff were uncertain of the cause of the calling out, non-pharmacological interventions were more likely to be applied. Interventions were often trial-and-error, and were based largely upon available time and resources.

Activity	Verbal	Physical Comfort	Environment
Games (dominoes, bingo)	Reassurance	Repositioning	Cohort Nursing
Music (singing, radio)	Verbal Distraction	Affection	Side Rooms
Animals	Reorientation	Pampering	
Television			
Tactile (Fidget blanket, memory box)			
Occupation			

Table 7.1: The categories of interventions identified in the study

7.3 Barriers and Facilitators to Intervention

Many pharmacological and non-pharmacological interventions were reported and observed in this study; however, most of the time, no intervention was provided to patients who call out; especially if that patient was unable to communicate a tangible need. Staff members and relatives of patient participants were forthcoming with explanations and justifications for how and why they were often unable to intervene. This section will detail both the barriers and the facilitators to delivering interventions identified in this study.

7.3.1 Acute Hospital Context

The acute hospital setting was identified as a barrier to delivering interventions for a number of reasons. These involved unfamiliarity, staffing structure, ward management, care planning, resources, collective culture, and the 'chaos' and unpredictability that can ensue in this setting.

7.3.1.1 Unfamiliarity

Staff members and relatives discussed the fact that the acute hospital context is an unfamiliar, strange, and scary environment for patients who call out. Most staff members empathised with people with cognitive impairment, acknowledging the mental challenges they could have in this setting, and why they likely get distressed.

> *"Then you've got to imagine that they've been taken out of their environment. They've got no idea what's going on a lot of the time. They're really scared, there's lots of noises, lots of different people."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

> *"There's been quite a marked contrast now, [calling out had increased] and I think it's the unfamiliar environment."*
>
> *PP124, Relative Interview, Daughter of Patient Participant 'Agnes'*

The context of the acute hospital itself was assumed to have a negative impact upon the patient's wellbeing, causing it to be more difficult for the patient to benefit from an intervention if the environment was perceived to be causing such distress.

7.3.1.2 Staffing Structure

The staffing structure was both praised and criticised. Staff were generally happy that in recent years, they had been gaining a better-trained workforce, with additional specialised members of staff.

> *I spoke to the staff nurse working on the ward, she said she didn't get any specific specialised training, but that the mental health nurses on the ward create care plans, which help her to feel confident about the type of care they are giving.*
>
> *PP107, Field Notes, Patient Participant 'Antonio'*

> *"We have the luxury of mental health nurses who will think in those sorts of terms [behaviour planning]. […] We also have the luxury of a relatively well-trained nurse workforce."*
> *PP001, Staff Interview, Male, Consultant*

However, staff reported a high workload, and when understaffed, would have an excess of patients to care for. Staff members considered the situation regarding staffing numbers had got worse, and that they were often under a lot of pressure.

> *I called the ward and spoke to a very stressed-sounding night shift staff nurse, she was caring for Martha and said she had 14 patients to care for and couldn't speak for long on the phone.*
> *PP103, Field Notes, Patient Participant 'Martha'*

> *"You might have people coming in and joining and then somebody else leaving, so it's never right. It's never the right number. The pressure we go through, we get put through because of bed situations."*
> *PP007, Staff Interview, Male, Deputy Ward manager*

> *"That is down to a lot of the time is shortage of staff. The wards at one time never used to be short of staff."*
> *PP011, Staff Interview, Female, Assistant Practitioner*

Relatives generally sympathised with the issue of understaffing, and believed that staff members did their 'best' under the circumstances they were faced with. A staff nurse in an interview suggested that additional staff members of a lower pay-grade and skill level employed on the wards would be beneficial.

> *"I mean in an ideal world you would have more, not necessarily trained staff, but more sort of auxiliary nurses, care assistants. At the moment we tend to work one on one, but maybe one and two,*

> *one and three would be, in an ideal world."*
> *PP009, Staff Interview, Female, Staff Nurse*

7.3.1.3 Ward Management

There were differences in management between the two study sites, but also across the individual wards throughout the sites. Ward managers had the authority to change some aspects of the structure of the ward, such as visiting hours. Longer visiting hours were believed to be beneficial in facilitating interventions for patients who call out, due to increased presence of relatives on the ward.

> *"Our visiting times have been lengthened, so, sister- she's allowed for visitors to come in from 11 in the morning to 8 o'clock at night as opposed to the hospital policy, which is half past 2 to 8 o'clock- that seems to help. So, relatives that can get here are here throughout the day, and they help with meals."*
> *PP004, Staff Interview, Female, Staff Nurse*

However, it was also suggested that visiting hours could be made to be longer still, for the benefit of the patient.

> *"Well to be quite honest the visiting hours are actually quite good. I mean it's 11.30 until 8pm. But why not let the families come in earlier, that sort of thing, so yeah. Especially when we're perhaps washing them, try and involve them in the care."*
> *PP009, Staff Interview, Female, Staff Nurse*

There were occasions in which the management and organisation of the ward appeared to be disorganised, or had poorly-planned routines.

> *There is a 'Care plan for dementia' document in Carol's notes. However, nothing has been filled out inside the document- it stated on the front of the document that it must be filled out. I asked a staff member for a blank version of this for my notes- she led me to an extremely unorganised filing cabinet, where we both looked through for about 20 minutes, and we couldn't find one. I*

> *left empty handed.*
>
> *PP112, Field Notes, Patient Participant 'Carol'*

> *It's lunch time. A kitchen staff member keeps ringing the dinner bell, and no-one is coming to take lunch out to the patients. She said "where is everyone?" the cleaner said "on board round", the kitchen staff member said "what a stupid time to have that! They need to change the time of that, all this food's going to be cold!"*
>
> *PP130, Field Notes, Patient Participant 'Edward'*

7.3.1.4 Collective Culture

In acute hospital care, staff members must care for multiple individuals in close proximity to one another. This causes complications in ensuring that each patient is content, as interests, wants, and needs may conflict across the group. A patient who is calling out may 'need' to be on a bay with others to lessen feelings of loneliness or isolation, however this can cause problems for the other patients, who may alternatively 'need' quiet in order to rest. A number of occasions were identified in which individuals perceived needs conflicted with the requirement for providing collective care.

> *Spoke to the HCA [healthcare assistant] who said that not last night, but the past few nights before, Jessie had been extremely loud and disruptive, and that the other patients on the bay all had very little sleep due to this and had been very annoyed.*
>
> *PP110, Field Notes, Patient Participant 'Jessie'*

> *"You're not just managing a patient, you're managing a group of patients, and having everybody tired, and everybody irritable, and everybody upset, and everybody not engaging in rehabilitation activities or medical care, is actually quite a big problem."*
>
> *PP001, Staff Interview, Male, Consultant*

On an acute ward, staff must decide what will work best for the group of patients they are caring for, which can sometimes conflict with the individual wishes or interests of the patients. Often, nursing teaching for patients exhibiting behaviours that challenge focuses on the delivery of person-centred, individualised care; however, in practice this can be difficult.

7.3.2 Staff Knowledge and Attitudes

Staff member's education, experiences, and attitudes could impact upon the delivery of interventions for people who call out. Staff could feel stressed and frustrated when a patient in their care was calling out, and more so when they could not identify why. Staff employed a number of mechanisms to enable them to cope with calling out, some positive, and some negative.

7.3.2.1 Education

Some staff members discussed the education they had received surrounding dementia care, and formal training sessions they had attended. Some valued this training in aiding their care of people who call out; they felt it worthwhile, and discussed putting their learning into practice.

> *"It's not always consistent, but we've had a training day once, some years ago when Alzheimer's society came in and talked about dementia, and tried to explain, you know when you say a patient is a "wanderer", well, they walk with a purpose, people don't just pace up and down for no reason, so you now need to try and work out what it is that's agitating them, so that's what- and we teach each other. I'm a mentor, so I pass it on to the student nurses that people don't walk for no reason up and down, so it's either they're in pain or they're hungry, you've got to explore all those things, are they thirsty."*
>
> *PP004, Staff Interview, Female, Staff Nurse*

> *"I did some dementia training by the Alzheimer's Society years ago. They gave us loads of ideas. I think that training was really good about trying to distract people. That was definitely something I got from there."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

Staff discussed their insight and previous opinions of dementia improving after training, and passing this information on to their colleagues. Some staff members had more negative views on the training provided, for a number of reasons. Sometimes they did not agree with what they were being taught, or that 'hands-on' practical learning was more effective, or that the training was too simplistic.

"There was a day put on by Alzheimer's Society, which was-interesting? […] they told us there was 'no such thing as challenging behaviour nor difficult behaviour'… and I'm thinking, 'actually that there really is'"
PP002, Staff Interview, Male, Mental Health Nurse

"Staff members helped you out and the bit of that you get on mandatory and the bit that you get on dementia training. But I do think a lot of it's got to be hands-on. Because what are you going to learn in a classroom? You're not going to get somebody shouting at you constantly for six hours. You do that on the ward."
PP012, Staff Interview, Female, Healthcare Assistant

"I've been on dementia study days and I've thought 'well you've not really told me anything I don't already know'"
PP014, Staff Interview, Female, Staff Nurse

Some staff members discussed additional self-directed learning; such as watching documentaries about dementia, or enrolling onto courses to aid in their knowledge of how to manage people who call out repetitively.

"When I'm at home I do actually watch any documentaries about dementia."
PP009, Staff Interview, Female, Staff Nurse

> *"I have enrolled to do some counselling courses, because I feel, you know, that would help and benefit here as well. Not just for patients but for relatives as well."*
> *PP011, Staff Interview, Female, Assistant Practitioner*

Overall, most staff members found training and education useful in some way to support patients who call out, despite the perceived simplicity of the training.

7.3.2.2 Experience

Staff reported that most knowledge surrounding dementia care was gained through experience, rather through organised training. Staff stated that experience had impacted more so upon the way in which they perceive and manage people who call out.

> *"You adapt to it more. At first, you're a bit 'oh', but when you've been in the job for years, it comes natural. You just go with it."*
> *PP005, Staff Interview, Female, Discharge Coordinator*

> *"I think it's experience really, you do, so learning is through experience and listening to people, people do give talks as well, but most of the stuff is what you experience what you impart to others when you, so people learn by listening to you talking on the ward rounds rather than you going and talking somewhere else."*
> *PP010, Staff Interview, Male, Consultant*

> *"Yeah, I feel more confident now; I think that comes with experience."*
> *PP014, Staff Interview, Female, Staff Nurse*

Staff spoke about feeling less stressed when a person in their care was calling out, and feeling more confident in how they managed it. They reported learning from others, and teaching each other how to respond and react to patients who call out.

7.3.2.3 Staff Negative Coping Mechanisms

Helplessness and Hopelessness

Some staff members reported a feeling of frustration or helplessness when a patient in their care was calling out, and not responding well to attempted interventions.

> *"There's quite a lot of helplessness and hopelessness about the problem […] Things you try often don't work, and therefore it's a problem that will often be avoided, and it takes a conscious effort of will to engage and make sure those patients aren't disenfranchised or ignored."*
>
> *PP001, Staff Interview, Male, Consultant*

> *"I know that I still roll my eyes sometimes if you hear them calling and you go, 'Oh no, not again.' But I think it's really important to stay focused about it."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

Some staff members discussed the benefit of taking 'time out' to reflect upon the situation and their own thought processes to combat these feelings; others talked about making sure to be aware of staying 'focused' and 'committed'.

Intentionality

Some staff members spoke as if they felt the person calling out was trying to purposely frustrate them with their behaviour, even within the context of the belief that calling out is due to an unmet need.

> *According to a staff member, last night between 3pm-8pm George was "terrible"- and shouting "I'll stop it if I stop it", and "help, help, help". The staff member said the calling out was "non-stop" and that he wouldn't answer at any point what the problem was. The healthcare assistant said she felt as if George knew his behaviour was annoying them, and that he was just doing it to annoy them.*
>
> *PP126, Field Notes, Patient Participant 'George'*

Some staff members and relatives reported the usefulness of regularly reminding themselves that the patient was not aware of their challenging behaviour, and that they were not intending to be 'difficult'.

> *"I just have to say this isn't her fault – which it isn't. I mean that's why I always want people to know how she was. I mean she was a very clever woman. And it's sad to see her like I see her now."*
>
> *PP121, Relative Interview, Cousin of Patient Participant 'Elaine'*

> *"But again, it's part of them, and they don't mean to disrupt you from your job."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

This attitude was reported to aid in reducing feelings of frustration towards the patient, and in turn made staff more likely to continue to attempt interventions.

Closing the door

Physically closing the door of people who were calling out in side rooms was observed. On site 2, signs were located outside the side room doors stating that doors must be kept open at all times. On two occasions, the only closed side room door out of a total of twelve was that of a patient participant who was calling out. Her relative reported being aware of this.

> *Judy is currently loudly shouting "help me" continuously, with between one and five seconds of silence between vocalisations. Her door has been shut, potentially to drown the noise out? I went in to see her, and she was asking for a bedpan.*
>
> *PP116, Field Notes, Patient Participant 'Judy'*

> *"I've heard them ignore my mum and I think they've just shut the door so that other patients don't have to hear my mum and neither do they."*
>
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

Judy’s door had been closed on a number of occasions throughout her admission, to her daughter’s discontent. In one instance, her daughter queried the reason for this, to which the staff member replied that they were unsure of the reason Judy’s door had been shut.

Mental blocking

Alongside shutting a door to block the sound of people who call out, staff members reported that they were also able to mentally ‘shut the door’. Staff discussed developing this ability over time.

> *“I mean the person who is calling out, obviously they're very loud, they can disrupt the thought process when you see the other patients, but you try to get, you get used to it, I think, after some time, to be able to block the sound as well.”*
>
> *PP010, Staff Interview, Male, Consultant*

> *“No, I think you do become a little bit desensitised to it once you’re here. When you experience it for a long period of time you do become a little bit desensitised.”*
>
> *PP013, Staff Interview, Female, Deputy Ward Manager*

The discussion of being able to ‘block the sound’ suggests that these staff members believed it was acceptable to do nothing to intervene with the patient’s calling out, in order to care for other patients.

Mockery

On rare occasions, rather than attempting to constructively intervene with a patient who was calling out, staff would instead imitate the sound the patient was making to others.

> *I was sat out on the bay, and a staff member came over to me to tell me about how “annoying” Martha was yesterday, and proceeded to imitate her calling out loudly, whilst rolling her eyes to display her disapproval of Martha’s behaviour. Martha was approximately two metres away from us. I was unable to tell if she*

> *had heard the nurse.*
>
> *PP103, Field Notes, Patient Participant 'Martha'*

> *The lady in the side room next to Edward is calling out repetitively. She called "heeeelp!!" in a bleating, quivery voice. A staff member imitated the patient's vocalisation loudly to a colleague and laughed whilst walking down the corridor away from her.*
>
> *PP130, Field Notes, Patient Participant 'Edward'*

Only very few staff members were observed imitating patients, but they would always do their imitation to another person, and in a public space, implying they found this to be an acceptable behaviour among themselves. In one instance, a staff member imitated a patient in front of a student nurse.

7.3.2.4 Care Plan Communication

Care plans are often used when patients display challenging behaviour. Ideally, a multi-disciplinary team (MDT) will together to decide on the best course of action to appropriately manage the patient's challenging behaviour. Some staff members reported cases in which care plans were used appropriately.

> *Some patients have what we call a 'night-time needs' form so we can look back at that and it will say 'calm', 'asleep' or 'aggressive' and we can put that into place. If somebody's saying that 'this patient was up and shouting' and so we will ask if they'll do a night-time needs. So, we can see is it just certain things that trigger, is it just a one-off, there's lots of things you can put in place before you actually can determine, you know, what somebody's like. So yeah, there's all sorts we do. I think sometimes with mental health, people don't realise really what does go into it.*
>
> *PP011, Staff Interview, Female, Assistant Practitioner*

There were however instances in which care plans were recommended by specialist staff members, but were not followed through.

> *I went back onto the ward Frank had been on previously to enquire about the nursing notes entry on 19.10 – [19.10 2:35pm 'continues on behaviour charts, shouting out 'don't let me fall' even when lying in bed with bedrails in situ, plan: to change primo mattress to foam mattress and put bed against wall with bedrails down at night to see if this helps him to settle overnight']. I asked the receptionist who I could speak to who the most regularly saw Frank overnight. She recommended a nurse who confirmed he had seen Frank regularly on night shifts. I asked him if the care plan had been executed in which Frank's bed was lowered and moved against the wall. He told me it had not been executed at any point, and that he was 'confident' in that. I asked him if he knew who wrote out the care plan in the notes, and he said he did not. I asked him if he thought the plan would have worked, he said he wasn't sure but it would have been a good idea to try.*
>
> *PP122, Field Notes, Patient Participant 'Frank'*

7.3.4 Availability of Individual Patient Information

Person-centred care relies on background knowledge of the patient, in order to tailor care to their individual needs or preferences. For example, always waking a certain patient up last on the ward, as staff were aware that the patient liked to wake up late at home.

> *"So, one of my main jobs is getting collateral history from whoever has been looking after this person, so family members, carers, care homes- whoever knows this person and how they function, or what they kind of like and don't like."*
>
> *PP002, Staff Interview, Male, Mental Health Nurse*

The ability or willingness of outside parties to offer background information had an effect on the ability of staff members to deliver person-centred care. Most of the patient participants in this study were too severely cognitively impaired to be able to provide personal information about their likes or preferences. Staff members reported communicating with care homes and relatives directly to access information, or completing personal profile written documentation.

7.3.4.1 Relatives

Staff members often stated that the best way to access background patient information was to speak to relatives. It was seen as a hindrance when a relative was not available or able to provide background information to the staff members caring for the patient.

> *"I think the biggest thing is getting information from families as to what will calm them down. I think that's the biggest thing. [...] I think if you get somebody who hasn't got any family, or their family are all very old and frail and can't come in and visit, I think it can be really difficult to get information like that."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

Relatives were acknowledged to have a full awareness of the characteristics of the patient, and were occasionally able to draw on experience to help staff members to diagnose their health condition. Staff members usually took reports from relatives of a change in personality or characteristic seriously and would act upon it.

> *"It can be either new to them and so, 'oh, this isn't my mum', or it can be 'well, yes, this is the fifth time my mum or dad has been like this, it's usually caused by' – and they're telling you."*
>
> *PP011, Staff Interview, Female, Assistant Practitioner*

> *"But I mean the last time she had a UTI [urinary tract infection] it was me that notified the nurses she'd got it, I requested that they did a urine sample. And they did the urine sample there and then that day and they found that she'd got a UTI."*
>
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

However, there were also occasions in which staff members did not trust what relatives said, or believed relatives to be misleading.

> *"I've told every member of staff that I've ever met if my mum is in a situation where you can't calm her down, ring me. And they've*

> *never done it."*
>
> *PP116, Relative Interview, Daughter of Patient Participant 'Judy'*

> *"Because some will say 'oh [they're] not like this at home'. And then I look at them sometimes and I find that a little bit hard to believe. And I'm thinking they must be a bit like this at home. But then you'll always hear 'yeah [they're] not like this at home, not at all.'"*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

This indicates staff members used their discretion at times to decide whether or not to accept relatives' advice.

7.3.4.2 Care Homes

Staff members would regularly communicate with care homes if necessary. On some occasions, the patient would have no accessible relative; or the patient's closest relative did not know the patient very well, or was too busy to discuss the patient's care with staff.

> *"You don't feel as guilty calling [care homes] at three o'clock in the morning to say, 'Is this normal for them?' Because they'll be there caring for the rest of the residents 24-7. I think some care homes are a lot better than others in coming up with plans for them and knowing exactly who they are."*
>
> *PP003, Staff Interview, Female, Junior Doctor*

> *"If people are from a care home and the care home are really busy and are not able to give us that information unless we ask for it. It depends completely on how proactive [they] are."*
>
> *PP006, Staff Interview, Female, Occupational Therapist*

Often, staff members would report using a combination of relative and care home staff report to access the necessary background information. However, this involved all parties being proactive, therefore the information required to deliver person-centred care was often not fully accessed.

7.3.4.3 Personal Profile Documentation

The 'This is Me' document is a booklet created by the Alzheimer's Society (Alzheimer's Society, 2019). It is a personal profile booklet with various questions about the person with dementia, which can be documented by anybody who knows the person, such as a relative or carer. It can be used to develop a deeper knowledge of the character of a person with dementia, in order to initiate personalised conversations and activities to better suit the person. Various hospitals in England use this document, or a site-adapted one. Information within personal profile documentation may be used to soothe a distressed patient who is calling out.

There were occasions in which the personal profile document proved to be an effective resource for delivering person-centred care, or for calming a patient who was previously distressed and calling out.

> *An activities coordinator was chatting to Claudine, he had Claudine's personal profile document at his side and was regularly referring to it. He started talking to her about Germany and bingo, and put a YouTube playlist of her favourite singer, Roy Orbison on for her to listen to. Claudine seemed very content, she was smiling for the first time since I'd seen her, and said to the activities coordinator "ooh you're lovely aren't you?"*
>
> *PP114, Field Notes, Patient Participant 'Claudine'*

There were also many times in which a patient participant had sparse, uninformative or no personal information completed on their behalf.

> *"We sometimes find that we give them to families and they just don't bother filling them in. It's like, because you're asking them to spend ten minutes putting a bit of information down, [they] just don't do it."*
>
> *PP012, Staff Interview, Female, Healthcare Assistant*

The personal profile document appeared to be considered a high priority by the hospital.

> *There are some new A4 posters up in the ward aimed at relatives, highlighting the importance of filling in the personal profile document.*
>
> *PP110, Field Notes, Patient Participant 'Jessie'*

Sometimes, the importance of the personal profile document was seen as a low priority by relatives, who considered that the basics of medical care should first be addressed before attempting to provide person-centred care.

> *"All very lovely, and yes, it's a nice piece of paper. But the basics don't get done, so what is the point of filling all that? I'll give you an example. When somebody's admitted and you've witnessed this, you go through all the paperwork, does the patient have any sores? This is on admission. Now a week or so ago I was visiting my mum. She said her leg was hurting, I had a look and she had a sore. Nobody had noticed that. So, it's all very well filling in forms, but you have to do something with them."*
>
> *PP124, Relative Interview, Daughter of Patient Participant 'Agnes'*

Overall, the personal profile document was generally deemed as a useful tool to aid in the delivery of person-centred care in the acute hospital, and to help alleviate the distress associated with calling out. However, sometimes these documents remained blank or sparsely-filled for the entirety of the patient participant's admission.

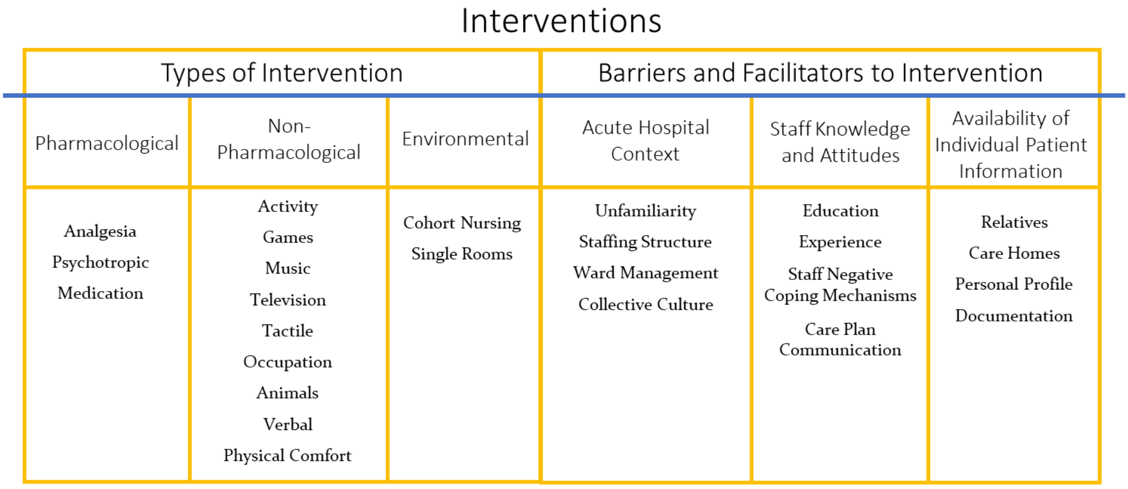
7.3.5 Barriers and Facilitators to Intervention: Summary

In the care of patients in the acute hospital who call out repetitively, often no interventions are conducted by staff. A number of reasons for this have been identified in this study. The hospital environment is often loud, busy and hectic and can leave patients feeling more distressed due to an unfamiliar environment. Staff attitudes can impact upon the likelihood that interventions will be delivered to patients who call out, alongside their knowledge and experience, and the coping mechanisms they use. Patient differences, such as difference in language spoken, visual or auditory impairments, and levels of motivation to engage in activities can cause intervention involvement to be problematic. The level of ability to access personal profile information can also hinder the provision of good quality person-centred care.

7.4 Summary

Many interventions were identified in this study, from basic verbal responses, to pharmacological intervention, to personalised and individualised activities (Figure 7.1). No single pharmacological or non-pharmacological intervention appeared to be more common or more accepted by staff than any other. There were no standardised methods of selecting or delivering interventions observed or reported within the study. Staff were aware of, and used multiple strategies to intervene with patients who were calling out, yet they did not always have the resources available to implement these, and were caring for multiple patients.

Staff frequently did nothing to intervene with patients who were calling out. A number of barriers and facilitators to delivering interventions in the acute hospital were found, including the setting in which the intervention is delivered, the knowledge of the staff, patient individual differences, and the availability of personal profile information designed to aid person-centred care. Staff reported finding this situation frustrating, and due to this could engage in a number of negative coping mechanisms, such as shutting doors, blocking the calling out, or imitating the sound to others. A number of recommendations and hypotheses can be drawn from these findings, and these will be discussed in the next chapter, along with a discussion of findings from the previous chapters.



Interventions

Types of Intervention			Barriers and Facilitators to Intervention		
Pharmacological	Non-Pharmacological	Environmental	Acute Hospital Context	Staff Knowledge and Attitudes	Availability of Individual Patient Information
Analgesia Psychotropic Medication	Activity Games Music Television Tactile Occupation Animals Verbal Physical Comfort	Cohort Nursing Single Rooms	Unfamiliarity Staffing Structure Ward Management Collective Culture	Education Experience Staff Negative Coping Mechanisms Care Plan Communication	Relatives Care Homes Personal Profile Documentation

Figure 7.1: A summary diagram of the interventions identified through interviews and observations in the study, and the perceptions of staff and families about the barriers and facilitators associated with intervening.

Chapter 8

Discussion and Conclusions

8.1 Introduction

This final chapter offers a discussion based upon the study findings presented in Chapters 5 to 7. The key findings are summarised, and then discussed in the context of the literature outlined in Chapters 1 and 2. A summary of the main strengths, limitations, and challenges of the study is discussed. An interpretation of the research findings is then detailed. The chapter concludes by considering the implications of the study in relation to future research, practice, and policy, focusing on the directions and potential impact of the study findings.

8.2 Summary of the Key Findings

The aim of this study was to understand how calling out presents itself within the acute hospital and beyond discharge, the beliefs surrounding the behaviour, and how others react or respond to it. The presentation of calling out, and the population that displays the behaviour is diverse.

Almost all patient participants had moderate to severe cognitive impairment. 19 had a recorded diagnosis of dementia, 6 had recorded delirium (of which 5 were DsD). Ten had no previously diagnosed delirium or dementia. Most patient participants had a high level of physical dependence. Mean length of hospital stay was 29 days, which is long even for people with dementia (Goldberg and Harwood, 2013; Goldberg et al. 2014; Sampson et al. 2009). One-third of patient participants died within three months of being recruited into the study, with 6/20 survivors changing their living situation after discharge, due to increased dependence. Eleven of the 19 remaining[6] patient participants were re-

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[6] One patient participant was still in hospital at follow up.

admitted into hospital during the follow-up period, however some of the patients with no reported readmissions were discharged only a few days prior to the follow-up date. Patient participants were most commonly admitted into hospital due to a fall or an infection; and had a mean of more than three comorbid conditions. Around one-third had a hearing impairment, and two-thirds had a visual impairment. Length of stay was almost two and a half times the national age-matched mean (National Audit Office, 2016), and many patient participants found difficulties in being placed into new care homes or nursing homes, often explicitly stated to be due to the challenging behaviour they exhibited. Most of the patient participants were recorded to be experiencing mild to moderate pain, although ascertainment was difficult using a behaviourally-based scale. Patient participants scored highly on a number of neuropsychiatric items of the NPI-NH, including agitation/aggression, apathy/indifference, anxiety, and irritability/lability. Most of the patient participants (76%) were deemed as having a 'probable major depressive episode' with 24% classified as having a 'definite major depressive episode'.

Identified types of calling out were: repetition of a tangible need, single word/phrase repetition, semantic repetition, and stream-of-thought vocalisation. Most patient participants persisted with their calling out throughout their admission, but some were found to be transient. Calling out was reported by staff and carers to often be related to agitation and distress, but there were also instances where this was not thought to be the case. Generally, staff judged presence of agitation and distress by body language or vocal content, as opposed to presence of the calling out alone. Calling out was also associated with socially problematic behaviour, with reports and observations of personal racism, sexual disinhibition, verbally confrontational language; and physically challenging and disruptive behaviour. The people who called out were often experiencing a physical and mental health decline, and were nearing the end of their life.

Needs relating to calling out were identified. These included biological needs, which incorporated functional (such as toileting, thirst, and temperature) and medical (such as infection, pain, and constipation) needs; psychological needs (depression, anxiety, and psychosis); and social relationship needs (such as attachment, belonging, and identity). Unanticipated needs were also ascertained, which were more problematic to understand and manage. The first of these included indeterminable needs, such as suicidal wishes, resource-deficient needs, and 'decontextualised' needs; such as a patient shouting for their shoes to be taken off when they were barefoot. The idea that sometimes patients do not have any 'real' needs at all was also commonly discussed, giving rise to the notion of 'futility'. A number of explanations for a judged lack of need in these patients were given, including "it's part of the dementia", "they don't know they're doing it", and "it's normal for them". These explanations for a lack of need were used regularly, and were commonly accepted between staff. Futility appeared to be a learned belief, and one that could frustrate staff to acknowledge. There were no observed or reported systematic assessments of need specifically associated with calling out for any of the patient participants.

Pharmacological interventions (analgesia, psychotropic medication, and sedation), and non-pharmacological interventions were identified through interviews and observations. Non-pharmacological interventions included activity, verbal, physical comfort, and environmental interventions. It was often found through observation that staff would do nothing therapeutically proactive when a patient in their care was calling out. Actions relating to this included closing the door, mental blocking, and imitating patients. Chapter 7 listed ways in which various factors would create either barriers or facilitators to conducting interventions with people who call out. These were based upon the context of the acute hospital, staff knowledge and attitudes, individual patient differences, and the availability of individual patient information.

8.3 Strengths and Limitations

The methods selected and developed for this study were concluded in Chapter 3 to be appropriate to answer the research question. However, limitations can arise either unexpectedly, or due to the chosen methods.

8.3.1 Study Strengths

This study is the first of its kind to characterise and explore calling out in the context of the acute hospital. An in-depth consideration of the existing literature and its gaps has facilitated in the development of the research questions and methods of study. The only previous study to investigate calling out in England in the context of the acute hospital was small scale, and open to bias (Inkley and Goldberg, 2016). This study gives an in-depth account, using multiple participant groups, and multiple methods of data collection, over the period of a year. This research was required to lay the groundwork for future research into calling out in the acute hospital. No previous research has followed patients who call out throughout admission and after discharge, or examined placement, readmission, or mortality. No quantitative data had previously been collected about patients specifically who call out in the acute hospital. Therefore, information regarding activities of daily living, length of stay, reasons for admission, calling out persistence, and comorbidity was previously unknown.

The use of critical realism as a philosophy has helped to develop a study that uses a variety of different sources to gain more reliable and valid findings. It supported the addition of the preliminary analysis period during the data collection, a recommended method of ongoing analysis (Lincoln and Guba, 1985). Critical realism allowed for the use of emergent methodology, which permitted the data collection process to develop to meet the study aims based on ongoing analysis.

The use of two hospital sites in the research has aided in the generalisability of the findings, alongside the fact that ten healthcare of the older person wards were utilised across these sites. It has allowed for some comparisons to be made across the two sites, and a more diverse range of participants to be recruited.

To further increase the confidence in the data collected, a process of data triangulation was employed. Using two or more different approaches to access information in research offers a more accurate and comprehensive depiction of the results than using just one approach (Tashakkori and Teddlie, 2003). The theory behind data triangulation is derived from Denzin (1978), in which the three corners of the triangle relate to time, space and person. As displayed in Figure 8.1, this study successfully employed all three of the necessary constructs to achieve triangulation, strengthening the confidence in the data.

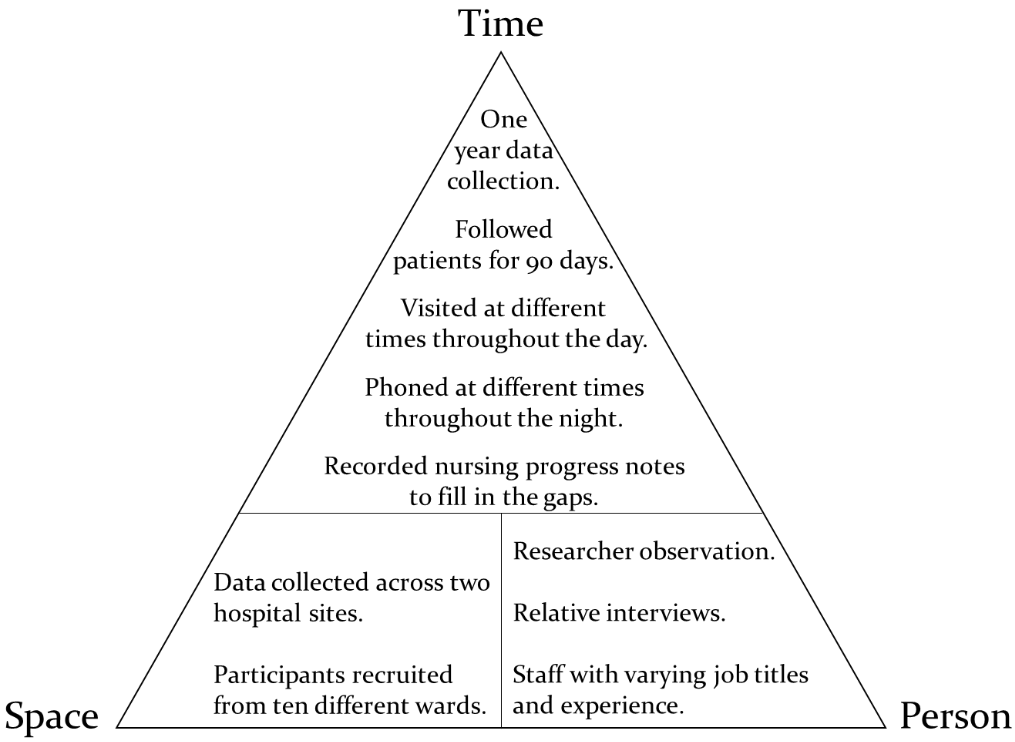

Figure 8.1: The necessary constructs to achieve triangulation

8.3.2 Study Limitations

The method of recruitment for this study was prone to a selection bias. Patient participants were often recruited based upon suggestions made by staff members. They may have had a tendency to suggest the more ‘interesting’ or severe cases in these situations, over-representing the patients exhibiting more severe calling out and/or challenging behaviour, and underrepresenting the very transient or mild cases. However, recruitment was conducted on a time-point basis, reliant on my capacity as a lone researcher to recruit a new participant.

Furthermore, there would often be around four to six potential patient participants available to recruit on a site at a certain time-point, usually with only the capacity to recruit one. The greatest bottleneck in recruitment was identifying and meeting with a family member who would be willing to be a personal consultee. Therefore, preferential recruitment was based upon the availability of a personal consultee, as opposed to the patient displaying the most ‘severe’ or ‘interesting’ behaviour. These factors will have contributed towards lowering the potential effects of a selection bias with regards to severity or persistence of calling out. Conversely, this suggests that availability of relatives or carers might be overrepresented in this study.

As is the case with many qualitative research studies, the sample size for each participant group was relatively small. This allowed for more detailed qualitative data to be collected per participant, however it caused the quantitative data to be of uncertain generalisability to the wider population. For example, the fact that one-third of patient participants died within the participation period may have been due to an unrepresentative sample. However, the selected method gave a deeper insight and understanding into an unknown phenomenon within a complex context, and this should not be overlooked. Whilst the quantitative data may not generalisable, the data points towards potentially important findings that could be investigated in future larger scale research.

The exhibition of behaviours that challenge in people living with dementia is common (Stokes, 2017), but their relationship with calling out remains largely unknown. This study identified a number of behaviours that challenge alongside calling out; however, without a control group for comparison, it is not possible to compare this result with patients who do not call out.

In qualitative research, it is best practice to involve at least two people on a team during the analysis of the data (Gale et al. 2013). This was not possible given the scope of this PhD. Therefore, analysis risked bias based upon my knowledge, experiences and beliefs. To mitigate these biases, a joint coding session was conducted alongside two of my PhD supervisors, in which the same transcript was coded by all parties beforehand and compared and contrasted in the session. This provided me with an insight into the different ways speech can be interpreted, and recognition of when I was making assumptions or placing values on a statement. This gave me more awareness of the way in which I coded for the remainder of the analysis. The steering group also provided assistance in reducing qualitative data analysis biases. Quotes from the data were presented to the steering group members for them to comment on, making use of various viewpoints from the data.

Not all patient participants had a formal diagnosis of dementia in their medical notes, despite the presence of cognitive impairment. However, a number of relatives in interviews expressed the challenges they had faced when attempting to have the patient participant diagnosed. These challenges were due to the inability to test a person with sensory impairments, and reluctance from GP's to refer to memory clinics due to old age. This supplements the fact that around 68% of the expected number of people are recognised in GP registers to have dementia (NHS Digital, 2018). Therefore, the percentage of patient participants with dementia within the present study is potentially higher than that reported.

8.5 Reflexivity

Often in ethnographic research, the researcher will identify themselves as either an 'insider' or an 'outsider' of the social group they are observing. Both can be problematic, as insiders may feel uncomfortable taking notes as opposed to participating with their social group, and outsiders lack the in-depth knowledge about the social group, and may feel the questions they ask are 'ignorant' (Gregory and Ruby, 2011). I identified myself as an outsider at the beginning of the study, however the further into the study I got, the more often I would begin to think of myself as an insider on occasion. I reported in my reflexive diary that I found myself feeling frustrated, and rolled my eyes along with a healthcare assistant. The patient in his care had just called out for a bed pan again, following him bringing her one with repeatedly no success for the third time in the space of 20 minutes. I had sympathy for the healthcare assistant, and understood his frustrations each time he returned from the patient's room with an empty bedpan, as the patient again had not been able to open her bowels.

I wondered if I would have reacted in the same way had this been the first patient participant I had recruited and not the 16th, and whether this meant that my beliefs around calling out were beginning to change, as I began to sympathise more with staff.

I was also mindful of the fact that two of my three PhD supervisors are registered clinicians/ healthcare professionals, and the biased opinions I might form about staff in the study due to this. I was conscious of the fact that these influences could cause me to justify staff members' actions more sympathetically during my observations, analysis, and interpretations. I was also conscious of the fact that this awareness could make me turn in the opposite direction so as to not appear too sympathetic of staff, and end up being overly critical of what I observed. To counteract this, I have reported verbatim in field notes where possible, to avoid an extra layer of interpretations where my preconceptions could influence the data.

8.6 Key Findings in Relation to Existing Literature

The underpinning theory behind calling out and agitated/distressed behaviours in the existing literature is the theory of unmet need. This was explained in Chapter 2 using the Needs-Driven Dementia-Compromised Behaviour model (NDDCB; Algase et al. 1996). The findings from the staff interviews in this study indicate that staff do possess knowledge of the theory of unmet need, and can describe how they would accomplish judging the unmet needs of patients who have impaired communication. Staff frequently expressed the idea that patients who call out have an unmet need. However, there were also many occasions in which staff reported that the patients did *not* have a need, resulting in feelings of futility in trying to manage calling out. Futility could be explained using Algase et al's (1996) model; as staff would sometimes link the cause of calling out to purely the background factors within the NDDCB model. For example, staff reported "it's the dementia" as a cause, mirroring 'neurological health' as a background factor in the NDDCB model. It was determined from the scoping review in Chapter 2 that reducing calling out down solely to a diagnosis of dementia was inappropriate (Cariaga et al. 1991); alongside this, the NDDCB model advises to take both proximal and background factors into account. However, findings from this study indicated that staff did not always do so. These findings suggest that the research and teaching centred around unmet needs requires further adaptation; as it does not provide support for occasions in which it is believed the patient has a need that cannot be met, and what to do in these instances.

Another major influence within dementia healthcare teaching is the work of Tom Kitwood. Many of the non-pharmacological interventions observed or reported by staff within this study assimilate Kitwood's (1997) flower of emotional needs; inclusion, attachment, comfort, identity, occupation, and love. Staff in this study would generally speak about the interventions without explicitly linking them to Kitwood, or person-centred care. Kitwood (1997) stated that distress is the result of the failure to meet the person's needs, and can be caused by a carer ignoring signs of distress, invalidating the person, and infantilising or patronising them. Despite staff members' inherent knowledge in this study surrounding some appropriate types of person-centred interventions; actions defined by Kitwood as 'malignant social psychology' were still apparent. Examples included staff members blocking or ignoring calling out patient participants, or mocking them by imitating them. This indicates that whilst staff report that attitudes are improving surrounding person-centred care, and that staff members are becoming more aware and educated around the care of people with dementia, more work is still required to avoid 'malignant' dementia care.

A number of the quantitative findings in this study corroborate with findings in the existing literature. The present study found that all patient participants had moderate to severe cognitive impairment, and all had executive functioning impairment. This supports previous studies, who also reported that patients calling out or displaying agitated behaviours had more severe cognitive impairment (Cohen-Mansfield and Libin, 2005; Draper et al. 2000). Similarly to Cariaga et al. (1991), this study also confirms that not all patients who call out have a diagnosis of dementia or delirium, despite all having moderate to severe cognitive impairment.

The rate of death recorded in this study is relatively similar to that of Sloane et al. (1999), who found that 23.4% patients died, however this was within a six-month period as opposed to the three-month follow-up period within this study. Sloane et al. conducted their research in a nursing home; therefore, the participants were likely to be less acutely ill.

The previous research surrounding the mental wellbeing of older people who call out holds many similarities with this study. Negative affect has been found in multiple ways in the previous literature to be associated with calling out. Anxiety was found by Draper et al. (2000), Hallberg and Norberg (1990), and Lemay and Landreville (2010) to be associated with calling out, which supports the results in this study, that 76% of patient participants displayed anxiety as assessed by the Neuropsychiatric Inventory, Nursing Home Version (NPI-NH; Wood et al. 2001).

The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, 1988) showed 76% of patient participants to be experiencing a ‘probable major depressive episode’; of which a number of previous studies report a depressed mood or negative affect to be associated with calling out (Cohen-Mansfield and Libin, 2005; Cankarturan, 2014; Cohen-Mansfield et al. 2012). Whilst the present study found the majority of patient participants to be in mild to moderate pain, a number of studies within the scoping review also discuss pain or discomfort to be related to calling out (Beck et al. 2011, Berastegui et al. 2017, Sloane et al. 1997, Hallberg and Norberg, 1990).

Staff suggested one of the reasons patients call out was for self-soothing or self-stimulation. There are a number of other conditions in which people report that this is the case, for example Tourette syndrome ‘tics’ (Zinner, 2004) and autistic ‘stimming’ (Sinha et al. 2004). Autistic stimming has been described as a ‘self-created sensory reward loop’ (Ambitious about Autism, 2017), enacted due to the sensation it creates, as opposed to the results it produces. It is possible that this is the mechanism behind why some patients call out, that they enjoy the feeling of calling out more than the attention or inattention that it evokes. The cause for requiring self-soothing or self-stimulating activities can be triggered by feelings of anxiety, depression, or boredom in people with dementia (Carlson et al. 1995). Generally, patient participants were unable to articulate why they call out; however, in the present study, Jessie (PP110) reported that calling out “gives me something to do”, indicating perhaps that she was holding boredom responsible for her behaviour. This reinforces the findings of Cohen-Mansfield et al. (2015) and Leon et al. (2018).

Some relatives reported a belief that a decline in physical ability in patient participants was associated with the onset of calling out. They would often refer to their relative having a 'stubborn' or 'proud' personality. The loss of ability to conduct daily activities could cause frustration, distress, and anger in these people, manifesting itself as calling out. Beck et al. (2002) did not find a significant improvement in calling out after conducting an 'activities of daily living' programme, however the present study supports the rationale behind the intervention used. A critical investigation into why the Beck intervention was unsuccessful might be useful, with the chance for adaptation.

Psychological attachment behaviours, such as a fixation that deceased parents are still alive (parent fixation) can be manifested in cases of stress, loss, or ill health, and can be expressed as challenging behaviours (Browne and Shlosberg, 2003). It is reported to be especially prevalent in adults with dementia. Miesen (1993) gives an account of the phenomenon of parent fixation wherein a person with dementia calls out attachment feelings or thoughts towards deceased parents. There was much evidence of this in the present study, with staff members regularly explaining this as a display of the patient's feelings of anxiety, as they would lean towards their parents for comfort. Nelis et al. (2014) explains this as an attempt to engage with the attachment figure, and observed it more regularly in residential settings where attachment needs were not met.

The types of calling out identified in this study were 1. repetition of a tangible need, 2. single word/phrase repetition, 3. semantic repetition, and 4. stream-of-thought vocalisation. The study by Nagaratnam et al. (2003) also identified four categories, which were 1. Persistent screaming, 2. Perseverative vocalisation 3. Continuous chattering, muttering, singing or humming, and 4. Swearing, grunting and bizarre noise-making. Nagaratnam et al.'s methodology included an office-based, retrospective design, in which physicians were asked about a total of twelve previous patients who called out. This is a less reliable method to ascertain types of calling out than the direct observation methods used in this study. Despite this, a number of similarities can be seen between the two typologies (Table 8.1). The current study, however, included repetition of a tangible need, which was not discussed in the Nagaratnam study. Calling out a tangible need was observed to cause the same level of distress to the patient, and the same amount of disruption to others as other types of calling out in this study, however, therefore it has been included.

Identified Types of Calling Out from this Study	Nagaratnam et al. (2003) Typology of Calling Out
Repetition of a tangible need	Not discussed
Single word/phrase	1. Persistent screaming, 2. Perseverative vocalisation, 4. Swearing, grunting and bizarre noise-making
Semantic repetition	1. Persistent screaming, 2. Perseverative vocalisation
Stream-of-thought vocalisation	3. Continuous chattering, muttering, singing or humming

Table 8.1: Types of calling out identified in this study compared with the typology work of Nagaratnam et al. (2003)

Staff members would more often refer to a patient's behaviour that challenges as being 'agitated' if it was combined with a physically challenging behaviour, such as kicking. This is in keeping with the agitation literature surrounding calling out, as more of a focus tends to be placed on the physical aspects of behaviours that challenge rather than the vocal. In the scoping review, it was detailed that more than half of the existing literature predominantly refers to calling out as an agitated behaviour. Much of the previous research discusses the factors that contribute to calling out to produce socially problematic behaviours, and this current research further supports this, using extensive direct observations and interviews to portray the varying difficulties relatives and staff members face when caring for people who call out repetitively.

A greater range of needs were identified and described compared with the Cohen-Mansfield et al. (2015) study. The Cohen-Mansfield study concluded that the most prevalent needs were loneliness/need for social contact, and boredom/sensory deprivation. Only one-third of Cohen-Mansfield's sample was found to possess the need of discomfort. The present study may have identified more needs because the patient participants were located in the acute hospital. Therefore, they had one or more acute medical needs, potentially causing additional distress and emphasising the internal feeling of unmet need.

Berastegui et al. (2017) conducted a focus group utilising clinical professionals brainstorming triggers for calling out. They agreed upon five 'trigger categories' for the cause of calling out. 1. Physical/emotional pain, 2. Discomfort or sensory loss, 3. Social isolation, under-stimulation/hypersensitivity, 4. Re-emergence of painful memories, and 5. Loss of language skills. Berastegui's first trigger category for calling out fits in with the biological medical and functional needs, and the clinical psychological needs in this current study, discussed in Chapter 6. Dissimilar to Berastegui's findings, sensory loss or impairment was reported by staff in the present study as both a barrier to delivering effective interventions and as a cause for the patient participant shouting louder; as opposed to it being a primary cause of calling out. Much evidence was found in this study to support Berastegui's third causal trigger, including the social relationship needs identified in Chapter 6. For example, staff members awareness of the need for patient participant inclusion in the social environment, and the benefits of physical contact. A weakness of Berastegui's study was the lack of observational evidence, and the lack of inclusion of the people who call out; this current study used more reliable methods to access the data. Berastegui's focus group expressed the opinion that calling out could occur for no apparent reason, holding similarities with this current study. However, the findings from this study go deeper to examine why staff believed this. The additional findings from this study can now help us to understand the mechanisms behind why staff ignore or avoid patients who call out.

Bourbonnais and Ducharme (2010) suggested that the calling out of patients with cognitive impairment is a unique language that can be learned. In an ethnographic study based in a care home, formal caregivers discussed being able to recognise different types of calling out in the same person, allowing them to interpret their unmet need. Care home staff reported this took a long time to achieve, and was likened to learning a new language. Staff in the present study did not express the ability to do this, potentially due to the fact that patients do not stay in hospital for as long as in a care home setting. This could cause hospital staff further difficulty in interpreting calling out.

Pharmacological interventions that were observed or reported in this study included analgesia, psychotropic medication, and sedation. This was found to be aligned with much of the previous literature into pharmacological treatment of calling out (Barnes et al. 2012; Rabinowitz et al. 2007). However, whilst a large number of studies of electroconvulsive therapy have been published reporting its effectiveness in reducing calling out or agitated/challenging behaviour (Aksay et al. 2014; Dahl, Lapid and Richardson, 2009; Fazzari, Marangoni and Benzoni 2015; Lau, Babani and McMurray, 2017; Roccaforte, Wengel and Burke, 2000; Sutor and Rasmussen, 2008), this form of intervention was not observed or reported in the study. Electroconvulsive therapy is still thought of as a controversial treatment due to its history of use in an unethical manner (Zhu et al. 2018), therefore it is likely to be rarely used and is possibly considered an extreme intervention in clinical practice. Staff also echoed the opinions within the literature that drug treatment is not always necessarily in the patient's best interest, and that non-pharmacological intervention if possible and where appropriate is better for the patient (Banerjee, 2009; Sivertsen et al. 2015; Lövheim et al. 2006).

The existing literature presented on non-pharmacological interventions within Chapter 2 was concluded to be generally poorly informed and poorly designed, with mixed results. Many of the interventions reported in the literature were observed or reported in this study, including music, audio, touch, and environmental (Ridder et al. 2013; Lin et al. 2018; Fu et al. 2013; Sust et al. 2015). Similarly to the results of the scoping review, no single intervention appeared to be the best accepted by relatives and staff members. One of the main problems with past intervention studies could be the lack of objective definition and measurement of calling out. The development of a more sensitive measure could help researchers to observe and record the differences before and after intervention.

This study mirrors findings presented in the scoping review in Chapter 2 regarding staff perceptions of minimal resources and low staffing levels (Clifford and Doody, 2018; van der Geer et al. 2009). It also reflects previous research stating that staff will avoid or ignore patients who call out (Inkley and Goldberg, 2016; Van Camp et al. 2005). However, it expands on these by recounting the actions staff take to actively avoid or ignore patients who call out, and also reports on the reasons staff give to justify these actions.

8.7 Interpretation

8.7.1 The Problem with the Theory of Unmet Need

The unmet needs observed and recorded in this study were easily understandable and meetable when they were simplistic in nature, such as basic functional or medical needs. The theory of unmet need, or the Need-Driven Dementia-Compromised Behaviour (NDDCB; Algase et al. 1996) model, provides suitable explanation for these situations, and allows hospital staff or carers to form an internal framework or 'mental checklist' to adequately meet these basic needs. However, the occasions in which staff struggled to comprehend the cause for calling out are suggested to be due to more complex, unobservable and unmeasurable mechanisms, which the NDDCB fails to appropriately address. There are four main factors suggested which ultimately hinder the usefulness of the NDDCB model in the acute hospital context.

1. **Difficulty to Ascertain the Unmet Need**

   Many staff members struggled considerably to establish the unmet needs of non-communicative patients who were calling out, or where the speech was difficult to interpret. Interventions and new knowledge are necessary with regards to staff members' communication skills, and recognition of body language cues.

2. **Existential Distress**

   Another cause for calling out could be existential distress (Bourbonnais and Ducharme, 2010). The population of patient participants within this study were an extremely dependent group of people, who required substantial amounts of help from carers to meet most of the needs that surfaced throughout their day. Due to the high proportion of deaths recorded in this study, alongside the rapid declines in mental and physical health, it is conceivable that these patients were aware of their situation or their potential mortality; and experienced mental anguish, or existential distress. This is a type of 'need', that cannot feasibly be met; and instead, distracting and soothing interventions such as sensory rooms could be considered.

3. **Impractical Needs**

   Needs which were understandable, yet unrealistic or unviable were documented in this study. These included instances such as patient participants asking to go home when they were still unwell, and requiring constant medical care. Another example was asking for dead relatives.

4. **Insufficient Resources**

All healthcare practices are limited by the resources available to them. Relatives in this study reported that some patient participants needed company, or somebody to hold their hand. Although staff members regularly reported being aware of the need for social stimulation, or physical attachment, this was not a need that could be regularly met in the patient participants due to the limited resources available.

8.7.2 What is a 'Need'?

Defining 'need' is complex, and becomes no more straightforward when adding an acute hospital context, and severely unwell people with communication difficulties. It is conceivable that things can be wanted but not needed, and conversely needed but not wanted; and also needed *and* wanted, but not available. This can change dependent on the knowledge a person has about a situation. Human actions and behaviours are largely need-driven (Deci and Ryan, 2002), with constant ongoing and fluctuating basic needs. The Oxford English Dictionary defines a 'need' as to: "Require something because it is essential or very important rather than just desirable." (Oxford University Press, 2018). However, within this study, the term 'need' was used regularly for 'desirable' requirements alongside 'necessary'.

Holmes and Warelow (1997) discuss the unclear distinction between needs and wants, and whether it is even viable to differentiate between them. They highlight issues surrounding a powerful social ideology of healthcare: that nursing staff should be dedicated to meeting patient needs. They argue that this ideology is problematic, due to the inherent difficulty in distinguishing between wants and needs, leading to an exploitative situation within the health care system. If it is expected that hospital staff must meet all the needs of the patients in their care, and 'desires' (such as wanting somebody to hold their hand constantly) are considered needs, the healthcare system is setting itself up for certain failure. It could be argued that it is becoming meaningless to refer to all patient desires as 'unmet needs' within healthcare teaching. A hierarchy of need, to target the more 'important' needs, and to help to differentiate between needs and desires could be a useful teaching tool to help hospital staff to prioritise their tasks.

8.7.3 Comparison with Other Behaviours that Challenge

All behaviours that challenge undoubtedly had a negative impact upon the hospital environment. Jackson et al. (2017) state that the influence of the hospital environment, along with sleep deprivation, leads to irritability and behavioural challenge, even when cognitive disorders such as delirium are not present. The people in this study were all within a collective environment shared with multiple other acutely unwell people, therefore any display of challenging behaviour will undeniably have caused a strain on the other people within the environment.

Whilst physically aggressive and physically non-aggressive behaviours that challenge were occasionally more difficult to manage for both staff and carers, these types of behaviour often did not last as long as calling out would.

Calling out differs from other behaviours that challenge, such as physical aggression, in that it has the ability to negatively impact upon a larger quantity of people. Many people were observed throughout the study to be affected by calling out even when they could not see the person who was calling out. The person calling out could be on the opposite end of the ward at times, and people would comment on how loud the calling out was. It is also something that when severe, could be produced constantly by the person calling out, as opposed to aggression which may only occur a couple of times a day. The use of foul, inappropriate, or sometimes even unlawful language was also relatively common in this study, and is something that many other people in the hospital found upsetting to hear.

A further difference between calling out and other behaviours that challenge is that it could continue alongside a severe decline in physical health. If a patient was bedbound, and unable to complete any basic daily living activities, they were often still able to call out. This was a particularly distressing observation, as it would draw attention from others to how acutely unwell the person was, and others were sometimes observed commenting on how they felt they could do little to help the person in distress.

8.7.3 Futility

The concept of futility is introduced in Chapter 7, and details a collective belief that some patients will continue to call out to no avail, and nothing can be done for these patients. In critical realism, it is important to consider why a group of people hold a collective system of thought, in order to understand the underlying processes that may be driving it (Bhaskar, 2013). These processes can be thought of as the social or psychological mechanisms that unconsciously operate to shape and influence us to think and act in the ways that we do (McEvoy and Richards, 2003). Using the tenets behind the philosophy of critical realism, two generative mechanisms behind futility have been theorised from the data.

Staff feelings of "*distress*" or "*heartbreak*" when a patient is calling out (when they do not think that intervention is likely to be effective) can increase staff vulnerability to burnout (Kokkonen et al. 2014). Staff employ rationalisations to minimise their discomfort, and this in turn leads to a group of carers holding a collective view that intervention or care is futile. Futility explains the rationalisation that operates to protect healthcare professionals from these uncomfortable emotions. If they can place accountability with the patient and their diagnosis or character, it removes the emotional upset associated with the belief that a staff member should be able to do something to help.

Two protective mechanisms are proposed to be operative, and help to explain the development and perpetuation of futility: ‘protection of professional identity’, and ‘protection of personal morality’.

8.7.3.1 Protection of Professional Identity

Hoeve et al. (2014) found nurses drew their professional identity in part from their public image. Hospital staff are continuously being monitored and audited to ensure they are doing their jobs properly (Harding, 2014). Regulatory bodies such as the United Kingdom Care Quality Commission (CQC) see a patient calling out repetitively with no response from staff as an example of poor care (CQC, 2012). This will be considered alongside other factors when rating whether the service is caring, and observations of staff members ignoring a patient calling out is used as evidence of the services being uncaring. This negatively affects the public image of hospital staff (Hoeve et al. 2014), amplifying the need for staff members to protect and defend their professional identity. Staff members frequently spoke about being “*good*”, “*specialist*”, and “*efficient*”, and reiterated how “*busy*” they are, and how hard they need to work.

A system of thought that some patients cannot be helped, allowed staff members to repair possible negative perceptions of their professional identity; improving how they perceive themselves as a member of a professional group. Placing responsibility for the problem with the patient, labelling them as somebody who ‘can’t be helped’, takes the problem away from staff, and moves away from internally labelling themselves as incompetent, even if highly competent. Such behaviour can protect staff members from feelings of frustration and failure.

8.7.3.2 Protection of Personal Morality

Hospital staff will often work in particular specialities due to professed personality characteristics, such as people having a generally caring nature opting to work with older people (Mann and Cowburn, 2005). They will enjoy seeing the difference they can make in patients’ lives, through paid employment involving work underpinned by values of care and compassion. Staff were eager to assert themselves and their co-workers as moral agents in interviews and in conversations with myself. Staff envisioned “If I had all the time in the world, I would talk to every patient, every day", and emphasised "everybody that works here are here because they care about people". During unstructured observation, a staff member assured me that they were "not ignoring" a patient, but that the patient was becoming "too reliant" on staff.

Staff seek to retain and maintain their moral identity as they are aware that not responding to patients may be interpreted by 'outsiders' (i.e. regulators or visitors) as well as themselves as uncaring or even neglectful. Through the process of futility, by collectively normalising the act of doing nothing, whilst rationalising the cause of the calling out; staff members are able to retain a perception of themselves as not morally culpable if they choose to do nothing and not intervene. Ignoring a patient who is shouting 'help!' if they do not have enough time to go over to the patient, would theoretically feel morally 'better' if they hold the belief that the patient is 'only' calling out and therefore needs no intervention.

One of the reasons why many previous intervention studies may have been unsuccessful, or display mixed findings, could be due to the generative mechanism of futility. If staff believe that a person who is calling out will do so 'no matter what' then they may be less likely to implement the intervention in the instructed standardised manner. Beliefs about futility could highlight the need for more meticulous assessments into whether interventions are being conducted and upheld properly when judging the outcomes of interventions.

This study has addressed the first three of the suggested inquiry stages of the critical realist DREIC (Describe, Retroduce, Eliminate, Identify, and Correct) model outlined in Chapter 3 (Bhaskar, 2013). The phenomenon of futility had been described, and mechanisms were introduced. A variety of methods have been used to describe the mechanisms from different viewpoints, using observations, case studies, and interviews with healthcare professionals and relatives. The mechanisms were developed based on the study data, and discussed with the expert steering group and supervisors in an attempt to eliminate 'false' mechanisms. The next stage of the DREIC inquiry would be to conduct a new piece of research which attempts to identify the mechanisms at work, and then corrects these mechanisms where necessary.

8.7.3.3 Issues Arising from Futility

Staff expressed a common belief that calling out repetitively was caused by unmet need, but simultaneously spoke of there being no 'real' need, or that need was social or emotional, and that given the time pressures and competing priorities of a busy medical ward, such needs could not be identified or legitimately met. 'Knowing when to intervene' was considered a skill, but there was little evidence that this was determined by systematic clinical assessment. Staff frequently 'blocked' or ignored calling out. A consequence was that real, tangible and meetable needs may have been neglected. Table 8.2 details a theoretical typology of needs and wants, involving possible scenarios and outcomes to illustrate the difficulty surrounding care needs in this population

Table 8.2: Theoretical typology of possible needs and wants in patients who call out repetitively and potential staff responses

Presence of a need	Presence of a want	Patient able to communicate need or want	Staff able to meet need or want	Example
Yes	No	Yes	Yes	Patient is thirsty, asks a staff member, who responds
Yes	Yes	Yes	No	Patient is anxious, tells staff member they have to go home, staff cannot let patient leave
Possibly	Possibly	Possibly	No	Staff block calling out, need is not heard
Yes	Possibly	No	Possibly	Patient is distressed, cannot communicate why, staff member has to deduce from body language, or use trial and error strategy

Possibly	Possibly	No	No	Patient is unable to communicate, staff member cannot determine if there is a need or not

Futility potentially inhibits good care of patients who call out; firstly because assessment is often superficial and not systematic; secondly because legitimate day-to-day needs may be missed; and thirdly because little is done to try to alleviate the apparent distress shown by these patients. Futility is 'socialised' because the belief is collectively held and communicated between staff members, endorsed by senior colleagues and becomes normative with professional socialisation. It may be more likely in environments where there are time pressures associated with heavy workload, understaffing, and the need to address multiple competing priorities, especially urgent physical healthcare needs where patients are acutely unwell.

Emotional labour (Hochschild, 1983) depends upon the ability of a staff member to supress their own personal negative emotions, such that they are able to influence a patient's emotions in a positive way (MacDonald and Mears, 2019). Bailey et al. (2015) observed that professional carers can find it challenging to display empathy and emotional contact within dementia care settings. Futility, especially when socialised, may inhibit the ability of staff to successfully provide this level of emotional care; this could in turn exacerbate any negative emotions being felt by the person with dementia, such as fear, loneliness, and depression.

Futility is a risk for this patient group; and to prevent this from occurring, staff and relatives need to remain open-minded and aware of the tendency to hold contradictory beliefs. Reflection upon beliefs, and challenging assumptions that are made about a patient who is calling out repetitively (Cordon, 2013) should instead be encouraged. Staff may be correct that calling out repetitively cannot be resolved for a given individual, but should be cautious in assuming this, or that no new need will arise. Instead, care should be based upon thorough and regular assessment, and therapeutic trials, as might be expected in mental health nursing practice (Keady et al. 2003).

8.7.4 Difficulties in Measuring Calling Out

The measures employed in this study to assess calling out included the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991), and the Pittsburgh Agitation Scale (PAS; Rosen et al. 1994). The CMAI had a ceiling effect for most of the patient participants, due to them regularly vocalising much more than three times per hour. The highest rating on the CMAI for each behaviour item is “3+ times per hour”. Despite this, the CMAI is currently the most widely used measure across the literature. The development of a new measure for the frequency of calling out would be useful for future intervention studies; to assess and measure more subtle changes in regularity, and could be used on a more short-term and regular basis. Whilst the PAS was found to be quick and easy, the subjectivity of some of the language used was found to be challenging for both staff members and myself. The grouping of item descriptions caused difficulty in accurately describing the behaviour of the participant. For example, a patient scoring ‘3’ on the PAS- Aberrant Vocalisation would display “loud, disruptive, difficult to redirect” calling out. Staff would struggle with this rating when a patient was loud and disruptive but not difficult to redirect. Some staff found issues with the simplistic ideas surrounding the notion of ‘redirection’; they elaborated that a patient could be ‘redirected’ but then shout again within a space of only a few seconds. Staff were unclear about how long a patient should not vocalise for, in order for the patient to have been successfully ‘redirected’.

Within the two-hour structured observations, the number of vocalisations were counted for the patient participants in each allocated three-minute time period, in order to display the frequency of calling out. However, it was difficult to say how many ‘times’ someone vocalised if the calling out was constant. When a person was exhibiting ‘stream of thought’ calling out, I found it extremely difficult to decide how many times that person had called out over the observation time. One observer might say that person has made just one vocalisation over a long time due to a lack of sufficient pauses; whereas another might count each single word as a vocalisation. I decided upon counting them as one vocalisation; firstly, as they appeared to be based upon a single ‘stream-of-thought’, and also so as to not appear to be overinflating the presentation. This might hint towards using volume or disruptivity as a measure for the outward presentation of calling out, due to the likelihood of disagreement surrounding this issue. However, it was occasionally implied by staff that the louder a patient was calling out, the more likely they were in distress. There were multiple occasions in which staff would refer to a patient participant as ‘more settled’ if they were calling out more quietly than normal. This was also the case where a participant had lost her voice due to ongoing calling out. There are many feasible situations in which a person could be quieter than another, due to a sore throat, or a dry mouth or other health conditions. Whilst a person calling out quietly causes less disruption for others in the vicinity, it should not imply that they are any less distressed than a person very loudly calling out. It should also be noted that a person could be feeling extremely distressed and may not be calling out at all. Cassell (2004) highlighted the internal nature of suffering, indicating the subjectivity and immeasurable-ness of suffering, distress, and also agitation.

8.8 Implications

8.8.1 Future Research

The previous literature surrounding calling out is lacking in many areas. It groups the behaviour with other behaviours that challenge with little empirical evidence for doing this, it has a poor working definition, and there is very little past research conducted in an acute hospital. This study lays a foundation of knowledge about calling out in the context of the acute hospital for further research to build upon. There are a number of routes future research in this context could take in expanding the knowledge-base, and being able to create and assess interventions for calling out. A number of types of calling out were observed in this study, including repetition of a tangible want/need, single word/phrase, semantic repetition, and stream-of-thought. It could be argued that these types should be considered as separate from one another, as it may help to distinguish what is driving the cause of the behaviour.

There is currently no objective standardised measure that assesses calling out as a single construct. The measures used within this study were adapted to only include the items or sections that focused on vocalisations. It is arguably difficult to objectively measure calling out, as much of the individual causes and feelings around it will generally be indeterminable due to the cognitive impairments of the person exhibiting the behaviour. Therefore, a measure of an objective aspect of calling out, such as disruptivity, is suggested as a method to develop a measure of calling out for use in a large scale, powered, and replicable intervention study. To enhance feasibility, the measure should be simple to read and understand, quick to conduct, and as objective as possible. A suggestion for the type of items that could go into a new measure is detailed in the appendices (Appendix Y). For the scope of the PhD, it was not possible to develop and validate a new measure, therefore this is simply a suggestion.

Another direction for future research would be to conduct a large, representative powered prevalence study. This would need to be multi-centred to achieve adequate numbers and generalisable data. This could be useful in assessing how much we would benefit from intervention across the country, and an effective way of measuring the impact of an intervention.

Further research is essential for the development of an effective intervention in the acute hospital. This study has examined what currently happens in practice, and the barriers and facilitators to intervening with people who call out. These findings can be utilised to develop an intervention that can be applied to the context, and critical realist methodologies can be used to measure the effectiveness of interventions on each site, and help to adapt each site's intervention for more efficient and effective use. A guidelines-based approach to intervention development could be considered, using similar methodology to that of Booth et al. (2018) in which theory, evidence, and practical issues were addressed systematically. Larger-scale phenomenological work may need to be undertaken to effectively advise the intervention.

Recruitment rates in this study were lower than they would have been if conducting a quantitative-based multi-researcher study. Recruitment rate was slowed by my individual capacity as a lone researcher, the requirement for consultee agreement for patients to participate, and the nature of the data to be collected, rather than by the number of eligible participants. It is conceivable that if the capacity for data collection were higher (with an additional researcher(s) and less intensive data to be collected), around 200-250 eligible patients could be recruited per year, or 18-21 per month. This is based on the assumption of data collection being based over ten wards, with a conservative average of three eligible participants admitted per ward per month (30 overall per month), and a participation rate of 60-70%.

There were no patient, consultee, or clinician- influenced withdrawals of participants from any participant group during the study. Some relatives of patient participants were difficult to access by telephone, and many eligible patient participants were not pursued due to this. Three relatives declined to participate, all of which were emotionally-charged refusals. One terminated a phone call saying it was 'not a good time'; another became frustrated, with the opinion the study would not do anything to help her mother; and the husband of an eligible patient participant became teary, and said he 'didn't want to make the wrong decision and make everything worse'. All were difficult social situations to manage, and future researchers would need to be prepared for occurrences such as this. Of the 30 patient participants recruited, one was lost to follow-up, due to unavailability of the relative over the telephone. This participant was seen again in hospital during observations of another patient participant, allowing for some follow-up data to be recorded.

The mean length of a hospital stay for older patients in the United Kingdom is 11.9 days (National Audit Office, 2016). Therefore, the 90-day participation period was designed to include admission, discharge, and a follow-up period of an average of 78 days. However, the unexpectedly long mean length of stay found in this study meant that on some occasions, patient participants had only been discharged for a few days before their follow-up date, and one participant was still in hospital, and had not yet been discharged on their follow-up date. In retrospect, it may have been more appropriate to have a longer participation period of up to 120 days, in order to capture all discharge locations and additional readmissions.

Accessing relatives for interview proved to be more difficult than with staff members. Many of them had jobs, other commitments, or other caring responsibilities. Some relatives found it difficult to get to the hospital to visit their relative, and wanted to prioritise talking to the patient participant when they did visit. Home visits and telephone interviews were found to greatly facilitate recruitment to interviews; therefore, in future research of this nature, these would again be necessary.

Overall, there were no issues identified in this study with regards to recruitment and retention rates. Longer than anticipated lengths of stay may have affected recruitment rates if conducting a large-scale, statistically powered study. A ceiling effect was found when conducting the CMAI, and item grouping within the PAS caused difficulty with accuracy in describing the patient participant. These issues would require consideration prior to conducting future research with this population type within the acute hospital.

8.8.2 Future Practice

The findings from this study provide an insight into the nature of calling out and its current management, which many healthcare professionals and ward managers may be unaware of.

Firstly, the finding that one-third of patient participants died within the 90 day participation period was unanticipated. No staff members mentioned in interviews that patients who call out are nearing the end of their life, and healthcare professionals have been surprised to learn of this throughout the ongoing dissemination of the research findings. If corroborated, these findings highlight the need for healthcare professionals to be aware of the likelihood of end of life for some of these patients. A palliative healthcare approach towards patients who call out would require the promotion and development of effective communication, attention, and psychological, social, and spiritual needs. Plans would need to be made with the patient and their relatives surrounding future decline, and the use of sedatives or painkillers. A focus should be placed on minimising investigation and treatment burden for these patients.

It might be useful for healthcare professionals to think more in terms of mental health-based or psychological clinical practice, or for additional training to be given to staff surrounding this. Staff working on the wards which employed specialist mental health nurses reported that they felt more confident in managing patients who called out, or who displayed challenging behaviours. Staff often reported patient participants as being more ‘settled’ if the patient was not calling out as loud as before, even if that was more likely due to a sore throat.

This implies staff could be trained more to look for facial expression cues and body language, rather than judging emotions from the calling out itself.

A great deal of emphasis was placed on activity by staff members. Generally, many activities were observed in the study, but staff often reported that there was not enough activities available for patients due to a lack of time and resources. Due to their severe physical and cognitive impairments, it is more likely that patients who call out repetitively in the hospital would benefit from activities such as sensory rooms (Mitchell et al. 2015), or aromatherapy (Fu et al. 2013); as opposed to games such as playing dominoes, which require a higher level of cognitive ability. The provided activity would need to be inexpensive, and able to be transported, due to the high quantity of patients who are bed-bound. A low-stress environment could also be introduced in the wards lacking a 'homely' feel. The addition of large decals or murals on walls, calming music, and homely effects such as wooden-style flooring and old-fashioned mounts around televisions could reduce feelings of distress or agitation in patients who call out (Brooke and Semlyen, 2019).

8.8.3 Future Policy

A fundamental problem that arose throughout this study was the issues surrounding discharge for patients who call out, but were medically fit. Community care did not have the provisions necessary to care for the patients displaying behaviours that challenge alongside their calling out. This led to patients who were well enough to leave hospital staying for many extra days, or occasionally, weeks. A focus needs to be placed on timely discharge from the hospital; but first, policies need to be put into place to provide community care with the abilities, skills, and resources to take care of these patients.

Policies that support the increased involvement of carers should be encouraged. The extension of visiting hours has been reported to improve patient wellbeing within the context of the acute hospital (Trueland, 2014); and was suggested by staff members in this study as a way of better managing calling out. John's Campaign (Dementia Partnerships, 2018) endorses open visiting in all healthcare settings, including the acute hospital. The removal or extension of visiting hours could be trialled on willing wards to see the effects or consequences this holds, and then potentially rolled out across the hospital if the effects were positive.

The Care Quality Commission (CQC, 2011) note three/four key themes underpinning the aspects of poor care within the acute hospital: leadership, attitudes/skills, and resources. These key themes could be used as a framework to drive national policies to improve the hospital care of people with dementia. Priority should be placed on ascertaining the correct leadership for healthcare of the older person wards, which may in turn enhance positive attitudes centred around dementia care. Resources will likely always be restricted due to the monetary limits at the ward's disposal; items such as fidget blankets or twiddle muffs are regularly readily donated when calls are made for them through social media, and more could be made of this. Items to block the sound of patients who were calling out such as ear plugs were suggested by staff to have been beneficial in the past, but supplies had run out; these are a cheap commodity that might be invaluable for staff members and other patients on more severely affected wards or bays.

8.9 CoRths Model

A summary model has been created to display the overall findings of the study (Figure 8.2). It depicts how empirical findings relate to and expand upon the Algase (1991) model (Figure 2.3, page 40). The red boxes and the black text within them originate from Algase's model. The underlined black text within these are factors identified in both Algase's research and the present study. The blue text within the red boxes are additions to Algase's model that have been identified in this study. The remainder of the boxes that contribute to the model are all additions to Algase's original model, derived from this study.

This model depicts the cyclical nature of unmet needs, caused by a vast quantity of background and proximal factors, that can co-occur. The type of need and ability to express a need can impact upon how it is managed by staff. Staff/carer inaction occurs when staff do not proactively seek out a need, or when the barriers to intervention are such that intervention does not occur. When an intervention is unsuccessful, re-assessment is required, which could this time either lead to success, staff inaction, or another failed intervention attempt. Once a cycle of the model is complete, the process may start again, with either the same or different needs.

The model brings to light a number of novel findings identified within this study: 1. It highlights an important distinction between types of need, and the potential combinations and complexities of need. In the context of dementia, there exists the potential inability to appreciate external reality, such as a patient calling out repetitively that they want to walk when they are physically unable to. It cannot be assumed that no effort has been made to identify and meet needs just because calling out persists; as it is conceivable that some needs may not be meetable. 2. If the need is not obvious, there is a requirement to actively look for it on multiple levels. This includes neurological, social, psychological, and behavioural. 3. All thought processes in relation to assessing and managing calling out can be impacted by socialised care futility. 4. The identification of barriers and facilitators emphasizes that just because an assessment has been made and a potential successful intervention has been identified, it does not mean staff will necessarily be able to conduct it.

There is a paradox that occurs with all preventative interventions, in that success is invisible. Therefore when care is enacted without fault in this setting, no problem exists to be identified. This ultimately causes the model to appear somewhat negatively skewed towards occasions where care could be improved.

Overall, these findings contribute towards clarifying a previously un-researched picture of calling out in the context of the acute hospital. They further the current understanding of what happens in this context, how it impacts upon others, and the knowledge, experiences, and beliefs of the staff members and relatives who care for people who call out.

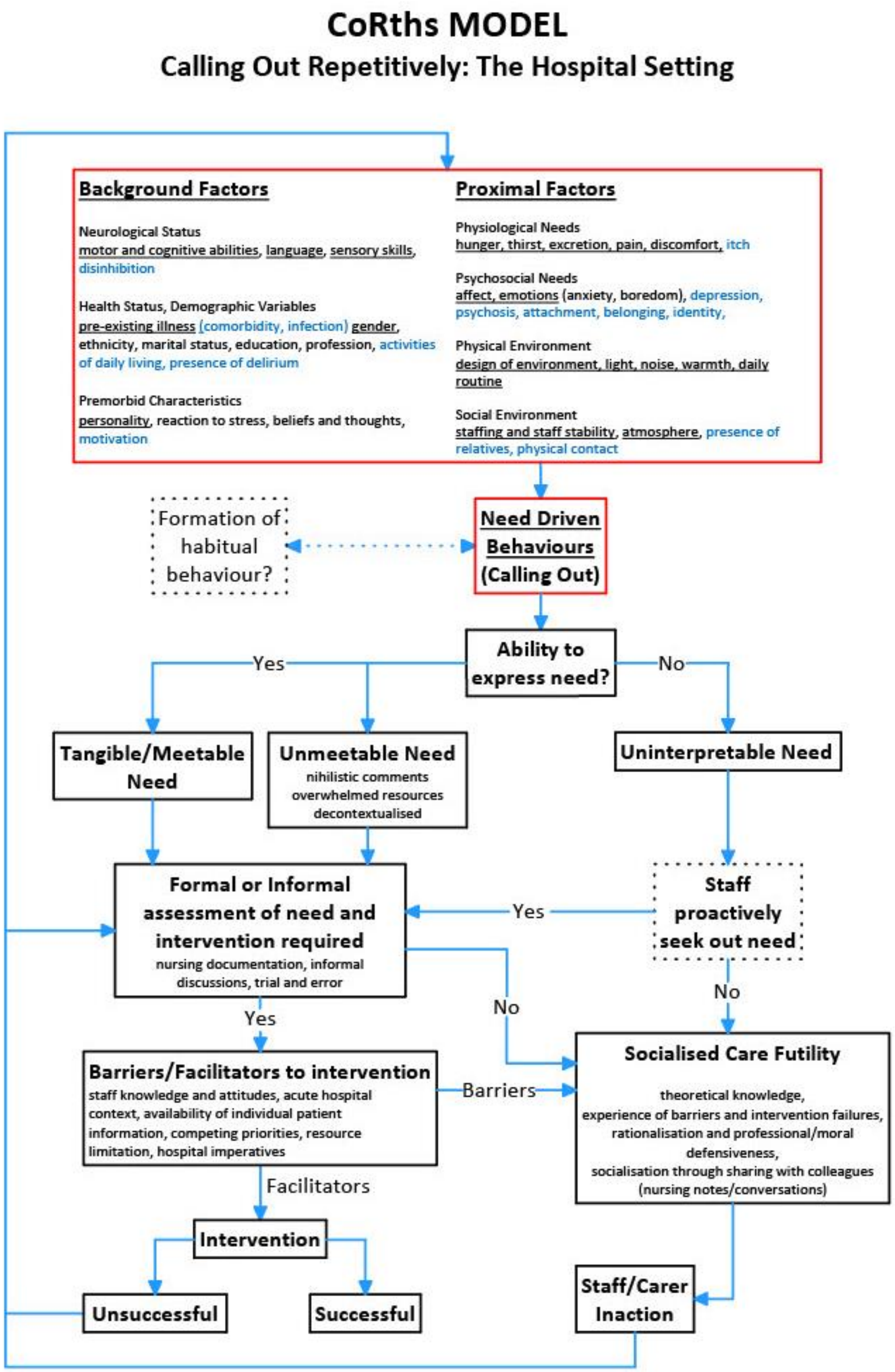

Figure 8.2: A summary model of the overall findings of the study

8.10 Final Conclusions

Calling out repetitively is an under-researched problem in the acute hospital. It covers a broad range of vocal behaviours, including repetition of tangible needs, words or phrases, sentences relating to the same topic (semantic repetition) and stream-of thought vocalisation. Calling out can be extremely loud shouting or screaming, or whispered at an almost inaudible level. A number of challenging behaviours can be exhibited alongside calling out, such as cursing and physical aggression. People who call out repetitively in the acute hospital are often moderately to severely cognitively impaired, experiencing dementia, delirium, or both; and are severely physically impaired. Many have multiple comorbid conditions alongside their cognitive impairment, and display signs of being in pain. Some patients may be close to the end of their life.

Calling out is thought to be related to the presence of a need that the patient cannot meet themselves due to their poor physical functioning, and cannot communicate easily to staff due to their cognitive impairment. Previous literature assumes that discovering and meeting patient needs will alleviate calling out behaviours. A large quantity of needs were identified in this study, however these also included needs which were more complex to resolve, such as decontextualised needs, resource-deficient needs, and unmeetable needs. A substantial number of interventions were identified, which were pharmacological (analgesia, psychotrophic medication, and sedation) and non-pharmacological (activity, verbal distraction, reassurance, and re-orientation, physical comfort, and environment). Barriers to delivering interventions were also identified, and these were focused on the acute hospital context, staff knowledge and attitudes, and the availability of individual patient information.

These findings provide a better understanding of the cognitive and functional abilities of people who call out repetitively within the acute hospital, and provide a detailed description of the 'problem' of calling out. Hospital care is complex for people who call out; and whilst the unmet needs model is useful in some cases, it can fall short in less straightforward circumstances, leaving healthcare professionals uncertain of what to do. Staff feelings of futility are theorised to be due to generative mechanisms of a want to protect professional identity and personal morality.

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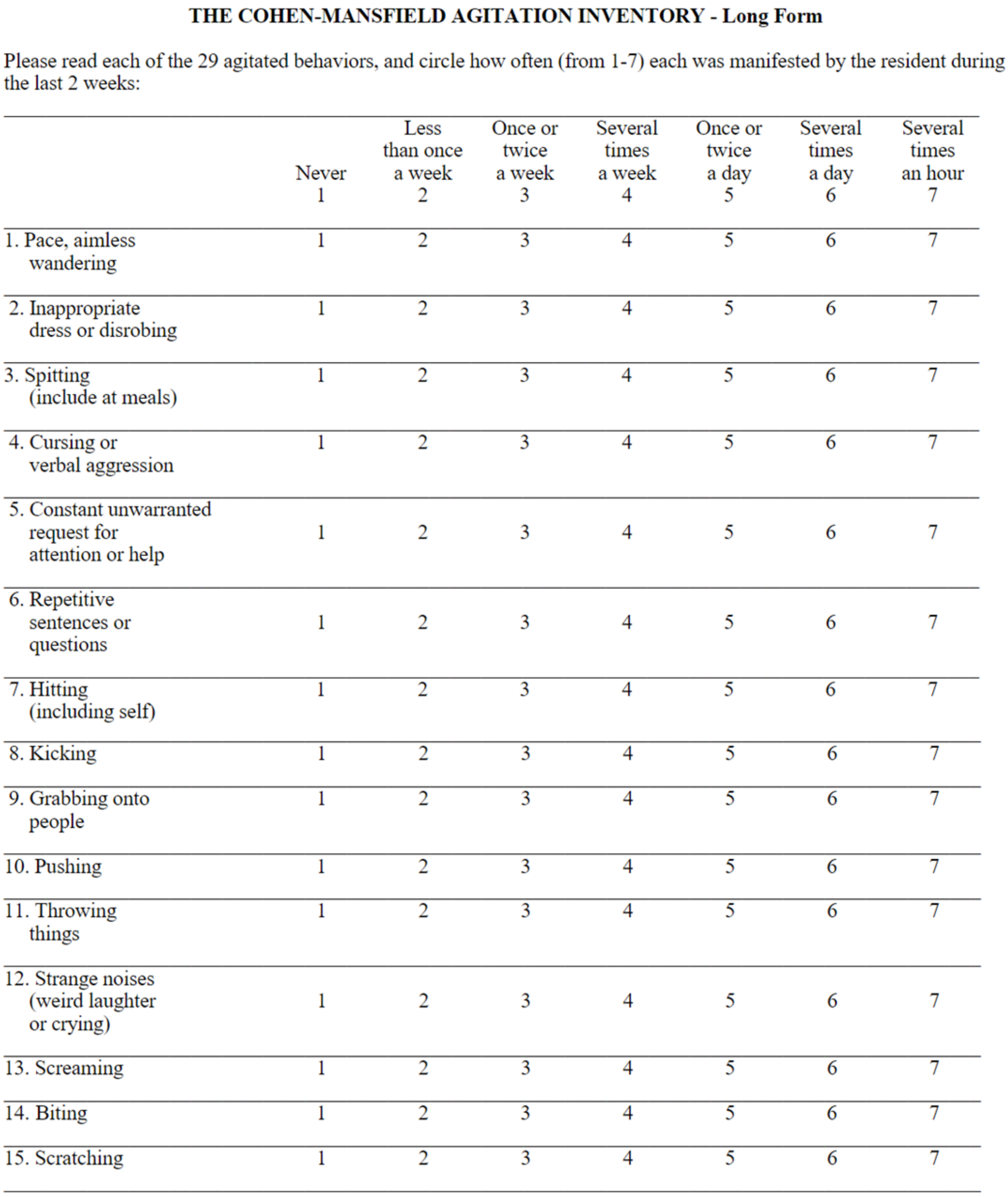
Appendices

Appendix A The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991)- page 1 of 2



THE COHEN-MANSFIELD AGITATION INVENTORY - Long Form

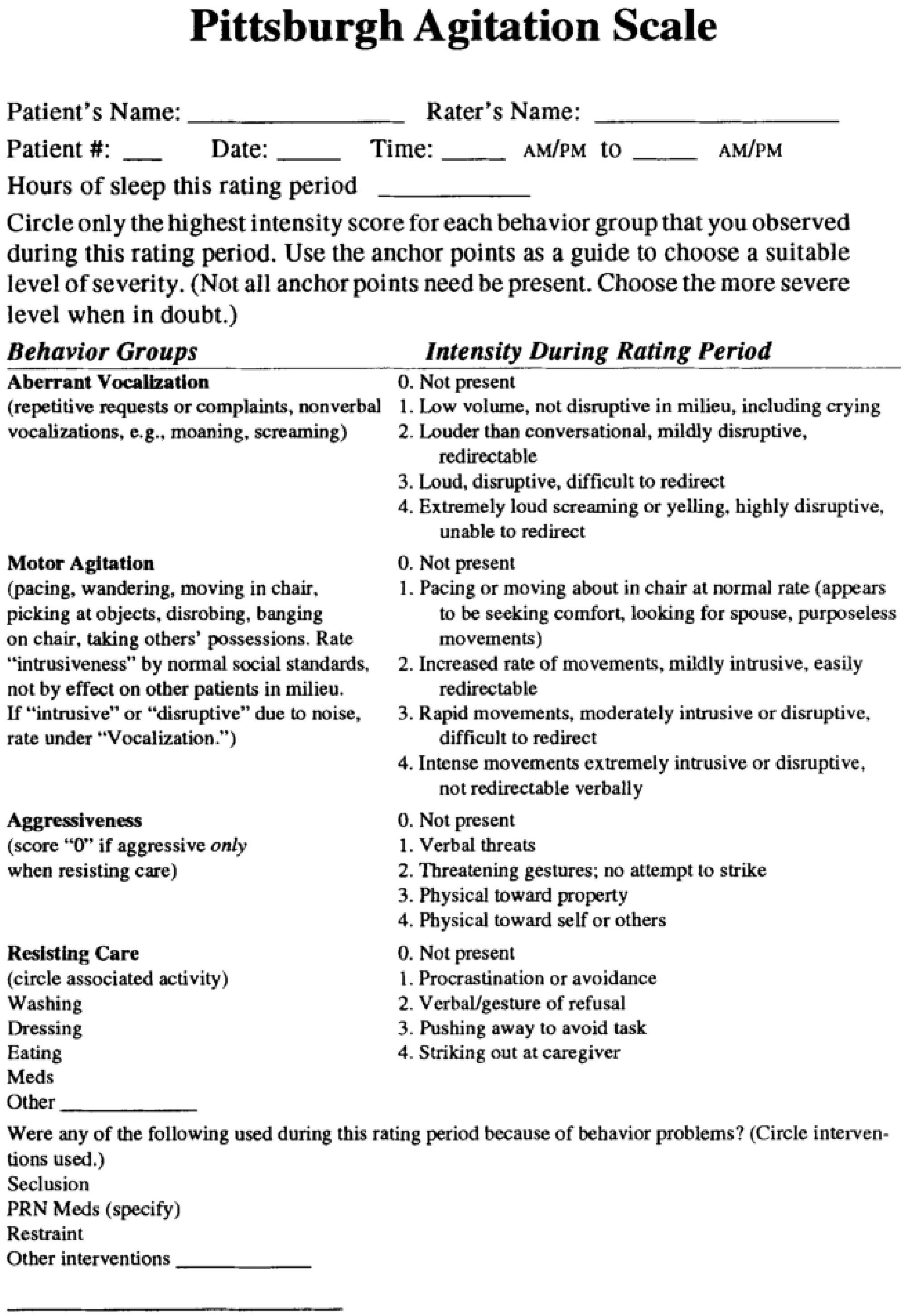
Please read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks:

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
1. Pace, aimless wandering	1	2	3	4	5	6	7
2. Inappropriate dress or disrobing	1	2	3	4	5	6	7
3. Spitting (include at meals)	1	2	3	4	5	6	7
4. Cursing or verbal aggression	1	2	3	4	5	6	7
5. Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6. Repetitive sentences or questions	1	2	3	4	5	6	7
7. Hitting (including self)	1	2	3	4	5	6	7
8. Kicking	1	2	3	4	5	6	7
9. Grabbing onto people	1	2	3	4	5	6	7
10. Pushing	1	2	3	4	5	6	7
11. Throwing things	1	2	3	4	5	6	7
12. Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
13. Screaming	1	2	3	4	5	6	7
14. Biting	1	2	3	4	5	6	7
15. Scratching	1	2	3	4	5	6	7

Appendix A The Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1991)- page 2 of 2

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
16. Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
17. Intentional falling	1	2	3	4	5	6	7
18. Complaining	1	2	3	4	5	6	7
19. Negativism	1	2	3	4	5	6	7
20. Eating/drinking inappropriate substances	1	2	3	4	5	6	7
21. Hurt self or other (cigarette, hot water, etc.)	1	2	3	4	5	6	7
22. Handling things inappropriately	1	2	3	4	5	6	7
23. Hiding things	1	2	3	4	5	6	7
24. Hoarding things	1	2	3	4	5	6	7
25. Tearing things or destroying property	1	2	3	4	5	6	7
26. Performing repetitious mannerisms	1	2	3	4	5	6	7
27. Making verbal sexual advances	1	2	3	4	5	6	7
28. Making physical sexual advances	1	2	3	4	5	6	7
29. General restlessness	1	2	3	4	5	6	7

Appendix B The Pittsburgh Agitation Scale (PAS; Rosen et al. 1995)



Pittsburgh Agitation Scale

Patient's Name: ________________ Rater's Name: __________________

Patient #: ___ Date: _____ Time: _____ AM/PM to _____ AM/PM

Hours of sleep this rating period ___________

Circle only the highest intensity score for each behavior group that you observed during this rating period. Use the anchor points as a guide to choose a suitable level of severity. (Not all anchor points need be present. Choose the more severe level when in doubt.)

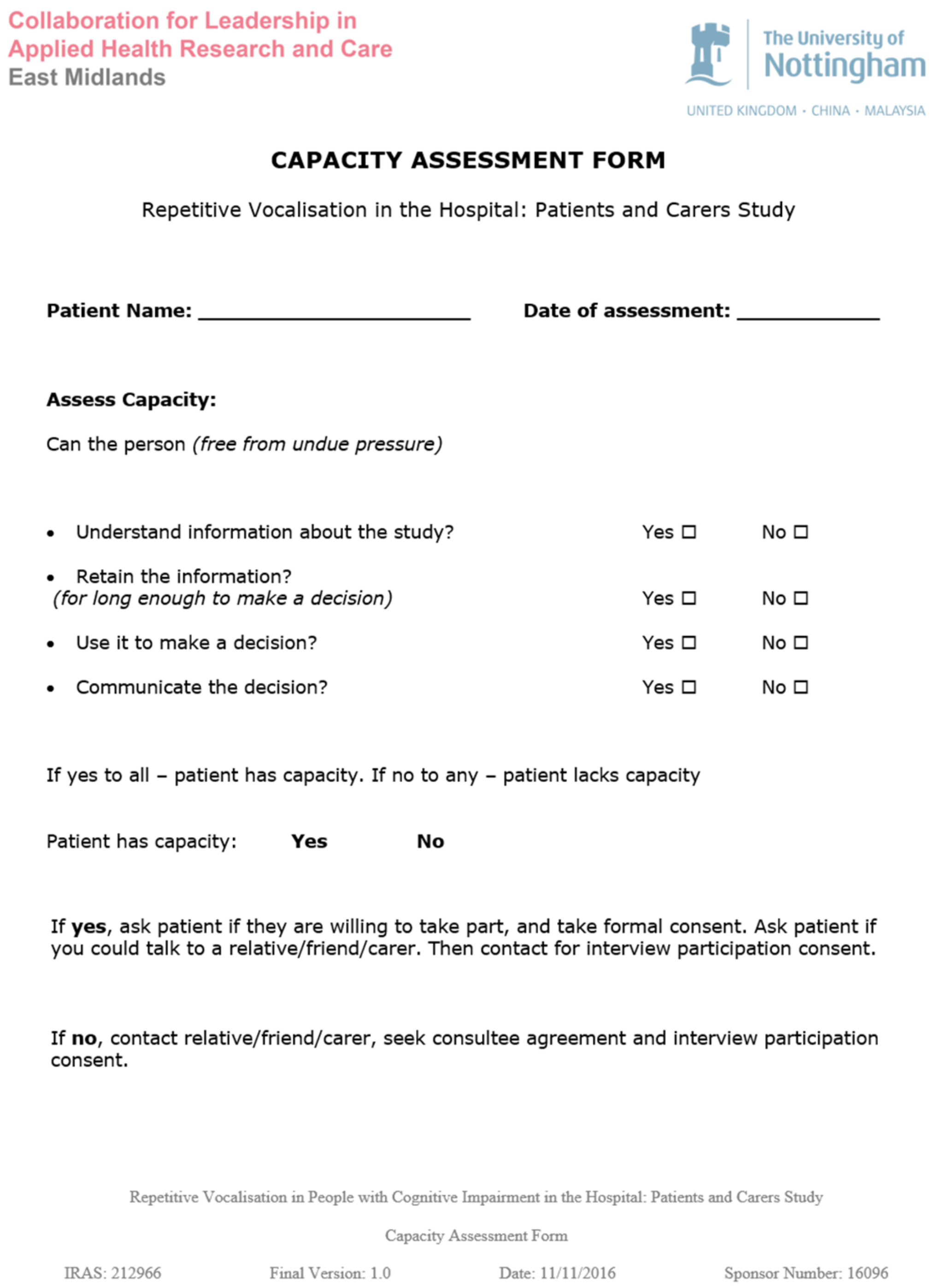
Behavior Groups	***Intensity During Rating Period***
Aberrant Vocalization (repetitive requests or complaints, nonverbal vocalizations, e.g., moaning, screaming)	0. Not present 1. Low volume, not disruptive in milieu, including crying 2. Louder than conversational, mildly disruptive, redirectable 3. Loud, disruptive, difficult to redirect 4. Extremely loud screaming or yelling, highly disruptive, unable to redirect
Motor Agitation (pacing, wandering, moving in chair, picking at objects, disrobing, banging on chair, taking others' possessions. Rate "intrusiveness" by normal social standards, not by effect on other patients in milieu. If "intrusive" or "disruptive" due to noise, rate under "Vocalization.")	0. Not present 1. Pacing or moving about in chair at normal rate (appears to be seeking comfort, looking for spouse, purposeless movements) 2. Increased rate of movements, mildly intrusive, easily redirectable 3. Rapid movements, moderately intrusive or disruptive, difficult to redirect 4. Intense movements extremely intrusive or disruptive, not redirectable verbally
Aggressiveness (score "0" if aggressive *only* when resisting care)	0. Not present 1. Verbal threats 2. Threatening gestures; no attempt to strike 3. Physical toward property 4. Physical toward self or others
Resisting Care (circle associated activity) Washing Dressing Eating Meds Other ____________	0. Not present 1. Procrastination or avoidance 2. Verbal/gesture of refusal 3. Pushing away to avoid task 4. Striking out at caregiver

Were any of the following used during this rating period because of behavior problems? (Circle interventions used.)

Seclusion
PRN Meds (specify)
Restraint
Other interventions ____________

____

Appendix C Patient Participant Capacity Assessment Form



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CAPACITY ASSESSMENT FORM

Repetitive Vocalisation in the Hospital: Patients and Carers Study

Patient Name: _______________________ **Date of assessment:** ____________

Assess Capacity:

Can the person *(free from undue pressure)*

• Understand information about the study?	Yes ☐	No ☐
• Retain the information? *(for long enough to make a decision)*	Yes ☐	No ☐
• Use it to make a decision?	Yes ☐	No ☐
• Communicate the decision?	Yes ☐	No ☐

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 relative/friend/carer. Then contact for interview participation consent.

If **no**, contact relative/friend/carer, seek consultee agreement and interview participation consent.

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study

Capacity Assessment Form

IRAS: 212966 Final Version: 1.0 Date: 11/11/2016 Sponsor Number: 16096

Appendix D Participant Information Sheet for Consultees- page 1 of 4

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PARTICIPANT INFORMATION SHEET - CONSULTEE

(Final version 2.0: 23/01/17)

IRAS Project ID: 212966

Title of Study: Repetitive Vocalisation in the Hospital: Patients and Carers Study

Name of Researchers: Jessica Beaver, Sarah Goldberg, Rowan Harwood

Invitation

Your relative (it could also be a friend or someone you care for, but for brevity this document will use the term 'relative') is being invited to take part in a research study. Before you decide whether you agree to their participation it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who can act as a consultee?

Where people cannot take the decision to consent to be involved in a research project then a consultee must be appointed. A consultee can either be 'personal' or 'nominated'. A personal consultee is someone unconnected with the research who knows the potential research participant in a personal capacity and is able to advise on the person's wishes or feelings. This can be a friend, family member or court appointee. A 'nominated' consultee' is someone unconnected with the research, appointed by the researcher, to advise the researcher about the person's wishes and feeling in relation to the project. This can be another health-care worker but they must not have any connection with the study. Before a nominated consultee is appointed, the researcher will take all reasonable steps to identify a personal consultee.

What is the role of the consultee?

The consultee advises the researcher on what the participant's wishes and feelings would be if they were able to consent for themselves, and on whether they should take part. The consultee does not give consent, only advice. The responsibility to decide whether the participant should be entered into the research lies ultimately with the researcher. Consultees will be provided with information about the research project and will be given the opportunity to discuss it and their role as consultee. All consultees must be able to understand their role and be willing to undertake it.

What is the purpose of the study?

We would like to learn more about calling out repetitively in the hospital. We want to find out why and how it happens, and how others react to it. We will do this by making observations and collecting information about people who call out in the hospital.

Why has my relative been chosen?

Your relative has been invited to take part because he/she has called out repetitively in the past 0-48 hours since his/her admission. We are inviting 30 participants like him/her to take part in this study.

Does my relative have to take part?

We would like you to think very carefully about whether or not this person would have wanted to join the study. If your opinion is that he/she would have decided to take part, you would be given this information sheet to keep and be asked to sign a declaration form indicating your view allowing your relative to participate in the study. If you later decide that he/she no longer wishes to take part, please inform us and he/she will be withdrawn from the study. You do not need to give a reason and it will not affect the standard of care your relative receives.

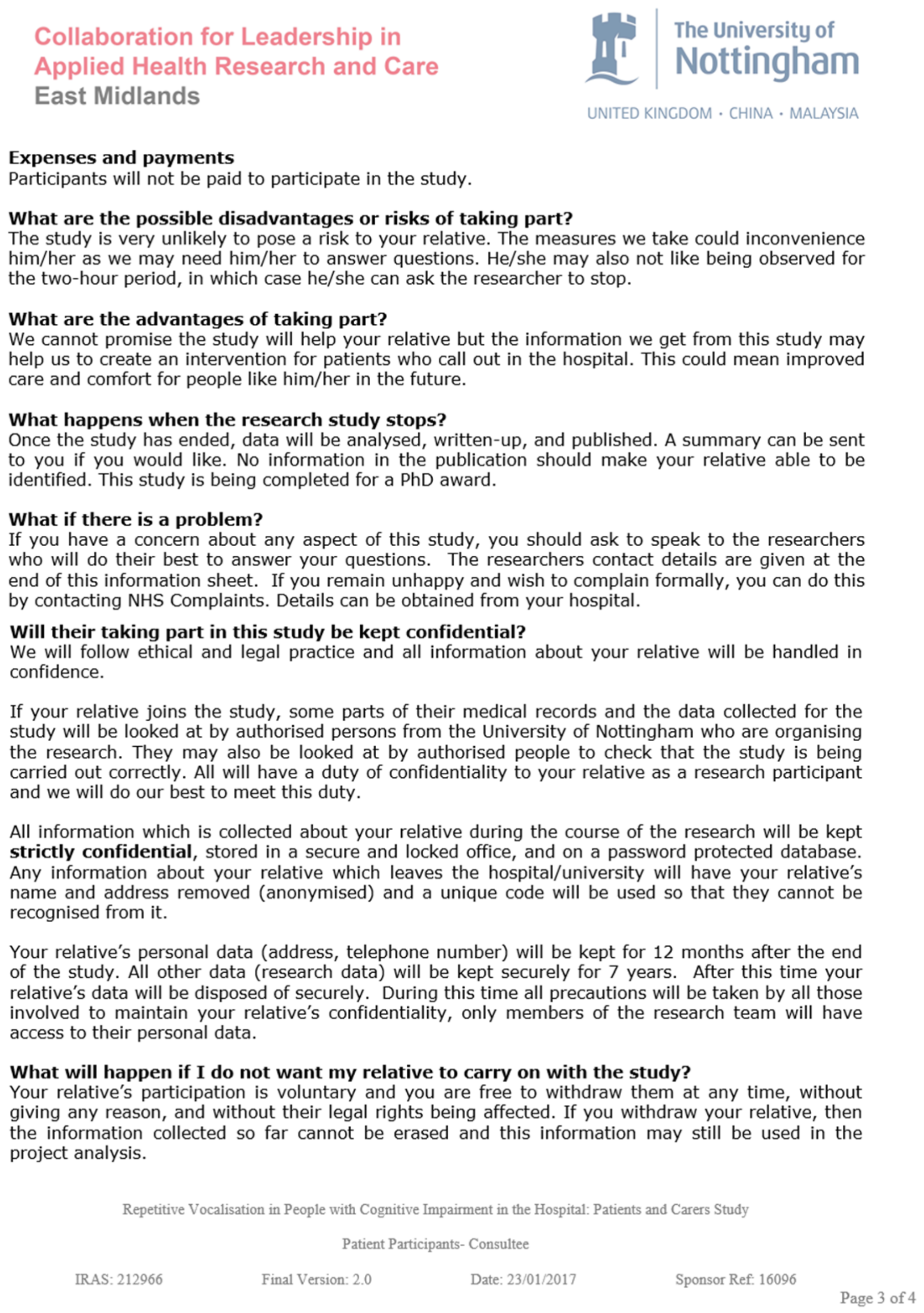
What will happen to my relative if they take part?

Information Gathering
We would like to collect some information about your relative. Most of the information will come from his/her medical notes, or from staff; however we may also ask him/her for clarification, or to give some answers to a questionnaire if he/she is able. Below is a table of information we would collect about your relative, and how we will collect it.

What we want to find out about	Who we will get the information from
How is his/her eyesight/hearing, does he/she use glasses or a hearing aid?	Medical notes, staff members, relatives/friends
How well can he/she do daily activities such as eating/ getting dressed?	Researcher interactions with you, medical notes, occupational health therapists
Is he/she feeling any pain?	Researcher/staff examination, medical notes
Does he/she have any mental health issues, such as anxiety or depression?	Interviews with relatives/friends, or a staff member who knows them best
Does he/she have any other health conditions, such as delirium?	Medical notes, staff members
His/her repetitive vocalisations, such as how frequent they are	Researcher observations, staff members
Demographics, such as age, gender, ethnicity, languages spoken	Medical notes, relatives/friends

Observation
We would also like to conduct one two-hour observation. This would be a two-hour observation of the bay your relative is situated, this will not be video recorded. A researcher will be taking notes of what happens during the observation period, but if he/she goes to the toilet, or he/she or another person pulls his/her privacy curtains shut, we will not observe this or take any notes. Short daily observations will also take place to collect information listed in the table above.

Follow-up
90 days after the date of your relatives admission into hospital, we will contact a family member/carer/friend to find out how he/she is doing. We will record where he/she got discharged to (own home/care home etc.), whether he/she has had any more readmissions into hospital, and if he/she still calls out. Once this final follow-up stage is complete, he/she will no longer be a participant in this study.



Expenses and payments
Participants will not be paid to participate in the study.

What are the possible disadvantages or risks of taking part?
The study is very unlikely to pose a risk to your relative. The measures we take could inconvenience him/her as we may need him/her to answer questions. He/she may also not like being observed for the two-hour period, in which case he/she can ask the researcher to stop.

What are the advantages of taking part?
We cannot promise the study will help your relative but the information we get from this study may help us to create an intervention for patients who call out in the hospital. This could mean improved care and comfort for people like him/her in the future.

What happens when the research study stops?
Once the study has ended, data will be analysed, written-up, and published. A summary can be sent to you if you would like. No information in the publication should make your relative able to be identified. This study is being completed for a PhD award.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints. Details can be obtained from your hospital.

Will their taking part in this study be kept confidential?
We will follow ethical and legal practice and all information about your relative will be handled in confidence.

If your relative joins the study, some parts of their medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to your relative as a research participant and we will do our best to meet this duty.

All information which is collected about your relative during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about your relative which leaves the hospital/university will have your relative's name and address removed (anonymised) and a unique code will be used so that they cannot be recognised from it.

Your relative's personal data (address, telephone number) will be kept for 12 months after the end of the study. All other data (research data) will be kept securely for 7 years. After this time your relative's data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your relative's confidentiality, only members of the research team will have access to their personal data.

What will happen if I do not want my relative to carry on with the study?
Your relative's participation is voluntary and you are free to withdraw them at any time, without giving any reason, and without their legal rights being affected. If you withdraw your relative, then the information collected so far cannot be erased and this information may still be used in the project analysis.

Appendix D Participant Information Sheet for Consultees- page 4 of 4

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Involvement of the General Practitioner/Family doctor (GP)
Your relative's GP will not be informed of his/her participation unless a situation arises in which the research team believe it to be essential that the GP knows.

What will happen to the results of the study?
Once the study has ended, data will be analysed, written-up, and published. A summary can be sent to you if you would like. No information in the publication should make your relative able to be identified. This study is being completed for a PhD award.

Who is organising and funding the research?
This research is being organised by the University of Nottingham and is being funded by the University of Nottingham and the Collaboration for Leadership in Applied Health Research and Care (CLAHRC).

Who has reviewed this study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect participant's interests. This study has been reviewed and given favourable opinion by Yorkshire & The Humber- Bradford Leeds Research Ethics Committee.

Further information and contact details

Chief investigator:

Dr Sarah Goldberg
Associate Professor
C Floor, School of Health Sciences
Queen's Medical Centre
Nottingham
0115 8230543
Sarah.Goldberg@nottingham.ac.uk

Co-investigators:

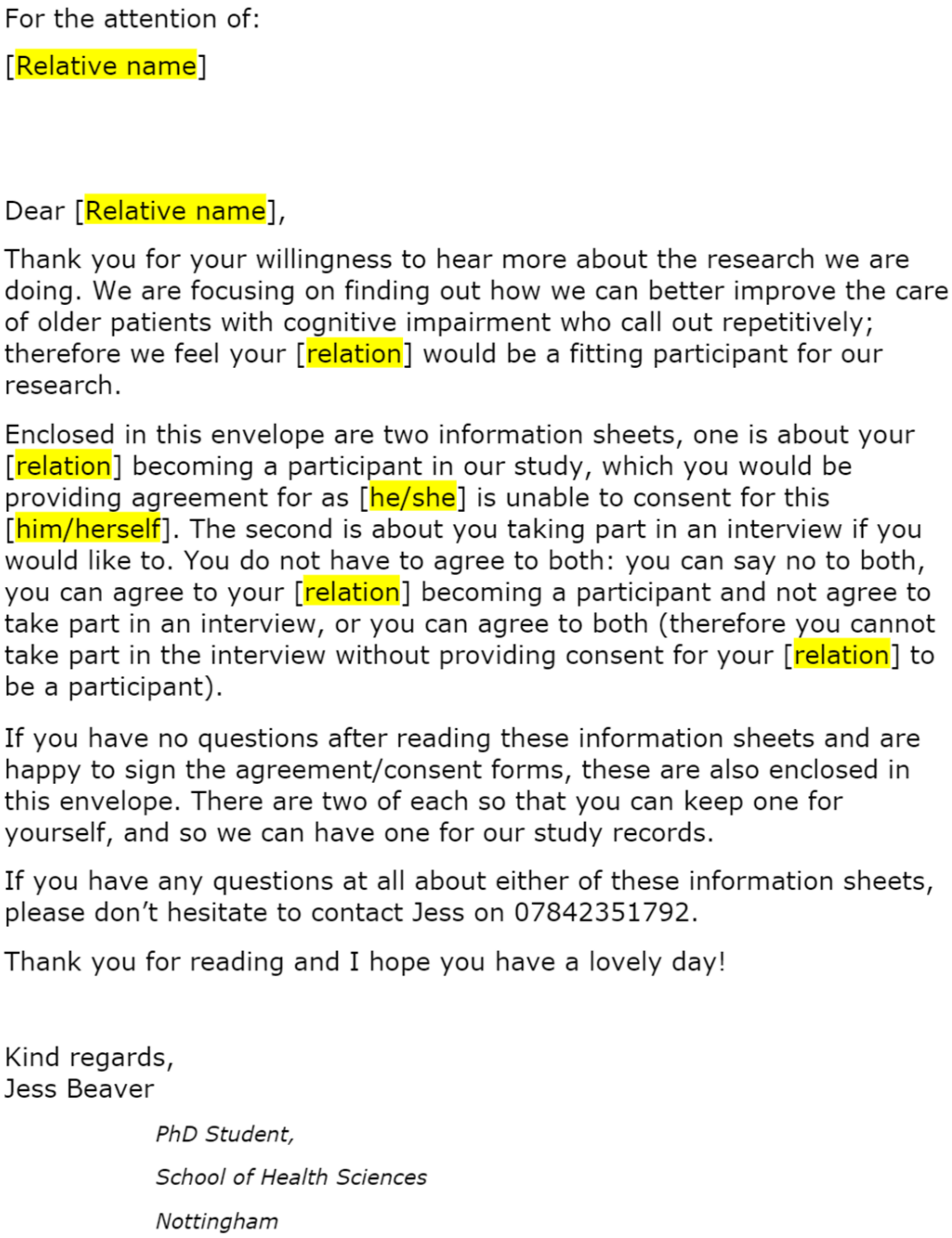
Jessica Beaver
PhD Student
B Floor, School of Health Sciences
Nottingham
07842351792
Jessica.Beaver@nottingham.ac.uk

Professor Rowan Harwood
Consultant Geriatrician
B Floor, Queen's Medical Centre
Nottingham
Rowan.Harwood@nuh.nhs.uk

Study Coordinating Centre: School of Health Sciences
University of Nottingham

Thank you for reading this

Appendix E Cover Letter for PIS and Advice Form



For the attention of:

[Relative name]

Dear [Relative name],

Thank you for your willingness to hear more about the research we are doing. We are focusing on finding out how we can better improve the care of older patients with cognitive impairment who call out repetitively; therefore we feel your [relation] would be a fitting participant for our research.

Enclosed in this envelope are two information sheets, one is about your [relation] becoming a participant in our study, which you would be providing agreement for as [he/she] is unable to consent for this [him/herself]. The second is about you taking part in an interview if you would like to. You do not have to agree to both: you can say no to both, you can agree to your [relation] becoming a participant and not agree to take part in an interview, or you can agree to both (therefore you cannot take part in the interview without providing consent for your [relation] to be a participant).

If you have no questions after reading these information sheets and are happy to sign the agreement/consent forms, these are also enclosed in this envelope. There are two of each so that you can keep one for yourself, and so we can have one for our study records.

If you have any questions at all about either of these information sheets, please don't hesitate to contact Jess on 07842351792.

Thank you for reading and I hope you have a lovely day!

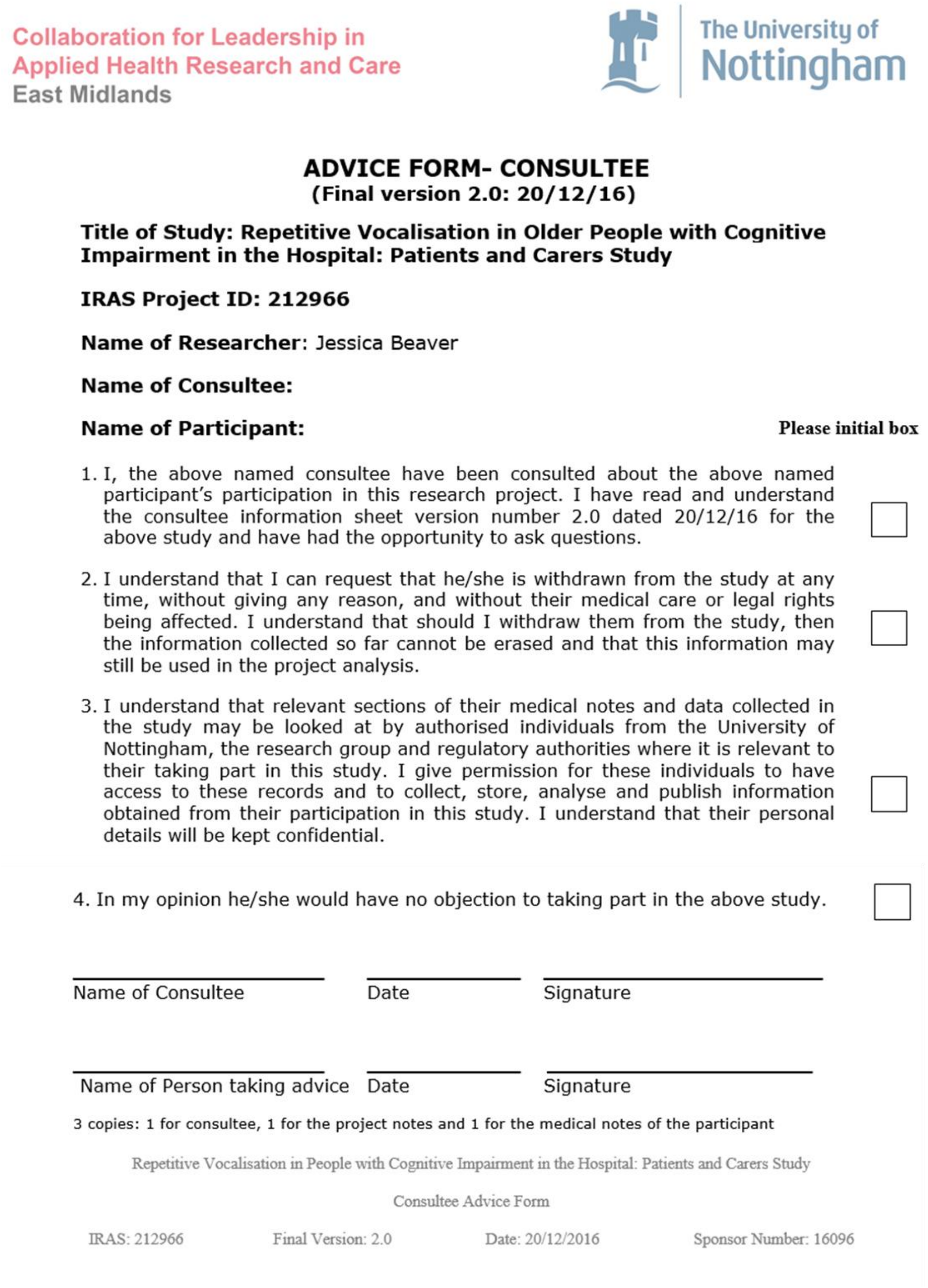
Kind regards,
Jess Beaver

PhD Student,

School of Health Sciences

Nottingham

Appendix F Consultee Advice Form



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ADVICE FORM- CONSULTEE
(Final version 2.0: 20/12/16)

Title of Study: Repetitive Vocalisation in Older People with Cognitive Impairment in the Hospital: Patients and Carers Study

IRAS Project ID: 212966

Name of Researcher: Jessica Beaver

Name of Consultee:

Name of Participant: **Please initial box**

1. I, the above named consultee have been consulted about the above named participant's participation in this research project. I have read and understand the consultee information sheet version number 2.0 dated 20/12/16 for the above study and have had the opportunity to ask questions. ☐
2. I understand that I can request that he/she is withdrawn from the study at any time, without giving any reason, and without their medical care or legal rights being affected. I understand that should I withdraw them from the study, then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of their medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to their taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from their participation in this study. I understand that their personal details will be kept confidential. ☐
4. In my opinion he/she would have no objection to taking part in the above study. ☐

Name of Consultee ______ Date ______ Signature ______

Name of Person taking advice ______ Date ______ Signature ______

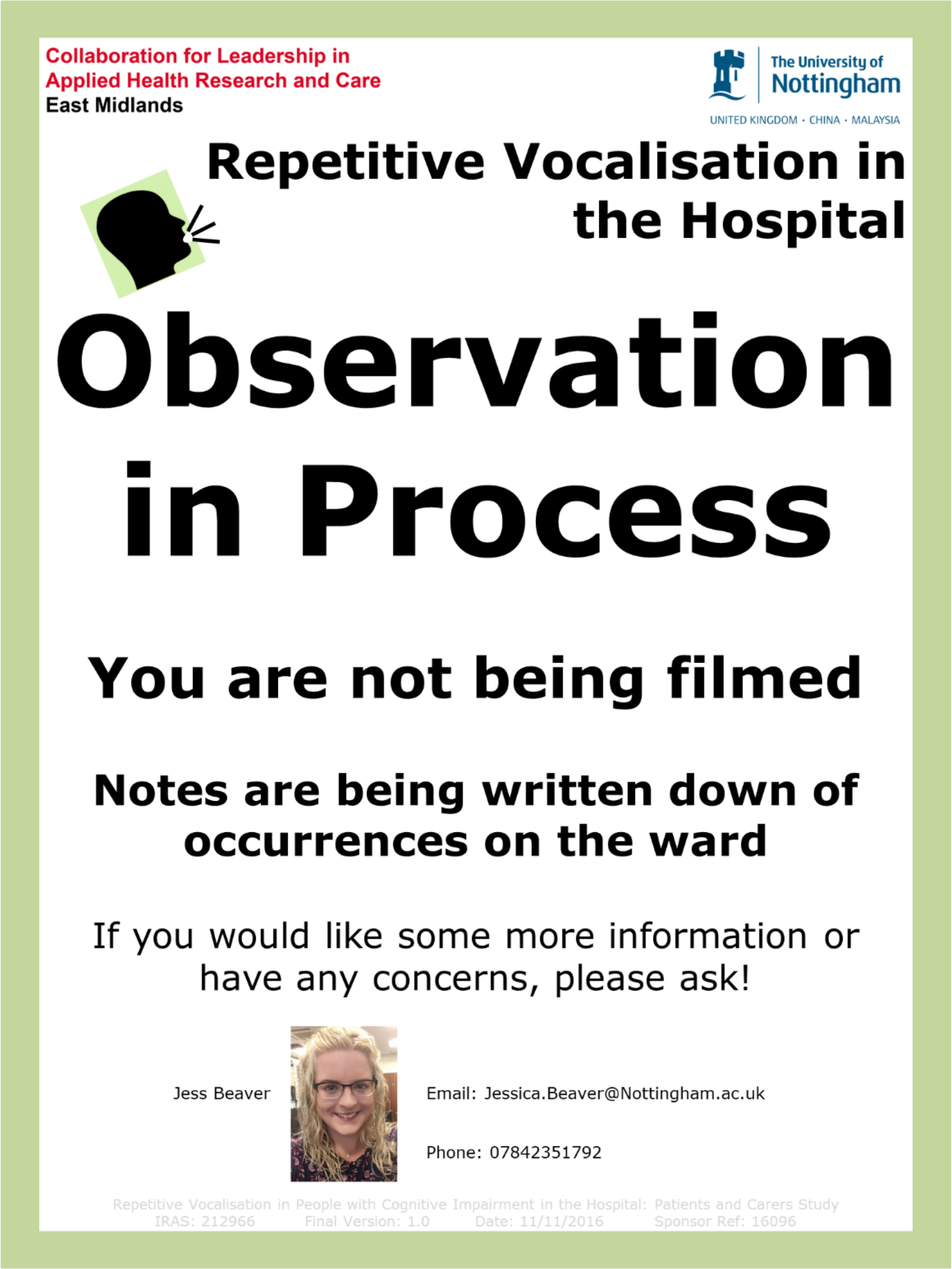
3 copies: 1 for consultee, 1 for the project notes and 1 for the medical notes of the participant

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study

Consultee Advice Form

IRAS: 212966 Final Version: 2.0 Date: 20/12/2016 Sponsor Number: 16096

Appendix G Observations Poster



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Repetitive Vocalisation in the Hospital

Observation in Process

You are not being filmed

Notes are being written down of occurrences on the ward

If you would like some more information or have any concerns, please ask!

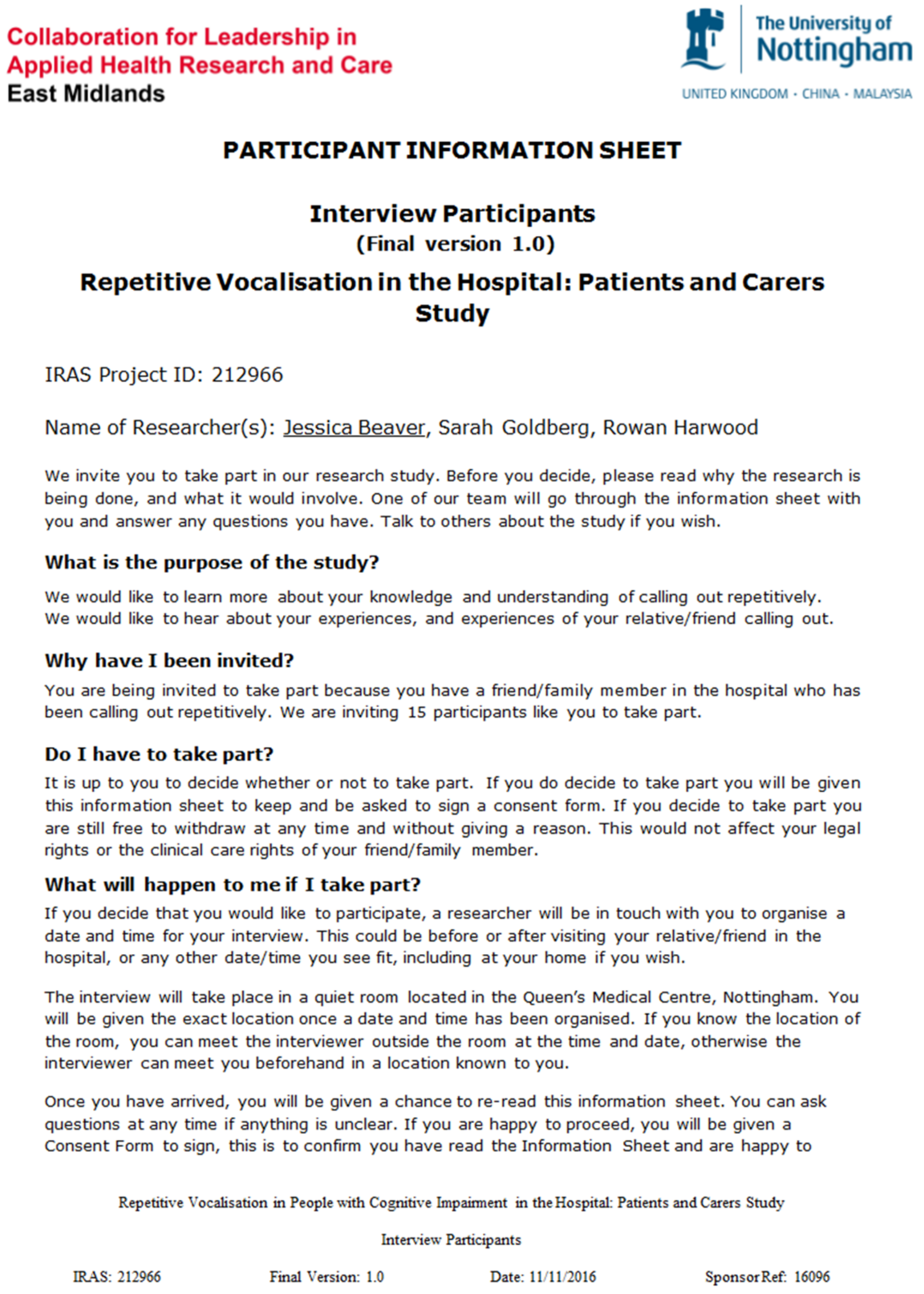
Jess Beaver

Email: Jessica.Beaver@Nottingham.ac.uk

Phone: 07842351792

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study
IRAS: 212966 Final Version: 1.0 Date: 11/11/2016 Sponsor Ref: 16096

Appendix H Participant Information Sheet for Relatives- page 1 of 4



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PARTICIPANT INFORMATION SHEET

Interview Participants

(Final version 1.0)

Repetitive Vocalisation in the Hospital: Patients and Carers Study

IRAS Project ID: 212966

Name of Researcher(s): Jessica Beaver, Sarah Goldberg, Rowan Harwood

We invite you to take part in our research study. Before you decide, please read why the research is being done, and what it would involve. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish.

What is the purpose of the study?

We would like to learn more about your knowledge and understanding of calling out repetitively. We would like to hear about your experiences, and experiences of your relative/friend calling out.

Why have I been invited?

You are being invited to take part because you have a friend/family member in the hospital who has been calling out repetitively. We are inviting 15 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or the clinical care rights of your friend/family member.

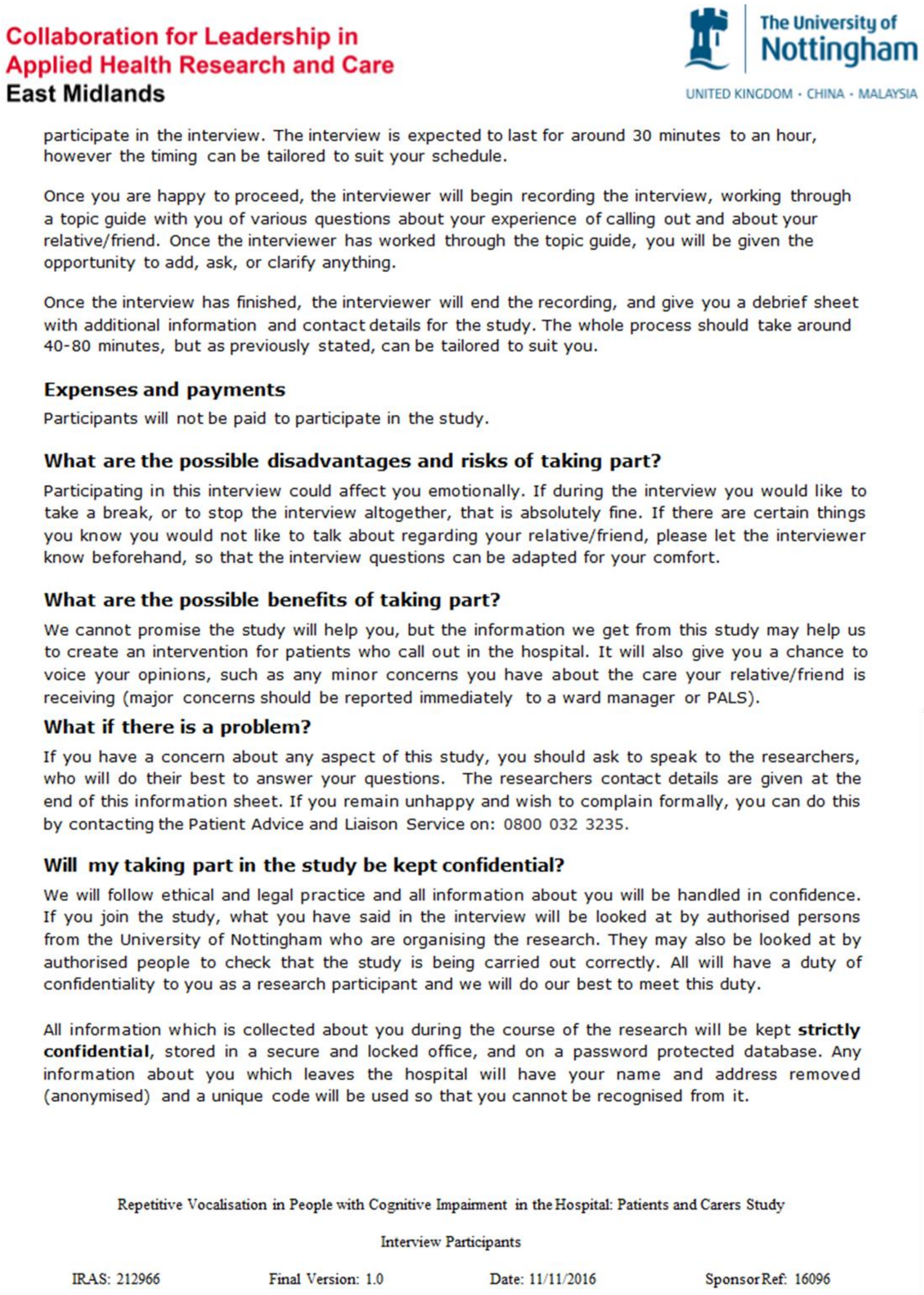
What will happen to me if I take part?

If you decide that you would like to participate, a researcher will be in touch with you to organise a date and time for your interview. This could be before or after visiting your relative/friend in the hospital, or any other date/time you see fit, including at your home if you wish.

The interview will take place in a quiet room located in the Queen's Medical Centre, Nottingham. You will be given the exact location once a date and time has been organised. If you know the location of the room, you can meet the interviewer outside the room at the time and date, otherwise the interviewer can meet you beforehand in a location known to you.

Once you have arrived, you will be given a chance to re-read this information sheet. You can ask questions at any time if anything is unclear. If you are happy to proceed, you will be given a Consent Form to sign, this is to confirm you have read the Information Sheet and are happy to

Appendix H Participant Information Sheet for Relatives- page 2 of 4



participate in the interview. The interview is expected to last for around 30 minutes to an hour, however the timing can be tailored to suit your schedule.

Once you are happy to proceed, the interviewer will begin recording the interview, working through a topic guide with you of various questions about your experience of calling out and about your relative/friend. Once the interviewer has worked through the topic guide, you will be given the opportunity to add, ask, or clarify anything.

Once the interview has finished, the interviewer will end the recording, and give you a debrief sheet with additional information and contact details for the study. The whole process should take around 40-80 minutes, but as previously stated, can be tailored to suit you.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

Participating in this interview could affect you emotionally. If during the interview you would like to take a break, or to stop the interview altogether, that is absolutely fine. If there are certain things you know you would not like to talk about regarding your relative/friend, please let the interviewer know beforehand, so that the interview questions can be adapted for your comfort.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study may help us to create an intervention for patients who call out in the hospital. It will also give you a chance to voice your opinions, such as any minor concerns you have about the care your relative/friend is receiving (major concerns should be reported immediately to a ward manager or PALS).

What if there is a problem?

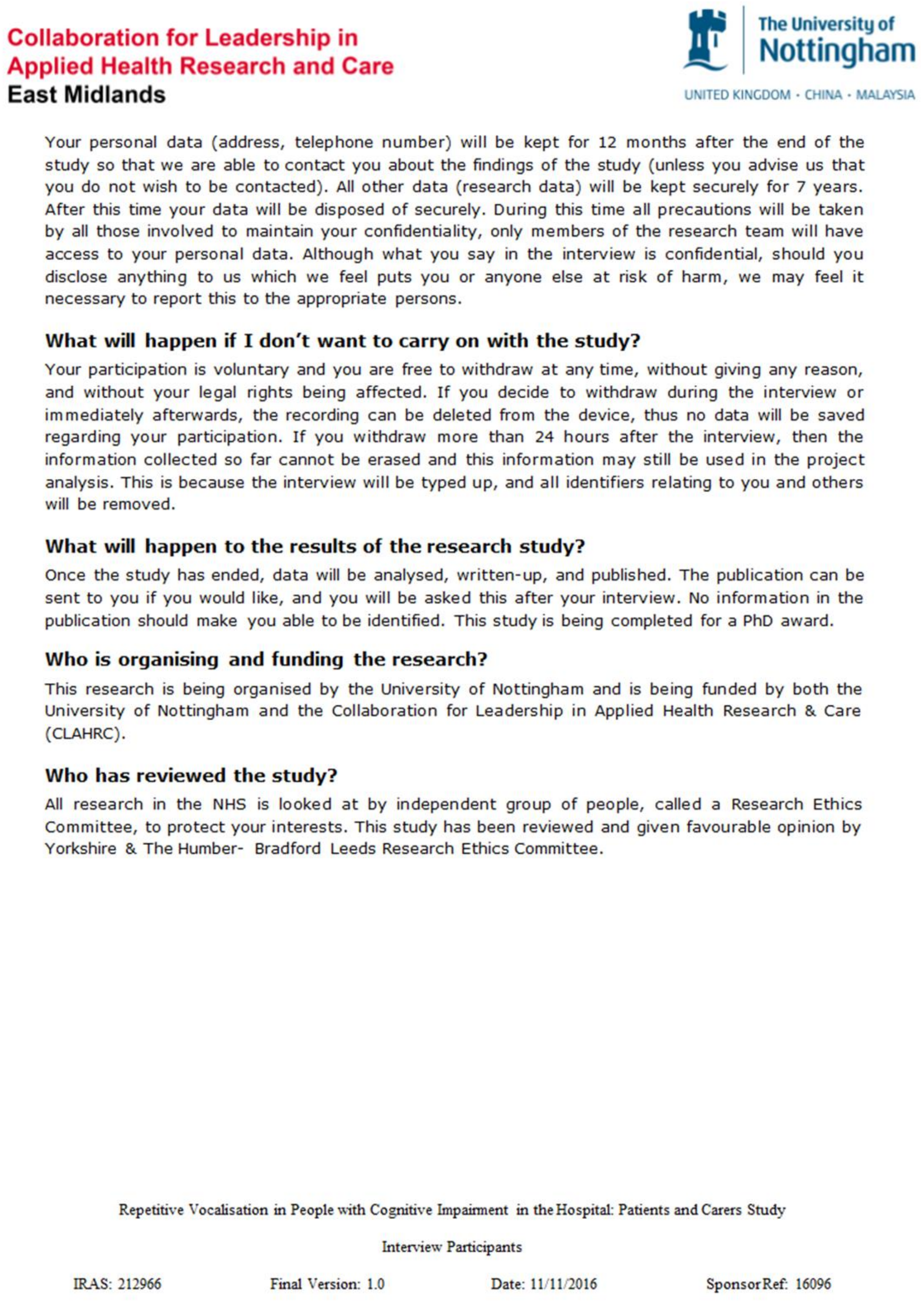
If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service on: 0800 032 3235.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, what you have said in the interview will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Appendix H Participant Information Sheet for Relatives- page 3 of 4



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Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data. Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at risk of harm, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you decide to withdraw during the interview or immediately afterwards, the recording can be deleted from the device, thus no data will be saved regarding your participation. If you withdraw more than 24 hours after the interview, then the information collected so far cannot be erased and this information may still be used in the project analysis. This is because the interview will be typed up, and all identifiers relating to you and others will be removed.

What will happen to the results of the research study?

Once the study has ended, data will be analysed, written-up, and published. The publication can be sent to you if you would like, and you will be asked this after your interview. No information in the publication should make you able to be identified. This study is being completed for a PhD award.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by both the University of Nottingham and the Collaboration for Leadership in Applied Health Research & Care (CLAHRC).

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Yorkshire & The Humber- Bradford Leeds Research Ethics Committee.

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study

Interview Participants

IRAS: 212966 Final Version: 1.0 Date: 11/11/2016 Sponsor Ref: 16096

Appendix H Participant Information Sheet for Relatives- page 4 of 4

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Further information and contact details

Chief investigator:

Dr Sarah Goldberg
Associate Professor
C Floor, School of Health Sciences
Queen's Medical Centre
Nottingham
0115 8230543
Sarah.Goldberg@nottingham.ac.uk

Co-investigators:

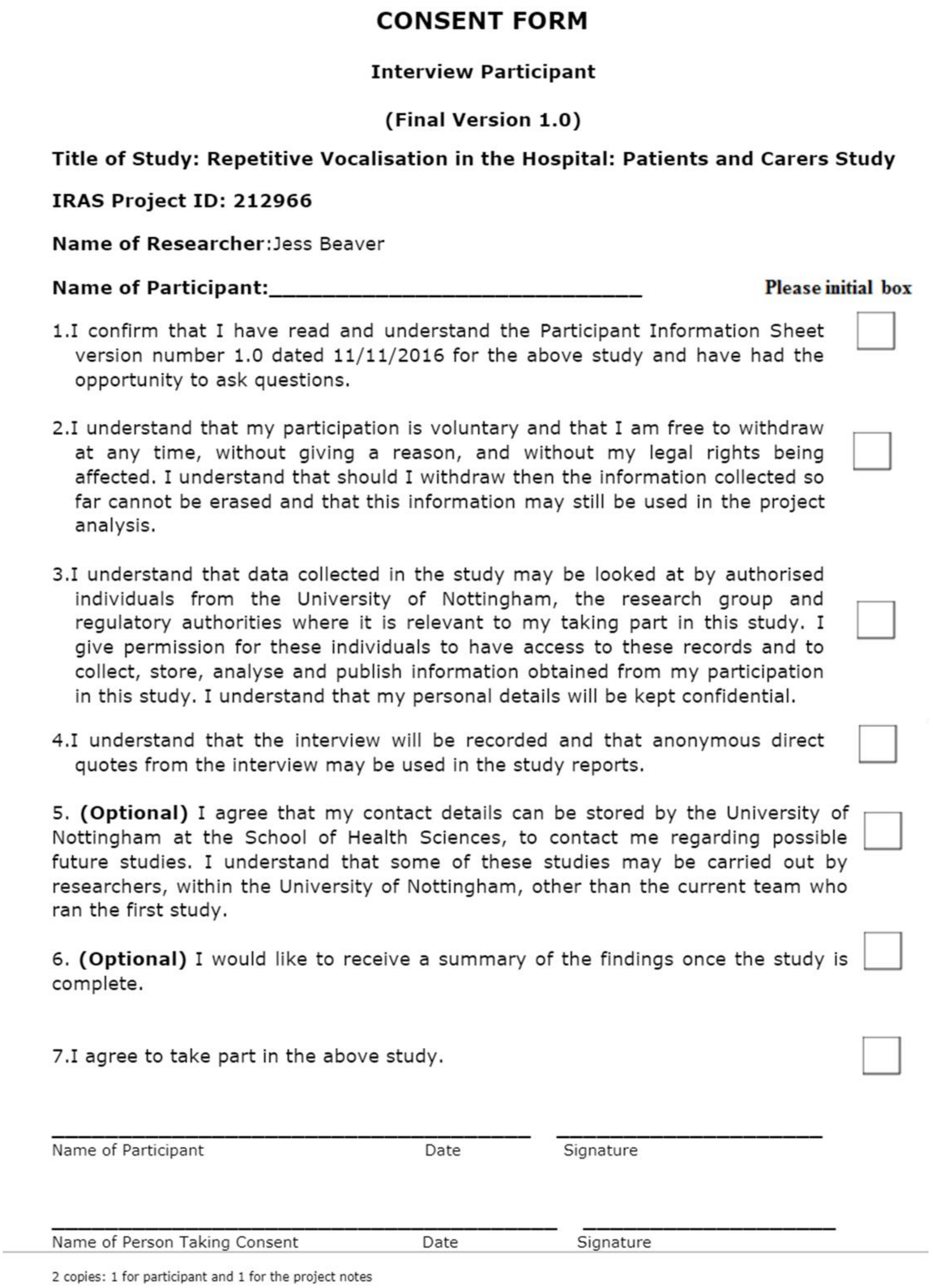
Jessica Beaver
PhD Student
B Floor, School of Health Sciences
Nottingham
07842351792
Jessica.Beaver@nottingham.ac.uk

Professor Rowan Harwood
Consultant Geriatrician
B Floor, Queen's Medical Centre
Nottingham
Rowan.Harwood@nuh.nhs.uk

Study Coordinating Centre:

School of Health Sciences
University of Nottingham

Appendix I Consent Form for Relatives



CONSENT FORM

Interview Participant

(Final Version 1.0)

Title of Study: Repetitive Vocalisation in the Hospital: Patients and Carers Study

IRAS Project ID: 212966

Name of Researcher:Jess Beaver

Name of Participant:______________________________ **Please initial box**

1.I confirm that I have read and understand the Participant Information Sheet version number 1.0 dated 11/11/2016 for the above study and have had the opportunity to ask questions. ☐

2.I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3.I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4.I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. **(Optional)** I agree that my contact details can be stored by the University of Nottingham at the School of Health Sciences, to contact me regarding possible future studies. I understand that some of these studies may be carried out by researchers, within the University of Nottingham, other than the current team who ran the first study. ☐

6. **(Optional)** I would like to receive a summary of the findings once the study is complete. ☐

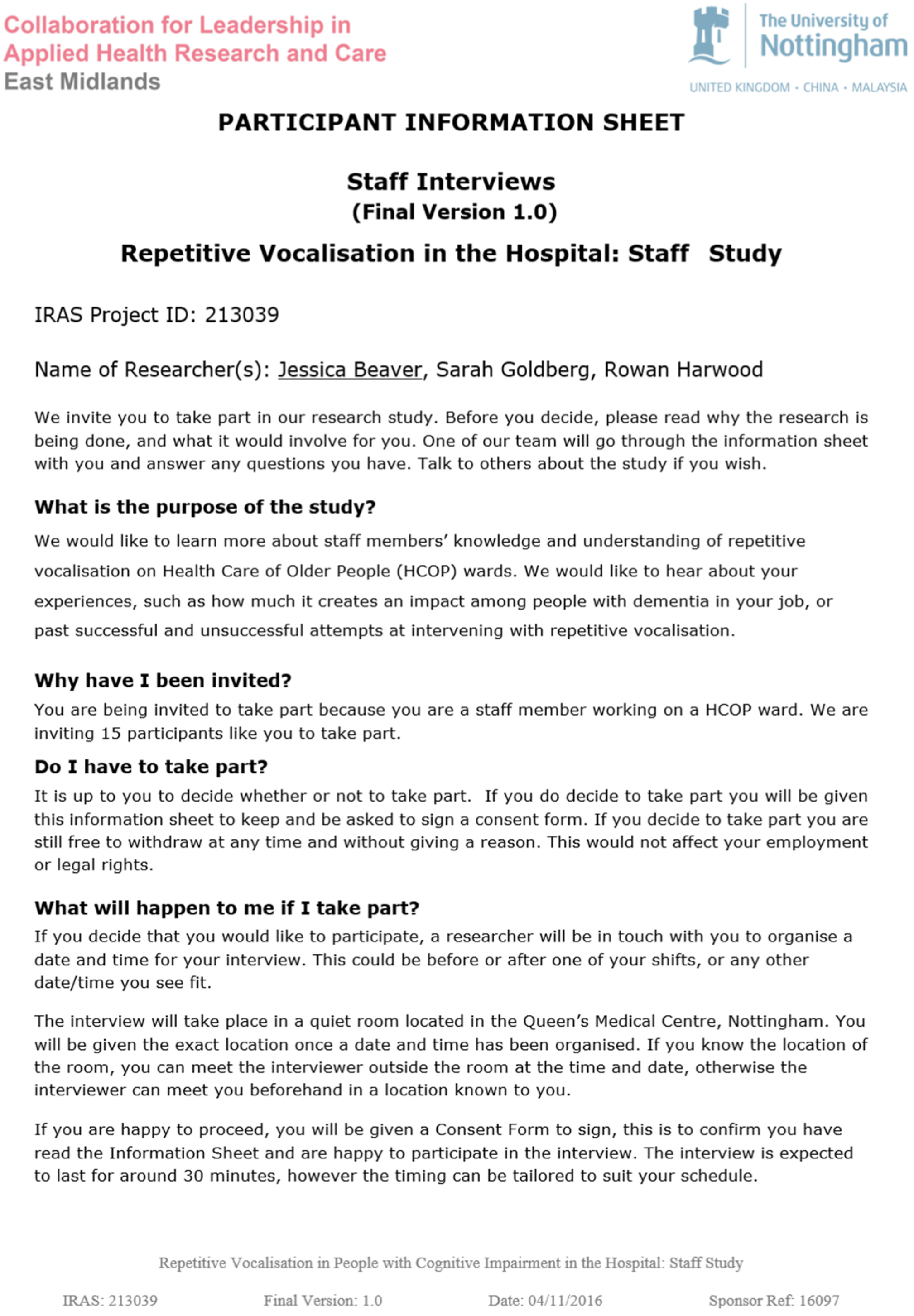
7.I agree to take part in the above study. ☐

______________________________________ ______________________
Name of Participant Date Signature

____ ______________________
Name of Person Taking Consent Date Signature

2 copies: 1 for participant and 1 for the project notes

Appendix J Participant Information Sheet for Staff- page 1 of 3



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PARTICIPANT INFORMATION SHEET

Staff Interviews

(Final Version 1.0)

Repetitive Vocalisation in the Hospital: Staff Study

IRAS Project ID: 213039

Name of Researcher(s): Jessica Beaver, Sarah Goldberg, Rowan Harwood

We invite you to take part in our research study. Before you decide, please read why the research is being done, and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish.

What is the purpose of the study?

We would like to learn more about staff members' knowledge and understanding of repetitive vocalisation on Health Care of Older People (HCOP) wards. We would like to hear about your experiences, such as how much it creates an impact among people with dementia in your job, or past successful and unsuccessful attempts at intervening with repetitive vocalisation.

Why have I been invited?

You are being invited to take part because you are a staff member working on a HCOP ward. We are inviting 15 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your employment or legal rights.

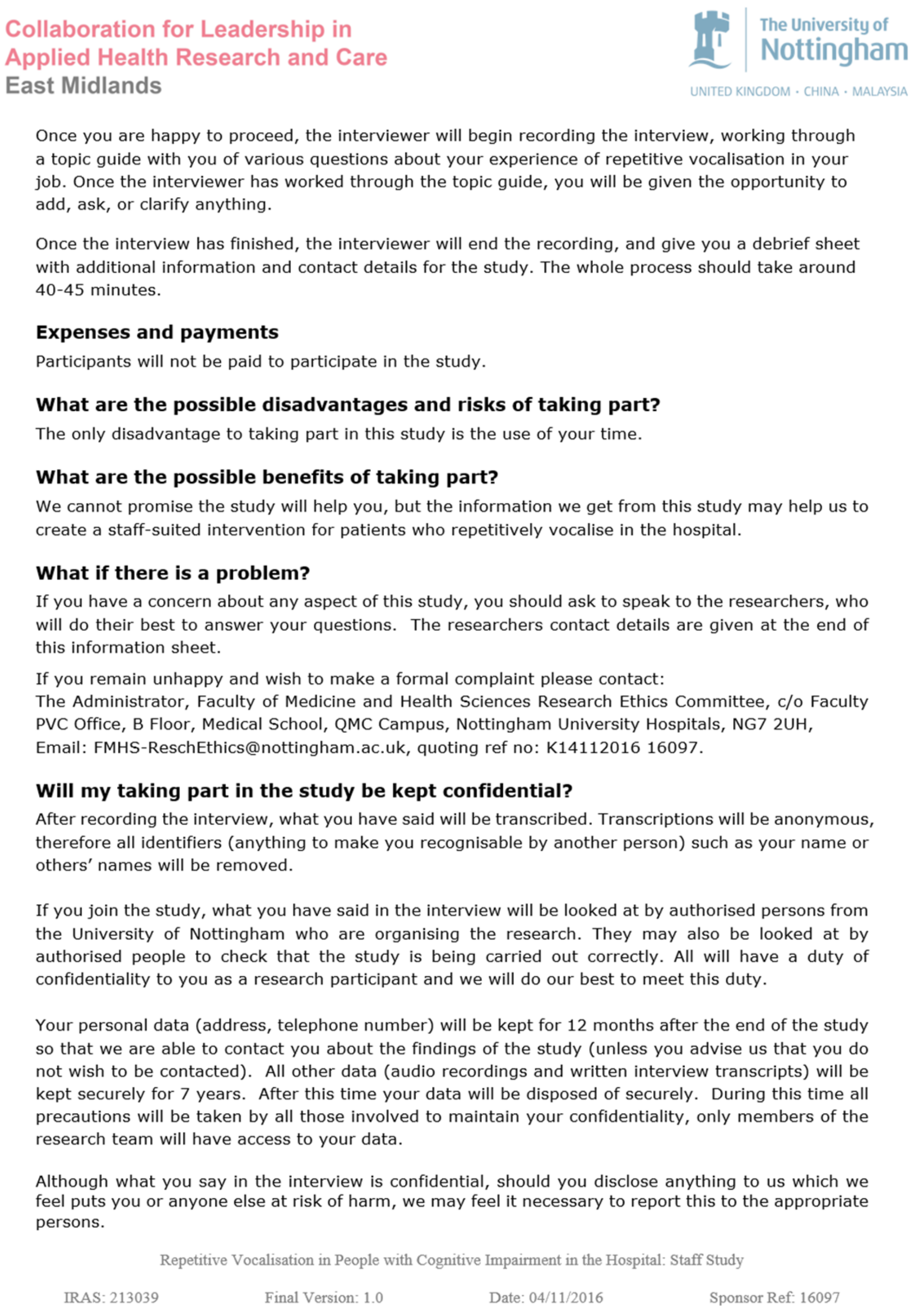
What will happen to me if I take part?

If you decide that you would like to participate, a researcher will be in touch with you to organise a date and time for your interview. This could be before or after one of your shifts, or any other date/time you see fit.

The interview will take place in a quiet room located in the Queen's Medical Centre, Nottingham. You will be given the exact location once a date and time has been organised. If you know the location of the room, you can meet the interviewer outside the room at the time and date, otherwise the interviewer can meet you beforehand in a location known to you.

If you are happy to proceed, you will be given a Consent Form to sign, this is to confirm you have read the Information Sheet and are happy to participate in the interview. The interview is expected to last for around 30 minutes, however the timing can be tailored to suit your schedule.

Appendix J Participant Information Sheet for Staff- page 2 of 3



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Once you are happy to proceed, the interviewer will begin recording the interview, working through a topic guide with you of various questions about your experience of repetitive vocalisation in your job. Once the interviewer has worked through the topic guide, you will be given the opportunity to add, ask, or clarify anything.

Once the interview has finished, the interviewer will end the recording, and give you a debrief sheet with additional information and contact details for the study. The whole process should take around 40-45 minutes.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

The only disadvantage to taking part in this study is the use of your time.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study may help us to create a staff-suited intervention for patients who repetitively vocalise in the hospital.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

If you remain unhappy and wish to make a formal complaint please contact:
The Administrator, Faculty of Medicine and Health Sciences Research Ethics Committee, c/o Faculty PVC Office, B Floor, Medical School, QMC Campus, Nottingham University Hospitals, NG7 2UH,
Email: FMHS-ReschEthics@nottingham.ac.uk, quoting ref no: K14112016 16097.

Will my taking part in the study be kept confidential?

After recording the interview, what you have said will be transcribed. Transcriptions will be anonymous, therefore all identifiers (anything to make you recognisable by another person) such as your name or others' names will be removed.

If you join the study, what you have said in the interview will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (audio recordings and written interview transcripts) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at risk of harm, we may feel it necessary to report this to the appropriate persons.

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Staff Study

IRAS: 213039 Final Version: 1.0 Date: 04/11/2016 Sponsor Ref: 16097

Appendix J Participant Information Sheet for Staff- page 3 of 3

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What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you decide to withdraw during the interview or immediately afterwards, the recording can be deleted from the device, thus no data will be saved regarding your participation. If you withdraw more than 24 hours after the interview, then the information collected so far cannot be erased and this information may still be used in the project analysis. This is because the interview will be typed up, and all identifiers relating to you and others will be removed.

What will happen to the results of the research study?

Once the study has ended, data will be analysed, written-up, and published. The publication can be sent to you if you would like, and you will be asked this after your interview. No information in the publication should make you able to be identified. This study is being completed for a PhD award.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by both the University of Nottingham and the Collaboration for Leadership in Applied Health Research & Care (CLAHRC).

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Faculty of Medicine and Health Sciences Research Ethics Committee, Ref no: K14112016 16097.

Further information and contact details

Chief investigator:

Dr Sarah Goldberg
Associate Professor
C Floor, School of Health Sciences
Queen's Medical Centre
Nottingham
0115 8230543
Sarah.Goldberg@nottingham.ac.uk

Co-investigators:

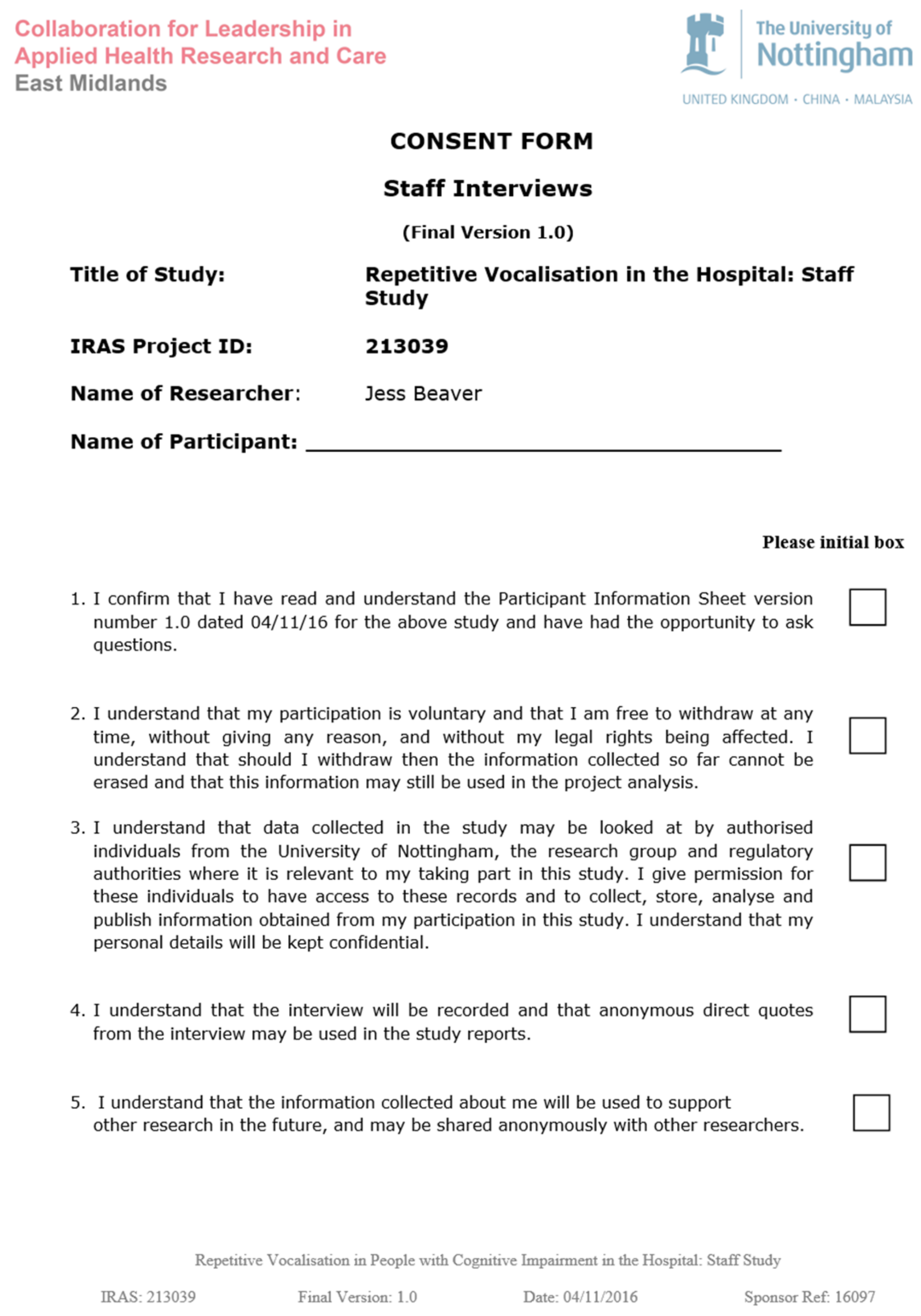
Jessica Beaver
PhD Student
B Floor, School of Health Sciences
Nottingham
07920499757
Jessica.Beaver@nottingham.ac.uk

Professor Rowan Harwood
Consultant Geriatrician
B Floor, Queen's Medical Centre
Nottingham
Rowan.Harwood@nuh.nhs.uk

Study Coordinating Centre:

School of Health Sciences
University of Nottingham

Appendix K Consent Form for Staff- page 1 of 2



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CONSENT FORM

Staff Interviews

(Final Version 1.0)

Title of Study: **Repetitive Vocalisation in the Hospital: Staff Study**

IRAS Project ID: **213039**

Name of Researcher: Jess Beaver

Name of Participant: ______________________________

Please initial box

1. I confirm that I have read and understand the Participant Information Sheet version number 1.0 dated 04/11/16 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

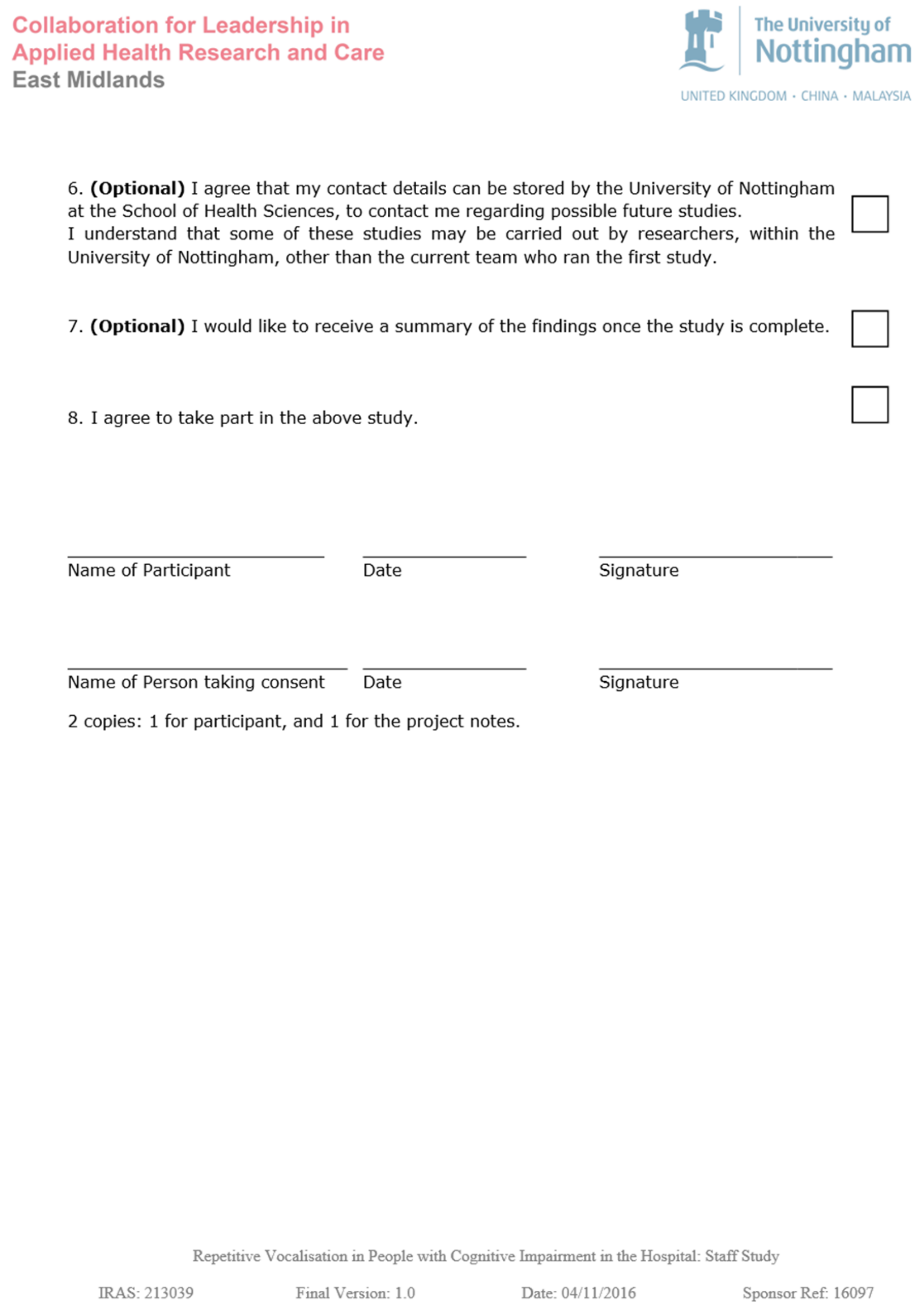
4. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Staff Study

IRAS: 213039 Final Version: 1.0 Date: 04/11/2016 Sponsor Ref: 16097

Appendix K Consent Form for Staff- page 2 of 2



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6. **(Optional)** I agree that my contact details can be stored by the University of Nottingham at the School of Health Sciences, to contact me regarding possible future studies. I understand that some of these studies may be carried out by researchers, within the University of Nottingham, other than the current team who ran the first study. ☐

7. **(Optional)** I would like to receive a summary of the findings once the study is complete. ☐

8. I agree to take part in the above study. ☐

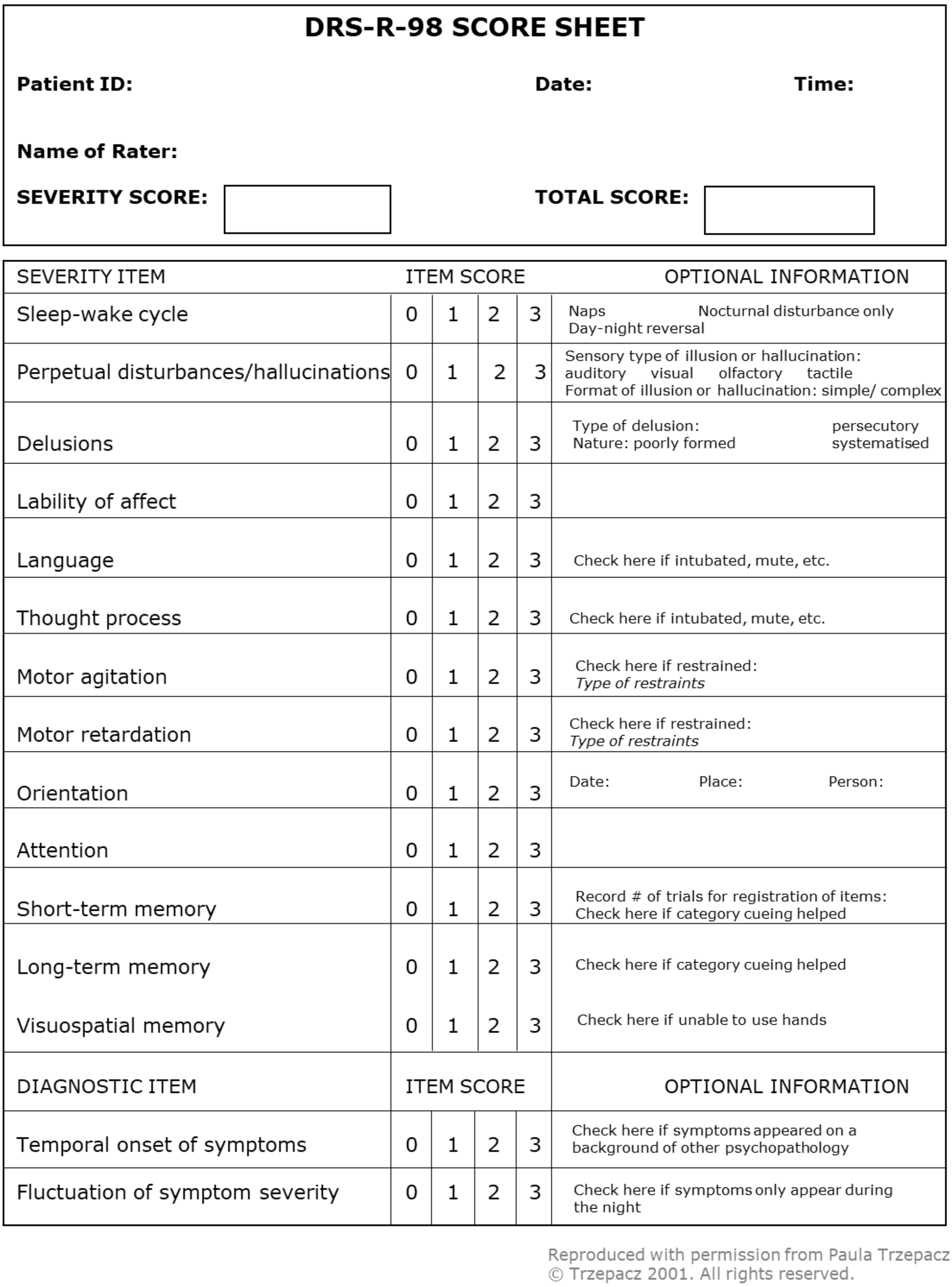
Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, and 1 for the project notes.

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Staff Study

IRAS: 213039 Final Version: 1.0 Date: 04/11/2016 Sponsor Ref: 16097

Appendix L The Delirium Rating Scale-Revised-98 (DRS-R-98; Trzepacz et al. 2001) study score sheet



DRS-R-98 SCORE SHEET

Patient ID: **Date:** **Time:**

Name of Rater:

SEVERITY SCORE: ☐ **TOTAL SCORE:** ☐

SEVERITY ITEM	ITEM SCORE				OPTIONAL INFORMATION
Sleep-wake cycle	0	1	2	3	Naps Nocturnal disturbance only Day-night reversal
Perpetual disturbances/hallucinations	0	1	2	3	Sensory type of illusion or hallucination: auditory visual olfactory tactile Format of illusion or hallucination: simple/ complex
Delusions	0	1	2	3	Type of delusion: persecutory Nature: poorly formed systematised
Lability of affect	0	1	2	3	
Language	0	1	2	3	Check here if intubated, mute, etc.
Thought process	0	1	2	3	Check here if intubated, mute, etc.
Motor agitation	0	1	2	3	Check here if restrained: *Type of restraints*
Motor retardation	0	1	2	3	Check here if restrained: *Type of restraints*
Orientation	0	1	2	3	Date: Place: Person:
Attention	0	1	2	3	
Short-term memory	0	1	2	3	Record # of trials for registration of items: Check here if category cueing helped
Long-term memory	0	1	2	3	Check here if category cueing helped
Visuospatial memory	0	1	2	3	Check here if unable to use hands
DIAGNOSTIC ITEM	ITEM SCORE				OPTIONAL INFORMATION
Temporal onset of symptoms	0	1	2	3	Check here if symptoms appeared on a background of other psychopathology
Fluctuation of symptom severity	0	1	2	3	Check here if symptoms only appear during the night

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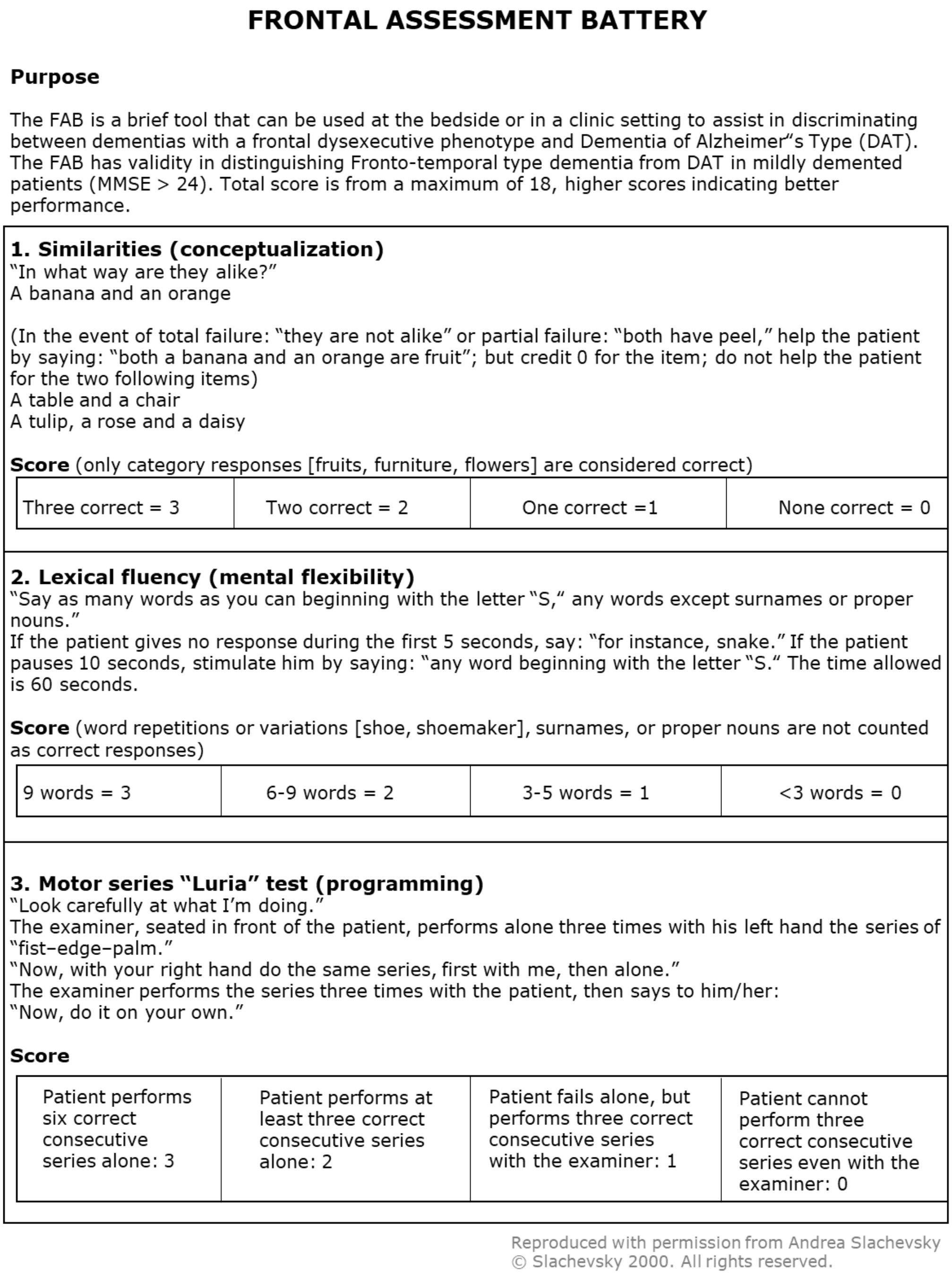
__Appendix M__ The Frontal Assessment Battery (FAB; Dubois et al. 2000)- page 1 of 2



FRONTAL ASSESSMENT BATTERY

Purpose

The FAB is a brief tool that can be used at the bedside or in a clinic setting to assist in discriminating between dementias with a frontal dysexecutive phenotype and Dementia of Alzheimer“s Type (DAT). The FAB has validity in distinguishing Fronto-temporal type dementia from DAT in mildly demented patients (MMSE > 24). Total score is from a maximum of 18, higher scores indicating better performance.

1. Similarities (conceptualization)
“In what way are they alike?”
A banana and an orange

(In the event of total failure: “they are not alike” or partial failure: “both have peel,” help the patient by saying: “both a banana and an orange are fruit”; but credit 0 for the item; do not help the patient for the two following items)
A table and a chair
A tulip, a rose and a daisy

Score (only category responses [fruits, furniture, flowers] are considered correct)

Three correct = 3	Two correct = 2	One correct =1	None correct = 0

2. Lexical fluency (mental flexibility)
“Say as many words as you can beginning with the letter “S,“ any words except surnames or proper nouns.”
If the patient gives no response during the first 5 seconds, say: “for instance, snake.” If the patient pauses 10 seconds, stimulate him by saying: “any word beginning with the letter “S.“ The time allowed is 60 seconds.

Score (word repetitions or variations [shoe, shoemaker], surnames, or proper nouns are not counted as correct responses)

9 words = 3	6-9 words = 2	3-5 words = 1	<3 words = 0

3. Motor series “Luria” test (programming)
“Look carefully at what I’m doing.”
The examiner, seated in front of the patient, performs alone three times with his left hand the series of “fist–edge–palm.”
“Now, with your right hand do the same series, first with me, then alone.”
The examiner performs the series three times with the patient, then says to him/her:
“Now, do it on your own.”

Score

Patient performs six correct consecutive series alone: 3	Patient performs at least three correct consecutive series alone: 2	Patient fails alone, but performs three correct consecutive series with the examiner: 1	Patient cannot perform three correct consecutive series even with the examiner: 0

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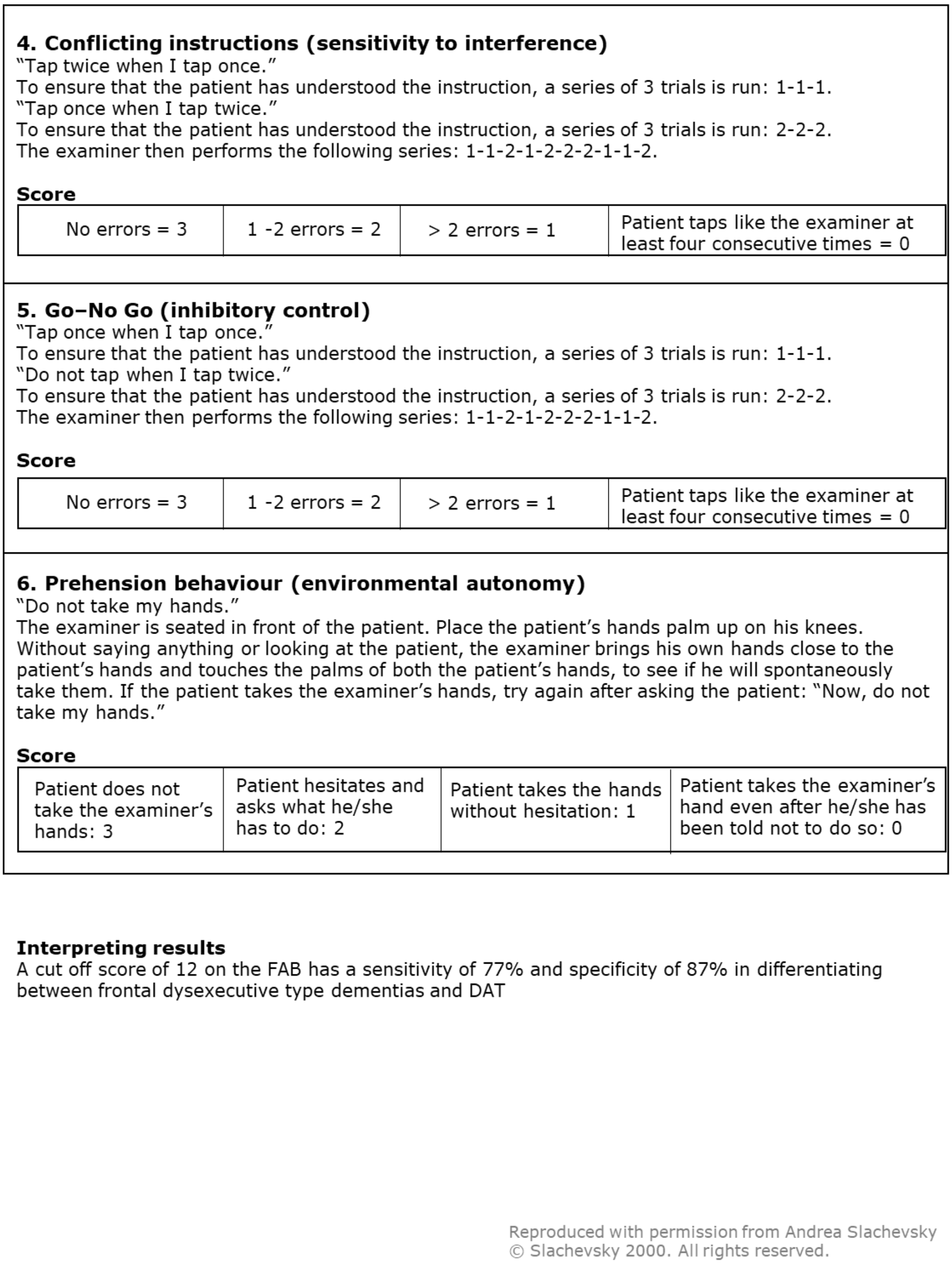
Appendix M The Frontal Assessment Battery (FAB; Dubois et al. 2000)- page 2 of 2



4. Conflicting instructions (sensitivity to interference)
"Tap twice when I tap once."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 1-1-1.
"Tap once when I tap twice."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 2-2-2.
The examiner then performs the following series: 1-1-2-1-2-2-2-1-1-2.

Score

No errors = 3	1 -2 errors = 2	> 2 errors = 1	Patient taps like the examiner at least four consecutive times = 0

5. Go–No Go (inhibitory control)
"Tap once when I tap once."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 1-1-1.
"Do not tap when I tap twice."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 2-2-2.
The examiner then performs the following series: 1-1-2-1-2-2-2-1-1-2.

Score

No errors = 3	1 -2 errors = 2	> 2 errors = 1	Patient taps like the examiner at least four consecutive times = 0

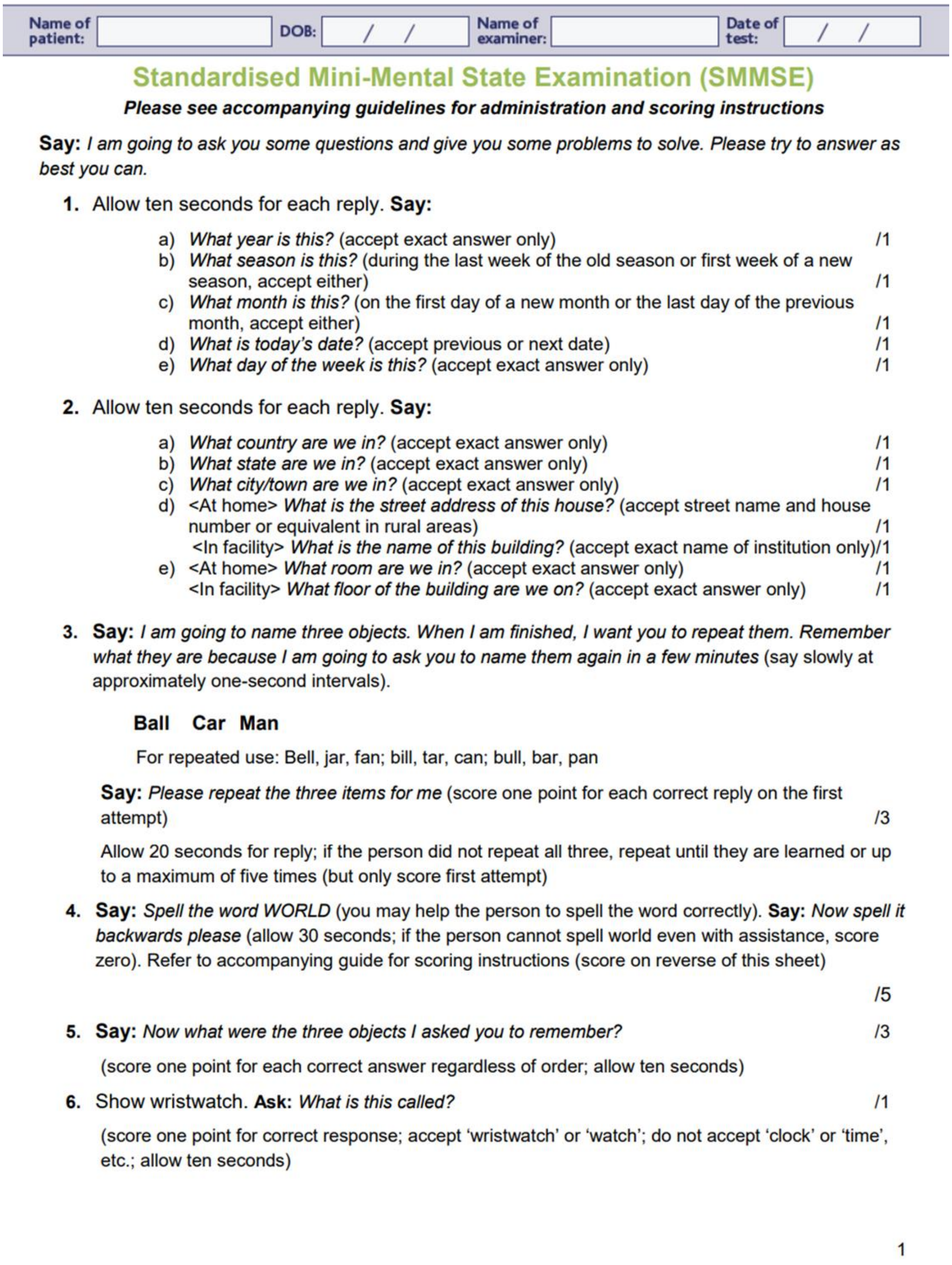
6. Prehension behaviour (environmental autonomy)
"Do not take my hands."
The examiner is seated in front of the patient. Place the patient's hands palm up on his knees. Without saying anything or looking at the patient, the examiner brings his own hands close to the patient's hands and touches the palms of both the patient's hands, to see if he will spontaneously take them. If the patient takes the examiner's hands, try again after asking the patient: "Now, do not take my hands."

Score

Patient does not take the examiner's hands: 3	Patient hesitates and asks what he/she has to do: 2	Patient takes the hands without hesitation: 1	Patient takes the examiner's hand even after he/she has been told not to do so: 0

Interpreting results
A cut off score of 12 on the FAB has a sensitivity of 77% and specificity of 87% in differentiating between frontal dysexecutive type dementias and DAT

Appendix N The Standardised Mini-Mental State Examination (sMMSE; Molloy and Clarnette, 1999)- page 1 of 3



Name of patient:		**DOB:**	/ /	**Name of examiner:**		**Date of test:**	/ /

Standardised Mini-Mental State Examination (SMMSE)

Please see accompanying guidelines for administration and scoring instructions

Say: *I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can.*

1. Allow ten seconds for each reply. **Say:**

a) *What year is this?* (accept exact answer only) /1
b) *What season is this?* (during the last week of the old season or first week of a new season, accept either) /1
c) *What month is this?* (on the first day of a new month or the last day of the previous month, accept either) /1
d) *What is today's date?* (accept previous or next date) /1
e) *What day of the week is this?* (accept exact answer only) /1

2. Allow ten seconds for each reply. **Say:**

a) *What country are we in?* (accept exact answer only) /1
b) *What state are we in?* (accept exact answer only) /1
c) *What city/town are we in?* (accept exact answer only) /1
d) <At home> *What is the street address of this house?* (accept street name and house number or equivalent in rural areas) /1
<In facility> *What is the name of this building?* (accept exact name of institution only) /1
e) <At home> *What room are we in?* (accept exact answer only) /1
<In facility> *What floor of the building are we on?* (accept exact answer only) /1

3. **Say:** *I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes* (say slowly at approximately one-second intervals).

Ball Car Man

For repeated use: Bell, jar, fan; bill, tar, can; bull, bar, pan

Say: *Please repeat the three items for me* (score one point for each correct reply on the first attempt) /3

Allow 20 seconds for reply; if the person did not repeat all three, repeat until they are learned or up to a maximum of five times (but only score first attempt)

4. **Say:** *Spell the word WORLD* (you may help the person to spell the word correctly). **Say:** *Now spell it backwards please* (allow 30 seconds; if the person cannot spell world even with assistance, score zero). Refer to accompanying guide for scoring instructions (score on reverse of this sheet)

/5

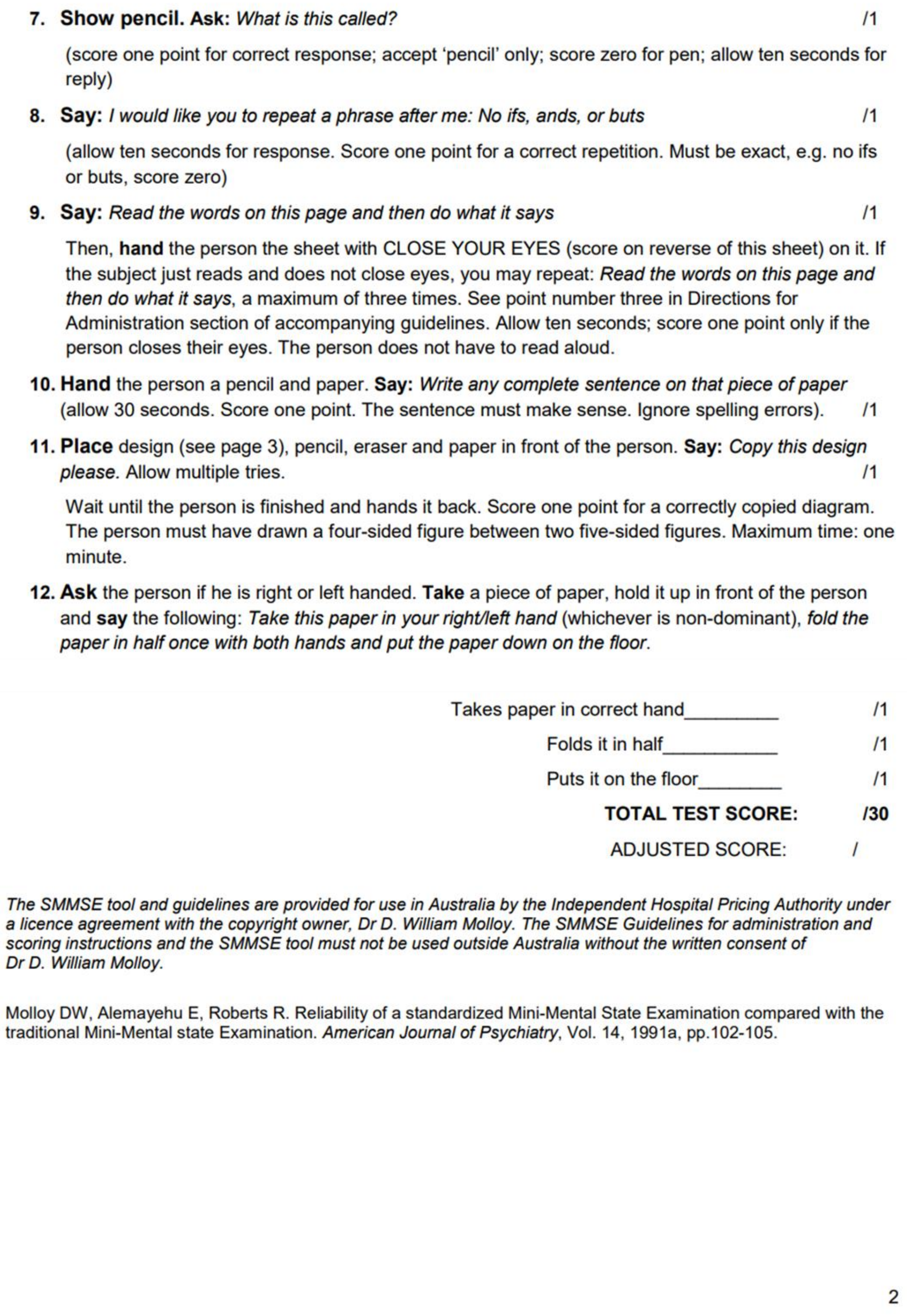
5. **Say:** *Now what were the three objects I asked you to remember?* /3

(score one point for each correct answer regardless of order; allow ten seconds)

6. Show wristwatch. **Ask:** *What is this called?* /1

(score one point for correct response; accept 'wristwatch' or 'watch'; do not accept 'clock' or 'time', etc.; allow ten seconds)

Appendix N The Standardised Mini-Mental State Examination (sMMSE; Molloy and Clarnette, 1999)- page 2 of 3



7. **Show pencil. Ask:** *What is this called?* /1

   (score one point for correct response; accept ‘pencil’ only; score zero for pen; allow ten seconds for reply)

8. **Say:** *I would like you to repeat a phrase after me: No ifs, ands, or buts* /1

   (allow ten seconds for response. Score one point for a correct repetition. Must be exact, e.g. no ifs or buts, score zero)

9. **Say:** *Read the words on this page and then do what it says* /1

   Then, **hand** the person the sheet with CLOSE YOUR EYES (score on reverse of this sheet) on it. If the subject just reads and does not close eyes, you may repeat: *Read the words on this page and then do what it says*, a maximum of three times. See point number three in Directions for Administration section of accompanying guidelines. Allow ten seconds; score one point only if the person closes their eyes. The person does not have to read aloud.

10. **Hand** the person a pencil and paper. **Say:** *Write any complete sentence on that piece of paper* (allow 30 seconds. Score one point. The sentence must make sense. Ignore spelling errors). /1

11. **Place** design (see page 3), pencil, eraser and paper in front of the person. **Say:** *Copy this design please.* Allow multiple tries. /1

    Wait until the person is finished and hands it back. Score one point for a correctly copied diagram. The person must have drawn a four-sided figure between two five-sided figures. Maximum time: one minute.

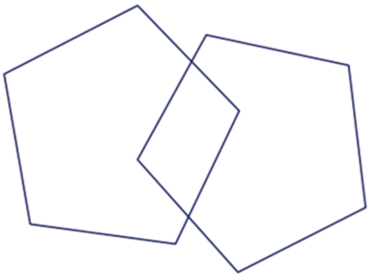
12. **Ask** the person if he is right or left handed. **Take** a piece of paper, hold it up in front of the person and **say** the following: *Take this paper in your right/left hand* (whichever is non-dominant), *fold the paper in half once with both hands and put the paper down on the floor.*

Takes paper in correct hand_________	/1
Folds it in half___________	/1
Puts it on the floor________	/1
TOTAL TEST SCORE:	**/30**
ADJUSTED SCORE:	/

The SMMSE tool and guidelines are provided for use in Australia by the Independent Hospital Pricing Authority under a licence agreement with the copyright owner, Dr D. William Molloy. The SMMSE Guidelines for administration and scoring instructions and the SMMSE tool must not be used outside Australia without the written consent of Dr D. William Molloy.

Molloy DW, Alemayehu E, Roberts R. Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental state Examination. *American Journal of Psychiatry*, Vol. 14, 1991a, pp.102-105.

Appendix N The Standardised Mini-Mental State Examination (sMMSE; Molloy and Clarnette, 1999)- page 3 of 3



Time:

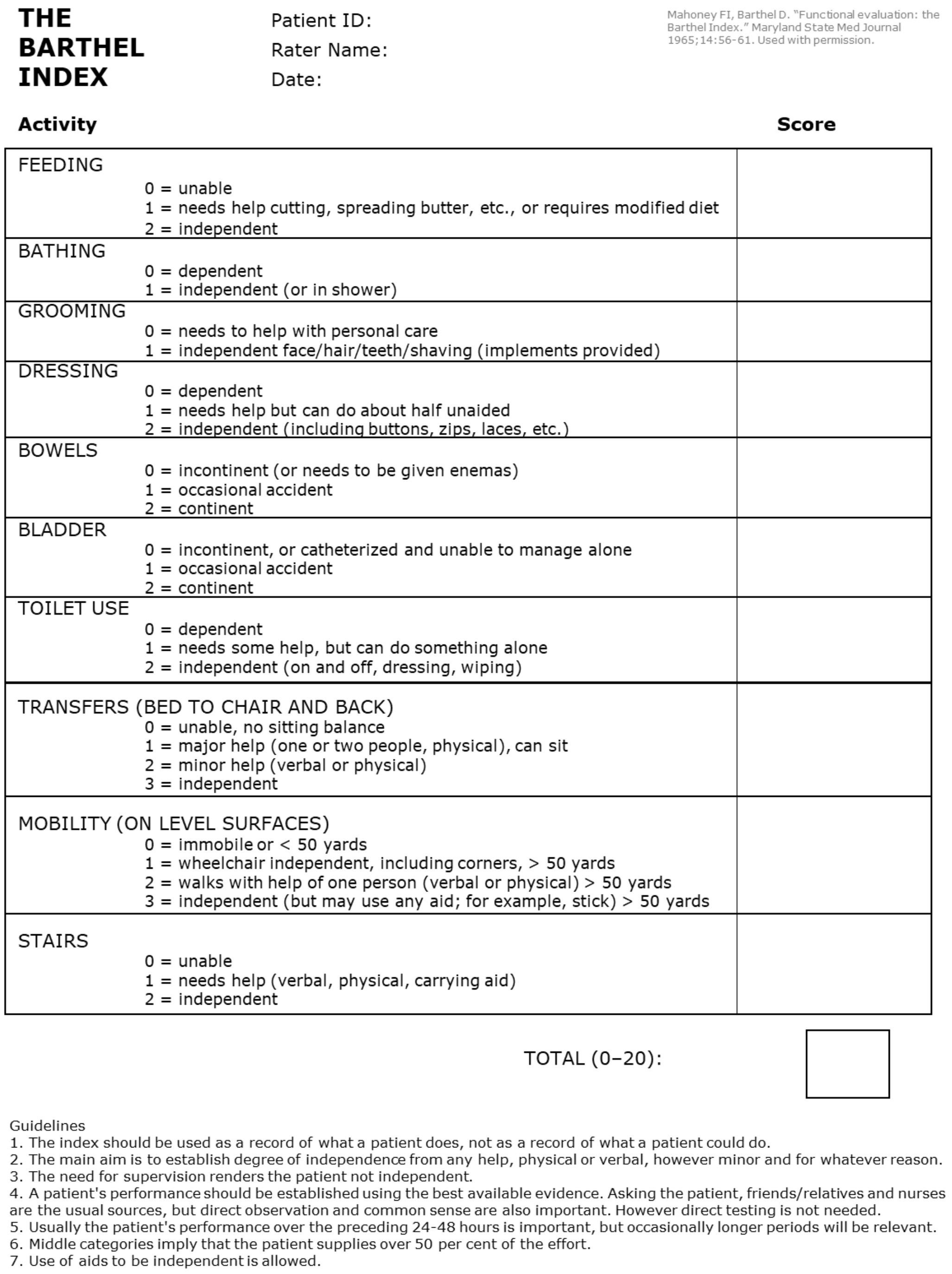
D	L	R	O	W

= ☐

CLOSE YOUR EYES

3

Appendix O The Barthel Activities of Daily Living (ADL) index (BI; Collin et al. 2009)



THE BARTHEL INDEX

Patient ID:
Rater Name:
Date:

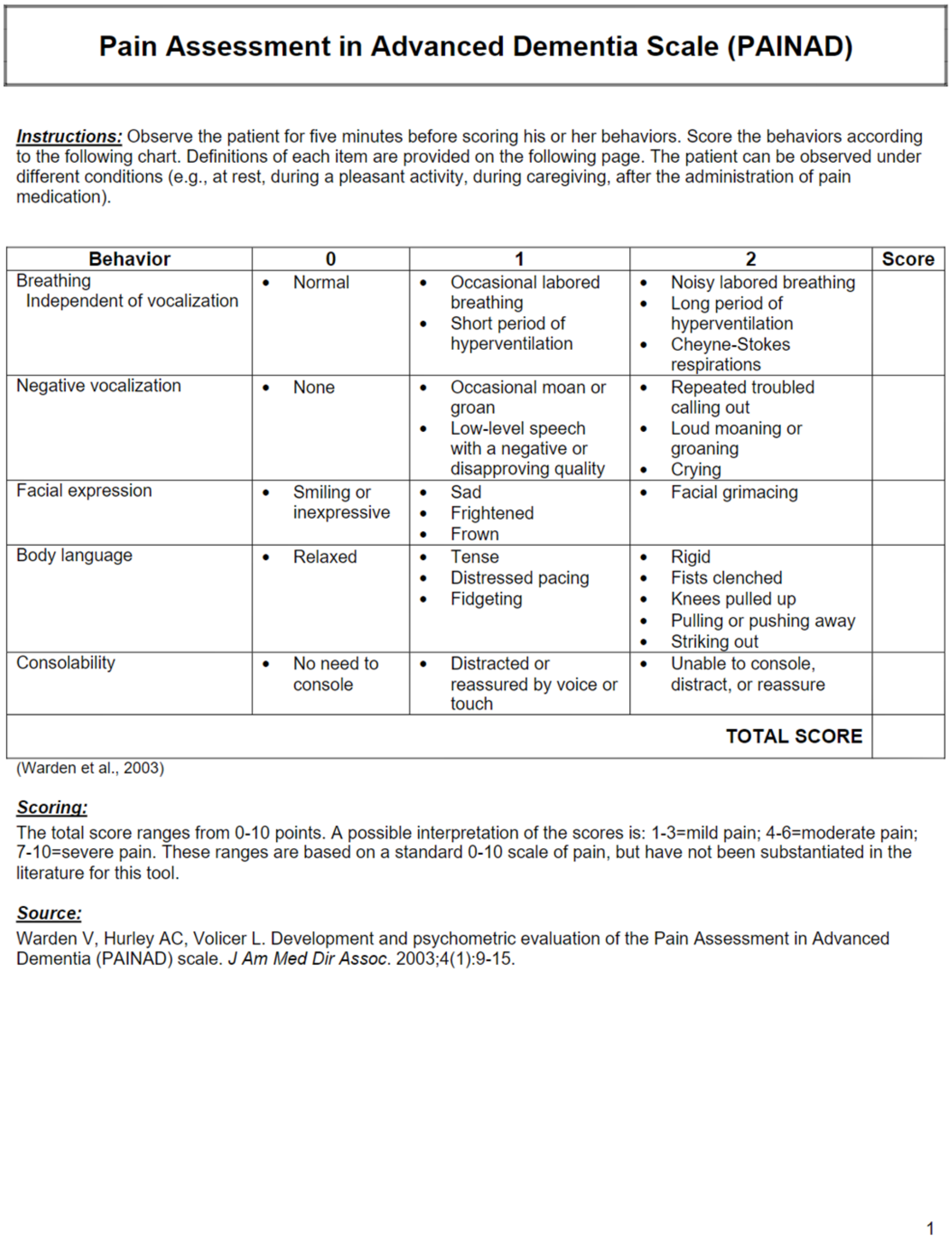
Mahoney FI, Barthel D. "Functional evaluation: the Barthel Index." Maryland State Med Journal 1965;14:56-61. Used with permission.

Activity	**Score**
FEEDING 0 = unable 1 = needs help cutting, spreading butter, etc., or requires modified diet 2 = independent	
BATHING 0 = dependent 1 = independent (or in shower)	
GROOMING 0 = needs to help with personal care 1 = independent face/hair/teeth/shaving (implements provided)	
DRESSING 0 = dependent 1 = needs help but can do about half unaided 2 = independent (including buttons, zips, laces, etc.)	
BOWELS 0 = incontinent (or needs to be given enemas) 1 = occasional accident 2 = continent	
BLADDER 0 = incontinent, or catheterized and unable to manage alone 1 = occasional accident 2 = continent	
TOILET USE 0 = dependent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping)	
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 1 = major help (one or two people, physical), can sit 2 = minor help (verbal or physical) 3 = independent	
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 1 = wheelchair independent, including corners, > 50 yards 2 = walks with help of one person (verbal or physical) > 50 yards 3 = independent (but may use any aid; for example, stick) > 50 yards	
STAIRS 0 = unable 1 = needs help (verbal, physical, carrying aid) 2 = independent	

TOTAL (0–20): ☐

Guidelines
1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

Appendix P The Pain Assessment in Advanced Dementia Scale (PAINAD; Warden et al. 2003) score sheet



Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	**0**	**1**	**2**	**Score**
Breathing Independent of vocalization	• Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
Consolability	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
			TOTAL SCORE	

(Warden et al., 2003)

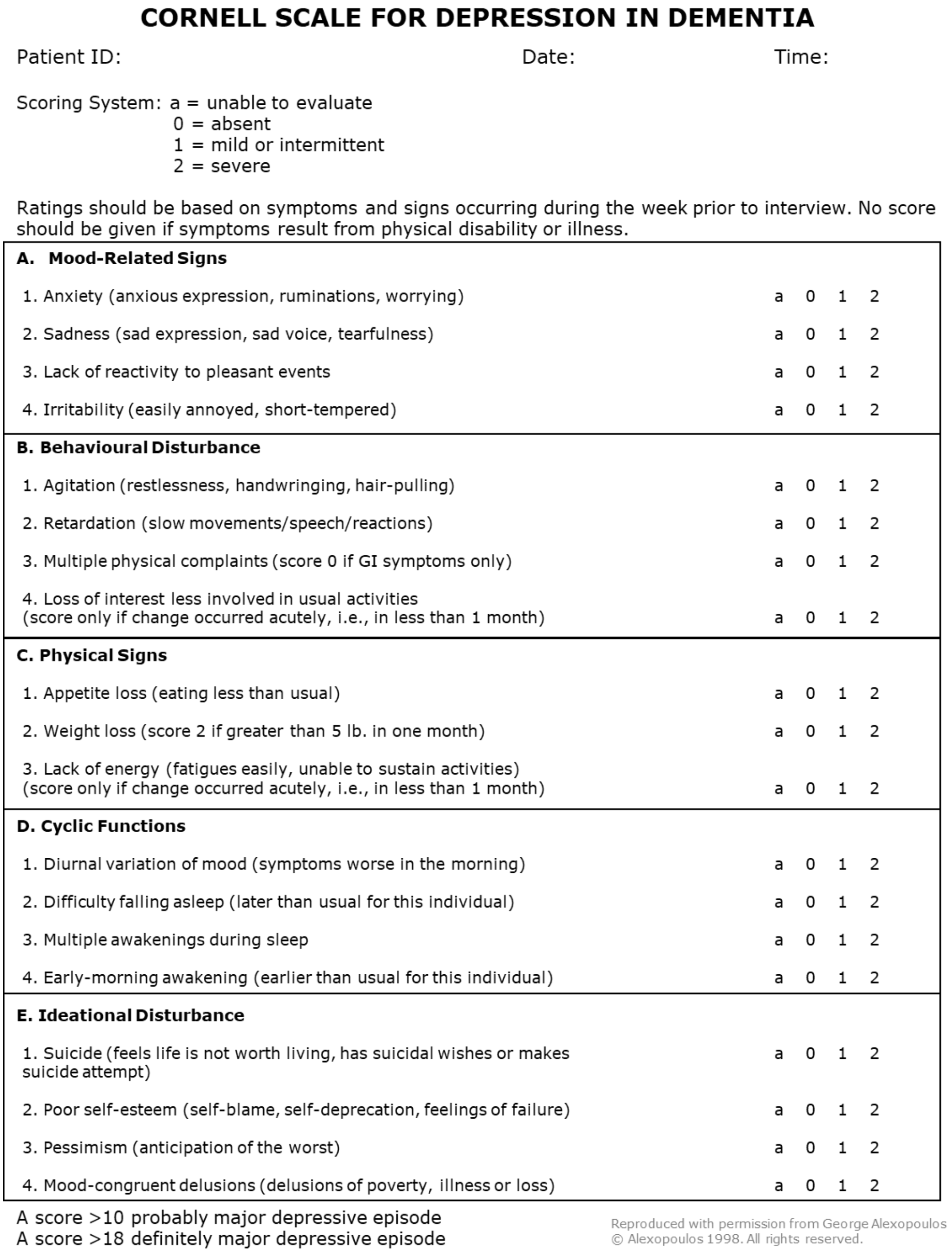
Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003;4(1):9-15.

Appendix Q The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, 1988)



CORNELL SCALE FOR DEPRESSION IN DEMENTIA

Patient ID: Date: Time:

Scoring System: a = unable to evaluate
0 = absent
1 = mild or intermittent
2 = severe

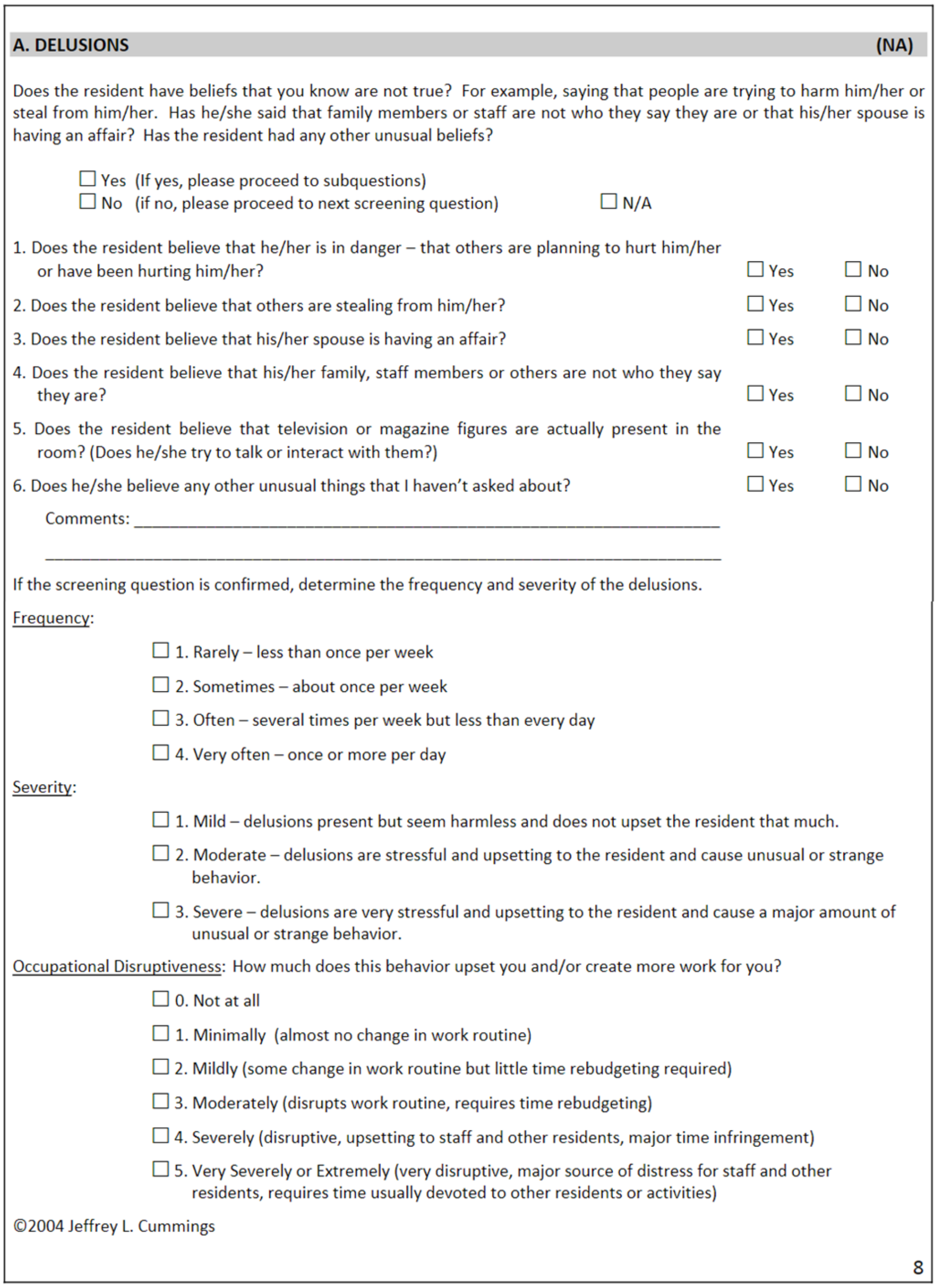
Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.

A. Mood-Related Signs				
1. Anxiety (anxious expression, ruminations, worrying)	a	0	1	2
2. Sadness (sad expression, sad voice, tearfulness)	a	0	1	2
3. Lack of reactivity to pleasant events	a	0	1	2
4. Irritability (easily annoyed, short-tempered)	a	0	1	2
B. Behavioural Disturbance				
1. Agitation (restlessness, handwringing, hair-pulling)	a	0	1	2
2. Retardation (slow movements/speech/reactions)	a	0	1	2
3. Multiple physical complaints (score 0 if GI symptoms only)	a	0	1	2
4. Loss of interest less involved in usual activities (score only if change occurred acutely, i.e., in less than 1 month)	a	0	1	2
C. Physical Signs				
1. Appetite loss (eating less than usual)	a	0	1	2
2. Weight loss (score 2 if greater than 5 lb. in one month)	a	0	1	2
3. Lack of energy (fatigues easily, unable to sustain activities) (score only if change occurred acutely, i.e., in less than 1 month)	a	0	1	2
D. Cyclic Functions				
1. Diurnal variation of mood (symptoms worse in the morning)	a	0	1	2
2. Difficulty falling asleep (later than usual for this individual)	a	0	1	2
3. Multiple awakenings during sleep	a	0	1	2
4. Early-morning awakening (earlier than usual for this individual)	a	0	1	2
E. Ideational Disturbance				
1. Suicide (feels life is not worth living, has suicidal wishes or makes suicide attempt)	a	0	1	2
2. Poor self-esteem (self-blame, self-deprecation, feelings of failure)	a	0	1	2
3. Pessimism (anticipation of the worst)	a	0	1	2
4. Mood-congruent delusions (delusions of poverty, illness or loss)	a	0	1	2

A score >10 probably major depressive episode
A score >18 definitely major depressive episode

Reproduced with permission from George Alexopoulos

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 1 of 13



A. DELUSIONS **(NA)**

Does the resident have beliefs that you know are not true? For example, saying that people are trying to harm him/her or steal from him/her. Has he/she said that family members or staff are not who they say they are or that his/her spouse is having an affair? Has the resident had any other unusual beliefs?

☐ Yes (If yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident believe that he/her is in danger – that others are planning to hurt him/her or have been hurting him/her?	☐ Yes	☐ No
2. Does the resident believe that others are stealing from him/her?	☐ Yes	☐ No
3. Does the resident believe that his/her spouse is having an affair?	☐ Yes	☐ No
4. Does the resident believe that his/her family, staff members or others are not who they say they are?	☐ Yes	☐ No
5. Does the resident believe that television or magazine figures are actually present in the room? (Does he/she try to talk or interact with them?)	☐ Yes	☐ No
6. Does he/she believe any other unusual things that I haven't asked about?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the delusions.

Frequency:

☐ 1. Rarely – less than once per week
☐ 2. Sometimes – about once per week
☐ 3. Often – several times per week but less than every day
☐ 4. Very often – once or more per day

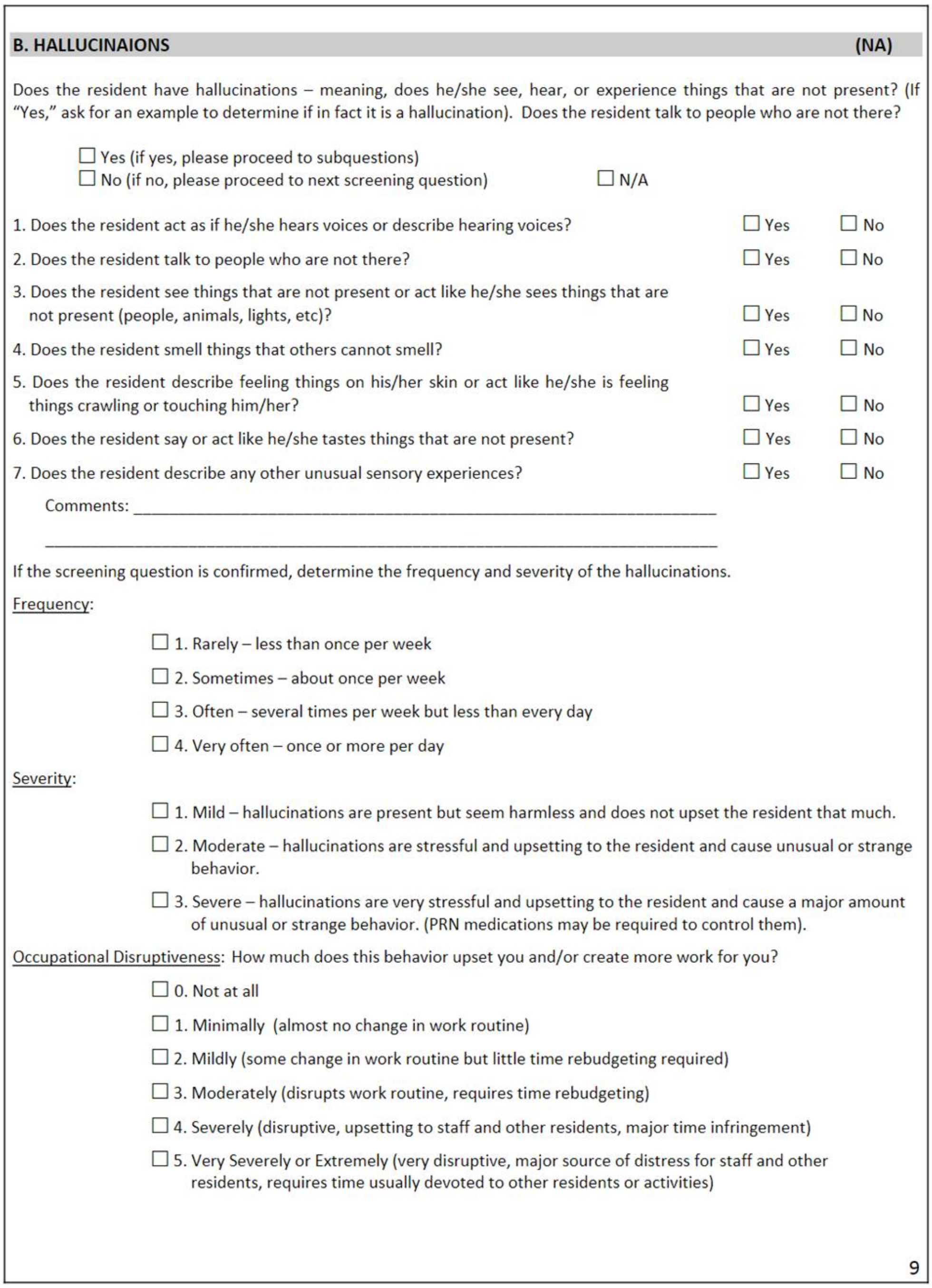
Severity:

☐ 1. Mild – delusions present but seem harmless and does not upset the resident that much.
☐ 2. Moderate – delusions are stressful and upsetting to the resident and cause unusual or strange behavior.
☐ 3. Severe – delusions are very stressful and upsetting to the resident and cause a major amount of unusual or strange behavior.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 2 of 13



B. HALLUCINAIONS **(NA)**

Does the resident have hallucinations – meaning, does he/she see, hear, or experience things that are not present? (If "Yes," ask for an example to determine if in fact it is a hallucination). Does the resident talk to people who are not there?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident act as if he/she hears voices or describe hearing voices?	☐ Yes	☐ No
2. Does the resident talk to people who are not there?	☐ Yes	☐ No
3. Does the resident see things that are not present or act like he/she sees things that are not present (people, animals, lights, etc)?	☐ Yes	☐ No
4. Does the resident smell things that others cannot smell?	☐ Yes	☐ No
5. Does the resident describe feeling things on his/her skin or act like he/she is feeling things crawling or touching him/her?	☐ Yes	☐ No
6. Does the resident say or act like he/she tastes things that are not present?	☐ Yes	☐ No
7. Does the resident describe any other unusual sensory experiences?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the hallucinations.

Frequency:

☐ 1. Rarely – less than once per week
☐ 2. Sometimes – about once per week
☐ 3. Often – several times per week but less than every day
☐ 4. Very often – once or more per day

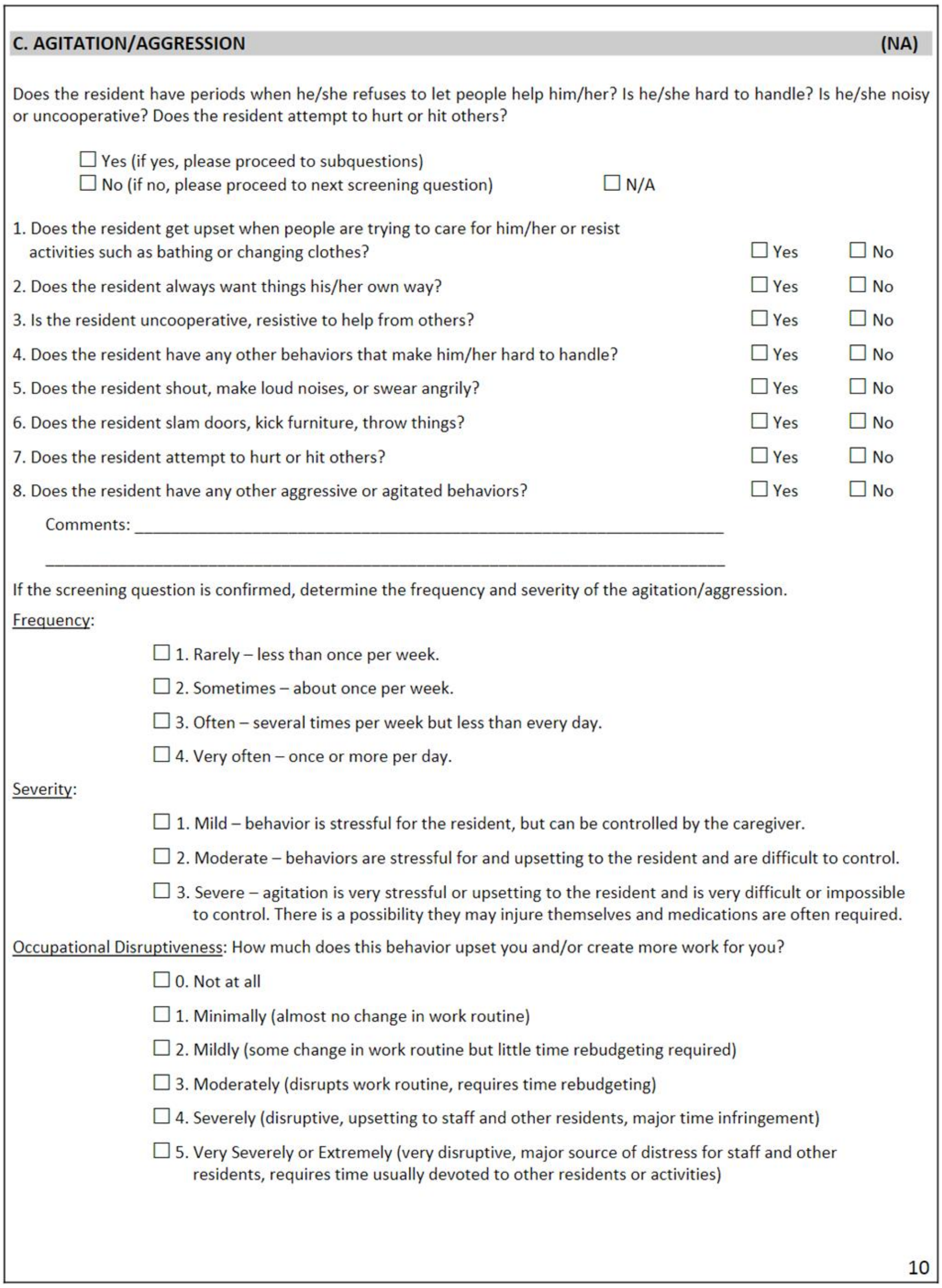
Severity:

☐ 1. Mild – hallucinations are present but seem harmless and does not upset the resident that much.
☐ 2. Moderate – hallucinations are stressful and upsetting to the resident and cause unusual or strange behavior.
☐ 3. Severe – hallucinations are very stressful and upsetting to the resident and cause a major amount of unusual or strange behavior. (PRN medications may be required to control them).

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 3 of 13



C. AGITATION/AGGRESSION **(NA)**

Does the resident have periods when he/she refuses to let people help him/her? Is he/she hard to handle? Is he/she noisy or uncooperative? Does the resident attempt to hurt or hit others?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident get upset when people are trying to care for him/her or resist activities such as bathing or changing clothes? ☐ Yes ☐ No
2. Does the resident always want things his/her own way? ☐ Yes ☐ No
3. Is the resident uncooperative, resistive to help from others? ☐ Yes ☐ No
4. Does the resident have any other behaviors that make him/her hard to handle? ☐ Yes ☐ No
5. Does the resident shout, make loud noises, or swear angrily? ☐ Yes ☐ No
6. Does the resident slam doors, kick furniture, throw things? ☐ Yes ☐ No
7. Does the resident attempt to hurt or hit others? ☐ Yes ☐ No
8. Does the resident have any other aggressive or agitated behaviors? ☐ Yes ☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the agitation/aggression.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day.

Severity:

☐ 1. Mild – behavior is stressful for the resident, but can be controlled by the caregiver.
☐ 2. Moderate – behaviors are stressful for and upsetting to the resident and are difficult to control.
☐ 3. Severe – agitation is very stressful or upsetting to the resident and is very difficult or impossible to control. There is a possibility they may injure themselves and medications are often required.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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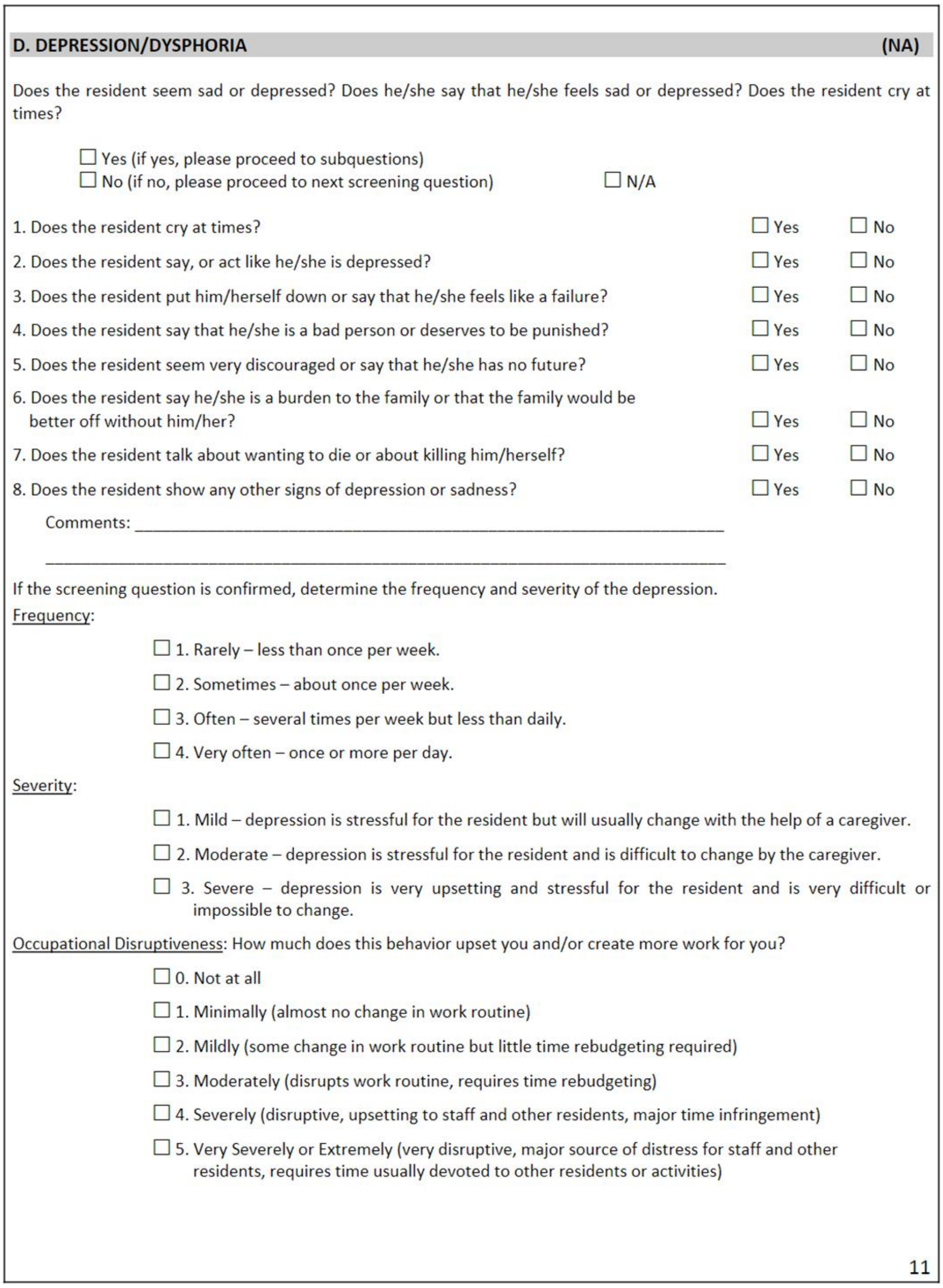
Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 4 of 13



D. DEPRESSION/DYSPHORIA (NA)

Does the resident seem sad or depressed? Does he/she say that he/she feels sad or depressed? Does the resident cry at times?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident cry at times?	☐ Yes	☐ No
2. Does the resident say, or act like he/she is depressed?	☐ Yes	☐ No
3. Does the resident put him/herself down or say that he/she feels like a failure?	☐ Yes	☐ No
4. Does the resident say that he/she is a bad person or deserves to be punished?	☐ Yes	☐ No
5. Does the resident seem very discouraged or say that he/she has no future?	☐ Yes	☐ No
6. Does the resident say he/she is a burden to the family or that the family would be better off without him/her?	☐ Yes	☐ No
7. Does the resident talk about wanting to die or about killing him/herself?	☐ Yes	☐ No
8. Does the resident show any other signs of depression or sadness?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the depression.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than daily.
☐ 4. Very often – once or more per day.

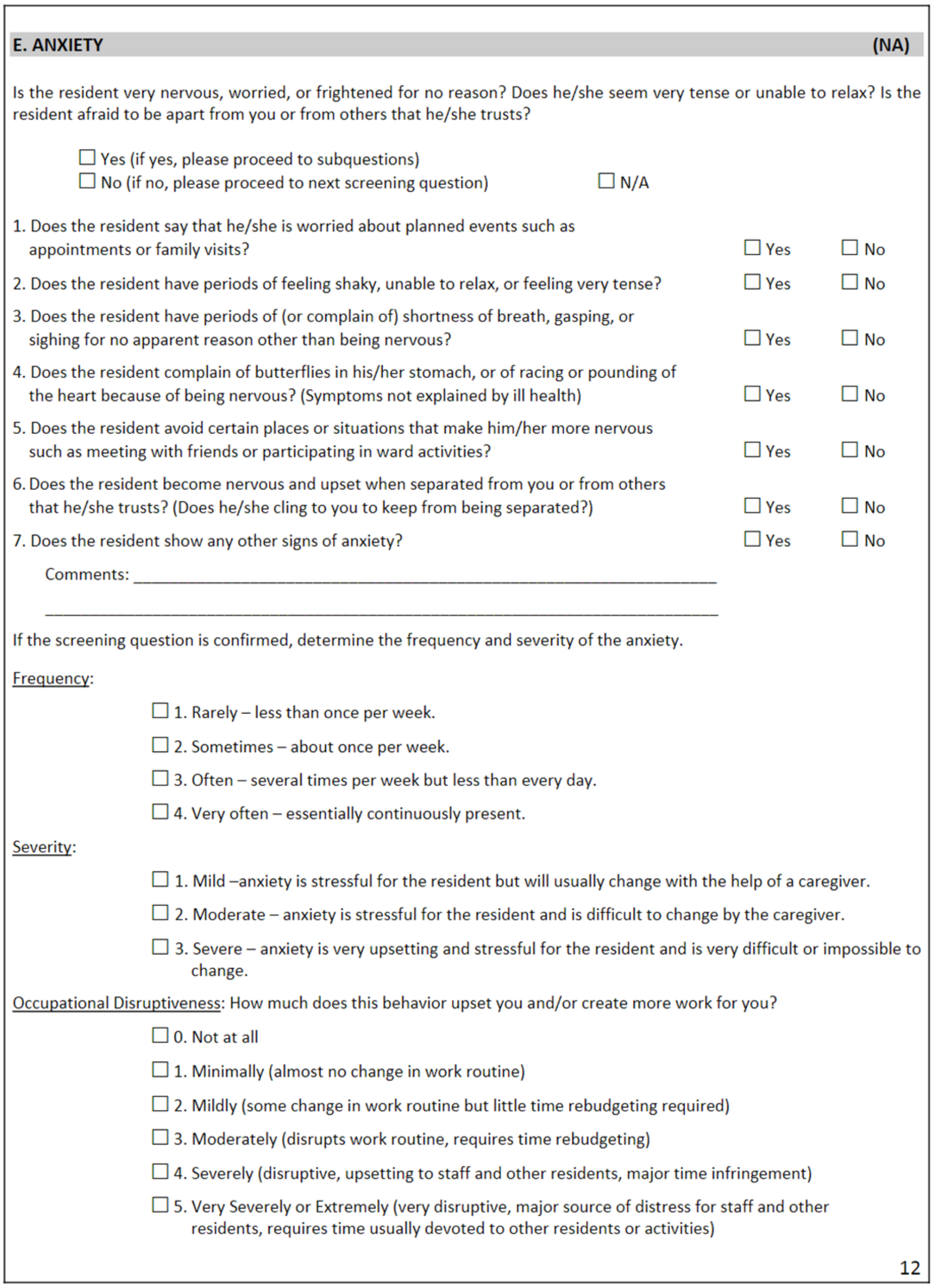
Severity:

☐ 1. Mild – depression is stressful for the resident but will usually change with the help of a caregiver.
☐ 2. Moderate – depression is stressful for the resident and is difficult to change by the caregiver.
☐ 3. Severe – depression is very upsetting and stressful for the resident and is very difficult or impossible to change.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 5 of 13



E. ANXIETY **(NA)**

Is the resident very nervous, worried, or frightened for no reason? Does he/she seem very tense or unable to relax? Is the resident afraid to be apart from you or from others that he/she trusts?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident say that he/she is worried about planned events such as appointments or family visits?	☐ Yes	☐ No
2. Does the resident have periods of feeling shaky, unable to relax, or feeling very tense?	☐ Yes	☐ No
3. Does the resident have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than being nervous?	☐ Yes	☐ No
4. Does the resident complain of butterflies in his/her stomach, or of racing or pounding of the heart because of being nervous? (Symptoms not explained by ill health)	☐ Yes	☐ No
5. Does the resident avoid certain places or situations that make him/her more nervous such as meeting with friends or participating in ward activities?	☐ Yes	☐ No
6. Does the resident become nervous and upset when separated from you or from others that he/she trusts? (Does he/she cling to you to keep from being separated?)	☐ Yes	☐ No
7. Does the resident show any other signs of anxiety?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the anxiety.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

☐ 1. Mild –anxiety is stressful for the resident but will usually change with the help of a caregiver.
☐ 2. Moderate – anxiety is stressful for the resident and is difficult to change by the caregiver.
☐ 3. Severe – anxiety is very upsetting and stressful for the resident and is very difficult or impossible to change.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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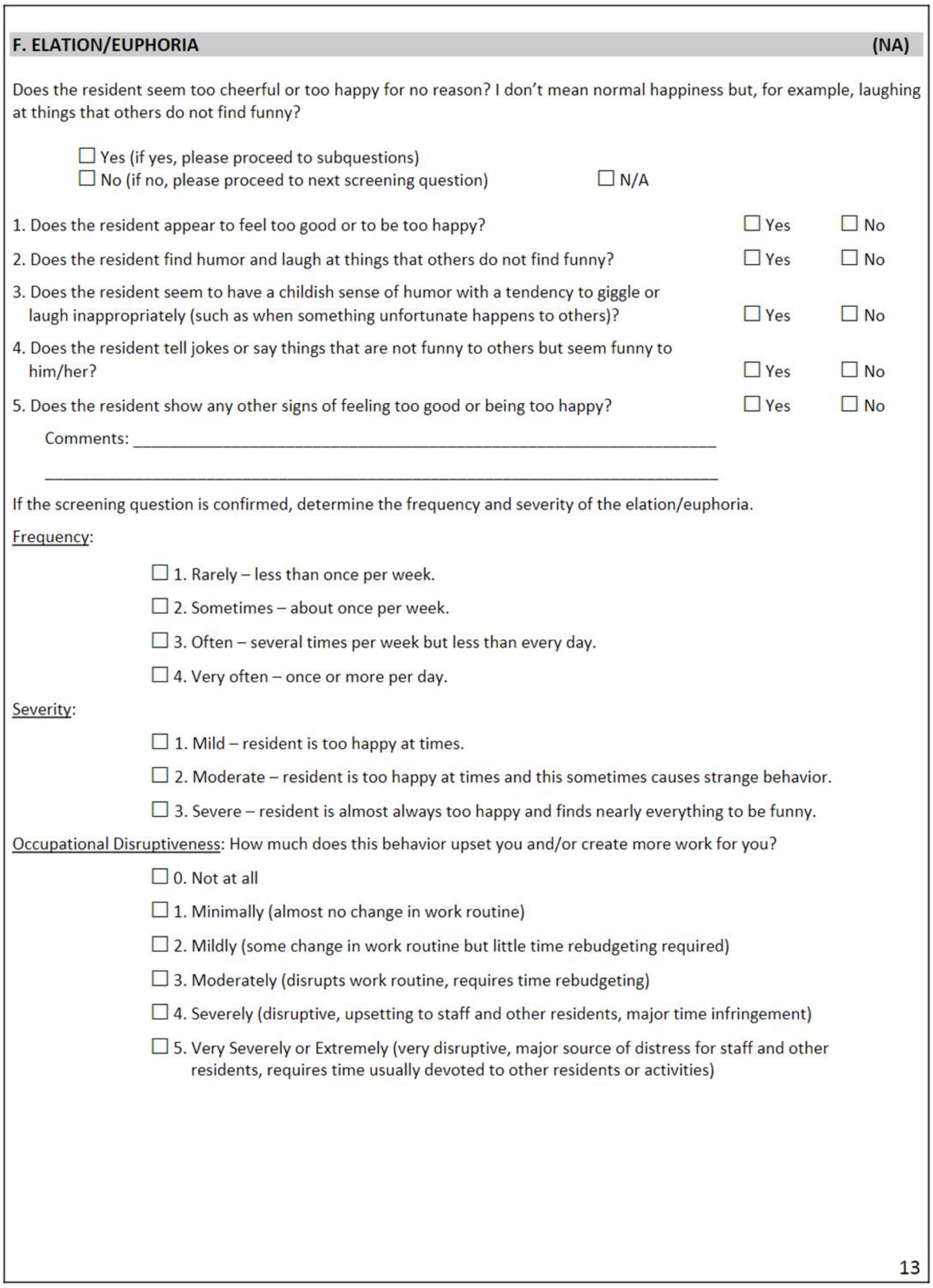
Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 6 of 13



F. ELATION/EUPHORIA **(NA)**

Does the resident seem too cheerful or too happy for no reason? I don't mean normal happiness but, for example, laughing at things that others do not find funny?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident appear to feel too good or to be too happy? ☐ Yes ☐ No
2. Does the resident find humor and laugh at things that others do not find funny? ☐ Yes ☐ No
3. Does the resident seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others)? ☐ Yes ☐ No
4. Does the resident tell jokes or say things that are not funny to others but seem funny to him/her? ☐ Yes ☐ No
5. Does the resident show any other signs of feeling too good or being too happy? ☐ Yes ☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the elation/euphoria.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day.

Severity:

☐ 1. Mild – resident is too happy at times.
☐ 2. Moderate – resident is too happy at times and this sometimes causes strange behavior.
☐ 3. Severe – resident is almost always too happy and finds nearly everything to be funny.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

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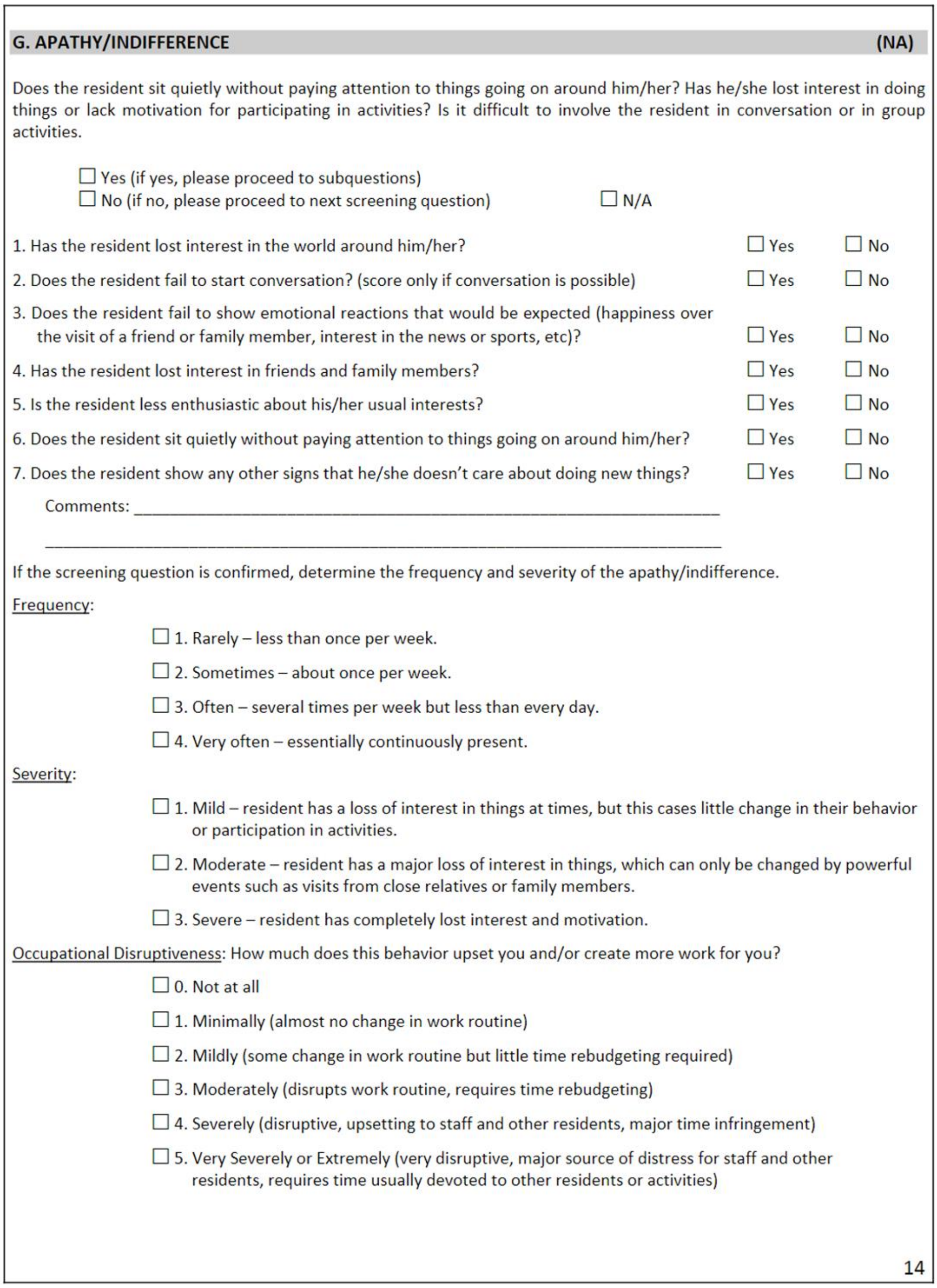
Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 7 of 13



G. APATHY/INDIFFERENCE **(NA)**

Does the resident sit quietly without paying attention to things going on around him/her? Has he/she lost interest in doing things or lack motivation for participating in activities? Is it difficult to involve the resident in conversation or in group activities.

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Has the resident lost interest in the world around him/her?	☐ Yes	☐ No
2. Does the resident fail to start conversation? (score only if conversation is possible)	☐ Yes	☐ No
3. Does the resident fail to show emotional reactions that would be expected (happiness over the visit of a friend or family member, interest in the news or sports, etc)?	☐ Yes	☐ No
4. Has the resident lost interest in friends and family members?	☐ Yes	☐ No
5. Is the resident less enthusiastic about his/her usual interests?	☐ Yes	☐ No
6. Does the resident sit quietly without paying attention to things going on around him/her?	☐ Yes	☐ No
7. Does the resident show any other signs that he/she doesn't care about doing new things?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the apathy/indifference.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

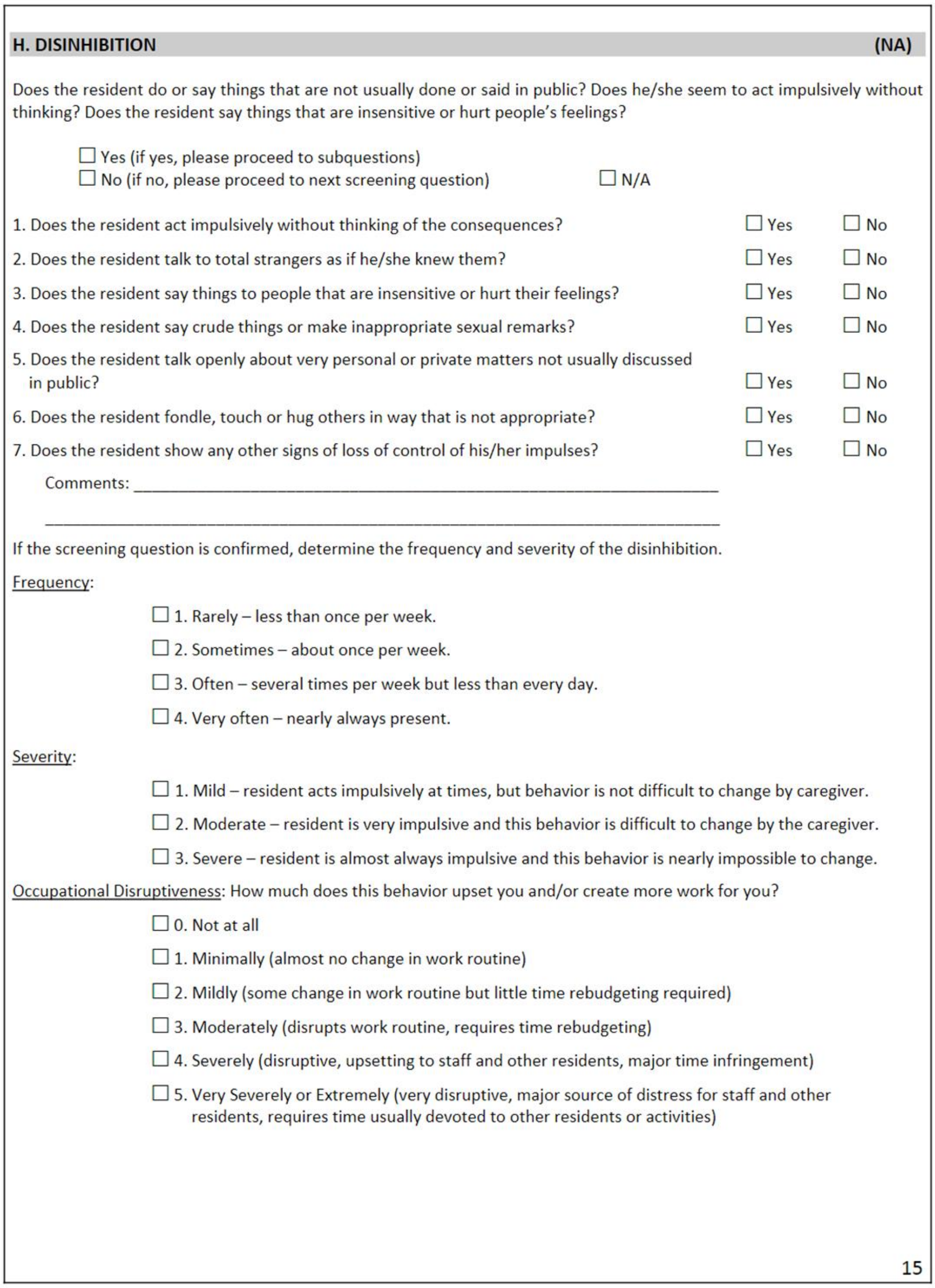
Severity:

☐ 1. Mild – resident has a loss of interest in things at times, but this cases little change in their behavior or participation in activities.
☐ 2. Moderate – resident has a major loss of interest in things, which can only be changed by powerful events such as visits from close relatives or family members.
☐ 3. Severe – resident has completely lost interest and motivation.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 8 of 13



H. DISINHIBITION **(NA)**

Does the resident do or say things that are not usually done or said in public? Does he/she seem to act impulsively without thinking? Does the resident say things that are insensitive or hurt people's feelings?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident act impulsively without thinking of the consequences? ☐ Yes ☐ No
2. Does the resident talk to total strangers as if he/she knew them? ☐ Yes ☐ No
3. Does the resident say things to people that are insensitive or hurt their feelings? ☐ Yes ☐ No
4. Does the resident say crude things or make inappropriate sexual remarks? ☐ Yes ☐ No
5. Does the resident talk openly about very personal or private matters not usually discussed in public? ☐ Yes ☐ No
6. Does the resident fondle, touch or hug others in way that is not appropriate? ☐ Yes ☐ No
7. Does the resident show any other signs of loss of control of his/her impulses? ☐ Yes ☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the disinhibition.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – nearly always present.

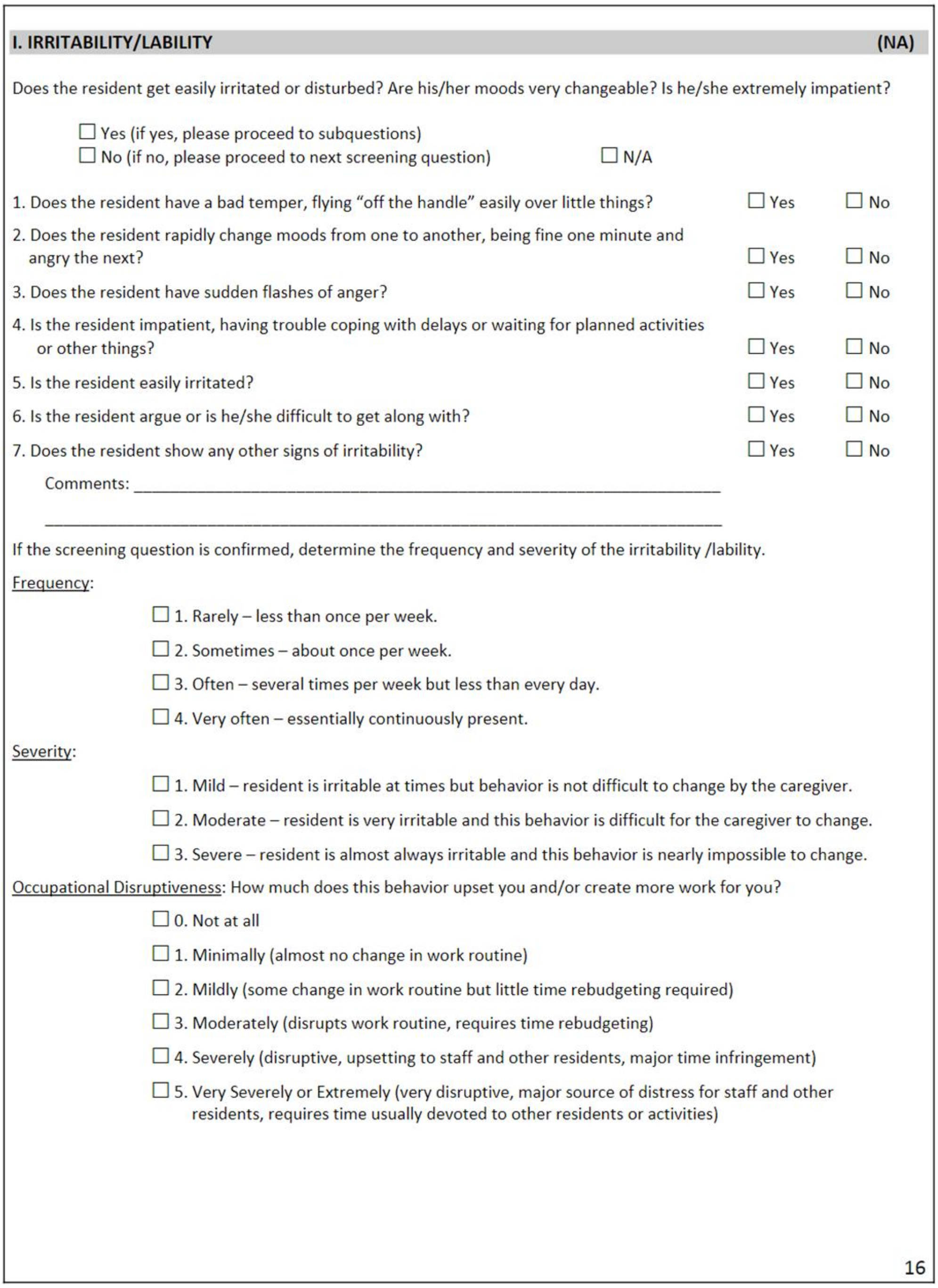
Severity:

☐ 1. Mild – resident acts impulsively at times, but behavior is not difficult to change by caregiver.
☐ 2. Moderate – resident is very impulsive and this behavior is difficult to change by the caregiver.
☐ 3. Severe – resident is almost always impulsive and this behavior is nearly impossible to change.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 9 of 13



I. IRRITABILITY/LABILITY **(NA)**

Does the resident get easily irritated or disturbed? Are his/her moods very changeable? Is he/she extremely impatient?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident have a bad temper, flying "off the handle" easily over little things? ☐ Yes ☐ No
2. Does the resident rapidly change moods from one to another, being fine one minute and angry the next? ☐ Yes ☐ No
3. Does the resident have sudden flashes of anger? ☐ Yes ☐ No
4. Is the resident impatient, having trouble coping with delays or waiting for planned activities or other things? ☐ Yes ☐ No
5. Is the resident easily irritated? ☐ Yes ☐ No
6. Is the resident argue or is he/she difficult to get along with? ☐ Yes ☐ No
7. Does the resident show any other signs of irritability? ☐ Yes ☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the irritability /lability.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

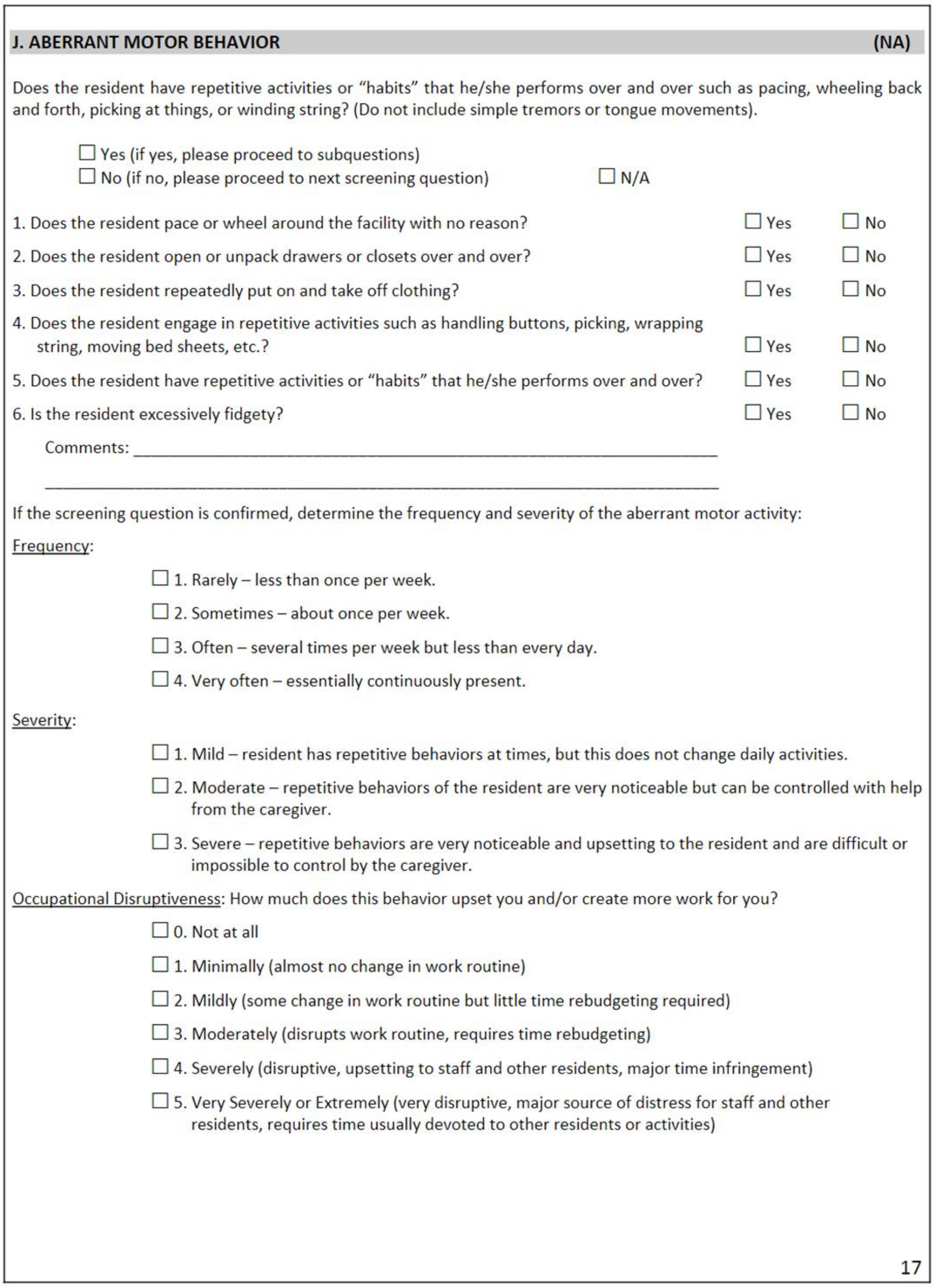
Severity:

☐ 1. Mild – resident is irritable at times but behavior is not difficult to change by the caregiver.
☐ 2. Moderate – resident is very irritable and this behavior is difficult for the caregiver to change.
☐ 3. Severe – resident is almost always irritable and this behavior is nearly impossible to change.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 10 of 13



J. ABERRANT MOTOR BEHAVIOR **(NA)**

Does the resident have repetitive activities or "habits" that he/she performs over and over such as pacing, wheeling back and forth, picking at things, or winding string? (Do not include simple tremors or tongue movements).

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident pace or wheel around the facility with no reason? ☐ Yes ☐ No
2. Does the resident open or unpack drawers or closets over and over? ☐ Yes ☐ No
3. Does the resident repeatedly put on and take off clothing? ☐ Yes ☐ No
4. Does the resident engage in repetitive activities such as handling buttons, picking, wrapping string, moving bed sheets, etc.? ☐ Yes ☐ No
5. Does the resident have repetitive activities or "habits" that he/she performs over and over? ☐ Yes ☐ No
6. Is the resident excessively fidgety? ☐ Yes ☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the aberrant motor activity:

Frequency:

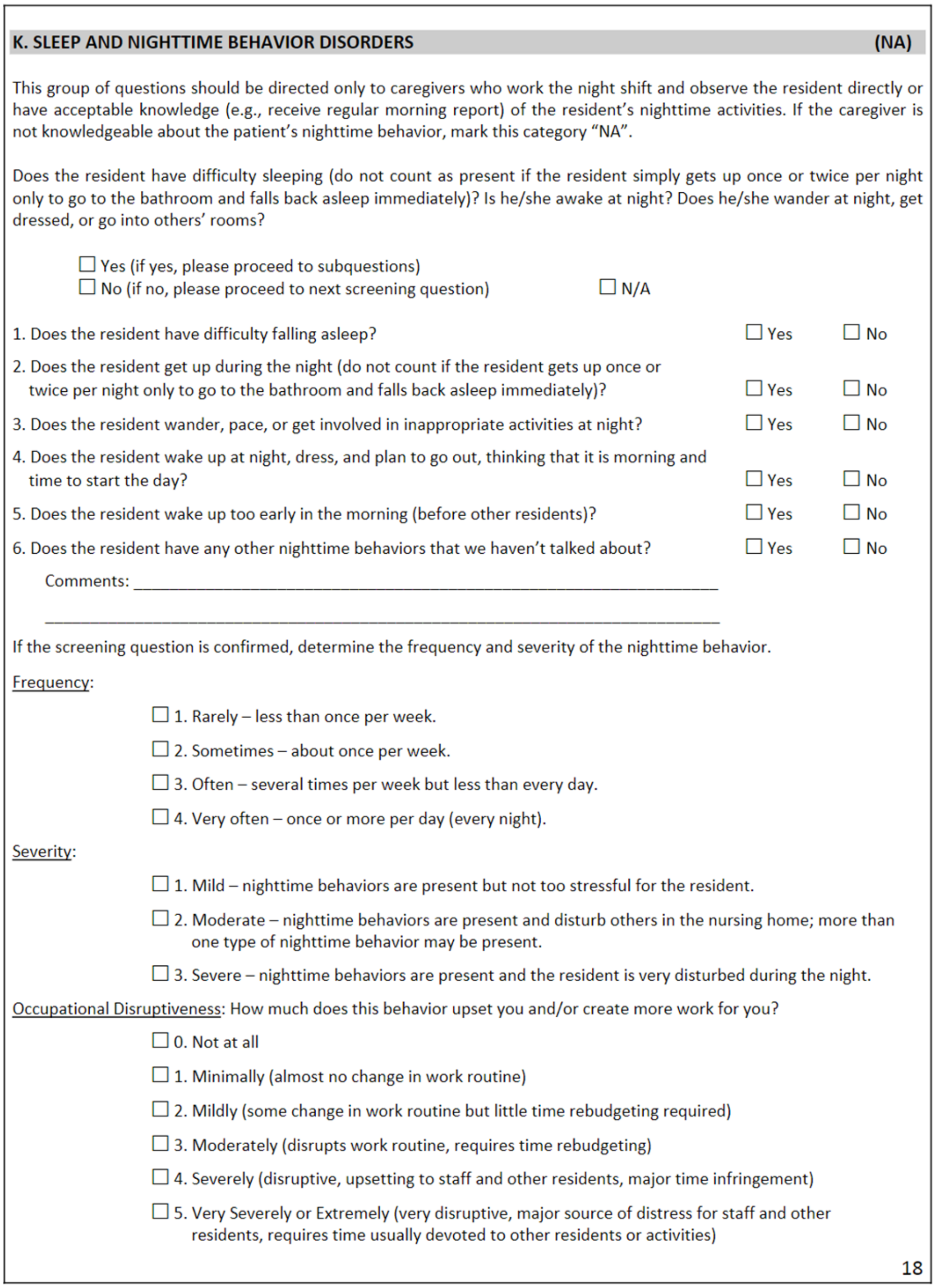
☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

☐ 1. Mild – resident has repetitive behaviors at times, but this does not change daily activities.
☐ 2. Moderate – repetitive behaviors of the resident are very noticeable but can be controlled with help from the caregiver.
☐ 3. Severe – repetitive behaviors are very noticeable and upsetting to the resident and are difficult or impossible to control by the caregiver.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)



K. SLEEP AND NIGHTTIME BEHAVIOR DISORDERS (NA)

This group of questions should be directed only to caregivers who work the night shift and observe the resident directly or have acceptable knowledge (e.g., receive regular morning report) of the resident's nighttime activities. If the caregiver is not knowledgeable about the patient's nighttime behavior, mark this category "NA".

Does the resident have difficulty sleeping (do not count as present if the resident simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she awake at night? Does he/she wander at night, get dressed, or go into others' rooms?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does the resident have difficulty falling asleep?	☐ Yes	☐ No
2. Does the resident get up during the night (do not count if the resident gets up once or twice per night only to go to the bathroom and falls back asleep immediately)?	☐ Yes	☐ No
3. Does the resident wander, pace, or get involved in inappropriate activities at night?	☐ Yes	☐ No
4. Does the resident wake up at night, dress, and plan to go out, thinking that it is morning and time to start the day?	☐ Yes	☐ No
5. Does the resident wake up too early in the morning (before other residents)?	☐ Yes	☐ No
6. Does the resident have any other nighttime behaviors that we haven't talked about?	☐ Yes	☐ No

Comments: ____

____

If the screening question is confirmed, determine the frequency and severity of the nighttime behavior.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – once or more per day (every night).

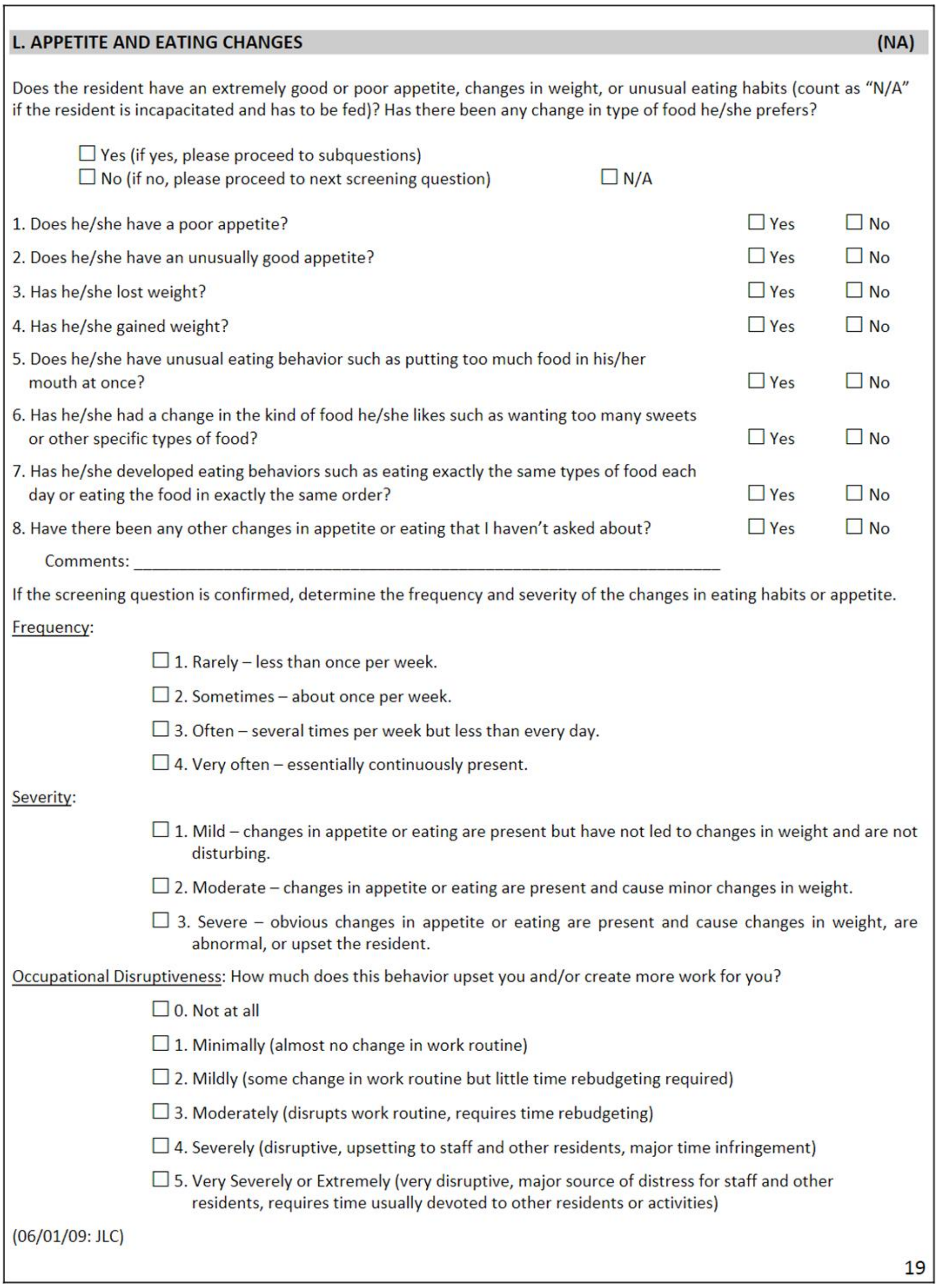
Severity:

☐ 1. Mild – nighttime behaviors are present but not too stressful for the resident.
☐ 2. Moderate – nighttime behaviors are present and disturb others in the nursing home; more than one type of nighttime behavior may be present.
☐ 3. Severe – nighttime behaviors are present and the resident is very disturbed during the night.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 12 of 13



L. APPETITE AND EATING CHANGES **(NA)**

Does the resident have an extremely good or poor appetite, changes in weight, or unusual eating habits (count as "N/A" if the resident is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

☐ Yes (if yes, please proceed to subquestions)
☐ No (if no, please proceed to next screening question) ☐ N/A

1. Does he/she have a poor appetite?	☐ Yes	☐ No
2. Does he/she have an unusually good appetite?	☐ Yes	☐ No
3. Has he/she lost weight?	☐ Yes	☐ No
4. Has he/she gained weight?	☐ Yes	☐ No
5. Does he/she have unusual eating behavior such as putting too much food in his/her mouth at once?	☐ Yes	☐ No
6. Has he/she had a change in the kind of food he/she likes such as wanting too many sweets or other specific types of food?	☐ Yes	☐ No
7. Has he/she developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order?	☐ Yes	☐ No
8. Have there been any other changes in appetite or eating that I haven't asked about?	☐ Yes	☐ No

Comments: ____

If the screening question is confirmed, determine the frequency and severity of the changes in eating habits or appetite.

Frequency:

☐ 1. Rarely – less than once per week.
☐ 2. Sometimes – about once per week.
☐ 3. Often – several times per week but less than every day.
☐ 4. Very often – essentially continuously present.

Severity:

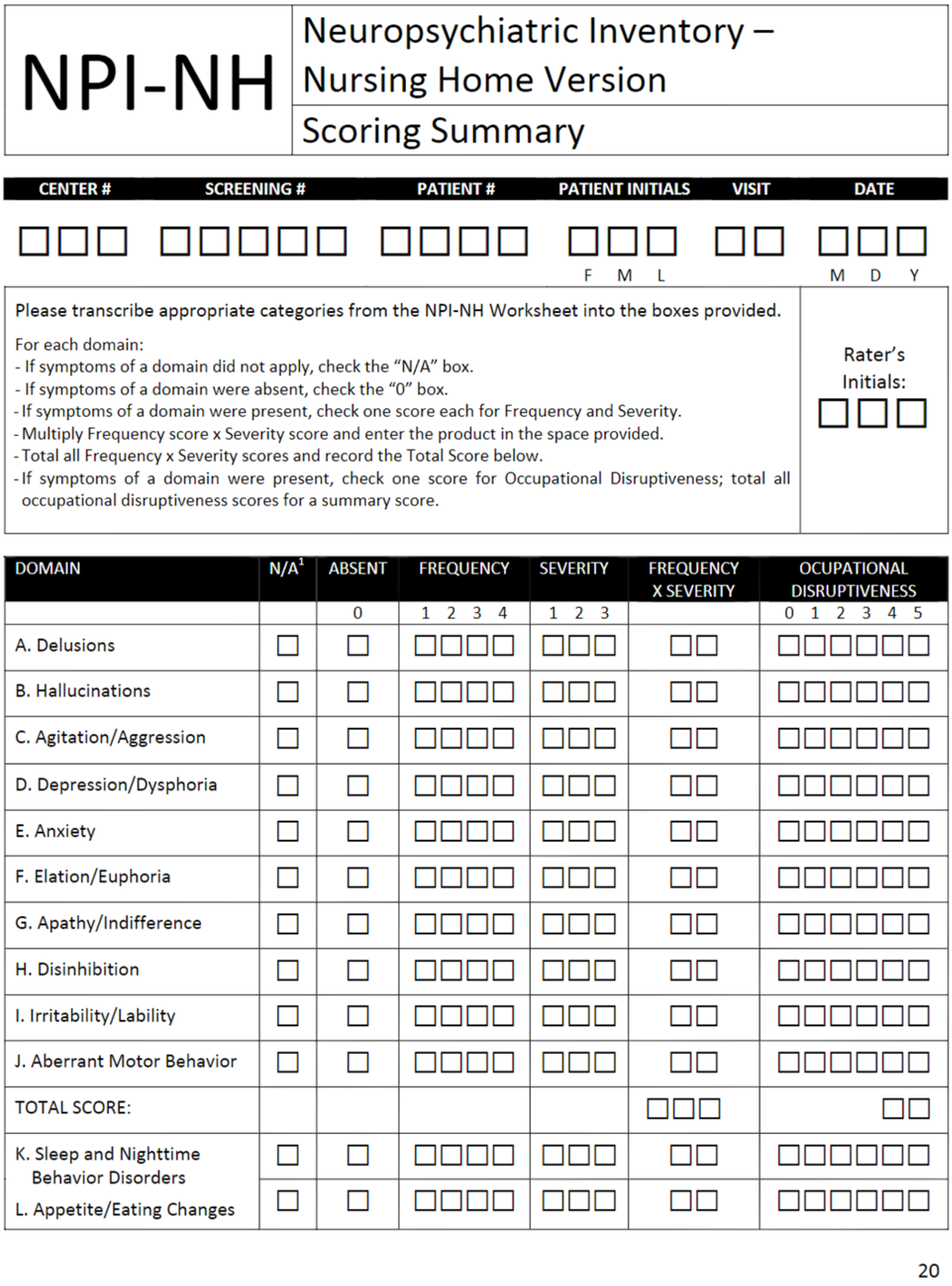
☐ 1. Mild – changes in appetite or eating are present but have not led to changes in weight and are not disturbing.
☐ 2. Moderate – changes in appetite or eating are present and cause minor changes in weight.
☐ 3. Severe – obvious changes in appetite or eating are present and cause changes in weight, are abnormal, or upset the resident.

Occupational Disruptiveness: How much does this behavior upset you and/or create more work for you?

☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

(06/01/09: JLC)

Appendix R The Neuropsychiatric Inventory-Nursing Home version (NPI-NH; Wood et al. 2001)- page 13 of 13



NPI-NH	Neuropsychiatric Inventory – Nursing Home Version
	Scoring Summary

CENTER #	SCREENING #	PATIENT #	PATIENT INITIALS	VISIT	DATE
☐☐☐	☐☐☐☐☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐
			F M L		M D Y

Please transcribe appropriate categories from the NPI-NH Worksheet into the boxes provided.

For each domain:
- If symptoms of a domain did not apply, check the “N/A” box.
- If symptoms of a domain were absent, check the “0” box.
- If symptoms of a domain were present, check one score each for Frequency and Severity.
- Multiply Frequency score x Severity score and enter the product in the space provided.
- Total all Frequency x Severity scores and record the Total Score below.
- If symptoms of a domain were present, check one score for Occupational Disruptiveness; total all occupational disruptiveness scores for a summary score.

Rater’s Initials: ☐☐☐

DOMAIN	N/A[1]	ABSENT	FREQUENCY	SEVERITY	FREQUENCY X SEVERITY	OCUPATIONAL DISRUPTIVENESS
		0	1 2 3 4	1 2 3		0 1 2 3 4 5
A. Delusions	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
B. Hallucinations	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
C. Agitation/Aggression	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
D. Depression/Dysphoria	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
E. Anxiety	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
F. Elation/Euphoria	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
G. Apathy/Indifference	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
H. Disinhibition	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
I. Irritability/Lability	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
J. Aberrant Motor Behavior	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
TOTAL SCORE:					☐☐☐	☐☐
K. Sleep and Nighttime Behavior Disorders	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐
L. Appetite/Eating Changes	☐	☐	☐☐☐☐	☐☐☐	☐☐	☐☐☐☐☐☐

20

Appendix S Structured Observation Sheet- page 1 of 2

Patient ID: Start Time: Date:

TWO-HOUR STRUCTURED OBSERVATION

Location of patient: Activity:

Light level: Sound level:

	T=0	**T=20**	**T=40**	**T=60**
Nature of RV				
Social Stimulation				
Trigger?				
Affect on Others				
Additional Notes				

Appendix S Structured Observation Sheet- page 2 of 2

Patient ID: Start Time: Date:

TWO-HOUR STRUCTURED OBSERVATION

Location of patient: Activity:

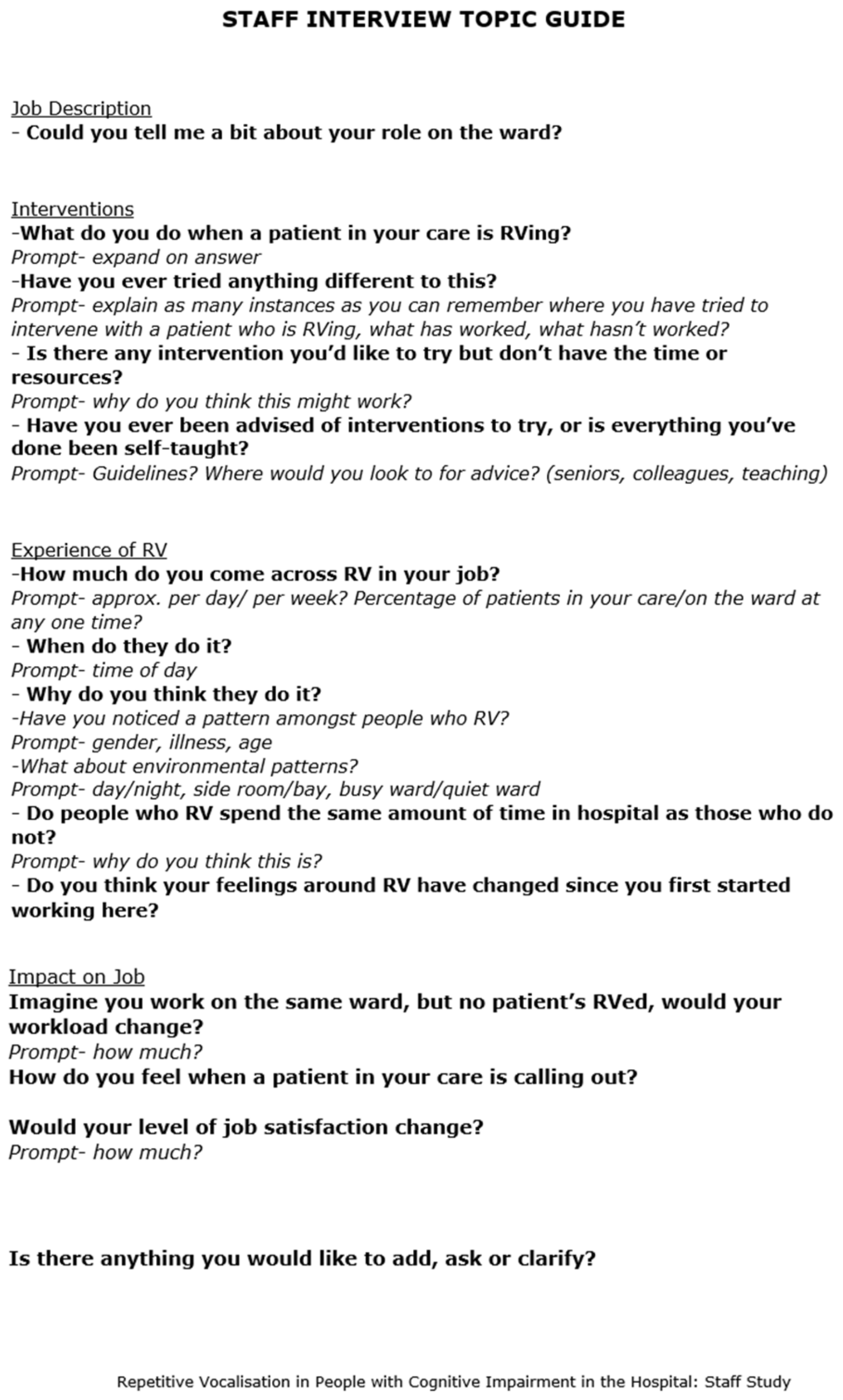
Light level: Sound level:

	T=80	**T=100**	**T=120**	Additional Comments
Nature of RV				
Social Stimulation				
Trigger?				
Affect on Others				
Additional Notes				

Appendix T Unstructured Observations/Field Notes Sheet

Date/ Time	**FIELD NOTES**

Appendix U Staff Member Interview Topic Guide



STAFF INTERVIEW TOPIC GUIDE

Job Description
- **Could you tell me a bit about your role on the ward?**

Interventions
-What do you do when a patient in your care is RVing?
Prompt- expand on answer
-Have you ever tried anything different to this?
Prompt- explain as many instances as you can remember where you have tried to intervene with a patient who is RVing, what has worked, what hasn't worked?
- **Is there any intervention you'd like to try but don't have the time or resources?**
Prompt- why do you think this might work?
- **Have you ever been advised of interventions to try, or is everything you've done been self-taught?**
Prompt- Guidelines? Where would you look to for advice? (seniors, colleagues, teaching)

Experience of RV
-How much do you come across RV in your job?
Prompt- approx. per day/ per week? Percentage of patients in your care/on the ward at any one time?
- **When do they do it?**
Prompt- time of day
- **Why do you think they do it?**
-Have you noticed a pattern amongst people who RV?
Prompt- gender, illness, age
-What about environmental patterns?
Prompt- day/night, side room/bay, busy ward/quiet ward
- **Do people who RV spend the same amount of time in hospital as those who do not?**
Prompt- why do you think this is?
- **Do you think your feelings around RV have changed since you first started working here?**

Impact on Job
Imagine you work on the same ward, but no patient's RVed, would your workload change?
Prompt- how much?
How do you feel when a patient in your care is calling out?

Would your level of job satisfaction change?
Prompt- how much?

Is there anything you would like to add, ask or clarify?

Appendix V Relative Interview Topic Guide

INTERVIEW PARTICIPANT TOPIC GUIDE

So you are [patient name]'s [relation] - *wait for confirmation-*
If friend- when did you meet? How often do you see each other?
If carer- when did you begin caring for ____________? How often do you see him/her?
If partner- how long have you been together?
If other relative- do you live close by? How often do you see each other?

How does he/she generally seem at home?
Do they seem happy? Are they ever anxious? Angry? Upset?

Does he/she RV at home?
If so, is it more or less severe/often as their current state?
If no, is this the first time?

How did hospital staff contact you about RV? Did they give any info?

Have you noticed any patterns amongst his/her RV?
Gender, illness, age,
Day/night, side room/bay, busy ward/quiet ward

[Patient name] has been saying [vocalisation words/sounds] is there any reason you think this is?
Any connections this has to him/her, anything that could be linked
Any reason why they think he/she vocalises

What sort of life has [patient name] had?
Jobs, children, trauma, stress

Have you tried anything to reduce his/her RV?
Past and current attempts, successful or unsuccessful?

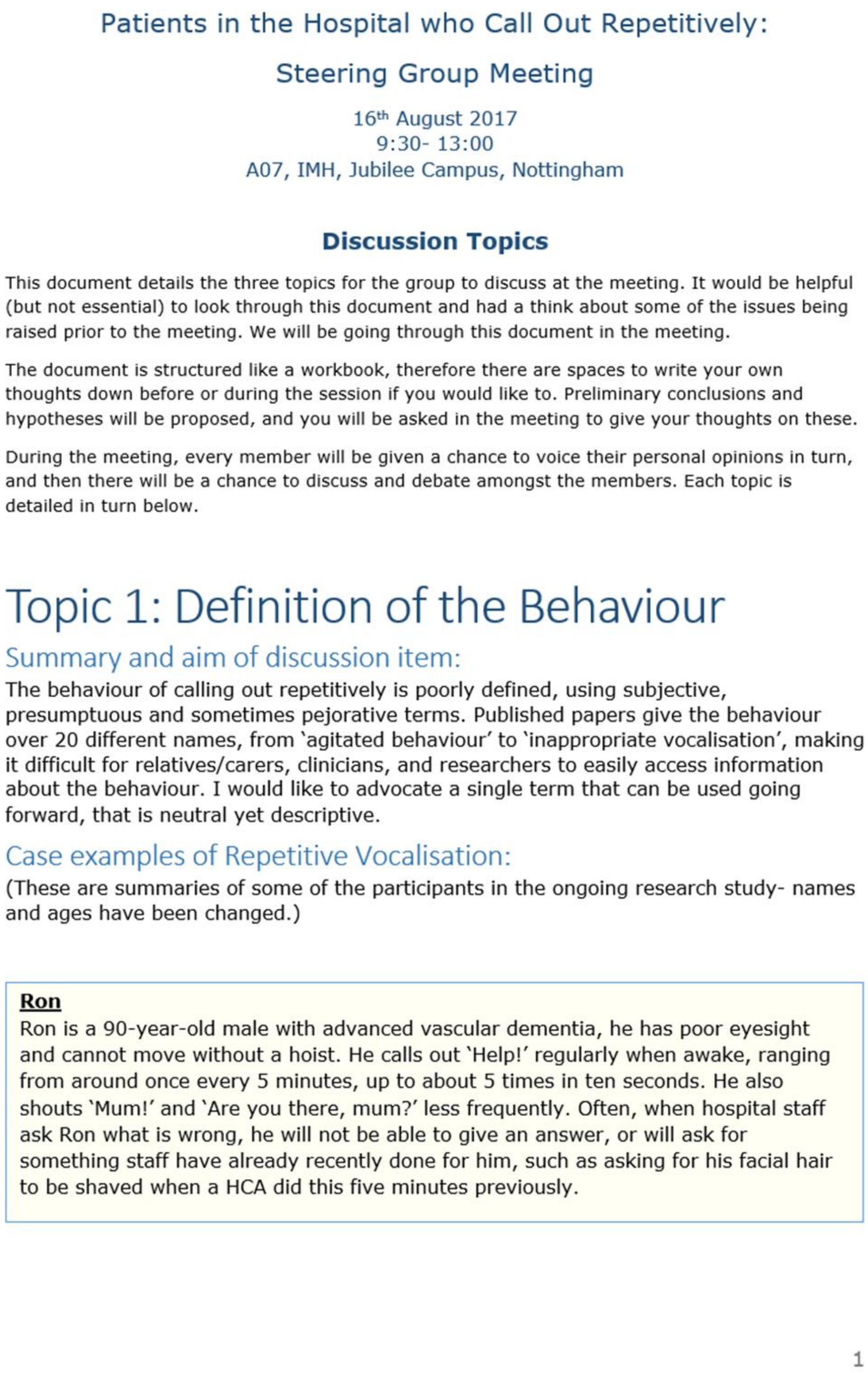
Is there any intervention you'd like to try but don't have the time or resources?
Why do you think this might work?

Do you know if staff members have tried anything?
Past/current, successful/unsuccessful
Is there anything you think they could/should be doing?

Is there anything you would like to add, ask or clarify?

Repetitive Vocalisation in the Hospital: Patient and Carer Study
Final Version 1.0 Date 11/11/2016 IRAS ID:212966 Sponsor Ref: 16096

Appendix W Steering Group Workbook- page 1 of 9



Patients in the Hospital who Call Out Repetitively:

Steering Group Meeting

16th August 2017
9:30- 13:00
A07, IMH, Jubilee Campus, Nottingham

Discussion Topics

This document details the three topics for the group to discuss at the meeting. It would be helpful (but not essential) to look through this document and had a think about some of the issues being raised prior to the meeting. We will be going through this document in the meeting.

The document is structured like a workbook, therefore there are spaces to write your own thoughts down before or during the session if you would like to. Preliminary conclusions and hypotheses will be proposed, and you will be asked in the meeting to give your thoughts on these.

During the meeting, every member will be given a chance to voice their personal opinions in turn, and then there will be a chance to discuss and debate amongst the members. Each topic is detailed in turn below.

Topic 1: Definition of the Behaviour

Summary and aim of discussion item:

The behaviour of calling out repetitively is poorly defined, using subjective, presumptuous and sometimes pejorative terms. Published papers give the behaviour over 20 different names, from ‘agitated behaviour’ to ‘inappropriate vocalisation’, making it difficult for relatives/carers, clinicians, and researchers to easily access information about the behaviour. I would like to advocate a single term that can be used going forward, that is neutral yet descriptive.

Case examples of Repetitive Vocalisation:

(These are summaries of some of the participants in the ongoing research study- names and ages have been changed.)

Ron
Ron is a 90-year-old male with advanced vascular dementia, he has poor eyesight and cannot move without a hoist. He calls out ‘Help!’ regularly when awake, ranging from around once every 5 minutes, up to about 5 times in ten seconds. He also shouts ‘Mum!’ and ‘Are you there, mum?’ less frequently. Often, when hospital staff ask Ron what is wrong, he will not be able to give an answer, or will ask for something staff have already recently done for him, such as asking for his facial hair to be shaved when a HCA did this five minutes previously.

Sylvia

Sylvia is a 68-year-old female with no diagnosis of dementia, she was admitted into hospital due to a fall and confusion, thought to be delirium. She shouts out relatives names, multiple phrases such as 'Help me please', 'I can't do it by myself', and 'Let me get up' alongside screeching sounds. Sylvia has hit two members of staff, bangs loudly on the table, and has been verbally abusive to a number of staff members. Sylvia is able to vocalise her needs, asking for the toilet or a drink when she needs.

Joan

Joan is a 75-year-old female with late-stage dementia. She requires major help with all aspects of daily living, and is unable to hold a basic conversation. She constantly mutters under her breath words such as 'Please', 'No' and 'Mum', and non-words, such as repetition of 'Weh'. She cries every now and again but stops within a few seconds. In the space of an hour, she cried about 5 times for about 10-20 seconds each time. To staff, she appears unable to vocalise her needs.

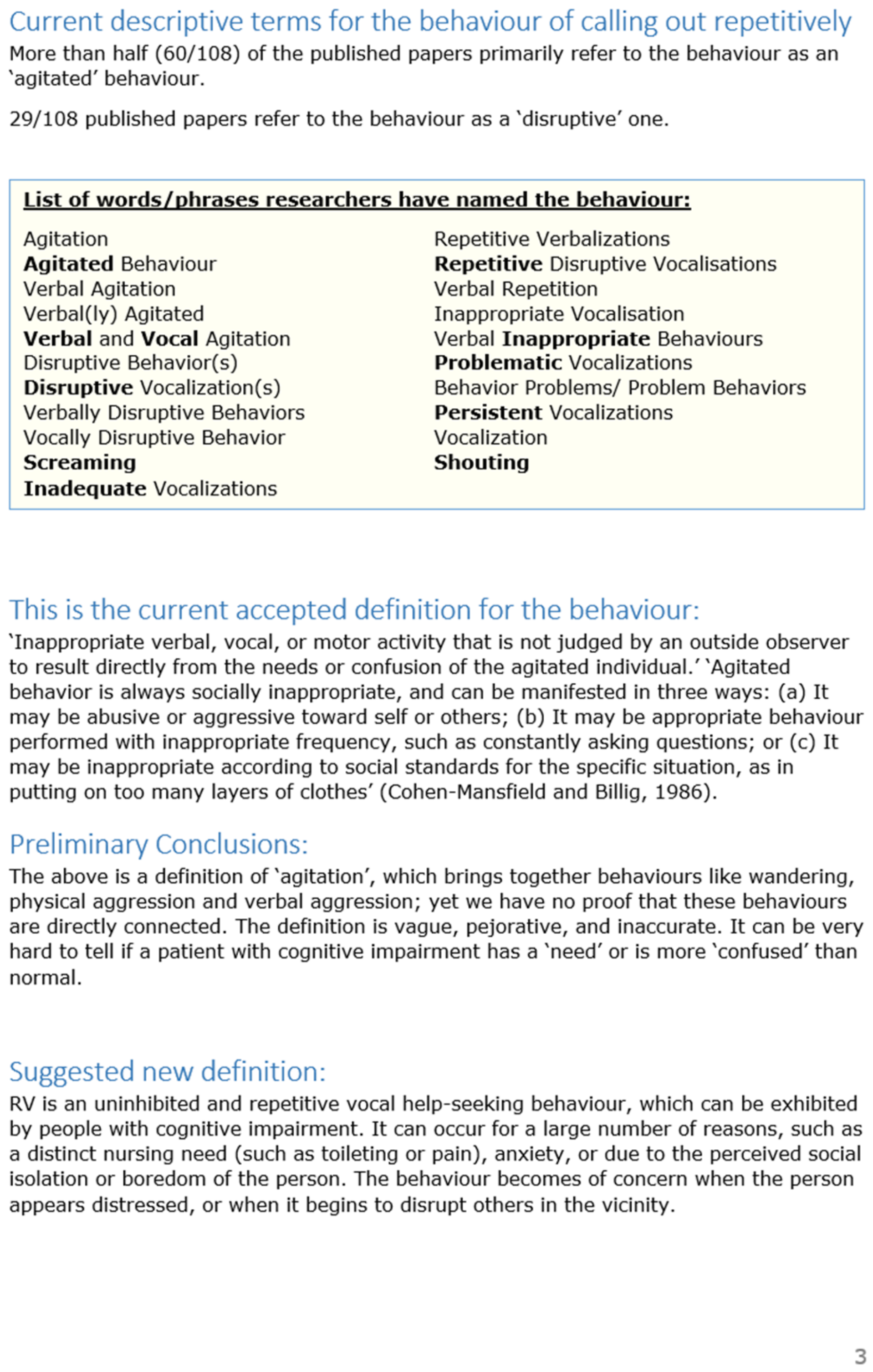
Discussion Point:

- What specific words could be used to describe these types of verbal/vocal behaviour? How would you describe the behaviours to somebody else?

Space for notes:

Consider: How we can define RV, and can we do it in a non-subjective and non-pejorative way?

What phrase is clinician and relative/carer friendly, and succinctly describes the behaviour?



Current descriptive terms for the behaviour of calling out repetitively

More than half (60/108) of the published papers primarily refer to the behaviour as an 'agitated' behaviour.

29/108 published papers refer to the behaviour as a 'disruptive' one.

List of words/phrases researchers have named the behaviour:

Agitation
Agitated Behaviour
Verbal Agitation
Verbal(ly) Agitated
Verbal and **Vocal** Agitation
Disruptive Behavior(s)
Disruptive Vocalization(s)
Verbally Disruptive Behaviors
Vocally Disruptive Behavior
Screaming
Inadequate Vocalizations
Repetitive Verbalizations
Repetitive Disruptive Vocalisations
Verbal Repetition
Inappropriate Vocalisation
Verbal **Inappropriate** Behaviours
Problematic Vocalizations
Behavior Problems/ Problem Behaviors
Persistent Vocalizations
Vocalization
Shouting

This is the current accepted definition for the behaviour:

'Inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual.' 'Agitated behavior is always socially inappropriate, and can be manifested in three ways: (a) It may be abusive or aggressive toward self or others; (b) It may be appropriate behaviour performed with inappropriate frequency, such as constantly asking questions; or (c) It may be inappropriate according to social standards for the specific situation, as in putting on too many layers of clothes' (Cohen-Mansfield and Billig, 1986).

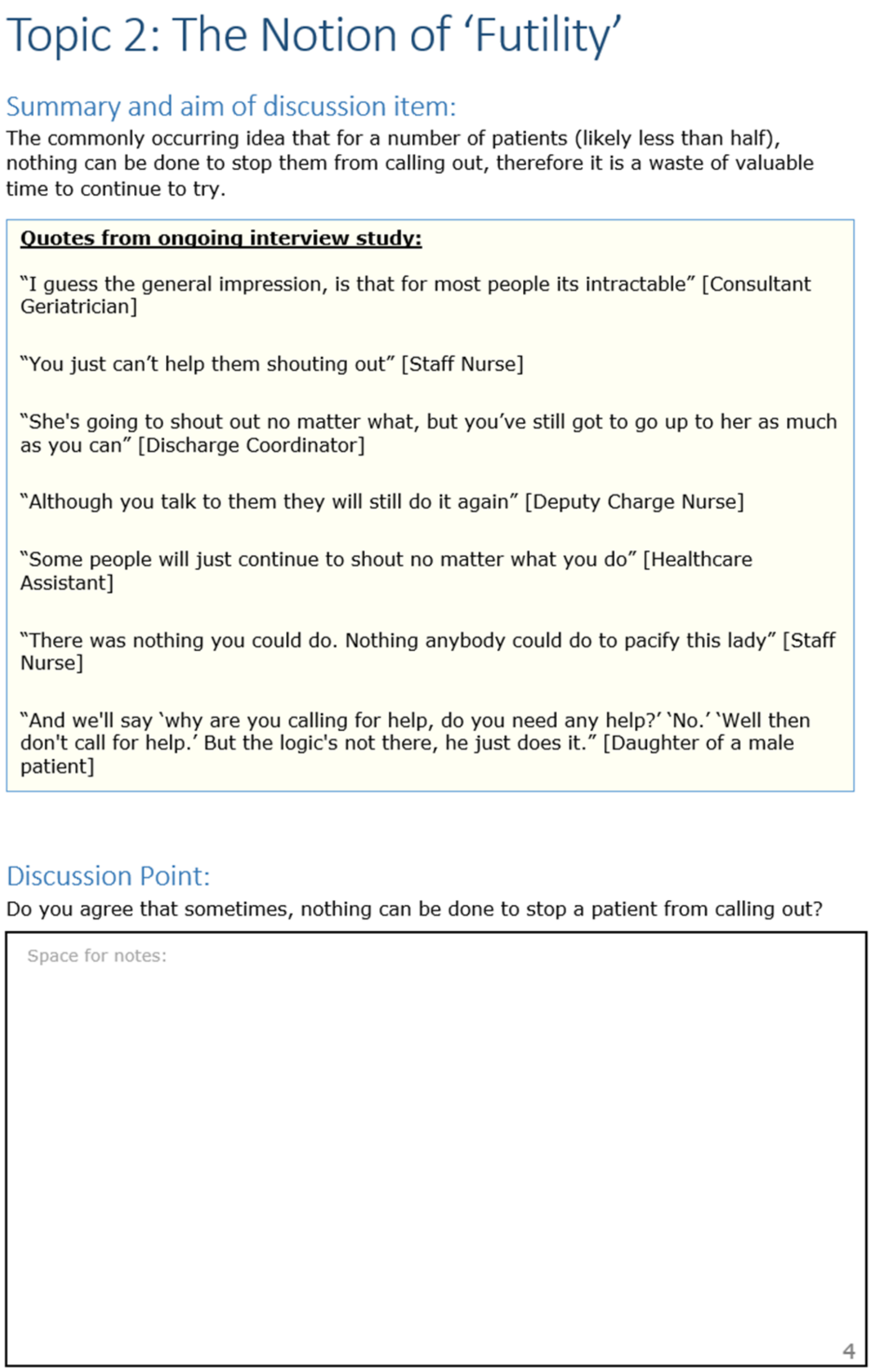
Preliminary Conclusions:

The above is a definition of 'agitation', which brings together behaviours like wandering, physical aggression and verbal aggression; yet we have no proof that these behaviours are directly connected. The definition is vague, pejorative, and inaccurate. It can be very hard to tell if a patient with cognitive impairment has a 'need' or is more 'confused' than normal.

Suggested new definition:

RV is an uninhibited and repetitive vocal help-seeking behaviour, which can be exhibited by people with cognitive impairment. It can occur for a large number of reasons, such as a distinct nursing need (such as toileting or pain), anxiety, or due to the perceived social isolation or boredom of the person. The behaviour becomes of concern when the person appears distressed, or when it begins to disrupt others in the vicinity.

3



Topic 2: The Notion of 'Futility'

Summary and aim of discussion item:

The commonly occurring idea that for a number of patients (likely less than half), nothing can be done to stop them from calling out, therefore it is a waste of valuable time to continue to try.

Quotes from ongoing interview study:

"I guess the general impression, is that for most people its intractable" [Consultant Geriatrician]

"You just can't help them shouting out" [Staff Nurse]

"She's going to shout out no matter what, but you've still got to go up to her as much as you can" [Discharge Coordinator]

"Although you talk to them they will still do it again" [Deputy Charge Nurse]

"Some people will just continue to shout no matter what you do" [Healthcare Assistant]

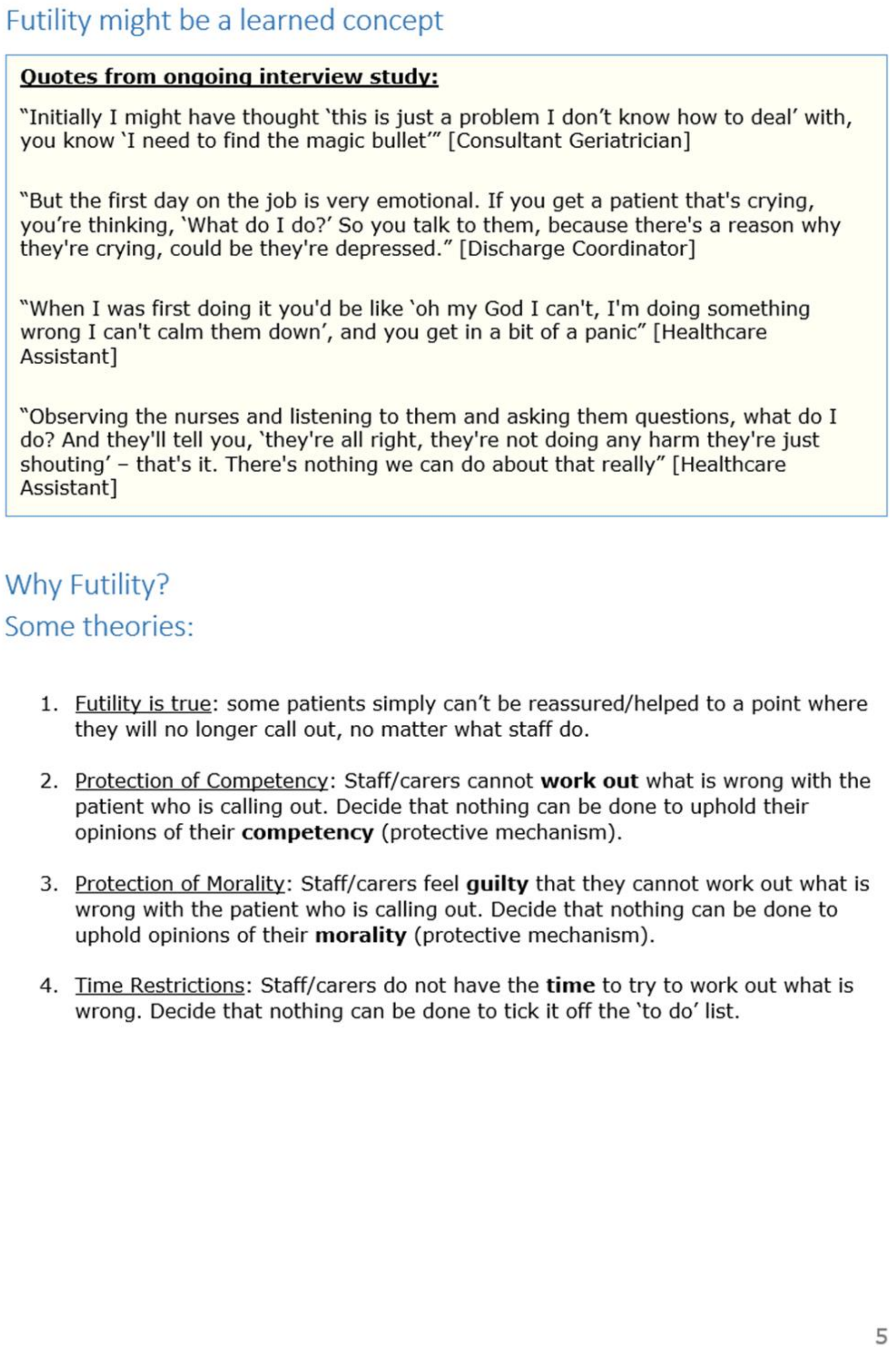
"There was nothing you could do. Nothing anybody could do to pacify this lady" [Staff Nurse]

"And we'll say 'why are you calling for help, do you need any help?' 'No.' 'Well then don't call for help.' But the logic's not there, he just does it." [Daughter of a male patient]

Discussion Point:

Do you agree that sometimes, nothing can be done to stop a patient from calling out?

Space for notes:



Futility might be a learned concept

Quotes from ongoing interview study:

"Initially I might have thought 'this is just a problem I don't know how to deal' with, you know 'I need to find the magic bullet'" [Consultant Geriatrician]

"But the first day on the job is very emotional. If you get a patient that's crying, you're thinking, 'What do I do?' So you talk to them, because there's a reason why they're crying, could be they're depressed." [Discharge Coordinator]

"When I was first doing it you'd be like 'oh my God I can't, I'm doing something wrong I can't calm them down', and you get in a bit of a panic" [Healthcare Assistant]

"Observing the nurses and listening to them and asking them questions, what do I do? And they'll tell you, 'they're all right, they're not doing any harm they're just shouting' – that's it. There's nothing we can do about that really" [Healthcare Assistant]

Why Futility?

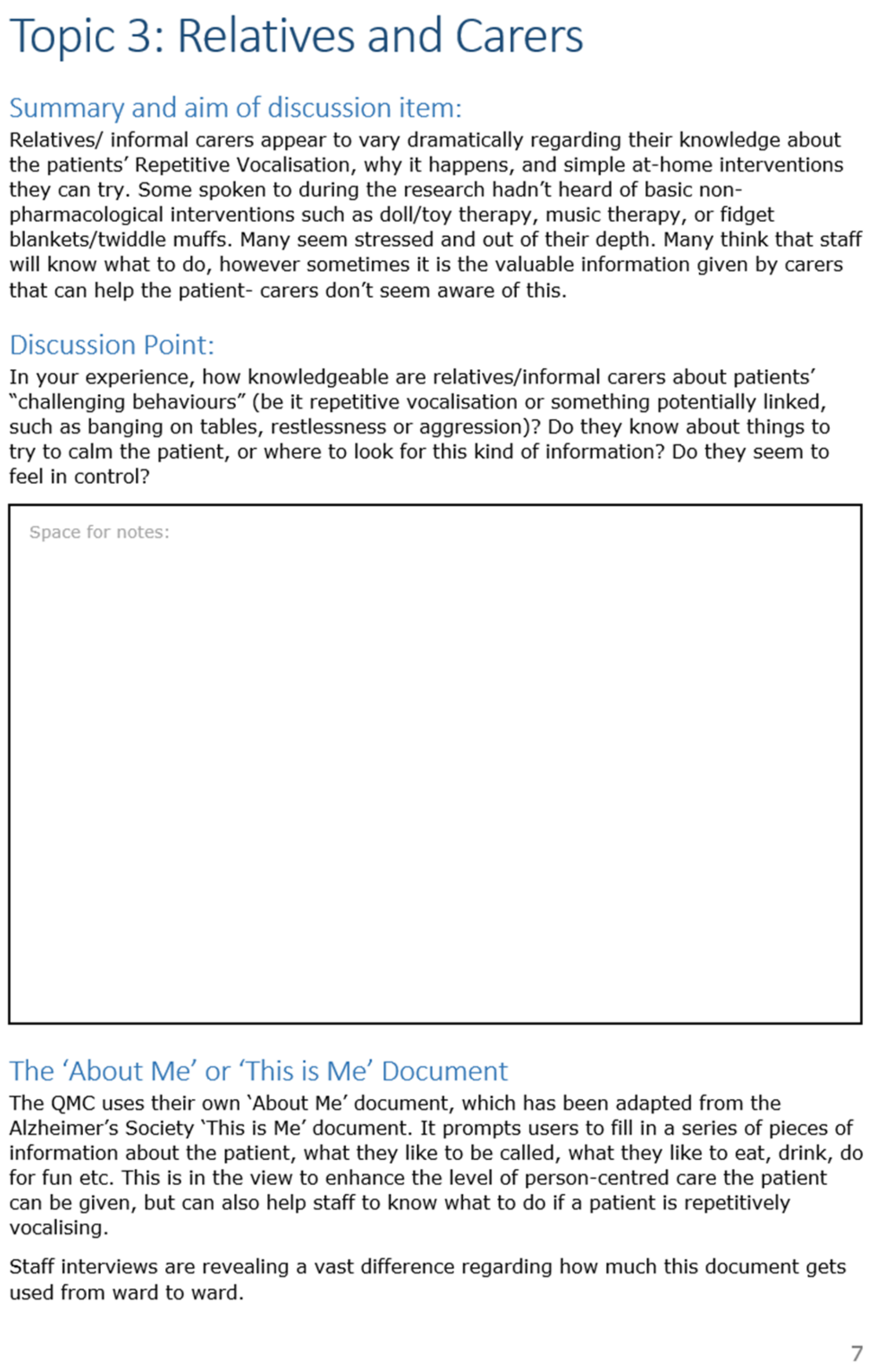
Some theories:

1. Futility is true: some patients simply can't be reassured/helped to a point where they will no longer call out, no matter what staff do.
2. Protection of Competency: Staff/carers cannot **work out** what is wrong with the patient who is calling out. Decide that nothing can be done to uphold their opinions of their **competency** (protective mechanism).
3. Protection of Morality: Staff/carers feel **guilty** that they cannot work out what is wrong with the patient who is calling out. Decide that nothing can be done to uphold opinions of their **morality** (protective mechanism).
4. Time Restrictions: Staff/carers do not have the **time** to try to work out what is wrong. Decide that nothing can be done to tick it off the 'to do' list.

Discussion Point:

What is your opinion on these theories? Which one (if any) do you think is correct? Do you have your own theory (or theories) as to why futility is established?

Space for notes:



Topic 3: Relatives and Carers

Summary and aim of discussion item:

Relatives/ informal carers appear to vary dramatically regarding their knowledge about the patients' Repetitive Vocalisation, why it happens, and simple at-home interventions they can try. Some spoken to during the research hadn't heard of basic non-pharmacological interventions such as doll/toy therapy, music therapy, or fidget blankets/twiddle muffs. Many seem stressed and out of their depth. Many think that staff will know what to do, however sometimes it is the valuable information given by carers that can help the patient- carers don't seem aware of this.

Discussion Point:

In your experience, how knowledgeable are relatives/informal carers about patients' "challenging behaviours" (be it repetitive vocalisation or something potentially linked, such as banging on tables, restlessness or aggression)? Do they know about things to try to calm the patient, or where to look for this kind of information? Do they seem to feel in control?

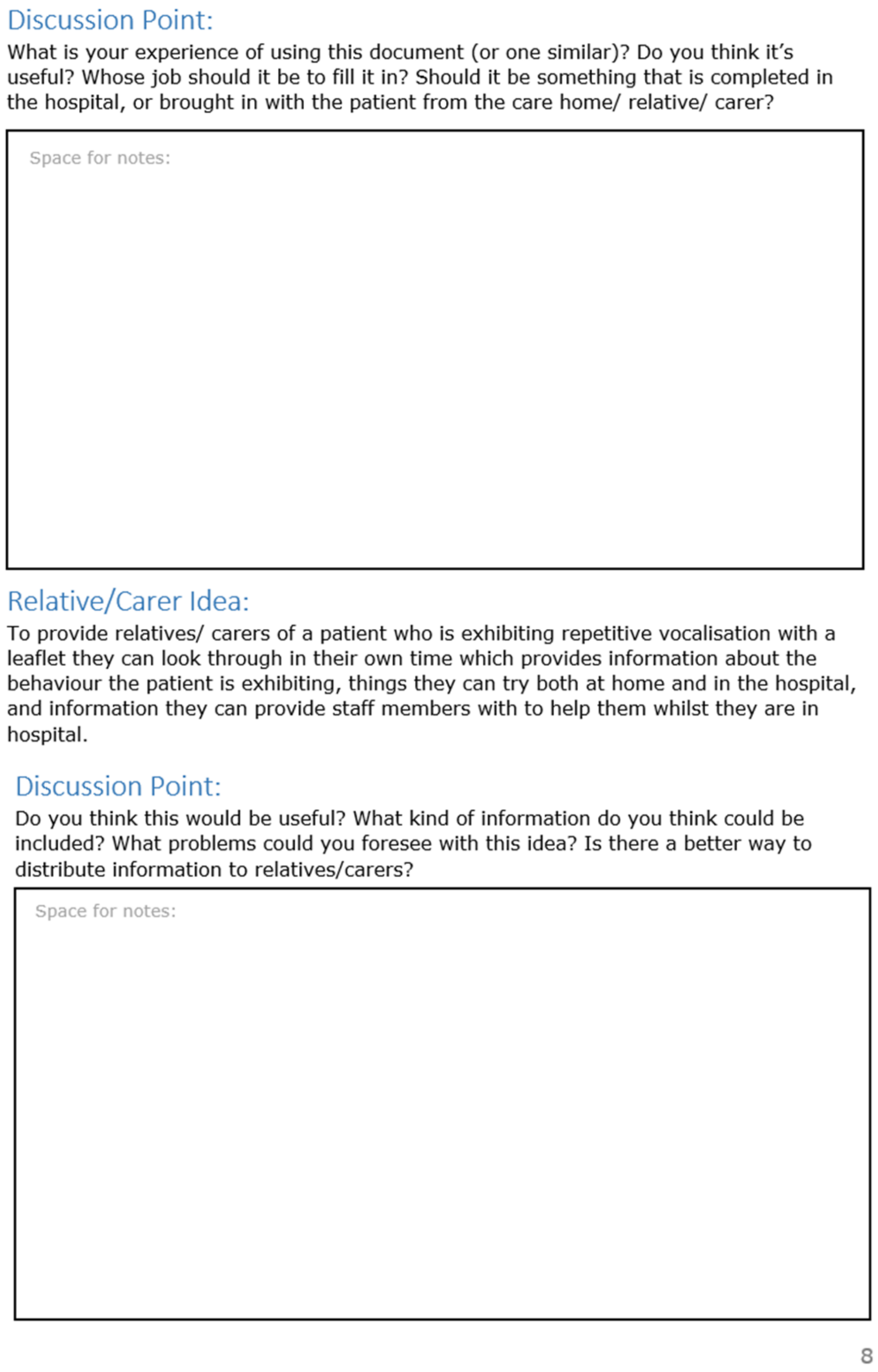
Space for notes:

The 'About Me' or 'This is Me' Document

The QMC uses their own 'About Me' document, which has been adapted from the Alzheimer's Society 'This is Me' document. It prompts users to fill in a series of pieces of information about the patient, what they like to be called, what they like to eat, drink, do for fun etc. This is in the view to enhance the level of person-centred care the patient can be given, but can also help staff to know what to do if a patient is repetitively vocalising.

Staff interviews are revealing a vast difference regarding how much this document gets used from ward to ward.

Appendix W Steering Group Workbook- page 8 of 9



Discussion Point:

What is your experience of using this document (or one similar)? Do you think it's useful? Whose job should it be to fill it in? Should it be something that is completed in the hospital, or brought in with the patient from the care home/ relative/ carer?

Space for notes:

Relative/Carer Idea:

To provide relatives/ carers of a patient who is exhibiting repetitive vocalisation with a leaflet they can look through in their own time which provides information about the behaviour the patient is exhibiting, things they can try both at home and in the hospital, and information they can provide staff members with to help them whilst they are in hospital.

Discussion Point:

Do you think this would be useful? What kind of information do you think could be included? What problems could you foresee with this idea? Is there a better way to distribute information to relatives/carers?

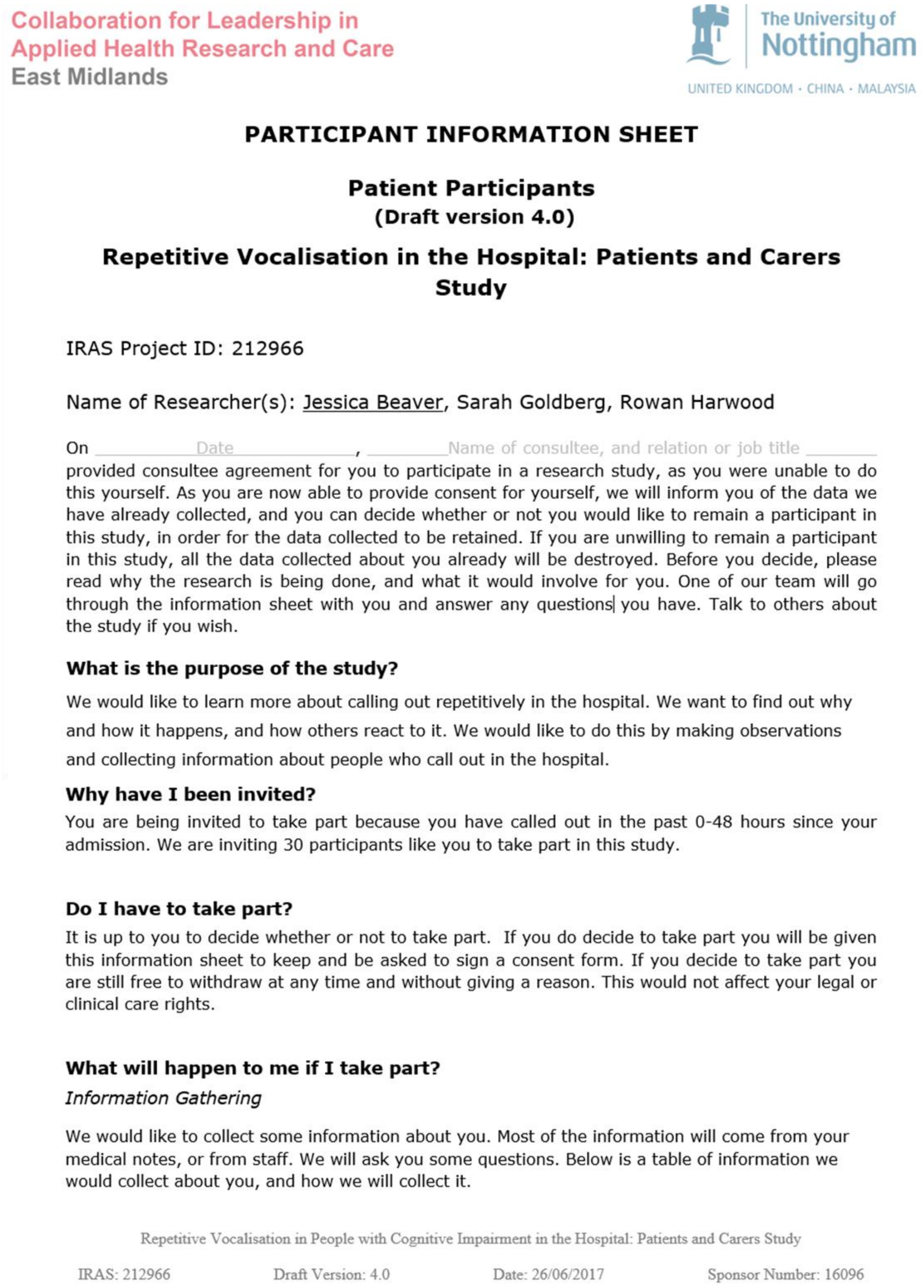
Space for notes:

8

Is there anything else you'd like the group to discuss?

Space for notes:

Appendix X Participant Information Sheet for Regained Mental Capacity- page 1 of 4



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PARTICIPANT INFORMATION SHEET

Patient Participants
(Draft version 4.0)

Repetitive Vocalisation in the Hospital: Patients and Carers Study

IRAS Project ID: 212966

Name of Researcher(s): Jessica Beaver, Sarah Goldberg, Rowan Harwood

On __________Date______________, _________Name of consultee, and relation or job title ________ provided consultee agreement for you to participate in a research study, as you were unable to do this yourself. As you are now able to provide consent for yourself, we will inform you of the data we have already collected, and you can decide whether or not you would like to remain a participant in this study, in order for the data collected to be retained. If you are unwilling to remain a participant in this study, all the data collected about you already will be destroyed. Before you decide, please read why the research is being done, and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish.

What is the purpose of the study?

We would like to learn more about calling out repetitively in the hospital. We want to find out why and how it happens, and how others react to it. We would like to do this by making observations and collecting information about people who call out in the hospital.

Why have I been invited?

You are being invited to take part because you have called out in the past 0-48 hours since your admission. We are inviting 30 participants like you to take part in this study.

Do I have to take part?

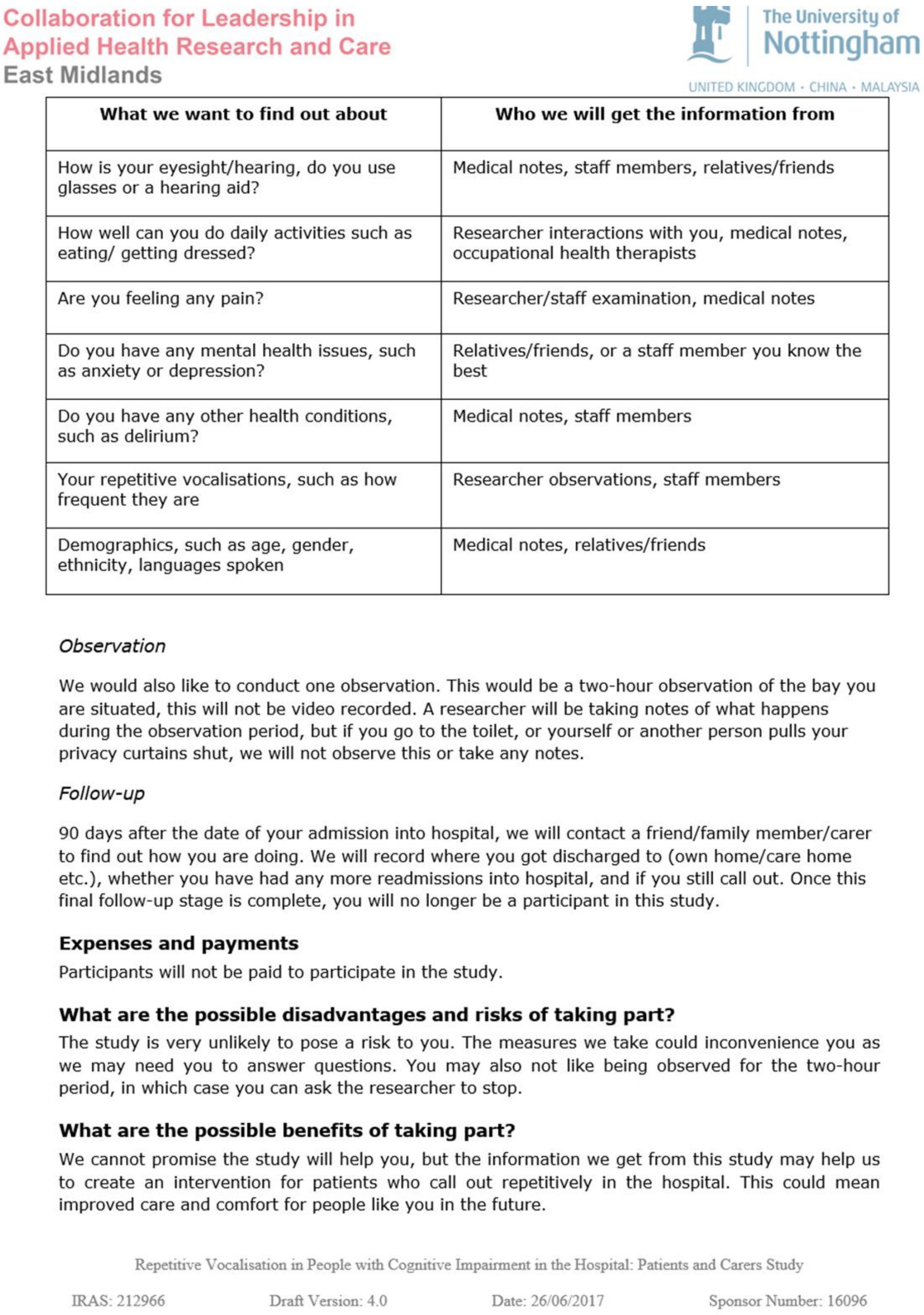
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal or clinical care rights.

What will happen to me if I take part?

Information Gathering

We would like to collect some information about you. Most of the information will come from your medical notes, or from staff. We will ask you some questions. Below is a table of information we would collect about you, and how we will collect it.

__Appendix X__ Participant Information Sheet for Regained Mental Capacity- page 2 of 4



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What we want to find out about	Who we will get the information from
How is your eyesight/hearing, do you use glasses or a hearing aid?	Medical notes, staff members, relatives/friends
How well can you do daily activities such as eating/ getting dressed?	Researcher interactions with you, medical notes, occupational health therapists
Are you feeling any pain?	Researcher/staff examination, medical notes
Do you have any mental health issues, such as anxiety or depression?	Relatives/friends, or a staff member you know the best
Do you have any other health conditions, such as delirium?	Medical notes, staff members
Your repetitive vocalisations, such as how frequent they are	Researcher observations, staff members
Demographics, such as age, gender, ethnicity, languages spoken	Medical notes, relatives/friends

Observation

We would also like to conduct one observation. This would be a two-hour observation of the bay you are situated, this will not be video recorded. A researcher will be taking notes of what happens during the observation period, but if you go to the toilet, or yourself or another person pulls your privacy curtains shut, we will not observe this or take any notes.

Follow-up

90 days after the date of your admission into hospital, we will contact a friend/family member/carer to find out how you are doing. We will record where you got discharged to (own home/care home etc.), whether you have had any more readmissions into hospital, and if you still call out. Once this final follow-up stage is complete, you will no longer be a participant in this study.

Expenses and payments

Participants will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

The study is very unlikely to pose a risk to you. The measures we take could inconvenience you as we may need you to answer questions. You may also not like being observed for the two-hour period, in which case you can ask the researcher to stop.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study may help us to create an intervention for patients who call out repetitively in the hospital. This could mean improved care and comfort for people like you in the future.

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study

IRAS: 212966 Draft Version: 4.0 Date: 26/06/2017 Sponsor Number: 16096

Appendix X Participant Information Sheet for Regained Mental Capacity- page 3 of 4

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What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers, who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. You can also speak to staff members, or your friends/relatives/carers if you have any worries. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service on: 0800 032 3235.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, data we have collected about you will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 3 years after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although data is confidential, should you disclose anything to us, or we see anything which we feel puts you or anyone else at risk of harm, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. Data collected up to that point will not be deleted unless you ask us to.

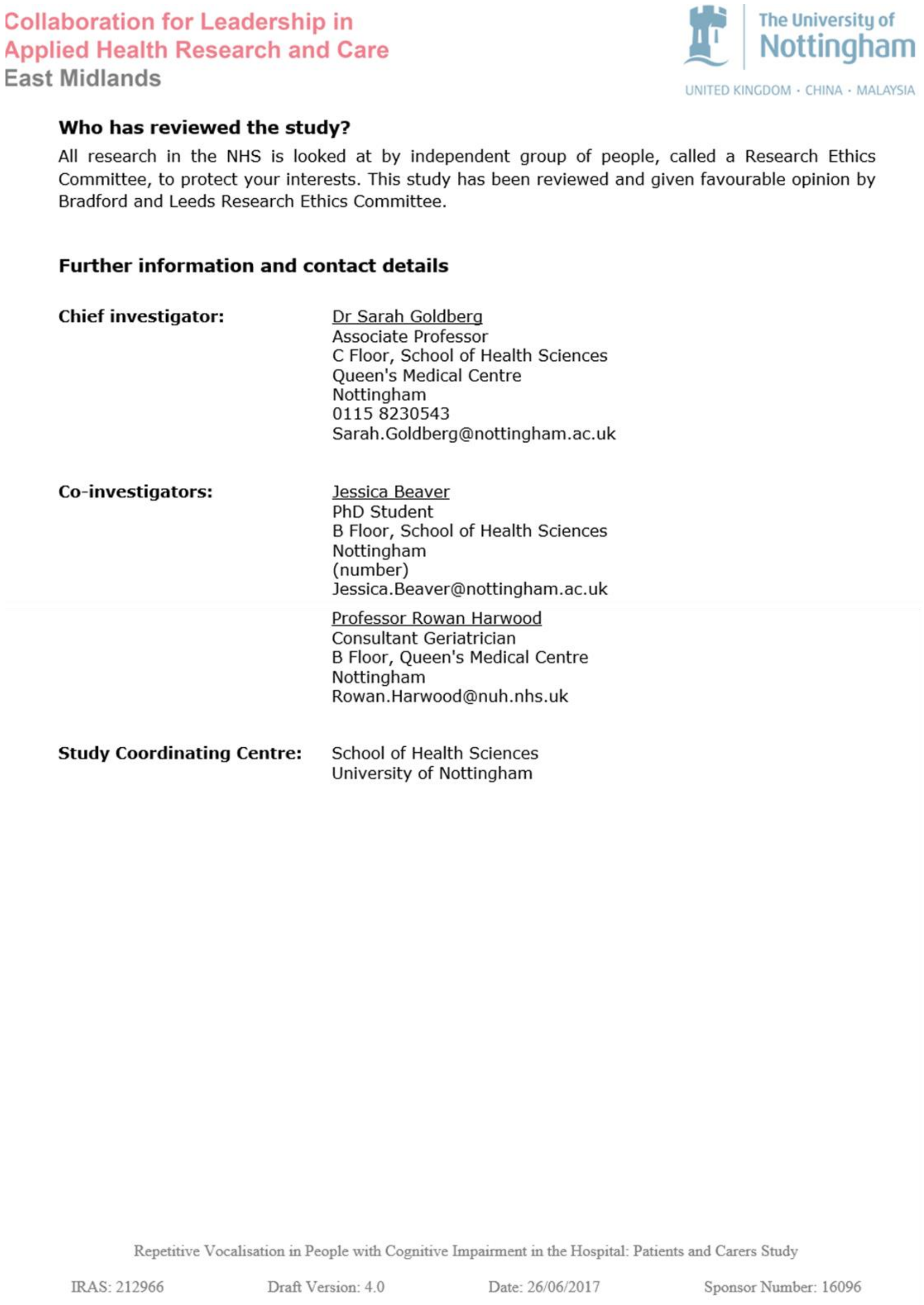
What will happen to the results of the research study?

Once the study has ended, data will be analysed, written-up, and published. A summary can be sent to you if you would like, and you will be asked this after your interview. No information in the publication should make you able to be identified. This study is being completed for a PhD award.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by both the University of Nottingham and the Collaboration for Leadership in Applied Health Research & Care (CLAHRC).

Appendix X Participant Information Sheet for Regained Mental Capacity- page 4 of 4



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Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Bradford and Leeds Research Ethics Committee.

Further information and contact details

Chief investigator:

Dr Sarah Goldberg
Associate Professor
C Floor, School of Health Sciences
Queen's Medical Centre
Nottingham
0115 8230543
Sarah.Goldberg@nottingham.ac.uk

Co-investigators:

Jessica Beaver
PhD Student
B Floor, School of Health Sciences
Nottingham
(number)
Jessica.Beaver@nottingham.ac.uk

Professor Rowan Harwood
Consultant Geriatrician
B Floor, Queen's Medical Centre
Nottingham
Rowan.Harwood@nuh.nhs.uk

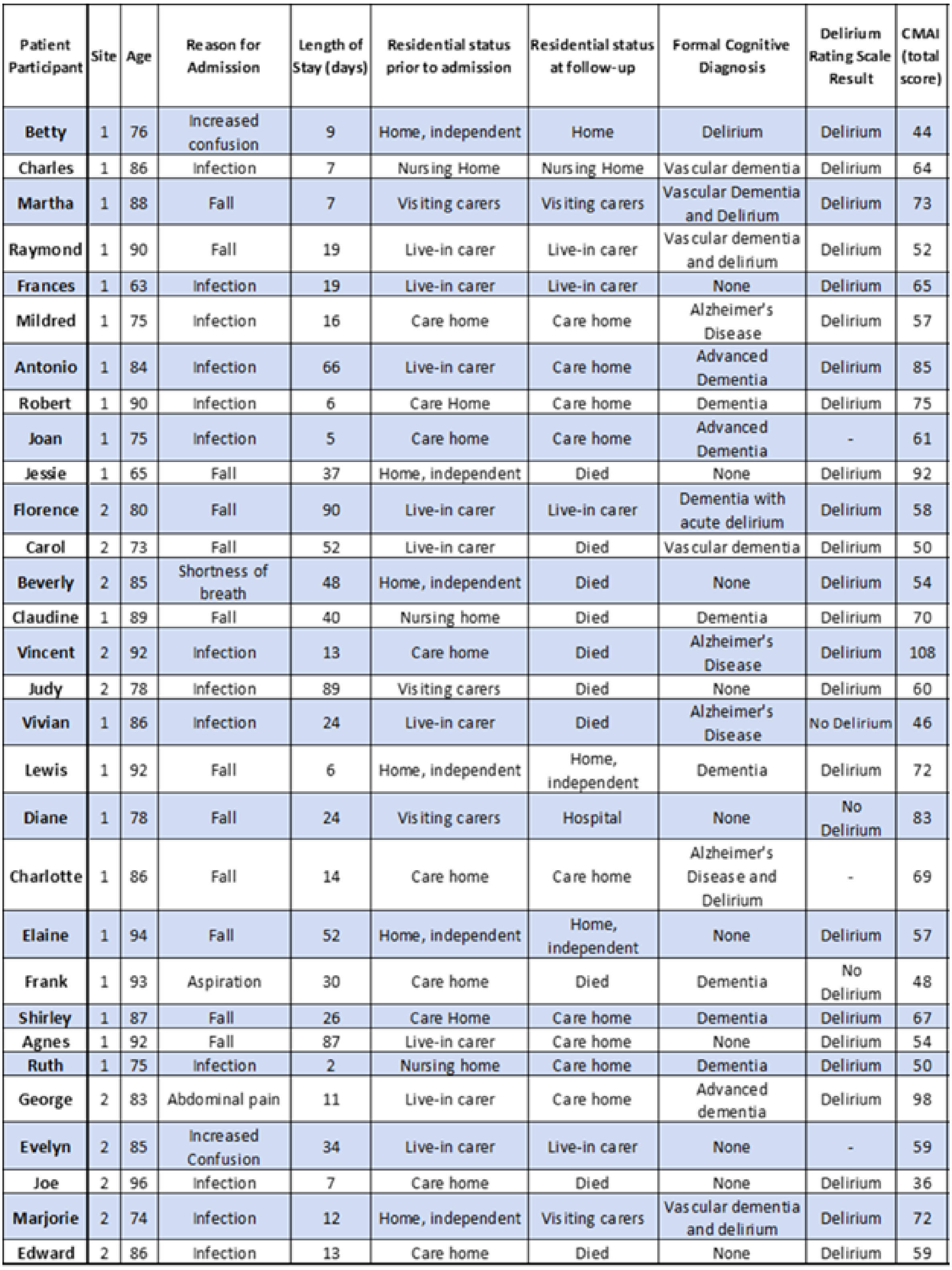
Study Coordinating Centre:

School of Health Sciences
University of Nottingham

Repetitive Vocalisation in People with Cognitive Impairment in the Hospital: Patients and Carers Study

IRAS: 212966 Draft Version: 4.0 Date: 26/06/2017 Sponsor Number: 16096

Appendix Y *A descriptive table of patient participants and their characteristics- page 1 of 2*



Patient Participant	Site	Age	Reason for Admission	Length of Stay (days)	Residential status prior to admission	Residential status at follow-up	Formal Cognitive Diagnosis	Delirium Rating Scale Result	CMAI (total score)
Betty	1	76	Increased confusion	9	Home, independent	Home	Delirium	Delirium	44
Charles	1	86	Infection	7	Nursing Home	Nursing Home	Vascular dementia	Delirium	64
Martha	1	88	Fall	7	Visiting carers	Visiting carers	Vascular Dementia and Delirium	Delirium	73
Raymond	1	90	Fall	19	Live-in carer	Live-in carer	Vascular dementia and delirium	Delirium	52
Frances	1	63	Infection	19	Live-in carer	Live-in carer	None	Delirium	65
Mildred	1	75	Infection	16	Care home	Care home	Alzheimer's Disease	Delirium	57
Antonio	1	84	Infection	66	Live-in carer	Care home	Advanced Dementia	Delirium	85
Robert	1	90	Infection	6	Care Home	Care home	Dementia	Delirium	75
Joan	1	75	Infection	5	Care home	Care home	Advanced Dementia	-	61
Jessie	1	65	Fall	37	Home, independent	Died	None	Delirium	92
Florence	2	80	Fall	90	Live-in carer	Live-in carer	Dementia with acute delirium	Delirium	58
Carol	2	73	Fall	52	Live-in carer	Died	Vascular dementia	Delirium	50
Beverly	2	85	Shortness of breath	48	Home, independent	Died	None	Delirium	54
Claudine	1	89	Fall	40	Nursing home	Died	Dementia	Delirium	70
Vincent	2	92	Infection	13	Care home	Died	Alzheimer's Disease	Delirium	108
Judy	2	78	Infection	89	Visiting carers	Died	None	Delirium	60
Vivian	1	86	Infection	24	Live-in carer	Died	Alzheimer's Disease	No Delirium	46
Lewis	1	92	Fall	6	Home, independent	Home, independent	Dementia	Delirium	72
Diane	1	78	Fall	24	Visiting carers	Hospital	None	No Delirium	83
Charlotte	1	86	Fall	14	Care home	Care home	Alzheimer's Disease and Delirium	-	69
Elaine	1	94	Fall	52	Home, independent	Home, independent	None	Delirium	57
Frank	1	93	Aspiration	30	Care home	Died	Dementia	No Delirium	48
Shirley	1	87	Fall	26	Care Home	Care home	Dementia	Delirium	67
Agnes	1	92	Fall	87	Live-in carer	Care home	None	Delirium	54
Ruth	1	75	Infection	2	Nursing home	Care home	Dementia	Delirium	50
George	2	83	Abdominal pain	11	Live-in carer	Care home	Advanced dementia	Delirium	98
Evelyn	2	85	Increased Confusion	34	Live-in carer	Live-in carer	None	-	59
Joe	2	96	Infection	7	Care home	Died	None	Delirium	36
Marjorie	2	74	Infection	12	Home, independent	Visiting carers	Vascular dementia and delirium	Delirium	72
Edward	2	86	Infection	13	Care home	Died	None	Delirium	59

Appendix Y *A descriptive table of patient participants and their characteristics- page 2 of 2*

Patient Participant	Site	Age	PAS-AV highest score (admission-discharge)	Continued to call out at follow-up	Cognitive Impairment (sMMSE)	Pain Rating (PAINAD)	Physical Impairment (Barthel ADL)	NPI-NH Score	CSDD Score	Readmitted during follow-up	Hours of unstructured observation	Hours of Structured Observation
Betty	1	76	2 (2-0)	No	Moderate	Mild	Severe	38	17	Yes	3	0
Charles	1	86	3 (3-2)	Yes	Severe	Moderate	Severe	54	25	No	4.5	1.5
Martha	1	88	4 (4-0)	No	Mild	Moderate	Moderate	19	20	Yes	5	2
Raymond	1	90	3 (3-3)	Yes	Severe	Moderate	Severe	24	2	Yes	5	2
Frances	1	63	3 (3-3)	No	Severe	Mild	Severe	15	9	Yes	3.5	2
Mildred	1	75	4 (4-2)	No	Severe	Moderate	Severe	25	8	Yes	4.5	2
Antonio	1	84	3 (3-2)	Yes	Severe	Mild	Moderate	15	12	No	8.5	2
Robert	1	90	4 (4-3)	No	Severe	Mild	Severe	-	-	Yes	3.5	1
Joan	1	75	2 (2-2)	Yes	Severe	Moderate	Severe	-	-	Yes	3	2
Jessie	1	65	3 (3-2)	N/A	Severe	Moderate	Severe	38	18	N/A	8.5	2
Florence	2	80	3 (1-0)	Yes	Severe	Mild	Severe	23	15	No	11	2
Carol	2	73	3 (3-0)	N/A	Severe	Mild	Severe	45	-	N/A	6	0
Beverly	2	85	3 (2-1)	N/A	Moderate	Moderate	Severe	25	18	N/A	5	0
Claudine	1	89	3 (2-1)	N/A	Severe	Moderate	Severe	22	17	N/A	4.5	2
Vincent	2	92	4 (4-3)	N/A	Severe	Severe	Severe	-	-	N/A	3	2
Judy	2	78	3 (3-3)	N/A	Moderate	Moderate	Severe	29	16	N/A	6.5	2
Vivian	1	86	3 (3-2)	N/A	Moderate	Mild	Severe	22	17	N/A	2.5	2
Lewis	1	92	3 (3-3)	Yes	Severe	None	Moderate	-		Yes	3.5	2
Diane	1	78	3 (3-3)	Yes	Moderate	Moderate	Moderate	27	12	N/A	7	2
Charlotte	1	86	2 (2-2)	Yes	Severe	Severe	Severe	45	22	No	2.5	2
Elaine	1	94	2 (2-0)	No	Moderate	None	Moderate	13	6	Yes	3.5	2
Frank	1	93	2 (2-2)	N/A	Severe	None	Moderate	ND	11	N/A	2	0
Shirley	1	87	3 (2-1)	Yes	Severe	Mild	Severe	34	24	Yes	6	2
Agnes	1	92	3 (3-2)	No	-	Mild	Severe	21	19	No	6.5	2
Ruth	1	75	2 (2-2)	Yes	Severe	None	Severe	34	17	No	2	2
George	2	83	4 (4-4)	Yes	Severe	Moderate	Severe	33	11	Yes	4.5	2
Evelyn	2	85	3 (2-1)	No	-	Mild	Moderate	30	8	No	6	2
Joe	2	96	3 (3-2)	N/A	Severe	Mild	Severe	21	14	N/A	2	2
Marjorie	2	74	4 (4-0)	No	Severe	Moderate	Mild	38	14	No	3	2
Edward	2	86	2 (2-2)	N/A	Moderate	Moderate	Severe	18	21	N/A	5.5	2

Appendix Z Suggestion for a New Measure of Calling Out, Disruptivity

Vocalisation Disruptiveness Scale

How many people can hear the patient when they are at their loudest? *As the rater, if you can hear the vocalisations very clearly when x distance away from the patient, mark down how many other people will remain that distance away from the patient for more than half of the time in 12/24 hours.*	
0	1
1-3	2
4-6	3
7-10	4
10+	5
Is the content upsetting or emotive? *If the content is mixed, mark down the most upsetting/emotive language you/ a staff member has observed during the rating period.*	
Neutral (*No emotive language*)	1
Calling for help (*Nurse, Help, Doctor, Please*)	2
Emotive (*Suicidal content, crying, emotional language "please don't leave me" "you're a liar"*)	3
Swearing	4
Abusive, strong language, swearing, threatening	5
How loud are the vocalisations? *Base 'conversational' on other conversations that have happened in the same/ nearby location*	
Very low level	1
Conversational	2
Louder than conversational	3
Loud/shouting	4
Extremely loud yelling/screaming	5
How redirectable are the vocalisations? *Are you or a staff member able to stop the vocalisations for any length of time?*	
Redirectable, patient remains quiet (or significantly quieter) for >1 hour after redirection	1
Redirectable, patient remains quiet (or significantly quieter) for >20 minutes after redirection	2
Redirectable, patient remains quiet (or significantly quieter) for >5 minutes after redirection	3
Redirectable, but patient instantly vocalises as soon as caregiver walks away	4
Not redirectable	5
Are the vocalisations constant when awake?	
Mainly quiet with small periods of calling out	1
Large periods of silence	2
Vocalises about half of the time	3
Small periods of silence	4
Constant vocalisation	5
VDS Score: /25	