Dementia Inpatient Study on The Recognition and Evaluation of Signs Signalling Emotional Distress

DISTRESSED

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The candidate confirms that the work submitted is his own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

The work in Chapter 2 of the thesis has appeared in publication as follows: How well are the diagnosis and symptoms of dementia recorded in older patients admitted to hospital? 2017, Crowther GJE, Bennett MI, Holmes JD. The candidate was responsible for the study design, data collection, analysis and write-up. The contribution of the other authors was supervision of the study and feedback on completed work.

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Abstract

Dementia is a common comorbidity in older people admitted to general hospital. People with dementia have a high prevalence of psychological symptoms, pain and delirium, which if left untreated can cause distress and predispose the person to worse outcomes. Identifying individual symptoms or the causes of distress can be difficult because people with more severe dementia often struggle to communicate. Systems are in place to help healthcare professionals recognise and treat individual symptoms, but they require the user to be able to apply and use them appropriately. This thesis describes the development and feasibility testing of a novel screening tool, which aims to improve distress recognition for dementia patients in a hospital setting.

Initially, to understand areas of unmet need, a retrospective review of 116 case notes of people with dementia admitted to hospital was undertaken. The results suggested a discrepancy between observed and expected psychological symptoms, delirium, and pain, and that existing systems used to identify and manage them were underutilised. It was hypothesised that encouraging healthcare professionals to identify distress, rather than specific symptoms, may be a simple and sensitive method for improving the recognition of psychological symptoms, pain and delirium downstream. However, how hospital healthcare professionals identify distress in dementia patients was previously undescribed.

Existing methods were explored using thematic analysis of 25 semi-structured interviews with healthcare professionals who regularly care for people with dementia. The participants interviewed all believed they could innately identify distress. However, common facilitators and barriers to this process were identified including: how the patient presents, familiarity with the patient, using the person's usual community carer as a source of information, staff training, ward culture, and competing ward priorities.

Following a series of design phases, the themes generated were combined with existing theories on implementing healthcare interventions to develop a novel distress screening tool, for use by healthcare professionals to assess dementia patients in a hospital setting. The Distress Recognition Tool (DRT), was deliberately simple and designed to complement existing hospital physical observation systems. As part of the assessment, community carers for the person with dementia are also asked to contribute to the process when visiting the ward. The DRT was further refined using

feedback from focus groups comprising healthcare professionals and community carers of people with dementia.

To test the use, usefulness and potential mechanistic impacts of the DRT, the tool was feasibility tested during the routine care of 32 consented patients with dementia admitted to a large teaching hospital. All staff on participating wards received DRT training and consequently the tool was used on average 0.9 times per participant day. Carers contributed to the assessment process on average 0.4 times per patient day. The feedback from healthcare professionals and community carers was positive but highlighted that more complex aspects of the DRT need refinement.

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Abbreviations

UK – United Kingdom

BPSD – Behavioural and Psychological Symptoms of Dementia

HCP – Healthcare professional

MMHU – Medical and Mental Health Unit

GP – General Practitioner

NHS – National Health Service

ID – Identification number

CI – Confidence interval

SD – Standard deviation

DisDAT – Disability Distress Assessment Tool

DS-DAT – Discomfort in Dementia of the Alzheimer's Type

CMAI – Cohen Mansfield Agitation Inventory

CQUIN – National Dementia Commissioning for Quality and Innovation

NEWS – National Early Warning Score

PEWS – Paediatric Early Warning Score

CSW – Clinical Support Worker

DRT – Distress Recognition Tool

cDRT – Carers Distress Recognition Tool

MDT – Multidisciplinary Team meeting

AMTS – Abbreviated Mental Test Score

Dementia in a General Hospital Setting

1.1   Dementia

Dementia is a progressive syndrome defined by a decline in cognitive functioning, judgment, thinking and emotional control (World Health Organisation, 1992). Dementia can be classified either by subtype or severity; for example, common subtypes of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and mixed vascular/Alzheimer's dementia. The subtypes have differing symptom profiles in the initial stages, but there is less variability once the disease has progressed in severity (World Health Organisation, 1992; American Psychiatric Association, 2013)

Dementia severity is classified as either mild, moderate or severe by the burden of cognitive decline (World Health Organisation, 1992):

Mild - Cognitive decline is severe enough to limit functional activities, but independent living is possible.

Moderate – The deficit is severe enough to seriously inhibit functional activity. Familiar material retained, but independent living not possible without support.

Severe - Complete inability to retain new information. Assistance is required for all activities of daily living. Communication is limited to single words or sounds.

Dementia severity worsens over the course of the syndrome; the longer people live with the disease, the greater the burden of cognitive deficit. (Clarke *et al.* 1991; O'Connor *et al.* 1989). It is by severity that clinicians judge a patient's treatment strategy; in moderate and severe disease the focus of treatment moves away from the maintenance of function and towards the maximisation of comfort (van der Steen *et al.* 2014).

1.2   Dementia prevalence

Dementia has increasing prevalence with age; rates in the United Kingdom (UK) range from 1.3% (ages 65-69) to 32.5% (over 95 years) (Prince *et al.* 2014). Worldwide it is estimated that there are 35.6 million people living with dementia, (World Health Organisation, 2012) and in the UK this translates to an estimated 850,000 people with the syndrome (Prince *et al.* 2014).

1.3   Non-cognitive symptoms of dementia

As well as the cognitive symptoms of dementia, people living with the syndrome also commonly experience non-cognitive psychological symptoms such as hallucinations, delusions and affective disturbances, and disturbed behaviours including aggression, wandering, and sexually inappropriate behaviour. These are sometimes referred to as Behavioural and Psychological Symptoms of Dementia (BPSD), a term introduced by the International Psychogeriatric Association (Finkel *et al.* 1996).

It is estimated that BPSD will be experienced by up to 90% of patients with dementia at some point during the course of the illness (Dorey *et al.* 2008), and can cause considerable distress for patients and their families (Finkel *et al.* 1996). Weighted means from three European studies (total n=836) demonstrate the most commonly observed symptoms of BPSD, which are listed below in descending order of prevalence (Robert *et al.* 2005).

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Depression (44.9%)

Anxiety (42%)

Agitation (35%)

Irritability (30.6%)

Aberrant Motor Behaviour (24.7%)

Delusions (22%)

Appetite disturbance (21.4%)

Sleep disturbance (14.3%)

Disinhibition (12.4%)

Hallucinations (8.5%)

Euphoria (6.8%)

</div>

Grouping the non-cognitive psychological symptoms of dementia and disturbed behaviour under the broad heading BPSD, is an oversimplification. Symptoms are commonly believed to be a driver of behaviour; for instance, anxiety causing aberrant motor behaviour. Furthermore treatment strategies usually target individual symptoms; for instance, using antipsychotic medication to target hallucinations (Tampi *et al.* 2016), with the desired benefit that it will reduce patient distress and subsequent irritability or sleep disturbance.

1.4   Dementia in a general hospital setting

People with dementia are more likely to be admitted to a general hospital than aged matched controls (Maslow, 2006). Common reasons for admission include pneumonia, urinary tract infection and acute cardiac syndrome (Sampson *et al.* 2009). In the UK, dementia prevalence in general hospitals in those over the age of 70 is around 42% (Sampson *et al.* 2009); although global figures range from 5 to 45% (Ames and Tuckwell 1994; Hickey *et al.* 1997; Kolbeinsson and Jonsson 1993; Laurila *et al.* 2004; Sandberg *et al.* 1998; Uwakwe 2000; Goldberg *et al.* 2012; Sampson *et al.* 2009; Royal College of Psychiatrists, 2005). Differences in prevalence data can be explained by the methods of assessment used, life expectancy in the host country (dementia is more prevalent in older age; Prince *et al.* 2014), and the community dementia prevalence in the host county (World Health Organisation, 2012).

When people with dementia are admitted to hospital they are a vulnerable group. Their cognitive symptoms mean that they struggle to adapt and orientate to their new environment (World Health Organisation, 1992). This is further compounded by the unfamiliar surroundings of a ward; in the UK, patents on hospital wards are usually nursed in 4-6 bedded bays, which can be busy, noisy and bright, or individual side rooms, which can be socially isolating (Goldberg *et al.* 2014). People with more severe disease also have difficulty communicating or understanding the symptoms they are experiencing. While on the ward they are invariably physically unwell, they usually have medical procedures performed on them, are given new medication, and necessary but intimate care. This can feel threatening, and may explain the high prevalence of aberrant motor behaviour (21%), irritability (20%), and difficulty sleeping (33%) observed in this group (Goldberg *et al.* 2012).

Whilst on the ward people with dementia are more susceptible to falls (van Dijk *et al.* 1993), have difficulty retaining information during specialist rehabilitation (Huusko *et al.*

2000) and are susceptible to delirium (Fick and Foreman, 2000). They have higher rates of sepsis (58%) and organ dysfunction (32%) compared to age matched controls (Shen *et al.* 2012), and mortality risk is also greater by a factor of 1.23 - 2.1 (Sampson *et al.* 2013; Marengoni *et al.* 2011). Additionally, the length of hospital stay is longer (Holmes and House 2000; Nightingale *et al.* 2001; Guijarroa *et al.* 2010), and the median survival time post admission is 1.6 years shorter compared to people without dementia (Sampson *et al.* 2013).

1.5 Psychological symptoms in people with dementia in a general hospital setting

BPSD in hospital are thought to be generated by an interplay between dementia severity, environment and other illnesses (Sampson *et al.* 2014). When people with dementia are admitted to a general hospital they are in an unfamiliar environment, and likely to be suffering with a physical complaint that caused the admission. It is unsurprising, therefore, that a high prevalence of BPSD is observed in this group (Sampson *et al.* 2014; Wancata *et al.* 2003; Hessler *et al.* 2017).

Three studies have described the prevalence of BPSD in a general hospital setting, in the UK, Austria and Germany (Sampson *et al.* 2014; Wancata *et al.* 2003; Hessler *et al.* 2017). A further UK-based study has described the prevalence of all mental health diagnoses amongst older adults in a general hospital setting, including symptoms more common in people with cognitive decline (Goldberg *et al.* 2012). While these data are less specific to the population in question, they support the prevalence data described below.

Prevalence estimates of a person with dementia experiencing any BPSD during their hospital stay vary between 28% and 76%. The lower figure is most likely a gross underestimation; although, the data was drawn from multiple hospital sites and a cohort of 372 patients, only people with mild and moderate dementia were sampled and within this cohort only severe BPSD were documented (Wancata *et al.* 2003). BPSD are more common in severe dementia, (Cerejeira *et al.* 2012) and all BPSD severities are relevant.

A more reliable estimate of overall BPSD prevalence in a general hospital setting (at any point during admission) lies between 69% and 81% (Hessler *et al.* 2017; Sampson *et al.* 2014). Both Sampson *et al.* (2014) and Hessler *et al.* (2017) present prospective

cohort studies describing the prevalence of BPSD in older people admitted to the general hospital. Both follow patients with dementia through their hospital admission. Sampson *et al.* (2014) studied medical inpatients only. Sampson *et al.* (2014) use a range of standardised symptom recognition tools including patient questionnaires, informant based interviews and observation. Hessler *et al.* (2017) use informant based screening tools completed by nurses only, potentially creating less reliable data. Despite using differing assessment methods, the prevalence of individual symptoms and behaviours described are largely similar (Table 1.1).

Table 0.1 The prevalence of common symptoms and behaviours in people with dementia in a general hospital setting.

	Sampson *et al.* (2014) % (95% CI)	Hessler *et al.* (2017) % (95% CI)
Symptom		
Depression	33.5 (27-40)	29.8 (24-35)
Anxiety	35.2 (29-41)	25.6 (21-31)
Delusions	11.3 (7-15)	5.6 (3-9)
Hallucinations	14.8 (10-19)	3.3 (2-6)
Behaviour		
Activity disturbance	43.9 (37-51)	27.8 (23-33)
Aggression	56.5 (50-63)	24.8 (20-30)
Irritability	-	24.8 (20-30)
Sleep disturbance	42.2 (36-49)	38.1 (33-44)
Apathy	-	21.1 (17-26)
Disinhibition	-	9.6 (7-14)
Total	74.8 (69-80)	75.9 (71-81)

The presence of psychological symptoms is relevant, not only because they are generally considered to be uncomfortable (Burns and Winbald 2006), but also because they are associated with increased mortality, adverse events, and length of stay (Sampson *et al.* 2014; Wancata *et al.* 2003). Psychological symptoms are also distressing for nursing staff to manage (Hessler *et al.* 2017), and tend to decrease satisfaction with hospital care by patient's family members (The Alzheimer's Society, 2009).

1.6   Pain and somatic symptoms in people with dementia in a general hospital setting

Older people are admitted to hospital for a very wide variety of reasons, common examples include falls, trauma, cardiac disease, infection, and respiratory disease (Latham and Ackroyd-Stolarz, 2014). Most illnesses have the potential to cause somatic symptoms; for instance, pain, nausea, dyspnoea, loss of motor or sensory function. All symptoms can cause discomfort and be distressing.

Pain is common in around 50% of people with dementia living in the community and residential homes (Takai *et al.* 2010; Hunt *et al.* 2015). McCarthy et al. (1997) demonstrated higher rates of pain in people with dementia compare to cancer patients during the last 6 months of life. People in pain have slower recovery times, and an increased prevalence of depression (Fishbain *et al.* 1997; Morrison *et al.* 2003). People with dementia who are in pain have increased levels of aggression and anxiety (Sampson *et al.* 2015).

Only one study has reported the prevalence of pain in people with dementia in a general hospital setting. Using observational pain screening tools on a UK sample from two hospital sites Sampson *et al.* (2015) reported that the prevalence of pain at any point during the admission was 19% at rest, and 57% on movement (n=230). 39% of patients (who were able to do so, n=218) self-reported pain at some point during their admission.

Pain in people with more severe dementia is difficult to confirm as the non-verbal signs by which it is identified, such as changes in behaviour and body language, are hard to specifically attribute to pain rather than any other symptom (Jordan *et al.* 2012). As a consequence, the prevalence figures presented maybe an over- or underestimation. Any untreated pain is a potential target for intervention and patients who do not receive appropriate analgesic treatment, demonstrate higher rates of discomfort, agitation and aggression (Husebo *et al.* 2011).

The prevalence of other somatic symptoms in dementia patients in a hospital or community setting is unknown. One might assume, however, that symptoms are as common in people without dementia and recognising them is important to relieve discomfort.

1.7   Delirium in people with dementia in a general hospital setting

Delirium superimposed on dementia occurs in up to two-thirds of hospital inpatients and published prevalence rates range from 32% to 89% (Fick *et al.* 2002). This wide range of prevalence is explained by differing delirium assessment techniques, variations in the study population, and variations in the diagnostic criteria used. The symptoms of delirium include: clouding of consciousness, delusions, hallucinations and either hypo- or hyperactivity (World Health Organisation, 1992). These symptoms show

considerable overlap with and compound existing psychological and cognitive symptoms seen in dementia. As well as being a disturbing personal experience for the patient, the presence of delirium is associated with a long-term decline in cognitive functioning, increased morbidity, mortality and length of hospital stay (Holmes and House 2000; Fick and Foreman 2000; Inouye *et al.* 1998).

1.8   Managing dementia in a healthcare setting

Patient outcomes may be improved if non-cognitive psychological symptoms, somatic symptoms, and delirium associated with dementia in a general hospital setting are managed well. Managing symptoms requires healthcare professionals (HCPs) to know which patients have dementia (are at risk), have the time, skills and resources to identify symptoms, and the resources to treat them. However, the cognitive and communication difficulties experienced by people with dementia complicate the assessment of symptoms. Furthermore, hospital ward environments are not always conducive to providing good dementia care.

To understand these barriers in greater detail, this section will provide an overview of the structures and processes of recognising and managing non-cognitive symptoms of dementia in hospital, reviewing existing care models that facilitate symptom recognition, and highlighting areas that are potential targets for intervention.

Models of healthcare

Providing quality care in a hospital setting is dependent on the correct structures (care environment) and processes (care delivery) being in place, to meet the individual needs of the patient (Donabedian, 1980). Structure and process are influenced by national and local policy, and culture.

To apply healthcare systems in clinical practice requires technical knowledge and interpersonal skills of those occupying the caring role. The application of care must be conducted in a setting with appropriate amenities to provide a comfortable environment (Donabedian, 1980). Technical knowledge should be evidence based and have the expressed intention to improve outcomes. The interpersonal skills of those caring for people with dementia are difficult to quantify, although caring techniques can be taught (Teodorczuk *et al.* 2010). Interpersonal skills are affected by the culture and

background of the person being cared for and their carers; consequently, there is not necessarily a 'one size fits all' approach.

The purpose of healthcare structure and process is to improve outcomes. Positive outcomes may differ depending on whether they are defined by the individual with dementia, their carers, the organisation in which the person with dementia is cared for, or a nationally defined standard. For example, a good outcome for the individual with dementia maybe to be pain free and comfortable (National Centre for Social Attitudes, 2013), but for an organisation it maybe a reduced length of hospital stay, and adverse events such as falls or morbidity (Espallargues *et al.* 2008). An overemphasis on organisation outcomes can divert focus away from the individual, for instance moving patients between wards to improve bed status, despite potentially compromising patient care (Tadd *et al.* 2011)

To better understand the barriers and facilitators to symptom recognition in people with severe dementia, this model of healthcare design has been applied to dementia care in a ward setting. This is illustrated in the framework displayed in Figure 1.1. Literature describing the individual components of the framework are appraised below, describing influences to care, staff skill base, structures, processes that contribute to managing dementia, and its associated symptoms on a hospital ward.

National influences

- National reports and enquiries.
- National culture and media.

Local influences

- Staff training.
- Ward leadership and culture.
- Organisational attitudes to risk safety and empowerment.
- Staff motivation.

Individual influences

- Patient and HCP past experience and expectations.
- Patient's ability to communicate.
- Patient profile.

Technical knowledge

- HCP knowledge of prevalent symptoms in dementia.
- HCPs have access to diagnostic information.
- HCPs have ability to recognise symptoms.
- Using standardised symptom recognition tools.

Interpersonal skill

- HCPs are able to build rapport and empathise with their patients.

Structure

- Ward layout and size.
- Adequate staff numbers with, time to identify symptoms.
- Access to symptom recognition tools.
- Access to specialist psychiatry liaison services.

Process

- Dementia identification.
- Recognising the patient requires assistance (is in distress).
- Recognition of the symptom causing distress.
- Steps taken for minimising symptoms.

Positive outcomes

- Symptoms are treated
- Reduction in complaints from carers.
- Reduction in distress related incidents (falls etc).
- Increased staff confidence and satisfaction.
- Improved cross specialty working.

Negative outcomes

- Symptoms remain untreated.
- Patient is distressed
- Increased distress related incidents and complaints.

Figure 0.1 A framework to demonstrate the influences structure, process, and outcomes of symptom recognition by HCPs for dementia in hospital.

1.9   The influences, structure and process of managing dementia on a hospital ward

National, local and individual influences

Raising the awareness of HCPs, patients and carers about dementia, and the common symptoms that people with dementia experience may maximise the rate of detection of symptoms, and empower patients and their carers to report them. Improving dementia awareness is a global priority (World Health Organisation, 2012). In the UK, the 'National Dementia Strategy' and 'Prime Ministers Challenge on Dementia' aim to improve dementia care, and specific policy has been created with the aim of improving care for people with dementia in a hospital setting (Department of Health, 2009b; Department of Health, 2013; Department of Health, 2009a). The national strategy is supported by non-government organisations, including The Kings Fund's (2014) 'Enhancing the Healing Environment', and the Royal College of Nursing's (2013) 'Commitment to the Care of People with Dementia in General Hospitals'. Both of these initiatives aim to improve the hospital environment, promoting dementia friendly wards, HCPs awareness of dementia, and the challenges it presents.

On a local level, it is hoped that by raising awareness and leadership, HCPs skill and motivation to provide quality dementia care can be improved and maintained. HCPs are generally motivated by either extrinsic or intrinsic factors (Deci and Ryan, 2002). In the instance of dementia care intrinsic motivation relates to the HCPs enjoyment at helping a person with dementia. The HCP gains extrinsic motivation from being as competent in their professional role as possible, by receiving positive feedback from patients and colleagues, and the avoidance of punishment. On a busy ward environment, caring for someone with dementia, particularly in the absence of risk to the patient or their immediate environment, can be a poor motivating task (Hynninen *et al.* 2015). There is rarely emotional reward or thanks from patient or family, and there are few negative incentives (punishments) that occur if the patient is not prioritised; patients with dementia often lack the capacity to complain about poor care and may not have strong advocates acting on their behalf (Bradshaw *et al.* 2013). Furthermore, staff in the UK often feel unsupported and demotivated by a system that often fails to prioritise older people; organisations promoting task based care over person centeredness, and a lack of emphasis on dementia care and training (Tadd et al. 2011) To help improve motivation, hospitals are being encouraged to adopt dementia leadership initiatives, such as appointing hospital dementia champions, and

establishing dementia working groups (Banks *et al.* 2014). Progress is slow however, and recommendations for improving care are often not realised (Tadd *et al.* 2011)

Patients and their carers are also being encouraged to contribute to and influence their care, by raising the awareness of HCPs to their individual care needs, and diagnostic information at the time of admission (The Alzheimer's Society, 2010; Butterfly Scheme, 2014). These national 'patient passport' schemes provide patients with an information pack that they complete at home and take with them to hospital each time they are admitted. These documents help to inform staff of the individual's diagnosis, usual needs, likes and dislikes.

Ward structure

Ward environments can be stark and confusing places for people with dementia (Moyle *et al.* 2008). They can be busy and hectic for HCPs who work there (The Alzheimer's Society, 2009). Managing mental health problems such as dementia is not always a priority (Goldberg *et al.* 2014), and the working environment is not always purposely designed for managing people with dementia. For HCPs to manage dementia and its associated symptoms, they need to operate in an environment conducive to providing care and have the appropriate amenities, time and resources. Furthermore, the environment which people with dementia are cared for needs to take into account the specific needs of the patients, this may in turn reduce symptom burden.

Environment

General hospital wards are designed for facilitating medical care and rarely meet good practice guidelines with regards to the design of living spaces for people with dementia (Greasley-Adams *et al 2014.*). Traditionally they are stark and repetitive, the atmosphere is often noisy and busy, and people with dementia can struggle to fully comprehend their surroundings, which can cause disorientation and fear (Houghton *et al.* 2016; Moyle *et al.* 2008). Guidelines to improve ward environments provide recommendations on ward décor to create dementia friendly environments (Topo *et al.* 2012; The Kings Fund, 2014). Examples of a dementia friendly environment include: providing legible signage, better lighting and colour schemes, and providing open space for meaningful activity. Such changes can potentially bring about a reduction of violent events and falls; although, only descriptive accounts of this are available thus

far (Spinks, 2012). The potential advantages of creating a more dementia friendly environment on symptom recognition are twofold:

- Due to the open layout HCPs are able to observe patients more easily, and more frequent HCP / patient interaction is encouraged (Brooke and Semlyen, 2017). This potentially increases the chance of symptoms being recognised.

- By enhancing the care environment there may be an overall reduction in psychological symptoms and distress related behaviour (Goldberg *et al.* 2013).

In a recent qualitative study, Brooke *and Semlyen* (2017) reported a thematic analysis of nurses and health care assistants views on the introduction of a dementia friendly ward environment. Ten focus groups with a total of 38 nurses and clinical support workers on a ward that had recently adopted environmental changes were held. Participants perceived that the ward was more friendly, the environment promoted greater interaction with patients and allowed them to offer more person-centred care. In turn some HCPs believed that this had a positive impact on reducing the number of BPSD on the ward; although, no analysis of why or data on BPSD prevalence was presented. Some HCPs were resistant to change, however, believing that certain initiatives, such as removing the ward nursing station, disrupted the ease of completing paperwork, potentially jeopardising patient safety.

Taking the concept of dementia friendly wards further are specialist medical and mental health units (MMHU). These are wards created specifically to manage older patients with physical illness and comorbid dementia and/or delirium. A handful of such wards have been created in the UK, the units aim to provide dementia friendly, person centred care in a tailored ward environment with the provision of staff with mental health and physical health care training. A review of 600 patients admitted with confusion randomised to either standard care or a MMHU, reported that on MMHU patients were happier, and there was greater satisfaction with care reported by patients and carers. The prevalence of psychological symptoms that staff recognised was not reported. However, despite there being regular psychiatry reviews (including mental state examinations) on the MMHU, there was no significant difference in the prevalence of psychological symptoms as recorded by the Neuropsychiatric Inventory. There were also no reported differences between the wards when observing length of

stay, mortality or readmission rates (the primary outcome measures) (Goldberg *et al.* 2013).

Adequate healthcare professional numbers with time to recognise and manage symptoms commonly associated with dementia

Lower HCPs numbers potentially reduce the amount of time they have available to spend per patient. Caring for people with dementia on a hospital ward is physically and mentally tiring (Hynninen *et al.* 2015), and in such circumstances the acknowledgement of mental health symptoms is not always a priority (Goldberg *et al.* 2014). In an observational study of care delivered by HCPs on general hospital wards Goldberg *et al.* (2014) described that meeting patient's basic physical needs and routine/task orientated jobs take up much of the time, and the provision of mental health care is sometimes deflected as a consequence. On medical wards it was reported that HCPs fail to acknowledge or engage in challenging issues arising from anxiety or distress. Particularly towards the end of a long shift, staff were observed to actively ignore patients exhibiting high levels of psychological distress (Goldberg *et al.* 2014).

Differing approaches to overcome this include either increasing the number of HCPs per patient, or providing more staff with specific training and experience in dementia (as is the case on specialised MMHUs described above) (Goldberg *et al.* 2014; California Nurses Association and National Nurses Organising Committee, 2008). Higher nurse to patient ratios are positively associated with lower mortality, reduced length of hospital stay, and fewer complications including wound infection and pressure sores (Kane *et al.* 2007; Rafferty *et al.* 2007; Needleman *et al.* 2002). In the context of dementia care, it might be presumed that providing increased staff numbers increases the opportunity for HCPs to recognise and manage distressing symptoms. In the United States of America and Australia the number of older patients per nurse recommended to maintain safe practice on elderly care wards is around 4 and 5 respectively (California Nurses Association and National Nurses Organising Committee, 2008; New South Wales Nurses' Association, 2010). In the UK there is no absolute staff to patient ratio set for managing older people (Royal College of Nursing, 2011b); however, ratio's on elderly medicine wards are 11:1 on average (Royal College of Nursing, 2011b). When the mean number of patients per nurse on elderly medicine wards is greater than 10:1, patient care is likely to be compromised (Ball, 2009).

Access to recognition tools

Symptom recognition tools exist and can assist HCPs to diagnose and monitor specific symptoms in dementia. To be useful, staff need to be aware of them, know which tool to use (is recommended by the hospital), and how to find them (Cochrane *et al.* 2007). There is no available evidence to demonstrate their availability and use on general hospital wards. A review of symptom recognition tools is displayed later in this chapter.

Access to liaison psychiatry services

Psychiatry liaison services are recommended as part of providing quality care for people in hospital with comorbid psychiatric illness (Royal College of Psychiatrists, 2005). Via a referral system these teams provide specialist psychiatric support and advice to the dementia patient's usual care team (Tadros *et al.* 2013).

Summary of ward structures

While providing increased numbers of staff, services or providing specialist dementia wards may help improve person centred care, patient experience and reduce adverse outcomes, there is no evidence that they improve the management of dementia, and symptoms commonly associated with dementia. It is likely, however, that these initiatives are an important step in both reducing symptom burden and increasing staff awareness. Affecting such structural change is a potential target for intervention but has significant economic costs. Understanding the process of symptom recognition and the HCP technical skills required to implement them may, therefore, be a more effective strategy.

Technical knowledge and interpersonal skills

Knowledge of how to care for people with dementia can be acquired through formal teaching or practical experience. In the UK, dementia care is usually provided by psychiatrists and psychiatric nurses (Jolley *et al.* 2006); however, when patients with dementia come into hospital they are most commonly admitted to elderly medicine, trauma and orthopaedics, and medical wards (Goldberg *et al.* 2012). It might be assumed that staff on these wards become more adept at caring for people with dementia with increased exposure; however, in the UK they do not have formal psychiatric training as standard and although psychiatric liaison teams are usually

available on a case by case basis, they are not part of the ward multidisciplinary team (Royal College of Psychiatrists, 2005).

Qualitative data from 64 doctors, nurses and allied health assistants in a UK teaching hospital revealed staff felt that education, induction and in-service training left them underprepared and unconfident to care for confused people. Participants admitted inadequate knowledge of dealing with mental health problems leading to frustration, stress and avoidance (Griffiths *et al.* 2014). 90% of nurses describe working with people with dementia challenging or very challenging (The Alzheimer's Society, 2009), and several observation studies have shown that although nurses strive to provide optimum care, it is not always achievable (Cowdell, 2010; Nolan, 2007).

Similar concerns have also been observed by the carers and families of people with dementia, when they come to visit hospital wards. As part of a Royal College of Nursing report (2011a) 'dignity in dementia transforming general hospital care', 1481 community carers of people with dementia were surveyed on barriers to dementia care in a general hospital setting. 79% of carers felt that staff had a poor understanding of caring for people with dementia and 75% felt that staffing levels were too low. As part of the same report 718 HCPs were also surveyed. They cited pressure of existing work load (77% of respondents) and insufficient staffing levels (75%) as barriers to care.

Ward process

Identifying people with a dementia diagnosis

To recognise and address the needs of a person with dementia in hospital, it is useful to identify those with the syndrome: the 'at risk group'. In the UK, it is recommended that dementia is diagnosed by a dedicated memory service (Royal College of Psychiatrists, 2016). In the mainstay, this service is managed by psychiatrists working in community mental health services; however, depending on local arrangements some cases maybe diagnosed by neurologists, physicians or general practitioners. The diagnosis and clinical information is stored in the patient's psychiatric notes and their general practitioner (GP) is informed of it. It is estimated that only 61% of all patients with dementia in England living in the community receive a formal diagnosis. Although, figures vary between geographical regions (NHS England, 2015), public health strategies for improving this rate are in underway (Department of Health, 2015).

Physical health is generally managed by a separate healthcare provider to mental health services. When a patient with known dementia is admitted to hospital, often there is no formal system to communicate this clinical information between healthcare providers. Due to data protection safeguards, the direct sharing of patient records between healthcare services is not routine. Instead, this information is provided informally (and therefore potentially inconsistently) via the patient, carer or GP.

This disjointed system of care can lead to two main types of oversight.

- The person with dementia does not have a formal diagnosis in the community and remains undiagnosed in hospital.
- The person with dementia has a formal diagnosis of dementia, but the diagnosis is not communicated to the medical team.

A combination of both oversights accounts for the large number of people with dementia who remain unacknowledged by their medical team despite a high hospital prevalence (42%) (Sampson *et al.* 2009). In the UK, the first type of error accounts for around 40% of cases and is a reflection of the low community diagnostic rates, which are calculated by the gap between expected and formally diagnosed cases in the community (NHS England, 2015). Prior to admission, it is unknown how accurately medical teams acknowledge and record a dementia diagnosis that has been formally made in the community.

Current attempts to identify hospitalised patients with dementia in England include asking all patients over the age of 75 years whether they have a dementia diagnosis, and routine screening for cognitive impairment (NHS Commissioning Board, 2014). UK hospitals are largely compliant (NHS England, 2015); however, without direct access to the psychiatric or primary care notes, information sources maybe unreliable. In addition, although the presence of cognitive impairment is highly predictive of dementia, it is not diagnostic and may simply reflect delirium as a consequence of reversible aetiology.

Recognising and identifying symptoms and delirium

There is a high prevalence of psychological symptoms, pain and delirium in people with dementia (Sampson *et al.* 2014; Sampson *et al.* 2015; Fick *et al.* 2002). People with

severe dementia sometimes struggle to comprehend and communicate their experiences to staff. Symptoms are therefore expressed through behaviour associated with distress, this can make it hard for HCPs to recognise exact symptoms profiles and formulate targeted treatment plans (Regnard *et al.* 2003). To aid diagnosis alternative communication techniques may be adopted; for instance, taking a collateral history and observing changes in the patient's body language, verbal sounds and facial expression (Hadjistavropoulos *et al.* 2000; Oosterman *et al.* 2016; Bourbonnais and Ducharme, 2010; Prkachin, 1992).

Missed or misidentified symptoms are a potential source of significant patient discomfort and harm; therefore, using all available tools to correctly identify the problem makes good clinical sense. Standardised symptom recognition tools can help HCPs identify psychiatric symptoms, pain and delirium in a person with dementia. Multiple tools exist for use in dementia and there are three main types: patient questionnaires, observational or informant-led.

Questionnaires are less useful as they require verbal communication by the patient, which may not be possible because of disease severity. Observational and informant tools are generally preferred, but they suffer from potential user bias and generally have lower interrater reliability than questionnaires (Feldt, 2000). The tools themselves can either look for specific symptoms such as pain and anxiety (Shankar, 1999; Abbey *et al.* 2004), or groups of symptoms or behaviours (Cummings *et al.* 1994).

A common theme of all observational symptom recognition tools, is that they ask the user to look for specific changes to body language, vocal sounds or facial expression. However, these changes are often universal signs of distress and their specificity for detecting specific symptoms has been questioned. (Jordan *et al.* 2012; van der Steen *et al.* 2015). There are a number of tools to support HCPs identify pain, but none have been shown to have clinical utility and pain is still poorly managed (Lichtner *et al.* 2014) (Husebo *et al.* 2011).

There is no published literature on how accurately HCPs identify symptoms commonly associated with dementia and delirium in a hospital setting, or how commonly symptom recognition tools are used. Understanding this, and whether there is a discrepancy between expected symptom prevalence and HCP acknowledgement of symptoms, may be a useful indicator of unmet need.

Treating common symptoms in dementia

Once a symptom such as pain or a collection of symptoms such as psychosis, have been identified, treatments exist to minimise them. These can be pharmacological agents such as antipsychotics, non-pharmacological treatments such as reminiscence therapy or just a simple reassurance and a hand to hold (Tampi *et al.* 2016; Douglas *et al.* 2004). Pharmacological treatments are wide-ranging, and have evolved over the years in a haphazard and anecdotal way. Because of this, many drugs are used off licence and are agents originally designed for use in other patient groups. However, there is growing evidence to support their use. Examples include antipsychotic drugs to treat psychosis and agitation (Tampi *et al.* 2016), analgesics to treat pain (Husebo *et al.* 2011), anti-depressants to treat agitation, low mood and anxiety (Henry *et al.* 2011), and anti-epileptics to treat anxiety and agitation (Crowther, 2013). All pharmacological treatment strategies carry potential side effects, and some medication to treat psychological symptoms are associated with increased risk of stroke (Banerjee, 2009), falls (Pariente *et al.* 2008), and cardiac arrhythmias (Rowland *et al.* 2007). Consequently, practitioners are advised that medications should be prescribed only where the benefits out weight the risk, and in some cases for a time limited period only (Banerjee, 2009).

Non-pharmacological treatment strategies generally produce fewer (if any) side effects, but are generally more time consuming. Strategies can be as simple as reassuring words, or creating a comfortable environment (The Kings Fund, 2014), or more complex therapies can be employed with reasonable efficacy (Woods *et al.* 2005).

Changes at whole ward level, for instance providing person centred care, reducing noise levels, and including family members can be effective strategies for improving patient satisfaction and quality of care (Goldberg *et al.* 2014). This was demonstrated by Goldberg *et al.* (2013), in a large randomised control trial comparing standard ward care against an enhanced ward for managing mental and physical health needs. No significant differences were observed in symptom burden, length of stay or cost however.

To assist clinicians deciding which treatment strategy to use, algorithms exist. They are widely available at both regional (Leeds Integrated Dementia Board, 2014), and national levels (Sadowsky and Galvin, 2012; Taylor *et al.* 2015). Their use is widely accepted as good clinical practice (Salzman *et al.* 2008; Desai and Grossberg, 2001),

they draw on a wide evidence base; however, no published evidence exists to demonstrate efficacy of any one algorithm. It is unknown how frequently treatment algorithms are actually used in clinical practice.

Outcomes

Poor dementia care including untreated psychological symptoms, pain and delirium are associated with worse patient outcomes and satisfaction with care (Sampson *et al.* 2014; Wancata *et al.* 2003; Sampson *et al.* 2015; Husebo *et al.* 2011; Holmes and House, 2000). If a dementia diagnosis is identified and any associated symptoms and delirium are diagnosed and treated, one might expect the person with dementia, their carers and HCPs to have a more positive experience. However, if a person with dementia is never identified, or their symptoms are undetected they are less likely to receive treatment. Consequently, the patient is likely to suffer, experience discomfort and distress (Figure 1.1).

Distress is a non-specific poorly defined term; however, it is generally recognised to be a negative experience (Kovach *et al.* 1999), and minimising it is a primary treatment goal in those with moderate to severe dementia (van der Steen *et al.* 2014). Knowing the prevalence of distress may, therefore, be useful as an indicator of unmet need and a potential 'proxy' for untreated symptoms or delirium (Regnard *et al.* 2003).

The prevalence of distress in people with dementia in a hospital setting is unknown. Furthermore, it is unclear from the literature what systems are in place to help HCPs communicate distress to each other in a hospital setting. Two observational screening tools to assist staff recognise distress in dementia exist: the 'Disability Distress Assessment Tool' (DisDAT) (Regnard *et al.* 2007), and the 'Discomfort in Dementia of the Alzheimer's type' (DS-DAT) scale (Hurley *et al.* 1992). However, both have limitations in this setting (outlined in Chapter 3), and it is unknown how regularly these tools are used in clinical practice.

1.10 Conclusion

Dementia is common in patients admitted to general hospital wards. While admitted people with dementia have a high prevalence of psychological symptoms, pain and delirium, which if not recognised can cause discomfort and distress. To identify and treat these symptoms HCPs must have adequate systems and processes in place.

In the UK, there is extensive work currently underway to improve the ward environment and dementia awareness. Undoubtedly further work can and needs to be done, but wholesale system change such as overhauling the staff to patient ratio is unrealistic in the current economic environment. Moreover, it is potentially unhelpful if the correct process and training are not in place for staff to utilise.

The process of recognising psychological symptoms, somatic symptoms and delirium requires HCPs to correctly identify people with dementia, then diagnose the symptom, before treating them. Standardised symptom recognition tools exist to assist staff with this. Although the prevalence of symptoms and delirium is known, it is not known how well these problems are actually identified in day to day practice, or what tools staff are using. Describing this may help us to better understand aspects of the care process that are amenable to intervention, by identifying areas of unmet need. In this instance, how well dementia and the common psychological symptoms, somatic symptoms, delirium and distress are being identified, and what formalised systems are being used to enhance diagnosis.

The key questions generated from this are displayed below and they will be addressed in the next chapter of this thesis.

- How accurately is dementia reported by staff on general hospital wards?
- How commonly are somatic symptoms, psychological symptoms and delirium reported on general hospital wards, and what is the discrepancy between observed and expected symptom prevalence?
- How is distress reported and communicated on general hospital wards?
- What, if any, standardised symptom recognition tools and treatment algorithms are used on general hospital wards?

Describing the population with dementia in a general hospital setting

2.1 Summary of previous chapter

Dementia is prevalent in around 42% of older people admitted to general hospital (Sampson *et al.* 2009). Patients with dementia often have difficulty communicating their needs, and in a hospital setting have a high prevalence of psychological symptoms (Sampson *et al.* 2014), pain (Sampson *et al.* 2015), and delirium (Fick *et al.* 2002). The presence of psychological symptoms and pain are associated with increased agitation and falls (Sampson *et al.* 2014). The presence of delirium is associated with increased morbidity, mortality and length of hospital stay (Holmes and House, 2000).

To accurately identify symptoms in people with dementia, HCPs must first know which patients have dementia (the at-risk group), then be able to identify the common symptoms and delirium (Figure 1.1).

In the UK, it is recommended that dementia is diagnosed and managed by dedicated memory clinics run by mental health trusts. Current attempts to identify patients with dementia when they are admitted to general hospitals, (which are run by physical healthcare trusts) include routine screening of all people over the age of 75 for cognitive impairment (NHS Commissioning Board, 2014). Hospitals are largely compliant (NHS England, 2015); however, without direct access to the psychiatric or primary care notes, information sources maybe unreliable.

To diagnose symptoms HCPs usually take a verbal history, but this is difficult in people with severe dementia who struggle to communicate verbally. Several standardised tools exist in order to assist clinicians identify psychological symptoms, pain and delirium in patients who cannot communicate; for example, the Neuropsychiatric Inventory (Cummings *et al.* 1994), the Abbey Pain Scale (Abbey *et al.* 2004), and Confusion Assessment Method (Inouye *et al.* 1990). These tools are all time consuming and require staff training if symptoms are identified, however, effective treatment is often available.

In a general hospital setting, previous attempts to describe dementia prevalence and the symptoms associated with it, have all involved prospective objective screening and subsequent clinical assessment (Ames and Tuckwell, 1994; Hickey *et al.* 1997; Kolbeinsson and Jonsson, 1993; Laurila *et al.* 2004; Sandberg *et al.* 1998; Uwakwe 2000; Goldberg *et al.* 2012; Sampson *et al.* 2009; Royal College of Psychiatrists, 2005; Sampson *et al.* 2014). The rigorous methods these studies employ may give an accurate account of the hospital prevalence, but they potentially overestimate the actual clinical record, that is, the number of patients with a pre-existing diagnosis of dementia identified as such during their hospital stay and the number of symptoms recorded by HCPs.

By describing how often HCPs actually record dementia diagnosis, common symptoms of dementia, and how frequently they use of symptom recognition tools, areas of unmet need may be exposed, providing the opportunity to identify potential targets for intervention.

If the symptoms commonly associated with dementia are not identified, patients are likely to experience discomfort and distress, the minimisation of which is a primary treatment goal (van der Steen *et al.* 2014). In this context, distress might act as a proxy for undiagnosed symptoms. The prevalence of distress in dementia in hospital is unknown, however, as are the current systems that HCPs use to identify and communicate distress. This chapter describes a study with the aim of identifying areas of unmet need describing the reported frequency of distressing symptoms, and distress in people with severe dementia in a hospital setting.

2.2   Objectives

In a cohort of people with a formal diagnosis of dementia admitted onto general hospital wards, the objectives of this study were to describe:

- The prevalence of reported dementia and accuracy of dementia diagnosis recording.
- The frequency of documented psychological symptoms, somatic symptoms and delirium.
- The use of existing tools and algorithms to identify and treat common symptoms in dementia.
- The frequency of documented distress, the language and systems used to communicate it.

2.3   Methods

Design

This was a record linkage study with retrospective case note review carried out between a large regional mental health care provider and the corresponding regional physical healthcare trust.

Participants

Patients included were over the age of 75 with a formal diagnosis of dementia, made in a memory clinic, admitted to the physical healthcare trust's hospital for longer than 48 hours.

Data collection rationale

Because of the local health system design, the most accurate record of a dementia diagnosis should be stored in the electronic notes (e-notes) made by the memory service, which is part of the regional mental health trust. By cross referencing health records from the mental healthcare and physical healthcare trusts, patients known to both healthcare providers were established, and subsequently individual patients with a formal diagnosis of dementia admitted to the general hospital could be identified.

Data collection technique

An electronic list of all people over the age of 75 admitted to the physical healthcare trust during May 2014 was obtained, they were identified only by their National Health Service (NHS) number, and appeared in order of date of admission. The list was provided by the trust health informatics department. May 2014 was chosen as it was a month that typically has an average number of admissions for the year.

The list was randomly ordered using computerised random number allocation, and the NHS numbers were cross-referenced against the mental health trust's psychiatric e-notes database. Randomising aimed to reduce any effect caused by the day of the week of admission, on types of admission, (more elective admissions on weekdays etc.). This established the number of cases admitted to the general

hospital, known to the mental health trust with any recorded mental health diagnosis (e.g. depression, schizophrenia, dementia). The e-notes system could not automatically identify those with dementia - the target population. To do this, the psychiatric e-notes of patients with a linked record were systematically hand searched. Hospital letters, patient notes and discharge summaries were scrutinised for any formal diagnosis of dementia, and the dementia subtype as recorded at patient's assessment with the memory service were noted. Where severity was indicated it was recorded by reviewing the most recently completed standardised objective memory test score, and hospital letters. Patients who had undergone formal diagnostic assessment for dementia by a Psychiatrist and had a formal diagnosis of dementia documented in the psychiatric notes were allocated a study identification (ID) number.

To calculate how accurately the general hospital documented dementia diagnosis, and the frequency of documented psychological symptoms, somatic symptoms, delirium, distress and the use of symptom recognition tools, the general hospital notes of the patients with dementia identified above were scrutinised. To do this, the general medical notes of the people identified with dementia were obtained from the medical records library. Notes were obtained in batches of 20 to reduce clinical disruption. Each set of paper notes contained medical and nursing documentation relating to the May 2014 admission, which was hand searched.

Where notes were missing due to clinical activity (for instance the notes were in an outpatient clinic or a ward), the patient number was noted and the notes re-requested at a later date. Where notes were archived, for instance, because of patient death, they were retrieved by the medical records department.

The following inclusion criteria were applied to the medical notes review:

- Medical notes were present and available for review during the data collection period.
- The May 2014 admission nursing and medical notes were present.

Where hospital notes were unavailable or incomplete the case was noted and excluded.

Each set of paper notes related to an individual patient and contained medical and nursing documentation relating to the May 2014 admission to hospital. For each patient, the medical notes, nursing notes and electronic discharge advice notifications were hand searched. This provided a record of the admission details, all significant diagnoses, nursing observations, medical investigations and symptoms at the point of admission, and during the hospital stay.

Data collection

The following information was documented anonymously on the data collection form displayed in appendix 1.

- Demographic details including, age, reason for admission, length of admission, and medical speciality providing care.
- Evidence of documented dementia diagnosis, subtype and severity.
- Documented psychiatric symptoms, somatic symptoms and delirium.
- Documented evidence of distress[1] (Regnard *et al.* 2007; Cohen-Mansfield, 1997).
- The use of any dementia specific standardised symptom recognition tools or treatment algorithms.

To avoid any ambiguity a diagnosis or symptom was only counted if the treating team had specifically written it. Commonly used euphemisms (for example, confusion) were not recorded.

Sample size

From expected dementia and symptom prevalence data, prior to data collection it was estimated that 100 sets of medical case notes (following exclusions), would be sufficient to demonstrate the prevalence of documented dementia and symptom frequency (primary outcome) with acceptable 95% confidence intervals (CI). However, it was planned that if greater numbers were necessary more from an available 200 would be reviewed. To check this, once 100 medical notes had been

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[1]Distress was defined as any language describing a negative emotional or behavioural state, or any language describing distress or agitation as defined by the DisDAT or Cohen Mansfield Agitation Inventory.

reviewed the data set was analysed, then re-analysed after each subsequent batch of 20. Once the confidence intervals were consistent, or unlikely to demonstrate significance without an unfeasible increase in numbers, data collection ended.

Data analysis

To calculate diagnostic accuracy, the percentage of dementia diagnoses, subtypes and severity documented by the general hospital was compared with the psychiatric e-notes, proportional agreement and kappa coefficients (κ) were calculated to demonstrate inter-rater agreement. Associations between the speciality of the team providing care and dementia severity with the accuracy of dementia diagnosis recording were tested using chi-squared test.

Descriptive statistics were used to display the documented symptom frequency, percentage and 95% confidence intervals. Associations between the speciality providing care and the frequency of symptom documentation were tested using chi-squared test. Where expected cell counts did not meet approximation for chi-squared test, Fisher's exact test was applied.

No direct comparisons between this data set and previously published prevalence data could be made due to differing methods and outcome measures (Sampson *et al.* 2014; Sampson *et al.* 2015; Hessler *et al.* 2017; Fick *et al.* 2002).

Descriptive statistics were used to display reported distress in the study group. To test for associations between distress reporting and symptom reporting, chi-squared test was used. Where data did not meet applicable standard approximations for chi-squared test, Fishers exact test was used.

All statistical data was generated using STATA (SE) software.

Data protection

Patient identifiable data in the form of medical and psychiatric notes were accessed only by the researcher, who held a contract with both the physical health and mental health trust. The psychiatric e-notes system was accessed using the mental health trust server via the secure general hospital server. The general hospital paper notes and electronic discharge notes were only accessed and reviewed in the hospital

medical records library. At no time was patient identifiable data removed from the hospital site.

In the initial stages of the study lists of patients were generated in the form of NHS numbers. This is a 10-digit code that identifies a patient and is universal across all NHS trusts. Cases known to both the general hospital and the mental health trust were identified and sourced using the NHS number. Once the case notes had been sourced the NHS number was no longer of use and was deleted from the study data, leaving only the study ID number to identify patients with, thus anonymising the data.

Data collection tools contained no patient identifiable data. All completed forms were stored securely in a locked cabinet on hospital property until the data were transferred to an electronic format, at which point completed data collection tools were destroyed.

All electronic data was kept in a password protected file on the password protected hospital secure server. All data collection, storage and use complied with the Data Protection Act (1998), and the University of Leeds information security policy.

Ethical considerations

During this study, there was no direct contact with participants, and there were no direct risks to individual research participants. The information accessed was part of the participants' confidential records. The general hospital trust's research committee confirmed that as the researcher was is a member of the direct care team of the participants, and data was intended to be used to improve patient services, identifiable patient information can be accessed without individual patient consent.

University of Leeds ethical approval was granted, number SoMREC/14/094.

2.4   Results

Data collection

A total of 3326 patients over the age of 75 were admitted electively or as an emergency to the general hospital in May 2014. 706 of them (21% [CI 20-23]) were registered with the mental health trust. From this number 275 psychiatric notes were reviewed (40% of total), of which 196 (71%) had a diagnosis of dementia, the remainder had other mental health diagnoses and were excluded. From the sample of 196 patients with dementia admitted to the general hospital, the paper medical notes were requested and reviewed. Data collection stopped once 153 notes had been reviewed as it was deemed that (following exclusions) this was an adequate number of cases to produce reliable enough data to achieve the research aims, as set out above. Following exclusions, 116 cases were included in the study (Figure 2.1).

Demographics

The mean age of the sample with dementia was 84.3 years old (range 75-98). There was a predominance of females (63%) to males (37%). The median length of hospital stay was 5 days (range 2-87) (Table 2.1). Neither dementia severity nor subtype were significantly associated with age, sex, length of stay, admission reason or the speciality providing care. The most commonly documented reasons for admission in the initial documentation were falls (28%, [CI: 20-36]), confusion (15%, [CI 9-22]) and infection (7%, [CI:4-13]).

The prevalence of formally diagnosed dementia in the general hospital

Prevalence was calculated by first demonstrating the proportion of dementia cases (n=196) from the number of mental health notes reviewed (n=275), 0.71. This proportion was assumed to be the same in all 706 cases known to the mental health trust admitted to the general hospital. Therefore, when extrapolated up one would estimate 501 admissions with known dementia, this is 15% (CI 14-16) of the total sample (3326).

```
┌─────────────────────────────────┐
│   Total admissions over 75 years old to   │
│    the general hospital in May 2014.      │
│              n=3326                        │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│  Registered with the mental health trust. │
│              n=706 (21%)                   │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐     ┌─────────────────────────────┐
│   Mental health e-notes searched.  │────▶│   No dementia diagnosis.     │
│              n=275 (8%)            │     │            n=79              │
└─────────────────────────────────┘     └─────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐     ┌─────────────────────────────┐
│   Dementia diagnosis confirmed.    │     │ Medical notes excluded. n=37 │
│              n=196 (6%)            │     │                             │
└─────────────────────────────────┘     │          Rational:           │
                 │                        │ May 2015 admission missing.  │
                 ▼                        │            n=2               │
┌─────────────────────────────────┐     │ Admission < 48 hours. n=26   │
│      Medical notes requested       │────▶│  Medical notes unavailable.  │
│              n=153 (5%)            │     │            n=9               │
└─────────────────────────────────┘     └─────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│         Total participating        │
│              n=116 (4%)            │
└─────────────────────────────────┘
```

Figure 2.1 Data collection flow chart.

Of those admitted to the general hospital with dementia, 51 out of the 116 case notes reviewed (44% [95% CI 35-53]) were classified as having moderate disease severity in the mental health notes. The distribution of dementia subtypes demonstrated a predominance of Alzheimer's (31% [CI 23-40]), vascular (22% [CI 16-31]) and mixed dementias (15% [95% CI 14-28]) (Table 2.1).

Table 2.1 Demographic details of those admitted to the general hospital with dementia.

	All dementia admissions	Dementia admissions by severity				Dementia admissions by subtype			
	Total N, %	Mild N, %	Mod N, %	Severe N, %	Unclassified N, %	Alzheimer's N, %	Vascular N %	Mixed N, %	Other N, %
Total	116	30 (26)	51 (44)	9 (8)	26 (22)	36 (31)	23 (20)	26 (22)	31 (27)
Age									
75 - 84	57 (49)	20 (35)	14 (24)	5 (9)	18 (32)	13 (3)	12 (1)	14 (25)	18 (32)
85 - 94	48 (41)	10 (21)	28 (8)	3 (6)	7 (15)	18 (8)	10 (21)	9 (19)	11 (23)
94+	11 (9)	0	9 (82)	1 (9)	1 (9)	5 (45)	1 (9)	3 (27)	2 (18)
Sex									
M	39 (37)	10 (26)	15 (38)	4 (10)	10 (26)	13 (33)	9 (23)	12 (31)	5 (13)
F	77 (63)	20 (26)	36 (46)	5 (6)	16 (20)	23 (30)	14 (18)	14 (14)	26(34)
Team providing care									
Elderly medicine	45 (39)	10 (22)	20 (44)	6 (13)	9 (20)	18 (40)	8 (18)	9 (20)	10 (22)
Medicine	51 (44)	15 (29)	24 (47)	3 (6)	9 (18)	13 26)	11 (22)	12 (24)	15 (29)
Surgery	17 (15)	5 (29)	7 (41)	0	5 (29)	5 (29)	3 (18)	3 (18)	6 (35)
Not classified	3 (3)				3 -		1 -	2 -	
Length of Stay									
< 4 days	45 (39)	13 (22)	18 (40)	4 (9)	10 (22)	12 (26)	10 (22)	10 (22)	13 (29)
4-7 days	33 (28)	8 (24)	14 (42)	4 (12)	7 (21)	14 (42)	7 (21)	5 (15)	5, (15)
8-14 days	10 (9)	3 (30)	3 (30)	0	4 (40)	4 (40)	1 (10)	1 (10)	5, (50)
>15 days	28 (24)	6 (21)	16 (57)	1 (4)	5 (18)	6 (21)	5 (18)	8 (29)	8, (29)

Accuracy of dementia diagnosis recording

Twenty six percent (CI 19-35) of patients admitted to hospital with an existing dementia diagnosis did not have the diagnosis documented in their medical notes.

Dementia subtype was recorded in 41 cases (48% [CI 37-58]), but the subtype recorded only matched the psychiatric e-notes in 25% of them (κ) = 0.05. Dementia severity was recorded in only 16 patients (18% [CI 12-28]) but accuracy of recording was better - 75% agreement (κ = 0.44).

There were no associations between the accuracy of dementia diagnosis recording and the specialty providing care or dementia severity (Table 2.2).

Table 2.2 The accuracy of dementia diagnosis and diagnostic information in the medical notes.

	Information recorded in the medical notes		
	Dementia diagnosis N % (CI)	Dementia Subtype N % (CI)	Dementia Severity N % (CI)
Total population (n=116)	86, 74 (66-81)	41, 48 (37-58) κ = 0.05	16, 18 (12-28) κ = 0.44
Specialty providing care Medicine (n=51) Elderly medicine (n=45) Surgery (n=17)	P = 0.32 34, 67 (53-78) 36, 80 (66-89) 13, 76 (52-90)		
Dementia Severity Mild (n=30) Moderate (n=51) Severe (n=9) Unknown (n=26)	P = 0.32 22, 73 (56 – 86) 36, 70 (57 – 81) 9, 100 (70 - 100) 19, 73 (53 – 86)		

Frequency of symptom recording

Psychiatric symptoms were documented once or more in 10% of case notes reviewed. Specific symptoms were infrequently documented; depression (4%) and delusions (4%) were the most common. Somatic symptoms were documented once or more in 62% (CI 53-70) of case notes reviewed. Pain was the most frequently documented symptom (37%), followed by incontinence (10%), nausea (9%) and dyspnoea (8%). Delirium was documented in 11% (CI 7-18). There was no

association between the speciality providing care, dementia severity and the frequency of documentation (Table 2.3).

The use of standardised tools for the recognition of psychological symptoms, pain, agitation and dementia were never documented.

Table 2.3 The frequency of symptom and delirium documentation in the medical notes.

	Information recorded in the medical notes		
	Somatic symptoms Symptom Type: N % CI)	Psychiatric Symptoms Symptom Type: N % (CI)	Delirium N % (CI)
Total population (n=116)	Any: 72, 62 (53-70) Pain: 43, 37 (29-46) Incontinence: 12, 10 (6-17) Nausea: 10, 9 (5-15) Dyspnoea: 9, 8 (4-14) Loss of function: 3, 3 (1-7) Constipation: 4, 4 (2-10) Other: 4, 4 (2-10)	Any: 12, 10 (6-17) Depression: 5, 4 (2-10) Anxiety: 3, 3 (1-7) Hallucinations 3, 3 (1-7) Delusions: 5, 4 (2-10)	13, 11 (7-18)
Specialty providing care	P=0.30	P=0.17	P=0.14
Medicine (n=51)	Any: 30, 59, (45-71)	Any: 4, 8 (3-19)	5, 10 (4-21)
Elderly medicine (n=45)	Any: 28, 52 (48–75)	Any: 8, 18 (9-31)	8, 18 (9-31)
Surgery (n=17)	Any: 11, 41 (21-83)	Any: 0, 0 (0-18)	0, 0 (0-18)
Dementia Severity	P=0.64	P=0.43	P=0.17
Mild (n=30)	Any: 21, 70 (52-83)	Any: 3, 10 (3-26)	4, 13 (5-30)
Moderate (n=51)	Any: 29, 57, (43-70)	Any: 8, 16 (8-28)	4, 8 (3-19)
Severe (n=9)	Any: 5, 56 (27-81)	Any: 0	3, 33 (12-64)
Unknown (n=26)	Any: 17, 65 (46-81)	Any: 1, 4 (1-18)	2, 8 (2-24)

Frequency of distress recording

Language indicating distress was used once or more during the admission in the case notes of 33% (95% CI 25-41) of patients reviewed. In patients where distress was indicated it was usually documented on more than one occasion (Figure 2.2). The language used by HCPs when documenting a distressed state was variable (Figure 2.3).

There were significant associations between the documentation of depression, anxiety and delirium, and the documentation of language indicating distress. There were no significant associations between delusions and hallucinations and the documentation of language indicating distress. There were no significant

associations documented between the documentation of somatic symptoms and language indicating distress (Table 2.4).

Standardised distress recognition tools (e.g. DisDAT) were never used. Where documentation indicated distress, treatment was attempted in 53% of cases, liaison psychiatry was contacted in 5% of cases and the hosting hospitals integrated dementia algorithm for managing distress and BPSD was never used.
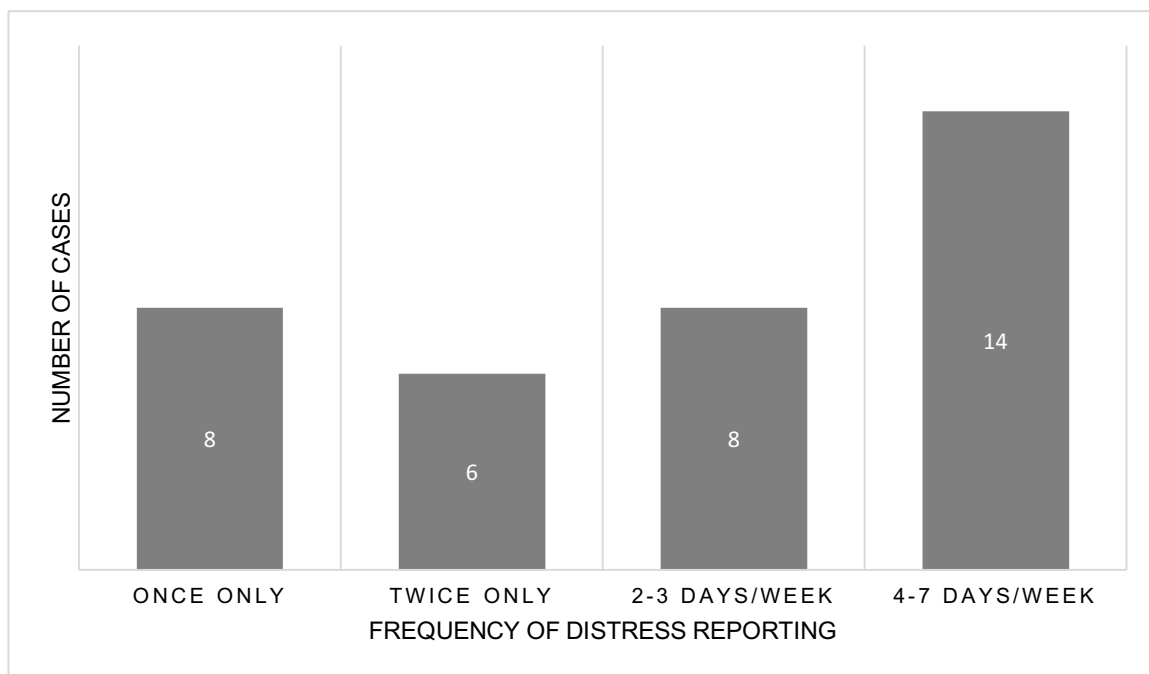
Figure 2.2 A chart to demonstrate the frequency of distress reporting per admission (in admissions where distress was documented n=38).

Table 2.4 Associations between the presence of documented symptoms and documented distress in the medical notes.

	Frequency of documented symptom, N	Documented distress also present N, % (95% CI) p
Any psychological symptom.	12	6, 50% (25-75) 0.33
Depression	5	4, 80% (37–96) 0.05*
Anxiety	3	3, 100% (43-100) 0.039*
Delusions	3	1, 33% (6-79) 1.0
Hallucinations	5	1, 20% (3-62) 0.65
Any somatic symptom	72	25, 35% (25-46) 0.95
Pain	43	13, 30% (18-45) 0.46
Delirium	13	9, 69% (42-87) 0.01*

Disorientated and confused (1)   **Frightened (1)**   **Refusing care (3)**
Suicidal (1)   **Refusing treatment (1)**   **Combative (1)**
Paranoid (1)   **Agitated** (13)   **Not sleeping (1)**
Withdrawn (2)   **Hitting out (1)**
Fed up (2)   **Uncooperative (2)**
Hostile (1)   **Asking to go home (3)**   **Weepy (1)**
Refusing food and fluid (2)   **Tearful (2)**
Upset (4)   **Verbally abusive (1)**   **Wandering** (10)
Throwing objects (1)   **Highly mobile (1)**   **Distressed (3)**   **Unsettled** (8)
Suspicious of staff (3)   **Calling family for help (1)**
Anxious (2)
Throwing tea (1)   **Shouting (2)**   **Restless (1)**   **Feels poorly (1)**
Screaming (1)   **Verbally aggressive (1)**   **Trying to leave the ward (1)**
Crying (1)   **Refusing investigations** (3)   **Trying to get out of bed (1)**

Figure 2.3 A dynamic word map to demonstrate the type and frequency of language used to document distress in dementia in the medical notes.

2.5   Discussion

Principle findings

The prevalence of formally diagnosed dementia in patients over 75 admitted to the general hospital was around 15%, lower than would be expected (Sampson *et al.* 2012). The diagnosis was documented in 74% of cases. Dementia subtype and severity were recorded in 35% and 14% of cases respectively, the accuracy of recording was poor.

The frequency of documented psychiatric symptoms (10%), pain (37%) and delirium (11%) in people with dementia in the general hospital was lower than would be expected (Sampson *et al.* 2014; Inouye, 1999; Sampson *et al.* 2015). There was no association between the documentation of dementia diagnosis, psychiatric symptoms or delirium, and speciality of the team providing care or dementia severity.

Language describing a distressed patient state was documented once or more in 33% of cases. The language used was varied.

Dementia specific standardised symptom recognition tools or treatment algorithms, were never used.

Strengths and limitations

The population characteristics of this sample were similar to other UK hospital samples of older people with dementia (Sampson *et al.* 2014; Sampson *et al.* 2015; Goldberg *et al.* 2012; Royal College of Psychiatrists, 2013) making it generalisable to the wider UK. It is of note, however, that this study is limited to a single hospital trust and mental health provider, and while the systems and procedures are largely typical for the UK, other models of care are available. Length of stay was shorter than might be expected compared with other UK hospital samples, (Goldberg *et al.* 2012, Sampson *et al.* 2014) this is possibly accounted for by the inclusion of elective cases as well as acute admissions. Repeating this study across other regions with contrasting systems of care may improve the validity of the data and provide useful evidence for quality improvement.

This was a retrospective study; all included cases had a dementia diagnosis made by an accredited memory service prior to the point of inclusion, locally this is the most accurate source of diagnostic information available. Patients who lacked a formal diagnosis were not included in this analysis. It is likely, therefore, that 15% is an underestimation of the true prevalence of dementia in hospitalised inpatients, a phenomenon previously described by Sampson *et al.* (2009). However, this approach is advantageous as it describes the documented clinical record and allows the number of inaccurately documented diagnoses to be identified.

Medical notes are live hand written documents, as a consequence they were not always available for review. Where medical notes were unavailable despite several attempts to obtain them, they were excluded them from the study. 11 sets of medical notes were unavailable in total (9 full sets, 2 relating to the May admission; see Figure 2.1), it is not believed these notes were systematically different from the rest of the cohort, or that their non-inclusion will affect the validity of the data.

Each set of notes was carefully scrutinised to reduce the opportunity for missed information. Where illegible information was written, it was reviewed in the context of the legible information around it. Despite this, inaccurate data classification is a potential source of error, although no known incidences of this occurred. Psychiatric notes were electronic therefore data stored is legible and organised, reducing, but not negating the opportunity for reviewer error.

The HCPs documenting the notes were unaware that the record would later be scrutinised, reducing recording bias. The data collection was carried out by one individual, which ensured consistency, but meant that it was not possible to test inter-rater reliability.

Dementia severity data were taken from the psychiatric notes. This method may create a skewed distribution, as patients who present at memory clinic often do so once the symptoms are more apparent (Stratford *et al.* 2003). In the mental health trust observed severity is reviewed at least yearly in all cases other than vascular dementia. Data were taken from the record made closest to the May 2014 admission date. As dementia is a progressive illness, the psychiatric notes may be inaccurate at the point when the patient was admitted to hospital, thus reducing the validity of severity agreement data.

The frequency of documented delirium was counted only where the word 'delirium' or 'delirious' was specifically written in the medical record. No attempt retrospectively diagnose delirium was made as this would not have reflected the treating teams true diagnostic understanding (Kuhn *et al.* 2014). The stringent and arguably overly simplified criteria may not reflect the complexity and ambiguity of real world diagnostic decision making. However it does reflect the percentage of people formally treated as having delirium.

The frequency of documented distress was calculated by a count of language used in the medical record that described a negative behaviour, emotion or action. Distress is a non-specific term and there are no common diagnostic criteria to describe it in dementia. Consequently, the interpretation of what documented language indicates distress is subjective, creating a high potential for inaccuracy when describing the frequency of distress documented in the medical notes. To improve standardisation the criteria used indicate distress and agitation in the Distress in Disability Tool (DisDAT) (Regnard *et al.* 2007), and the Cohen Mansfield

Agitation Inventory (CAMI) (Cohen-Mansfield, 1996) were applied retrospectively (Appendix 2); however, as neither of these are designed for this purpose the scores cannot be published or considered reliable data. This data collection technique attempted to ensure a sensitive method for recording the best possible estimate of the frequency of recorded distress events. Despite these efforts there is subjectivity in the data collection process, introducing potential error and bias in interpretation. Had this study access to greater resources, analysis of the notes by different reviewers may have allowed for consensus decision making improving reliability.

The frequency of documentation of some symptoms was rare; for example, only three people were documented as being anxious. As a consequence, the study lacked power to be able to significantly demonstrate some associations. Some symptom reporting was so infrequent that it was beyond the feasibility afforded to the study to be able to increase data collection numbers to a point to increase power.

Meaning of the study in the context of existing evidence

Dementia prevalence data

Worldwide dementia prevalence in a hospital setting ranges between 5-45%, (Ames and Tuckwell, 1994; Hickey *et al.* 1997; Kolbeinsson and Jonsson, 1993; Laurila *et al.* 2004; Sandberg *et al.* 1998; Uwakwe, 2000; Goldberg *et al.* 2012; Sampson *et al.* 2009). These estimates have all been measured using either prospective longitudinal cohort or cross sectional surveys of hospital populations. All have used objective memory assessment tools to screen patients admitted to hospital then subsequent clinical assessment to estimate the dementia prevalence as accurately as possible.

The prevalence recorded in this study was only 15%. However, this figure is a reflection of the clinical record, not true prevalence. This differs from previously published prevalence data as it is retrospective and only cases with a dementia diagnosis made prior to admission, in community memory clinics were included. This is highly specific - undoubtedly causing an underestimation. However, in the context of the study this is acceptable because the aim was to describe dementia diagnosis recording, not to describe true dementia prevalence.

Diagnostic accuracy

Documenting a person's dementia diagnosis is a defined standard in hospital admission documentation, however, subtype and severity recording is not (NHS Commissioning Board, 2014). Inaccuracy in the dementia diagnosis documentation leads to there being a greater chance of HCPs not having all clinically relevant patient information available to them. This potentially means that patients with specific symptom profiles and care needs being overlooked.

This study demonstrates that in the host hospital, the diagnosis remains unknown in about a quarter of patients, who already have a formal dementia diagnosis in the community. This figure also has to be considered in the context that community diagnostic rates are 60%. With this in mind a further 40% of cases will not have a diagnosis known by the mental health or physical healthcare trust, so not be identified by the study methodology (NHS England, 2015).

Some psychological symptoms are more common and treatment strategies more effective dependant on the severity and subtype of the dementia (Cerejeira *et al.* 2012; Boot *et al.* 2013). Knowing a person's dementia subtype and severity can, therefore, help refine treatment regimes.

It was previously unknown how dementia severity and the speciality providing care affect the accuracy with which dementia is identified by HCPs. It might be assumed that they are associated; the cognitive symptoms of dementia are more overt in severe disease (World Health Organisation, 1992), and those with experience in dementia care might be expected to more easily be able to recognise symptoms. The proportion of diagnoses recorded accurately in those with mild, moderate and severe dementia were; 71%, 73% and 100% respectively. Due to the small number of severe cases, however (n=9), there was no significant association between dementia severity and the accuracy of dementia diagnosis recording (p=0.32). The rate of diagnostic accuracy was better in elderly medicine than medicine or surgery, (80 vs 67 vs 76%), but statistical comparison was underpowered and no significant difference was observed between specialities providing care (p=0.32).

Severity and subtype data were recorded in 14% and 35% of cases respectively. Even in cases where dementia severity and subtype were documented, the accuracy of the information recorded was questionable, with levels of agreement

between the mental health and the general hospital notes having a kappa coefficient of 0.05 and 0.44 respectively.

Symptom recording

People with dementia in a general hospital are known to experience a high prevalence of psychological symptoms (70-80%), and pain (c.50%) (Sampson *et al.* 2014; Sampson *et al.* 2015; Hessler *et al.* 2017). The prevalence of other somatic symptoms such as nausea, dyspnoea, and motor or sensory deficit is not described in the academic literature, however, they might assume to be at least as common as they are in people who do not have dementia. Delirium is common in around two-thirds of people with dementia in a hospital setting (Fick *et al.* 2002), and the presentation has considerable overlap with other psychological symptoms, making diagnosis difficult at times (Jackson *et al.* 2017).

The frequency of documented symptoms was low. Figures were generated by a count of the symptoms documented in the medical notes. Documentation provides an account of what the author has recognised, remembered and seen as relevant. A lower than expected number of reported symptoms does not reflect low rates of symptom prevalence. It does, however, reflect the true clinical record. The clinical record is an important indicator of the patient experience as it is unlikely that a symptom will be actively treated without it being documented (General Medical Council, 2013).

The expected prevalence of psychological symptoms, pain and delirium in those with dementia described above are generated by using standardised diagnostic tools administered by practitioners trained to use those tools on patients with known dementia or cognitive impairment (Sampson *et al.* 2014; Sampson *et al.* 2015; Inouye 1999; Fick *et a*l. 2002). Data presented is also collected from homogenous patient groups; for example, those under geriatric care or those under surgical care (Sampson *et al.* 2015; Morrison and Siu, 2005). Data in this study were collected retrospectively from live patient notes, and the symptoms observed were diagnosed and recorded by a range of HCPs with an unknown level of expertise managing dementia. A gap between expected and recorded rates may be expected, but the discrepancy observed is unlikely to be accounted by this alone, and represents a potential unmet need despite it. As the demographics of the cohort are largely similar to those observed in previous prospective observational studies (Sampson

et al. 2014) the low frequency of reported symptoms are unlikely to reflect a genuine low symptom prevalence, but instead a mismatch between symptom prevalence and symptom recording.

The discrepancy between expected and reported pain, was less than the discrepancy observed when describing psychological symptoms. This may be caused by several factors:

•   HCPs on hospital wards are more comfortable recognising pain/other somatic symptoms than psychological symptoms (Goldberg *et al.* 2014).
•   Systems are in place for reporting pain, and well-used algorithms are used to treat it (World Health Organisation, 1990; Vargas-Schaffer, 2010).

Given that dementia is more prevalent with advancing age (Prince *et al.* 2014) HCPs working on wards, which specialise in caring for older people might be assumed to be more adept at recognising symptoms associated with dementia than their colleagues on other wards, but this was not the case. Although the frequency of psychological symptom and delirium reporting was low in all specialities, it is of note that no psychological symptoms were recorded in the records of people cared for by surgical specialities; however, the study lacked power to demonstrate significance (p=0.17).

An explanation for the discrepancy between observed and expected symptoms is that symptoms of all types can be difficult to recognise and diagnose in those who have a reduced capacity for verbal communication (Regnard *et al.* 2003). As a consequence, standardised tools to assist clinicians identify common symptoms exist (Abbey *et al.* 2004; Cummings, 1997; Inouye *et al.* 1990). If these strategies do not work most hospital trusts have access to specialist assessment by a liaison psychiatrist.

Standardised diagnostic tools were never used, and specialist liaison psychiatry services were requested in only 5% of the cases where psychological symptoms were reported.

Distress in dementia

Untreated psychological symptoms, pain and delirium can lead to discomfort, agitation, and increased morbidity for patients (Sampson *et al.* 2015; Fick and Foreman, 2000; Holmes and House, 2000), potentially causing distress (Regnard *et al.* 2003). The term distress is non-specific, and there are no common diagnostic criteria to describe it. This makes it difficult to set a strict definition for when a person is in distress, yet treating it is a key goal in this group (van der Steen *et al.* 2014).

The prevalence of distress in dementia in a hospital setting is unknown. One might assume (given the high prevalence of psychological symptoms, pain and delirium), the prevalence of distress is also high (if these symptoms go untreated). Given the discrepancy between observed and expected psychological symptoms, pain and delirium, one might expect there to be high levels of distress.

The frequency of distress (or language indicating distress) documented by HCPs was 33%, which is lower than the prevalence of most known individual psychiatric symptoms (other than delusions and hallucinations), or pain. 74% (n=28) of people observed to be in distress had multiple entries of it in the medical notes, and 37% of cases had distress documented most days of the week. As the prevalence of distress is unknown these data simply act to describe the documented situation, though it can be speculated that either some patients' distress is going undetected or unreported, or that HCPs were acting on distress but not documenting occurrence, or that the 67% of patients with no distress documented had adequate symptom control and care throughout their stay to meet their needs.

If the latter scenario were the case, one might expect an association between reported distress and reported psychological or somatic symptoms, none were observed. When individual symptoms were considered, associations between distress and anxiety (p=0.05) and distress and depression (p=0.004) were observed. It is of note, however, that only 3 cases of each were recorded, limiting the reliability of this result.

A key treatment goal is that attempts should be made to alleviate discomfort and distress (General Medical Council, 2013; Nursing and Midwifery Council, 2015). Strategies are available to do this, and in the host hospital trust a specific treatment

algorithm for managing distress in dementia has been designed and is available to all HCPs (Leeds Integrated Dementia Board, 2014). On this basis, in the 33% of cases where distress was documented, it might be expected that attempts to investigate or treat the distress would have been made. The documentation of distress triggered a targeted investigation or treatment of the distress in only 53% of cases. Treatment ranged from reassurance given, to investigation by a liaison psychiatry team and treatment with antipsychotic medication. The hospital's treatment algorithm for treating distress was never used according to the documented evidence.

The process of treating distress requires HCPs to recognise it, acknowledge it, investigate the cause of it, and minimise/alleviate the cause (Figure 1.1). If they are unable to complete these tasks personally due to a lack of technical ability or skill, then HCPs would be expected to escalate the issue to a colleague. The number of people with documented distress that remained untreated suggests that HCPs are either unaware what systems or treatment strategies are available to alleviate distress, or that they did not document their action.

Hospital systems rely on collaborative working, HCPs handing over patient information to one another at the start of each shift, during ward meetings and when a problem is identified (British Medical Association, 2004). This information sharing can be done verbally. However, significant information should be documented in the medical record (General Medical Council, 2013; Nursing and Midwifery Council, 2015). Clear communication of patient information is a key element of ward safety and commutation errors are caused by differing styles of communication (Leonard *et al.* 2004). For this reason verbal communication of clinical information is recommended to be done in a formalised way (British Medical Association, 2004). The language used to describe distress by HCPs was very varied (Figure 2.3), ranging from descriptive: 'refusing food and drink', to accusatory: 'hostile'. There were no systems in place to report distress, and standardised screening tools to improve distress recognition in people with dementia (such as the DisDAT) were never used in the population studied (Regnard *et al.* 2007).

Clinical implications

The systems and processes that contribute to good dementia care rely on HCPs knowing their patient's needs and responding to them (Figure 1.1). A key aspect of

that is knowing which patients have dementia and their symptom burden. This study was designed to highlight areas of unmet need in the process of reporting dementia and symptoms associated with dementia in hospital. To do this, key outcomes of care were reviewed including the accuracy of dementia diagnosis recording, the reported frequency of common symptoms in dementia, and the frequency of reported distress in dementia.

A potential target for improving dementia care might be to increase the accuracy with which HCPs correctly identify people with the syndrome. To improve the accuracy of dementia diagnosis recording HCPs need access to reliable diagnostic information from general practitioners or the mental health trust. A major potential reason for diagnostic inaccuracies is that in the system described is that physical health and mental health trusts do not routinely share diagnostic information and the computerised notes systems are not compatible with one another. Other potential reasons for lack of accurate dementia diagnosis recording include: oversight on the part of the admitting doctor to ask about a dementia diagnosis, documentation error, or a fear of incorrectly diagnosing dementia (Lliffe and Manthorpe, 2004).

To improve the current system, there needs to be closer collaboration between mental health and physical health trust information systems and an awareness that HCPs should enquire. Some initiatives are already in place to try to improve this; for example, the National Dementia Commissioning for Quality and Innovation payment framework (CQUIN) provides financial incentives to hospitals which identify people with a diagnosis of dementia admitted to hospital (NHS Commissioning Board, 2014). The healthcare trust that hosted this study, reports that it complies with the national dementia CQUIN in 94% of patients admitted over the age of 75, a figure in line with national rates. However, if the hospital does not have access to a reliable information source when asking this question, (for instance the psychiatric notes), then the process is fallible.

Nationally reliable, integrated electronic healthcare records systems, may also reduce the chance of missed information. In the UK the government plans to implement such a system by 2020, but it does not come without significant technological and data protection challenges (Parliamentary Office of Science and Technology, 2016).

People with dementia and their carers are also encouraged to play an active role in their care, informing hospital staff of their diagnosis and approaches to care that make them feel most comfortable. Systems are already in place to empower patients to do this; for instance, the Butterfly Scheme and 'This is me' booklet produced by the Alzheimer's society. However, they all require opt in by the person with dementia and the capability to bring the information to hospital (The Alzheimer's Society, 2010; Butterfly Scheme, 2014).

For those with dementia, but no formal community diagnosis, the assessment can theoretically take place in a hospital setting, but this is not common practice (Russ *et al.* 2012). The diagnostic process can often be complicated by factors common in an elderly population in hospital, such as comorbid delirium (Jackson *et al.* 2017), and the physical and psychological stressors of being in hospital. Furthermore, many clinicians hesitate to diagnose dementia for fear of the stigma it may cause, a fear of making an incorrect diagnosis, and causing undue stress for patients and their families (Illiffe and Manthorpe, 2004).

Once HCPs are aware who has a dementia diagnosis and that they may have difficulty communicating their care needs, the next step in the process of care is to identify common and distressing symptoms as and when they arise (Figure 1.1). The low symptom reporting frequency observed in this cohort is likely to be generated by HCPs either failing to recognise or report symptoms and delirium. Reasons for this could include:

- People with dementia often have difficulty communicating verbally, limiting their ability to vocalise problems.
- Symptoms maybe comorbid, so difficult to tell apart in people who have limited capacity for verbal communication (for instance pain and depression).
- Recognising symptoms, particularly psychiatric symptoms requires clinical expertise. HCPs on wards are often busy and recognising psychiatric symptoms is not always priority (Goldberg *et al.* 2014).
- For symptoms to be recognised they have to be 'severe enough' for patients to complain about them, and to reach the HCPs treatment threshold.

Based on healthcare design theory, strategies to improve symptom recognition could either be targeted at the ward system design (number of available staff etc.) or staff technical knowledge and skill. Increasing staffing levels to reduce the patient to HCP ratio has been recommended (Royal College of Nursing, 2011b; The Kings Fund, 2014). In the current economic environment, however, it is unlikely to become a reality. Furthermore, even if extra HCPs are available, they still need the skill and knowledge to be effective carers.

A HCPs knowledge base should be evidence based and is taught both in the classroom and through practical experience. In the mainstay, advanced dementia care and symptom recognition is carried out by mental health nurses or old age psychiatrists, who have had specialist undergraduate and postgraduate training. The majority of care on hospital wards, however, is carried out by CSWs or registered clinical nurses, neither of whom are likely to have specialist mental health training as standard (The Alzheimer's Society, 2009). Raising awareness of all staff of common symptoms to be aware of in dementia is undoubtedly a good thing, but training all HCPs to recognise individual symptoms would be economically and logistically unpractical.

A further potential target to improve symptom recognition is to use available standardised symptom recognition tools. Some tools are readily available and have good reliability and validity. Indeed, in the host trust several are recommended as part of the local dementia algorithm (Leeds Integrated Dementia Board, 2014). Despite this tools were never used in the cohort studied, indicating that HCPs were either unaware of them, didn't know how to use them, or didn't have time to use them. One further draw back to symptom recognition tools in this instance, is deciding which patient to use them on and when they should be used.

Lessons maybe learnt from other specialities, where simple scorning tools have been used to good effect to help HCPs to recognise 'trigger' symptoms, which if identified can encourage further investigation by personnel with appropriate skill levels, or further screening tools. Examples of this include the National Early Warning Score (NEWS) (otherwise known as the Modified Early Warning Score (MEWS)), which helps monitor patients for indicators of critical illness, and the Waterlow Pressure score for detecting early signs of pressure ulcers (Royal College of Physicians, 2015; Bridel, 1993). Both these tools are recommended to be used at

regular intervals as part of routine ward care. When caring for people with dementia on hospital wards, asking staff to routinely identify a common sign present in all people with uncomfortable symptoms could be a reliable way to trigger further, more targeted, intervention downstream. Distress is a potential candidate for this.

Targeting distress as a sensitive trigger symptom would require HCPs to recognise it and report it. This study has demonstrated that in the host hospital, there are no clear systems for recognising distress and there is no clear shared method of communication between HCPs (Figure 2.3). In people who struggle to communicate verbally, distress can be detected through body language, verbal sounds and facial expression, (Manfredi *et al.* 2003; Hadjistavropoulos *et al.* 2000; Bourbonnais and Ducharme, 2010), but the barriers and facilitators to recognising distress in people with dementia on hospital wards are currently unknown. A better understanding of them may help develop theories to improve distress recognition and subsequent symptom recognition in this vulnerable group.

2.6   Conclusions

Dementia and associated psychological symptoms, pain and delirium are under reported in patients on the hospital wards studied. The reasons for this are likely to be multifactorial and changes to both ward systems and processes need to be considered to improve it. Changes to ward systems are the current target for some national initiatives, and beyond the scope of this project.

The results suggest that in the cohort studied the processes in place to help HCPs recognise the common symptoms and delirium in dementia are failing. No recommended standardised tools are being used and the available treatment algorithms are not being used. Although this study was only done on one hospital site, the results are likely to be transferable to other UK hospitals with similar training programmes and systems.

It is hypothesised that rather than training all HCPs to recognise individual symptoms or to expect them to use lengthy screening tools, using simple sensitive indicator might be a useful target for intervention. Distress is a potential candidate for this.

The next chapter will go on to explore the concept of distress and its potential application as a screening system for use in dementia care.

Developing a strategy for intervention

3.1   Summary of previous chapters

Dementia and the psychological symptoms, pain and delirium commonly associated with it are prevalent in older people in a hospital setting (Sampson *et al.* 2009; Sampson *et al.* 2014; Sampson *et al.* 2015; Hessler *et al.* 2017; Fick *et al*. 2002). The results from Chapter 2 suggested under reporting of all of them, indicating a potential unmet need. It is argued that given the complex nature of recognising specific symptoms in people with dementia who struggle to communicate their need verbally, without significant changes to ward systems and training this is unlikely to improve. Such changes have practical and economic barriers, however, and it is hypothesised that using a broader, more easily recognisable indicator of patient need, such as distress could prove an effective, sensitive trigger for more specialised investigation downstream. In the cohort investigated, distress was documented in about a third of the people with dementia, but no clear systems were being used to communicate distress, and it was unclear how the information about the distressed individual was being used.

In this chapter, the concept of distress and its potential as a trigger for further investigation will be explored.

3.2   Distress as a concept in dementia

Identifying specific symptoms in people who struggle to communicate verbally is difficult. Symptoms are problems as told by the patient to the assessor (Kumar and Clark, 2016; Regnard *et al.* 2003). Untreated symptoms cause discomfort and distress. Distress is common in those with severe dementia, particularly at the end of life (van der Steen, 2010), and treating it is a key goal in this group (van der Steen *et al.* 2014). In this instance, distress is being used as a 'catch all' non-specific proxy to indicate the presence of underlying discomfort, the cause of which warrants further investigation. A representation of this concept, displayed within the framework of symptom recognition is displayed below in Figure 3.1.

Using distress in such a way is widely recommended when providing care for people who struggle to communicate verbally (Regnard *et al.* 2003; Kovach *et al.* 1999; McCarthy et al. 1997). However, there is still limited understanding about how to implement effective strategies for recognising it in a healthcare setting.
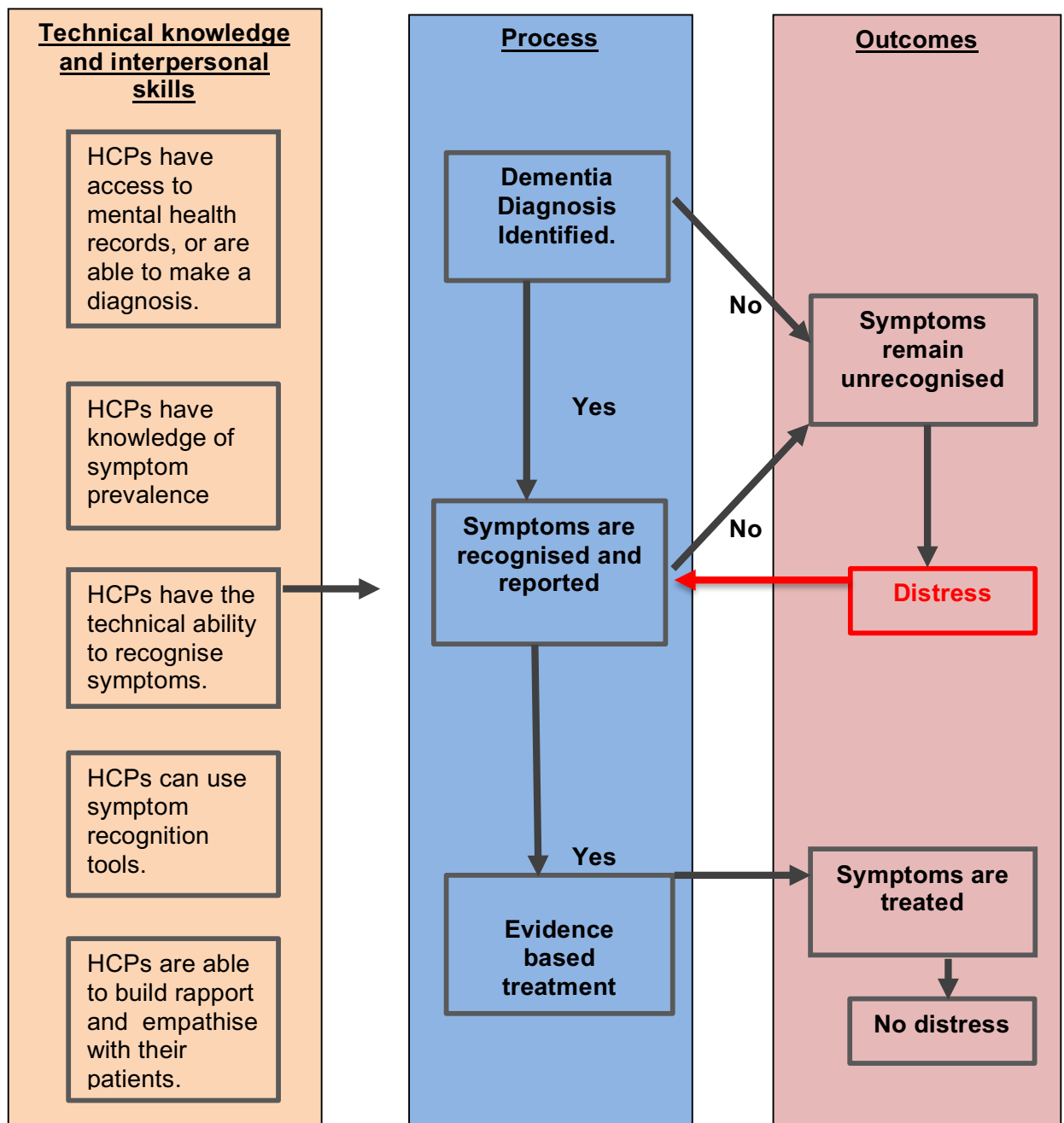
Figure 3.1 A framework to demonstrate the process of symptom recognition in relation to distress.

3.3   Identifying distress in dementia

When a person who cannot communicate verbally experiences distress, it is believed they display their suffering through non-verbal cues including facial expression, body language and vocal sounds (Manfredi *et al.* 2003; Hadjistavropoulos *et al.* 2000; Bourbonnais and Ducharme, 2010). The interpretation of these cues allows the assessor to formulate an opinion that the person is in distress (Kovach *et al.* 1999). Both professional and non-professional carers are thought to be able to accurately identify pain and/or distress using non-verbal cues and examples are illustrated below:

Facial expressions indicating happiness, disgust, surprise, sadness, anger and fear are sensitively recognised by healthy individuals (Ekman, 1993). This interpretation is believed to be innate, though subject to cultural differences and environment factors (Barrett *et al.* 2011). The way in which healthy adults express pain by their facial expression is consistent, examples include: brow lowering, eye closing, and levator contraction (Prkachin, 1992). These expressions are similar in people with severe dementia. In a study of 9 people with severe dementia Manfredi *et al.* (2003) demonstrated that 18 assessors could recognise pain (during the debridement of ulcers) from facial expression alone with a sensitivity of around 0.7 and interclass correlation coefficient of 0.64. These positive findings are from a small cohort only, but consistently reported (Oosterman *et al.* 2016; Shega *et al.* 2008).

Signs of pain or distress displayed by body language include guarding, rubbing, bracing, and withdrawing from stimulus. The validity of body language as a way of communicating internal states in animals was described by Darwin (1872), and numerous examples in the literature can be found of how humans who struggle to communicate verbally display distress through their actions and posture (Franck *et al.* 2000). Identifying pain through body language alone in people with severe dementia has been demonstrated to be a valid technique (Hadjistavropoulos *et al.* 2000), but challenges to this hypothesis have been made by Shega *et al*. (2008), who demonstrated an internal reliability coefficient of only 0.32 when trying to identify pain though observation of body language alone in 14 people with moderate cognitive impairment and back pain. They argue that in the group with cognitive impairment facial expression was a more reliable indicator of pain, demonstrating significantly higher incidence of grimacing and frowning, and less posturing and guarding than the non-cognitively impaired control group.

Vocal sounds, such as screaming, shouting, and groaning are commonly observed in people with severe dementia (Bourbonnais and Ducharme, 2010). By interpreting pitch,

volume, tone, and consistency these sounds are often attributed to an internal emotional state. Scream interpretation can, for example, be used to sensitively determine the different stages of labour in women giving birth (Baker and Kenner, 1993). In people with dementia it is reported that interpreting screams and vocal sounds can be a good indicator of pain and distress (Bourbonnais and Ducharme, 2010).

3.4   Innate distress recognition

In reality our interpretations of body language, facial expressions and sounds are not used in isolation and the interpretation of distress is a subconscious amalgamation of the whole state. The ability to recognise these cues is essential to human social interaction and something we do innately in day to day social interactions (Montagne *et al.* 2005; Richards, 2013). On general hospital wards, an alteration in comfort is one of the most common nursing diagnoses (Gordon and Mahriner, 1983). It is unlikely though that on each occasion the nurse reporting it, runs through a check list of cues they have observed; they are using innate recognition.

The accuracy with which HCPs can innately recognise distress in dementia is unknown. Sundin et al. (2000), interviewed 10 professional carers of people with aphasia following stroke (a group who also struggle to communicate need verbally). They described that all carers believed they could communicate non-verbally with their patients, 'sensing their feelings and experiencing similar feelings them selves'. The validity of this study is questionable, however, all interviewees were selected for being good non-verbal communicators and the sensitivity with which assessors could actually detect need was not evaluated. However, the concepts discussed are not alien and are similar to the transference of emotion described in psychotherapy (Freud, 1949). In other groups who lack the ability to communicate verbally, for instance infants, it is believed that carers can sensitively identify distress innately, but this had not been tested formally (Selekman and Malloy, 1995). Indeed, no evidence exists describing the sensitivity of HCPs to innately recognise distress in patients who cannot communicate verbally, either in a community or hospital setting.

3.5   Existing tools to help healthcare professionals identify distress

A potential way to formalise and improve rates of distress detection and reporting, is to use standardised distress assessment tools on all 'at-risk' patients (those with

dementia). Several tools exist to help clinicians do this, and have potential application in a hospital setting, however none were used in the cohort studied in Chapter 2.

To identify existing screening tools for detecting distress in dementia and their psychometric properties a review was conducted. Published papers were included if they described the design and validation of distress screening tools for use in dementia. The search strategy and identified studies are described in Appendix 2.

Only two screening tools were identified, neither of which had published additional validation studies: the 'Disability Distress Assessment Tool' (DisDAT) (Regnard *et al.* 2007), and the 'Discomfort in Dementia of the Alzheimer's type' (DS-DAT) scale (Hurley *et al.* 1992). Study quality was assessed by the researcher using the 14 point QUADAS tool (Whiting *et al.* 2003).

After the search a content analysis describing the published tools to assess pain and lack of comfort in dementia was published (van der Steen *et al.* 2015). No further distress tools or subsequent validation studies were identified from this review that met the inclusion criteria.

Appraisal of tools to help healthcare professionals recognise distress

Both the DS-DAT and DisDAT are observational screening tools for use by HCPs on people with cognitive impairment who lack the ability to communicate verbally.

The DisDAT requires the user to assess 9 domains including appearance, jaw movement, appearance of eyes, skin appearance, vocal sounds, speech, habits and mannerisms, body posture and body observations. It aims to measure a change in distress behaviour from a baseline, taken when the person with cognitive impairment is not in distress and it therefore requires the person completing it to first establish a baseline profile. This has advantages as it is personalised to the individual and allows assessors who may not be familiar with the patient, to quickly establish 'normal behaviour'. Establishing a baseline may be impractical task, however, as the baseline assessment needs to be carried out by someone with prior knowledge of the patient, and when the patient is comfortable. Patients with dementia may not have available carers, and in a general hospital setting patients are often at their least comfortable at the beginning of the admission, during the acute phase of their illness.

No indication is given as how long the tool takes to complete or how regularly it should be completed (Regnard *et al.* 2007). Interventions that are time consuming are less likely to be completed in a hospital setting (Cochrane *et al.* 2007). No information as to how the DisDAT tool was developed is published and content validity is not justified (Regnard *et al.* 2007).

The DisDAT was originally designed for use in people with severe intellectual disability; a group with communication needs similar to those with severe dementia. The tool was tested in a group of 25 people with severe intellectual disability, some of whom (an undisclosed number) had Down syndrome and Alzheimer's type dementia. There were no withdrawals from the study. The average age of the sample group was 55, far lower than the average age of people with severe dementia (O'Connor *et al.* 1989). The test population, while having some similar characteristics to people with dementia, may have differing needs and symptom profiles, limiting the transferability of the tool to a wider population.

No reference standard or Delphi consensus was used to test the psychometric properties of the tool. There is no published validity, reliability, sensitivity, specificity, positive predictive value or negative predictive value data of the DisDAT so one cannot comment on its usefulness as a screening tool. The authors did comment on its ease of use; only two thirds of users finding it easy to complete and 72% of users seeing a clinical use for the tool (Regnard *et al.* 2007).

The DS-DAT requires the user to assess the person with dementia on the frequency, intensity and duration of 9 distress domains including noisy breathing, negative vocalisation, content facial expression, sad facial expression, frightened facial expression, frown, relaxed body language, tense body language and fidgeting. It generates a distress score dependant on the observations made. Each time it is completed the patient should be observed for five minutes. No indication is given as to how frequently it should be completed. No guidance is given on what score would indicate a distressed state (Hurley *et al.* 1992). It is proposed that the tool be completed by HCPs, no guidance is given as to how familiar the HCP should be with the patient.

The DS-DAT was developed using content analysis from 45 semi-structured interviews with nurses on the common physical signs of distress. The nurses had an average of 5 years for caring for people with dementia. The results were refined by senior nurses

and it was piloted on 82 people with dementia over 6 months. The content largely conforms with common published distress indicators, and this combined with the rigour of the development process suggests a reasonable level of content validity.

In the final stages of testing, the DS-DAT authors conducted a longitudinal study on 82 subjects and the number of withdrawals was not commented on. The test was used in isolation; no reference standard or Delphi consensus was used as a comparator.

The same subjects were reviewed with the DS-DAT by multiple assessors; an r statistic of 0.9 suggested high levels of interrater reliability. Construct validity was demonstrated by repeated distress measurements on the same patients with and without a fever (a fever being presumed to cause a distressed state). Significant differences in distress scores p<0.001 were observed between the distressed and non-distressed states indicating construct validity. No sensitivity, specificity, negative predictive value or positive predictive value data were published, and no follow up studies have been published. The authors did not comment on the ease of use or uptake of the tool.

Both these distress recognition tools have merit; the aims of the tools, and their content are worthwhile and potentially valid. Both tools ask their users to look for signs that are often recognised innately as part of normal social interaction (Montagne *et al.* 2005; Richards, 2013), perhaps overly formalising a process that is already done. They both have impracticalities that make their use on a busy hospital ward difficult to initiate. Both tools lack psychometric data to support their use.

It might be argued that observational symptom recognition tools, designed to measure pain, agitation or psychological symptoms in dementia, such as the Abbey Pain Scale, Cohen Mansfield Agitation Inventory or Neuropsychiatric Inventory measure distress also (Abbey et al. 2004; Cohen-Mansfield, 1997; Cummings et al. 1994). These tools encourage their users to look for similar non-verbal communication cues as the DisDAT or DS-DAT. However, using such tools in the first instance potentially leads the user to assume causality before fully investigating the distress, focusing on specific symptoms before exploring all possibilities.

3.6   Track and trigger systems in other areas of healthcare

The concept of using distress as a sensitive indicator for further investigation is a similar concept to track and trigger systems used in physical healthcare. Track and trigger systems encourage staff to routinely look for sensitive and easily observable

signs that can act as an indicator for further investigation (National Institute for Health and Care Excellence, 2007). Examples include the National Early Warning Score (NEWS) (Royal College of Physicians, 2015) and the Paediatric Early Warning Score (PEWS) (Tibballs *et al.* 2005). These are both systems that ask HCPs to routinely take patients vital signs including blood pressure, pulse and temperature. Results that lie outside normal physiological parameters generate a score, and the higher the score the more abnormal the result. High scores trigger a set escalation protocol, with the aim of improving the appropriate use of critical care and reducing mortality. PEWS has been demonstrated to significantly (p>0.001) improve the forewarning time for recognising unwell children (Akre *et al.* 2010). The effectiveness of the MEWS system has been questioned. A Cochrane review of two randomised control trials of hospitals using MEWS were inconclusive demonstrating either no effectiveness at reducing critical care admissions or a reduction in overall mortality (McGaughey *et al.* 2007).

Other examples of track and trigger systems in healthcare include self-monitoring of blood glucose in diabetes (Nathan *et al.* 1993), and the monitoring of pressure sores in a hospital setting (Bridel 1993).

3.7 How do healthcare professionals investigate and manage distress in hospital? Understanding the barriers to care

In this chapter, the concept of using distress as a trigger for further investigation of people with dementia has been explored. The theories of how distress is identified in people with communication difficulties have been appraised, as have existing standardised distress screening tools. It is unknown, however, how HCPs view or manage distress in a clinical environment, and what the barriers and facilitators for this are.

To enhance understanding in this area - and explore whether targeting distress could be an effective intervention - one must first understand the existing practice, and the barriers and facilitators that stand in the way of delivering care in the current system (National Institute for Health and Clinical Excellence, 2007). These can be at a systems level; for instance, economic or practical barriers, or personal barriers, dependant on the HCP (The Kings Fund, 2014). Common types of personal barriers in healthcare include HCPs awareness and knowledge of the problem, HCP skill, acceptance and belief of the problem, and motivation for change, (National Institute for Health and

Clinical Excellence, 2007). In the instance of distress recognition, identifying these requires the researcher to have an understanding of:

- How HCPs currently view distress in dementia, and whether it is identified as a problem that needs intervention.
- How aware HCPs are that people in dementia experience distress, and how they communicate it.
- How HCPs currently identify distress in dementia, what skills they use, and training they have had.
- Whether HCPs are motivated to identify distress, is it viewed as an important part of care?
- What the current systems barriers to distress recognition in a ward environment are?

Developing a better understanding of how HCPs recognise and react to distress in those with dementia on hospital wards, and the barriers that inhibit their ability to do so, may help inform future systems to improve it. The following chapter describes a qualitative study that uses semi-structured interviews with HCPs to do this.

Chapter 4

Describing the barriers and facilitators for Distress Recognition

4.1   Summary of previous chapters

Dementia is a common co-morbidity in elderly people admitted to the general hospital (Royal College of Psychiatrists, 2005). Those with dementia in hospital often have difficulty orientating to their surroundings, communicating their needs and they are susceptible to psychological and somatic symptoms and delirium; all of which can cause distress (World Health Organisation, 1993; Sampson *et al.* 2014; Sampson *et al.* 2015; Goldberg *et al.* 2012; Fick *et al.* 2002).

One of the most widely accepted strategies to relieve distress in this group is to identify the cause of it and treat accordingly. Algorithm driven management protocols, standardised symptom recognition tools and targeted holistic or pharmacological treatment strategies exist to help clinicians identify the causes (Abbey *et al.* 2004; Reisberg *et al.* 1997; Fuchs-Lacelle and Hadjistavropoulos, 2004; Cummings *et al.* 1994; Cohen-Mansfield *et al.* 1989). If distress is not identified in the first instance, however, subsequent investigation and treatment is likely to be suboptimal, and the person with dementia is likely to suffer.

In Chapter 2, such a deficiency in the identification of distress and some of the common causes of distress was suggested, when a discrepancy between the expected and observed prevalence of psychological and somatic symptoms was described in people over the age of 70 admitted to a large teaching hospital in the UK. Furthermore, in the cohort studied there were no formal systems to report or communicate concerns about a patient in distress, and the available hospital treatment algorithm to help people with dementia in distress was never used.

It is hypothesised that if people, with dementia, in distress are identified accurately, this might allow for better investigation and treatment of causes of it downstream, using the pre-existing systems, which are already in place but underutilised.

Limitations of existing research and knowledge gaps

Descriptions of the presentation of distress in an individual who has a reduced capacity for communication are numerous and well-documented. Examples include: changes in body language, facial expression, speech and behaviour (Manfredi *et al.* 2003; Hadjistavropoulos *et al.* 2000; Bourbonnais and Ducharme, 2010). Individual presentations of distress are wide ranging and differ dependant on personal circumstance and environment. In the mainstay healthy adults can interpret emotions with relative accuracy (Ekman, 1993).

Those with dementia differ from those without it because they often lack the capacity to communicate verbally, and can struggle to understand the nature and cause of their distress. No evidence exists to demonstrate whether the accuracy with which assessors can identify distress in this group compared to individuals without dementia differs. However in similar groups, for example, infants and those with severe learning disabilities, it has been suggested that carers might sensitively identify distress innately (Selekman and Malloy, 1995).

Only two standardised tools to assist HCPs identify distress in those with communication difficulties has been developed: the DisDaT and the DS-DAT (Regnard *et al.* 2007; Hurley *et al.* 1992). Both of these tools were reviewed in the previous chapter; neither have published psychometric properties and both are impractical to be used regularly in a hospital environment.

Recognising distress in those with dementia on a hospital ward brings further challenges because patients are cared for in an unfamiliar, busy environment and they are often experiencing uncomfortable physical symptoms, and staff are often busy. The effects this has on the HCPs ability to accurately recognise distress is unknown. Developing a better understanding of how HCPs recognise and react to distress in those with dementia on hospital wards, and the barriers that inhibit their ability to do so, may help inform future systems to improve it.

4.2   Research Questions

- What do HCPs understand by the term "distress"?
- What are the barriers, and facilitators, to HCPs recognising distress in people with dementia who have a reduced ability to communicate verbally?

- What are the barriers, and facilitators, to HCPs reporting and treating distress in people with dementia who have a reduced ability to communicate verbally?

4.3   Consultation and development

To develop the research questions and methodology that form the basis of this study the researcher presented the results from Chapter 2 "Describing the population with dementia in a general hospital setting" at regional, national and international academic meetings in the field of old age psychiatry, general psychiatry and elderly medicine. One to one meetings with local and national experts in the field have also been held.

4.4   Methodology

The research questions aim to understand how HCPs perceive distress in dementia and the barriers, and facilitators, to recognising and reporting it. To do this one has to dissect what is a complex social interaction between a patient, who has potentially limited capacity for verbal communication, and one or more HCPs. This interaction is experienced and interpreted subjectively, influenced by the hospital environment, altered by the patient's current physical and mental health status and the professional role of the healthcare professional. Qualitative methods are a good approach to explore complex social phenomena as one does not have to start with preconceptions. This in turn might then be used to develop a theoretical basis to describe this interaction and generate ideas for systems that might capitalise on facilitators, and avoid barriers to enable HCPs to provide better care for patients in the future. (Mays and Pope, 1995; Braun and Clarke, 2006; Patton, 2002).

There are a number of qualitative methods that can be employed to identify barriers in the healthcare process. Broadly, they are either observational or survey studies (Bryman, 2012). Observational techniques allow the researcher to describe an interaction which is genuine, an advantage over survey techniques (Cicourel, 2007). Without interviewing the participants, however, it is difficult to infer how the interaction is understood and interpreted by the HCP (Bryman, 2012). Furthermore, observational studies in the UK healthcare system have previously described inadequacies in the provision of psychological care on general hospital wards, (as described in Chapter 1 (Goldberg *et al.* 2014)). A phenomenon that is supported by the data presented in Chapter 2.

Common data collection techniques for surveys include either questionnaires, structured interviews, semi-structured interviews, unstructured interviews or focus groups (Bryman, 2012). Structured interviews and questionnaires are quick and potentially allow the researcher to sample greater numbers. However, the questions are generally closed and do not allow for exploration of a topic (Bryman, 2012). When exploring poorly understood social constructs this is a disadvantage and limits the potential to improve understanding. Also, questionnaires to HCPs generally have a poor rate of return and carry a greater risk of missed data through incomplete answering of questions (Cook *et al.* 2009).

Focus groups are semi-structured group discussions comprising between four and ten participants (Kitzinger, 1995). They are particularly advantageous for exploring how the group understands a topic, not just thinking as individuals. In a healthcare setting, this can mean that group dynamics and preconceived ideas about hierarchy potentially become significant factors for bias (Kitzinger, 1995). In the context of exploring the barriers to distress recognition, if HCPs were in a group with colleagues they perceive to be more senior or experienced, then they may feel intimidated causing socially desirable answering. This could create missed opportunities for data collection. Organising focus groups also presents practical difficulties. Participants need to be available at the same time. On a hospital ward, this can create staffing issues, and takes HCPs away from their clinical work. As a consequence recruitment is often difficult (Barbour, 2007).

Semi-structured interviews loosely follow a series of predefined topic areas, but ask opened questions and the interviewee is encouraged to explore the topic more fully (Britten, 1995). Unstructured interviews cover fewer areas, but do so in much greater detail, allowing the interviewee to dictate the direction of conversation, the interviewer facilitating them and probing for greater depth and clarity (Britten, 1995). Both techniques encourage participants to provide a rich and detailed account of the topic in question (Patton, 2002). The former, however, allows for a greater level of topic focus and gives the interviewer more control of the interview direction, and therefore lends itself well as a methodology to explore the barriers to change the current system.

This study aimed to explore the perceptions of HCPs. Interviews were considered the appropriate data collection method to do this, and were deemed to be advantageous

over other data collection techniques such as ward observation, as they can provide first-hand accounts from people with direct caring experience.

4.5   Methods

Study design

This study collected data using semi-structured interviews with HCPs who regularly care for people with dementia on hospital wards. Data were analysed using thematic analysis.

Participants

On hospital wards, patients will have routine and ad hoc contact with nurses and clinical support worker's (CSW's) multiple times throughout the day and night, dependant on need. They will have contact with physiotherapists and doctors from the team providing care on a regular, but usually on a less frequent basis. All team members have responsibility for care provision and escalating problems, should the need arise.

Hospital wards are organised by the health speciality providing care. These can be either acute (1-4 days) or longer stay (> 4 days) wards depending on the clinical and social circumstances. People admitted to hospital with comorbid dementia could be on any type of ward; however, because the population with dementia is predominantly over 65 years old (Prince *et al.* 2014), a higher proportion of patients with dementia can be found on wards that care specifically for older people or conditions that are common in older people.

Ideal participants to be interviewed would have experience caring for people with dementia in hospital, in order to be able to provide valid commentary on it. Potential participants, therefore, included HCPs in permanent employment on one or four wards that have a high proportion of patients with comorbid dementia (identified in Chapter 2). The wards were based in a large teaching hospital trust, and spread over two separate hospital sites. Details of the wards included can be found below in Table 4.1. The professional roles of participants included doctors, nurses, CSWs, nurses and physiotherapists. Other clinical team members such as occupational therapists and social workers, who have less clinical contact during the initial phases of a person's

stay and were not included. HCPs in a non-clinical role, (hospital porters, domestic staff, administration staff) were not included.

Table 4.1 Summary of the wards included in the study.

Number[2]	Ward Speciality	Ward Type	Gender of patients	Ward Description
1	Elderly Medicine	Acute	Mixed	Cares for medically unwell people over the age of 80, for up to 4 days.
2	General Medicine	Acute	Mixed	Cares for medically unwell people of all ages (including elderly people) for up to 4 days.
3	Elderly Medicine	Longer stay	Male	Cares for medically unwell people over the age of 80.
4	Orthopaedic Surgery	Longer stay	Female	Predominantly cares for older people admitted with bone fractures.

Sampling

To sample a diverse range of opinions, criterion purposive sampling was used with variables including ward type, professional role and experience level. A sampling frame was used to guide selection and ensure that diversity within all variables was represented, however maximum numbers of any one group were not specified. Criterion purposive sampling is a technique widely used in qualitative research. It aims to sample cases based on predefined criteria and attempts to provide data that is information rich and representative of all opinions within the population studied (Patton, 2002). This is advantageous over random sampling whereby outlying opinion may be missed by chance (Palinkas *et al.* 2015).

In instances where a group from the sampling frame were not represented after initial selection, snowball sampling was used. This is a technique where existing participants suggest potential participants from their acquaintances, or in this case their colleagues (Palinkas *et al.* 2015). Participants were asked to identify colleagues that met the underrepresented criteria.

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[2] Ward number assigned by research investigator and does not relate to the hospital ward numbering system.

Recruitment

On each of the wards in Table 4.1 the ward manager, lead consultant (Doctor) and physiotherapy managers were contacted by email, asking them to inform all CSW's, nurses, physiotherapists and doctors on their ward about the study. The details of those who expressed an interest in the study were then passed onto the researcher, who emailed them inviting them to participate. This email explained the purpose of the study, gave a description of the interview procedure, and a copy of the participant information sheet was provided (see Appendix 3). Those who were happy to participate were invited to attend an interview at a mutually agreeable time and venue. Where identified, potential participants who did not respond to the invitation email, were sent two reminder emails spaced one month apart. Despite repeated requests some groups were difficult to access, in these instances snowball sampling was used.

Data Collection

All interviews were held in pre-booked meeting rooms at the participant's place of work. Where possible, common pitfalls for interviewing were avoided (Field and Morse, 1989). Outside interruptions and distractions were minimised by holding the interview in side rooms off the main ward at quieter times of the clinical day, often during the night. The rooms did not have a telephone, and participants absolved themselves from clinical duties during the interview. Participants were generally not nervous, however, all participants were reassured before the interview that all data was anonymized, and there were no 'right or wrong answers'. Audio recording equipment was placed out of direct eye line to reduce the impact on participant anxiety.

Before the interview, an outline of the process was given, and the researcher checked that the participant had received and read the participant information sheet. A paper copy for the participant information sheet was also given at the interview for further reference. The researcher then addressed any questions that participant had about the study, and the participant consent form was reviewed and signed (a copy of the consent form can be found in Appendix 4).

Interviews were semi-structured and audio recorded. Semi-structured interviews were favoured over a structured interview or a questionnaire because this technique would allow participants to better express how they understand and deal with distress (Britten, 1995).

In order that the data gathered was relevant to answer the research questions, a topic guide was written in advance (see Appendix 5), and used by the researcher during the interview. Questions for the topic guide were written to be open, neutral, and understandable to all levels of training (avoiding jargon or assumed knowledge) (Patton, 2002). Towards the end of the interview participants were also presented with a simple table demonstrating the difference between expected and documented symptoms in dementia taken from data presented in Chapter 2. This aimed to stimulate further ideas about the barriers and facilitators to distress recognition and reporting.

Analysis occurred simultaneously with data collection allowing for emerging codes and themes to enhance subsequent data collection. The topic guide content and structure was regularly reviewed to reflect this, so that it could be adapted for maximum impact.

Reflective practice was undertaken after each interview. An aspect of this was reviewing interview technique using Burges six point directiveness scale (Burgess, 1982). As the interviewer is a clinician in the field of dementia care, particular attention was paid to reducing the impact of the interviewers views (influenced by previous clinical exposure) leading participants into giving responses that mirror the opinions of the interviewer, or assuming meaning rather than exploring an answer fully (Britten, 1995).

All participants were sent an email after the interview thanking them for their participation and offering to address any questions or concerns that might have arisen as part of the process.

Data management

All the audio recordings of the interviews were transcribed in full. The first four interviews were transcribed by the researcher; this allowed for better familiarisation with the material. Subsequent transcripts were transcribed by appropriately trained personnel.

The computer based qualitative software programme NVIVO 10 was used to store, organise and assist in the analysis of the dataset. Such software is widely available and a commonly used tool to assist organising and analysing large datasets (Tesch, 1991).

To improve familiarity with the data and encourage free coding intially, the first 2 transcripts were hand coded and then transferred onto NVIVO 10. Transcript 15 was also hand coded and transferred. This was done to try and stimulate a fresh approach to the data, and explore new themes without the confines of a predefined coding system.

Data analysis

The aim of analysis was to understand how HCPs understand distress in dementia, and the barriers and facilitators, to recognising and reporting dementia on a hospital ward. The dataset were interview transcripts describing the caring experience, systems and ward interactions when caring for people with dementia.

Thematic analysis is a method for identifying and reporting repeating patterns within the data to create themes which describe a rich and detailed account of the topic being explored (Braun and Clarke, 2006). Data is analysed and coded to look for reoccurring patterns and allows the analyst to look for the meaning of those patterns. Thematic analysis is independent of a strict theoretical framework (Aronson, 1994), and in this context allows for a description of both social interactions and hospital systems.

Themes within the data can be identified at an inductive or deductive level. In the latter, the researcher approaches the data with a pre-existing knowledge base (Braun and Clarke, 2006). This approach inevitably introduces the potential for the researcher's assumptions to influence data interpretation. In this instance, an inductive approach to coding was used as far as possible; although due to the researcher's previous clinical experience, knowledge of the theory of distress recognition, and an awareness of the failings of the current system as described in Chapter 3, undoubtedly influenced interpretation. This was mitigated as far as possible by coding, reflective practice and credibility checking with other coders.

Generating codes and themes

To approach the data systematically Braun and Clark's (2006) 6 phases of thematic analysis were used as a framework; these are summarised in Table 4.2.

Table 4.2   A reproduction of the phases of thematic analysis as proposed by Braun and Clarke.

Phase	Description of Phase
1.Familiarising yourself with the data	Data transcription, reading and re-reading data, making memos and notes on initial ideas.
2.Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire dataset, collating data to the relevant code.
3. Searching for themes	Collating codes into potential themes, gathering all the data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire dataset, generating a thematic map of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	Selecting extract examples for each theme, final analysis of each extract, relating back of the analysis to the research question and literature, producing a report of the analysis.

Familiarisation with the data began after the first interview by listening to, transcribing and reading the transcript. On each read through of the transcript, memos and notes were made, capturing the thoughts of the researcher and highlighting details of relevance to the research question.

Initial coding of data began after the fifth interview. Initial codes were inductive, derived from that data without a predefined construct or coding system, allowing for codes to be flexible and free-form. The research questions guided the areas of interest. The researcher worked systematically through each transcript looking for examples and excerpts that seemed to say something about the research questions. After the first five transcripts, there were multiple free text codes, many of which were similar, but not grouped. To organise the codes into a manageable dataset all the codes were reviewed and collated where appropriate. This was done by reviewing each code and the data extract(s) it referred to one-by-one. Codes that were similar, or that contained similar data extracts were grouped together and the given a code name and detailed description about the meaning of the code, and data extracts within it. An example of this process is shown in Figure 4.1. Once the process was complete it was rechecked to ensure the code name, description and data extracts within it were logical and relevant to the research questions.

Data extract: *"Sometimes relatives can tell you that patients with dementia aren't usually that bad. Which triggers you to think right well what could be the problem here?"*

Data extract: *"You will be able to tell straight away. I mean even if it's a new patient it's just a case of asking the relatives and family or people who have looked after them before"*

Code: Involve carers in the assessment.

Description: Asking the opinion of informal carers may improve the accuracy with which distress is detected.

Code: Use available resources to identify distress.

Description: Using readily available resources to become more familiar with patients, may improve the accuracy of distress recognitoin.

Combined code to incorporate both data extracts: 'Communication with informal carers'.

Description: A patients informal carers, (their family members, friends etc.), often have a greater knowledge of the person with dementia's baseline behaviour. Listening to their opinion as to whether the person is in distress can be a useful source of information.

Figure 4.1 A worked example of the initial code collating process.

Once these initial codes had been generated, subsequent data extracts were coded directly into them if they fitted. Where novel data emerged, new codes were created accordingly. A further review of all the codes, using the procedures described above, took place after interviews 10 and 15.

After the first 10 transcripts were coded, analysis was briefly paused to allow for initial searching for potential themes. All the codes and data extracts within them were reviewed, and similar codes were combined. This process involved writing each of the 85 codes and its descriptor on separate pieces of paper. They were then grouped by similarity, a process that was refined until they were in seven piles, each representing a theme. From this an initial thematic framework was created (Braun and Clarke, 2006).

This process was repeated twice more after the 15th and 20th transcript had been coded, each review providing an opportunity to conceptualise the data in greater depth, generating a final thematic framework (Figure 4.2) with 4 potential themes and 29 sub-themes. From the final 5 transcripts, no novel codes emerged and data extracts were therefore coded directly into existing codes and themes. At this point it was felt that data saturation had been achieved, and as all the healthcare professional groups from the sampling frame had been interviewed, data collection stopped.

Trustworthiness of the data

The trust that a reader can place in data presented is dependent on the quality of the methods described and the rigour which they are carried out (Shenton, 2004). Further confidence can be given by a researcher applying appropriate methods to demonstrate validity of the data collected, and reliability of data analysis (Mays and Pope, 2000).

Validity

In this study a number of measures were adopted to improve the validity of data:

Reflexivity: The effects of the researcher's prior assumptions, experience and knowledge has on data collection and analysis is unavoidable; however, understanding these potential biases can help minimise their impact. Reflective practice can help the researcher to monitor their own biases, and provide greater insight to the data (Guba and Lincoln, 1989). After each interview the researcher listened back to the audio

recording and made comments on the interview style, question structure and listening skills, being critical of biases, leading questions or any areas where information was not explored thoroughly. Memos were made, and where necessary, specific comments were linked to points on the transcription. Furthermore, the first two interview transcripts were reviewed by another analyst to identify examples of directive questioning, or assumed meanings that could be reduced in subsequent interviews by changing interview style.

Peer scrutiny: Getting fresh perspectives to challenge coding can allow a researcher to develop themes and appreciate different perspectives on the dataset (Shenton, 2004). Data was presented at local and national meetings to achieve this.

Multiple coding: Initial coding of two of the first three interviews were undertaken separately by two analysts. While similarity between analysts occurred, this exercise allowed for differing interpretations of data extracts to be identified. It was an opportunity for the researcher to think of coding in every possible way, and to develop skills in coding. Reviews to check the credibility of codes and emerging themes by the separate analyst also took place; after interview 10 and interview 15. This process helped develop new perspectives on the data, and the evolution of new themes. It also ensured the justification of coding, and the identification of potential analyst biases.

Reliability

The reliability of the analysis of qualitative data can be improved by having data analysed separately by independent researchers and comparing the results, thus generating an inter-rater reliability (Mays and Pope, 2000).

At the end of analysis, a final credibility check took place to assess the reliability of codes. A random sample of 40 quotes from the transcripts that had previously been coded, were given to an analyst with no previous knowledge of the project. A list of all potential codes was then given to the analyst, and they were asked to apply the appropriate code to the appropriate quote. The percentage agreement was 76% with a Cohen's kappa of 0.75 - indicating a substantial level of agreement.

Ethical Considerations

Ethical approval was granted by the University of Leeds Research Ethics Committee, reference number: SoMREC/14/094. As participants were NHS employees, NHS ethical approval was not deemed necessary.

The main points considered were:

Patient confidentiality - Interview participants had the potential to discuss specific cases to illustrate examples of distress. Before the interview, participants were asked not to disclose any information that could potentially identify a person with dementia or their carer. If during the interview identifiable information was disclosed, the interview was paused, and the identifiable information was recorded over, thus deleting it. If patient identifiable information was only discovered on transcription it was removed from the transcript.

Participant confidentiality - No personal identifiable details were recorded during the interview other than on the consent form. Where audio data contained reference to the participant (for example the ward they work on, or position they hold within the hospital), it was anonymised on transcription.

Disclosures of abuse - All participants were informed that if they revealed something that suggested a vulnerable person or persons may be in imminent danger, or historic acts of abuse or wilful neglect, then their clinical manager would be contacted so that appropriate action could be taken. This would only ever be done with the participant's knowledge.

Participant distress - Participants were asked to discuss times they have recognised a patient's suffering; this could be potentially upsetting. Provision was made that if the participant were to become upset during the interview, they would be asked whether they would like the interview to be continued, paused or terminated. In either instance, the participant would be invited to debrief with the researcher after the interview.

Data Protection

The procedures for confidentiality and security of data were reviewed and approved by the University of Leeds, Ethical Approval Committee, prior to any data collection.

Participant details were stored separately from the data collected and all data collection, storage and use complied with the data protection act (1998), and the University's Information Security Policy.

All electronic data was kept in a password protected file on the researcher's university computer (also password protected). Written data (consent form), was kept in a locked cabinet inside the researcher's university office, which is also locked when not in use. The details are scheduled to be archived at the end of the project and will be destroyed 7 years from the end of the project.

4.6   Results

Participants

The initial email informing potential participants of the study, and inviting them to express an interest in participating was sent to 156 HCPs. 35 replied either directly to the researcher by email, or via their ward manager. Of this number 19 were interviewed. The 16 who did not go onto be interviewed failed to respond to two separate follow up emails, and so were assumed to no longer wish to participate and were withdrawn.

21 participants were invited to participate through snowball sampling, 9 responded to the initial request and 6 went on to be interviewed. Of the 3 who did not go onto be interviewed, 2 failed to respond to two separate follow up emails and so were assumed to no longer wish to participate and were withdrawn. A final participant left the trust before a convenient interview date could be organised. Participant recruitment and numbers are illustrated in Figure 4.2.

A range of participants from differing professional backgrounds and ward types were interviewed. The median number of years experience that participants had since professional qualification was 5, (range: 4 months to 22 years). The range of participants interviewed is displayed in Table 4.3

Potential participants initially invited to express interest to participate
N=156

Potential participants invited to express interest to participate by snowball sampling
N=21

Potential participants expressed interest, and invited to participate
N=35

Potential participants expressed interest, and invited to participate
N=9

Failed to respond to follow up emails and withdrawn
N=16

Failed to respond to follow up emails and withdrawn
N=2

Moved from trust.   N=1

Participants interviewed
N=25

Figure 4.2 Flow chart describing the number of participants approached and recruited.

Results of the Thematic analysis

Analysis of the transcripts produced 4 themes and 29 codes, which describe how staff perceive distress on the ward, and the facilitators and barriers, to recognising and acting on it. Figure 4.3 illustrates this in a theoretical framework, and demonstrates how the themes and codes relate to existing procedures on the ward to bring about a greater or lesser chance of a person in distress being identified and treated. Each

theme and sub-theme are then described in detail, illustrated with verbatim quotes from the interviews. Quotes are in italic font to distinguish them from the main text. Each quote is identified by the participant and line number from the original transcript.

Table 4.3 The cohort interviewed.

Study ID	Profession	Speciality	Gender	Years since qualification
24	CSW	Elderly Medicine	F	4
8	CSW	Medicine	F	1
3	CSW	Elderly Medicine	F	11
20	CSW	Orthopaedic Surgery	F	5
21	CSW	Orthopaedic Surgery	F	1
12	Consultant Doctor	Elderly Medicine	F	16
23	Consultant Doctor	Elderly Medicine	M	11
10	Consultant Doctor	Elderly Medicine	F	22
22	Consultant Doctor	Orthopaedic Surgery	M	18
9	Consultant Doctor	Elderly Medicine	F	22
25	Junior Doctor	Medicine	M	8
4	Junior Doctor	Orthopaedic Surgery	F	5
5	Junior Doctor	Orthopaedic Surgery	F	<1
11	Junior Doctor	Elderly Medicine	F	10
18	Junior Doctor	Orthopaedic Surgery	M	6
1	Nurse	Elderly Medicine	F	9
6	Nurse	Medicine	F	10
7	Nurse	Medicine	F	1
2	Nurse	Elderly Medicine	F	5
13	Nurse	Orthopaedic Surgery	F	9
19	Physiotherapist	Elderly Medicine and Medicine	F	16
16	Physiotherapist	Orthopaedic Surgery	F	1
15	Physiotherapist	Orthopaedic Surgery	F	1
17	Physiotherapist	Orthopaedic Surgery	F	4
14	Physiotherapist	Elderly Medicine/Orthopaedic Surgery	M	4
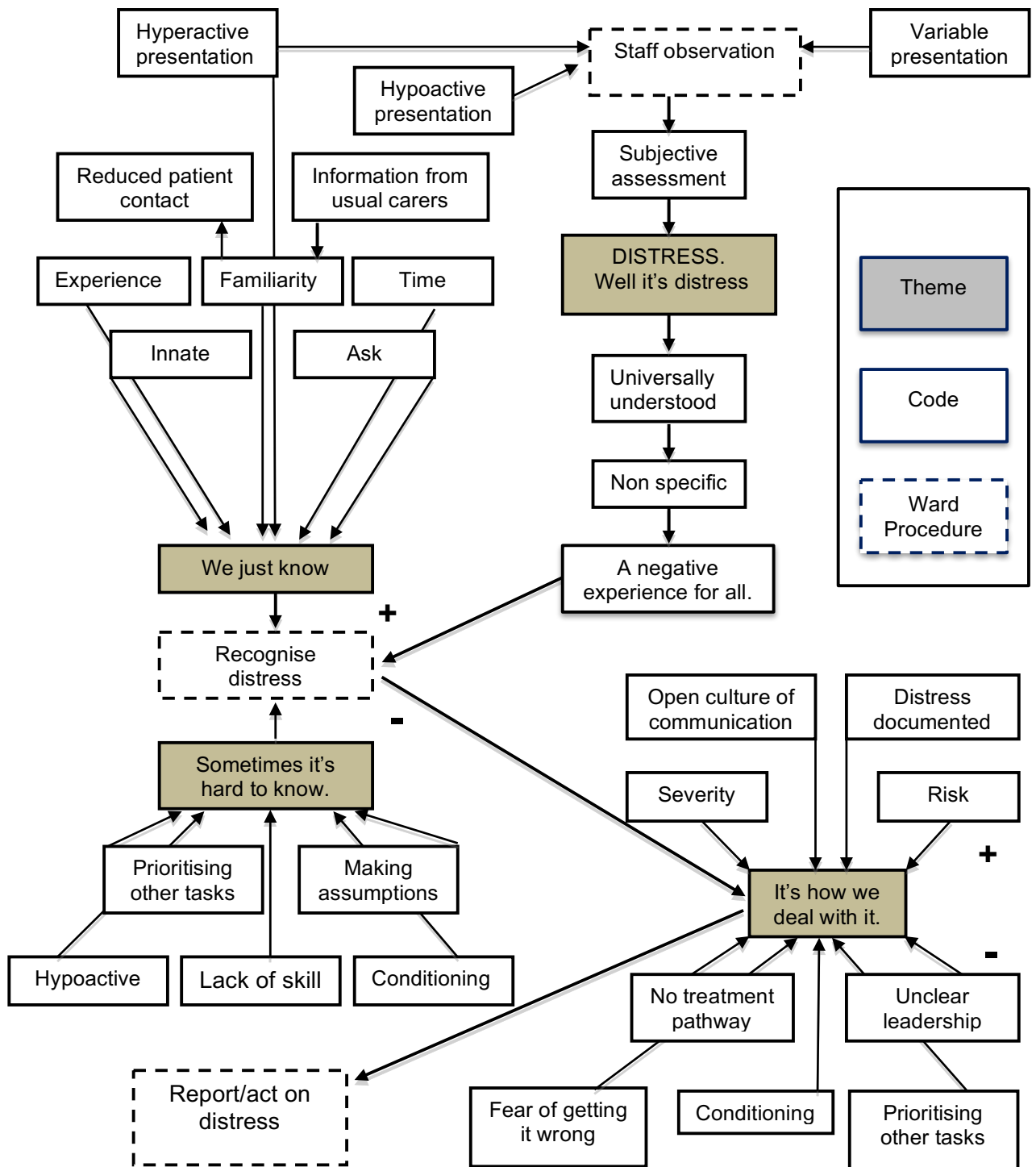
Figure 4.3 Theoretical framework displaying the barriers and facilitators to distress recognition and reporting.

4.7   Description of themes

Theme: "Distress is… well it's distress"

The term distress was universally understood by participants independent of background, training, speciality or experience. Those with more training generally tried to give more technical answers. However, all had the same base meaning: it was described as a person's emotional or behavioural response to an external or internal negative stimulus.

"To me distress can mean a number of things. It could be em… an emotional response to something that's going on around them, something internally happening with them or it could be a distressed response to pain, environment, fear… It's anything that's invoking in them a reaction that's causing them harm." (13, 33)

Participants described that patients with dementia who have a reduced capacity for communication, present in a wide range, "*almost infinite",* number of ways when they are distressed. Most participants described patients with dementia in distress as being very active (hyperactive presentation), both physically and verbally. Examples of hyperactive physical behaviour ranged from wandering to physical violence and refusal of treatment. Hyperactive signs of verbal distress included shouting out, wailing, or saying words or phrases over and over again. All but one participant then went on to describe scenarios where people in distress presented quietly (hypoactive presentation). The behaviour described in this instance included being withdrawn, refusing food and hiding under the bed covers. Verbal signs included reduced communication or crying.

"[Distress] could manifest itself as the really overt, so people who are erm... physically able to express that, who may be crying, maybe shouting, maybe very tearful, maybe sometimes perhaps just sort of more agitated or looking uncomfortable. Sometimes I see people who actually are very withdrawn within themselves, and look fearful but very quiet." (10,30)

Participants generally gave examples of extreme behaviour, but acknowledged that the signs observed were on a spectrum, and were variable potentially changing from one person to another, and one moment to the next. It was also acknowledged that the type of presentation does not necessarily correlate to severity of suffering.

"How I could feel distress can be completely different to how you feel distress. I mean I'm quite an emotional person, so I could be sat there very quietly crying my eyes out, to someone else who is there and doesn't say a word." (3, 97)

The majority of participants believed that all such descriptions fell under a broader meaning of the term 'distress'. This was thought to be an advantage because it is an easily usable term, and was thought to be universally understood by staff members and lay people regardless of training or background. It was identified as potentially disadvantageous, however, as distress is non-specific, and subjectively assessed potentially leading to the over investigation of patients and unnecessary work.

All participants identified that distress was a negative experience for the patient, particularly if they were unable to fully express this need. In such instances, several participants described patients as "*tormented*". All participants felt that if possible, distress should be alleviated.

"I can only imagine and it must be horrible. It must be so frustrating for one. It must feel… (sighs) I can't think of the word.… It must feel never-ending for them. It must feel… that no matter what they say or do… 'cos some of them can say things but can't… verbalise exactly how they're feeling. They must feel so helpless." (13, 227)

The experience of caring for someone in distress was often acknowledged as being upsetting for HCPs too. Some participants reported feelings of helplessness, particularly when it was perceived nothing could be done to alleviate the distress. Another common feeling described by participants was frustration, generated by the perceived chaos and extra workload created by a person in distress.

"Something's not right and when you try and explain it frustrates them that they don't fully understand why they can't go home and things like that so it is something that we do see quite a lot of. And it is quite sad to see, you can be the best nurse in the entire world, you can be the happiest smiliest nurse in the world but they don't want to see a smiling nurse they want to see their family. So it is difficult, and it would be wonderful to come up with a way around that or a way to help at least." (20, 50)

"You're like constantly fighting battles to try and calm people down, relax them. And it does create extra work for the nurses, and the staff here, especially if they're aggressive, or determined to get off the ward. You know, refusing their treatment, and then you know, you're not helping them." (7, 97)

Theme: "We just know"

Despite variability in presentation, every participant felt they were able to accurately distinguish a patient with dementia in distress, from one who is not. Participants described this ability as natural or that they "just know". This concept seemed to transcend experience or training backgrounds.

"You know, you know what distress is. You just know what it is so you can think right this patient's distressed. I might not know what, what symptoms or signs they're showing but you know that they are distressed." (8, 351)

"I think it's [recognising distress is] one of those things that is a gut instinct a lot of the time. I think you can usually tell if a patient's distressed if they look unhappy." (9, 32)

Exploring this concept in more detail participants often struggled to describe how they developed this skill - the majority believing it to be innate, a natural inclination to recognise those in need, which is motivated by a desire to care for a fellow human being. Within this, however, participants recognised that they required empathy towards their patients, motivation, pride in their work and enough flexibility to be able to spend time with patients, to allow them to exercise this ability.

"I don't know what makes someone be good at being able to tell if someone's distressed, but I think if someone cares about their job, and cares about what they do, and cares about the people they're looking after, then those things make them you know… and if you have the qualities that you know, you can… you're looking out for your patients and you're not just seeing to their physical needs but you're going beyond that. So I think anyone can identify someone who's in distress, you just have to care and have the time." (11, 100)

Having universally described the ability to recognise distress as natural, participants gave mixed responses on whether this skill could be enhanced with training or experience. The majority of participants stated they had attended formal dementia training courses, but none could identify how the course helped them to recognise a distressed individual. Commonly participants believed that the ability to recognise distress was not something that required training. The same participants, however, when asked how their skills at recognising a distressed individual could be improved answered *"with more training"*.

Participants were contradictory about how their experience and time spent caring for people with dementia facilitated them to more accurately recognise people in distress. Both experienced and inexperienced staff stated that while experience was helpful, it is not necessarily the biggest determining factor. The more inexperienced a participant was, the greater the role they perceived experience to have.

"I think that [experience] helps you 1) recognise, and 2) manage, be you a healthcare assistant or a consultant, or whatever. And I think also...you don't necessarily need years of experience." (12, 141)

"I'm sure at some point it was something I had to learn and now it's just become a, almost an intuition of 'I know that this patient is distressed because they're in an unfamiliar environment versus this patient has got an illness that's driving this.' And there is something just there isn't there? I think as you, as you go through your training it just becomes easier and easier to … to spot those ones." (25, 101)

"A change in someone's usual behaviour" was commonly described as a sign that a person with dementia might be distressed. Participants acknowledged, therefore, that familiarity with their patient's usual behaviours, that is, their mannerisms, tone of voice, likes and dislikes can be useful information because it provides a *"baselin'"*. Several factors were acknowledged as being particularly helpful in establishing this baseline including getting to know the person with distress well over the course of their stay, and speaking to their usual carers.

"I think it's easier [to recognise distress] in those patients when we've had them for some time and you see a change in them." (13, 99)

On wards where patients only usually stay for <48 hours, and for doctors who manage large patient numbers (particularly out of normal working hours), participants cited a lack of patient contact as a potential barrier to distress recognition. Participants working on long stay wards stated that this was also a problem when staff turnover was high or when staffing levels were low (increasing the patient to staff ratio). In such instances familiarisation with the person with dementia can come from other sources, such as the patient's usual carers in the community, or other staff members who know the patient well.

"It's difficult at times to know if it's [the symptoms observed] a variation from normal particularly if you're on call because you might get called to see a patient that you don't know, you've never met before and you don't know how they act or even how their baseline functioning is. So you rely quite heavily on the nursing staff to say 'no this patient isn't right. They're definitely not themselves. They normally act like this.' " (4, 17)

"You get to know their norm. And a lot of times if you're unable to know their norm, family and friends who come to visit will tell you what, what's not normal for them and then you'll have an idea of what to look for." (20, 66)

In instances where staff members were unsure about a patient's usual behaviour and family or other staff were not available to ask, participants recognised that the 'This is me' booklet was a useful resource. This is a small booklet kept by the patient's bedside that families are invited to complete, stating their loved ones, likes, dislikes and usual behaviour.

Theme: "Sometimes it is more difficult to know"

While all participants described a sense of "*just knowing*" when patients are in distress, many also described factors, that if present, could reduce the sensitivity with which they are able to recognise distress. No participant identified that they personally lacked empathy or the natural ability to recognise distress, but some believed that other staff may not be as skilled at doing this.

"I think some people are good and some people aren't, and I don't think that's necessarily down to experience. Because some people's non-verbals will be so small and so… it, it's not a, a sudden wince of a face, it's, it's a difference in them. It's when you're talking to someone and seeing a sadness in someone. Or seeing something in them. And, and not everyone's good at picking that up. A lot of people just say well yes she's fine! She ate, she drank, she did this, she's ok. And they just don't see that, and I don't think that's something training can give you particularly and I don't think that's something experience, I think you either are able to see that… or you're not." (13,157)

Participants believed that they were worse at identifying distress when they were busy and distracted by other events on the ward. Factors that were specifically sited were low staffing levels, staff prioritising *"task orientated"* jobs (tasks that are mandatory at a set time, for instance delivering medications, or changing beds), or prioritising medically unwell patients. They felt this allowed them less time to spend observing patients in distress who were not critically compromised or at risk of causing harm. There were often feelings of guilt associated with participants having to prioritise tasks ahead of distress recognition, despite the fact that staff were following ward protocol in doing so.

"You know, you've come in to nursing to try and make the patients feel like a person, not a bed number, not an inconvenience, but when staffing's short you have to...you do, you have to prioritise, regardless of how hard that is. But if there's staff of course we'll ask somebody to sit with them for a while… And sometimes it's also, like I say, having the time and the staffing. Because we've just moved wards we've had... every shift we've had fifteen patients. Personally having fifteen patients. It is you know... all you're thinking of about then, instead of it being patient orientated... we should be doing our job around our patient, but we don't. We're task orientated, washing, dressing, beds, whatever comes in the afternoon, whereas it should be – I think, meeting the needs of the patient as and when they arise, not when it suits us. But you have fifteen patients you're just hoping that no one gets too unwell. You spot the signs of somebody being too unwell, you don't have time to look at if somebody's tired, or even aggressive, you're just trying to juggle what you can." (6, 215)

Another factor that participants believed reduces the chance of a person in distress being identified was a hypoactive or quiet presentation. Participants stated that these patients where harder to identify by chance (for instance, when walking past the bed of the patient in distress). It was felt that unless the assessor was specifically looking for

distress, it might not be identified. It was also believed that quiet patients who were not creating the risk or furore of hyperactively distressed patients on the ward might be easily overlooked.

"People who are up at the nurses' station erm... or you know, causing upset with other patients, wandering, shouting out, crying out, erm... sort of being physically aggressive, properly aggressive, and obviously those are the people who get more attention in a way, because you know, clearly something has to be done about the person who's wandering around the ward and causing mayhem. But that doesn't mean that their distress is more than those who are sitting quietly." (11, 68)

Finally, participants identified that people with dementia are sometimes assumed to be in a chronic state of distress, or staff become conditioned to their distress. This can lead to an assumption that the patient does not require specific attention to alleviate the distress as it "*is normal for them*". In those that were regularly exhibiting signs of distress while on the ward (for instance crying or shouting out) staff identified there can be a culture of believing that the distress is intractable, and therefore that spending time attempting to alleviate it is futile.

"I think quite often… particularly with patients with dementia… people… see someone who's agitated, who's being disruptive, or in our eyes being disruptive, as very loud, shouting out… and that can quite often just… people will say, 'they've got dementia, that's their behaviour, they're behaving like that', without stepping back and saying well actually is this different to how they're normally? Is there something behind this behaviour?" (13, 71)

"As soon as you don't recognise it [distress] as an unmet need, you try and then start to cover it up. So you try and tell the patient to be quiet or to try and sedate them and then nothing… what, you know is a short term fix becomes a long term problem for that patient. And they're the ones you can really struggle to unpick, you know, once people start going down that route." (25, 122)

Theme: "It's how we deal with it…"

It was widely acknowledged by participants that recognising distress is only the first step of a process to reduce patient suffering. Once a healthcare professional has been afforded the skill (natural or developed), time, motivation and resources to recognise a distressed person with dementia participants discussed how they use the information.

"As a human being you can look at someone and you can tell that that person's in distress, but how we all deal with it is something that's developed over time." (3, 217)

Participants described firstly making a personal decision about whether the distress requires acting on or not. Participants disclosed that the severity of the dementia and

the risk caused by it are the main factors for acting. If a person's distress is mild or just fleeting, then some participants felt that perhaps nothing needed to be done. Participants also felt that the investigation and treatment of patients in distress would be prioritised (independent of distress severity) if they were causing risk to themselves or others. This generally describes those with a hyperactive presentation who for example are wandering and liable to fall, or violent towards staff or other patients.

"Even if we pick it up [distress and psychological symptoms] at a low level, do we need to do something about it? Is that going to help? Is that going to hinder?" (9, 318)

"It depends what the patient's doing. If the patient's been aggressive, hitting, punching, kicking, chucking their food all over, then obviously that is [going to be documented and acted on], but if a patient's erm... just laid in bed, you wouldn't necessarily put 'patient appears or seems withdrawn, not verbalising, not communicating." (6, 119)

As with distress recognition, participants identified that on wards where behaviour associated with distress is common place in people with dementia, there can be a tendency to become conditioned to it, and make an assumption that the behaviour is *"normal"*. This has the potential to increase the severity threshold at which distress will get investigated or treated.

"I think this is people don't document, people don't ignore symptoms, well I suppose they do ignore symptoms. They just think that's them and therefore I'm not going to document anything about that." (13, 356)

Participants also felt that the level of action taken might be dependent on other ward activities going on at the time the person was distressed; for instance, if the distress occurred at a time of day when staff were busy with ward tasks or dealing with a more critical situation, thus meaning the person with distress has to be prioritised as less urgent.

"So I think we're all… kind of trained and recognise it and relatively good at managing it. But I think sometimes people are very busy and they just want to get out of it what they need to get out of it. And they're quite happy to… almost overlook the distress. Or maybe just pass it on that you know someone else needs to sort this out." (25, 71)

When a person with dementia is recognised as being in distress, and the healthcare professional believes it warrants attention, there were mixed responses as to what the assessor does with the information, and no formalised treatment pathways were acknowledged. The majority of participants stated that in the first instance they act directly to try and alleviate the distress themselves. Strategies for doing this were

haphazard and dependant on training background. However, in the mainstay participants stated that they would either try to reassure the person in distress, or use a check list to rule out the possible causes of it.

"You're always supposed to have a professional face whenever you're with these patients. And they always say you know you shouldn't get attached, things like that, but we're human. I get to know say Grandma round the corner. I get to know what Enid is like. I get to know Margaret, she loves to sing. I, I get to know them and you kind of, you do go on your break thinking how do I cheer her up? How do I make her feel better? How do I make it more comfortable here in hospital? And you do, you juggle round in your head what can you do? Do I ring her daughter? Do I perhaps sit and read with her for a little bit if I get chance? Do I, you know, things like that. So it does, it does stay in your head a little bit!" (20, 161)

"Normally [to investigate distress] what we would do is we'd go down the route of… simple things, you know: Are they in pain? Are they in retention? Are they faecaly impacted? Erm… you know if they've got poor eyesight or poor hearing and they can't tell what's going on around them, can we correct those easily? Can we get people to come in that they know to try and, you know, make them feel like they're in a familiar environment? Erm… you know there are all kinds of various, I mean you know the list of why somebody might be distressed in hospital is kind of endless because it could be that at night time, the woman in the bed opposite likes to come and sit on their bed or mess with their dressings or whatever." (9, 186)

Once staff have exhausted their checklist, most describe escalating the problem to a more senior colleague, or someone with a greater level of experience managing dementia. There were no clear pathways for doing this, and it was unclear where responsibility for the information lay. Generally, CSW's said that they would tell the nurse they were working with. CSW's also stated that it would be rare that they would document anything in this instance, relying on the nurse to do so if they deemed fit. Nurses stated that they would escalate to a junior doctor and the junior doctor stated that they would escalate to a senior doctor or the liaison psychiatrist. Junior doctors appeared the most reticent to refer on, fearing that they may be seen to be *"overreacting",* and also feeling that senior colleagues would not have the time to prioritise the situation – this was particularly evident in surgical specialities. There was also a feeling amongst the junior doctors that the distress needed quantifying or describing accurately. This was not an opinion shared by their more senior consultant colleagues.

"I think I would manage to write that down, but it might be more difficult for more junior members of staff. You know, I've had quite a number of years refining that and thinking about how I'm going to say it or document it, but maybe more junior members of staff would feel a bit foolish writing things in the notes, or wouldn't know how to phrase it, or they'd think it you know, yeah, I think I can recognise how that would be difficult." (11, 141).

A concern raised by several participants was a fear of "*saying the wrong thing*" or feeling inhibited to act on their instinct that someone was distressed if they could not formally describe the problem. This seemed particularly acute with the junior doctors, who seemed worried that they might not be listened to.

"It's difficult [to describe distress] 'cos sometimes the… when you talk about things you think this would sound ridiculous if I wrote it down on paper. And someone else who didn't know the patient read it back, then they wouldn't understand what I was trying to get at. I think it is important to write about if people are distressed and I think we do need to document it more, but it is kind of difficult to know what to write and to know how much info, especially working in a surgical environment quite often erm… it's more about the surgical problems rather than anything else. So… you kind of think if I do write this down, is anyone actually going to read it? Is anyone going to be bothered about it? So yes, it's difficult to document it." (4, 227)

Conversely on some of the wards, all staff are encouraged to escalate information at daily patient safety briefings and ward rounds. In these meetings efforts were being made to change the traditional hierarchical communication culture by welcoming the use of non-technical language and contributions from all staff members.

"We try and make sure that actually on both the wards that we're working at the moment, at patient safety briefings in the morning, anyone can volunteer any worry they have about a patient. So it may be someone who is distressed in some way, or it may be something completely different. We try and make that very open in the sense that 'look, has anyone just got a bad feeling about anyone today?', so anyone can volunteer anything". (10, 183)

Recording that a person was in distress in the medical record appeared to be ad hoc and dependant on multiple variables, as described above. However, the action of recording the distress was believed to be a factor that determined whether distress was acted upon or not. A permanent record of the distress is more difficult to ignore than an individual staff member's memory of it. Furthermore, some participants felt that without a clear plan on how to solve the problem, there was little point in acknowledging it - a lack of clear treatment direction inhibiting any positive action.

"You know any doctor would probably comment on pain in the notes. Nurses certainly would because that's something that we know how to treat. We probably don't document low mood because we don't know how to treat it. So: Mrs Smith looks a bit low mood this morning. So what? What, what can I do to make her better? So you know, it's probably why it's not a very efficient use of time documenting something that you can't do anything about." (22, 152)

It was explored whether it was useful to use technical/medical language to describe distress or the causes of it, for example, describing the cause of the distress or specific

aspect of the presentation. Participants felt that without specific training or experience many HCPs may lack the confidence and ability to do this. Staff with less experience also felt they lacked the confidence to use technical language.

"Where you've got a big team of people with a broad range of contributions, everything perhaps from the consultants to the ward housekeepers to the health carers etc., if you try and get really specific with terminology or classifications or things like that, I think it might reduce their I don't know, erm...I think they feel they're able to contribute more if they can put it in their own terms." (10, 131)

When asked directly no participants stated that they used standardised recognition tools to help understand the cause of the distress. No participants used the existing algorithms to investigate and treat the distress.

"I actually don't really know of any specific tools that we do have to use, I've never used a specific tool, apart from you know, good old-fashioned history, examination, documentation." (11,155)

Despite these barriers and concerns the overwhelming feeling from the staff interviewed was that they wanted to help their patients in every way possible. Participants felt saddened and angry when describing cases were people with dementia who were in distress were not given the care they deserved because of the system caring for them. There were uplifting examples of staff going the extra mile to provide genuine warmth and affection to help others.

"It was really sweet to see the other day. The [Clinical Support Worker] was just sat holding her hand and stroking her hair, and I've never seen her [the patient in distress], look as calm and as relaxed… And you can see the pain in this lady's eyes, an emotional pain and it had gone for that time. She wasn't settled all day but for that time we could see that she had that… and to be honest that's all we wanted with this lady." (13, 343)

4.8   Discussion

The aim of this study was to develop a better understanding of how HCPs recognise and react to distress in those with dementia on hospital wards, and the barriers and facilitators, which enhance or inhibit it. To do this, HCPs who regularly care for people with dementia in hospital were interviewed, and their responses were analysed for common themes.

Principle findings

Within the population interviewed, distress is a universally recognised term. It is broad in its aetiology and presentation, but describes a negative patient experience that requires assessment and treatment.

Participants believed that distress could be recognised innately by HCPs when observing a patient. However, recognition was enhanced by speaking to the patient, having dedicated time to observe the patient, staff motivation, the assessors' level of clinical experience and familiarity with the patient. Ways of improving familiarity with the patient included listening to the opinion of their usual community carers when they come to visit.

Distress was thought to be more likely acted upon if it was severe or causing risk. Staff felt more able to report distress where ward systems allowed open communication, and less able to report if they felt intimidated about misidentifying distress, or where no clear systems were in place to document and treat it. Assuming a distressed state is normal for a patient was described as a potential cause for both under recognition and under reporting of distress.

Strengths and limitations

The HCPs interviewed all care for people who have dementia, providing first-hand accounts from those with direct experience. The participants were also from a range of specialities, professional backgrounds and had varied levels of experience, and therefore, fulfilled the sampling frame. Data saturation was reached providing evidence that the findings are robust.

To improve reliability, data was coded in every way possible, and initially coded by more than one analyst. Credibility checking with independent coders demonstrated a substantial level of agreement.

The analysis was conducted by the researcher, using the computer based software NVIVO 10. Using software brings advantages of allowing the researcher an enhanced ability to manage large data sets with reduced clerical work. It can also help the researcher to organise memo's and codes more easily, to code systematically and it can provide an audit trail of the coding process. Concerns for its use, however, include making analysis an overly rigid process, and an increased pressure on researchers to focus on data volume rather than depth (St John and Johnson, 2000).

All participants worked in the same healthcare trust (albeit on two separate hospital sites), and therefore the hospital systems and general staff management styles were similar between all wards sampled. This limits transferability to other healthcare trusts and wards.

Participants were a self-selecting group who had knowledge that this was a study on distress recognition in dementia patients at the point of volunteering. It is likely that they had an interest in the subject or wanted their views to be known. This has the potential to create biased and polarised results. Further potential biases were created by the line managers sending the invitation email; some staff may have felt coerced to participate, by wanting to please their manager. To reduce the impact of this, the email was standardised and written by the research lead. Direct recruitment by the research lead was not possible due to data protection safeguards on the participant's email addresses.

On hospital wards when staffing levels are temporarily too low, and the position cannot be filled by other colleagues, an external agency is used to provide staff, known as 'bank staff'. Bank staff are less likely to know ward systems and cultures as they are temporary employees. Their shifts will also be intermittent, therefore familiarity with colleagues, patients and patients' families is harder to achieve. No bank staff were interviewed as they are not employed by the hospital trust included in the study. This creates a potential missed source of data.

Every interview was conducted by the researcher who is a clinician that specialises in dementia care and a novice qualitative researcher. Clinicians, while versed in interview

skills do not necessarily possess the skills to be effective interviewers in qualitative research, which requires the exploration the participants own framework, rather than working with a predefined structure (Britten, 1995). The researcher practised reflexivity, in both private reflective practice and supervision, identifying weakness and addressing them where possible.

Participants were all aware that the researcher was a clinician specialising in dementia care. This creates potential biases:

- The participant assuming the researcher has prior knowledge therefore, not exploring topics fully.

- The participant was feeling self-conscious about a lack of topic knowledge and therefore feeling inhibited, or compelled to answer questions technically rather than honestly.

The UK health care system is hierarchical, and consequently, junior staff potentially felt inhibited by a clinician of perceived seniority, and likewise, the interviewer may feel inhibited by participants of perceived seniority. These were mitigated as far as possible by regularly reviewing interview style during reflective practice.

The interview was audio recorded. Audio recording ensures that the information is captured in as much detail as possible, but can cause some participants to feel nervous, potentially inhibiting responses.

The meaning of the results in the context of a clinical setting

Providing good clinical care requires the application of technical knowledge and interpersonal skills by HCPs. To succeed the care must be conducted in a setting with appropriate amenities, and time must be dedicated for it (Donabedian, 1980). In this instance good clinical care refers to recognising a person with dementia who is in distress and appropriately responding to their need.

The process of recognising and responding to distress requires the healthcare professional to:

- Have a shared understanding of what distress is, be aware to look for it in those with dementia, and be motivated to do so.

- Have the skill and time to recognise distress.

- Have the systems in place to report and treat distress.

The results have suggested both facilitators and barriers that if enhanced or overcome might have the potential to increase the proportion of people in distress who are correctly identified, investigated and treated.

Have a shared understanding of what distress is, be aware to look for it in those with dementia, and be motivated to do so:

All interviewees were aware that distress is common in those with dementia, and believed it required treating for the benefit of the patient and those around them. All interviewees had a similar understanding of distress regardless of training and experience. Some interviewees felt that the term was too broad and simple, though all agreed that more complex alternatives, for instance identifying specific symptoms or emotions was too complex for all HCPs to use. Using the broad umbrella term 'distress' as a way if identifying patients in need of further assistance, is likely to be sensitive but non-specific. The consequences of using a sensitive, but non-specific measure are that some patients who are not in distress will be investigated as if they were (Parikh, 2008). This is time consuming for staff and could potentially expose patients to un-necessary investigation. A more specific, but less sensitive describer would potentially leave patients suffering unnecessarily.

HCPs are generally motivated either by extrinsic or intrinsic factors (Deci and Ryan, 2002). In this instance, intrinsic motivation relates to the HCPs satisfaction at helping a person in distress. The HCP gains extrinsic motivation from being as competent in their professional role as possible, receiving by positive feedback from patients and colleagues, and the avoidance of punishment.

All interviewees seemed motivated to help people in distress, which is unsurprising given they are in a caring profession. The over-riding feeling, however, was a sense of fear, hopelessness and frustration about not having the time dedicated to recognise distress, or knowing how to help their patients in the face of what is often a complex clinical scenario. Potential ways of overcoming this are to make distress recognition a

routine ward task, and to work to change ward culture that gives parity to emotional and physical discomfort.

Having the skill and time to recognise distress

All HCPs interviewed believed they possessed the necessary interpersonal skills to be able to recognise distress. This supports existing opinion on assessing distress, in those who cannot communicate verbally (Selekman and Malloy, 1995). The accuracy with which observers can detect distress in those with dementia innately has not been tested and is a potential area for further work.

Both modifiable and un-modifiable factors were cited as facilitators to enhancing an assessor's ability to recognise distress. Unmodifiable factors include: the years of clinical experience of the healthcare professional, the presentation of the person in distress, and the severity of their dementia. Modifiable factors include: increasing familiarity with the patient, staff training and a change to existing hospital systems.

Dementia is a condition that affects individuals with varying severity (Schmitt and Wichems, 2006), and the symptom profile is dependent on the interplay of the disease, environment and patient personality. Being familiar with a patient allows a HCP to understand the patients usual pattern of behaviour, and so be more responsive to a change in behaviour that might indicate distress. Familiarity will be enhanced by the amount of time the patient spends on the ward and consistent staff provision. These factors are largely unmodifiable, but may be enhanced by reducing the number of times a patient changes ward during an admission, and allocating named HCPs as key workers for dementia patients during their stay.

Some participants highlighted the importance of knowing how their patient communicates most effectively. Any system to help improve distress recognition should encourage users to make every effort to understand this, maximising the potential for them to have their needs understood and met.

A further way of potentially enhancing familiarity is to use a patient and family centred care approach (The Kings Fund, 2017), by seeking advice from the person with dementia's usual carers. This will often be a family member or close friend. This approach has delivered positive outcomes in other specialities (Clay and Parsh, 2016), and indeed in many hospitals in the UK patient's usual carers are already invited to

contribute to ward care filling out a patient passport which documents a person with dementia's usual routines likes and dislikes. Several different types of patient passport system are available and widely used (Butterfly Scheme, 2014; The Alzheimer's Society, 2010). Interviewees recognised the importance of listening to any concerns a person's usual carer might raise that a patient is in distress, but cited finding the time to do this as a problem. Encouraging family members or carers to write down their concerns, so they can be read by staff at a convenient time, could be a way of overcoming this.

It must also be considered that familiarity might also have the converse effect, with HCPs becoming conditioned to distressed behaviour, assuming that it is the normal for the patient, and therefore, being less sensitive to subtle changes.

It might be assumed that a HCPs experience in dementia care, would enhance their ability to recognise distress in their patients. No evidence for this exists, and participant responses about it were mixed. Experience in any case is unmodifiable. A potential way of overcoming inexperience, however, is with training. Interviewees were often contradictory about the benefit of training on a skill which they had previously identified as innate. In those who felt training might benefit their ability to recognise distress the response almost always felt disingenuous to the interviewer, like a learned answer to be given to any question of 'how might an NHS system be improved?'

Hospital wards are often busy environments, and nationally staffing levels in elderly care fall below recommended operating levels (Royal College of Nursing, 2011b), affording time for non-essential tasks may therefore be difficult. HCPs have set roles and routine tasks that need completing. Leadership styles are generally task orientated (The Kings Fund, 2015) and ad hoc needs-led jobs are triaged by physical rather than emotional compromise (FitzGerald *et al.* 2010), (unless their emotional state potentially causes risk to their physical health, through suicide/self-harm etc.).

Participants described consciously prioritising other ward tasks ahead of acknowledging those in distress. This may at times be entirely valid. However, interviewees described feeling frustrated and helpless when mandatory ward tasks took priority over attending to someone who is in distress.

Making the observation of distress a mandatory task, much as physical health care observations are, may overcome some of these barriers described. If this were the

case, however, any proposed observation system would have to be quick and simple so no minimal extra strain is placed on the already strained systems.

Having the systems in place to report and treat distress.

The reduction of suffering in those with dementia is a key treatment goal (van der Steen *et al.* 2014). When a person is identified as being in distress it should be either addressed directly, or communicated to a member of the clinical team who has the necessary skills or available resources to address it.

If a person with severe dementia and limited capacity for communication is identified as being in distress, and it is not clear why, standardised symptom recognition tools exist to help rule in or out a cause for example pain or psychological symptoms (Abbey *et al.* 2004; Reisberg *et al.* 1997). Causes can potentially be any medical or psychiatric condition, or the environment the patient is in, so treatment options downstream and their efficacies are extremely varied. Treatment algorithms exist to assist clinicians with this, and their use is widely accepted as good clinical practice (Salzman *et al.* 2008). In the absence of treatment algorithms distress can be treated by interventions initiated by HCPs, these can be as simple as a reassuring hand hold, or complex and require skill specialist psychiatric opinion. The hospital where the interviews were carried out has both specific dementia algorithms and specialist old age psychiatry referral services. Consistently participants stated that they were unaware of any systems or treatment algorithms for helping those who they believed to be in distress. Increasing HCPs awareness of the existing systems for investigating and treating patients in distress may have the potential to improve patient care.

The open communication of information between professionals without fear of judgement caused by hierarchy or ward culture can improve patient safety, and patient care (Beckett and Kipnis, 2009; Thompson *et al.* 2011). Some participants, particularly junior staff or those in surgical specialities stated that they felt worried at times about communicating when they believed someone was in distress to senior staff, for fear of being wrong, or bothering senior colleagues with "*trivial*" matters. Some interviewees were also concerned that senior colleagues might view term distress as too "*non-specific*" or "*non-medical*" - a view not shared by their more senior colleagues. Finding a language for effective communication of patient need that that transcends training and experience is important as then all HCPs can have a shared method of communication, possibly increasing the likelihood of that patient receiving appropriate

care downstream. Using simple terminology might help this. However, such an intervention would require a significant change in ward culture.

4.9 Conclusions

The results of this analysis suggest the need for a formalised ward system that legitimises the use of a HCPs time to recognise and respond to emotional distress, placing this aspect of care in line with a person's physical needs. Any such system should build on HCPs existing skill base and try to enhance known facilitators such as the knowledge a person's usual carer has. If staff recognise that a person is in distress a clear plan as to how to access the existing resources to help the person needs to be conveyed. The next chapter describes the development of potential systems to achieve this.

Development of the Distress Recognition Tool

5.1   Summary of previous chapters

Chapter 1 of this thesis described the prevalence of dementia in a general hospital, and the common symptoms that people with it endure. It went on to review the systems and processes used to identify and manage dementia in hospital.

A potential need to improve or enhance these systems was identified in Chapter 2 when a discrepancy between the expected and reported prevalence of psychological symptoms, pain and delirium was described. It was also suggested that the prevalence of reported distress was lower than might be expected, and the language and systems used to describe and report it were varied.

It was hypothesised that identifying distress in people with dementia might act as a sensitive trigger for further investigation downstream, using existing but underutilised hospital systems. To develop this theory, a qualitative study was undertaken and reported in Chapter 4. The results suggested that distress could be identified innately, but it was believed that the process could be enhanced by staff experience, familiarity with the patient and a formalised intervention to encourage healthcare professionals to look for and report distress.

The scope of this chapter will be to describe the development of such an intervention. Based on the Medical Research Council's guidance on the development, implementation and evaluation of complex interventions, (the key elements of which are displayed in Figure 1), the evidence base and developed theory described in the previous chapters, will be combined in order to design the intervention (Medical Research Council, 2006). It will then be refined using feedback from primary stakeholders.
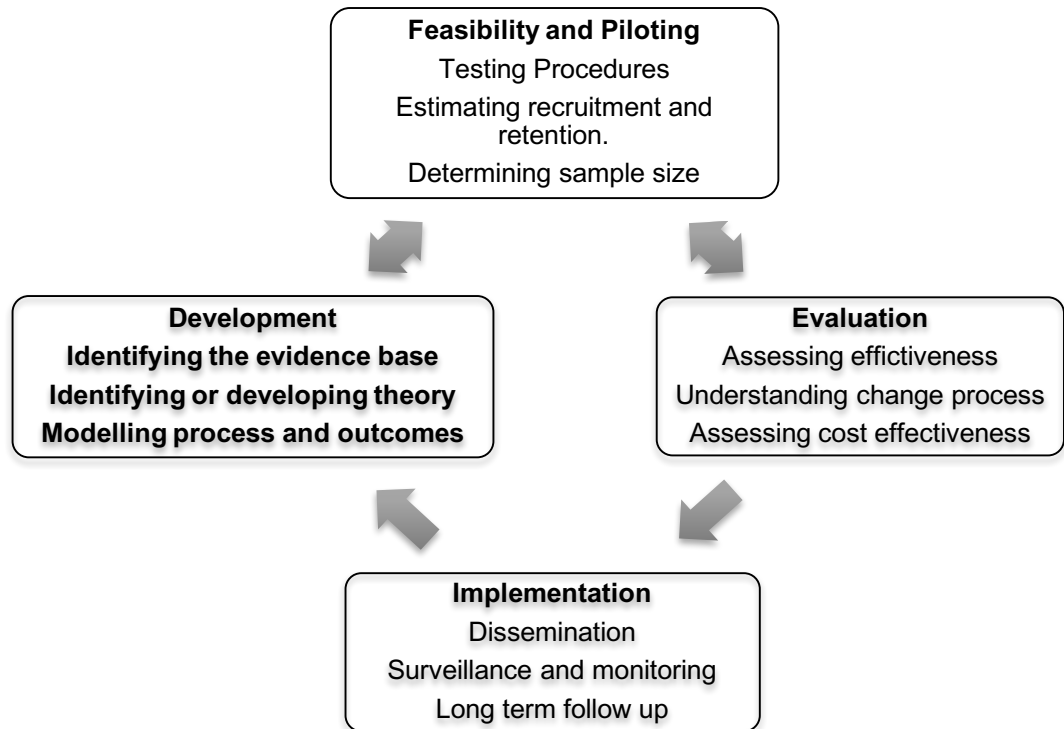
Figure 5.1 A reproduction of the Medical Research Council's key elements of complex intervention development (Medical Research Council, 2006).

5.2   Intervention development

Target symptom

Distress is a potentially sensitive symptom which can act as a trigger to investigate and treat the underlying BPSD aetiology. In both the presented evidence base (Chapters 2 and 3), and theory testing (Chapter 4), distress is thought to be simple to identify and highly prevalent.

Combining evidence base and developed theory

To develop potential interventions that could help HCPs sensitively recognise distress in a hospital setting, evidence from previous studies describing how HCPs recognise distress in people with a reduced capacity for verbal communication (described in Chapter 3) was combined with the facilitators and barriers for distress recognition identified in Chapter 4.

The evidence base suggests that carers can recognise distress cues displayed by body language, facial expression, speech, vocal sounds and behaviour with reasonable accuracy (Manfredi *et al.* 2003; Hadjistavropoulos *et al.* 2000; Bourbonnais and Ducharme, 2010). It is hypothesised that in groups who have similar communication difficulties (children and those with severe learning disability), these cues can be recognised innately (Selekman and Malloy, 1995); however, the sensitivity of this as a screening mechanism is unknown. HCPs interviewed in Chapter 4 believed that they could accurately identify a person in distress by simply observing them, no matter their training background or experience level. This skill was thought to be innate, but enhanced or hindered by several factors, which are summarised in Table 5.1.

Based on these results it was decided to design a screening tool that not only utilised staff innate ability to recognise distress, but also tried enhancing it by encouraging assessors to actively take time to observe patients and use all available resources, such as the patient's family members or carers.

A potential solution to overcoming the identified barriers that HCPs are too busy and task orientated is to legitimise distress recognition as a ward task by designing it to complement existing ward systems and making any intervention quick and easy to use. Distress in this instance is being used as an early warning sign that further investigation and or treatment needs to take place, much like existing track and trigger systems in use on medical wards currently such as the NEWS or the Waterlow pressure index (Royal College of Physicians, 2015; Bridel, 1993). It was hypothesised that by incorporating any intervention into existing systems that are already regularly and routinely used, such as the NEWS, might give any screening tool a higher chance of being used regularly.

Table 5.1 Facilitators and barriers to distress recognition identified in Chapter 4.

Facilitators	Barriers
Assessors innate skill.	A lack of innate skill.
Have enough time for distress recognition.	Being too busy.
Use community carers knowledge.	Prioritising other tasks.
Familiarity with the patient.	Unfamiliarity with the patient.
Observe behaviour and body language.	Becoming conditioned to the distress.
Ask the patient.	Being task orientated.
Experience in a caring role.	Mistaking distress for pain.
Empathy.	Reduced staffing levels.
Job Motivation.	A hypoactive presentation.
Dementia training.	Acute ward environment.

5.3 Established theory on design features for implementing successful interventions

The uptake of proposed guidelines and interventions by HCPs in a clinical setting is poor (Grol and Jones, 2000; Schuster *et al.* 1998) and understanding the barriers to intervention take up and taking measures to minimise them during the design phase is therefore important. The literature on the barriers to guideline and implementation acceptance and use by HCPs is extensive. As a consequence two review articles, Gagliardi et al. (2011) and Cochrane et al. (2007), have been used in as a basis to provide a summary of the main barriers and facilitators. Both publications provide a systematic review of qualitative evidence, providing a secondary thematic analysis to produce a meta-framework that combines themes from the reviewed literature. While both reviews focus primarily on the uptake of guidelines, not interventions, the barriers described are also applicable to intervention implementation.

The reviews suggest a guide or framework to consider when implementing guidelines. The data presented have good face validity, and have been built up from an amalgamation of 256 and 18 qualitative studies respectively (Gagliardi *et al.* 2011; Cochrane *et al.* 2007), which were a mixture of surveys, focus groups and interviews. No evidence is presented, however, on whether the framework content is valid or reliable when applied in a clinical setting.

Both reviews recommend that for a guideline to be successfully implemented it needs to be adaptable for all users, easily used and understood, valid, applicable,

involve service users where possible, and it needs to overcome organisational/system barriers. These concepts are explored in detail below.

Tool content

A lack of knowledge about a topic area and perceived lack of skill are two common suggested reasons that guidelines and interventions are not used in clinical practice (Gagliardi *et al.* 2011). Any potential distress screening tool should be designed to be used by all HCPs on a ward. This potentially means it is as usable by a CSW in their first few weeks of work, or a consultant with 30 years of experience. The information displayed needs to cater for those who lack clinical knowledge and experience, and all users need to feel confident and comfortable using it.

A key area highlighted by Cochrane *et al*. (2007) is that users need to understand how to interpret and apply the intervention. Any distress screening tool needs to have specific instruction on how to use it, or a training package that accompanies it. To improve usage, interventions must also give the user confidence that it can improve outcomes (Gagliardi *et al.* 2011). In this instance, any distress screening tool must give clear instruction about what actions to take if someone is in distress and in due course evidence must be available to show that it improves patient outcomes.

Carer involvement

A facilitator to guideline implementation is involving patients and their carers in the decision making process, providing a level of accountability and improving communication between HCPs and family members (Cochrane *et al.* 2007). In this instance, involving carers in the process could both improve the accuracy of the tool (Table 5.1), and improve HCP/carer relationships.

Tool design

For a guideline or intervention to be used the content must be organised and presented in a format that promotes ease of use (Cochrane *et al.* 2007). Staff must also have the time to use it, and the hospital systems must be able to accommodate it; either by incorporating it into existing procedures or adapting others to make

room for it. There must also be the resources available to implement it, and staff must have access to it when it is required (Gagliardi *et al.* 2011).

Tool implementation

For any intervention to be used, staff need to be aware of it, know how to access it and know how to use it (Gagliardi *et al.* 2011). Any proposed screening tool, will need to be advertised in ward meetings, via the trust communications systems.

Summary of desirable design features of the tool:

- Simple to use.
- Usable by all staff independent of experience level or training background.
- Build on existing skills with minimal training requirements.
- Using existing ward resources – carers and patient information.
- Clear and concise.
- Clear instructions on use.
- Clear instructions on positive outcomes.
- Well-advertised.
- Complimenting existing systems.
- Cost effective.

5.4   Prototype screening tool design

Three prototype Distress Recognition Tools (DRTs) for HCP's were designed. All, can be used by any HCP (no matter what training background), and are intended to be incorporated into, and completed as part of the existing National Early Warning Score (NEWS) system.

NEWS was chosen as it is already a widely-used ward system and is understood by HCPs from different professional backgrounds. The NEWS is generally completed by CSWs and nurses, but all HCPs can complete it. The NEWS is reviewed by doctors, most days as part of ward rounds and team meetings, and any high scores are reviewed more regularly on a needs-led basis. The NEWS is also reviewed by physiotherapists before every contact. It is a screening tool system that is already used regularly and routinely, HCPs can complete it at any time, and as minimum it is completed twice daily for every patient.

The starting point for each tool was the HCP's innate distress recognition skill. The differing tools prompt HCPs on what parameters to observe to a greater or lesser extent. All the tools recognise that the usual community carer of a person with dementia, if they have one, is a potentially excellent judge of distress. They are therefore invited to contribute to the assessment process, two carers DRTs (cDRT) were designed, either can be incorporated into any of the HCP DRTs. The tools are displayed below:

DRT for HCPs 1:

Briefly observe this patient's facial expression, body language, behaviour and speech. Ask the patient if they are upset or worried about anything.

	Document the date and time of the observation in the appropriate box below.									
Do you think this person is in distress?	Yes									
	No									
Does this person's usual carer believe they are in distress?	Yes									
	No									

DRT for HCPs 2:

Briefly observe and score your patient in each category. The first three questions (in green) are possible indicators of distress, which may help you to decide whether you believe this person is in distress or not.

	Document the date and time of the observation in the appropriate box below.									
Is this person shouting out, overactive or aggressive?	Yes									
	No									
Is this person withdrawn and sad, or refusing care?	Yes									
	No									
Is there a change in this person's usual pattern of behaviour?	Yes									
	No									
	Unsure									
Do you think this person is in distress?	Yes									
	No									
Does this person's usual carer believe they are in distress?	Yes									
	No									

DRT for HCPs 3:

Briefly observe the following domains and complete the tool below.

Sad/upset			Facial Expression Happy/neutral		Fearful/angry	
3	2	1	0	1	2	3
Withdrawn/motionless			Body Language Relaxed		Overactive	
3	2	1	0	1	2	3
Mute/inaudible			Vocal Sounds Normal volume		Loud/shouting	
3	2	1	0	1	2	3
Negative			Speech Content Positive		Angry	
3	2	1	0	1	2	3
Crying/refusing care			Behaviour Calm/compliant		Violent/aggressive	
3	2	1	0	1	2	3
No distress			Carer distress rating Some distress		Severe distress	
0			2		3	
Date						
Time						
Distress not present. Score of 0-5			Distress present. Score > 5 or any individual score of 3			

All HCP DRTs:

(Optional) Why do you think this person is in distress? (Reason/date)

Please state if their usual carer has suggested a reason they are in distress? (Reason/date)

If a person is identified as being in distress:

- Acknowledge the distress and reassure the patient.
- Check their physical observations and depending on your level of competence and training; seek help or treat any sign of physical compromise directly.
- If they are medically stable, refer to the Leeds 'Managing Behavioural and Psychological Symptoms in Dementia' Algorithm for treatment strategies: http://www.leeds.gov.uk/docs/Leeds%20guideline%20-%20Behavioural%20and%20Psychological%20Needs%20in%20Dementia.pdf
- Refer to the patients 'This is me' booklet for information about possible antecedents and tips on what makes them feel calm.
- If the following strategies are unsuccessful escalate to a senior colleague or the psychiatry liaison service on: xxxx

Carers DRT:

People in hospital can have difficulty expressing their needs at times. Those who know them best can sometimes tell when they are in distress accurately. If you are a regular carer for the person you are visiting today, please indicate on the chart below whether you feel they are in distress or not. This information will then be used by the ward staff, so that attempts can be made to address any discomfort your loved one is in.

Option 1:

	Document the date and time of the observation in the box below.									
Do you think the person you are visiting is in distress?	No									
	Yes									

Option 2:

I believe the person I am visiting today is in:										
Date										
No Distress										
Some distress										
Severe distress										

On all carers distress screening tools:

Why do you think they are in distress? (Reason/date)

5.5   **Feedback on potential distress recognition tools from primary stakeholders.**

To get feedback on the tool prototypes, and choose the most appropriate one to take forward to feasibility testing, a series of focus groups were held with HCPs, and community carers (mostly family members) of people with dementia. Focus groups can be a good way of gathering attitudes towards a product or concept through facilitated discussion (Krueger, 2015). In this instance, it was hoped by getting feedback from the people who would potentially be using the tool, it could be refined to be as user friendly as possible, while still performing its function.

5.6   **Aim**

To refine and further develop the DRT.

5.7   **Objectives**

- To receive feedback from HCPs and carers on the design, content and application of the proposed distress recognition tools.
- To get feedback from carers of people with dementia on the design, content and application of the proposed distress recognition tools.

- To establish how able and comfortable carers would feel contributing to the assessment process in a hospital setting.

5.8 Methods

Participants

The focus groups were held with two separate stakeholder groups, HCPs and carers.

Healthcare professionals:

Participants all worked on an elderly medicine ward, which cares for a high proportion of people with dementia at a large teaching hospital, it was the proposed site for a future feasibility study of the DRT. A sampling frame was used to ensure that participants came from a range of specific variables, (professional experience, gender, professional role) so that a wide range of opinion could be sampled.

Carers:

Participants were recruited from a local 'Dementia Café Carers Group'. The Dementia Cafe is a forum whereby the carers of people with dementia meet on a monthly basis, it is a social occasion that provides support and education. All attendees care for someone on a non-professional basis in the community. They were selected as they represent a similar cohort that would be invited to complete the carers section of the DRT in a hospital setting.

Recruitment

HCPs:

Focus groups were held at the end of the daily ward MDT meeting, to allow maximum ease of attendance by potential participants. An email inviting participants to take part in the focus groups was sent to potential participants (all clinical ward staff) via the ward manager and consultant. The email listed the date, time and location of the focus groups and included an attached participant information sheet (displayed in Appendix 6). The focus group was also verbally advertised at the start of the ward meetings.

Carers:

The Dementia Café is held once a month. The focus group was the only item on the agenda on the date selected. Carers were invited to attend the focus group by email, and by verbal invitation at the Dementia Café held the month before the focus group. On the date of the carers focus group, the researcher and the Dementia Café facilitator verbally invited carers to attend the focus group and handed out participant information sheets (displayed in Appendix 7), explaining the purpose and aim of the focus group. No participant received financial remuneration for their time.

Consent procedure

Before discussion started the researcher gave each attendee a participant information sheet, outlining the aims and procedures of the project. If the attendees were happy to proceed two copies of the consent form (displayed in Appendix 8) were signed by each participant, one was retained by the participant and one by the researcher.

Data collection

Two HCPs and one carers focus group were held. All were held in private rooms, free of outside distraction. To facilitate optimum participation, the ideal group size for focus groups is 7-9 people (Bickman and Rogers, 2009)). It was planned that if a greater number of participants wished to attend, the group would be divided into two sessions, unless it was impractical to do so.

The researcher moderated each focus group. At the start of each group all participants were given copies of the prototype DRTs, and a brief introduction on their development and intended use. They were then given as much time as they desired to read and ask questions about the tool.

The group moderator used a predefined topic guide. Questions for the topic guide were written to be open, neutral, and understandable to all levels of training (avoiding jargon or assumed knowledge) (Patton, 2002). The topic guide is reproduced in Appendix 9. All the focus groups were audio recorded.

Analysis

The aim of analysis was to gather opinion from primary stakeholders on how the DRT should be applied, whether the content and design was usable, and whether it was perceived a distress screening tool would be useful in its intended setting. The data collected was based on HCPs' and non-professional carers' opinions on the presented tools in the context of hospital systems and their experience caring for people with dementia. Analysis did not seek to ascertain opinion about the caring experience, rather the practical application of the tools. Due to the pragmatic nature of the data, a framework approach to analysis was taken (Braun and Clarke, 2006). Data was coded directly under three predefined themes: tool design, attitudes towards the tool, and application of the tool (Braun and Clarke, 2006).

Analysis took place after all the groups had taken place. Familiarisation with the data began by listening to each group and reading the transcripts individually. On reading through the transcripts, memos and notes were made, capturing the thoughts of the researcher and highlighting details of relevance to the research questions.

The researcher worked systematically through each transcript looking in greater detail for examples and excerpts that seemed to answer the research questions. Each excerpt was assigned a code. Text was open coded (inductively), but only under the given theme headings. After initial analysis, the free form codes within each theme were grouped by similarity and collated.

Data Protection

The procedures for confidentiality and security of data were reviewed and approved by the University of Leeds, Ethical Approval Committee, prior to any data collection.

Participant details were stored separately from the data collected and all data collection, storage and use complied with the data protection act (1998), and the University's Information Security Policy.

All electronic data was kept in a password protected file on the researcher's university computer (also password protected). Written data (consent form), was kept in a locked cabinet inside the researcher's university office, which is also

locked when not in use. The details are scheduled to be archived at the end of the project and will be destroyed 7 years from the end of the project.

Ethical Considerations

Ethical approval was granted by the University of Leeds Research Ethics Committee, reference number: MREC15-128. The main areas of consideration were patient and participant confidentiality and welfare.

It was possible that at times focus groups participants may have referred to themselves or their patients or the person they care for to illustrate examples of how the tool might be useful. Before the interview, both in the information sheet and verbally, participants were asked not to disclose any information that could potentially identify themselves or individuals they care for. If during the focus group identifiable information was disclosed, it was deleted at the time of the recording. If patient identifiable information was only discovered on transcription it was be removed from the transcript.

During the interview participants, may have recalled times that a patient or the person they care for had been in distress. This is potentially upsetting for the participant. If any participant were to become upset during the interview, they would be asked whether they would like to withdraw from the group, and invited to debrief with the researcher who has experience working with people with dementia and their carers.

5.9   Results

Two HCP and one carer focus groups were held. HCP group one was attended by 5 people, and 7 people participated in HCP group two.

Due to practical constraints 13 people attended the carers focus group and the median time in the role caring for someone with dementia was 3 years (range: 1-13). The ratio of women to men was 8:5.

12 people attended the HCP groups over two sessions. All clinical professional roles were represented. The median time spent in their role was 2 years (range: 2 months-24 years). The ratio of women to men was 5:1.

Group interaction

In all groups, the researcher acted as the group moderator. The researcher is a senior HCP specialising in dementia care. All participants were aware of this but were not aware that that the researcher had designed the tools being discussed. The researcher was not a professional colleague or clinician (directly or indirectly) to any participant. Before each group, it was explained to participants that the moderator's role was unrelated to clinical practice, and where possible they should be viewed as a neutral group member there only to prompt discussion (Bryman, 2012).

The carers focus group members were determined by their membership to the Dementia Café and willingness to participate. All group members knew one another socially through the group. They all cared for someone with dementia, but not all had experience of the person they care for being admitted to hospital. Those who had had experience of the person they cared for being admitted to hospital, tended to have more to say on the topic, particularly if that experience had been a negative one. However, all participants were encouraged to contribute.

The HCP groups were stratified to create more homogeneity and account for differing occupational roles having different priorities for the tool. One group contained only nurses, physiotherapists, CSWs and OTs, and the other only doctors. This is an artificial stratification, but reflects the differing roles HCPs would have in process of DRT completion as intended. It will (in general), be completed more regularly by the first group and the second group are more likely to only encounter results when concern is escalated. It was also more practical to organise groups in this way due to staff commitments on the wards. All participants worked on the same ward. Participants with more experience or more senior professional roles tended to dominate the conversation.

Analysis

Analysis of the transcripts produced 12 codes, which were grouped under the 3 themes: attitudes towards the tool (5 codes), application of the tool (3 codes), and tool design (4 codes). HCP and carer responses were considered separately. Each theme is detailed below, illustrated with verbatim quotes from the interviews. Quotes

are in italic font to distinguish them from the main text. Each quote is identified by the focus group and line number from the original transcript.

Healthcare Professionals

General attitudes towards the tool

HCPs felt that there was a role for a distress screening tool on the ward. There was enthusiasm to see a screening tool in practice and, it was thought that such a tool may be most useful on wards with less experience of caring for people with dementia.

There was concern raised by a minority that all people on a hospital ward might be in distress because they are unwell, so any DRT used may capture the presence of physical illness, not unmet emotional needs.

"So the bit I don't understand; if you're in hospital by definition you should be distressed. So when would I accept the reaction? I mean "I am sad or upset because I've got pneumonia and I can't breathe, I am withdrawn and emotional. I'm thinking I can't go back to my normal life because I've got reduce mobility at the moment". So these kinds of [thoughts], they reflect distress, but they can be quite a normal physiological response to being in hospital." (HCP2, 121)

HCPs welcomed the section of the DRT that allowed carers to be able to identify distress and the reasons for it, citing a person's community carer as being the expert at looking after them. It was felt this would be particularly helpful for new or chronically distressed patients. A suggestion made for improving this was to include a section for carers to add comments about routines or comfort items that might help the patient.

"They're their own expert in that individual patient, so it makes you utilise their knowledge. Especially with dementia patients, because their behaviour is so different, and the family are the people that know them the best." (HCP 1, 116)

Application of the tool

Participants supported the use of the tool, to be combined with the NEWS chart. It was believed that this would improve the frequency with which HCPs look for distress and complete the tool. It was noted that the majority of patients would only have the NEWS completed twice a day, however, at c.1600 hrs and c.0600 hrs. It was felt that as most patients are asleep or drowsy at 0600 hrs, the DRT would be

less effective at this time as a consequence. It was suggested that the DRT be available to be completed at any time of day as well as during observations. It was also believed that encouraging the use of the DRT at other times of day might increase the range of HCPs using it. This is because usually only CSWs and nurses complete patient observations.

"If it's done with obs. then obviously it's the responsibility of the nurses because they're doing the obs., whereas we as therapists, if we're seeing the patient then we should be doing this as well, rather than just with the obs." (HCP1, 95)

Tool design

On consideration of the three DRTs presented, participants in both groups strongly favoured DRT1 and 2. DRT1 was felt to be quick and simple and as a consequence would have a greater chance of being completed regularly. It was felt that HCPs would be able to complete the DRT1 accurately, however, staff with limited experience may feel less confident doing so. Other drawbacks to DRT1 identified were that the question asked is subjective and there is no way of indicating distress severity.

DRT3 was received positively. Participants believed that it encouraged the user to think about "*all components of distress*". Another potential advantage of this tool is that it provides a score, which potentially allows distress severity to be tracked during a person's time on the ward. It was hypothesised that DRT3 might be particularly helpful on wards less used to caring for patients with dementia, and that by encouraging HCPs on these wards how to look for distress, those in need may be identified more regularly and staff may become more adept at helping them. The major drawback to DRT3 identified was that it was more time consuming and complicated, so was less likely to be completed regularly.

"The question [DRT1] is quite simple, but I like the bit [DRT3] where it actually asks someone to expand on why they actually think they're distressed, which is really helpful for us when we go to see the patients in the morning. Sometimes you've not seen the patient at all, and you're not familiar with their behaviours, so if you can see those behaviours and you recognise them and can compare them to what we see, that sort of gives you a baseline." (HCP1, 65)

Both groups independently said that they would like both DRT1 and 3 used in combination. Using DRT1 as an initial screening question on the NEWS chart, then if distress was positively identified by it, or by the carers distress tool, then the user

should be directed to DRT3 in order to objectify that opinion and provide a severity score.

"And I think as much as when you first look at it you're like "Yep, I can understand, yes the patient's in distress", but actually you're not then justifying why you think that. So it could be quite a subjective opinion unless you've got some evidence from what you're seeing from the patients. And that's where the screening tool in number two comes in. So it would be good to use one as you think they're in distress, and then use number two as the reasoning why and justification of it." (HCP1, 182)

All participants found the instructions easy to follow, were in favour of using the traffic light colour scheme, and for the tools to be in the style of the NEWS chart, to improve familiarity and uptake.

Carers

General attitudes towards the cDRT.

All participants in the carers group agreed that when vising their loved one in hospital they would feel comfortable completing a distress recognition screening tool. They also universally felt they were able to tell when the person they care for is in distress.

"I know really when [my wife] is not well, when she is distressed, and actually she'll stand up and she'll walk to edge of room and she, she gazes. She's not here. She's in another world of her own." (carers 393)

There was no concern amongst participants that they would feel intimidated or embarrassed telling HCPs their opinion. It was commented by some participants, however, that others might.

"Some people may be more placid and would expect nurses and doctors to know to do best…" (carers, 35)

The groups greatest concern was that their opinions and comments they left on the cDRT would be ignored, or not viewed at all by the HCPs, even if it were a mandatory task. There was a fear for what happened to their loved one when they left the hospital and were not looking out for them.

"When my wife goes into hospital, as she goes in, she's in distress, distress all the time. I feel guilty because she's mumbling away and people are looking and thinking oh I bet that woman's on drugs. And it's, it's difficult. And she doesn't even know her date of birth, or anything like that. So if I'm there, that's fair enough I can answer all

them questions, but if she was left on her own she wouldn't have a hope…" (Carers, 355)

Application of the tool

Participants were asked how comfortable they would feel giving their opinion on what the cause of distress was. They universally felt comfortable doing this accurately and recognised and gave examples of how simple knowledge could both save time, and inform HCPs.

'My Grandma had the nurses looking round for some white glasses! They don't exist!' (carers, 286)

Tool design

Participants found the instructions on both tools presented were simple to follow, and were sufficient to be able to complete them. When comparing the two tools presented most participants preferred cDRT2, which asks for an opinion on whether the person was in no, some or severe distress. All participants preferred the colour scheme to be based on the traffic light system.

'I think the [second] one's better. Well I mean severe distress is… severe. Whereas I might be just a bit anxious and, and… what not. (carers, 209)

As well as having a section to comment why the person is in distress participants requested that they might also be able to comment on possible solutions, that could contribute to the 'This is me' booklet. Their experience in hospital was they were ill informed about the booklet so an alternative opportunity to populate it might be a benefit.

5.10 Discussion

Strengths and limitations

In this study focus groups were used to ascertain structured feedback on the DRT, much in the way one might use focus groups for market research (Morgan, 1988). Using this methodology provided feedback that was pragmatic and may help the usability of future versions of the DRT.

HCP attitudes and opinion about distress in dementia have already been explored extensively in the previous chapter, so were not a primary focus of the interview. When participants in all groups were asked about their perception of a need for the tool and the basic theory of its application (innate distress recognition), answers were almost unanimously positive. While this level of agreement did not generate much discussion around the topic, it does validate the theories formulated in the previous chapter.

The HCP groups were deliberately selected from only one ward because of their expertise caring for people with dementia and likelihood to be using the DRT in subsequent studies. Potential stakeholders in the DRT include all hospital staff on most ward types, hospital managers, patients, and carers. Only a small range and number of stakeholder groups were interviewed, limiting the transferability of the data. The data generated will influence the next design stage of the tool only. Subsequent, or final versions will benefit from feedback using a wider cohort.

Carers of people with dementia are also critical stakeholders, both in the application and potential outcomes of any future DRT. Making the DRT user-friendly for this group is crucial. All members of the carer group had experience of living with and caring for someone with dementia, and the majority had experience of that person being in hospital.

People with dementia are crucial stakeholders, but could not be interviewed because they are likely to have limited capacity for communication. In such instances, it is standard practice to seek opinion from those who care for them (Department of Health, 2005). Only 3 focus groups were held, this number is low (Bryman, 2012); however, all groups from the sampling frame were captured.

The size of the carers focus group was larger than recommended (13) (Bryman, 2012). It was intended that group size should be no larger than 10, and larger groups should be split. This transpired to be impractical, as participants did not wish to wait for the first group to finish. A large group can be potentially intimidating for some and inhibit conversation (Bryman, 2012). This factor was partially negated by the fact that all group members knew one another beforehand.

It was planned for a research assistant to attend the focus groups to assist with note taking. As it transpired on the day of the groups they were unable to attend, so the

researcher moderated and took notes. This has the potential to either reduce the quality of note taking, or moderating.

All participants were recruited directly from natural groups, this had the advantage that participants all knew one another (Bryman, 2012). However, it was also observed on reflection that certain assumptions about pre-existing knowledge were made. This was advantageous in the HCP group, as it made the conversation more direct and topics were covered efficiently. In the carers group, however, the moderator had to stop the conversation on occasion to check that all participants understood. Within the HCP group, although there was a good range of experience levels, the median number of experience years was only 2. This relative inexperience does, however, reflect ward staffing.

Group interactions amongst the HCPs were dominated by those in more senior professional roles. Group stratification by professional background attempted to minimise this, but within the groups dominance was still evident. In general, senior doctors and consultants dominated the doctors group and senior nurses dominated the other HCP group. This has the potential to push more dominant individual's opinions to the fore. To account for this the moderator tried to encourage junior staff to contribute.

The carers focus group was self-selected and contained generally motivated and compassionate individuals, by the nature of them attending such a forum. This has the potential to bias results. Sampling a random population of carers in subsequent feedback sessions maybe a way of countering for this.

The moderator was also the DRTs designer and researcher. There is a potential for this to cause bias, preconceived opinions potentially influencing the group. Furthermore, the all participants were aware of the moderators clinical background in dementia care. For HCPs, this can potentially cause participants to inhibit responses (for fear of "saying the wrong thing"). For carers, their prior experiences either positive or negative with dementia services, may influence their attitude and responses to the moderator and research topic. Group dynamics towards the moderator are unpredictable, but to minimise their impact the moderator kept to the predesigned topic guide where possible. After each focus group the moderator also listened back to the recording reflexively (Guba and Lincoln, 1989).

Summary of the main findings from the focus groups:

- HCPs and carers feel comfortable and competent completing all aspects of the tools presented.
- The tool should be used as part of NEWS, but also whenever an HCP has concerns.
- HCPs preferred DRT1 as an initial 'quick' screening tool, but if distress is identified by either the carer or HCP, the DRT should be used to validate it.
- The tool should use a traffic light colour system (red/distress green/no distress) and match the style of the NEWS chart to improve familiarisation.
- Carers should be given the opportunity to suggest solutions for helping.
- HCPs should be encouraged to acknowledge that carers concerns, and opinions have been seen.

The feedback was collated and used to design the final DRT which is displayed below.

Checking DRT design with primary stakeholders:

The DRTs displayed were reviewed by the ward leaders, which included 6 senior consultants in elderly medicine and 2 ward managers (who were also senior nurses) on elderly medicine wards. Feedback was positive and no suggestions for improvements were made.

Distress Recognition Tool for Healthcare Professionals 1 (DRT1)

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Each time this persons physical observations are taken, briefly observe their facial expression, body language, behaviour, vocal sounds and speech. Ask the patient if they are upset, worried or distressed about anything.

Date/Time																						
Do you think this person is in distress?	No																					
	Yes																					
From the cDRT does this persons usual carer believe they are in distress?	None																					
	Some																					
	Severe																					
	N/A																					
If either assessor believes the patient is in distress, complete the distress recognition tool for healthcare professionals 2 overleaf. If neither assessor believes the patient is in distress no further action is required																						
Score on distress screening tool 2.	<4																					
	>5																					

(Optional) Why do you think this person is in distress? (reason/date):_____

_____

Please state if their usual carer has suggested a reason they are in distress? (reason/date):_____

_____

If a person is identified as being in distress:

1. Acknowledge the distress and reassure the patient.
2. Check their physical observations and depending on your level of competence and training; seek help or treat any sign of physical compromise directly.
3. If they are medically stable, refer to the Leeds 'Managing Behavioural and Psychological Symptoms in Dementia' Algorithm for treatment strategies: http://www.leeds.gov.uk/docs/Leeds%20guideline%20-%20Behavioural%20and%20Psychological%20Needs%20in%20Dementia.pdf
4. Refer to the patient's 'This is me' booklet for information about possible antecedents and tips on what makes them feel calm.
5. If the following strategies are unsuccessful escalate to a senior colleague or fax a referral to the psychiatry liaison service on: 65598

Study ID number:

Distress Recognition Tool for Healthcare Professionals 2 (DRT2)

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To be completed only if the patient has been recognised as being in any distress on the DRT1 or cDRT

	Date																				
	Time																				
Facial expression	sad/upset	3																			
		2																			
		1																			
	neutral/happy	0																			
		1																			
		2																			
	fearful/angry	3																			
Body Language	withdrawn	3																			
		2																			
		1																			
	relaxed	0																			
		1																			
		2																			
	over active	3																			
Speech Content	negative	3																			
		2																			
		1																			
	positive	0																			
		1																			
		2																			
	angry	3																			
Vocal sounds	mute/quiet	3																			
		2																			
		1																			
	normal vol	0																			
		1																			
		2																			
	loud/shouting	3																			
Behaviour	crying/refusing care	3																			
		2																			
		1																			
	calm	0																			
		1																			
		2																			
	aggressive	3																			
Carer rating	None	0																			
	Some	2																			
	Severe	3																			
Total Score																					

Distress Recognition Tool for Carers (cDRT)

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FACULTY OF MEDICINE AND HEALTH

People in hospital can have difficulty expressing their needs at times. Those who know them best can sometimes tell when they are in distress most accurately by noticing a change in their behaviour, body language or speech. If you are a regular carer for the person you are visiting today, please indicate on chart below whether you feel they are in distress, and the date and time that you observed this. This information will then be used by the ward staff, so that attempts can be made to address any discomfort your loved one is in.

Date/Time																				
Do you believe the person you are visiting today is in distress?	None																			
	Some																			
	Severe																			

Why do you think they are in distress? (Reason/Date)_____

_____

_____

We appreciate hospital wards can be a busy, confusing and scary place at times. If you know of any routines, strategies or familiar comforts that your loved

one enjoys and may be soothed by, please note them down in the 'this is me' booklet which should be located at their bedside. Alternatively let a member of

staff know, or write it down here.

_____

_____

_____

Study ID number:

Feasibility testing of the DRT in its intended environment

6.1 Summary of previous chapter

Chapter 5 described the process of designing the DRT, a novel screening tool to help HCPs detect distress in people with severe dementia in a hospital setting. The DRT was then refined using information gained from focus groups with primary stakeholders. This chapter will describe the next stages of the tool development, subjecting it to feasibility testing in its intended environment.

6.2 Developing complex interventions

Feasibility testing and modelling process and outcomes are essential stages of developing and implementing novel complex interventions (Medical Research Council, 2006). The aim of feasibility testing is to observe the potential for successful implementation of an intervention, to determine whether it should be taken forward to further evaluation (Bowen *et al.* 2009). It is suggested there are eight areas of focus to be addressed, these areas and how they relate to the implementation of the DRT are displayed below (Bowen *et al.* 2009).

Acceptability	How do HCPs and carers perceive the tool and see a role for it on the ward in the future? Does it fit with existing ward systems?
Implementation	What are the optimum strategies for raising awareness of the tool, and training HCPs and carers to use it?
Practicality	Can it be completed and how long does it take to complete?
Adaption	Is the DRT fit for purpose, are the questions it asks answerable in a clinical setting?
Integration	Does the tool complement existing ward systems, and how might it influence care?
Limited efficacy testing	Is there any indication that the DRT effectively screens for distress?
Demand	What proportion of patients benefit, is there a need for the tool?
Expansion	Would it be practical and cost effective to scale up existing study methods into every day care?

Feasibility studies can also test the methods, resources and processes that might be required for subsequent evaluation trials, should an intervention be taken forward (Tickle-Degnen 2013). The next section of this chapter describes a feasibility study with the aim of observing the uptake, use, and mechanisms of impact of the DRT.

6.3 Objectives

- To assess the acceptability, uptake and completion quality of the DRT.
- To explore the possible mechanisms by which the DRT might impact on patient care and ward systems.

6.4 Methods

Overview of the study

The DRT and cDRT were placed into the usual care of participants with dementia on two hospital wards. Mixed methods were used including quantitative outcome measures, observational data and qualitative interviews.

Location

Two single sex wards (one male, one female), which specialise in elderly medicine at a large teaching hospital. Both wards care for a high proportion of people with comorbid dementia, based on prevalence figures previously obtained in Chapter 2.

Implementation of the tool

On the two wards, all permanent HCPs including doctors, nurses, CSWs, physiotherapists and occupational therapists were given training by the researcher on to how to use the DRT. Training took place at patient safety meetings and ward handovers until all staff had received training. Training sessions lasted 5 minutes. The researcher gave verbal instruction from a pre-rehearsed script as to how to complete the tools. HCPs were requested to complete the DRT whenever a participating patient's routine physical observations were taken (a minimum of 12 hourly). They were asked to observe the patient and consider whether they believed the patient is in distress or not. They were also asked to check the cDRT each time the DRT was completed and transfer the opinion of the carer, if it had been given.

Where either the carer or HCP believed the patient was in distress, the HCP was asked to complete the DRT2 to generate a distress score. Because no psychometric data is available for the DRT no instruction was given on how to escalate the information other than the written instructions on the DRT1.

The cDRT was placed at the end of the participants' bed on a clipboard. During the consent/assent process (outlined below), carers were given training on how to complete the cDRT. Carer training took approximately 2 minutes and was given by the researcher from a pre-rehearsed script. Carers were asked to complete the cDRT each time they visited the ward by observing the person with dementia and considering whether they believed they were in distress or not. Carers were also asked that if they believed the person they were visiting was in severe distress or need of urgent attention to tell a HCP immediately.

On the day of discharge from the ward (including death or ward transfer), or end point of the study, whichever was sooner, the DRT and cDRT were collected by the researcher. A copy of the completed tools was made and retained by the researcher, the original was stored in the 'observations' section of the participant's medical record.

Participants*:*

For all participants, the DRT was placed in the patient file next to their NEWS observation chart. This file is located as standard in a holder at the end of a patient's bed.

Participants were consented patients with dementia admitted to the study wards, and their usual (non-professional) carers who could potentially complete the cDRT. Inclusion and exclusion criteria for both groups are listed below.

Patients

Inclusion Criteria:

- A diagnosis of dementia made by a specialist doctor in memory clinic prior to admission.
- Admission to a ward included in the study.

Exclusion criteria:

- No diagnosis of dementia.
- The presence of delirium not superimposed on a previously diagnosed dementia.
- Those with clinical concerns such that nursing and/or medical staff do not feel they should be approached.

All patients who met inclusion criteria on the ward at the start of data collection, and all new admissions during the data collection period were eligible for inclusion.

Carers

Inclusion criteria:

- Is a primary community carer for a participant.
- Plans to visit the participant in hospital at least once weekly.

Exclusion criteria:

- The carer receives remuneration performing their caring role.
- The carer is employed by an agency to provide care in the community.
- The carer lacks capacity to consent to participation.
- The carer is unable to complete the cDRT.

Where more than one primary carer was identified, they were both invited to complete the cDRT. Where no carer was identified, the cDRT aspect of the tool was not used.

Study length

The study was scheduled to last for a total of six weeks, with recruitment over four weeks, and follow up continued for two weeks after the last participant was recruited. This timeframe was chosen to allow for sufficient participant bed days to estimate reliable usage data, within a practical timeframe. Estimations were calculated from the data obtained in Chapter 2 which demonstrated that around 15% of the population over the age of 75 admitted to general hospital would have known dementia, with a median length of stay of 5 days. Each ward has 31 beds, and each ward has, on average, 3 admissions per day. The total estimated number

of patients on the ward at the start of the study then subsequently admitted during the study was therefore 248. Based on this, the estimated total number of patients eligible for inclusion in the study was 40, providing around 200 participant bed days' worth of DRT usage data.

Recruitment

Patients

As part of the standard ward procedure, all patients admitted are reviewed by their medical team at the earliest possible opportunity after admission. Those identified as having a pre-existing diagnosis of dementia were verbally informed about the project, given a copy of the patient participant information sheet (Appendix 10), and asked if they would be willing to talk to the researcher about participating in the study. Participants were informed that if they decided not to take part that this would not adversely affect their care.

Where a person eligible for inclusion into the study was deemed by the care team to lack capacity to make the decision about whether the researcher could approach them or not, their care team identified their next of kin, carer or someone close to the person (who does not receive remuneration for this role) who could act as a 'personal consultee'. This person was then asked if they would be willing to talk to the researcher about the person they care for participating in the study.

Carers

After a participant was consented to take part in the study, (or at the same time as the personal consultee was approached to assent for participation), the person acting as personal consultee or the participant's usual carer (who does not receive remuneration for this role), was asked by the researcher to consider participating in the study, by completing the cDRT when they visit. They were informed about the study and their role in it, and given the carers participant information sheet (see Appendix 11).

Consent Procedures

Patients

Many patients eligible for inclusion were acutely ill, had dementia, delirium or both and were not be able to give fully informed consent. If written informed consent had to be obtained from all participants, including those who lack capacity, the very population whose care it was intended to improve would be excluded, biasing the sample and rendering the results meaningless. The procedure for obtaining consent was therefore developed to comply with mental capacity legislation governing England and Wales (Mental Capacity Act, 2005, Sections 30-34).

Where the care team indicated, a potential participant had capacity and was willing to be approached about the study, the researcher visited them at the earliest possible opportunity. At this initial meeting, the researcher checked that they had received the patient participant information sheet, verbally explained the study aims and procedures and answered any questions the potential participant had. Participants were given 24 hours to decide whether they wanted to participate and time to discuss the study further with relatives/carer, or the researcher if they wished. They were also informed that if they decide not to take part that this will not adversely affect their care. If patients did not consent, they were not approached further.

The researcher is experienced in assessing mental capacity and obtaining informed consent. Regardless of their initial capacity assessment by their care team, all potential participants were given a further brief, structured assessment of their capacity to consent based on the criteria outlined in the Mental Capacity Act 2005. In those deemed not to have capacity to consent a personal consultee was sought as set out above. In those with capacity, written informed consent was obtained from them, and their decision to participate was documented in the medical record. A copy of the participant consent form is located in Appendix 13.

Where a person eligible for inclusion into the study was deemed by the care team or researcher to lack capacity, and a personal consultee was available and willing to be approached, the researcher contacted them at the earliest possible opportunity. In such instances, verbal and written information (the patient participant information sheet) was still given to the participant.

If the personal consultee was available on the ward, that is, during visiting times, they were approached by the researcher and given verbal information and the personal consultee participant information sheet (included in Appendix 12). They were encouraged to consider the person's prior wishes or thoughts regarding taking part in research and given time (24 hours) to consider this. If the consultee agreed to give assent, the researcher obtained written documentation of this via the personal consultee assent form (included in Appendix 14).

If the personal consultee was not available on the ward (that is, lived a distance from the hospital or is not able to visit), the researcher contacted them by telephone and explained in detail the nature and purpose of the study. If verbal assent was given, it was documented in the medical notes, and the personal consultee was sent the personal consultee participant information sheet, and the consultee consent form in the post, with a stamped addressed envelope. The patient was included in the study from the point of verbal assent. If subsequently, after 10 days, the personal consultee did not return the signed consent form or changed their decision, the person was withdrawn from the study and any data collected was destroyed. If the personal consultee did not give verbal assent over the telephone, they were not approached further.

If the participant or personal consultee indicated at any time during the study that they should not participate further, they were immediately withdrawn from the study and all data collected was destroyed.

Carers

Carers eligible to complete the cDRT were given the carers participant information sheet (provided in Appendix 11), informing them of the study and their role in it. They were given 24 hours to decide whether they wished to participate. If carers did not agree to participate they were not approached further. If they consented for the study, written informed consent was obtained from them on the carers consent form (provided in Appendix 15)

If a patient consented to participation, but did not have an identified carer or their carer did not consent to completing the cDRT, the cDRT was removed from the bedside and the DRT1 and 2 were used as standalone tools. In cases where more

than one primary carer was identified, each identified carer was consulted for participation as set out above.

HCPs

Consent for participation was not sought from individual staff members, the ward was consented as a whole and individual participation by virtue of working on the ward environment was assumed. If, however, a staff member did not wish to attend training for the tool, or did not wish to complete the tool they could opt out at any point, and it would be recorded in the training record.

Data collection

Data collected on the DRT was designed to demonstrate whether the tool was used and usable in its intended environment, and explore its potential mechanisms of impact. A range of qualitative and quantitative data were collected to achieve this.

DRT use

On the day of discharge the participants medical record, DRT and cDRT were scrutinised by the researcher. The following information was noted on the 'DISTRESSED data collection tool' (displayed in Appendix 16).

Information recorded from the medical record:

- Gender.
- Whether the participant has a regular carer in the community.
- Length of stay.
- Dementia subtype.
- Abbreviated Mental Test Score on admission.
- Charlson comorbidity index score[3].
- Average NEWS score during stay.
- Average NEWS score on days where distress is recorded.
- Average pain score on days where distress is recorded.
- Whether delirium was recorded on days where distress is recorded.

Information recorded from the DRT:

- Whether any data is recoded on the tool.

---

[3] Charlson comorbidity index displayed in Appendix 16

- The frequency with which the HCPs complete the DRT.
- The frequency with which the participant is noted to be in distress.
- The frequency with which the cause of distress is suggested.
- The level of agreement between carers and HCPs as to whether the participant is in distress.

Information recorded on the carers DRT:

- Whether any data is recorded on the tool.
- The frequency with which the cDRT is completed.
- The frequency with which the participant is noted to be in distress.
- The frequency that a cause of distress is suggested.

Observing mechanisms of impact

To better understand how the DRT might affect patient care several domains of ward practice were observed. If the DRT improved the reporting of distress, the information gained was most likely to be either shared amongst other HCPs or acted upon directly. Direct action should be documented in the participant's medical record. The formal sharing of patient information is done either in patient safety meetings at the start of the day or during the MDT meeting.

Participants medical records were accessed at the point of discharge. The following information was recorded:

- The number of times that the DRT results have been documented/transposed into the medical record by a member of the treating team.
- The actions taken to investigate and alleviate and distress recorded.

To observe any effect the DRT had on the communication of distress, patient safety meetings and MDTs in the first and last two weeks of the study were attended and observed by the researcher. Patient safety meetings are meant to be held daily every morning on each ward. They are held 10 minutes apart and last for around 10 minutes, so it is possible to attend both ward meetings each day. MDTs last for around one hour and are held at 1300hrs on both wards. Attendance alternated between wards. The whole meeting was observed, and where the DRT was discussed in the meeting, it was recorded by taking of field notes. The researcher never intervened or contributed to the meeting discussions.

Feedback from primary stakeholders

To gain feedback on the DRT and cDRT primary stakeholders were interviewed. Interviews were semi-structured and followed a topic guide led by the interviewer. The topic guide included areas including: the usability and layout of the tool, the usefulness of the tool in a clinical setting, and the potential impact of the tool on care. The interview style was narrative encouraging interviewees to relate their experiences freely with prompts from the interviewer where necessary. Interviews were held on the study wards.

A purposive sample of carers and HCPs who had completed the cDRT and DRT were invited to participate. The sampling frame is displayed in Table 6.1, and was designed to explore the perspectives across specific variables, which included different care roles and those who have had the opportunity to complete the DRT, but done so frequently or infrequently. Only HCPs and carers previously recruited to complete the DRT and cDRT were included, but the recruitment and consent procedures for this aspect of the study were considered a separate process. A participant information sheet and consent form for both carers and HCPs can be found in Appendices 17, 18, 19, and 20.

The ideal for purposive sampling is to continue recruitment until no new themes are identified in subsequent interviews (data saturation) (Patton, 2002). Interviews continued until data saturation occurred and the sampling frame had been exhausted.

Table 6.1 Initial purposeful sampling frame for semi-structured interviews with primary stakeholders.

Role	Characteristics
Carer	Has consented to using the cDRT and done so frequently.
Carer	Has consented to using the cDRT, but has not completed it, or done so rarely.
CSW	Has cared for a participant and completed the DRT frequently.
CSW	Has cared for a participant, but has not completed the DRT or done so rarely.
Nurse	Has cared for a participant and completed the DRT frequently.
Nurse	Has cared for a participant, but has not completed the DRT or done so rarely.
Consultant in Elderly Medicine	Has observed staff using the DRT and been able to observe any effect the DRT may have had on ward meetings and participant outcomes.
Ward Manager	Has observed staff using the DRT and been able to observe any effect the DRT may have had on ward meetings and participant outcomes.

Interviews were recorded and transcribed verbatim. Transcriptions were analysed for themes relating to the usability and application of the DRT, and feedback on how the DRT might be improved.

Analysis

Quantitative and qualitative data were presented alongside one another to demonstrate the uptake, ease of use, and mechanisms of impact of the DRT. Descriptive statistics were used to display demographic data of participants. Uptake of the DRT, and all of its individual components were measured by the frequency of its use and completeness of the data recorded. The completed DRTs were analysed and descriptive statistics were used to display data obtained, alongside observational data collected by the researcher on the wards.

Following checks that data conditions were met (data were normally distributed and the standard deviations of the two groups were similar (one no more than twice the other)), comparisons between uptake and completeness of the DRT at the beginning and end of the trial to demonstrate the effect of training and any subsequent decay or improvement were analysed using unpaired t-test

To test the effect of the researcher being present on the ward and DRT completion, associations between the completion rate of the DRT on weekends were compared with weekdays. Associations between recorded distress, physiological disturbance (measured by NEWS score), and pain were calculated using paired t-test.

Transcribed interviews were analysed using thematic analysis on the computer based software NVIVO 10. The aim of analysis was to gather opinion from primary stakeholders on the usability and application of the DRT. Analysis took place after all the interviews had taken place. Due to the pragmatic nature of the data a framework approach to analysis was taken (Braun and Clarke, 2006). Data was coded directly under two predefined themes: ease of use and mechanisms of impact and then further subdivided by either HCP or carer. The theme topics were chosen by the researcher and defined ahead of data collection (Braun and Clarke, 2006).

Familiarisation with the data began by listening to each interview and reading the transcripts individually. On reading through the transcripts, memos and notes were made, capturing the thoughts of the researcher and highlighting details of relevance to the research questions.

The researcher worked systematically through each transcript looking for examples and exerts that described the use and application of the DRT. After the first read through of the transcripts, there were multiple free text codes, many of which were similar but not grouped. To organise the codes into a manageable dataset, all the codes were reviewed and collated into existing themes where appropriate. This was done by reviewing each code and the data extract/extracts it referred to one by one. Codes that were similar, or that contained similar data extracts were grouped together and then given a code name and detailed description of the meaning of the code and data extracts within it. This process was repeated twice, each review providing an opportunity to conceptualise the data in greater depth, generating a final 2 themes and 11 codes.

Data Protection

The procedures for confidentiality and security of data were reviewed and approved by the Leeds Bradford NHS Research Ethics Committee, before any data collection (REC number 16/YH/0487). Each participant was given a study identification (ID) number. This number appeared on all documentation used for data collection and acted as the sole patient identifier for the duration of the study. An electronic study ID link document was created so that if a patient requested to withdraw from the study, the correct information could be deleted.

Participant details (name) were only recorded on consent forms and the study ID link document. Any document containing participant details were stored separately from the data collected and all data collection, storage and use complied with the data protection act (1998), and the University of Leeds information security policy.

All electronic data was kept in a password protected file on the researcher's university computer (also password protected). Written data (consent forms), were kept in a locked cabinet inside the researcher's university office, which is also locked when not in use. Audio data (stakeholder interview recordings) were deleted from the portable recording device on the day of the interview, stored on the researcher's university computer and secured in the same way as all other research data. The files and documents are scheduled to be archived at the end of the project, and will be destroyed 7 years from the end of the project.

Ethical Considerations

Ethical approval was granted by the Leeds Bradford NHS Research Ethics Committee, reference number: 16/YH/0487. The main areas of consideration were participant welfare, participant confidentiality, and researcher welfare.

Participant welfare

The DRT is observational, and no additional burden or discomfort to the participant should be caused by it, the practice of distress recognition it encourages should already be part of good routine care (van der Steen *et al.* 2014). The risk of any harm caused by the practice of observation is minimal, although participants could

find it personally intrusive. The management plan that the DRT suggests is already part of standard hospital practice; the DRT, however, may act as a gateway to allow a greater proportion of those in need to access it. If either the participant or carer were to indicate they felt unhappy about the study, they were free to withdraw at any point.

No details observed on the ward were recorded, disclosed to others or published in a form that could identify a participant or ward staff member. However, if something observed suggested that a vulnerable person or persons may be in imminent danger, then the ward manager would be contacted so that appropriate action could be taken. This would only ever be done with the knowledge of all involved parties.

During stakeholder interviews, there may have been instances where interviewees discuss times they have recognised a patient suffering. This is a potentially distressing topic and could be upsetting for the interviewee. If the interviewee were to become upset during the interview, they would be asked whether they would like the interview to be continued, paused or terminated. In either instance, the interviewee would be invited to debrief with the researcher after the interview. The researcher has experience working with people with dementia and in training people to care for people with dementia.

Participant confidentiality

The researcher had access to the medical record of all included participants and attended ward meetings about them. Participant information was only ever accessed on the ward to which they were admitted, which was on NHS property. Information was never removed or altered from the hospital record, and the researchers only role in ward meetings was observational. Only the information required to meet the outcome measures of the study was noted, and all data collected was anonymised. The researcher completed NHS and University of Leeds health informatics training which was up to date at the time of data collection.

At times during stakeholder feedback, interviewees may refer to and be invited to discuss specific examples of patients in distress. They may also wish to discuss examples of care received during a participant's hospital stay. Before the interview, both in the information sheet and verbally, interviewees were asked not to disclose any information that could potentially identify themselves or the person with

dementia they care for. If during the interview identifiable information was disclosed, then the information was deleted at the time of recording.

Researcher welfare

The researcher has extensive knowledge and experience assessing and treating people with dementia and the symptoms that cause distress in dementia. However, the researcher was on the ward in a purely observational capacity. This was made explicit to HCPs on the ward and carers visiting the ward. If professional advice was sought, then the requester was politely directed to pre-existing local resources including the Leeds Dementia Algorithm and the Psychiatry Liaison Team for Older People.

6.5 Results

Overview

The study lasted 52 days in total. HCP DRT training took place over the first 14 days of the study. Participant recruitment occurred until day 40 of the study, one week longer than planned to account for public holidays.

DRT training

All permanent ward HCPs received an instructional email on when and how the DRT should be used. Face-to-face training sessions lasting five minutes in total took place on both wards at a total of five patient safety briefings, (attended by all ward HCPs on shift) and 28 nursing handovers (attended by nurses and CSWs on shift). A log of HCPs trained was kept. At the end of the 14-day training period, five HCPs remained untrained and each were given one-to-one training at the first convenient opportunity. The number and range of regular ward staff attending training can be viewed in Table 6.2. Agency and bank nursing staff, students visiting the ward and locum medical staff did not receive formal training.

When student nurses joined the ward, and were due to complete observations, they were given ad hoc DRT training. More regular agency and bank staff were given ad hoc training.

Table 6.2 The number of regular HCPs who received face-to-face DRT training.

Staff group	Ward numbers	Number trained	Percentage trained
Nurses[4]	25	25	100
CSWs[5]	32	32	100
Consultant doctors	6	6	100
Registrar doctors	4	4	100
FY1-CT2 doctors[6]	6	3	NA
Physiotherapists	6	6	100
Occupational therapists	2	2	100

All participating carers were given training on how to complete the cDRT immediately after they were consented to participate.

Participants

There were 59 eligible patients admitted to the wards during the study period. A total of 32, were included in the study, which equated to 346 bed days. A flow chart describing participant numbers and exclusions is demonstrated in Figure 6.1.

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[4]During the study period, registered agency and bank nursing staff covered a total of 337 hours.

[5]Unregistered bank and agency staff covered a total of 988 hours.

[6]Registrar, FY1 and CT2 doctors regularly changed due to shift patterns, and locum medical staff were regularly used. Furthermore, out of normal working hours on call junior doctors who did not have DRT training were responsible for ward work.
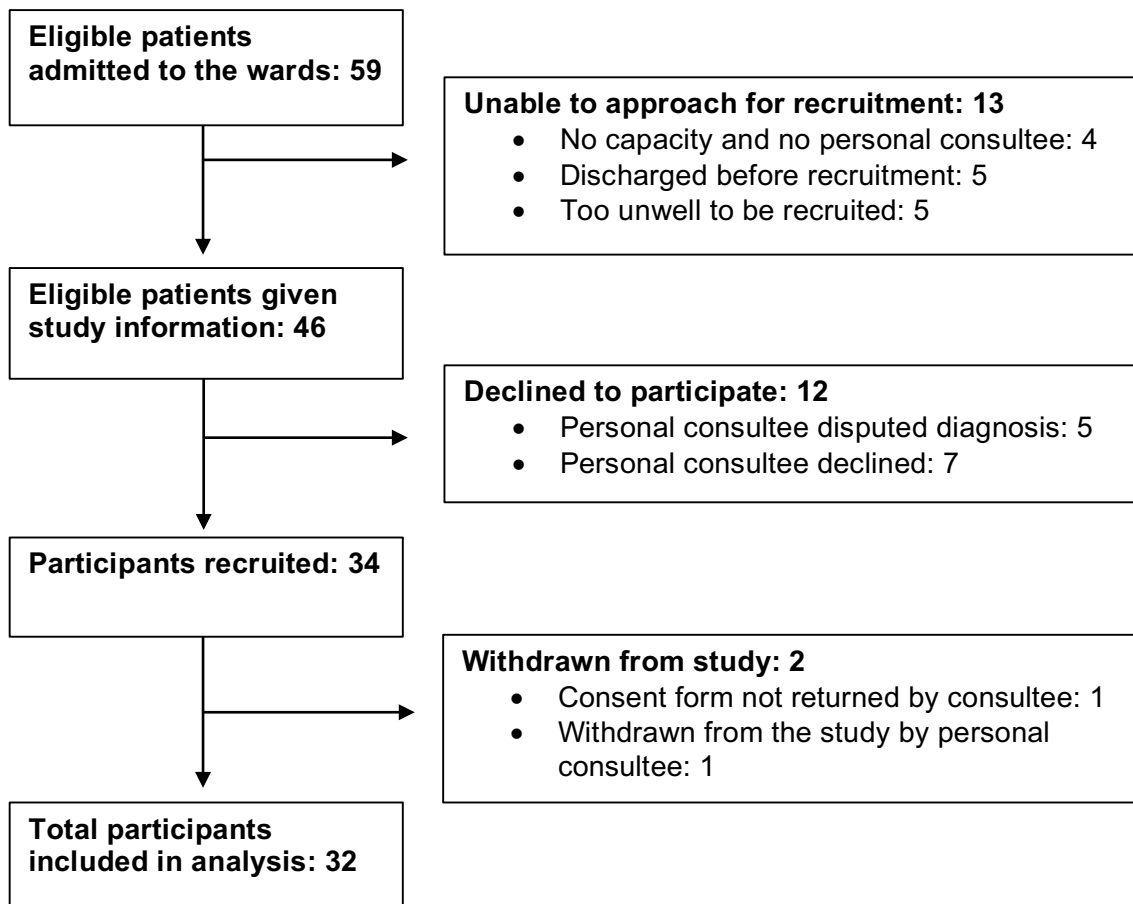
Figure 6.1 Participant numbers included in the DRT feasibility study.

Participant demographics

Demographic information of the 32 patient participants is displayed below in Table 5.3. Age, gender ratio and distribution of dementia subtypes were typical of the UK population with dementia (Sampson *et al.* 2009; Goldberg *et al.* 2012). The average Abbreviated Mental Test Score (AMTS) on admission was 4. Dementia severity was not described as it was not feasible to accurately measure in an acutely unwell population in an unfamiliar environment.

All but one participant lacked capacity to consent to the trial, and personal consultees were used to give assent, in these cases. 27 participants had an identified carer to complete the cDRT. 5 participants did not have a carer who was planning to visit the ward regularly, and therefore did not have the cDRT included in their care.

Table 6.3 Participant demographics.

Characteristic	Number (range)
Gender	
Male	13
Female	19
Median Age	82 (68-94)
Dementia Subtype	
Alzheimer's	16
Vascular	11
Mixed	1
Lewy body	1
Unknown	3
Mean Abbreviated Mental Test	4
Mean Charlson Comorbidity Index	6.5
Median length of stay in study	9 (1-36)

Stakeholder interviewees

Ten potential participants were invited to attend an interview to give feedback on the DRT, all agreed and participated. The range of participants interviewed included 3 carers, 3 CSW's, 2 nurses and a ward manager and a consultant.

DRT use

Ward observations

DRT's were checked daily to ensure they were in the correct position, and had sufficient space to be completed. DRTs and cDRTs remained in place, however, as they were only identifiable by study ID occasional confusion was caused when patients moved bed number. Any DRTs out of place were always promptly replaced by the researcher.

On both wards, DRT's were completed mainly by CSWs and nurses. Where student nurses were on shift, they would also regularly complete the physical observations and therefore the DRT. Prior to training, student nurses were observed to be omitting the DRT and after training they completed the DRT regularly.

On both wards, at times where patients were at risk of falling, specific falls bays were created. These are 6 bedded bays were all patients at risk of falling are placed

together and observed by a HCP 24 hours a day. This observation task was often given to bank or agency staff, who would also be expected to conduct the physical observations, and therefore the DRT. Agency and bank HCPs were observed to fill the DRT in less regularly, even if the HCP had received ad hoc DRT training.

An initial common mistake made by HCPs, was completing the (more visible) cDRT instead of the DRT1, suggesting an implementation issue of the positioning of the DRTs. This caused an initially falsely high completion rate of cDRT forms and under completion of DRT1 forms. It also caused some confusion for carers when they came to complete the cDRT and found it already filled in for that day. This error was highlighted in subsequent patient safety meeting training sessions and the frequency with which it occurred diminished rapidly.

cDRT completion by carers was very variable depending on how frequently they were able to visit and whether they remembered to complete the cDRT when they did visit. Where a participant had more than one nominated carer to complete the cDRT, it was observed that this increased the frequency of which the cDRT was completed, as they both filled it in on visits.

DRT analysis

DRT1 was completed 312 times in total, an average of 0.9 times per patient per day. The NEWS chart was completed 712 times, an average of 2.1 times per days, indicating the DRT1 was completed on around 44% of observations taken. The cDRT was completed an average of 0.5 times per participant (with cDRT in use) per day. cDRT frequency data does not take into account how often the participant was visited by their identified carer(s).

It was apparent during ward observations and subsequently on analysis (Table 6.4) that throughout the study some HCPs became easily confused as to when to complete DRT2. In 34 cases, DRT2 was not completed when it was indicated. On 49 occasions, it was completed in the absence of distress on DRT1 or cDRT. A further common mistake was for HCPs to complete DRT2 instead of DRT1. All three errors were observed from the beginning of the study and did not improve, despite highlighting the errors in subsequent training sessions, indicating implementation issues.

The transposition of the cDRT data onto the DRT was inconsistent on both wards. Common errors included not transposing information the carer had recorded and transposing incorrect information. Where the carer had not visited that day, or not recorded any information despite visiting, the HCP should have transposed the cDRT result as NA, but this was frequently not completed.

Participants were identified as being in distress on 23 separate occasions by a HCP (7% of DRT1 completions). The HCP suggested a cause for the distress on four occasions. Participants were identified as being in some or severe distress on 39 occasions by their carer (26% of cDRT completions). The carer suggested a cause for the distress on 38 occasions. Carer distress suggestions were never transposed to the DRT.

From the total of 52 distress events, the DRT 1 and cDRT corresponded on only 6 occasions. There were 12 occasions where the carer noted distress, but the HCP had recorded that they believed the participant was not in distress or vice versa (on entries made in the same 12-hour period). Of the 34 distress episodes, whereby no correspondence data was available, either the carer did not visit that day, the DRT was not completed that day or the participant did not have a cDRT as part of routine care (as they did not have a nominated carer).

The number of DRT1 forms completed per day, appropriate completion of DRT2 forms, and transposition of cDRT forms by HCPs did not change significantly between the first 14 days of the study (during training), and the last 38 days (post training) (p=0.7, 0.2, 0.7 respectively; see Table 6.5). There was no significant difference between completion of the DRT on a weekday and a weekend and average DRT1 completion rate was 0.94 and 0.8 (p=0.1) respectively.

Table 6.4 The frequency and completeness of DRT completion by HCPs.

Aspect of DRT	Events N	Proportion Per patient day	Proportion
NEWS completed	712	2.1	-
			Per NEWS
DRT1 completed	312	0.9	0.44
			Per DRT
Distress recorded by any party	52	0.15	0.17
HCP suggested cause of distress.	4	0.01	0.01
DRT2 completed	67	0.19	**Per DRT2**
In the presence of distress	18	0.06	0.35
In the absence of distress	49	-	0.19
cDRT completed	150	0.43	**Per cDRT**
cDRT transposed accurately	24	0.07	0.16
cDRT transposed inaccurately	12	0.03	0.18
Cause of distress suggested by carer	38	0.11	0.25
Agreement on distress recorded on cDRT and DRT[7].	6	-	**Per distress event** 0.12
Disagreement on distress recorded on cDRT and DRT.	12	-	0.38

Table 6.5 The completion rate of the DRT elements, comparing during and after training and weekdays and weekends.

	Completion per patient day		P
	Proportion During training	**(95% CI)** After training	
DRT1	0.86 (0.68 – 1.03)	0.89 (0.79 – 0.99)	0.7
DRT2	0.12 (0.00-0.23)	0.06 (0.02-0.09)	0.2
cDRT transposed[8]	0.25 (0.11-0.39)	0.22 (0.15-0.29)	0.7
	Weekday	Weekend	
DRT1	0.94 (0.84-1.04)	0.8 (0.64-0.95)	0.1

[7]Within the same 12-hour period.
[8]Includes all transpositions including those where the cDRT is not completed and HCP has transposed as NA.

Feedback from primary stakeholders

HCPs

All HCPs interviewed believed the DRT was a useful and worthwhile intervention, however, some believed some aspects of its application could be improved. Positives highlighted were its ease of use, brevity and lay out, which made it easy to adopt into routine care. In particular, HCPs found it helpful that the layout and colour coding matched the existing NEWS observations charts, and that the tool was completed at same time as the NEWS. It was believed that the tool did not take excess time to complete, most participants believing it took them between 2 and 10 seconds to make a judgement and complete the tool.

"It wasn't too wordy and was quite quick and fill out which I think helped it be filled out so much on this ward, because it wasn't to arduous. I thought 'I'll do this again'. It was quite quick and easy to do." (Nurse, 6, 47)

A suggestion for improvement was printing the DRT on the observations chart, rather than having it as a separate sheet of paper. It was felt this would reduce the chances of HCPs forgetting to fill it in, a commonly cited reason for non-completion.

"The biggest barrier [to completing the DRT] was forgetting, just with it being new. Apart from that, it's easy." (Nurse, 5, 210)

Participants stated that initially they had concerns that the DRT would be extra paperwork and therefore an inconvenience, but all HCPs interviewed reported that it soon became easy to complete. Those interviewees in a senior or management position noted that no HCPs had complained to them that it was arduous to complete.

"I did expect to start off with that the staff doing the observations would have been more negative, but they have been quite positive about it through the study." (Ward manager, 9, 49)

There were mixed reactions as to the usefulness and usability of the DRT2. The majority of HCPs interviewed believed it was useful to be able to objectify their opinion that someone was in distress, particularly if there was a difference of opinion between HCPs themselves or HCPs and carers. It was felt the DRT2 was most useful for less experienced staff, helping them to recognise hypoactive presentations.

"It triggers you to think about things that you wouldn't necessarily think about which is why I like this [the DRT2], rather than the other one [the DRT1] just because it has… You might think that someone is settled but actually you think on this one, they are not. This sort of highlights things that you don't tend to go straight for." (Nurse, 5, 302)

The DRT2, however, did cause some confusion, and one interviewee explained they "*didn't even know there was [a DRT2]*", indicating a training and implementation deficiency.

When asked about whether the cDRT was a useful aspect to the tool there were mixed opinions. While all participants agreed that it was a good thing that carers were able to contribute to the assessment process, some believed that most family members were unsure how to recognise distress in the person with dementia. Several participants observed that the carers who completed the cDRT were the generally more proactive ones and therefore already likely to come and verbally report distress anyway. It was also observed by one participant that during the study carers were verbally reporting distress, but not documenting it on the cDRT.

"I thought it was really good bringing in the carers involved. Even with the information about the patient aside I think it made carers feel a lot more confident in the care and they felt a lot more involved. It's a way of including the family without having to go out of your way in a way to get them involved in the care. And also they are an expert on the patient so it's really handy to have their information on board." (Nurse 6, 146)

"I think the people that had filled it in that I'd seen they were quite vocal with us anyway so they would tell us and tell us what's normal for them so we already knew it" (CSW, 7, 167)

The low rate of transcription of the cDRT to the DRT was explored further. Particularly amongst the CSWs it appeared there was some confusion as to how the cDRT should be used. Two of the three CSWs interviewed seemed unaware how the information on the cDRT should have been transcribed or used, despite both having attended training. This indicates a need to simplify this process and improve training.

"I didn't know they [visiting carers] did write anything. Where would they have written it? I knew they could tick there and stuff but I didn't know if that bit was for us or for the relatives. I didn't know I was meant to copy it on to there [The DRT1]." (CSW, 7 118)

Carers

The carers interviewed had mixed experiences using the DRT. While all reported that it was easy to understand, well laid out and easy to complete, there were some implementation issues.

"It's colour coded, it's a pretty simple straight forward task, and you know where you can write in to depth, and even somebody who isn't educated enough, and you will get that, as well as cultural barriers, language barriers, but I think it is a very very basic tool… It's very very easy to understand and do as an exercise." (Family member of participant, 8, 73)

One participant struggled to find the cDRT after her mother moved beds and the clipboard was in a different location (due to infection control protocol). Another issue raised was that carers felt uncomfortable completing the cDRT in front of their loved one, particularly if the person with dementia was suspicious. This was not an isolated occurrence, and one cDRT had to be removed from routine care due to the anxiety it was causing in the participant.

"I'm always very cautious about discussing anything in front of her, because I don't want her to feel as though we are talking about her all the time, so filling that form in I probably would have done it quite quickly anyway, so it needs to be quite concise. I think on the day that I did it I said that I was filling a sheet in for her meals, which is what we used to do for what meals she wanted for the next day." (Family member of participant, 3, 146)

All carers believed they could easily recognise if the person they cared for was in distress.

"We know him as a person, we know him as a character. And we can see that on his face, in his eyes, the expressions. Today he's fast asleep, you know he's at peace, when he is distressed he will, you know try to grab things, he will try to get up, he will try to move himself, and you can see that lost look in his eyes." (Family member of participant, 8, 349)

DRT association data

Fourteen participants (44%) were recorded as being in distress on either the DRT1, cDRT or both at some point during the study. In paired t-testing, there was no significant difference between participants NEWS scores recoded on days when they were believed to be in distress (0.78) compared to their and average NEWS score for the duration of the study (0.55) (p=0.36). Participants were never reported

to be in pain on the pain chart on days where distress was also recorded on the DRT.

Potential mechanisms of impact

General ward observations

Patient safety meetings were held every weekday morning on the female study ward and the majority of weekdays days on the male study ward, (some days were missed if other ward priorities took precedence). At this meeting all staff have the opportunity to raise safety concerns about patients and the following areas are specifically covered: skin condition, falls risk, discharge planning, NEWS score, and any urgent/outstanding jobs. The DRT was not part of the patient safety meeting agenda.

Observation of patient safety meetings took place in the first and last two weeks of the study. 62 patient safety meetings were observed in total, 40 on the female ward and 22 on the male study ward (meetings were less frequent on this ward). During the first two weeks of observations, the DRT was not mentioned in any patient safety meetings.

During the last two weeks of the study, the DRT was mentioned in two meetings on the female ward and no meetings on the male ward. In the meetings where the DRT was used, it was on the agenda as a topic to be specifically covered by the person chairing the meeting. A participant in distress was identified and discussed on both occasions.

MDT meetings

MDT meetings are held daily on both study wards, during these meetings each ward patient is discussed in detail, with all HCPs involved in their care invited to contribute where possible.

Observation of MDT meetings took place daily, throughout the study alternating between wards (as the meetings occurred simultaneously). A total of 38 MDT's were observed across the two wards.

Participants in distress were identified regularly at this meeting. More frequently the doctors would discuss specific symptoms and solutions for reducing the impact of these symptoms. The DRT and high scores on the DRT, however, were not mentioned, despite some patients having been identified as being in distress on the DRT1 and/or DRT2.

Participant notes

Of the 32 participants, the DRT was specifically mentioned in the notes of five participants, and the total number of mentions was nine. The presence of distress was specifically documented a total of 17 times in four sets of notes. In each instance distress was used as a specific terminology. In a further four sets of notes (one documented event per set) an absence of distress was noted, "no distress present".

Evidence of the DRT influencing escalation of care was observed in four participant's medical notes. On seven separate observations, distress was investigated by the care team following DRT distress observation. This led to two subsequent referrals to the psychiatry liaison team for older people and one escalation of care to a more senior member of the care team.

Feedback form primary stakeholders

All HCPs interviewed believed the DRTs biggest influence on patient care was to raise the general awareness of staff to distress. This effect was non-specific, however, as more senior HCPs believed that people in distress were being escalated as a concern more quickly and discussed in ward hand overs or between team members.

'I thought that it was good that there was more discussion around distress and behavioural and psychological symptoms of dementia like that was more on everyone's radar so I thought that awareness of that was increased during the time of the Tool being used.' (Consultant, 10, 20)

Several participants highlighted that the DRT was being completed, but no further action was being taken. It was believed the DRT could be more effective if it was on the regular agenda at either patient safety briefings or MDT, asking specifically if any patients were being identified as distressed over the past 12 hours.

'The safety huddle would be a really good place for us to implement [discussion about the DRT] that. It's just collating the data all together so you can say this person's had this and that, or even have it on the whiteboard as a separate section so if someone is on this Tool we need to review this and carry on.' (Nurse, 6, 184)

All carers interviewed wanted their views to be known and acted on by HCPs. Two from the three interviewed did not believe that HCPs were acknowledging their comments or opinions. They also felt that because there was no space on the cDRT to indicate the HCP had checked it, they could not be reassured of this. A suggestion for improving this was that HCPs should have space to sign the cDRT to acknowledge that they have seen the carers views.

6.6   Discussion

The aim of this study was to observe the potential for successful implementation of a novel screening tool, the DRT, to determine whether it should be taken forward to further evaluation. The DRT was evaluated for its integration onto the ward, acceptability, uptake, completion, usefulness and potential mechanisms of action. The feasibility study design used mixed methods to test both how well the tool is used, and how well it is accepted in a busy and often frantic clinical environment.

Principle findings

The DRT1 was completed an average of 0.9 times per day by HCPs. Completion frequency was consistent throughout the study. When completing the DRT1 HCPs found it quick and easy to complete and believed it was an accurate screening tool and beneficial to patient care.

DRT2 forms were completed far less frequently than indicated and completion errors were common. There were no associations between recorded distress and physiological discomfort (pain and high NEWS).

cDRT completion was variable depending on carer involvement, however, it was completed on average 0.4 times per patient per day. Carers welcomed the opportunity to complete the cDRT and believed there was a role for it, but were suspicious that staff did not acknowledge their views. HCPs appreciated carer input and saw it as useful. However carer opinions on the cDRT were rarely transposed onto the DRT.

Strengths and limitations

Feasibility studies are integral to answer the question "can this work?" and are central to developing successful complex interventions, (National Institute for Health Research, 2017; Medical Research Council, 2006). It is hoped that by rigorously testing the DRT the end product can be relevant and practical and ready to take onto further testing and eventual implementation.

The methods used were diverse to produce data that could answer the research question from multiple angles, providing practical and reliable results. Combining qualitative and quantitative data helped to achieve this. The data produced while perhaps a little crude, is pragmatic.

The wards used to conduct the study, care only for older people, and are likely to have a high prevalence of dementia as a consequence (Prince *et al.* 2014). This is useful as it meant the population sampled was relevant, allowed for a reasonable number of potential participants and HCPs were motivated and used to providing care for people with dementia.

The prior experience of HCPs and carers makes them potentially more likely to be able to accurately complete the DRT. This makes the result less generalisable to other hospital wards, who care for older people (for instance surgical wards). If the study is repeated or run on a larger scale, wards with less experience of providing dementia care should be included.

The majority of participants lacked the capacity to consent. The consent procedures used were robust and in line with the Mental Capacity Act, and all possible measures to ensure participant welfare were reviewed.

The study was conducted during the months of December and January 2016/17. This was a time of severe pressure on hospitals in the UK and the older population was one of the most affected groups (British Broadcasting Company, 2017). For the duration of the study there were two extra 'corridor beds' per ward and no extra staffing to cover this. Staff were under severe time and work pressure, so introducing the DRT at this time could be viewed as extra work and an inconvenience. No HCP raised concern about this once they had experience of

using the tool. However the increased pressure could have potentially reduced the frequency of DRT completion.

A further disadvantage of the time of year were the multiple public holidays disrupting usual ward care. This meant there were fewer opportunities for recruitment during the holiday period. As a consequence, recruitment was extended by one week.

There were fewer participants than originally anticipated in the sample size estimation. This is not because there were fewer admissions with dementia, but due to the high number of potential participants who could not be recruited, or whose personal consultee declined for them to participate. Numbers could have been increased by using professional consultees.

The presence of the researcher on the ward was a potential bias for completion rates. The researcher conducted all training, and was present on the ward on weekdays throughout the study. The presence of the researcher may act as an aide memoire for HCPs to complete the DRT, and potentially artificially inflate the DRT completion rate. However, DRT completion rate on weekends and bank holidays, (when the researcher was not on the ward), were not significantly different from completion rates on weekdays (0.85 and 0.94 respectively; p=0.1).

Considerations for future DRT implementation

The aim of feasibility studies is to test the potential for successful implementation of an intervention, to determine whether it should be taken forward to further evaluation. With this in mind the performance of the tool in the study in the following domains will now be considered; acceptability and implementation, practicality and adaption, integration, limited efficacy testing, demand and expansion (Bowen *et al.* 2009).

Acceptability and implementation

For the DRT to be accepted and ultimately implemented into routine care, HCPs and carers have to be aware of it, have the knowledge and skill to use it, the tool has to be accessible and fit into existing ward systems (Gagliardi *et al.* 2011).

HCPs were made aware of the DRT in training sessions, by email and by witnessing its use on the ward. At the end of the training period all permanent ward HCPs had attended training and were aware of the tool, and how to complete it. Training sessions were short as the tool is relatively simple, the layout is familiar (based on NEWS chart), and the systems it is integrated into (NEWS) are well established on the ward. For practical reasons training sessions were given at existing ward meetings and handovers, this gave the opportunity for optimum attendance as it is mandatory for all staff on shift to attend handover and safety briefings. Both meetings are at a busy time of day, however, and HCPs had other tasks to attend to. It is likely that this distraction reduced the potential impact of training. Staff also often attended multiple training sessions, by virtue of the mandatory nature of the proceeding meetings. Although repeated exposure to training may reinforce knowledge, it also has the potential to create some frustration. If the DRT were to be introduced into routine practice, mandatory training sessions would need to be conducted on each ward and introduced as part of the induction of new staff.

Carers were given training on using the cDRT at the point of consent. Carer training was short and carers seemed to understand how to use the tool without issue. In the qualitative study carried out and described in Chapter 4, HCPs all believed they had the necessary skill to identify distress in dementia. This opinion was further supported by HCPs interviewed in this study, who all believed they could accurately complete the screening question "do you think this person is in distress?" as displayed on the DRT1.

Carers interviewed, both in preparatory focus groups and in this study believed they could accurately recognise when the person they care for is in distress. Neither HCPs nor carers were given training on how to recognise a distressed person, rather being told to use their impressions based on a short period of observation. The reliability with which assessors can accurately recognise distress using the tool was beyond the scope of this study.

The DRT was integrated as far as practically possible into the existing ward NEWS observations system. The NEWS observation system is used at least twice daily for every patient; its completion is mandatory, audited regularly and is part of ward culture. Furthermore, the system or systems very similar to it (MEWS) are used throughout UK hospitals (National Institute for Health and Care Excellence, 2007).

The tool was designed to look like the NEWS chart and sat next to it in the patient observation file at the end of the bed. It was not practical to have the DRT printed on the NEWS chart. Feedback from stakeholders indicated by integrating the DRT into the NEWS increased the frequency with which it was completed and meant that it became a routine task. A regular comment made by staff, is that the DRT should be printed on the NEWS chart. This could potentially increase the completion frequency further.

A downside of integrating the DRT into the NEWS system it that it potentially limits the range of HCPs using it. It is rare that doctors, physiotherapists or Occupational Therapists complete the NEWS, though there is nothing stopping them doing so should they wish to. This effect was observed on the ward, and by far the majority of DRT completions were carried out by CSWs.

Practicality and adoption

DRT1

HCPs were observed to complete the first part of the DRT1 (answering the screening question "do you think this person is in distress?") with ease, this is supported by HCP feedback and completion rate of the DRT1.

The DRT1 was completed 0.9 (0.87-0.93) times per participant per day. If completed as recommended (each time the physical observations were taken) completion rate should have been around 2.1 times per patient per day. Ward observations by the researcher indicated that the DRT was less likely to be completed if bank or agency staff were completing the physical observations. Bank and agency staff did not attend formal training, and when questioned were often not aware of the DRT or how to complete it. It might also be hypothesised that they have less motivation to complete the DRT as they gain less from the research and improving hospital systems.

Completion rate of all aspects of the DRT remained consistent during and after training (Table 6.5). It was hypothesised that the completion rate may be lower in the first 2 weeks, a time when not all staff had received training on the tool, but this was not observed. The reported main reasons for non-completion for the DRT by

HCPs was that they forgot. It was again suggested that if the DRT was printed on the NEWS this might be negated.

DRT2

HCPs were asked to complete the DRT2 each time they or the carer believed and indicated the participant was in distress on the DRT1. The DRT2 was completed as indicated in only 35% of distress incidents. Furthermore, there were 49 occasions that the DRT2 was completed where it was not indicated. For an intervention to be successful, it needs to be able to be interpreted and understood by all users (Cochrane *et al.* 2007). During both ward observation and on during feedback with stakeholders it was apparent that some HCPs struggled to understand this aspect of the tool. Two out of the three CSWs interviewed were not aware of how to complete the DRT2, one did not realise that it existed, despite having attended training. In feedback given the nurses, ward manager and consultant were aware of DRT2, and its purpose, but had not often completed it.

The DRT2 was seen as a useful aspect of the tool by the majority of stakeholders, but it was poorly applied. This indicates that further work needs to be conducted to either simplify the tool, or improve the training into how to use the tool.

cDRT

It is likely the cDRT completion rate was affected by how regularly a person's carer visited them and how motivated they were to complete the tool. Five participants did not have a carer that could visit them, so did not have a cDRT. Feedback and ward observations indicated that carers did not have any difficulty completing the cDRT when they attempted it. All carers and HCPs interviewed saw the potential benefit of it, and wanted to see its continued use. Factors observed that reduced the likelihood of the cDRT being completed were the carer being able to remember to complete it, the carer having the language skills to complete it, and the carer being able to find the cDRT. The latter was made more difficult when the patient was in a side room as the cDRT was located outside the room.

cDRT transposition

The frequency of transposition of the cDRT was lower than the completion for the DRT1. If the tool was being completed fully, every time the DRT1 was filled in, a

record of the cDRT should have been entered, even if the cDRT had not been completed that day. cDRTs were transposed 0.23 times per patient per day. If the tool was completed accurately rates should have matched DRT1 completion rates (0.9). This discrepancy indicates that HCPs did not know to look at or transpose the cDRT exposing either a training deficiency, or that this process was too time consuming. Stakeholder feedback on the issue indicated that HCPs valued and observed the carer opinion, and wanted this element of the DRT to remain. Reasons suggested for non-transposition were that it was not relevant to transpose negative (non-distressed) results, that transposition was too time consuming, or that they couldn't locate the cDRT.

Carers were suspicious that HCPs were not acknowledging their opinion on the cDRT and the completion data presented suggests this suspicion may be justified (transposition rate 0.23 per participant per day, no carers comments transposed to the DRT). As all stakeholders identified that the cDRT was an important part of the tool a possible improvement suggested was that HCPs should be asked to sign the cDRT daily to demonstrate to carers they have checked it.

Demand

It is proposed that a version of the DRT, with modifications based on these results, would be used in all hospital in patients with dementia. This study did not attempt to measure prevalence of dementia, but the estimated prevalence of dementia in older people admitted to medical wards in hospital is 42% (Sampson *et al.* 2009).

Limited efficacy testing

It was beyond the scope of this study to conduct efficacy testing on the tool. It is of note, however, that 44% of participants were reported as being in distress at some point during the study. While not directly comparable this figure is a contrast with the number of people with documented evidence of distress or language indicating distress in Chapter 2 (33%).

As distress is such a non-specific sign, one might be suspicious that by recording it, but one is actually just recording the presence of pain or physiological discomfort (Jordan *et al.* 2012). It is potentially relevant, therefore, that there was no association between positive distress scores on the DRT1 and a higher than

average NEWS score (indicating physiological discomfort) observed (p=0.36), and participants were also never reported to be in pain on days where distress was recorded.

Expansion

The economic impact of implementing the DRT is relatively low and involves only the cost of printing and training HCPs and carers. The time taken to complete the DRT is short, and the steps taken to help the person in distress should already be part of routine ward care, although may be employed more regularly.

6.7   Conclusions

The DRT in its current form was well received by both staff and the carers of people with dementia. Both groups recognised a need for such a tool and wanted it to be used in mainstream practice. However, several barriers to using it in its current format were identified. In particular HCPs struggled to complete the DRT2 as intended or transpose carers comments on the cDRT to the DRT1.

In Chapter 7, the final chapter of this thesis, following an overview of the whole project and its strengths and weaknesses, the DRT will be further reviewed and refined in an attempt to overcome these barriers. The chapter will then go on to examine how the tool can be further tested as part of the ongoing development process

Applying the DRT in a clinical setting

7.1   An overview of the DISTRESSED study

Dementia is common in older people admitted to general hospital (Sampson *et al.* 2009). People with dementia in hospital are susceptible to a range of common and uncomfortable symptoms, which if identified accurately can often be treated (Sampson *et al.* 2014; Sampson *et al.* 2015). Because people with severe dementia struggle to communicate verbally, symptoms can be difficult diagnose using traditional methods; for example, asking the patient for a verbal account of the experience. Clinicians should still strive to diagnose them, however, as untreated symptoms are generally uncomfortable and are associated with worse patient outcomes (Husebo *et al.* 2011; Sampson *et al.* 2015; Holmes and House, 2000), and are believed to cause distress (Regnard *et al.* 2003).

This study aimed to better understand areas of unmet symptom management facing those with severe dementia in hospital and explored strategies to improve this. This has been achieved using a four-phase mixed methods project.

Phase one, 'describing the population with dementia in a general hospital setting' was a record linkage study with retrospective case note review carried out between a large regional mental healthcare provider and the corresponding regional physical healthcare trust. By reviewing 116 patient records of people with known dementia admitted to the general hospital, the documented frequency of dementia, psychological symptoms, somatic symptoms, and delirium was described. Data on the documented use of symptom recognition tools, treatment algorithms and documented behaviour, or emotion indicating distress were also presented.

Following analysis of phase one data in the context of the existing literature, it was hypothesised that distress could potentially act as a universal sign, which if identified sensitively and reliably, might act as a trigger for the diagnosis and management of specific symptoms downstream using the existing, but underutilised systems. However, it was poorly understood how HCPs recognise distress in people with dementia in a hospital setting. Phase two, 'Describing the Barriers and

Facilitators for Distress Recognition' used the thematic analysis of semi-structured interviews with HCPs, to explore this.

The results of phase two, combined with existing theory on developing complex interventions, were used to design three prototype distress screening tools, which in phase three 'The Development of the DRT' were taken to focus groups of both HCPs and community carers of people with dementia.

The final DRT was refined and updated, and in phase four was taken to feasibility testing in its intended environment, that is, two hospital wards that care for older people. The tool was introduced into the routine care of 32 patients and its use, usability, and potential mechanisms of action were tested using mixed methods.

7.2   Summary of principle findings in the context of the existing literature

Phase 1: Describing the population with dementia in a general hospital setting

The prevalence of formally diagnosed dementia in patients over 75 admitted to the general hospital was around 15%. The diagnosis was documented in 74% of cases. The prevalence of documented psychiatric symptoms, pain and delirium was 10%, 37% and 11% respectively. There was no association between the documentation of dementia diagnosis, psychiatric symptoms or delirium and specialty of the team providing care or dementia severity.

Both dementia prevalence and reported symptom frequency recorded were lower than would be expected (Sampson *et al.* 2014; Inouye 1999; Sampson *et al.* 2015; Royal College of Psychiatrists, 2005). The discrepancy in dementia prevalence described is likely to be explained by both the large number of people with dementia who remain undiagnosed in the community (40%; NHS England, 2015), and the number of individuals whose community dementia diagnosis does not get communicated to the general hospital. Both reflect deficiencies in the current dementia care system in the UK and the national initiatives that are in place to try to improve this (NHS Commissioning Board, 2014).

The discrepancy between observed and expected symptom prevalence data may be generated by either an under recognition or reporting of symptoms in a hospital

setting. All previously published hospital symptom prevalence data is calculated using standardised symptom recognition tools on patients in hospital. While this is an adequate method for describing the true prevalence, it does not describe the frequency with which symptoms are actually reported and treated on hospital wards day to day. The difference between expected and observed prevalence is important because a discrepancy could indicate either a systems failure, or unmet patient need. It is of note, however, that documentation is only a brief reflection of the clinical picture. To gain a better understanding of the 'true' prevalence, a mixed methods approach including the observation all patient/HCP interactions would be more accurate, but this was beyond the practical confines afforded to this study.

Language describing a distressed patient state was documented once or more in 33% of cases. The language used was varied. Distress prevalence in dementia in a hospital setting has not previously been described, nor has the language commonly used to document in hospital records. Given the high prevalence of symptoms, one might expect a similarly high prevalence of distress, but this was not observed. The variation in language used to communicate distress between HCPs suggests a lack of shared communication systems. This could cause misunderstanding and potential missed opportunities for care provision (Leonard *et al.* 2004).

Despite dementia specific standardised symptom recognition tools, being available, and specific dementia treatment algorithms being recommended for people with distressing symptoms in the host hospital trust (Leeds Integrated Dementia Board, 2014) their use in clinical practice was never documented. No evidence exists to demonstrate the uptake of such tools in other healthcare systems.

Phase 2: Describing the barriers and facilitators for distress recognition

Within the population interviewed, distress was a universally recognised term. It was noted to be broad in its aetiology and presentation; however, participants believed it described a negative patient experience that requires assessment and treatment.

Participants believed that distress could be recognised innately by HCPs when observing a patient. However, recognition was enhanced by speaking to the patient, having dedicated time to observe the patient, staff motivation, the assessors level of clinical experience and familiarity with the patient. Ways of improving familiarity with

the patient included listening to the opinion of their usual community carers when they come to visit.

Staff felt more able to report distress where ward systems allowed open communication, and less able to report if they felt intimidated about misidentifying distress, or where no clear systems were in place to document and treat it. Distress was thought to be more likely acted upon if it was severe or causing risk. Assuming that a distressed state is normal for a patient was described as a potential cause for both under recognition and under reporting of distress.

The data presented in this study, was novel and specifically described the challenges of detecting distress in a busy hospital setting. However, the results resonate with studies that have demonstrated the accuracy of using non-verbal communication to recognise distress in similar patient groups who struggle to communicate verbally. (Bourbonnais and Ducharme, 2010; Hadjistavropoulos *et al.* 2000).

Phase 3: Development of the DRT

The DRTs developed in phase three were all designed to be simple, rely on the HCPs ability to recognise distress innately, and all involve input from the community carers of people with dementia when they visit the ward. Other novel aspects of the tools were that they were all designed to complement and be used as part of the existing ward NEWS observations system.

Two other standardised DRTs for use in dementia exist, the DS-DAT and the DisDAT (Regnard *et al.* 2007; Hurley *et al.* 1992). These tools differ in both design and implementation to the prototype tools described above. It is argued in Chapter 3 that there are design flaws in the usability of these tools in a busy hospital setting, namely, their ease of use and adaptability to existing ward systems. The data collected in phase two, suggested that HCPs believed they could recognise distress innately without the need for prompts, but required a system to report and escalate their concern.

When the prototype distress recognition tools were taken to focus groups, participants felt comfortable and competent completing all aspects of the tools presented, particularly the use of innate distress recognition. Participants felt the

layout for the tool, and using it as part of the existing ward NEWS system would improve usability and rate of completion. While HCP participants welcomed the tools use of innate distress recognition, they also wanted the more complex DRT (prototype number 3), to objectify their opinion in those deemed to be in distress.

Carers welcomed the opportunity to be able to contribute to the assessment process and it was suggested they should be given the opportunity to suggest solutions for helping the person with dementia as well. The feedback was analysed and informed the design of the final DRT, which consisted of 3 elements, that is, DRT1, DRT2 and cDRT.

Phase 4: Feasibility testing of the DRT in its intended environment

On testing in routine patient care the DRT was completed a modest amount; 0.9 times per patient per day by HCPs. Completion frequency was consistent throughout the study. When completing the DRT1 HCPs found it quick and easy to complete and believed it was an accurate screening tool and beneficial to patient care. DRT2s were completed far less frequently than indicated and completion errors were common. There were no associations between recorded distress and physiological discomfort (pain and high NEWS).

The cDRT completed less often and completion consistency was variable depending on carer involvement. It was completed on average 0.4 times per patient per day. Carers welcomed the opportunity to complete the cDRT, believed there was a role for it, but were suspicious that staff did not acknowledge their views. HCPs appreciated carer input and saw it as useful. However, carer opinions on the cDRT were rarely transposed onto the DRT.

These data suggest that the DRT is usable in its current environment and that both HCPs and carers see a need for it. However, there are some implementation, design and training issues that require improving, particularly for the cDRT and DRT2. No comparison data are available.

7.3   The strengths and limitations of the DRT in a clinical setting

In the UK, the current system for manging complex symptoms in dementia has observable failings, both suggested by this thesis and existing literature (Royal College of Psychiatrists, 2013; The Alzheimer's Society, 2009; Morrison and Siu,

2000). The solution is likely to be multifaceted, dependant on changing ward culture, staffing provision and improving staff skill. However, these all take time and have significant resource implications. This thesis argues that screening for common symptoms represented by the broad descriptor, distress, may be a way to improve symptom recognition, and has proposed a novel intervention, the DRT, to screen for distress regularly in all people with dementia in hospital.

In the United States and Europe it is estimated that between 30-50% of patients do not receive recommended interventions (Grol, 2001; Schuster *et al.* 1998).The success or failure of any intervention in healthcare is dependent on multiple factors: the general socio-political environment into which it is introduced, the characteristics of the intervention, the characteristics of the systems, and staff and management of the organisation adopting the intervention (Wisdom *et al.* 2014). The strengths and limitations of the DRT in the context of alternative tools and the challenges of introducing the DRT into healthcare settings will be the focus of this discussion.

Socio-political environment

The emphasis that society and the government places on dementia care and how dementia is viewed culturally is variable between countries (World Health Organisation, 2012). Within the UK, however, improving dementia care in hospitals is a priority (James Lind Alliance, 2017; Department of Health, 2015). This is positive, but unmodifiable in the context of this project.

Intervention characteristics

Intervention target

Screening is the process of identifying healthy individuals from a population who may have or be at risk of developing a disease or condition (Public Health England, 2015). In this instance, distress is the condition, and those with dementia the population. A diagnostic tool, differs as it is applied only to those where there is pre-existing clinical suspicion of the condition or disease. While the DRT is designed for use in a specific population only (those with dementia), it has not been described as a diagnostic tool as it is used regularly in all individuals regardless of a clinical suspicion of distress.

Public Health England (2015), recommend that when considering any screening tool, the condition screened for should be an important health problem, epidemiologically understood and that all cost effective primary preventions should have been undertaken, as far as possible, prior to the test. In the context of the DRT, distress is being used as a proxy or marker of possible underlying psychological symptoms, somatic symptoms, delirium or unmet needs. These are common, and if left untreated, can cause considerable discomfort and worse outcomes for the patient (Sampson *et al.* 2014; Sampson *et al.* 2015; Fick *et al.* 2002). A criticism of using distress in this context, however, is that although the prevalence of the main causes of distress are known, the prevalence of distress in hospital is unknown. It is presumed to be high, given the high symptom burden in dementia, but no formal testing has been reported, and furthermore, without psychometric testing of a distress recognition tool (such as the DRT or DisDAT), no validated tool exists to measure it.

Psychological symptoms, pain and delirium are common and it might be argued that they should be screened for individually using existing standardised symptom recognition tools, for example using the Abbey Pain Scale (Abbey *et al.* 2004), or the Cornell Scale for Depression in Dementia, (Alexopoulos *et al.* 1988). The drawbacks to these, and other such similar tools are that they require training and take a considerable length of time for the HCP to complete. An exception to this is delirium, whereby in some simple screening programmes are being introduced with relative success (Gesin *et al.* 2012; Healthcare Improvement Scotland, 2016).

Alternative descriptors for underlying discomfort could also be considered instead of distress; for example, agitation, refusal of care, shouting or aggression. These were all common phrases to describe patients in distress demonstrated in Chapter 2, Figure 2.3. The majority of these terms describe a hypoactive or hyperactive state only; none cover both simultaneously. For example, if HCPs screened all patients for aggression or agitation, those who were quiet and withdrawn, but equally distressed, may not be detected. HCPs interviewed in Chapter 4 believed distress described both a hypoactive and hyperactive state.

A further consideration is deciding which population to apply the DRT to. Around 50% of people with dementia in hospital are likely to be undiagnosed (Sampson *et al.* 2009), however their symptoms and care needs are no different from an individual with a formal dementia diagnosis. Likewise, people with dementia in

hospital are not exclusive in their communication needs; people with severe learning disabilities, dysphasia, severe delirium or who are sedated also have potential difficulty communicating verbally. Limiting the DRT to those with dementia is potentially denying others access to a beneficial care tool. If the DRT is a valid and reliable intervention, consideration of which groups to apply the DRT to needs to take place.

Understanding distress

Distress is an individual experience, the interpretation of it may differ between people, meaning distress severity, intensity and frequency are dependant not only on the stimulus, but also the person. Furthermore, as people with severe dementia are unable to reliably communicate their experience, it is unknown whether they experience and respond to distress differently from people without dementia. It is assumed that the experience is uncomfortable (Regnard *et al.* 2003; Kovach *et al.* 1999).

HCPs and carers interviewed as part of this study all believed they could accurately identify a person in distress, but whether this is reliable is highly questionable. Being able to interpret others' emotional need is a hallmark feature of empathy (Halpern, 2003), and those in a caring profession may wish to see themselves as empathetic, but this does not mean that they are. A way of trying to overcome this is to prompt assessors to look for specific distress cues such as grimacing or guarding (Kovach *et al.* 1999). Other distress screening tools (the DisDAT and DsDAT) adopt this method (Regnard *et al.* 2007; Hurley *et al.* 1992). By asking HCPs to do this may help them recognise subtle signs of distress and improve the sensitivity of the tool. It may also be argued, however, that this method asks HCPs to spend time on a task they do innately anyway. By directing HCPs to look for predefined markers of distress also potentially limits the range of observable signs, reducing the adaptability of the tool. A future area of work, however, would be to conduct psychometric testing and further feasibility trials of comparing the DRT against the existing tools, to contrast performance and use.

Distress is non-specific

Distress is broadly defined (Oxford English Dictionary, 2013), and can be caused by an almost infinite number of situations; for instance, a person could be equally distressed because they are in severe pain or because their daily routine has been

changed. The observed behaviour and emotion in response to both scenarios could be the same. A criticism of measuring distress in dementia is that tools are merely measuring common symptoms and therefore, specific symptom recognition tools for these symptoms should be used instead (Jordan *et al.* 2012; van der Steen *et al.* 2015). In Chapter 2, however, it was observed that symptom recognition tools were not being used in the cohort studied suggesting either a lack of staff knowledge or barriers to the implementation of the tools. When this was explored in greater detail in Chapter 4, HCPs believed that identifying individual symptoms was too complex a task for all ward staff and no participants were aware of any standardised symptom recognition tools in dementia in current use.

Defining distress severity

When a person is admitted to hospital it is usually because they are acutely unwell or an illness is preventing them from functioning safely in the community. In many cases patients are experiencing uncomfortable symptoms such as pain, nausea or dyspnoea. The person is away from their home environment, and in the case of people with dementia, they may well struggle to orientate and adapt to their surroundings. With this in mind, it might be expected that every person experiences some distress during their stay. Not all of these distress events are severe and it might be argued that not all are worth the resources, or potential disruption caused by investigation or treatment.

In medicine, most treatment decisions are weighed up by considering the risk caused by the treatment, against the potential benefit of the treatment. For example, in a person with carotid artery occlusion of greater than 70%, the risk of stroke without surgery is greater than the risk caused by the surgical procedure used to treat it, so the operation is performed (Warlow, 1991). These figures are based on evidence derived from randomised control trials. How and when to treat distress is less well defined and indeed, cannot be defined with quantitative parameters. Each situation needs to be individually weighed up considering the patient, the environment, the cause of the distress, and the available treatments. The point at which distress is severe enough to be recorded on the DRT1 or cDRT was left deliberately open to take this into account. When the HCPs were questioned about this in Chapter 4, they unanimously believed they "just knew'" when someone was in distress and when action was required.

The DRT2 does try to define the point at which distress should be investigated and treated. Its aims are twofold: to help the HCP demonstrate why they believe the person they are caring for is, or is not, in distress and to provide an estimation of the distress severity. The numbering system and cut off point of 5 is arbitrary. However, it can be argued using any such numbering system is indeed a contradiction, as a major premise of the tool is that is utilises innate distress recognition.

The numbering system of the DRT2 was first conceptualised because of its similarity with the NEWS charts and it was believed it would help users to clarify the decision-making process. HCPs in focus groups and during stakeholder feedback felt the numbering system was useful, perhaps because it is directive, or reassuringly similar to other systems they are used to.

The accuracy with which the DRT, cDRT or DRT2 measure distress is unknown. As there are no validated gold-standard tests to compare reliability, validity, sensitivity and specificity against, any future psychometric testing of the DRT will be against expert opinion.

Social and cultural influences on distress recognition

Because the DRT relies on innate distress recognition, it is susceptible to social influence. The person completing the DRT is acting within a ward environment, they are likely to be influenced by this and the opinions of colleagues. To underestimate the influence of these would be a fundamental attribution error (Smith *et al.* 2003).

Where distress or behaviour associated with distress is very common on a ward, HCPs may become desensitised to it (Jones, 1924). A level of distress may be seen as 'normal', whereas for the patients and their carers it is anything but. This was a phenomenon identified by HCPs in Chapter 4 and one which is also well described in the published literature (Greenwood, 1993). Because of this, on wards where HCPs have a high tolerance of distress, the DRT may be less sensitive. Safeguards to overcome this are the use of the DRT2 to objectify opinion and the use of the cDRT, using the carer as an independent witness of distress. The carer in this instance is less likely to be influenced by ward culture, at least in the initial stages of the admission. However, the converse may also be true. For example, a carer may have become desensitised to chronic distress at home, this will then continue when they come to hospital, making the HCPs a potentially more sensitive arbiter of distress.

The 'bystander effect' is a social phenomenon describing how passers-by are less likely to offer help to an individual in need if others are present (Latane and Darley, 1968). On a hospital ward, designed to be a caring environment, it is hoped that an individual in need is recognised. However, if everyone in a group misleads one another, by defining a situation as less important that it is, or assuming that someone else is looking after that person they maybe become ignorant to an area of need (Miller and McFarland, 1987). The DRT asks individuals to answer individually, rather than act as a group. However, if all staff members and carers believe an individual is not distressed daily, and record their opinion as such, subsequent assessors may be influenced by this and may conform to the majority. This effect may have a greater significance if senior HCPs are observed by more junior members of staff recording that a person is or is not in distress (Milgram, 1963). Using the usual community carers of patients to comment on the presence or absence of distress, attempts in part to overcome this, increasing the accountability of HCPs for their decision and getting fresh perspectives. However, these assessors may be equally susceptible to similar social pressures.

Intervention design

If distress is selected as an appropriate sign to screen for in this setting, as a minimum the proposed intervention should be simple, safe, validated, and the results should be available in a timely fashion with an agreed policy on how to investigate individuals with a positive result (Public Health England, 2015). In a review of innovation adoption Wisdom *et al*. (2014) surmise that to improve the chances of the intervention being used, it should be clear in purpose, simple, advantageous over current practice, need minimal skill to apply the tool, observable, transferable, cost effective, evidence based, and complement practice and users norms.

Including the DRT, there are three known distress screening tools. The DS-DAT and DisDAT are potential alternatives to the DRT and these are described in detail and critiqued in Chapter 3 (Regnard *et al.* 2007; Hurley *et al.* 1992). Like the DRT, both tools screen for distress in people with difficulty communicating verbally with the aim of improving recognition rates. In contrast to the DRT, these tools are implemented ad hoc on an individual basis and encourage staff to look for specific distress cues. Nether the DS-DAT nor DisDAT have been designed or tested in an acute hospital setting for use in dementia. The DS-DAT has no published feasibility

data on the ease of use or time take to completion, but there are 9 domains to complete, similar to the DisDAT. The DisDAT also requires a baseline assessment at comfort, which may be hard to achieve in a hospital setting.

The major drawbacks to both the DS-DAT and DisDAT for use in an acute hospital setting are their practical application. Both take considerable resources to complete them, and have significant drawbacks in how they are applied practically, particularly the need for obtaining a baseline assessment with the DisDAT.

The DRT is shorter as it uses innate distress recognition and is also intended to be used routinely for all patients with dementia, complementing existing systems. By doing this, it is intended that the DRT is fit for its intended environment and therefore, used frequently allowing a greater number of patients to be screened. It is also hoped by making use routine, HCPs become more aware of distress, changing ward culture as the concept is reinforced and discussed regularly (Smith *et al.* 2003). The potential payoff for the DRTs brevity compared to its more complex counterparts (DS-DAT and DisDAT), are reduced sensitivity. No psychometric data for any of the tools is published, however, and no head to head comparisons of the tools have been made. To justify the selection of one tool over another, and to provide an evidence base, a comparison of both their ease of use in a clinical setting, reliability and validity should be made. This is an area for further work.

A potential limitation in the design stage of the DRT was not seeking feedback from focus groups on the DisDAT or DS-DAT for comparison. If greater resources had been available, the tools could also have been feasibility tested on the wards and performance could be compared.

Intervention outcomes

For any screening intervention to be successfully adopted there should be an effective intervention for patients identified with the condition. Evidence should be obtained from high quality randomised control trials that the programme is effective in reducing morbidity, mortality or improving quality of life. There should also be evidence that the programme is clinically, ethically and socially acceptable to clinicians and the public (Public Health England, 2015).

In this instance, distress is being used as a proxy for psychological symptoms, somatic symptoms and delirium in dementia, which are common, and have the

potential to cause patient harm when untreated (Sampson *et al.* 2015; Holmes and House, 2000; Nightingale *et al.* 2001). In feasibility testing, the DRT was acceptable to HCPs and patients' carers. It is unknown if it is acceptable to patients and this was not tested because the majority of participants lacked capacity to provide feedback.

The treatments available for distress are debatable. To treat distress the stimulus causing it needs to be removed. This can be as simple as responding to a person's hygiene needs, or it could be a complex pharmacological intervention such as diagnosing hallucinations and prescribing antipsychotic medication. There are some instances where the distress does appear intractable, even in these instances medication can be prescribed, however, creating some benefit, albeit only short term (Rayner et al. 2006).

Because some causes of distress are difficult to diagnose and treat, treatment algorithms exist. These generally rule in or out potential causes of distress and treat them accordingly. The general principle of using treatment algorithms are recommended (Salzman et al. 2008), and the treatments and strategies they recommend should be individually evidence-based (Leeds Integrated Dementia, Board, 2014); however, no single algorithm has a specific efficacy figures. A clearer evidence base on the efficacy of using a specific treatment algorithm would help to support the argument for using any future versions of the DRT in clinical practice.

Characteristics of the systems, staff and management of the organisation adopting the intervention

Implementing a new intervention, such as the DRT, on a hospital ward requires changing existing systems and procedures (Donabedian, 1980), then having the staff adopt the changes under the leadership of senior management. In this instance, it would be a requirement that the DRT was physically introduced into the hospital observation chart (system) and for staff to use it regularly as part of the observations procedure.

Ward systems

Interventions are more likely to be successfully implemented in environments whereby staff have good pre-existing knowledge and skills, and in systems that have capacity to accept change (Aarons *et al.* 2011). Hospital systems and the daily

running of a ward are variable, and are dependent on the speciality providing care and routine ward activities. Some aspects of care in the UK are largely universal, however, and include taking physical observations and the subsequent recording of them on the NEWS chart (Royal College of Physicians, 2015). Interventions that contribute to the restructuring of practice, rather than introducing new practice have a greater chance of success. The conditions in which the intervention is applied, further make it more or less likely to be adopted (Johnson and May, 2015). These conditions include HCPs having adequate time and resources to carry out the intervention, and the intervention being made a priority.

One of the major advantages of the DRT over other standardised symptom recognition tools in dementia, is its integration with the NEWS chart, complementing existing ward systems. Because completion of the NEWS is a mandatory task, incorporating the DRT into it, is likely to improve completion, even though DRT completion is not mandatory. The colour scheme and layout of the DRT also deliberately match those of the NEWS chart so that the intervention is familiar and simple.

The aspects of the tool, which were less familiar to HCPs, more time consuming and more complex, the cDRT and DRT2, were less well used. Both the DRT2 and cDRT require a change in ward culture, that is, staff remembering to, and trusting the importance and reliability of the carers opinion. This poses significant implementation challenges, which require training, reinforcement and championing by ward leaders.

HCP characteristics

Changing the behaviour and practice of HCPs is difficult (Eccles *et al.* 2005). Barriers to implementing change include a lack of awareness of the intervention, lack of belief the intervention will work, staff not understanding or having the skill to implement the intervention, or a belief that the intervention undermines staff authority (Cabana *et al.* 1999). The intervention is more likely to be implemented into routine care if feedback is given to staff on its use and effectiveness (audit) (Greenhalgh *et al.* 2004).

When implementing the DRT, staff readily accepted the aspects of the tool they were used to, the DRT1, but completion and feedback for the more complex novel aspects of the tool, the DRT2 and cDRT were less positive. The cDRT introduces

new methods of assessment, using family and community carers to contribute to ward assessments. The accuracy and benefit of this is (currently) untested. The carers ability to assess distress may be both inaccurate and influenced by alternative agendas, such as family dynamics or the relationship between family members and ward staff.

Although all HCPs interviewed, both in focus groups and in feasibility testing believed that having the opinion of the dementia patient's carer was beneficial and useful, it must be considered whether this is the socially desirable answer, but one that does not readily translate into clinical practice. This was reflected in the responses given by carers both in the focus group and during feasibility testing feedback, perceiving that staff did not listen to or note their opinion. During feedback carers interviewed suggested that HCPs should sign the cDRT to demonstrate they had read and acknowledged it.

Changing this practice and improving communication between HCPs and carers will require a significant change in culture over time. Changing culture is extremely difficult, particularly in an organisation the size of the NHS (Scott *et al.* 2003). However, on wards that are already used to caring for people with dementia this may be easier, enabling staff to practice what is already desired; a change in culture, rather than a change of culture (Scott *et al.* 2003). It can be argued that attitudes towards dementia care are already changing because dementia friendly wards are now common place (The Kings Fund, 2014), and national dementia initiatives are becoming more visible (The Alzheimer's Society, 2010). Changing culture in this environment, therefore, should be a question of using this existing momentum (Scott *et al.* 2003).

In the short time that the DRT was used on the wards, staff reported that they had observed an increased awareness of distress, and the topic of distress was discussed regularly in patient safety meetings. Sustained change requires leadership and ongoing momentum (Scott *et al.* 2003). If the intervention or any similar intervention is going to have any impact on ward culture and attitudes, strong leadership and permeant reminders (such as patient safety meeting agendas) will be essential, so that it becomes engrained into normal thinking.

Management and ward culture

Organisations where staff collaborate and leaders champion change and innovation are more conducive to the successful adoption of new interventions (Wisdom *et al.* 2014). Promoting shared professional values, patient centeredness, and a positive learning and research environment are also believed to be beneficial (Wisdom *et al.* 2014). A lack of resources, formal training structures and a fear of change are negatively associated with the successful adoption of intervention (Greenhalgh *et al.* 2004; Aarons *et al.* 2011). Furthermore, organisations or systems that do not allow staff to deliver perceived high standards of care can be demoralising leading to lower standards of care provision (Tadd *et al.* 2011)

In the UK, hospital ward culture, leadership models and systems vary from hospital to hospital, and vary between different specialities. The transferability of feasibility data between the test wards to other ward environments therefore is limited. The DRT was implemented on a ward specialising in healthcare for older people; one might assume, therefore, that staff are more experienced in managing dementia. The ward - as is the case with many hospital ward environments - was busy (NHS Digital, 2017), and the capacity for accommodating change and adopting new skills was therefore potentially limited.

A busy resource limited environment is a common theme on most UK hospital wards (NHS Digital, 2017; Royal College of Nursing, 2011b). Introducing any system that creates extra workload and paperwork for HCPs can be met with opposition, but it is more likely to be successful if relevant education is provided to individuals and groups, implementing ward champions for the intervention, making the intervention part of local of national regulation and by providing organisational support and time for the intervention (Robertson and Jochelson, 2006, Tadd *et al.* 2011). HCPs are also more likely to use the tool if it is clearly demonstrated to be beneficial either to patient care or ward efficiency.

While the DRT was perceived as quick and easy to use, the DRT2 and cDRT were not as well used. And although the DRT was felt easily usable by the HCPs on the test wards introducing the DRT or any similar tool in wards with less existing knowledge of dementia may prove challenging.

When the DRT was introduced, ward leaders supported its use and in the initial stages of the study raised awareness of the tool, HCPs also received regular reminders to use it initially with repeated training sessions in patient safety meetings. The speciality of the ward it was introduced in, enthusiasm of the team leaders for its introduction, and presence of the researcher on the ward, meant that conditions for regular use for the DRT were ideal. It is not clear whether the level of DRT use observed would be sustainable if it was part of regular ward use. Strategies that might improve sustained behaviour change include introducing the DRT as regular agenda in ward safety meetings. These meetings are led by senior HCPs, therefore, providing leadership on the intervention and regular reminders. How the DRT is accepted and used on wards that are less receptive to change, and less enthusiastic about dementia care is unknown. Feasibility testing the DRT in this environment could provide useful data on this and is an area of potential further work.

7.4   Conclusions and further work

By all predictions, dementia is likely to be an ongoing and increasingly prevalent syndrome effecting older people (Ferri *et al.* 2005). The need for providing good quality hospital care to this population is paramount; this study has suggested areas for improvement, explored how existing systems might be modified to do this, and suggested a screening tool as a potential way to improve care.

The DRT that has been developed and feasibility tested is by no means a sole solution for the challenges faced by people with dementia in a hospital setting. It aims to be an intervention that can go some way to raising staff awareness of distress and improve the rate of identification of patients who maybe suffering unnecessarily, if used as part of existing ward systems and treatments.

The advantages of the tool are its simplicity, ease of use, and implementation. It is, however, a blunt instrument measuring a poorly defined phenomena. If the DRT does accurately identify distress, it could have a beneficial clinical role to play by allowing more people to access appropriate care.

After refining of the tool using data from the feasibility study and further focus groups, it is hoped that psychometric testing of the tool can take place. As there are no exiting validated tools to test the DRT accuracy will be measured against expert

opinion. It is proposed that the DRT and separately the individual components of it (DRT1, DRT2 and cDRT) be applied regularly by HCPs on a random sample of patients with dementia in a hospital setting. The same patients would then immediately be assessed for distress by an expert (old age psychiatrist, elderly medicine physician or senior nurse). The results of the DRT would be compared against expert opinion and between assessors to test construct validity, internal consistency, interrater reliability, test-retest reliability, sensitivity, specificity, false positive rate and false negative rate of the DRT and it's individual components. In order to demonstrate any difference in psychometric properties between the DRT and existing distress tools, it is also proposed that the DissDAT be applied to the same cohort simultaneously and results compared.

If the DRT is demonstrated to be adequately reliable and valid, it's effectiveness will be tested in a randomised control trial, measuring the differences in outcomes of patients with the DRT in use against usual care.

Appendices

Appendix 1 - Search strategy for identifying standardised tools for the assessment of distress in dementia.

Inclusion criteria:

Any controlled trial pertaining to the development of a standardised tool for the recognition of distress in those with severe dementia.

Exclusion criteria:

Trials of tools measuring pain, behaviour, or symptoms associated with distress in dementia.

Trials of tools measuring distress in people with mild or moderate severity dementia.

Papers for this review were searched for using OVID with the following electronic databases: PsychINFO, PsychArticles, EMBASE and MEDLINE.

Search terms:

Search one: dementia.

Search two: a) distress, b) discomfort. These search terms were combined using the Boolean term *or*.

Search three: assessment.

The results of the three aforementioned searches were then combined using the Boolean term *and*. The search was limited to English language articles, and duplicates were removed.

Ongoing trials were also searched for using the clinical trials database.

1479 articles were identified and searched by hand for relevance. The search revealed two distress recognition tools; the 'Disability Distress Assessment Tool' (DisDAT) (Regnard *et al.* 2007), and the 'Discomfort in Dementia of the Alzheimer's type' (DS-DAT) scale (Hurley *et al.* 1992).

Appendix 2 - Questionnaire for medical notes review.

Study ID number _____   Age _____   Ward number_____

 Speciality of ward_____

Is there a dementia diagnosis documented in medical notes?

Yes   No

a) Is the dementia sub-type documented?   Yes   No

     If yes what was it?_____

b) Is the dementia severity documented?   Yes   No

     If yes what was it and what were the reasons given for severity classification?

---

1) **What was the Primary reason for the admission?_____**

     _____

2) **What other co-morbid medical disorders are documented?**

Co-morbidity	Present Y/N
Myocardial Infarction	
Congestive Heart Failure	
Peripheral Vascular Disease	
Cerebrovascular Disease	
Dementia	
COPD	
Connective Tissue Disease	
Peptic Ulcer Disease	
Diabetes Mellitus	
Moderate to Severe Chronic Kidney Disease	
Hemiplegia	
Leukemia	
Malignant Lymphoma	

Solid Tumor	Metestatic	Non metestatic
Liver Disease		
AIDS		

(Charlson co-morbidity index (Charlson 1987))

3) What other major co-morbid psychiatric disorders are documented?

Diagnosos	Present Y/N	
Depression		
Anxiety		
Bi-Polar		
Schizophrenia		
Psychotic disorder NOS		
Personality disorder	Type	
Drug dependence	Substance	
Alcohol dependence		
MCI		
Other		

4) What was the total length of the admission (days)?_____

5) Does the patient have a documented diagnosis of delirium in the medical notes?   Yes   No

6) Which of the following psychiatric symptoms were documented during the admission?

Symptom	Severity	Symptom investigated?	Symptom minimised/ treated?	Specialist services required?
Depression/Dysphoria				

Anxiety				
Elation/Euphoria				
Hallucinations				
Delusions				
Other (specify)				

7) **Which of the following somatic symptoms were documented during the admission?**

Symptom	Severity	Symptom investigated?	Symptom minimised/treated? How and with what result?	Specialist services required?
Pain				
Nausea				
Functional loss (motor/ sensory /speech)				
Sensory impairment				
Incontinence				
Constipation				
Dyspnoea				
Hunger				
Thirst				
Other (specify)				

8) **Is there documentation to indicate the patient is in distress?**

If yes, describe any documented observations of the patients appearance or behaviour to indicate distress.

Appearance	Documented evidence Y/N	language used to document behaviour
Facial appearance		
Grimace		
Frown		
Startled		
Frightened		
Sad		
Angry		
Other		
Jaw Movement		
Grinding		
Biting		
Rigid		
Other		
Appearance of eyes		
Little eye contact		
Avoiding contact		
Closed eyes		
Tearful/crying		
Other		
Skin Appearance		
Pale		
Flushed		
Sweaty		
Clammy		
Other		
Vocal sounds		

Crying out		
Wailing		
Shouting		
Screams		
Muttering		
Other		
Speech		
Loud		
Soft		
Whispering		
Fast		
Slow		
Other		
Body Posture		
Rigid		
Jerky		
Tense		
Floppy		
Restless		
Other		
Appetite		
Increased		
Decreased		
Sleep		
Increased		
Decreased		

(Adapted from the disability distress assessment tool DisDAT. ((Regnard *et al.* 2007))

Behaviour	Documented	Frequency.	language

	Y/N							used to document behaviour
		<1/52	1-2/52	2-6/52	1-2/7	2-23/7	>1/hr	
Pace, aimless wandering								
Inappropriate dress or disrobing								
Spitting (include at meals)								
Cursing or verbal aggression								
Constant unwarranted request for attention or help								
Repetitive sentence or questions								
Hitting (include self)								
Kicking								
Grabbing onto people								
Pushing								
Throwing things								
Strange noises (weird laughter or crying)								
Screaming								
Biting								
Scratching								
Trying to get to a different place (eg out of the room,								

building)			
Intentional falling			
Complaining			
Negativism			
Eating/drinking inappropriate substances			
Hurt self or other (cigarette, hot water etc)			
Handling things inappropriately			
Hiding things			
Hoarding things			
Tearing things or destroying property			
Performing repetitious mannerisms			
Making verbal sexually advances			
Making physical sexual advances			
General restlessness			

(Adapted from the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, Marx and Rosenthal 1989))

1) **Was treatment of distressing emotions or behaviours attempted?**
      Yes   No
2) **Was the patient referred to psychiatric liaison team?**   Yes

    No

3)   Was the Distress in Dementia Pathway for Managing Behavioural and Psychological Symptoms in Dementia used?

   Yes   No

Appendix 3 - Healthcare Professional Participant Information Sheet.

Participant Information Sheet (Version 4)

Research title: Dementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Contact t: 07703288239 email: hssgcr@leeds.ac.uk

Project supervisor: Dr John Holmes, Senior Lecturer, Old Age Psychiatry. Contact – email: j.d.holmes@leeds.ac.uk

LTHT R&I number: LP15/234   **Research   ethics   committee   approval number:** SoMREC/14/094

Description: You are invited to participate in a research study that aims to explore how distress and symptoms that cause distress in people with dementia are recognised and reported on general hospital wards. It is hoped that this work will go on to improve the systems by which those with dementia in distress are detected, so that they can receive treatment and suffering can be reduced.

This study is being conducted by the principal investigator Dr George Crowther, and forms part of a postgraduate degree research project at the University of Leeds. The University of Leeds Research Ethics Committee and the Leeds Teaching Hospitals Trust Research and Development Department have approved it.

Procedures: With your permission we would like to collect information about; your understanding of distress and the symptoms that cause distress in people who have dementia, how a distressed individual is recognised on the ward, and what systems are in place for reporting distress to colleagues so the sufferer can be treated. This will involve attending a one to one interview, which will aim to gather your opinions on these topics. The interview style will be relaxed to allow you to speak freely about these topics. So that your opinions can be accurately recalled the interview will be audio recorded on a dictaphone and the interviewer may take some notes as you speak. After the interview the recording will be stored as a password protected audio file on the PI's password protected drive on the University of Leeds secure server. It will be deleted from the dictaphone device at the earliest possible opportunity (at latest, the evening of the day of recording). All the interviews will then be transcribed in full. The interview will be transcribed, to enable the principal investigator to recall, recognise and understand your opinions after the interview has finished.

Multiple interviews will be conducted, with varying HCPs all following the same structure. After all of the interviews are completed the opinions and comments will be collated so that common themes can be recognised, and suggestions can be made that might improve patient care.

Your confidentiality: All of your responses will be kept confidential. Any personal details provided will be kept separately from the audio recordings and recording transcriptions. Any person identifiable data on the audio recording (for example the ward you work on, or position you hold within the hospital), will be deleted from the transcript at the point of transcription. Once the audio recording is transcribed it will

be kept only in a password protected file on the secure University of Leeds server, accessible only to Dr Crowther.

All electronic data (transcriptions etc.) will be kept in a password protected file on the secure University of Leeds server. Any written data (for example the consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project written and electronic data will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will disseminated so that others can benefit from the knowledge acquired. This will be done via posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. As part of this process the principal investigator may wish to use opinions expressed in the interview or direct quotes taken from the interview. Any information used will be anonymised and your personal details will never be published.

Others confidentiality: At times in the interview you may wish to, or be invited to discuss specific cases that help illustrate your opinions. In this instance please do not to disclose any information that could potentially identify a person with dementia or their carer. If during the interview identifiable information is disclosed then the interview will be paused and the audio recording wound back to before the identifiable information was disclosed. You will be asked not to use the identifiable information again, before we continue. The identifiable information will be recorded over, thus deleting it. If patient identifiable information is only discovered on transcription it will be removed from the transcript. In this instance you will not be informed of any removal of information.

Risks to participants: There may be instances where you discuss times you have recognised patients' suffering, but have been unable to help for one reason of another. This is a potentially upsetting topic. If at any time you become upset during the interview, you will be asked whether they would like the interview to be continued, paused or terminated. In either instance you will be invited to debrief with the PI after the interview. The PI has experience working with people with dementia and in training hospital staff to care for people with dementia.

No details given in the interview will be disclosed to others or published in a form that can identify you. However if you reveal something that suggests that a vulnerable person or persons may be in imminent danger, or you reveal historic acts of abuse or willful neglect then your clinical manager will be contacted so that appropriate action can be taken. This will only ever be done with your prior knowledge.

Time commitments: The interview will be conducted by the principal investigator and will last between 30-60 minutes.

Interview location: The interview will take place at either St James's University Hospital, Leeds General Infirmary or The University of Leeds. The location can be chosen by yourself dependant on which is the most convenient. Your chosen location will be confirmed at least one week before the interview date.

Payments: You will not be paid to take part in this study.

Participants rights: It is your decision whether you chose to take part in this study or not, participation will not affect your employment rights. Your consent to participation can be withdrawn at any time up to, during or after the interview, until the time analysis has begun. To withdraw from the study please contact the principal investigator at any time using the details below. Once you have been withdrawn from the study, all audio recordings and transcriptions and transcription notes that you have contributed to will be deleted. It will be noted on your consent form that you have chosen to withdraw, the date of withdrawal and the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 4 - Distressed barriers and facilitators study, Healthcare Professional consent form.

The DISTRESSED Study, Participant Consent Form (Version 4).

Research title: Dementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Contact t: 07703288239 email: hssgcr@leeds.ac.uk

Project supervisor: Dr John Holmes, Senior Lecturer, Old Age Psychiatry. Contact – email: j.d.holmes@leeds.ac.uk

LTHT R&I number: LP15/234

Research ethics committee approval number: SoMREC/14/094

Please read 'The DISTRESSED study Participant Information Sheet (version 4)' before continuing with this form.

Key point summary of the project:

- Interviews will be informal and will explore your understanding of distress and the symptoms that cause distress in people who have dementia and how a distressed individual is recognised on the ward.
- Interviews will be held at a hospital or university location convenient to you, and will take 30-60 minutes.
- Every precaution will be taken to protect your confidentiality at all times.
- If you disclose information that suggests a vulnerable person or persons may be in imminent danger, or you reveal historic acts of abuse or willful neglect then your clinical manager will be contacted. This will only ever be done with your prior knowledge.
- Please refrain from disclosing any identifiable patient information.
- If at anytime you are distressed by the interview content a formal debrief will be available to you.
- You may withdraw from the study at any time until analysis has begun.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the participant information sheet. A copy of the signed and dated consent form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet (version 4)

	Initial
I confirm that I have read and understand the DISTRESSED Study participant information sheet (version 4), explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis has begun without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. If I choose to withdraw I can contact the principal investigator on georgecrowther@nhs.net . Any data I have provided will be destroyed as set out in the Participant Information Sheet (version 4)	
I agree to participate in The DISTRESED Study interview as set out in the participant information sheet (version 4)	
I agree for the interview to be audio recorded, transcribed and stored as set out in the DISTRESSED Study participant information sheet (version 4).	
I understand and agree that if I disclose information that suggests a vulnerable person or persons may be in imminent danger, or I reveal historic acts of abuse or willful neglect then my clinical manager will be contacted. This will only ever be done with my prior knowledge	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree for the data collected from me to be stored and used in relevant future research.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.

Appendix 5 – Distressed barriers and facilitators study, topic guide

Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study.

Semi-structured interview; topic guide.

<u>**Aim:**</u>
To observe why reported psychological symptoms and distress in people with dementia on general hospital wards are lower than expected.

<u>**Topic guide:**</u>
1. **What do you understand by the term distress?**
2. **What is distress?**
3. **What does it look like?**
4. **Does it present in different ways?**
5. **Is it easy to recognise, can everyone do it?**
6. **What training do you need?**
7. **Is experience helpful?**
8. **Do you think that people with dementia commonly experience distress?**
9. **What do you think causes distress in people who have dementia who are on a hospital ward?**
10. **What systems are currently in place for helping to recognise the person in distress?**
11. **If you or your colleagues thought that someone with dementia on the ward, what would you do about it?**

    Table 1.
12. **In a recent study it was demonstrated that the frequency of documented symptoms that one might associate with distress in people with dementia in hospital is lower than expected, why do you think this is?**
13. **What language is used to describe distress?**
14. **What systems are in place for documenting distress and getting help for the individual.?**
15. **How can people with dementia in distress be helped on a general hospital ward?**
16. **What do you perceive as barriers to distress recognition and reporting in people with dementia on hospital wards?**
17. **What training, procedures or systems do you think would help improve distress reporting and recognition?**

Table 1: A table to demonstrate the difference between documented and observed symptoms in people with dementia on general hospital wards.
.

Symptom	Predicted symptom frequency (%).	Documented symptom frequency (%).
Pain	**53.7**	**37.7**

Depression/low mood	**33.5**	**4.3**
Anxiety/Worry	**35.2**	**2.6**
Hallucinations	**14.8**	**4.3**
Delusions	**11.3**	**2.6**
Agitation	**56.5**	**11**
Activity disturbance	**43.9**	**-**
Distress	**-**	**33**
Delirium	**66**	**11**

Appendix 6 - Distress recognition tool focus groups with healthcare professionals, participant information sheet.

Healthcare Professional Participant Information Sheet

Research title: **D**ementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study, Focus Groups.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Contact t: 07703288239 email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

LTHT R&I number: LP16/84687   **Research ethics committee approval number: MREC 15-128**

Description: You are invited to contribute to a focus group that aims to get your feedback on a proposed new diagnostic tool, to help recognise distress in people with dementia when the are in hospital. It is hoped that this tool can then be refined before undergoing initial tests to check its usability and effectiveness.

This study is being conducted by the principal investigator Dr George Crowther, and forms part of a postgraduate degree research project at the University of Leeds. The University of Leeds Research Ethics Committee, NHS Research Ethics Committee and the Leeds Teaching Hospitals Trust Research and Development Department have approved it.

Procedures: Using staff opinion and experience in LTHT we have developed a very simple screening tool (see overleaf), for all staff to use on a regular basis to help identify people in distress who cannot communicate their need effectively due to dementia. This tool us used primarily by ward based healthcare professionals, but there is an element of it which we propose will be completed by the persons usual carer when they visit. With your permission we would like to know your opinions on the good and bad points about this tool so that it can be improved. This will involve attending a focus group that will be held immediately after the morning ward meeting. The focus group will be relaxed to allow you to speak freely. So that your opinions can be accurately recalled the interview will be audio recorded on a Dictaphone and the group leader may take some notes as you speak. After the focus group the recording will be stored as a password protected audio file on the PI's password protected drive on the University of Leeds secure server. It will be deleted from the Dictaphone device at the earliest possible opportunity (at latest, the evening of the day of recording). The conversations from the focus group will then be transcribed in full, to enable the principal investigator to recall, recognise and understand your opinions after the interview has finished.

Focus groups with varying healthcare professionals and the carers of people with dementia will be held, all following the same structure. After the focus groups are completed the opinions and comments will be collated so that common themes can be recognised, and suggestions can be made that might improve the tool.

Your confidentiality: All of your responses will be kept confidential. Any personal details provided will be kept separately from the audio recordings and recording transcriptions. Any person identifiable data on the audio recording (for example the ward you work on, or position you hold within the hospital), will be deleted from the transcript at the point of transcription. Once the audio recording is transcribed it will be kept only in a password protected file on the secure University of Leeds server, accessible only to Dr Crowther.

All electronic data (transcriptions etc.) will be kept in a password protected file on the secure University of Leeds server. Any written data (for example the consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project written and electronic data will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study combined with future work will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. As part of this process the principal investigator may wish to use opinions expressed in the focus groups or direct quotes taken from the groups. Any information used will be anonymised and your personal details will never be published.

Others confidentiality: At times in the focus group you may wish to discuss specific cases that help illustrate your opinions. In this instance please do not to disclose any information that could potentially identify a person with dementia or their carer. If during the focus group identifiable information is disclosed then the session will be paused and the audio recording wound back to before the identifiable information was disclosed. You will be asked not to use the identifiable information again, before we continue. The identifiable information will be recorded over, thus deleting it. If patient identifiable information is only discovered on transcription it will be removed from the transcript. In this instance you will not be informed of any removal of information.

Risks to participants: There may be instances where you discuss or recall times you have recognised patients' suffering, but have been unable to help for one reason of another. This is a potentially upsetting topic. If at any time you become upset during the focus group, you will be asked whether you would like continue with the group or leave a little early. In either instance you will be invited to debrief with the PI after the interview. The PI has experience working with people with dementia and in training hospital staff to care for people with dementia.

Time commitments: The focus group will be conducted by the principal investigator and will last up to 60 minutes.

Interview location: The interview will take place on ward 8 at St James's University Hospital after the morning meeting.

Payments: You will not be paid to take part in this study.

Participants rights: It is your decision whether you chose to take part in this study or not, participation will not affect your employment rights. Your consent to participation can be withdrawn at any time up to or during the interview. It is also

possible to request the withdrawal of specific comments after the focus group has ended up until the time analysis has begun. To withdraw from the study please let the principal investigator know at any time using the details below. If you withdraw from the focus group after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for comments to be withdrawn retrospectively, the specified extract will be deleted from the transcript. It will be noted on your consent form that exerts have been deleted, but it will not specify details of the deleted comments, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

As we do not store your personal contact details, we will not contact you as a standard mater with the results of the focus group, however if you would like further information please do not hesitate to contact Dr Crowther on the email address above.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 7 - Distress recognition tool focus groups with carers, participant information sheet.

Carers Participant Information Sheet

Research title: **D**ementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study, Focus Groups.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Contact t: 07703288239 email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

LTHT R&I number: LP16/84687   Research ethics committee approval number: MREC 15-128

Description: You are invited to contribute to a focus group that aims to get your feedback on a proposed new diagnostic tool, to help recognise distress in people with dementia when the are in hospital. It is hoped that this tool can then be refined before undergoing initial tests to check its usability and effectiveness.

This study is being conducted by the principal investigator Dr George Crowther, and forms part of a postgraduate degree research project at the University of Leeds. The University of Leeds Research Ethics Committee, NHS Research Ethics Committee and the Leeds Teaching Hospitals Trust Research and Development Department have approved it.

Procedures: Using staff opinion and experience in LTHT we have developed a very simple screening tool (see overleaf), for all staff to use on a regular basis to help identify people in distress who cannot communicate their need effectively due to dementia. This tool us used primarily by ward based healthcare professionals, but there is an element of it which we propose will be completed by the person's usual carer when they visit. With your permission we would like to know your opinions on the good and bad points about this tool so that it can be improved. This will involve attending a focus group that will be held during the Carers Leeds Dementia Café. The focus group will focus on the tool, but will be relaxed to allow you to speak freely. So that your opinions can be accurately recalled the interview will be audio recorded on a Dictaphone and the group leader may take some notes as you speak. After the focus group the recording will be stored as a password protected audio file on the PI's password protected drive on the University of Leeds secure server. It will be deleted from the Dictaphone device at the earliest possible opportunity (at latest, the evening of the day of recording). The conversations from the focus group will then be transcribed in full, to enable the principal investigator to recall, recognise and understand your opinions after the interview has finished.

Focus groups with healthcare professionals will also be held, all following the same structure. After the focus groups are completed the opinions and comments will be collated so that common themes can be recognised, and suggestions can be made that might improve the tool.

Your confidentiality: All of your responses will be kept confidential. Any personal details provided will be kept separately from the audio recordings and recording transcriptions. Any person identifiable data on the audio recording (for example the area you live in), will be deleted from the transcript at the point of transcription. Once the audio recording is transcribed it will be kept only in a password protected file on the secure University of Leeds server, accessible only to Dr Crowther.

All electronic data (transcriptions etc.) will be kept in a password protected file on the secure University of Leeds server. Any written data (for example the consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project written and electronic data will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study combined with future work will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. As part of this process the principal investigator may wish to use opinions expressed in the focus groups or direct quotes taken from the groups. Any information used will be anonymised and your personal details will never be published.

Others confidentiality: At times in the focus group you may wish to discuss specific examples that help illustrate your opinions. In this instance please do not to disclose any information that could potentially identify you or the person you care for. If during the focus group identifiable information is disclosed then the session will be paused and the audio recording wound back to before the identifiable information was disclosed. You will be asked not to use the identifiable information again, before we continue. The identifiable information will be recorded over, thus deleting it. If patient identifiable information is only discovered on transcription it will be removed from the transcript. In this instance you will not be informed of any removal of information.

Risks to participants: There may be instances where you discuss or recall times when the person you care for you has been in hospital. This is a potentially upsetting topic. If at any time you become upset during the focus group, you will be asked whether you would like continue with the group or leave a little early. In either instance you will be invited to debrief with the PI after the interview. The PI has experience working with people with dementia and their carers.

Time commitments: The focus group will be conducted by the principal investigator and will last up to 60 minutes.

Interview location: The interview will take place at the Carers Support Dementia Café, Church of Nazrine, Albion Street, Morley, Leeds, LS27 9BX.

Payments: You will not be paid to take part in this study.

Participants rights: It is your decision whether you chose to take part in this study or not. Non participation or withdrawal form the study will not affect the care that you or the person you care for receives in anyway. Your consent to participation can be withdrawn at any time up to or during the interview. It is also possible to request the withdrawal of specific comments after the focus group has ended up until the time

analysis has begun. To withdraw from the study please let the principal investigator know at any time using the details below. If you withdraw from the focus group after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for comments to be withdrawn retrospectively, the specified extract will be deleted from the transcript. It will be noted on your consent form that exerts have been deleted, but it will not specify details of the deleted comments, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 7 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

As we do not store your personal contact details, we will not contact you as a standard mater with the results of the focus group, however if you would like further information please do not hesitate to contact Dr Crowther on the email address above.

Appendix 8 - Distress recognition tool focus groups, consent forms.

**<u>The DISTRESSED Study – Healthcare Professional Focus Groups.
Participant Consent Form.</u>**

Research title: Dementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Contact t: 07703288239   email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ. email: m.i.bennett@leeds.ac.uk
LTHT R&I number: LP16/84687

Research ethics committee approval number: MREC 15-128

Please read 'The DISTRESSED study, Healthcare Professionals Participant Information Sheet' before continuing with this form.

Key point summary of the project:

- Focus groups will be informal and are designed to get your feedback on a proposed new diagnostic tool for identifying distress in people with dementia on the ward.
- Focus groups will be held on Ward 8 meeting room after the morning meeting and will take 10-20 minutes.
- Every precaution will be taken to protect your confidentiality at all times.
- Please refrain from disclosing any identifiable patient information.
- If at anytime you are distressed by the interview content a formal debrief will be available to you.
- You may withdraw from the study at any time until analysis has begun.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the DISTRESSED Study participant information sheet, explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis has begun without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. If I choose to withdraw or retract any comment I can contact the principal investigator on georgecrowther@nhs.net . Any data I have provided will be destroyed as set out in the Participant Information Sheet.	
I agree to participate in The DISTRESED Study interview as set out in the participant information sheet.	
I agree for the interview to be audio recorded, transcribed and stored as set out in the DISTRESSED Study participant information sheet.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree for the data collected from me to be stored and used in relevant future research.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant			
Years post qualification		Years in current role	
Participant's signature			
Date			
Name of lead researcher	G Crowther		
Signature			
Date*			

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the participant information sheet. A copy of the signed and dated consent form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet.

The DISTRESSED Study – Carers Focus Groups. Participant Consent Form.

Research title: Dementia **I**npatient **S**tudy on The **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress – The DISTRESSED Study.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Contact t: 07703288239   email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ. email: m.i.bennett@leeds.ac.uk
LTHT R&I number: LP16/84687

Research ethics committee approval number: MEC15-128

Please read 'The DISTRESSED study, Carers Participant Information Sheet' before continuing with this form.

Key point summary of the project:

- Focus groups will be informal and are designed to get your feedback on a proposed new diagnostic tool for identifying distress in people with dementia in hospital.
- Focus groups will be held at the Carers Leeds Dementia Café and will take 10-20 minutes.
- Every precaution will be taken to protect your confidentiality at all times.
- Please refrain from disclosing any identifiable information about you or the person you care for during the group.
- If at anytime you are distressed by the interview content a formal debrief will be available to you.
- You may withdraw from the study at any time until analysis has begun.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the DISTRESSED Study carers participant information sheet, explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis has begun without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. If I choose to withdraw, or wish to retract any comment I can contact the principal investigator on georgecrowther@nhs.net . Any data I have provided will be destroyed as set out in the Participant Information Sheet.	
I agree to participate in The DISTRESED Study interview as set out in the participant information sheet.	
I agree for the interview to be audio recorded, transcribed and stored as set out in the DISTRESSED Study participant information sheet.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree for the data collected from me to be stored and used in relevant future research.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Years acting as a carer	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date	

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the participant information sheet. A

copy of the signed and dated consent form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet.

Appendix 9 - Distress recognition tool focus groups topic guide.

Both tools ask you to make a quick judgement about whether the person you care for is in distress. Are you comfortable doing this?

Both tools ask you to help inform the doctors and nurses, is that good does it empower you, or are you scared they may disagree?
Would you rather just go and find the nurse and tell them?
Do you think this tool might help your opinion be heard?
Is it helpful having carer input? If not why not?

Tool 1 - Layout
1) What do you like about the overall layout?
2) What do you dislike about the overall layout?
3) What would you change about the layout?

Tool 1: Tool user guide/instructions:
1) Are the instructions on how to use the tool simple to follow?
2) Are the instructions detailed enough?
3) How can they be improved?

Tool 1: Tool diagnostic questions.
1) Is the diagnostic question 'do you think the person you care for is in distress?' easy to complete?
2) Do you think you could complete this tool confidently or does it feel intimidating?
3) Do you think you could complete this tool accurately?

Tool 2 - Layout
4) What do you like about the overall layout?
5) What do you dislike about the overall layout?
6) What would you change about the layout?

Tool 2: Tool user guide/instructions:
4) Are the instructions on how to use the tool simple to follow?
5) Are the instructions detailed enough?
6) How can they be improved?

Tool 2: Tool diagnostic questions.
4) Is the diagnostic question 'do you think the person you care for is in distress?' easy to complete?
5) Do you think you could complete this tool confidently or does it feel intimidating?
6) Do you think you could complete this tool accurately?

Overall impression.
1) Do you think there is a need for this tool?
2) Would you use this tool? – if not why not.

Any other comments?

Appendix 10 - Distress recognition tool feasibility study participant information sheet.

DISTRESSED - A feasibility study of a novel distress recognition tool Patient, participant information sheet (version 2, 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16/87666

Research ethics committee approval number:

Invitation and brief summary:

We know that when people who have dementia are admitted to hospital it can be disorientating, uncomfortable and upsetting, it is common and natural therefore that from time to time you might feel emotional distress. When you are unwell, it can be difficult to communicate this distress to nurses and doctors on the ward, but they still have to be able to spot that you need help or reassurance. This is part of the normal job of the staff looking after you, but to help them do it more accurately we have designed a very short screening tool for them to complete every time they see you.

To help us understand if this screening tool is useful, you are invited to participate in a study that will incorporate it into your routine care while you are on the ward.

Background to the research:

Hospital wards can be busy, loud places. When you are staying here, you are likely to be feeling poorly, the meals are probably not what you are used to, and the ward routine is not necessarily the same as yours. If you have dementia or a memory problem, it can be hard to adjust to this, the result of which can be emotional distress. It is one of the jobs of the staff looking after you to recognise when you are in distress or unhappy, and try to address the cause of it, but this can be easier said than done, particularly if you are poorly and unable to think and communicate as clearly as you might at home or to people who know you well. We aim to help staff to recognise distress more easily so that the correct measures can be taken to help you feel happier and more comfortable during your stay.

After much consultation with ward staff and some carers of people with dementia, we have designed a distress screening tool. This is a kind of checklist or aide memoire that asks the nurses, support workers or doctors to briefly ask themselves 'Do I think this person is in distress today?' every time they come to take your temperature and pulse.

We recognise that the staff on the ward may not know you very well, especially if you have only just been admitted. For this reason we also value the opinion of people that know you well at home. As such we are asking that if you have a carer or relative that knows you well at home, they also let us know if they think you are in distress, so that the nurses, doctors and support workers can take their opinion on board and hopefully provide any care or reassurance you need. To do this they will be asked to fill in a brief form simple asking them if they think you are in distress. This form will be located at the end of your bed and can be completed as frequently as they like.

If the team looking after you identify that you are distressed, they should act to try and find out why that is and help you to feel better. There are already systems in place to help them do this, and the screening tool signposts the team to these systems.

What's involved?

If you agree to take part in the study, the screening tool will be placed in the observation charts, which are usually located at the end of your bed. These charts are already filled in regularly and it is where the readings such as your blood pressure, temperature and pulse are recorded. Every time the nurse, support worker or doctor comes to fill in the observation chart, they will also fill in the distress screening tool too.

If you identify a person that knows you well at home, they will also be invited complete the carers distress screening tool. The carers distress screening tool will placed on a clip board at the end of your bed. If you have nominated a carer they will then be invited to complete it every time they visit, should they wish to. If you do nominate a carer they will also fully informed about the study and we will ensure they are happy to be part of the study, in a similar way to this.

Both the tools are deliberately simple to use, and work on the theory that we are all quite good at naturally recognising distress, however it can be useful to be reminded to do it, and how to help. As such the tools simply ask the person filling them in to observe your body language, facial expression, behaviour, speech and to ask you if you are in distress. The whole process should take a matter of seconds and does not involve any participation from yourself if you don't want it to.

The tool will be used in your routine care for the duration of your stay on the ward.

After you have been discharged from the ward, the principal investigator will look at the completed screening tools and your confidential medical notes which are completed for the duration of your stay in hospital. The reason for accessing this information is to see whether the tool has been completed as intended and to see how the information it recorded has been used. No information from your medical record will be altered or removed. So that the research team can demonstrate to others how the tool has been used some information from your medical record will be recorded. This information will include how frequently the tool was used, the number of times you were distresses, the cause of distress (if known) and the

circumstances that occurred around the time of the distress. The principal investigator will also note down how the ward staff used the information that you were in distress to try to help you. No personally identifiable information will be recorded.

What would taking part involve for me?

The screening tools that we are proposing to introduce into your routine care is observational. This means that the person completing it will simply observe your body language and whether or not you seem in distress. They may also ask you from time to time if you feel distressed. The screening tool does not involve any invasive investigations, procedures or drug treatments.

If your treating team is concerned that you are in distress then they will try to find out why, and help you with it. This might involve investigations such as blood tests, a physical examination and/or treatment of any problems they find. This process would be part of standard ward procedure in any case, however, by having the screening tool incorporated in your routine care may mean you have a greater chance of receiving such care.

What are the possible benefits of taking part?

It is hoped that by having the screening tool introduced into your routine care on the ward that the people looking after you might better recognise any times you are in emotional distress and need help. This may in turn improve the chances of that distress being acknowledged, and reduced.

It is also hoped that if the tool is shown to be useful that after more testing, it might become part of every ones routine care, potentially benefiting the wider population.

What are the possible disadvantages of taking part?

When the screening tool is filled in it requires the nurse or your allocated carer from home to briefly observe your body language, facial expression and general demeanour, this could feel intrusive. If you feel uncomfortable about this at any point you can request that the screening tool, or any aspect of it, is withdrawn from your routine care.

If your treating team is concerned that you are in distress then they will try to find out why, and help you with it. This might involve investigations such as blood tests, a physical examination and/or treatment of any problems they find. This process would be part of standard ward procedure in any case, however, by having the screening tool incorporated in your routine care may mean you have a greater chance of receiving such care.

Everyone invited to take part in this study has a diagnosis of dementia or significant memory problem. Having the distress recognition screening tool at the end of your bed will be a potential visible reminder and indicator to healthcare staff and possibly other people on the ward (if they are aware of the study) that you have dementia or a memory problem. While the wards are dementia friendly and a dementia diagnosis is nothing to hide, you may find this visible reminder is intrusive or an invasion of your confidentiality.

What happens to the information recorded?

Any information written on the distress recognition tool will remain in your observation file until the time you leave the ward. After this time the sheets will be filed in your medical notes and stored as per hospital policy. From team to time if the medical team recognise you are distressed and act on it, they will probably discuss it in ward rounds and team meetings and record what they have done and why in your medical notes, this is standard hospital practice. After you have left the ward the research team will look at the information to see whether the tool has influenced the care you have received. The research team will also attend ward rounds and team meetings to see if the tool is influencing every day ward care.

The research team will record times where the tool has influenced your care as a way of demonstrating its usefulness. They will do this by observing ward meetings and after you leave the ward they will review your medical notes. They will record if the distress tool has been used and how it has influenced your care. The research team will not record any personally identifiable information when collecting this data. No information will be removed from your file or taken off the ward.

Any written information recorded when collecting data will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. All electronic information (for example a record of the number of times the distress tool was used) will be kept in a password protected file on the secure University of Leeds server. After the end of the project written and electronic data will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. Your personal details will never be published.

What are my rights?

It is your decision whether you chose to take part in this study or not, participation will not effect your rights or access to any care on the ward. Your consent to participation can be withdrawn at any time up to or during the study. It is also possible to request withdrawal after the study has ended up until the time analysis of the data has begun. To withdraw from the study please let you nurse know or contact the principal investigator directly using the details below. If you withdraw from the study after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for data to be withdrawn retrospectively, the specified data will be removed. It will be noted on your consent form that data have been deleted, but it will not specify details of the deleted data, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

If you have consented to participation, but during the course of the study you lose the ability to make a decisions for any reason, you will still be included in the study, unless you specifically request otherwise on the consent form.

What happened next?

If you are happy to take part the Principal Investigator will visit you in order to obtain your consent to participate. If you name a carer from home who you wish to fill in the carers tool, they will also be provided with information on the project and consent to participate will be obtained form them.

Further Supporting Information.

You will not be paid to take part in this study.

This study has been designed and funded by Dr George Crowther, an academic clinical lecturer in old age psychiatry, who is funded by the National Institute of Health Research. Support and review of the study has been provided through supervision at the Leeds Institute of Health Science, University of Leeds and the Leeds Teaching Hospitals Trust, Elderly Medicine Clinical Support Unit.

Ethical review and approval for the project has been given by…..

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 11 - Carers distress recognition tool feasibility study participant information sheet.

DISTRESSED - A feasibility study of a novel distress recognition tool, Carers participant information sheet (version 3, 23/11/16)

Full Research title: **D**ementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry.

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee reference number: 16/YH/0478

Invitation and brief summary:

We know that when people who have dementia are admitted to hospital it can be disorientating, uncomfortable and upsetting, it is common and natural therefore that from time to time they might feel emotional distress. It can be difficult for people with dementia to verbally communicate this distress to nurses and doctors on the ward, which can make it more difficult to recognise and subsequently treat. To improve the accuracy with which staff identify distress in people with dementia we have designed a very short screening tool for them to complete called the Distress Recognition Tool (DRT for short). A very important aspect of this assessment tool is your opinion as a carer, as no one knows the person being looked after better than you. As such we are asking you to tell the nurses if you believe the person you care for is in distress by answering a few simple questions every time you come and visit.

To help us understand if the DRT is useful, you are invited to participate in a study that incorporates it into the routine ward care of the person you care for.

Background to the research:

Hospital wards can be busy, loud places. When patients are staying here, they are likely to be feeling poorly, the meals are probably not what they are used to and the ward routine is not necessarily the same as at home. When people have dementia or a memory problem, it can be hard to adjust to this, the result of which can be emotional distress. It is one of the jobs of the ward staff to recognise when someone is distressed or unhappy, and try to address the cause of it, but this can be easier said than done, particularly if the person they are looking after is poorly and unable

to think and communicate as clearly as they might at home. We aim to help staff to recognise distress more easily so that the correct measures can be taken to help patients feel happier and more comfortable during their stay.

After much consultation with ward staff and some carers of people with dementia, we have designed a distress screening tool called the Distress Recognition Tool (DRT). This is a kind of checklist or aide memoire that prompts the nurses, support workers or doctors to briefly ask themselves 'Do I think this person is in distress today?' every time they come to take a temperature and pulse.

We recognise that the staff on the ward may not know the person they are caring for very well, especially if that person has only just been admitted. For this reason your opinion, as a carer of the person with dementia, is hugely important. As such we are asking that if you come to visit the person you usually care for at home, you assist us by completing a 'carers Distress Recognition Tool' (or cDRT for short), to let us know if you think the person you usually care for is in distress. The nurses, doctors and support workers can take you opinion on board and hopefully provide any care or reassurance the person you care for needs.

If the team looking after the person you care for identify that they are distressed, they should act to try and find out why that is, in order to help them feel better. There are already systems in place to help them do this, and the screening tool signposts the team to these systems.

What's involved?

If you agree to take part in the study, the carers screening tool will be placed on a clip board at the end of the bed of the person you care for, you should find it there every time you visit. Each time you visit we ask that you would take a few seconds to observe the person you are visiting and note down on the chart whether or not you feel they are in distress. If you wish you can also write down why you believe they are in distress and strategies that help him/her at home. The next time the nurse, doctor of support worker then comes to take his/her temperature and pulse, the information you have recorded should be noted down and taken in to account.

The tool is deliberately simple to use, and works on the theory that we are all quite good at naturally recognising distress, however it can be useful to be reminded to do it, and that is always helpful to listen to the opinions of others. Completing the tool requires observation only and is not invasive. The whole process should take no longer that 30 seconds.

This study will last for 6 weeks only. If the study finishes before the person you care for is discharged from the ward, the DRT will be removed from their routine care.

What would taking part involve for me?

The cDRT is an observational tool. This means that to complete it you simply need to observe the person you are visiting. This does not necessarily need to be a separate process from your normal interaction with him/her. You are simply being asked to observe their body language, facial expression, speech, reactions to you and give your global overall impression as to whether you think they are in distress or not. You would then be expected to write this down on the cDRT (located at the end of the bed) with the pen provided. If you think that you know why he/she is in distress and what can be done about it, you are encouraged to let the ward staff know by writing it in the space provided on the cDRT. If you believe the person you

are visiting is in distress we would also ask that you tell the ward staff verbally, so they can act as soon as possible to help.

If you wish to take part, the Principal Investigator will obtain your formal written consent that you are happy to do so and understand the details of the study.

What are the possible benefits of taking part?
There are not direct benefits for you by completing the tool, however it is hoped that by having the DRT introduced into the routine care of the person you usually care for, any distress they might experience can be better recognised. This may in turn improve the chances of that distress being acknowledged, and reduced.

It is also hoped that if the tool is shown to be useful, once more testing has been done, it might become part of every ones routine care, therefore potentially benefiting the wider population.

What are the possible disadvantages of taking part?

Although filling in the cDRT is not a lengthy process, it still takes around 30 seconds and this is time you may otherwise have spent with the person you are visiting.

Completing the cDRT requires you to briefly observe the person you are visiting's body language, facial expression and overall demeanour. It is possible that this could feel intrusive for him/her, particularly if they are already feeling uncomfortable or anxious. If you feel at any point that the cDRT is having a negative impact on your relationship with the person you care for you can choose not to complete the tool that day, or withdraw from the study altogether, at which point the cDRT will be removed from the routine care of the person you care for.

What happens to the information recorded?

Any information written on the distress recognition tool will remain in your observation file of the person you care for until the time they leave the ward. After this time the sheets will be filed in the medical notes and stored as per hospital policy. The person you care for or their personal consultee has already given permission for this to happen. The research team will then review the cDRT and record the number of times the tool has been used and how it has influenced care. The research team will not record any personally identifiable information when collecting this data.

Any written information recorded when collecting data (for example your signed consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. All electronic information (for example a record of the number of times the distress tool was used) will be kept in a password protected file on the secure University of Leeds server. After the end of the project written and electronic data will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. Your personal details will never be published.

What are my rights?

It is your decision whether you chose to take part in this study or not, participation will not effect your rights or access to any care on the ward for the person you care for. <u>The person you care for will receive the same level of care whether you choose to participate or not.</u>

<u>You do not have to decide immediately whether you wish to take part. Over the next 24 hours please take time to discuss the study further with the person you care for, relatives, ward staff or the principal investigator if you wish. If you need longer than 24 hours to decide this can be accommodated.</u>

Your consent to participation can be withdrawn at any time up to or during the study. It is also possible to request withdrawal after the study has ended up until the time analysis of the data has begun. To withdraw from the study please let a nurse know or contact the principal investigator directly using the details below. If you withdraw from the study after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for data to be withdrawn retrospectively, the specified data will be removed. It will be noted on your consent form that data have been deleted, but it will not specify details of the deleted data, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

What happened next?

If you are happy to take part the Principal Investigator will visit or telephone you in order to obtain your formal consent to participate.

<u>At a later date, but within the time frame of the study (six weeks), the principal investigator may approach you again in order to get your views and feedback on the DRT. This will be done via a brief interview, and you will be advised about the process and consented for it separately.</u>

Further Supporting Information.

You will not be paid to take part in this study.

This study has been designed and funded by Dr George Crowther, an academic clinical lecturer in old age psychiatry, who is funded by the National Institute of Health Research. Support and review of the study has been provided through supervision at the Leeds Institute of Health Science, University of Leeds and the Leeds Teaching Hospitals Trust, Elderly Medicine Clinical Support Unit.

Ethical review and approval for the project has been given by Yorkshire and the Humber – Bradford Leeds Research Ethics Committee.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 12 - Distress recognition tool feasibility study, personal consultee information sheet.

DISTRESSED - A feasibility study of a novel distress recognition tool Consultee, participant information sheet (version 3 23/11/16)

Full Research title: **D**ementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\8666

Research ethics committee reference number: 16/YH/0478

Introduction:

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

Invitation and brief summary:

We know that when people who have dementia are admitted to hospital it can be disorientating, uncomfortable and upsetting, it is common and natural therefore that from time to time you might feel emotional distress. When you are unwell, it can be difficult to communicate this distress to nurses and doctors on the ward, but they still have to be able to spot that you need help or reassurance. This is part of the normal job of the staff looking after you, but to help them do it more accurately we have designed a very short screening tool for them to complete every time they see you.

To help us understand if this screening tool is useful, you are invited to participate in a study that will incorporate it into your routine care while you are on the ward.

Background to the research:

Hospital wards can be busy, loud places. When you are staying here, you are likely to be feeling poorly, the meals are probably not what you are used to and the ward routine is not necessarily the same as yours. If you have dementia or a memory problem, it can be hard to adjust to this, the result of which can be emotional distress. It is one of the jobs of the staff looking after you to recognise when you are in distress or unhappy, and try to address the cause of it, but this can be easier said than done, particularly if you are poorly and unable to think and communicate as clearly as you might at home or to people who know you well. We aim to help staff to recognise distress more easily so that the correct measures can be taken to help you feel happier and more comfortable during your stay.

After much consultation with ward staff and some carers of people with dementia, we have designed a distress screening tool. This is a kind of checklist or aide memoire that asks the nurses, support workers or doctors to briefly ask themselves 'Do I think this person is in distress today?' every time they come to take your temperature and pulse.

We recognise that the staff on the ward may not know you very well, especially if you have only just been admitted. For this reason we also value the opinion of people that know you well at home. As such we are asking that if you have a carer or relative that knows you well at home, they also let us know if they think you are in distress, so that the nurses, doctors and support workers can take their opinion on board and hopefully provide any care or reassurance you need. To do this they will be asked to fill in a brief form simply asking them if they think you are in distress. This form will be located at the end of your bed and can be completed as frequently as they like.

If the team looking after you identify that you are distressed, they should act to try and find out why that is and help you to feel better. There are already systems in place to help them do this, and the screening tool signposts the team to these systems.

What's involved?

If you agree to take part in the study, the screening tool will be placed in the observation charts, which are usually located at the end of your bed. These charts are already filled in regularly and it is where the readings such as your blood pressure, temperature and pulse are recorded. Every time the nurse, support

worker or doctor comes to fill in the observation chart, they will also fill in the distress screening tool too.

If you identify a person that knows you well at home, they will also be invited complete the carers distress screening tool. The carers distress screening tool will placed on a clip board at the end of your bed. If you have nominated a carer they will then be invited to complete it every time they visit, should they wish to. <u>If they believe that you are in distress they will be asked to note it on the tool, and inform a member of staff on the ward so that they can act to help you</u>. If you do nominate a carer they will also fully informed about the study and we will ensure they are happy to be part of the study, in a similar way to this.

Both the tools are deliberately simple to use, and work on the theory that we are all quite good at naturally recognising distress, however it can be useful to be reminded to do it, and how to help. As such the tools simply ask the person filling them in to observe your body language, facial expression, behaviour, speech and to ask you if you are in distress. The whole process should take a matter of seconds and does not involve any participation from yourself if you don't want it to.

The tool will be used in your routine care for the duration of your stay on the ward.

After you have been discharged from the ward, the principal investigator will look at the completed screening tools and your confidential medical notes which are completed for the duration of your stay in hospital. The reason for accessing this information is to see whether the tool has been completed as intended and to see how the information it recorded has been used. No information from your medical record will be altered or removed. So that the research team can demonstrate to others how the tool has been used some information from your medical record will be recorded. This information will include how frequently the tool was used, the number of times you were distresses, the cause of distress (if known) and the circumstances that occurred around the time of the distress. The principal investigator will also note down how the ward staff used the information that you were in distress to try to help you. No personally identifiable information will be recorded.

What would taking part involve for me?

The screening tools that we are proposing to introduce into your routine care is observational. This means that the person completing it will simply observe your body language and whether or not you seem in distress. They may also ask you from time to time if you feel distressed. The screening tool does not involve any invasive investigations, procedures or drug treatments.

If your treating team is concerned that you are in distress then they will try to find out why, and help you with it. This might involve investigations such as blood tests, a physical examination and/or treatment of any problems they find. This process would be part of standard ward procedure in any case, however, by having the screening tool incorporated in your routine care may mean you have a greater chance of receiving such care.

What are the possible benefits of taking part?

It is hoped that by having the screening tool introduced into your routine care on the ward that the people looking after you might better recognise any times you are in

emotional distress and need help. This may in turn improve the chances of that distress being acknowledged, and reduced.

It is also hoped that if the tool is shown to be useful that after more testing, it might become part of every ones routine care, potentially benefiting the wider population.

What are the possible disadvantages of taking part?

When the screening tool is filled in it requires the nurse or your allocated carer from home to briefly observe your body language, facial expression and general demeanour, this could feel intrusive. If you feel uncomfortable about this at any point you can request that the screening tool, or any aspect of it, is withdrawn from your routine care.

If your treating team is concerned that you are in distress then they will try to find out why, and help you with it. This might involve investigations such as blood tests, a physical examination and/or treatment of any problems they find. This process would be part of standard ward procedure in any case, however, by having the screening tool incorporated in your routine care may mean you have a greater chance of receiving such care.

Everyone invited to take part in this study has a diagnosis of dementia or significant memory problem. Having the distress recognition screening tool at the end of your bed will be a potential visible reminder and indicator to healthcare staff and possibly other people on the ward (if they are aware of the study) that you have dementia or a memory problem. While the wards are dementia friendly and a dementia diagnosis is nothing to hide, you may find this visible reminder is intrusive or an invasion of your confidentiality.

What happens to the information recorded?

Any information written on the distress recognition tool will remain in your observation file until the time you leave the ward. After this time the sheets will be filed in your medical notes and stored as per hospital policy. From time to time if the medical team recognise you are distressed and act on it, they will probably discuss it in ward rounds and team meetings and record what they have done and why in your medical notes, this is standard hospital practice. After you have left the ward the research team will look at the information to see whether the tool has influenced the care you have received. The research team will also attend ward rounds and team meetings to see if the tool is influencing every day ward care.

The research team will record times where the tool has influenced your care as a way of demonstrating its usefulness. They will do this by observing ward meetings and after you leave the ward they will review your medical notes. They will record if the distress tool has been used and how it has influenced your care. The research team will not record any personally identifiable information when collecting this data. No information will be removed from your file or taken off the ward.

Any written information recorded when collecting data will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. All electronic information (for example a record of the number of times the distress tool was used) will be kept in a password protected file on the secure University of Leeds server. After the end of the project written and electronic data will be securely archived and scheduled for destruction 10 years later. All data storage and

use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. Your personal details will never be published.

What are my rights?

It is your decision whether you chose to take part in this study or not, participation will not effect your rights or access to any care on the ward. You will receive the same level of care whether you choose to participate or not.

You do not have to decide immediately whether you wish to take part. Over the next 24 hours please take time to discuss the study further with your relatives, carers, ward staff or the principal investigator if you wish. If you need longer than 24 hours to decide this can be accommodated.

Your consent to participation can be withdrawn at any time up to or during the study. It is also possible to request withdrawal after the study has ended up until the time analysis of the data has begun. To withdraw from the study please let you nurse know or contact the principal investigator directly using the details below. If you withdraw from the study after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for data to be withdrawn retrospectively, the specified data will be removed. It will be noted on your consent form that data have been deleted, but it will not specify details of the deleted data, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

What happened next?

If you are happy to take part the Principal Investigator will visit you in order to obtain your consent to participate. If you name a carer from home who you wish to fill in the carers tool, they will also be provided with information on the project and consent to participate will be obtained from them.

Further Supporting Information.

You will not be paid to take part in this study.

This study has been designed and funded by Dr George Crowther, an academic clinical lecturer in old age psychiatry, who is funded by the National Institute of Health Research. Support and review of the study has been provided through supervision at the Leeds Institute of Health Science, University of Leeds and the Leeds Teaching Hospitals Trust, Elderly Medicine Clinical Support Unit.

Ethical review and approval for the project has been given by the Yorkshire and Humber – Bradford Leeds Research Ethics Committee.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: georgecrowther@nhs.net.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 13 - Distress recognition tool feasibility study, consent form.

DISTRESSED - A feasibility study of a novel distress recognition tool Patient, participant consent form (version 2 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Contact t: 07703288239   email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ. email: m.i.bennett@leeds.ac.uk

IRAS number: 216613

LTHT R&I number: LP16/87666

Research ethics committee approval number:

Please read the 'DISTRESSED, feasibility study participant information sheet' before continuing with this form.

Key point summary of the project:

- The distress recognition tool will be used as part of your routine care while you are on the ward.
- At regular periods during your stay the healthcare staff will make observation on whether they feel you are distressed.
- If you nominate one, your usual carer at home will be asked (and consented) to make observations on whether they feel you are distressed.
- The research team will access relevant sections of your medical notes and ward meetings about your care to observe any impact the distress recognition tool is having. No personally identifiable information will be collected or stored with this data.
- No information in your medical record will be altered, or removed by the research team.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the 'DISTRESSED, feasibility study participant information sheet', explaining the above research project and I have had the opportunity to consider the project, ask questions about the project and have had these answered satisfactorily.	
I understand my participation is voluntary and that I can request to be is withdrawn from the study at any time up until data analysis has begun without giving any reason and without my medical care or legal rights being affected. Details of how to withdraw are given in the participant information sheet.	
If during the course of the study I lose the ability to make a decisions for any reason, I will still be included in the study.	
I understand that the distress recognition tool will be used as part of my routine care while on the ward, and give my permission for staff to complete it about me.	
If they give their consent to participate as well, I agree for my usual carer from home (insert name or not applicable) …………………………… to complete the carers distress recognition tool about me if they visit on the ward.	
I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the research team where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I understand that relevant ward meetings about my medical care may be attended by individuals from the research team where it is relevant to my taking part in this research. I give permission for these individuals be party to the information spoken in these meetings.	
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	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.	
I agree to take part in the above study.	

Name	
Signature	
Date	
Name of lead researcher	

Signature*	
Date	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties it will be copied twice. The original will be form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet. The participant will receive one copy, and the other copy will be kept in the patient's medical record.

Appendix 14 - Distress recognition tool feasibility study, personal consultee assent form.

DISTRESSED - A feasibility study of a novel distress recognition tool Consultee consent form, (version 2 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Contact t: 07703288239   email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ. email: m.i.bennett@leeds.ac.uk

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Please read the 'DISTRESSED, feasibility study consultee participant information sheet' before continuing with this form.

Key point summary of the project:

- The distress recognition tool will be used as part of the routine care of the person you are acting as a consultee for while they are on the ward.
- At regular periods while the person you are acting as a consultee for is on the ward the healthcare staff will make observation on whether they are distressed or not.
- If you nominate one, the usual carer at home will be asked (and consented) to make observations on whether they feel the person you are a consultee for is distressed.
- The research team will access relevant sections of the medical and nursing notes of person you are acting as consultee for, they will also attend ward meetings about the persons, care to observe any impact the distress recognition tool is having. No personally identifiable information will be collected or stored with this data.
- No information in the medical record will be altered, or removed by the research team.

	Add your initials next to the statement if you agree
I (name of consultee)……………………………………… have been consulted about (name of potential participant's)…………………………… participation in this research project. I have had the opportunity to consider the information provided, ask questions about the study and had them answered satisfactorily and understand what is involved.	
I confirm that I have read and understand the 'DISTRESSED Study feasibility trial participant information sheet', explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand his/her participation is voluntary and that I can request he/she is withdrawn from the study at any time up until data analysis has begun without giving any reason and without my medical care or legal rights being affected. Details of how to withdraw are given in the participant information sheet	
I understand that the distress recognition tool will be used as part of his/her routine care while on the ward, and give my permission for staff to complete it about him/her.	
If they give their consent to participate as well, I agree for his/her usual carer from home (insert name or not applicable) …………..……………… to complete the carers distress recognition tool about him/her if they visit him/her on the ward.	
I understand that relevant sections of his/her medical notes and data collected during the study, may be looked at by individuals from the research team where it is relevant to him/her taking part in this research. I give permission for these individuals to have access to his/her records.	
I understand that relevant ward meetings about his/her medical care may be attended by individuals from the research team where it is relevant to him/her taking part in this research. I give permission for these individuals be party to the information spoken in these meetings.	
I understand that the information collected about him/her will be used to support other research in the future, and may be shared anonymously with other researchers	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.	
In my opinion he/she would have no objection to taking part in the above study.	

Name of consultee	

Consultee's signature	
Date	
Relationship to participant	
Name of lead researcher	
Signature*	
Date	

*To be signed and dated in the presence of the participant.

 Once this has been signed by all parties it will be copied twice. The original will be form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet. The participant will receive one copy, and the other copy will be kept in the patient's medical record.

Appendix 15 - Distress recognition tool feasibility study, cDRT consent form.

DISTRESSED - A feasibility study of a novel distress recognition tool Carers consent form (version 2 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry. Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Contact t: 07703288239   email: hssgcr@leeds.ac.uk

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ. email: m.i.bennett@leeds.ac.uk
IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Please read the 'DISTRESSED feasibility study – Carers Participant Information Sheet' before continuing with this form.

Key point summary of the project:

- You are requested to complete the carers Distress Recognition Tool every time you visit the person you care for in hospital.
- The research team will review the number of times you have used the tool and how it has been completed. No personally identifiable information will be collected or stored with this data.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the 'DISTRESSED, feasibility study carers participant information sheet', explaining the above research project and I have had the opportunity to consider the project, ask questions about the project and have had these answered satisfactorily.	
I understand my participation is voluntary and that I can request to be is withdrawn from the study at any time up until data analysis has begun without giving any reason and without my medical care or legal rights being affected. Details of how to withdraw are given in the participant information sheet.	
I understand that the carers distress recognition tool will be used as part of the routine care of the person I usually care for in the community and they are happy for me to complete it about them.	
I understand that the information I provide on the carers distress recognition tool will be looked at by individuals from the research team and other healthcare professionals on the ward. I give permission for these individuals to have access to the information I provide.	
I understand that the information I provide will be used to support other research in the future, and may be shared anonymously with other researchers	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to this information.	
I agree to take part in the above study.	

Name	
Signature	
Date	
Name of lead researcher	
Signature*	
Date	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties it will be copied twice. The original will be form will be kept with the project's main documents which must be kept in a secure location, as set out in the DISTRESSED Study participant information sheet. The participant will receive one copy, and the other copy will be kept in the patient's medical record.

Appendix 16 - Distress recognition tool feasibility study, DRT data collecton tool.

DISTRESSED - A feasibility study of a novel distress recognition tool Data collection tool (version 2, 25/10/16)

Full Research title: **D**ementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Participant study ID_____

Gender_____

Length of hospital stay_____

Carer identified: Yes   No

Dementia subtype_____

Dementia AMTS score_____

Charleston Comorbidity index score (see appendix 1 for scoring criteria) _____

_____

Average MEWS score during stay_____

HCP Distress Recognition Tool Analysis	
Was any data recorded on the DRT 1?	Yes
	No
Was any data recorded on the DRT 2?	Yes
	No
Number of days DRT 1 recorded any data.	
Total number of times DRT 1 was completed.	

Maximum number of times DRT 1 was completed in one day.	
Minimum number of times DRT 1 was completed in 1 day.	
Number of times the HCP believed the participant was in distress on the DRT1	
Number of times the carer believed the participant was in some distress on DRT 1	
Number of times the carer believed the participant was in severe distress on DRT1	
Number of occasions HCP and carer agreed that the participant was in distress on DRT1.	
Number of times HCP and carer disagreed that the participant was in distress on DRT1.	
Number of times the HCP and carer agreed the participant was in no distress on DRT1.	
The number of times that DRT 2 was completed?	
The number of times all sections of DRT 2 were completed?	
Average DRT 2 score when the HCP believed the participant was in distress on DRT 1?	
Average DRT 2 score when carer believed the participant was in some distress on DRT 1?	
Average DRT 2 score when carer believed the participant was in severe distress on DRT 1?	
Average DRT 2 score when carer and HCP believed the participant was in distress on DRT1?	
Average MEWS score on days where distress was noted on DRT1.	
Average MEWS score where distress was scored as >2 on DRT2.	
Average MEWS score where distress was scored as >5 on DRT2.	
Average MEWS score where distress was scored as >7 on DRT2.	
Average MEWS score where distress was scored as >10 on DRT2.	
Average pain score on days where distress was noted on DRT1.	
Average pain score where distress was scored as >2 on DRT2.	
Average pain score where distress was scored as >5 on DRT2.	
Average pain score where distress was	

scored as >7 on DRT2.	
Average pain score where distress was scored as >10 on DRT2.	
Was delirium recorded on days where distress was noted on DRT1.	
Was delirium recorded on days where distress was scored as >2 on DRT2.	
Was delirium recorded on days where distress was scored as >5 on DRT2.	
Was delirium recorded on days where distress was scored as >7 on DRT2.	
Was delirium recoded on days where distress was scored as >10 on DRT2.	
Number of occasions HCP completed causes section of DRT 1?	
Number of days HCP completed causes section of DRT 1?	
Free text – the causes listed.	

Carer Distress Recognition Tool Analysis	
Was any data recorded on the c DRT	Yes
	No
Number of days cDRT recorded any data.	
Total number of times cDRT was completed.	
Maximum number of times cDRT was completed in one day.	
Minimum number of times cDRT was completed in 1 day.	
Number of times the carer believed the participant was in some distress on cDRT	
Number of times the carer believed the participant was in severe distress on cDRT	
Average MEWS score on days where distress was noted on cDRT.	
Average MEWS score when some distress was noted on the cDRT.	
Average MEWS score when severe distress was noted on the cDRT.	
Average pain score on days where some distress was noted on the cDRT.	
Average pain score on days where severe distress was noted on cDRT.	
Number of days delirium was recorded on days where some distress was noted on cDRT.	
Number of days delirium was recorded on days where severe distress was noted on cDRT.	
Number of occasions carer completed causes section of cDRT?	
Free text – the causes listed.	

Medical record review	
The number of times the DRT has been mentioned in the medical record.	
The number of times distress has been mentioned in the medical record.	
Was there evidence that the DRT advice was used?	
If so how?	
The number of times any distress was investigated.	
Number of times the Leeds Distress Algorithm was used.	
Was this participant referred to liaison psychiatry?	

Appendix 1 Charlson comorbidity index scoring criteria

Charlson co-morbidity index scoring system	
Condition	Score
Myocardial Infarction	1`
Congestive Heart Failure	
Peripheral Vascular Disease	
Cerebrovascular Disease	
Dementia	
Chronic Pulmonary Disease	
Connective Tissue Disease	
Peptic Ulcer Disease	
Mild Liver Disease	
Diabetes without end organ damage	
Hemiplegia	2
Moderate or severe renal disease	
Diabetes with end organ damage	
Tumour without metastases	
Leukaemia	
Lymphoma	
Moderate or severe liver disease	3
Metastatic solid tumour	6
Aids	
Age: for each decade >40 add 1 to the score	
Total	

Appendix 17 - Distress recognition tool feasibility study, stakeholder interviews, carers participant information sheet.

<u>**DISTRESSED - A feasibility study of a novel distress recognition tool**</u>
<u>**Feedback from primary stakeholders - carers participant information sheet**</u>
<u>**(version 2, 25/10/16)**</u>

Full Research title: **D**ementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Description: You are invited to feedback on the carers Distress Recognition Tool (cDRT) which has recently been used on the ward where the person you care for is a patient. It is hoped that the cDRT can then be refined before undergoing further trials to test its accuracy.

This study is being conducted by the principal investigator (PI) Dr George Crowther, and forms part of a postgraduate degree research project at the University of Leeds. A NHS Research Ethics Committee and the Leeds Teaching Hospitals Trust Research and Development Department have approved it.

Procedures: Using staff and carers opinion and experience we have developed a very simple screening tool, the Distress Recognition Tool (DRT) for all staff to use on a regular basis to help identify people in distress who cannot communicate their need effectively due to dementia. An essential element to this is for the person with dementia's usual carer at home to complete the carers Distress Recognition Tool (cDRT). You have previously consented to complete the cDRT when you visit the person you care for on the ward.

With your permission we would like to know your opinion on the good and bad points about this tool so that it can be improved. This will involve attending a short interview to discuss the tool. The interview will be relaxed to allow you to speak freely. So that your opinions can be accurately recalled the interview will be audio recorded on a Dictaphone and the principal investigator may take some notes as you speak. After the interview the recording will be stored as a password protected audio file on the PI's password protected drive on the University of Leeds secure server. It will be deleted from the Dictaphone device at the earliest possible

opportunity (at latest, the evening of the day of recording). The conversations from the interview will then be transcribed in full, to enable the PI to recall, recognise and understand your opinions after the interview has finished.

Interviews with varied healthcare professionals and the carers of people with dementia will be held, all following the same structure. After the interviews are completed the opinions and comments will be collated so that common themes can be recognised, and suggestions can be made that might improve the tool.

Your confidentiality: All of your responses will be kept confidential. Any personal details provided will be kept separately from the audio recordings and recording transcriptions. Any person identifiable data on the audio recording (for example your name, or the name of the person you care for), will be deleted from the transcript at the point of transcription. Once the audio recording is transcribed it will be kept only in a password protected file on the secure University of Leeds server, accessible only to Dr Crowther.

All electronic data (transcriptions etc.) will be kept in a password protected file on the secure University of Leeds server. Any written data (for example the consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project written and electronic data will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. As part of this process the principal investigator may wish to use opinions expressed in the interview or direct quotes taken from the groups. Any information used will be anonymised and your personal details will never be published.

Others confidentiality: At times in the interview you may wish to discuss specific cases that help illustrate your opinions. In this instance please do not to disclose any information that could potentially identify a person with dementia or yourself. If during the interview identifiable information is disclosed then the recording will be paused and the wound back to before the identifiable information was disclosed. You will be asked not to use the identifiable information again, before we continue. The identifiable information will be recorded over, thus deleting it. If patient identifiable information is only discovered on transcription it will be removed from the transcript. In this instance you will not be informed of any removal of information.

Risks to participants: There may be instances where you discuss or recall times you have recognised the person you care for suffering. This is a potentially upsetting topic. If at any time you become upset during the interview, you will be asked whether you would like continue with the interview or leave a little early. In either instance you will be invited to debrief with the PI after the interview. The PI has experience working with people with dementia and their families.

No details given in the interview will be disclosed to others or published in a form that can identify you. However if you reveal something that suggests that a vulnerable person or persons may be in imminent danger, or you reveal suspected

acts of abuse or wilful neglect then the ward clinical manager will be contacted so that appropriate action can be taken. This will only ever be done with your prior knowledge.

Time commitments: The interview will be conducted by the principal investigator and will last up to 30 minutes.

Interview location: The interview will take place at either St James's University Hospital or The University of Leeds. The location can be chosen by yourself dependant on which is the most convenient. Your chosen location will be confirmed at least one week before the interview date.

Payments: You will not be paid to take part in this study.

Participants rights: It is your decision whether you chose to take part in this study or not, participation will not affect your rights, or the treatment received by the person you care for. Your consent to participation can be withdrawn at any time up to or during the interview. It is also possible to request the withdrawal of specific comments after the interview has ended up until the time analysis has begun. To withdraw from the study please let the principal investigator know at any time using the details below. If you withdraw from the study after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for comments to be withdrawn retrospectively, the specified extract will be deleted from the transcript. It will be noted on your consent form that exerts have been deleted, but it will not specify details of the deleted comments, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: hssgcr@leeds.ac.uk.

As we do not store your personal contact details, we will not contact you as a standard mater with the results of the interviews, however if you would like further information please do not hesitate to contact Dr Crowther on the email address above.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 18 - Distress recognition tool feasibility study, stakeholder interviews, carers consent form.

DISTRESSED - A feasibility study of a novel distress recognition tool
Feedback from primary stakeholders - carers consent form (version 2, 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ

email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Please read 'DISTRESSED – feasibility study feedback from primary stakeholders carers participant information sheet' before continuing with this form.

Key point summary of the project:

- Interviews will be informal and will explore your views on the Distress Recognition Tool.
- Interviews will be held at a hospital or university location convenient to you, and will take around 30 minutes.
- Every precaution will be taken to protect your confidentiality at all times.
- If you disclose information that suggests a vulnerable person or persons may be in imminent danger, or you reveal suspected acts of abuse or willful neglect then the ward clinical manager will be contacted. This will only ever be done with your prior knowledge.
- Please refrain from disclosing any identifiable patient information.
- If at anytime you are distressed by the interview content a formal debrief will be available to you.
- You may withdraw from the study at any time until analysis has begun.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the 'DISTRESED – feasibility study feedback from primary stakeholders interview participant information sheet', explaining the above research project and I have had the opportunity to consider the project, ask questions about the project and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis has begun without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. Details of how to withdraw are given on the participant information sheet.	
I agree to participate in 'DISTRESED – feasibility study feedback from primary stakeholders interview' as set out in the participant information sheet.	
I agree for the interview to be audio recorded, transcribed and stored as set out in the 'DISTRESED – feasibility study feedback from primary stakeholders interview participant information sheet'.	
I understand and agree that if I disclose information that suggests a vulnerable person or persons may be in imminent danger, or I reveal suspected acts of abuse or willful neglect then the ward clinical manager will be contacted. This will only ever be done with my prior knowledge	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree for the data collected from me to be stored and used in relevant future research.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	

Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the participant information sheet. A copy of the signed and dated consent form will be kept with the project's main documents which must be kept in a secure location, as set out in the 'DISTRESED – feasibility study feedback from primary stakeholders interview participant information sheet'

Appendix 19 - Distress recognition tool feasibility study, stakeholder interviews, healthcare professional participant information sheet.

DISTRESSED - A feasibility study of a novel distress recognition tool
Feedback from primary stakeholders – healthcare professionals participant information sheet (version 2, 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

Principal investigator: Dr George Crowther, Clinical Lecturer, Old Age Psychiatry, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ

Email: hssgcr@leeds.ac.uk   Tel: 07703288239

Project supervisor: Professor Mike Bennett, Leeds Institute of Health Sciences, Charles Thackrah Building, Clarendon Road, University of Leeds, LS2 9LJ.

Email: m.i.bennett@leeds.ac.uk   Tel: 01133434858

IRAS number: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Description: You are invited to feedback on the Distress Recognition Tool (DRT) which has recently been used on the ward you work on. It is hoped that the DRT can then be refined before undergoing further trials to test its accuracy.

This study is being conducted by the principal investigator (PI) Dr George Crowther, and forms part of a postgraduate degree research project at the University of Leeds. A NHS Research Ethics Committee and the Leeds Teaching Hospitals Trust Research and Development Department have approved it.

Procedures: Using staff opinion and experience in LTHT we have developed a very simple screening tool, the Distress Recognition Tool (DRT) for all staff to use on a regular basis to help identify people in distress who cannot communicate their need effectively due to dementia. This tool has been in use on the ward you work on for the last month. With your permission we would like to know your opinion on the good and bad points about this tool so that it can be improved. This will involve attending a short interview to discuss the tool. The interview will be relaxed to allow you to speak freely. So that your opinions can be accurately recalled the interview will be audio recorded on a Dictaphone and the principal investigator may take some notes as you speak. After the interview the recording will be stored as a password protected audio file on the PI's password protected drive on the University of Leeds secure server. It will be deleted from the Dictaphone device at the earliest possible opportunity (at latest, the evening of the day of recording). The conversations from the interview will then be transcribed in full, to enable the PI to recall, recognise and understand your opinions after the interview has finished.

Interviews with varying healthcare professionals and the carers of people with dementia will be held, all following the same structure. After the interviews groups are completed the opinions and comments will be collated so that common themes can be recognised, and suggestions can be made that might improve the tool.

Your confidentiality: All of your responses will be kept confidential. Any personal details provided will be kept separately from the audio recordings and recording transcriptions. Any person identifiable data on the audio recording (for example the ward you work on, or position you hold within the hospital), will be deleted from the transcript at the point of transcription. Once the audio recording is transcribed it will be kept only in a password protected file on the secure University of Leeds server, accessible only to Dr Crowther.

All electronic data (transcriptions etc.) will be kept in a password protected file on the secure University of Leeds server. Any written data (for example the consent form) will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project written and electronic data will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

It is hoped that the results of this study will be written up as part of the PI's postgraduate research degree thesis and disseminated so that others can benefit from the knowledge acquired. Dissemination will be done via the thesis and posters or presentations given at academic meetings both locally and nationally, and papers published in academic journals. As part of this process the principal investigator may wish to use opinions expressed in the interview or direct quotes taken from the groups. Any information used will be anonymised and your personal details will never be published.

Others confidentiality: At times in the interview you may wish to discuss specific cases that help illustrate your opinions. In this instance please do not to disclose any information that could potentially identify a person with dementia or their carer. If during the interview identifiable information is disclosed then the session will be paused and the audio recording wound back to before the identifiable information was disclosed. You will be asked not to use the identifiable information again, before we continue. The identifiable information will be recorded over, thus deleting it. If patient identifiable information is only discovered on transcription it will be removed from the transcript. In this instance you will not be informed of any removal of information.

Risks to participants: There may be instances where you discuss or recall times you have recognised patients' suffering, but have been unable to help for one reason of another. This is a potentially upsetting topic. If at any time you become upset during the interview, you will be asked whether you would like continue with the interview or leave a little early. In either instance you will be invited to debrief with the PI after the interview. The PI has experience working with people with dementia and in training hospital staff to care for people with dementia.

No details given in the interview will be disclosed to others or published in a form that can identify you. However if you reveal something that suggests that a vulnerable person or persons may be in imminent danger, or you reveal historic acts of abuse or wilful neglect then your clinical manager will be contacted so that appropriate action can be taken. This will only ever be done with your prior knowledge.

Time commitments: The interview will be conducted by the principal investigator and will last up to 30 minutes.

Interview location: The interview will take place at either St James's University Hospital or The University of Leeds. The location can be chosen by yourself dependant on which is the most convenient. Your chosen location will be confirmed at least one week before the interview date.

Payments: You will not be paid to take part in this study.

Participants rights: It is your decision whether you chose to take part in this study or not, participation will not affect your employment rights. Your consent to participation can be withdrawn at any time up to or during the interview. It is also possible to request the withdrawal of specific comments after the interview has ended up until the time analysis has begun. To withdraw from the study please let the principal investigator know at any time using the details below. If you withdraw from the interview after signing the consent form, it will be noted on your consent form that you have chosen to withdraw and the date of withdrawal. If you wish for comments to be withdrawn retrospectively, the specified extract will be deleted from the transcript. It will be noted on your consent form that exerts have been deleted, but it will not specify details of the deleted comments, the date of the data destruction will also be recorded. These written details will be kept in a locked cabinet inside in a University of Leeds office, which is also locked when unoccupied. After the end of the project this information will be securely archived and scheduled for destruction 10 years later. All data storage and use will comply with the data protection act (1998), and the University of Leeds's Information Security Policy.

Contact information: If you have any questions concerns or complaints about this study please contact the principal investigator, Dr George Crowther on: hssgcr@leeds.ac.uk.

As we do not store your personal contact details, we will not contact you as a standard mater with the results of the interviews, however if you would like further information please do not hesitate to contact Dr Crowther on the email address above.

Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints that cannot be directed to the principal investigator please contact the Leeds Teaching Hospital Trust Research and Innovation Department on: 0113 39 20154.

Appendix 20 - Distress recognition tool feasibility study, stakeholder interviews, healthcare professional consent form.

DISTRESSED - A feasibility study of a novel distress recognition tool
Feedback from primary stakeholders – healthcare professionals consent form
(version 2, 25/10/16)

Full Research title: Dementia **I**npatient **S**tudy on **T**he **R**ecognition and **E**valuation of **S**igns **S**ignalling **E**motional **D**istress (DISTRESSED). A feasibility study to observe the use and usefulness of a novel distress recognition tool.

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IRAS: 216613

LTHT R&I number: LP16\87666

Research ethics committee approval number:

Please read the 'DISTRESSED – feasibility study feedback from primary stakeholders healthcare professionals participant information sheet' before continuing with this form.

Key point summary of the project:

- Interviews will be informal and will explore your views on the Distress Recognition Tool.
- Interviews will be held at a hospital or university location convenient to you, and will take around 30 minutes.
- Every precaution will be taken to protect your confidentiality at all times.
- If you disclose information that suggests a vulnerable person or persons may be in imminent danger, or you reveal historic acts of abuse or willful neglect then your clinical manager will be contacted. This will only ever be done with your prior knowledge.
- Please refrain from disclosing any identifiable patient information.
- If at anytime you are distressed by the interview content a formal debrief will be available to you.
- You may withdraw from the study at any time until analysis has begun.

	Add your initials next to the statement if you agree
I confirm that I have read and understand the 'DISTRESSED – feasibility study feedback from primary stakeholders participant information sheet', explaining the above research project and I have had the opportunity to consider the project, ask questions about the project and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until data analysis has begun without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. Details of how to withdraw are given on the participant information sheet.	
I agree to participate in the 'DISTRESED – feasibility study feedback from primary stakeholders interview' as set out in the participant information sheet.	
I agree for the interview to be audio recorded, transcribed and stored as set out in the 'DISTRESED – feasibility study feedback from primary stakeholders interview participant information sheet'.	
I understand and agree that if I disclose information that suggests a vulnerable person or persons may be in imminent danger, or I reveal historic acts of abuse or willful neglect then my clinical manager will be contacted. This will only ever be done with my prior knowledge	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree for the data collected from me to be stored and used in relevant future research.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	

Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the participant information sheet. A copy of the signed and dated consent form will be kept with the project's main documents which must be kept in a secure location, as set out in the 'DISTRESED – feasibility study feedback from primary stakeholders interview participant information sheet'.

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