

**Understanding what supports dementia-friendly  
environments in general hospital settings: a realist  
evaluation**

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## Abstract

**Background:** Improving care for people living with dementia when they are admitted to hospital is a national priority. Interventions have been designed and implemented to support staff to improve how they provide care to patients with dementia. However, there is limited understanding of how these interventions work in practice and what the outcomes are for patients and their family carers.

**Objective:** To develop, test, and refine a theory-driven explanation of what supports hospital staff to provide dementia-friendly care and with what outcomes for people living with dementia and their carers.

**Method:** A two-phase study design employing realist methodology. Phase one was a realist review which combined evidence from stakeholder interviews and literature searches. Phase two used realist evaluation to analyse data collected from two NHS Hospital Trusts in the East of England to test the theory developed in phase one.

**Findings:** Initial scoping in the realist review identified three candidate theories which structured the literature searches and analysis. Six related context-mechanism-outcome configurations were identified and collectively made the initial programme theory. The review found that single strategies, such as dementia awareness training, would not on their own change how staff provide care for patients with dementia. An important context was for staff to understand behaviour as a form of communication. Organisational endorsement for dementia care and clarity in staff roles was important for staff to recognise dementia care as a legitimate part of their work.

The realist evaluation refined the programme theory. While the study sites had applied resources for patients with dementia differently, there were crosscutting themes which demonstrated how key mechanisms and contexts influenced staff actions and patient outcomes. When staff were allocated time to spend with patients and drew on their knowledge of the patient with dementia and dementia care skills, staff could provide care in ways that reassured patients and recognised their personhood. However, accepted organisational and social norms for care practices influenced whether staff considered providing skilled dementia care was an important contribution to the work on the ward. This impacted on how staff prioritised their work, which influenced whether they recognised and addressed patient needs such as pain or hunger, made attempts to reduce distress, and if patients and carers considered they were listened to. Organisational focuses, such as risk

management, influenced how patient need was defined and how staffing resources were allocated. Staff commitment to continuing in dementia care was influenced by whether or not they valued dementia care as skilled work.

Discussion: Single strategies, such as the use of dementia awareness training, will not on their own improve the outcomes for patients with dementia when they are admitted to hospitals. In addition, attention needs to be paid to the role of senior managers and their knowledge of dementia to support staff to provide care in ways that recognise the needs of the person. The way dementia care is valued within an organisation has implications for how resources are organised and how staff consider their role in providing dementia care. Evidence from observations demonstrated that when staff are supported to provide good dementia care, patients experienced positive outcomes in terms of their needs being addressed and reducing distress. Dementia care needs to be recognised as skilled work by the staff and the organisation.

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## Glossary of terms

**1:1:** Member of staff assigned to care for patients with dementia who need additional support.

**Bay:** The area on a hospital ward where patients are cared for.

**Behaviours that challenge:** A range of behaviours that patients with dementia can exhibit which complicates the delivery of care for their acute condition. These behaviours are understood as a communication of an unmet emotional, social, physical, or medical need.

**Carer:** A person who normally has responsibility for supporting the person living with dementia. This can be a family member or friend who is not performing the role as the employee of an organisation.

**Change agent:** A member of staff who supports the implementation of an intervention.

**Dual-frailty ward:** A ward where staffing resources are organised to address both physical and mental health needs to deliver best-practice care for people living with dementia and/or delirium.

**General hospital:** A type of hospital with an emergency department that can manage many types of acute and chronic conditions.

**Intervention:** Term used to include initiatives, interventions, and programmes which aim to support staff work well with patients with dementia.

**Neuropsychiatric Inventory:** A tool for recording behavioural and mood symptoms of people living with dementia, completed with a caregiver.

**Patient with dementia:** A person living with dementia who has been admitted to general hospital. It is recognised that this term can be contentious as it has implications for the person's role in their care and contribution in decision making. However, in this study it is used as a concise way to express that the person living with dementia is being treated in a particular context for care, i.e. general hospital.

**Person-centred care:** A model of care that places the person at the centre of care.

**Research network monitors:** A group of volunteers from the Alzheimer’s Society who monitored the progress of the research and provided insight from their own experiences of caring for relatives with dementia.

**Stakeholder:** In this study, a stakeholder was defined as a person with experience of designing, implementing, using, or receiving an intervention to improve dementia care.

**This is me:** An Alzheimer’s Society booklet used across care settings which details biographical information about a person’s interests, preferences, and routines that can be used to inform care planning.

## List of abbreviations

**4AT:** Rapid assessment test for delirium

**AMTS:** Abbreviated Mental Test Score

**CQUIN:** The Commissioning for Quality and Innovation framework

**DoLS:** Deprivation of Liberty Safeguards

**FN:** Field note

**GP:** General Practitioner

**HCA:** Healthcare assistant

**MMSE:** Mini-Mental State Examination

**NHS:** National Health Service

**NICE:** National Institute of Clinical Excellence

**PRN:** Pro re nata (when necessary)

**RAMESES:** Realist And Meta-narrative Evidence Syntheses: Evolving Standards

**RCN:** Royal College of Nursing

**RN:** Registered Nurse

**SN:** Student Nurse

**VERA:** Validation, emotion, reassurance, activity

## Introduction

This study aimed to understand how dementia-friendly healthcare in general hospitals was supported, and with what outcomes for patients with dementia and their carers. I was motivated to research this from a longstanding interest in mental health, experience in researching healthcare services for older people, and the growing area of work around dementia-friendly communities. In particular, I was interested in how notions to improve the inclusion and accessibility of healthcare for people living with dementia fitted with the values of complex, bureaucratic organisations which predominantly focus on physical and medical health concerns. These seemingly conflicting interests highlight the context-dependent nature of influencing change to care practices and is compatible with realist inquiry as the research method for the study.

My background is in psychology (BSc in Psychology and MSc in Mental Health Studies). I have worked as a research assistant investigating healthcare service delivery for older people living in their own homes and in care homes. My previous research experiences have focused on primary care.

## Rationale for the research question

People living with dementia are more likely to experience complications during their admissions to general hospitals, which has implications for their independence and health at discharge (Alzheimer's Society, 2009). These complications are considered to occur, in part, due to factors related to the general hospital environment, the way services are organised, and staff's ability to provide care that recognises the impact dementia has on a person (Cowdell, 2010). The primary reason for hospital admission is often not related to the person's dementia, and as such dementia care is of a lower priority than caring for the person's acute medical and physical health needs (Clissett et al., 2013). Limited understanding of dementia and how to work with patients with dementia can lead to inappropriate care or treatment, such as the use of antipsychotics for behaviours that challenge (White et al., 2016). There has been a national drive to improve the quality of care for patients with dementia in general hospitals with the aim of improving their outcomes. The increased focus on dementia care in general hospitals has resulted in the implementation of strategies and interventions that aim to create dementia-friendly healthcare environments in general hospitals (Department of Health, 2015; Health Education England, 2016). However, to date, there has been limited evaluation of these interventions, and even less

understanding of how they encourage staff to provide care that is dementia-friendly, or what the outcomes are for people living with dementia and their families. In understanding how context influences staff motivation to provide dementia-friendly care, and what the outcomes of this are for patients, it is possible to improve the design of interventions and the likelihood of their uptake in practice.

## Intervention

Interventions, also known as programmes, initiatives, approaches, or tools, aim to influence a change in behaviour to achieve a desired outcome. For the purposes of this study, they will be referred to under the rubric of intervention. In realist inquiry, it is not the intervention itself that brings about a change in behaviour, rather it is how the inherent resources an intervention provides and how the context interventions are implemented into interact with the reasoning of those using the interventions that will affect outcomes (Pawson and Tilley, 1997).

The concept of what constitutes an intervention in realist evaluations of healthcare has been applied broadly, covering interventions aimed at organisational level, service level, and patient level (Herepath et al., 2015). For example, Greenhalgh et al. (2009) evaluated a modernisation intervention aimed at whole-scale transformation in healthcare services, Dalkin et al. (2016) investigated how palliative care registers are used when working with people with non-malignant diseases, and Clark et al. (2005) investigated patients experiences of cardiac rehabilitation. In terms of what constitutes a dementia-friendly intervention for this study, these are understood as tools, approaches, and interventions designed to provide care in ways that address the dementia-related needs of people living with dementia when they are admitted to general hospital. This includes the use of biographical tools, staff with expertise in dementia care, training and education, and modifications to the environment.

For the purposes of this study the definition of an intervention does not include practice development, which is a methodology for transforming healthcare cultures through a continuous process of improvement that encourages the emancipation of individuals (McCormack and Garbett, 2003), and has been the subject of a realist review (McCormack et al., 2007).

## Environment

The environment of a general hospital ward can include the physical environment and the psychosocial environment. The physical environment in general hospital wards refers to man-made structures and adaptations including; ward layout and how the space is organised, flooring, lighting, access, furniture, signage, and colour schemes and contrast (Day et al., 2000). The psychosocial environment describes the social organisation and the emotional atmosphere of the ward (Edvardsson et al., 2012; Prato et al., 2018). This includes ward routines and activities, and whether the ambiance is inclusive, supportive, calm, and welcoming.

In recent years, there has been financial support for some general hospitals to improve the physical environment of wards such as refurbishments, the use of wayfinding design and signage, and attention to colour and contrast (Waller et al., 2013). Such adaptations to ward environments are recognised as influencing patient outcomes such as wellbeing, orientation, and safety (Day et al., 2000; Waller et al., 2013). However, studies also highlight the importance of the psychosocial environment on patient outcomes (Borbasi et al., 2006; Edvardsson et al., 2012; Prato et al., 2018). While improvements to the physical environment can help to reduce sensory overload and support independence, general hospital staff have an important role in maintaining a calm atmosphere where patients feel safe (Edvardsson et al., 2012; Porock et al., 2015; Scerri et al., 2015). As such, the concept of environment for this study encapsulates the built environment, the psychosocial environment, and considers how activities within the ward impact on staff responses and patients outcomes.

## Flow of the thesis

This dissertation is formed of five chapters. Chapter one describes the development of dementia-friendly concepts and how it can be applied in healthcare settings. Some of the complexities for treating people living with dementia in general hospitals are set out, and there is discussion of implementing interventions with reference to change agents and social influence theory.

Chapter two discusses realism as a research methodology and how the concepts are applied in this project. It describes the methods of data collection and analysis for both the realist review and the realist evaluation. The process for developing, testing, and refining the programme theory is

explained. A critical review of realist inquiry examines some of the strengths and limitations of the methodology. Finally, I discuss research dilemmas I faced throughout the study, and the way data collection methods were designed to adhere to the principles of realist methodology.

Chapter three sets out the evidence used in the realist review to develop the programme theory. It describes the three stage process from initial exploration of current research supported by interviews with stakeholders, to the development of a programme theory consisting of six context-mechanism-outcome configurations. This work was taken forward in the realist evaluation, the findings from which are discussed in chapter four.

Chapter four discusses evidence from the realist evaluation which tested and refined the initial programme theory developed in the review. It explains how the context-mechanism-outcome configurations were modified from the evidence, and summarises the components of the refined programme theory.

Chapter five discusses the thesis in light of the findings from this study and related literature. It details this study's contribution to understanding what works, for whom, and in what circumstances, for staff to practice dementia-friendly healthcare, and how this influences outcomes for patients with dementia and their carers.

## Chapter one: Background

In this chapter I will set out key considerations for people living with dementia when admitted to general hospital, the concept of dementia-friendly, and consider its application in general hospitals. A discussion of person-centred care, behaviours that challenge, pain, and managing risk in patients with dementia will provide an outline of some of the complex issues around providing good dementia care in general hospitals. There will be a discussion about the implementing of interventions in general hospital settings, with reference to the use of education and training, change agents and social identity theory. Finally, I will set out the aims of the research with reference to specific objectives and questions for both phases of the study.

### Admission to general hospital for people living with dementia

Admission to general hospital is a difficult and frightening experience for people living with dementia. Environments are busy and noisy, multiple staff are involved in patient care, ward routines can be inflexible, staff may not understand a person's needs, and restrictions on visiting can limit contact to people who provide them with reassurance and comfort. Services and the staff providing care for patients with dementia are increasingly aware of the complexity in addressing an acute condition while meeting the specific needs of a person's dementia (Alzheimer's Society, 2009; Alzheimer's Society, 2016). Wide recognition of the disparities in healthcare outcomes for people living with dementia admitted to general hospital has led to a national drive to prioritise dementia on the healthcare agenda (Department of Health, 2009). In response to this, interventions have been developed and implemented with the aim of improving services for patients with dementia.

### Dementia

Dementia is the umbrella term for a range of long-term conditions which include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. All are characterised by progressive cognitive decline in areas including, but not restricted to, memory, perception, language, and decision making. These impairments impact on a person's ability to engage in social situations and perform day-to-day activities (World Health Organization, 2010). In the UK, it is estimated there are currently around 850,000 people living with dementia (Alzheimer's Society, 2014). While many factors have been suggested to contribute to the development of the condition, including genetic and life style influences (Livingston et al., 2017), age is recognised as a major risk factor: 80% of dementia occurs in people aged 75 or over (Carone et al., 2014).

## General hospital and dementia

The prevalence of dementia in general hospital patients aged over 70 is high, with estimates ranging from 25% to 40% in this patient group (Alzheimer's Society, 2009; Royal College of Psychiatrists, 2005; Sampson et al., 2009). This variation reflects a lack of consistency in diagnosing dementia (Sampson et al., 2009) and recording dementia diagnoses in hospital notes (Burn et al., 2018). Dementia is rarely the primary reason for admission to general hospital, and patients with dementia commonly have co-morbid conditions (Alzheimer's Society, 2009; Alzheimer's Society, 2016; Bunn et al., 2014a; Poblador-Plou, 2014; Royal College of Psychiatrists, 2013). As a result, dementia care is viewed as low priority and time consuming for hospital staff (Moyle et al., 2011). The quality of inpatient services for patients with dementia vary across the country and outcomes have been widely reported as inequitable when compared to outcomes for people without cognitive impairments (Royal College of Nursing, 2013; Royal College of Psychiatrists, 2017). Patients with dementia are vulnerable to hospital-acquired complications, with higher rates of adverse incidents reported than in patients without cognitive impairment (Bail et al., 2013). Falls, infections, poor nutrition and hydration, and the onset of delirium impact on the length of stay and functional abilities for patients with dementia, which may result in a care home admission (Bail et al., 2015; Bunn et al., 2014b; Orsitto et al., 2009).

Studies have identified a number of reasons for the disparity in health outcomes for patients with dementia including:

- a lack of leadership at both Trust level and senior clinician level for dementia has meant improvements in dementia care have been a low priority for general hospitals (Royal College of Psychiatrists, 2013);
- inadequate knowledge and training in the healthcare workforce for dementia and dementia care (Elvish et al., 2014; Surr et al., 2016);
- the complexity of assessing the risk and benefits of treatment options. For example, issues around the inclusion of people living with dementia in the management of their co-morbid conditions (Bunn et al., 2014a);
- widespread use of detrimental care practices, such as the use of antipsychotics for behavioural management (White et al., 2016);
- negative attitudes, stigma, and discrimination towards patients with dementia (Benbow, 2012; Cowdell, 2010; Swaffer, 2014);
- environments which are confusing for patients with dementia (Waller and Masterson, 2015).

The English National Dementia Strategy and subsequent Prime Minister's Challenges on dementia (Department of Health, 2009; Department of Health, 2012a; Department of Health, 2015) set out ambitions to improve the quality of care for people living with dementia across health and social care, with key objectives for general hospitals. The focus of improvements were: education and training to develop a dementia aware healthcare workforce; leadership that supports quality improvements in dementia care; development of care pathways; and involvement of liaison mental health teams in assessments and care planning. Organisations, such as the Dementia Action Alliance and The Kings Fund, have supported hospital commitments to improve their care provision and environment by sharing best practice and funding discrete projects (Dementia Action Alliance, 2014; Waller et al., 2013). While hospitals are making progress in addressing organisational issues, such as leadership, training, and the use of mental health liaison services, staff and carers report variability in services at patient level (Royal College of Psychiatrists, 2017). Areas highlighted for improvement included: food provision; the collection and use of personal information in care planning; access for staff to specialist dementia support, especially during out-of-hours; and involvement of patients with dementia in decision making.

The increased focus on dementia care in general hospitals has resulted in the implementation of strategies and interventions that aim to create dementia-friendly healthcare environments in general hospitals (Department of Health, 2015; Health Education England, 2016).

## Dementia-friendly

The concept of dementia-friendly has been applied to various aspects of physical and social environments that promote accessibility, inclusion, and acceptance for people living with dementia (Crampton, 2012; Keady et al., 2012; Lin and Lewis, 2015; World Health Organization, 2012). Programmes to develop dementia-friendly communities have included building awareness and understanding of the condition across generations, organisations, and the general public (Alzheimer's Society, 2017; Dementia Action Alliance, 2017), supporting the independence and safety of people living with dementia (Mitchell and Burton, 2010), and encouraging involvement from people living with dementia to improve services in their local areas (Dementia Alliance International, 2017; Dementia Empowerment and Engagement Project, 2017). The term, dementia-friendly, is not without controversy, with some commentators highlighting this could distract from real investment in services for people living with dementia (Shakespeare et al., 2017) and side-line important issues such as rights (Rahman and Swaffer, 2018). The developing language and impetus

for improving inclusion and accessibility for people living with dementia as a social movement based on disability rights is gaining momentum (Mental Health Foundation, 2015).

In evaluating what elements were important for creating dementia-friendly communities, The Joseph Rowntree Foundation developed the Four Cornerstones Model (Crampton, 2012). The model identified the importance of place, people, networks, and resources, with the voice of the person with dementia at the centre of the model. In health care, the SPACE model draws on similar principles but considers the specific context of health care. It was developed by The Royal College of Nursing (RCN) for assessing whether general hospital environments were dementia-friendly (Royal College of Nursing, 2013). A survey of healthcare professionals, people living with dementia, and their carers highlighted key areas for improving the caring environment of general hospitals, forming the five areas of focus for the SPACE principles:

1. Staff who are skilled and have time to care
2. Partnership working with carers, family and friends
3. Assessment and early identification of dementia
4. Care plans which are person centred
5. Environments which are dementia-friendly

(Royal College of Nursing, 2013)

When considered at patient level, dementia-friendly healthcare is the practice and organisation of care that is aware of the impact dementia has on a person's ability to engage with services and manage their health. It promotes the inclusion of people living with dementia and their carer in treatments, care decisions, and discussions, with the aim of improving outcomes for the patient and carer (Department of Health, 2009; Department of Health, 2012a; Department of Health, 2015; Royal College of Nursing, 2013).

Interventions to promote dementia-friendly healthcare environments have been diverse in terms of their design and application in practice (Dewing and Dijk, 2014; Mayrhofer et al., 2014a; Mayrhofer et al., 2014b). Some were developed in response to the National Dementia Strategy (Department of Health, 2009), and The Prime Minister's Challenge (Department of Health, 2012a; Department of Health, 2015), but others predate these. Examples of interventions include dementia awareness training of healthcare staff, and training in dementia appropriate care (Health Education England, 2015), the development of resources to support staff in their assessments and care of people with dementia (Williams, 2011), and the modification of the environment to reduce confusion and

increase orientation within the ward to promote independence (Waller, 2012). Such schemes have drawn on a range of evidence sources including consensus methodologies and evidence on what supports person-centred care informed from studies in care homes. They have been incentivised by policy driven imperatives, such as the Commissioning for Quality and Innovation (CQUIN) targets, to improve the identification of people living with dementia (Department of Health, 2012b).

These interventions have been commissioned and implemented with the aim of improving outcomes for people living with dementia and their carers. However, rigorous evaluations of the interventions are lacking (Dewing and Dijk, 2014). Their success and sustainability is threatened by staff turnover, lack of coordination between health and social care organisations, funding restrictions, and inadequate management support (Dewing and Dijk, 2014). Currently there are few studies evaluating interventions, but measures of effectiveness have been recorded. They have primarily focused on economic costs, length of admission, readmission rates, and place of discharge. Evidence of effectiveness of interventions, as defined by these terms, has been limited, and, arguably, these measures may be inappropriate for this patient population (Goldberg et al., 2013). Further encouraging results have been demonstrated in qualitative studies investigating patient, carer, and staff experiences of interventions (Clissett et al., 2013; Spencer et al., 2013), although opportunities for providing person-centred care were not always optimised and were not found to be standard practice across staff members (Clissett et al., 2013).

There is a need to understand what it is about an intervention that will support awareness, understanding, and inclusion for people living with dementia when admitted to general hospital, what it is about the settings that influences staff use of best practice in dementia care, and how this influences outcomes for patients with dementia and their carers. Realist approaches (Pawson, 2006b; Pawson and Tilley, 1997) recognise that the effectiveness of programmes to address the known problems of being a patient with dementia is contingent not only on specific training, for example, in being dementia aware, but also on “contextually situated decision making” (Rycroft-Malone, 2008).

### Complexities in caring for patients with dementia in general hospitals

Four key issues increase the complexity of caring for patients with dementia in general hospitals. These are the provision of person-centred care, behaviours that challenge staff and other patients,

the recognition and management of pain, and managing risk in ways that recognise patient preferences. These are discussed below.

### Providing person-centred care in general hospitals

Person-centred practices for people living with dementia are recognised as best practice in the National Institute for Health and Care Excellence (NICE) guidelines (2006) and can be considered a fundamental aspect of dementia-friendly healthcare provision. Influenced by Carl Rogers' work in developing person-centred therapy (Rogers, 1974), Kitwood (1997) developed a model for dementia care that promoted the importance of personhood. He postulated that personhood is 'bestowed' on a person by others. His work has been highly influential, and further developed to incorporate the relational aspects that are important in dementia care to recognise the role of the caregiver, as well as the person with dementia (Brooker, 2007; McCormack, 2004; Nolan et al., 2004).

Person-centred care, in terms of its use in dementia care, is broadly understood as placing the person with dementia at the centre of care provision, and recognising their individual needs and rights (Brooker, 2007). However, understanding of person-centred care and its application in practice has been inconsistent (Dewing and McCormack, 2017; Moyle et al., 2013). A lack of understanding of the concepts in person-centred care, or the ability to adequately articulate them, has led to different interpretations (Brooker, 2003). Dementia Care Mapping (DCM) is an observational tool which records the processes of care and the outcome of those processes for people living with dementia in terms of wellbeing (Innes and Surr, 2001). It has provided a way of operationalising the concepts to evaluate and improve the quality of care. Trials in care homes have demonstrated how the use of DCM or training in person-centred care, which they define as a holistic approach to care that supports the personhood of people living with dementia, has reduce agitation and anti-psychotic prescribing (Chenoweth et al., 2009; Fossey et al., 2006). However, person-centred care and the use of DCM in general hospitals has yet to be fully realised (Goldberg and Harwood, 2013). The competing demands and values for care by professionals and the organisation they work for may conflict with person-centred practices that aim to support patient preferences (McCormack, 2004). Studies have highlighted these issues, including: the high level of need and monitoring required to support patient safety which impacts on staffing resources and the ability to attend to other patients' needs (Nolan, 2007); the complications of an acute illness combine with the person's dementia exacerbating the person's distress (Borbasi et al., 2006); care philosophies for acute care can conflict with those for dementia care (Clissett et al., 2013); and staff with limited knowledge or skills in dementia care (Turner et al., 2015).

A number of studies in general and rehabilitation hospitals found that while staff profess to value person-centred approaches and considered them useful to their practice, there was limited evidence of the approach being used, with most care remaining task focused (Bolster and Manias, 2010; Goldberg et al., 2014; Innes et al., 2016). Person-centred care has been observed to occur as discrete moments rather than being integral to staff practice (Clissett et al., 2013; Ekman et al., 2011; McCormack et al., 2011). For example, Innes et al. (2016) observed that caring interactions were generalised and rushed. This was partially attributed to the challenges of caring for people living with dementia in a busy environment where there were competing patient needs, such as acute illness which was necessary to prioritise. While staff wanted to provide good care to patients with dementia, their capacity to understand care from the patient's perspective was limited by their knowledge of dementia and opportunities to reflect on care. The authors considered that kindness is not enough to work well with the individual and complex needs of patients with dementia. As McCormack et al. (2011) argue, developing and supporting a workforce to provide person-centred care requires sustained commitment from organisations to make person-centred care fundamental to professional practices, to thus ensure person-centred care is not confined to pockets of activity. They highlight workplace culture, a learning culture, and the physical environment as factors that influence person-centred care practices.

Training in person-centred care practices with general hospital staff has demonstrated a change in attitudes to caring for patients with dementia (Surr et al., 2016). However, a higher level of training was needed to increase staff confidence in their ability to care for patients with dementia, and satisfaction for working with patients with dementia (Surr et al., 2016). Whether these outcomes were maintained after training, their impact on care provision, and influence on patient outcomes was not measured. There is a need to understand how training in dementia care is supported within the work environment and encouraged as an essential part of staff work (Turner et al., 2015).

### Behaviours that challenge

Neuropsychiatric symptoms, or behaviours that challenge, are common in people living with dementia (Steinberg et al., 2008), and 75% of those admitted to general hospital will exhibit behaviours that challenge staff during their stay (Sampson et al., 2015). Onset of these behaviours is disruptive for staff and other patients, and are considered to be an expression of an unmet need (Stokes, 2000). The term 'behaviours that challenge' covers a wide range of behaviours that are broadly categorised as psychotic (e.g. hallucinations, delusions), affective (e.g. depression, anxiety),

apathy (e.g. apathy, changes to appetite), and hyperactivity (e.g. agitation, irritability) (Livingston et al., 2017). While some behaviours are more commonly linked to sub-types of dementia, such as hallucinations in dementia with Lewy bodies, they can occur across all dementias, and at all stages of the condition's progression (Kales et al., 2015). Types of behaviours are not specifically linked to internal or external causes, but can represent a number of reasons and differ between individuals, which complicates identification and management of the patient's unmet need (Sampson et al., 2015).

Previously considered a symptom of dementia and an inevitable part of the condition's progression, behaviours that challenge are now considered to be related to expressions of an unmet need (Stokes, 2000) and are exacerbated by the presence of an acute illness or condition such as pain (Closs et al., 2016; Fick et al., 2002). It is now argued that when behaviours are framed as communication, staff can interpret the behaviour as meaningful, seek to understand the cause, and take action (Dupuis et al., 2012). By not pathologising the behaviour, understanding and identification of the deficits within the care approach or the environment can be assessed and addressed.

## Pain

The recognition and treatment of pain in people living with dementia is acknowledged as difficult and often undetected (Ballard et al., 2011; Sampson et al., 2015). Co-morbid conditions for people living with dementia are high (Bunn et al., 2014a) and pain as a symptom of these or acute complaints is common; for example, musculoskeletal conditions such as arthritis, and as the result of falls, pressure sores, and infections (Black et al., 2006). Pain is considered a contributing factor in the onset of behaviours that challenge (Sampson et al., 2015), and can lead to inappropriate prescribing to address the behaviour rather than the pain (Ballard et al., 2011). Where pain is not managed well, this can lead to complications in the treatment and recovery of acute conditions, including reduced functional abilities and reduced quality of life (Lichtner et al., 2015).

For people living with dementia their ability to report pain might be compromised by their cognitive impairment. As such, pain assessment tools which use observation as a method for determining whether or not pain is present have been developed. A large number of tools to assess pain in people living with dementia are in existence (Lichtner et al., 2014). These tools have been developed in specific care settings with specific populations, although their use in research and clinical settings can extend beyond the original context (Table 1).

Table 1: Common pain assessment tools detailing their development by place and population

<b>Tool</b>	<b>Setting originally developed in</b>	<b>Population originally tested with</b>
Abbey Pain Scale (Abbey et al., 2004)	Care Home	Advanced dementia
PAINAD (Warden et al., 2003)	Inpatient dementia special care units (hospital)	Advanced dementia
Doloplus-2 (Hølen et al., 2005)	Care Home	Advanced dementia
NOPPAIN (Snow et al., 2004)	Care Home	Not specified
PACSLAC (Fuchs-Lacelle and Hadjistavropoulos, 2004)	Care Home	Advanced dementia
PADE (Villanueva et al., 2003)	Care Home	Advanced dementia
CNPI (Feldt, 2000)	Hospital	Patients with dementia with hip fractures
ADD Protocol (Kovach et al., 1999)	Care Home	Advanced dementia
DS-DAT (Hurley et al., 1992)	Care Home	Advanced dementia

The Royal College of Nursing (2013) recommend the use of the Abbey Pain Scale (Abbey et al., 2004) or Dolphus-2 pain scale (Hølen et al., 2005) for assessing pain in patients with dementia, although neither were originally designed for use in hospitals. A meta review of the psychometric properties and clinical utility of 28 pain assessment tools found insufficient evidence to recommend any one of the tools for use in particular care settings (Lichtner et al., 2014). Closs et al. (2016), in their study of pain assessment and management in general hospitals, concluded that pain assessment tools had not been designed to consider the way patient care was organised on hospital wards. As such, improving pain detection and treatment would require tools which better suited the multidisciplinary nature of the setting.

## Assessing and managing risk

While patients with dementia are at risk of hospital-acquired complications common to other patients, such as pressure sores, there are specific risks which complicate their care, such as falls, leaving the treatment ward, and removing intravenous catheters and tubes (Cotter, 2005; Robinson et al., 2007; Victor et al., 2014). Some strategies for addressing these risks can restrict patient movement, which has implications for maintaining a patient's other abilities, such as mobility and continence, and can lead to further complications, such as infections and pressure sores (White et al., 2016). Limited understanding of how risk management strategies impact on patient outcomes and competing demands on the ward could influence how risk is addressed. Environmental adaptations can address some of these factors, such as the use of locked entrances to wards to reduce the risk of patients leaving (Zieschang et al., 2010). Staffing resources can be used to monitor patients at risk, however whether this is an effective intervention is influenced by staff experience of working with patients with dementia, their interpretation of their role, and may be implemented without a thorough assessment and understanding of what the patient's needs are (Dewing, 2013).

Balancing the need to minimise harm while recognising the autonomy of the patient is difficult, and for staff in general hospitals caring for patients with dementia, it is complicated by concerns of the consequences of an incident to both the patient and the staff themselves. The safety culture of an organisation can impact on how staff prioritise patient needs, which can lead to reduced attention on functional abilities and psychosocial needs (Dahlke et al., 2017).

## Implementing change

As demonstrated in the above section, there are many considerations staff face when adapting care practices to be more dementia-friendly. The organisation of general hospitals is often hierarchical, with policies which, while important to protect staff and patients, can limit staff autonomy to provide care in ways to meet the needs of patients with dementia. Overcoming the organisational and social contexts to influence change is a complex process (Grol and Grimshaw, 2003). A number of theories from different disciplines, such as adult-learning theories, social influence theories, and organisational theories provide the basis for how change can be addressed and will influence the design of interventions. For example, in developing dementia care training interventions, the aim might be to provide staff with an experiential understanding of what it is like to live with dementia with the aim that they will recognise how they can adapt their work and apply it in practice.

Education and training in dementia and dementia care skills has been a core focus of investment to improve the healthcare workforce's knowledge in dementia care and address negative attitudes towards people living with dementia (Elvish et al., 2014; Mayrhofer et al., 2014a; Surr and Gates, 2017). In 2015, Health Education England published its 'Dementia Core Skills Education and Training Framework' (Health Education England, 2015). The document provided a comprehensive outline of the essential skills and knowledge for dementia care for staff working across health and social care sectors. A three-tier structure aimed to support targeting training as appropriate to staff needs, defined by their anticipated contact and role in care with people living with dementia:

- tier 1 focuses on developing awareness in dementia and dementia care and is recommended for all staff;
- tier 2 addresses the basic skills for staff likely to have contact with people living with dementia;
- tier 3 concentrates on enhanced knowledge for experts and staff with leadership roles.

NHS Trusts across England have been encouraged to use the framework as a basis for staff development, while adapting the information to fit their local needs.

Methods of training delivery for hospital staff vary and include class-based, experiential learning, online courses, workbooks, train-the-trainer models, and the use of experts to provide training on the ward. A recent literature review of training methods found that training which had relevance to staff roles, had practical application, and included understanding the experience of the person with dementia and their carer were the most effective strategies for engaging staff (Surr and Gates, 2017). However, the review was unable to comment on how training influenced changes in practice as evidence for robust post-training follow-up of staff and patient outcomes was limited.

In addition to education and training, charities, not-for-profit organisations, and NHS Trusts have developed tools for identifying patients with dementia and supporting the collection of biographical information which can inform care planning and working well with patients with dementia (Alzheimer's Society, 2013; The Butterfly Scheme, 2018). While these tools have been well received by staff, patients, and family carers, to date there has been no evaluation of their impact on patient care or staff actions for care.

Studies in the diffusion of best-practice recognise that passive processes, such as the use of guidelines, are limited in their ability to change practice (White, 2011). In recognising that

knowledge diffusion and change are social processes, general hospitals have used staff who support the implementation and uptake of interventions as change agents (Draper, 2009; Greenhalgh et al., 2004; Thompson et al., 2006). The term change agent encompasses a variety of roles which are sometimes theoretically interchangeable and sometimes conceptually distinct (Thompson et al., 2006). Terms have included change agent, opinion leader, champion, and resource nurses. The use of change agents for improving dementia care in general hospitals has been promoted in strategy documents and reports. For example, the National Dementia Strategy (Department of Health, 2009) recognised the importance of leadership for dementia care in hospitals to drive forward change and set the organisational agenda for quality improvements to care. To promote changes at ward level, the National Audit of Dementia Care in General Hospitals (Royal College of Psychiatrists, 2013) recommended the use of dementia champions from across the workforce skills mix. Hospitals report incorporating these roles, although their impact on patient care has yet to be fully realised (Royal College of Psychiatrists, 2017). In a review of change agents, McCormack et al. (2013) found that the characteristics of staff performing these roles were poorly described, limiting the ability to identify key features that would support their role. However, they did recognise that the different characteristics would support different activities and different outcomes.

As patients with dementia are admitted across many adult wards in general hospitals for a variety of acute needs (Alzheimer's Society, 2009; Royal College of Psychiatrists, 2017), it is important that staff across specialist disciplines are supported for working with patients with dementia. Social identity theory recognises the influence of group membership on how people perceive themselves and others, and is considered a factor in influencing behaviour (Kreindler et al., 2012). Studies of staff working with patients with dementia in hospitals have found professional groups define themselves in terms of their expertise in comparison with other groups, and maintain priorities for care through actions which reward or punish members' compliance to group norms (Kessler et al., 2010; Schneider et al., 2010). A study of end-of-life care in care homes found that common goals for resident care, and a recognition of the expertise of each professional group involved, could improve collaborative working (Amador et al., 2016).

Due to the complexity of the way that people respond in different situations to the resources inherent in interventions, it is unlikely that any one intervention or theory for change will work across settings. Instead it is important to identify common mechanisms to understand how, and why, outcomes are influenced.

## Research Aims and Objectives

The purpose of the study was to develop and test an evidence-based and context-relevant explanation of how interventions support staff to provide dementia-friendly healthcare in general hospitals. This, in turn, would explain how outcomes for patients with dementia and their carers are influenced. To address this aim, specific objectives were identified for the different phases of the study. The realist review of dementia-friendly interventions was designed to build a programme theory of what supports staff to provide good dementia care in general hospitals. The review protocol and review findings have been published (Handley et al., 2015; Handley et al., 2017) (Appendix 1 and Appendix 2). The specific objectives for phase one were:

1. To understand how and why dementia-friendly interventions in general hospital settings are thought to achieve the desired patient and carer outcomes
2. To understand how and why context influenced the creation of dementia-friendly healthcare environments
3. To develop evidence-based explanations to understand what it is about dementia-friendly interventions in general hospitals that works for people living with dementia and their carers, in what circumstances, and why.

The aim of phase two was to test and refine the programme theory developed in phase one, based on evidence from the two case study sites. The programme theory suggested that:

If staff understand behaviour as communication of unmet needs, there is organisational endorsement of best-practice in dementia care, and clarity in staff responsibilities for patients with dementia (context), this will help reinforce the use of resources to provide good dementia care (mechanism resource). Staff will understand why care needs to be adapted, and consider they have the capacity and capability to make a difference to patient care (mechanism reasoning), causing them to modify care provision (staff outcome) and leading to improved patient outcomes (patient outcome).

Based on this programme theory, the objectives for phase two were:

1. To understand how and why context influences the provision of dementia-friendly care practices
2. To understand how resources to support good dementia care influence outcomes for patients with dementia and their carers

3. To understand how the needs of patients with dementia and their carer are identified and addressed by staff
4. To understand how hospital staff understand dementia-friendly healthcare and what they think supports them to provide good dementia care

## Chapter Summary

The proportion of the hospital patient population with dementia, combined with the inequity of outcomes for this group, has made it a national imperative that improvements for dementia care in general hospitals are addressed. Complicating factors involved in providing good care for patients with dementia include how person-centred care can be applied in general hospital settings, addressing behaviours that challenge through non-pharmacological interventions, improving the recognition and management of pain, and promoting positive risk management strategies. Interventions are being implemented to support staff with these, and other issues, in the care of patients with dementia to provide a service which can better meet their complex acute and psychosocial needs. The evidence-base for such interventions is limited, therefore it is important to understand how, why, and if at all, these resources are influencing practices in dementia care and improving patient and carer outcomes.

## Chapter two: Methodology and methods

In this chapter I discuss the rationale for the study design, and the choice of methods I used for the realist review and realist evaluation. I then provide an overview of realism and the key principles of the approach, including the concepts of context, mechanism, outcome, and programme theory. Following this, I describe in-depth how the concepts and methods used were applied for each phase, with reference to how these correspond with the principles of realist inquiry. I debate the ethical issues that were addressed, and how members of Patient and Public Involvement groups supported the study throughout the process. Finally, I provide a critical review of realist inquiry and discuss some of the decisions and dilemmas I faced using the methodology.

### Study design

The study involved a two-phase study design, which incorporated a realist review in phase one to build a programme theory that was then tested in phase two using realist evaluation (Figure 1). The aims and objectives were outlined in Chapter two (see Research Aims and Objectives, p30).

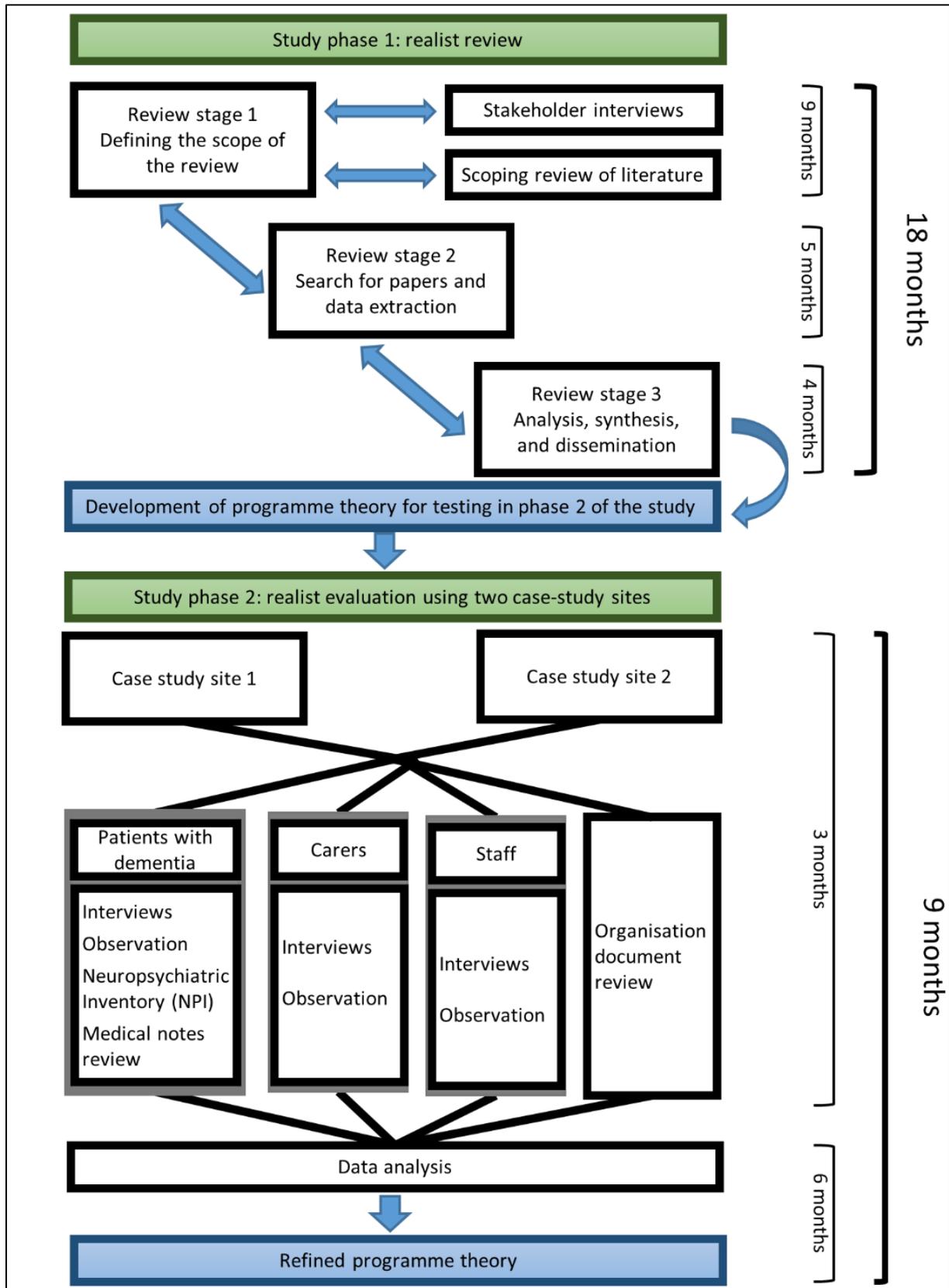
### Conceptual framework

Interventions which aim to improve the care of patients with dementia in general hospitals are complex social programmes as they rely on staff volition for how resources of interventions are used which influences outcomes. In order to understand why these interventions work, or not, it is important to understand how the reasoning of those using them is influenced by context. The decisions staff make for care influence patient outcomes, therefore it was necessary for me to identify a research method that could inform this area of understanding. Experimental design was not considered appropriate for this study as the approach understands the intervention as the cause of outcomes. Additionally, contextual influences are, as far as possible, controlled for, and are not considered part of the explanation. Realist evaluation recognises that interventions will have different degrees of success, which are influenced by the context and explained through mechanisms.

### The rationale for realist inquiry

Pawson (2006b) describes social interventions as “complex systems thrust amidst complex systems”

Figure 1: Overview of study design



(Pawson, 2006b, p35). Complexity is inherent in both design and implementation of interventions supporting dementia-friendly healthcare. They are multicomponent and rely on human agency that is influenced by individual, service, and organisational pressures. Realist inquiry acknowledges these features and incorporates them to develop a theory-driven account of how different aspects influence reasoning and outcomes.

Evaluating interventions has often relied on research methods that allow the comparison of data before and after the introduction of an intervention, often also employing a control group. However, in most general hospitals, interventions to develop dementia-friendly healthcare are already in use. While implementation is widespread, there is limited understanding of how interventions aimed at, for example improving staff knowledge of dementia, influences staff to adapt the way they provide care of patients with dementia, and whether this has an impact on patient outcomes. These interventions are showing promise, however the evidence-base is largely qualitative or draws on service evaluations. This would make a traditional systematic review problematic, as to provide a useful synthesis of evidence there needs to be sufficient high quality studies. Realist review is useful when there is a paucity of evidence as, unlike systematic review where the intervention is the unit of analysis, in realist review the theory is the unit of analysis. This allows for the inclusion of studies reporting findings from different interventions that are linked by theory to contribute to synthesis. Interventions to improve dementia care in general hospitals are heterogeneous by the type of intervention used, such as education, environmental adaptations, and access to dementia experts, and how they have been locally adapted. However, commonalities in the ambitions for their use, such as improved knowledge of working with patients with dementia, provide an understanding through theory to explore the relationship of the factors within the interventions and the circumstances they are being used in.

## Realism

In developing realist evaluation, Pawson and Tilley (1997) drew on realist philosophy to counter the limitations of positivist-based approaches in addressing the 'black box' problem to understand how and why change occurs for complex, social interventions (Astbury and Leeuw, 2010). Realism is a methodological approach for research grounded in the realist philosophy of science (Bhaskar, 1978). As a philosophy of science, realism is broadly understood as positioned between positivism and relativism philosophies (Pawson, 2006b). Ontologically, realism accepts that there is a reality that exists independent of our knowledge and that we understand reality through psychological and social processes (Pawson, 2006b; Sayer, 1984). In applying this understanding to dementia care in

general hospitals, the objective reality is that patients with dementia are admitted to the hospital, however their experience of this and related outcomes are dependent upon how staff approach their care, which will be influenced by many related factors. For example: staff knowledge of dementia; the model of care they use for working with patients with dementia; how dementia care is prioritised within their working environment; and the way patients express unmet needs will all impact on how care is provided and influence the outcomes for the patient. Therefore, in realist research evidence and analysis are not limited to observable events, but seek to understand how events are generated through mechanisms (Astbury and Leeuw, 2010). As mechanisms are 'hidden', our knowledge of them can only ever be partial and therefore, a theory. It is this internal potential of social interventions, the individuals using them, and their association with the circumstances they enter that leads to change (Pawson and Tilley, 1997). Therefore, realist inquiry is concerned with understanding the causal powers and providing an explanation for them.

Pawson and Tilley (1997) describe social interventions as "theories incarnate" (Pawson and Tilley, 1997, p26). By this, they understand that there will be a theory about what the intervention provides and how this is anticipated to lead to change. This theory may or may not be explicitly expressed by those who have designed and implemented the intervention, and may not always reflect how the interventions work in reality (Marchal et al., 2012). The theory should explain how the intervention or group of interventions are thought to encourage change, and then to test and refine the theory through empirical evidence. In terms of this study, a plausible theory, that articulated how the relationship between contexts and mechanisms influence outcomes for patients with dementia in general hospitals, was developed from the existing evidence base. The theory was then tested through primary data. In this way, my research has improved understanding for improving patient outcomes beyond input/output understandings of interventions, such as training, to understand why and how they work, or not (Astbury and Leeuw, 2010).

### Concepts in realist inquiry

Key concepts in realist inquiry are described in Table 2 with references to their use in this study.

Table 2: Key concepts in realist inquiry

<p><b>Context</b> describes the pre-existing circumstances of an environment that an intervention is introduced to. This can include, but is not limited to; psychological, social, organisational, geographical, economic, and political aspects that influence mechanisms and outcomes (Pawson and Tilley, 1997). In this study, contexts included staff and patient characteristics, expectations for care, the ward environment, and organisational policies.</p>
<p><b>Mechanism</b> is key in realist inquiry to explaining why things work or not. Mechanisms are not the interventions themselves, but the resource the intervention provides, (such as knowledge about dementia, skills for working with patients with dementia), and the reasoning of staff using the intervention (such as recognising the benefit of working differently).</p>
<p><b>Outcomes</b> can be the intended or unintended results of the context-mechanism association. Patient outcomes of interest for this study included; patient wellbeing, reduced distress, adverse incidents (such as falls or hospital acquired infection), reduction in the onset of behaviours that challenge, maintenance of functions (such as activities of daily living).</p>
<p><b>Context–mechanism–outcome configuration (CMOC)</b> is the unit of analysis in realist inquiry that specifies the relationship between the elements. It supports the building, testing, and refining of the programme theory. CMOCs are abstracted to the middle-range to ensure they are useful for analysis (Wong, 2017). Multiple CMOCs contribute to the overall programme theory.</p>
<p><b>Demi-regularities</b> Lawson’s (1997) notion of demi-regularities describe the semi-predictable pattern of outcomes. They are useful for understanding how context can affect outcomes. Detecting these patterns within the data was supported by the use of ‘if...then’ statements. For example, if a patient has a high risk of falls, then this will influence the quantity and quality of interactions with staff.</p>
<p><b>Middle range theory</b> Pawson and Tilley (1997) promote the use of middle range theory as a way of making research findings generalisable across studies and settings. Merton (1957) considered explanations should be produced that “are sufficiently abstract to deal with different spheres of social behaviour and social structure so that they transcend sheer description” (p67). In this way, Merton was emphasising how middle range theories could support associations across broad phenomena to link descriptive evidence.</p>
<p><b>Programme theory</b> describes how the different components are related in an explanatory account of what works, for whom, in what circumstances (Pawson and Tilley, 1997).</p>

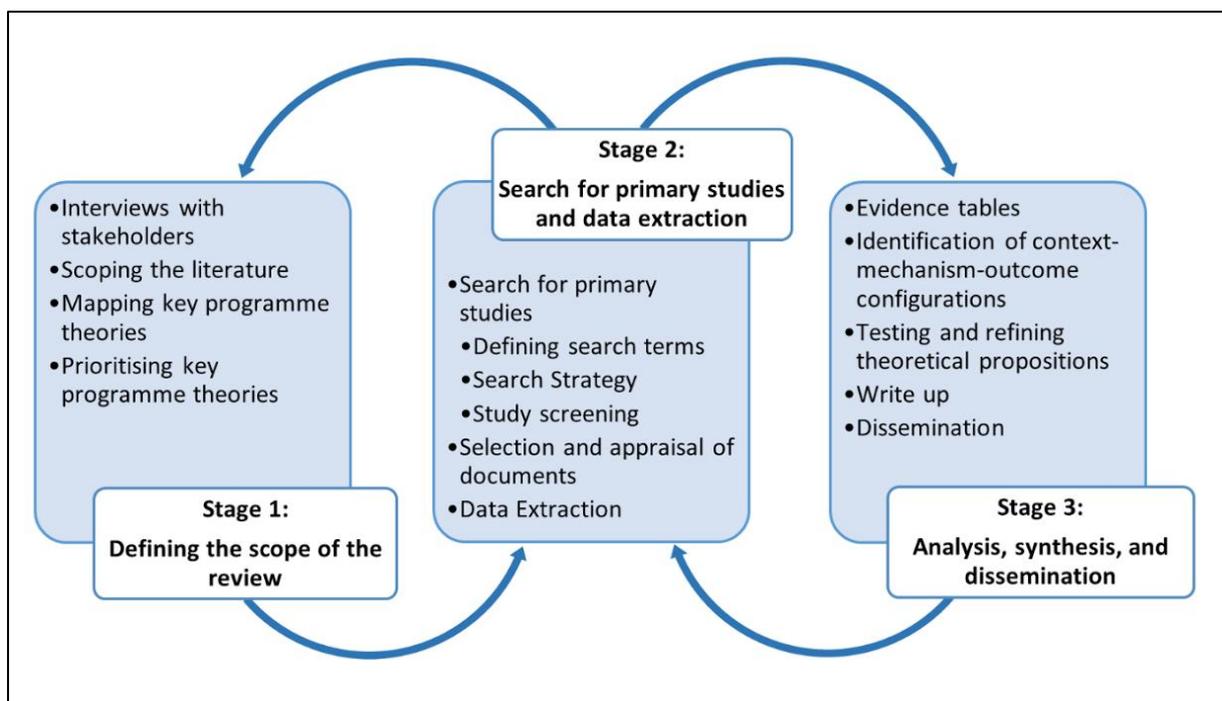
## Phase one: the realist review

Realist review is an iterative process; while there are defined stages to the study these did not necessarily follow a linear process. This realist review was conducted in three overlapping, iterative stages:

1. defining the scope of the review
2. structured searches, screening, and data extraction
3. analysis and synthesis

Each of the stages informed and refined understanding, with sources identified and revisited throughout the review as new interpretations emerged to support theory building (Figure 2).

Figure 2: Iterative stages of the realist review



### Stage one: Defining the scope of the review: concept mining and theory development

This stage was used to refine the direction of the review through evidence-informed decisions that focused the stages that followed. The objectives of stage one were to:

1. identify national and international interventions and approaches to develop dementia-friendly healthcare

2. explore and define theoretical assumptions about how and why interventions were thought to work, (or not)
3. clarify what were understood to be the significant mechanisms for change

Two methods were employed for initial theory development; interviews with stakeholders and a scoping of the literature.

## Stakeholders

Realist review guidelines (Wong et al., 2013) consider the involvement of stakeholders during the scoping stage of the review useful for making sense of the subject area. Pawson (2006b) recommends the involvement of stakeholders throughout the review process. For this study, stakeholders were interviewed once and were not further involved in the development of the emerging context-mechanism-outcome configurations (CMOCs) or building the programme theory. Testing of the programme theory was planned through an expert steering group workshop which did not happen. This event did not occur due to time limitations, but the theory was shared and tested through two channels: 1) with the research network monitors group (see Public Involvement, p87); 2) at a seminar for dementia-friendly healthcare (see AgeNet Seminar, p88). At this preliminary stage, the stakeholders' role was to help to identify, articulate, and formulate propositions. By including stakeholders with different experiences of designing, implementing, using, or receiving interventions to improve dementia care, this helped to develop the theory from different perspectives that would take account of variations in contexts, responses, and outcomes. For the purpose of this study, stakeholder interviews were used to develop insight for how dementia-friendly interventions were thought to work and with what outcomes to complement evidence from the literature scoping (Manzano, 2016). The interviews helped me identify gaps in the scoping of interventions, develop more understanding of how context influenced outcomes, and begin to conceptualise potentially important mechanisms. These interviews supported the development of the candidate theories that would inform the review focus and process. Ethics approval for the interviews was secured from the University of Hertfordshire Ethics Committee (HSK/PG/UH/00339, Appendix 3).

## Recruitment

Stakeholders were defined as people with experience in designing, implementing, using, and receiving dementia-friendly interventions. Stakeholders were purposively sampled from a range of

settings and backgrounds for their ability to support theory building (Table 3 and Table 4). It had been anticipated that more people living with dementia would be included in this stage of the review. Agreement to introduce the study at an Alzheimer’s Society group for people living with dementia had been obtained with the aim of recruiting attendees for interview. However, shortly after the group was informed funding had been cut, and due to the group’s uncertain future, the meeting did not take place.

*Table 3: Stakeholder background and their contribution to theory building*

<b>Background</b>	<b>Contribution to theory building</b>
Academic (n=7)	History and development of interventions, aims/theories of interventions
Commissioners (n=2)	Service motivations for implementing interventions. Intervention mechanisms and staff reasoning.
Healthcare staff (n=5)	Use of interventions in practice. Context interventions are implemented into. Motivations for using interventions. Outcomes for staff.
Person living with dementia (n=1)	Outcomes for patients with dementia and their carers

Manzano (2016) emphasises the importance of knowing what each stakeholder will be able to contribute to theory development. For example, stakeholders with experience of designing and implementing interventions helped provide some insight into the relationship between context and mechanism. These conversations led to understanding of some of the competing theories for developing dementia-friendly environments (Table 5).

## Interviews

Interviews were semi-structured and took place as telephone, skype, or face-to-face interviews. With permission, interviews were digitally recorded and transcribed verbatim. A topic guide was developed (Appendix 4), however, as each stakeholder contributed a different perspective to the interviews, this was broad to accommodate in-depth questioning of the different elements stakeholders could reasonably contribute to (Manzano, 2016). Interviews were theory-driven in that they discussed emerging ideas from the literature, and whether these corresponded to the stakeholders’ experiences. Specifically, interviews aimed to: clarify interpretations of dementia-

Table 4: Sampling frame for stakeholders participating in the realist review

Group	Inclusion Criteria	Recruitment process	Number recruited	Who was recruited
Nursing	Experience of developing, delivering, or using intervention	Telephone, email, snowballing	6	SK01 – Academic and clinician in gerontological nursing SK04 – Academic and clinician in gerontological nursing SK06 – Clinical Quality Lead for nursing SK11 – Academic and clinician in gerontological nursing SK14 – Senior nurse with experience on specialist and general ward SK15 – Dementia Lead for an NHS Trust
GP	Experience of developing, delivering, or using intervention	Email, conference abstract	2	SK05 – GP who created a dementia-friendly practice SK13 – Academic and GP
Physiotherapist	Experience of developing, delivering, or using intervention	Email, telephone, snowballing	3	SK09 – Dementia Lead for an NHS Foundation Trust SK10 – Clinical Quality Lead for physiotherapy SK12 - Physio technician and dementia champion in rehabilitation unit
Social Work	Experience of developing, delivering, or using intervention		2	SK07 – Academic in social care SK08 - Academic in social care
Person living with dementia	Experience of accessing healthcare services and hospital admission since diagnosis		1	SK03 – diagnosed with vascular dementia three years prior to interview
Education	Experience of developing and delivering intervention	Email	1	SK02 – Nursing academic responsible for training healthcare professionals in dementia care

Table 5: Competing theories for developing dementia-friendly environments in healthcare

Theory	Example
Awareness of dementia and best practice	“to make it dementia-friendly, and I’m talking really frontline here, you need education about what dementia is so you can get staff to understand that they might need a different approach” (SK01)
Improving the efficiency and the effectiveness of the services	“when you get a person with a physical health problem who has also got a mental health problem, like dementia, it can be a real challenge to manage them really well, and I suppose it’s that whole process of everything that we can do to be better at supporting and managing that group of people.” (SK06)
Valuing people living with dementia	“it should be connected to our values and beliefs about dementia, people with dementia, and what it means to be human, and sort of the spaces and places that we all need to flourish.” (SK04)
Addressing stigma	“it’s almost an assumption that that person gets categorised as having dementia, so they’re all going to be having the same problems and immediately that one-to-one supervision is put in place, so as soon as the person gets up, it’s very much sit down again, sit down, what do you want, without actually looking at what they need, what they want.” (SK10)

friendly healthcare; identify the range of interventions in use; explore how change in practice might be achieved; and understand the influence of context in staff use of resources in practice.

### Scoping the literature

A broad scoping of the literature was performed to identify national and international initiatives (Box 1). Searches were date restricted to 2000 to reflect the impact of Kitwood (1997) work on dementia care practices that promote the importance of person-centred care and personhood.

### Analysis

Interview transcripts, along with papers from the scoping of the literature were uploaded into NVivo 10 and were analysed using framework analysis (Ritchie and Spencer, 2002). I considered framework analysis appropriate at this stage of the study, as the aim was to generate the initial theories from the competing accounts of the stakeholders and in the literature (Gale et al., 2013) from which the more detailed literature review would be based.

*Box 1: Stage 1 search terms and strategy*

An unstructured search using PubMed, CINAHL, and Google Scholar databases to identify literature related to initiatives that support the development of dementia friendly environments in healthcare.

Date restricted to 2000 - 2015

Search terms:

“dementia friendly”, “dementia friendly AND health care”, “dementia appropriate AND health care”, “dementia awareness AND health care”, “dementia person-centred care AND health care”, “dementia champions”, “dementia AND liaison”

“dementia AND ward”, “dementia education”, “dementia training”, “dementia nurse specialist”, “dementia lead\*”

## Framework Analysis

Framework analysis was developed by social policy researchers Ritchie and Spencer (2002) and is recognised as a pragmatic approach to analysis (Ward et al., 2013). The method has been applied to healthcare research (Ward et al., 2013), dementia care research (Sampson et al., 2008; Smebye et al., 2012), and as part of theory development in realist reviews and realist evaluations (Abhyankar et al., 2013; Bhanbhro et al., 2016). The method shares processes used in other qualitative analysis methods including data immersion, reduction, and the comparison between themes. However, framework analysis is epistemologically diverse in that analysis can be shaped from the data and existing knowledge, unlike inductive, iterative methods such as grounded theory (Ward et al., 2013). As such, it aligns with the principles of realism and realist inquiry (Snape and Spencer, 2003). The method allows for a theme- or case-based analysis, displaying an abstracted representation of the evidence in charts which can be traced back to the source data.

Framework analysis was used to analyse data from the stakeholder interviews and literature identified in stage one of the realist review to understand the concepts of dementia-friendly healthcare and to develop the three candidate theories that would structure the next stage of the review. A five-step process is recommended for data analysis, which entails:

1. familiarisation
2. identifying a thematic framework
3. indexing
4. charting
5. mapping and interpretation



Research Objectives	Emerging data themes		Initial thematic framework
Outcomes	Person living with dementia Carer Staff Organisation	→ → → →	Person living with dementia Carer Staff Organisation
What supports change or not	Conflicts with other priorities CQUIN/Financial incentives Deskillling Empathy Staff motivation Personal experience Top-down/Leadership Expertise Multidisciplinary working Flexibility versus restrictions to practice Staff turnover Group think Everybody's business Policies  Reinforcement  Role driven Training Understanding	→ → →  → →  →  → →  → → → →	Conflicting priorities National policy initiatives Motivation  Leadership Experts  Ability to be person focused  Shared ethos  Organisational policies and priorities Reinforcement and encouragement Role and responsibility Training

These initial themes were tested using two interview transcripts and two papers (see Appendix 5).

### Indexing

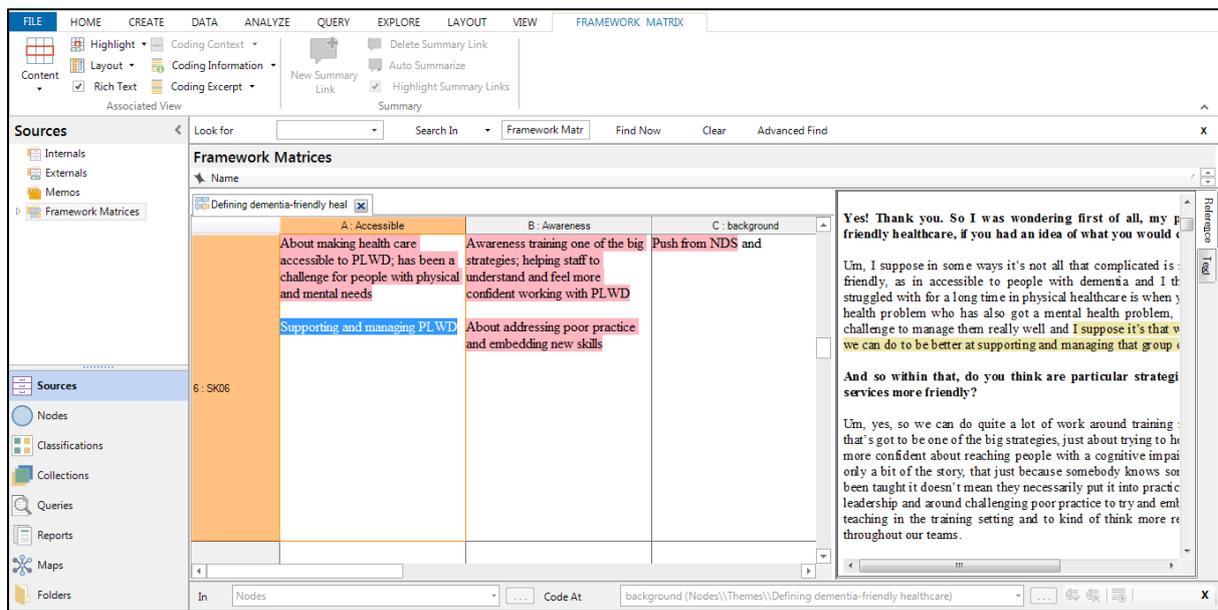
Interview transcripts and PDFs of papers were imported into NVivo 10. A coding tree was developed based on the themes identified (see Table 6) where the 'Research objectives' formed the parent nodes and the 'Initial thematic framework' formed the child nodes. Text was coded into these nodes and new nodes were created where themes had not previously been identified or as understanding developed and new themes emerged. The coding context often included one or two sentences, but could comprise of a paragraph. Where text was relevant to more than one theme, data were multiply coded. A selection of coding was shared with my supervisors to debate and challenge interpretations.

### Charting

Once all data had been coded, four framework matrices were created based on parent nodes of the coding tree. These were 'Defining dementia-friendly healthcare', 'Range of interventions',

‘Outcomes’, and ‘What supports change’. All cases (interviews and papers) were included in each matrix, however not all cells contained data. For example, with the exception of references to person-centred care, most cells for the ‘Defining dementia-friendly healthcare’ matrix were empty for papers as relevant data were not identified. Cases were listed down the vertical axis and themes were displayed along the horizontal axis. Charting involved abstraction and synthesis of the data that related to particular themes. Data relating to each cell were read and distilled to summarise themes (Figure 3).

Figure 3: Example of charting data within the framework matrices

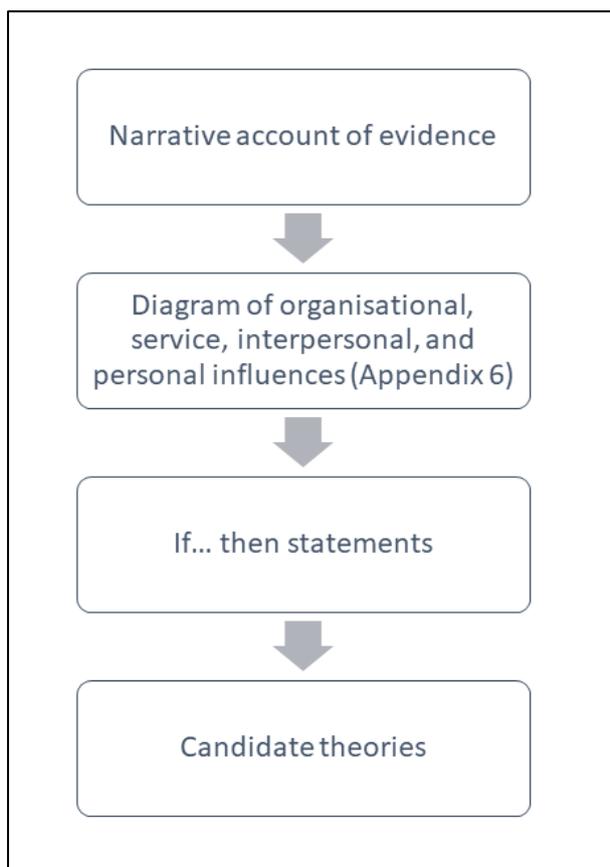


### Mapping and interpretation

Data were then mapped and interpreted to define the concepts, with the aim of identifying candidate theories (Figure 4). To understand the complexity of factors that might support good practice in dementia care, a narrative account of the evidence was created (see Stage 1: Defining the scope of the review: concept mining and theory development, p93). All identified elements that might contribute, or not, to the uptake of an intervention and lead to change in staff practices which influenced patient and carer outcomes, were mapped diagrammatically to demonstrate the numerous organisational, service, interpersonal, and personal influences (Appendix 6). Explanations and associations for the outcomes were set out using if... then statements (see If... then statements, p122). These statements, based on the evidence, made explicit how resources or staff activities were thought to have influenced outcomes without a need to further categorise or define context and mechanisms at this stage (Pearson et al., 2015). The focus of these statements was to

understand: 1) staff outcomes, such as using best practice with patients with dementia; and 2) patient outcomes, such as reduced distress and improved wellbeing. A conceptual framework (Pawson, 2006b) was developed based on discussion of the 'if... then' statements with supervisors which grouped the statements into three areas. A key theme of the change agent was identified, along with the different conceptions of how and why a change agent might support dementia-friendly healthcare. Three overlapping theories of the role and influence of change agents were used to inform the next stage of literature searches and synthesis.

Figure 4: Flow chart for mapping and interpreting data



### Decisions for the review from stage one

A number of decisions were made in stage one of the review that refined the scope and inclusion criteria for stage two:

- An early decision was made to not include interventions for end-of-life care with people living with dementia. This care was considered to have a different focus to care that was aiming to maintain or return people's health and function to their baseline.

- Initially, interventions in both primary and secondary care were considered. However, most activity was located in secondary care, and as such a decision was made to focus the review on dementia care in general hospitals.
- A key context for implementing interventions was thought to be staff who supported the implementation and uptake of interventions, broadly understood as change agents. Search terms were developed to recognise the potential importance of this.
- Evidence largely reported the outcomes for staff from interventions, such as how training had improved knowledge in dementia and dementia care, and confidence for working with patients with dementia. However, there appeared to be limited understanding of how interventions influenced patient and carer outcomes. From this, a decision was made to focus the review on literature that reported patient and carer outcomes.

Outcomes of interest were defined to include:

- **Reduced distress:** Admission to hospital for people living with dementia is a frightening experience (Dewing and Dijk, 2014). Distress can complicate care and treatment for acute conditions and influence staff decision making for managing the patient.
- **Onset of behaviours that are challenging for staff:** This outcome is, in part, linked to distress. It is also problematic for staff and can lead to inappropriate treatment to reduce the behaviour (White et al., 2016).
- **Changes in mobility:** Patients with dementia are at risk of reduced functional abilities after admission to hospital (Alzheimer's Society, 2009). Reduced mobility may have implications for discharge planning.
- **Use of medication:** Patients with dementia have been found to have medication used inappropriately. The focus for medication use was pain relief, as patients with dementia have been found to receive less pain relief than other patients (Closs et al., 2016), and anti-psychotics use (White et al., 2016).
- **Adverse incidents:** Patients with dementia are at high risk of adverse incidents during hospitals stays such as falls, infections, nutritional and hydration problems, and delirium (Alzheimer's Society, 2009). These complicate their care, extend their length of stay, and may impact on place of discharge.
- **Improved wellbeing:** The use of person-centred care has been recognised to improve the wellbeing of patients with dementia and has been measured using Dementia Care Mapping (Kitwood, 1997).

- **Patient and carer experience:** Poor care impacts on both the patient and carer's experience of hospital (Clissett et al., 2013).

## Stage two: retrieval and review

### Searching for relevant studies

Search terms were revised to include elements of the theoretical assumptions from the three candidate theories derived during stage one. The inclusion/exclusion criteria were refined to reflect the decisions from stage one (see Decisions for the review from stage one, p46). As with stage one, searches were date restricted to from 2000 to reflect the impact of Kitwood (1997) work on dementia care practices.

Electronic database searches (Box 2), extensive lateral searching, including forward and backward citations, and contact with experts was used to identify relevant literature. Emerging themes around the management of pain and behaviours that challenge led to additional, purposive searches that applied the same inclusion criteria. Searches continued in an iterative manner until it was considered there was enough relevant evidence for theory development and saturation was achieved (Pawson et al., 2005; Wong et al., 2010).

### Study screening and data extraction

Search results were downloaded into EndNote bibliographic software and duplicates deleted. Titles and abstracts were screened according to selection criteria to identify potentially relevant papers. Full texts of these manuscripts were screened for relevance (the contribution the study could make to the theory building), and rigour (that studies were of sufficient quality to provide credible evidence to specific components of the proposition) (Pawson, 2006b; Wong et al., 2013). Considerations for the contributions and reliability of evidence continued throughout the synthesis as concepts developed and appraisals of the data were shared and debated with supervisors.

A bespoke data extraction form was designed to reflect the theoretical propositions and organise relevant contributions and challenges to the theories (Appendix 7). Study characteristics, such as discipline, design, and sample characteristics were recorded, along with implicit and explicit strengths and weaknesses of the studies (Wong et al., 2013). A sample of the papers and their completed data extraction forms (6/28) were shared with supervisors to concur the relevance of data identified, agree the data extraction process, and reduce the potential for bias. Data relating to

Searches initially ran September 2015, search alerts scanned to February 2016

Language restricted to English

Date restricted 2000 – 2016

Search terms:

(dementia AND (friendly OR appropriate OR awareness OR champion OR liaison OR ward OR environment OR education OR training OR nurse specialist OR lead\* OR person-centred care) AND (hospital OR acute care OR secondary care))

Additional search terms incorporating elements of the candidate theories from stage one:

dementia AND (change agent OR champion OR knowledge transfer OR knowledge translation OR opinion leader)

Additional search terms reflecting emerging themes in stage two. Searches ran January 2016, search alerts scanned to February 2016

(dementia AND (pain) AND (hospital OR acute care OR secondary care))

(dementia AND (behaviour\* OR BPSD) AND (hospital OR acute care OR secondary care))

Databases:

Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA) (244), CINAHL (610), PubMed (4253), NHS Evidence (819) and Scopus (410)

the change agent's characteristics, the intervention resources, contextual factors (for example, workforce, knowledge of dementia), explicit and implicit theories for how interventions were anticipated to work, and patient and carer outcomes were extracted. Data were compiled into tables which detailed the contribution to theory development. These were discussed at length with supervisors, and challenges to interpretations were debated as a test of credibility. Following these discussions, data were re-organised into tables by the theoretical proposition they addressed to support analysis (Appendix 8).

### Stage 3: analysis and synthesis

A realist analysis of data adheres to a generative explanation of causation and looks for recurrent patterns of outcomes and their associated mechanisms and contexts (CMOC). The focus of this study was to understand what had supported staff to take action to influence patient outcomes. A

process of retroduction, where explanation for the causal process of an outcome is inferred (Sayer, 1984), was used to identify possible mechanisms that might explain demi-regularities evident across the studies. These explanations were discussed with supervisors and the Research Network Monitors (see Public Involvement, p87) to test their plausibility. Discussions were grounded in the evidence and included debate around: the key characteristics change agents, i.e. what it was about change agents and what they were trying to achieve that influenced outcomes; how resources from interventions influenced staff reasoning; the impact of context and its relationship with implicit and explicit mechanisms; and possible undesired outcomes (such as potentially stigmatising practises and broad application of strategies to patients that might conflict with notions of person-centred care). This led to the development of context-mechanism-outcome configurations (CMOCs) which aimed to explain what it is about an intervention that works, for whom, and in what circumstances. Together, these CMOCs made up the programme theory.

## Phase 2: Realist evaluation using a case study approach

Realist evaluation is a method for understanding how and why interventions work or not (Pawson and Tilley, 1997). When designing a realist evaluation, data collection methods are chosen based on their potential to contribute to theory testing and refinement (Pawson and Tilley, 1997). For this study, a two-site case study design, using multiple methods of data collection, was considered appropriate as it provided the opportunity to investigate, in-depth, how two general hospitals had applied resources for patients with dementia differently. Case study is an established research methodology (Stake, 1995; Yin, 2013a), however it can also be used, as I have, as a method for studying phenomena. Using a naturalistic approach supported the evaluation of complex interventions within complex social settings (Baskarada, 2014). Insights into how mechanisms were generated within particular contexts, with what outcomes, and for whom were developed from using both within and cross case comparisons (Pawson and Tilley, 1997).

A criticism of case study design has been the generalisability of findings from one case study setting to another (Marchal et al., 2010; Yin, 2013b). This is, in part, due to the way samples are selected, leading to questions around how representative cases are, and the level of inference that can be made from findings. However, realist evaluation that employs a case study design is able to base the generalisability of the findings in the programme theory. Where this is developed and tested from existing evidence, it can improve the external validity of the research (Marchal et al., 2012). The programme theory for this realist evaluation was developed from published studies and service

evaluations before testing at the case study sites. This may have improved the transferability of the refined programme theory.

### Data collection methods

Realist evaluation starts with a theory about how programmes work, which, through iterative testing based on evidence, results in a refined programme theory (Pawson and Tilley, 1997). There have been guidelines for the reporting of systematic reviews, RCTs, and other research methods for some time to ensure researchers, commissioners, and readers have clarity in definitions of the quality and rigour of the research. Reporting guidelines are now also available for realist review (Wong et al., 2013) and realist evaluation (Wong et al., 2016). In terms of the transparency and reliability of the conduct of the evaluation, the guidance states that methods for data collection should be theory driven, and their rationale and contribution to theory should be clearly explained (Wong et al., 2013; Wong et al., 2016). Data collection methods for this study were selected for how they would provide evidence to uncover patterns and themes to contribute to theory testing (Table 7).

*Table 7: Contribution to theory testing by data collection method*

Data collection method	Contribution and justification
Semi-structured interviews: <ul style="list-style-type: none"> <li>● Staff</li> <li>● Patients with dementia</li> <li>● Carers</li> </ul>	To understand the contexts and mechanisms that influence staff practice for dementia care.  To understand patient and carer outcomes such as their experience of dementia care in hospitals, and how good outcomes were defined
Non-participant observation	Evidence for the context of how things happen during patient and staff interactions and with what outcomes. Practice may be different to perception of practice.  To provide evidence of the experience of patients who lacked the capacity to consent to interviews.

Data collection method	Contribution and justification
Medical notes review	Information on patient characteristics such as diagnosis of dementia, reason of admission, co-morbid conditions, prescribed medication, place of residence.
Neuropsychiatric Inventory	To understand the patient characteristics in terms of behaviour and mood.  Different behaviours may lead to different staff responses and be prioritised in different ways.
Organisational documentary review	To understand how stated organisational policies might impact on staff practices and patient outcomes.

Decisions for sample size in realist evaluation are based on the understanding that fragments of data will be used to build and test the theory (Manzano, 2016). O'Reilly and Parker (2013) argue that the appropriate sample size should be grounded in the methodological and epistemological frameworks of the research. In realist sampling it is important to consider how the data will be used to develop and test interpretations and explanations (Emmel, 2013). As such, decisions for participant recruitment were adapted throughout the data collection process to address gaps in the evidence. In the original study design, the aim was to recruit up to 60 people for the study from across the sites (10 staff, 10 patients with dementia, 10 carers at each site). However, it became apparent upon entering site 1 that it would be necessary to interview more members of staff to cover the range of skills and professions involved in supporting the provision of dementia care to adequately test the programme theory. While recruitment of patients with dementia was achieved for medical notes review and the Neuropsychiatric Inventory, only two patients with dementia from each site participated in interviews. Observation data was able to supplement theory testing around patient outcomes. It was also difficult to recruit carers for interview, and this is recognised as a limitation of the study (see Strengths and limitations, p223).

Decisions regarding how data collection informed theory testing also informed when it was considered enough data had been collected (Mukumbang et al., 2016). As with the realist review, saturation was considered to be attained when it was thought there was enough evidence to robustly test the programme theory and improve the validity of the findings.

## Ethical approval

Phase two of the study was reviewed by the East of England Essex Research Ethics Committee who made a favourable judgement on 11<sup>th</sup> August 2016, reference: 16/EE/0263 (Appendix 9). Health Research Authority approval was received on 26<sup>th</sup> August 2016 (Appendix 10). Research and development approval and access was obtained on 28<sup>th</sup> October 2016 at site 1, and on 9<sup>th</sup> January 2017 at site 2.

## Recruitment of study sites

Sites were purposively sampled for their financial investment into services for patients with dementia. It was considered that due to the investment, they were likely to pay greater attention to training and care for working with patients with dementia. By understanding the processes in these environments designed to use best practices with patients with dementia, the study could focus on testing the theoretical propositions against the evidence (Emmel, 2013).

Three potential case study sites in the East of England were identified during phase one of the study. Initial discussions about the study took place with key staff at each site; Research and Development Manager (site 1), Dementia Lead (site 2), and Ward Manager (site 3). These sites were contacted because they had implemented different approaches for supporting patients with dementia who had behaviours that were challenging for staff. Site 1 had a dual-frailty ward that addressed patients' acute and dementia needs. The ward was purpose built, ward staff received regular input into patient care from the mental health team, and had a high ratio of healthcare staff to patients at all times of the day and night. At site 2 a team of healthcare assistants had been trained to provide 1:1 support for patients with dementia who presented with a risk to themselves or others, or had behaviours that were challenging for staff. They worked across the hospital providing support for patients' personal care, ensuring their safety, and meeting psychosocial needs. Site 3 had recently refurbished an elder care ward to improve the flooring, lighting, and signage. While all sites expressed an interest in the study, further follow up with site 3 came to an end due to staff changes. The remaining two sites were taken forward for the study.

## Description of study sites

Site 1 is a dual-frailty unit based in a general hospital. The general hospital is one of three hospitals within this NHS Trust, situated in the East of England. The Trust serves a population of between

500,000 and 700,000. While the population in general is more healthy and affluent than the England average, there are pockets of deprivation. There are approximately 500 beds in the general hospital and the Trust employs over 4000 staff. The general hospital is the core location for inpatient emergency care and for all patients who need the specialist emergency facilities, such as intensive care. It also provides elective care for higher risk patients, together with a full range of outpatient and diagnostic services.

The general hospital opened in the 1940s and is built on the site of a 19<sup>th</sup> century workhouse. New buildings were added in the 1980s and in the last ten years there has been additional investment to modernise some of the facilities. One area to benefit from this has been the Elder Care Wing, which houses the dual-frailty unit.

Site 2 is a general hospital in an NHS Trust in the East of England. The general hospital is one of four hospitals within the Trust and is the main hospital for emergency and inpatient care. It provides general and specialist services to a population of around 600,000 people, covering both an urban and rural population. As with site 1, in general the population is more healthy and affluent than the England average, but there are pockets of deprivation. The general hospital has approximately 700 beds and, across the Trust, has a workforce of around 5000 staff.

Originally built in the 1970s, in recent years there has been substantial financial investment in new facilities and refurbishing some of the wards. Not all wards that took part in the study had benefited from this investment.

A description of ward layouts and the organisation of staff at both sites are included in Chapter four (p155-159, Appendix 18 and 19).

### Introducing the study to the sites

Research and Development staff at each site identified a local investigator to support the study by acting as my point of contact to support the study by; helping to identify relevant policies and paperwork, and helping to identify study participants. At site 1 this was a band 6 nurse who worked on the ward. At site 2 this was the Dementia Lead for the Trust. At site 2, the local investigator was the main point of contact for negotiating and coordinating my access throughout the data collection period. At site 1, the local investigator had a period of leave after our initial meetings about the study. During their absence, their role to support the study was facilitated by other senior staff on

the ward. The local investigators supported introduction of the study to staff, and provided information about regular staff meetings of interest, such as the Dementia Strategy Group meetings, negotiating my access to attend these in an observer capacity. I attended two staff handovers at each site in the first week of data collection and maintained a high visibility on the wards throughout the data collection period. In this way I was able to introduce myself and the study to staff, patients, and visitors to the wards to answer any questions they had. This helped to build familiarity for myself of their roles and work, and for them with me to help gain their trust.

### Staff recruitment

Staff approached for interviews were identified during the data collection period for their ability to provide evidence that could be used to test the programme theory. Manzano (2016) highlights that different participants will contribute different evidence to different parts of the theory being tested. She states that “a variety of perspectives are needed to investigate informal patterns and unintended outcomes”. For this reason, staff working in different roles were identified and invited to be interviewed for their contribution to theory testing. (Table 8, Table 9, Table 10).

*Table 8: Staff interviews by role and contribution to theory testing*

Staff role	Contribution to theory testing
Housekeepers, healthcare assistants, and nurses	How apply training and other resources for care of patients with dementia, how and why prioritise work with patients
Nurses band level 6+, managers	Expectations of staff working with patients with dementia, how to support staff
Dementia Leads, doctors, psychiatrists, and allied health professionals	Contribution of role to patient with dementia, how to support ward staff (e.g. training, advice), theories for use of different resources

### Patient Recruitment

Patients at both sites were subject to the same criteria for participation in the study:

#### *Inclusion criteria*

- Have a diagnosis of dementia

- Do not have a formal diagnosis of dementia but have been identified by staff (or family members) as having dementia or cognitive impairment

#### *Exclusion criteria*

- Do not have dementia
- Are not thought to have a cognitive impairment
- Patient is receiving palliative care
- Patient does not speak English
- (for interviews only) Lacks capacity to consent

Eligible patients were identified differently at the two sites. At site 1, due to the referral criteria for being transferred to the ward, all patients on the ward were eligible unless they were receiving end-of-life care. This was because the priorities and focus for end-of-life care were different to those for patients anticipated to return to their previous level of function and place of residence. At site 2, eligible patients were identified by the Dementia Lead who was responsible for checking patients had a formal diagnosis of dementia.

#### Carer recruitment

Carers were recruited separately from patients with dementia. They were identified through their visits to the wards and from discussions with staff about patients' visitors. Despite efforts to make myself available at popular visiting times and discuss the study with visitors, only two carers were recruited for interview. Small recruitment numbers for carers have been reported in other studies of patients with dementia in hospitals, even though researchers made themselves available (Lichtner et al., 2015). Staff were not able to provide information about family members who were not regular visitors to the ward. Attempts to contact family members involved conversations on the ward, or leaving participant information sheets by patient's bedsides, or with staff. This method was unsuccessful and checks on paperwork showed information had been put to one side by staff when tidying up bedside tables, or not collected. Where staff had been given the information sheets to pass on to carers, it was unclear if this was passed on unless a reply was received. For those carers who were spoken to, many were happy to talk informally during discussions of the study. However, committing to formal interviews were problematic as carers were concerned for their relative during a time of crisis, were often looking into alternative living arrangements for their relative, and had practical concerns around the time they spent at the hospital.

Table 9: Sampling framework for staff, patients with dementia, and family carers participating in interviews at site 1

Professional group	Inclusion criteria	Recruitment process	Number recruited	Who was recruited
Nursing	Experience of working on the ward, role in developing Dementia Strategy and policies for the Trust	Face-to-face	7	ST0101 – Acting ward manager for 6 months, grade 6 on ward since opened, previously elder care ward ST0102 – Grade 5, one year on ward ST0104 – Grade 5, one year on ward ST0105 – Grade 6, since opened, previously elder care ward ST0112 – Grade 6, since opened, previously elder care ward ST0113 – Grade 7, ward manager for frailty unit, previous unit manager ST0114 – Dementia Lead
Healthcare Assistants	Work on ward	Face-to-face	3	ST0103 – Since ward opened, previously elder care ward, experience of caring for relative with dementia ST0107 – Since ward opened, first healthcare assistant role ST0108 – One year, previously in community, experience of caring for relative with dementia
Medical staff	Work on ward, role in developing Dementia Strategy and policies for the Trust	Face-to-face, email	4	ST0109 – Geriatrician ST0110 – Senior House Officer (SHO) ST0115 – Registrar ST0116 - Psychiatrist
Therapy staff	Work on ward, role in developing Dementia Strategy and policies for the Trust	Face-to-face	2	ST0106 – Activities co-ordinator, 3 months, previously worked in community ST0111 – Occupational therapist, grade 7
Patients with dementia	Cared for on the ward	Face-to-face	2	PT0101 – Diagnosed with dementia with Lewy Bodies and delirium PT0102 - Diagnosed with Alzheimer’s Disease
Family Carer	Family carer for a patient with dementia cared for on the ward	Face-to-face	1	CA0101 – Family member was transferred to ward after several weeks on Care of the Elderly ward, they were discharged to new care home

Table 10: Sampling framework for staff, patients with dementia, and family carers participating in interviews at site 2

Professional group	Inclusion criteria	Recruitment process	Number recruited	Who was recruited
Nursing	Experience of working on the ward, role in developing Dementia Strategy and policies for the Trust	Face-to-face	5	ST0201 – Dementia Lead, four months in role, previous experience in the community ST0210 – Grade 5, one year’s experience on elder care ward ST0218 – Carers Lead ST0219 – Grade 6, orthopaedic ward ST0220 – Ward manager, elder care ward
Healthcare assistants (ward)	Work on ward	Face-to-face	2	ST0202 – Seven years’ experience on elder care ward ST0205 – Orthopaedic ward for 12 years, brief time working on 1:1 team before returned to ward, dementia champion
1:1 team	Work in 1:1 team, role in developing Dementia Strategy and policies for the Trust	Face-to-face	7	ST0203 – HCA, since team started, previous experience in community ST0204 – Matron, one of responsibilities is 1:1 team ST0206 – Team lead, over 10 years nursing experience, dementia champion ST0209 – HCA, since team started, previously emergency department, dementia champion ST0211 – HCA, six months, previously in community ST0212 – HCA, one month, previously in community ST0215 – HCA, one year, previously in community
Medical staff	Work on ward	Face-to-face, email	3	ST0213 – SHO ST0214 – Consultant in Elder Care Medicine ST0217 - Psychiatrist
Therapy staff	Work on ward	Face-to-face	1	ST0216 – Occupational therapist, dementia champion
Housekeepers	Work on ward	Face-to-face	2	ST0207 – Previous experience as HCA, part-time on elder care ward ST0208 – Full-time on elder care ward
Patients with dementia	Cared for on ward	Face-to-face	2	PT0201 – Diagnosed with Alzheimer’s disease, admitted to orthopaedic ward PT0202 – Diagnosed with Alzheimer’s disease, admitted to orthopaedic ward
Family carer	Family member of patient cared for on ward	Face-to-face	1	CA0201 – Family member was admitted to a Care of the Elderly ward, they were discharged to a care home

## Non-participant observation

Observation has been used as a method for research in hospitals with patients with dementia (Closs et al., 2016; Goldberg et al., 2014; Schneider et al., 2010) and in realist evaluations in hospital settings (McGaughey et al., 2017; Rycroft-Malone et al., 2010). Both structured and unstructured methods have been used to record activities. Structured approaches for observation, such as Dementia Care Mapping (Kitwood and Bredin, 1997), have been used in studies in care homes and hospitals (Chenoweth et al., 2009; Goldberg et al., 2013). However their use in another hospital-based study found the tools to be insensitive to patient mood and not appropriate for recording the experience of acutely ill patients (Goldberg and Harwood, 2013). For this study, non-participant observation was structured in that it was organised to reflect the different routines of the ward. A topic guide developed from the literature review helped to focus important aspects to record (Calnan et al., 2013). Observations recorded the way space within the ward was used, movements, and verbal and non-verbal communications.

Observation is useful for understanding how things happen in the real world (Mays and Pope, 1995). Interventions are conceptualised to work in a particular way to produce a desired outcome, but the way they are interpreted and put into practice will vary (Pawson and Tilley, 1997). One of the advantages of using observation is to overcome potential biases of what people might report in interviews where there may be selective recall and be influenced by how people want to present themselves (Mays and Pope, 1995). Observations in this study complemented data from interviews and provided insight into: 1) how interventions were used in practice; 2) how staff recognised and address patient needs; and 3) how context influenced staff actions or routines they may have been unaware, for example around risk management.

Gold (1958) identifies four types of role for researchers undertaking observation; from complete participant to complete observer. However, it is acknowledged during observation periods the researcher may move between the roles as appropriate to the events as they occur. For example, while my research role was defined as non-participant observer, there were times when I became a participant in the observation, such as making drinks for patients and joining in activities sessions.

Observation is useful for recording events, but is heavily reliant on the researcher as a method for data collection and several factors need to be acknowledged for their influence on the data produced. When using observation, the researcher takes an active role in the research process, from deciding what to record, how it is recorded, and interpreting the data (Hammersley and

Atkinson, 2007; Mays and Pope, 1995; Mulhall, 2003). It is impossible to record everything occurring in an area of observation. Therefore, the process is inevitably selective and relies on the researcher to document what they observe.

While researchers may attempt to represent the events they record as an objective account, it is important to acknowledge the researcher's perception of reality is influenced by their interpretation of it (Sayer, 2000). As an outsider with no clinical background, I was aware that I would not necessarily understand all the choices staff made for patient care and attempted to clarify the purpose of actions when this occurred.

Writing field notes is recommended as soon as possible to the observed action to retain the quality and faithfulness of events, ideally during the observation period (Hammersley and Atkinson, 2007). However, this may not always be possible due to researcher concerns regarding their influence activities or the impact of overtly recording events which might lead participants to feel they are being scrutinised and take offence (Hammersley and Atkinson, 2007). Researchers using observation as a method need to be sensitive to their influence on the setting and participants and adjust the way they approach data collection accordingly (Holloway and Galvin, 2016). In the case of this study, where situations appeared inappropriate to overtly record, for example if when there were disagreements about patient care, I chose not to write notes in situ, and instead waited until I had left the area to make notes.

While overt observation aims to inform all potential participants of the purpose and conduct of the research, there are a number of factors that might impact how informed participants are. Firstly, they may have unexpectedly entered the area of observation. Secondly, there may be misunderstanding of the purpose of the research or clarity in what people have consented to participate in (Holloway and Galvin, 2016). In the case of this study with patients with dementia, it is highly likely a number of participants had limited recall around discussions of the research. I made efforts to remind participants of my role and the research as appropriate and used posters to highlight the research to people who entered the field of observation.

There has been limited reporting of the experience and outcomes for patients with dementia where interventions to improve their care have been implemented. Previous research in older care hospital wards with patients with dementia suggested their ability to express their experiences of care may be limited, and their carers may only have a partial insight into the care they have received (Goldberg and Harwood, 2013). The use of observation ensured the experiences of care of patients

with dementia who may have had limited ability to recall or verbalise their experiences were represented in the study.

### *The process of non-participant observation for this study*

The length of time for observations were negotiated with the ward manager during initial meetings, and a timetable for observations was agreed. Observation periods ranged from two to six hours. Previous research reported that observation periods of at least two hours ensured that researcher effect on behaviour was minimised (Clissett et al., 2013; Mulhall, 2003). While data collected suggest staff did not alter their behaviour due to my presence, staff and patients regularly acknowledged me by starting conversations and offering explanations of what they were doing. Some valuable insights were gained during these conversations from both staff and patients that helped the analysis process and contributed to theory testing. For example, one patient expressed their displeasure at having to participate in an activity despite spending considerable time engaged in it, suggesting that occupation was not always for the benefit of the patient.

Two observation periods were arranged each week for up to six weeks at each site. The location of the observation, i.e. which bay observations took place in, was decided on the day. This was informed by information about how patients had been earlier in the day or overnight, from observations during walks round the ward, and, at site 2, whether or not patients were receiving additional staffing input (Table 11, Table 12). These decisions were based upon the potential for observations to contribute to theory testing and for identifying where observations would not be appropriate. For example, at site 2 in one bay, two patients with dementia were receiving end of life care. As this was part of the exclusion criteria, and out of respect for the patients and their families, observations took place in a different bay. Observations were performed in bays following negotiation with the ward manager, staff working in the bay, and with patients in the bay. I did not directly observe personal care, toileting, or consultations performed behind curtains, although information heard from behind curtains, such as the detail of conversations, were recorded when considered relevant to the study (Goldberg et al., 2014).

Observations were hand written at the time of observation. Sketches of the bay and positions of staff and patients were used to help inform how the space was being used and positions of staff in their interactions with patients. In the literature, researchers employing observation methods discuss taking regular breaks to develop notes, and inform notes where there are concerns for recording information that might be seen by participants and cause concern or upset (Hammersley

and Atkinson, 2007). Breaks were taken to write up where such issues were a concern, and a private area away from the ward was found to do this. Transcription was performed at the earliest opportunity following observations: from within a couple of hours to up to three days later.

While attempts were made to record broadly the activities in the bays, I acknowledge that the information recorded was limited by one observer making notes and that there was a potential for bias in the recordings (Hammersley and Atkinson, 2007). Hospital wards can be busy places and decisions needed to be made around what to record. This study was interested in what supported dementia-friendly care and as such focused recordings on interactions between staff and patients. This may have privileged interactions between more physically disruptive and demanding patients at the expense of less challenging patients. However, as Pawson and Tilley (1997) acknowledge, knowledge can only ever be partial and evidence from studies are contributions to the wider understanding of circumstances rather than a complete picture.

It did not appear that my presence on the ward made staff feel uncomfortable or conscious of having to adapt their work accordingly. Many staff working outside of the wards were observed visiting and spending time with patients, and staff appeared used to people visiting. At both sites, open visiting had been running for a length of time and staff had become accustomed to their work being more visible and transparent to visitors on the wards. Additionally, observation is a method that is commonly used in hospital wards to assess patients, for teaching practices, and for audits, so it is likely that it would not be an unusual practice within the ward.

The literature discusses the importance of the relationship between the researcher and participants (Hammersley and Atkinson, 2007). Developing a rapport with staff and patients to gain their trust in me and the research was important. As someone without a clinical background, I was only able to be involved in activities that a visitor might attend to. This allowed me some freedom to retain a distance from participating in some areas of the ward activity. Staff, volunteers, and patients performing activities would at times involve me in the activities. I engaged in discussions with patients and sometimes was asked for drinks, which, after checking there were no dietary issues such as the use of sweeteners, I would get for them.

Table 11: Sampling frame for observations at site 1

Observation code	Time of day	Number of hours	Number of patients on bay	Description of main staff during observation	Main activities taking place
OB0101	07.00 – 11.00	4	Female bay = 8  Male bay = 8	(07.00 – 10.00) Two registered nurses (RN), two healthcare assistances (HCA), volunteer, doctor, psychiatrist, physiotherapist  (10.00 – 11.00) Two RNs, two HCAs	Handover, food and drinks, medications, personal care, clinical observations, doctors' ward round.  HCA supports with one patient with a puzzle, personal care.
OB0102	10.30 – 13.30	3	Male bay = 8  Female bay = 8	(10.30 – 12.00). Two RNs, two HCAs (one is bank who regularly helps on the ward), two doctors  (12.00 – 13.30) Two RNs, two HCAs, and activities co-ordinator.	Doctors' ward round, drinks for patients, film on the TV, clinical observations, personal care.  Lunch with a singer from a charity.
OB0103	07.00 – 13.30	6.5	Male bay = 8	Two RNs, two HCAs, occupational therapist, two phlebotomists, activities co-ordinator, two doctors, psychiatrist, ward manager.	Breakfast, medications, blood samples, clinical observations, personal care, doctors' ward round, food and drinks, puzzle, painting.
OB0104	14.00 – 19.00	5	Female bay = 8	Two RNs, two HCAs, ward sister.	Clinical observations, food and drinks, medications, TV, personal care, visitors.
OB0105	16.00 – 22.00	6	Female bay = 8	Two RNs (one is bank), two HCAs, doctor, psychiatrist, pharmacist. Following handover; two RNs, two HCAs (one is bank who regularly works on ward)	Food and drinks, personal care, clinical observations, PRN for agitation, visitors, handover, TV.
OB0106	18.00 – 21.00	3	Male bay = 8	Two RNs (one bank), student nurse (SN), two HCAs, two security staff Following handover; two RNs, two HCAs	Visitors, food and drinks, personal care, medication, handover.

Observation code	Time of day	Number of hours	Number of patients on bay	Description of main staff during observation	Main activities taking place
OB0107	07.00 – 11.30	4.5	Male = 8	Two RNs, SN, two HCAs, doctor, ward manager, phlebotomist, activities co-ordinator, social worker	Handover, doctors' ward round, medication, personal care, clinical observation, TV, newspaper activity, blood samples, fall.
OB0108	07.00 – 12.00	5	Male = 8	Two RNs, three HCAs (one new, one bank), ward manager, two doctors, phlebotomists, member of mental health team	Handover, personal care, medication, clinical observations, doctors' ward round, fall.
OB0109	08.00 – 10.00 11.00 – 13.00	4	Female = 8	Two RNs, two HCAs, two doctors, psychiatrist, pastoral care,	Medication, personal care, food and drinks, colouring and picture activities.

Table 12: Sampling frame for observations at site 2

Observation code	Time of day	Number of hours	Number of patients on bay	Description of main staff during observation	Main activities taking place
OB0201	10.00 – 13.30	3.5	Male = 4 (1 with diagnosis of dementia)	HCA, phlebotomist, wound care specialist nurse, RN, two doctors, two physiotherapists, housekeeper	Food and drink, personal care, blood sample, clinical observations, doctors' ward round
OB0202	10.00 – 11.00 11.30 -13.30	3	Female = 4 (2 with diagnosis of dementia)	HCA, 1:1, RN, phlebotomist, housekeeper	Medications, clinical observations, food and drinks, visitor, personal care, blood sample,
OB0203	07.30 – 09.30 10.30 -12.00	3.5	Female = 4 (2 with diagnosis of dementia)	HCA, 1:1, RN, housekeeper, doctor, SN	Handover, medications, clinical observations, food and drinks, visitor, personal care, doctors' ward round
OB0204	12.00 – 15.00	3	Female = 3 (3 with diagnosis of dementia)	HCA, housekeeper, RN, volunteer, phlebotomist, 1:1	Food and drinks, medication, clinical observations, visitor, blood sample, personal care
OB0205	10.30 – 14.00	3.5	Female = 4 (3 with diagnosis of dementia)	HCA, housekeeper, RN (bank staff), pastoral care	Personal care, food and drink, wordsearch, medication, clinical observations

Observation code	Time of day	Number of hours	Number of patients on bay	Description of main staff during observation	Main activities taking place
OB0206	13.30 – 17.00	3.5	Female = 3 (3 with diagnosis of dementia)	HCA, doctor, SN, housekeeper, RN, member of discharge team	Food and drink, personal care, conversations at length, medication, clinical observations,
OB0207	09.30 – 12.00	2.5	Female = 4 (2 with diagnosis of dementia)	HCA, 1:1, RN, two doctors, pharmacist, housekeeper	Medication, food and drink, personal care, clinical observation, doctors' ward round
OB0208	17.30 – 22.00	4.5	Female = 4 (1 diagnosis of dementia)	HCA, 1:1, RN, SN, housekeeper, doctor Following handover Two HCAs (one agency), RN	Food and drink, clinical observations, personal care, medication, handover, visitors
OB0209	11.30 – 13.30	2	Female = 4 (1 diagnosis of dementia)	HCA, RN, volunteer (mostly no staff during observation)	Food and drink, clinical observations, personal care, medication
OB0210	19.00 – 21.00	2	Female = 4 (1 diagnosis of dementia)	Two HCAs, RN	Handover, personal care, medication, clinical observations
OB0211	09.30 – 12.30	3	Female = 4 (2 diagnosis of dementia)	Two HCAs (one agency), housekeeper, doctor, RN, two phlebotomists, social worker	Personal care, food and drink, doctors' ward round, medication, clinical observations, blood sample, visitor
OB0212	14.00 – 16.00	2	Female = 4 (1 diagnosis of dementia)	1:1, RN, physiotherapist, pet therapy, housekeeper	Book activity, visitors, clinical observations, physiotherapy, pet therapy, food and drink
OB0213	09.30 – 12.30	3	Male = 6 (3 diagnosis of dementia) Activity room from (2 patients with dementia) Female = 4 (1 diagnosis of dementia)	(09.30 – 11.00) Two 1:1s, HCA, RN, doctor  (11.00 – 12.00) Dementia Lead, Matron, 1:1 Team lead  (12.00 – 12.30) HCA	Personal care, medication, prep for theatre  Reminiscence activity, make-up, colouring, drinks  Food and drink

## *Researcher role*

Development of the study protocol included discussions about the nature of my role in the case study sites. It defined my role as equivalent to that of an unqualified visitor to the ward, such as a family member. As such, judgements on what to be involved in were made on a case-by-case basis that considered balancing the needs of the research with moral concerns for patients and staff, and in relation to my abilities to address a situation. I do not have a clinical background, and as such am not bound by a clinical code of ethics to intervene in patient situations, only researcher ethics. I have no training in health care and have spent little time in general hospitals. As such, I have no biases around ward routines, concerns for risk, or prioritising physical over psychological needs. A member of the research network monitor group commented they saw this as an advantage to be free of “the inevitable conditioning” from training as a healthcare professional (Comments during Research Network Monitors meeting, 4<sup>th</sup> July 2017).

While I wanted staff to recognise I was on the ward to carry out research, I also did not want to appear threatening. In my first visit to the ward at site 1, I dressed professionally in a trouser suit. However, due to the informal nature of the ward and the dress code I observed in other professionals not wearing uniforms, this felt too formal and I considered it might be a barrier to developing relationships with staff and patients. In my next visit to the ward I exchanged the jacket for a cardigan, maintaining a professional but more approachable look. At all times I wore my lanyard to help staff and patients quickly recognise my official capacity on the wards. As all staff wear lanyards, at first glance it was difficult to distinguish that I was not a member of staff, and I was sometimes mistaken as a member of staff. Each time I explained my role on the ward. However, these encounters did make me consider if more obvious clothing was necessary. Other researchers have described the difficulties in choice for what to wear to balance blending in but not being covert (Allen, 2004; Dewing, May 2013). In the case of Dewing (May 2013), her focus was to support people living with dementia to recall her, resulting in use of a bright orange top. I did not consider this would be useful in the setting as drawing attention to myself during observations might be distressing for patients or encourage more attention from them, therefore disrupting data collection. Instead I wore black or grey trousers, and a green or black shirt with black cardigan.

Allen (2004) also speaks of the uncomfortable feeling that researchers have when observing overstretched staff and the conflicting desire to support them. Often I struggled with my role as researcher where staff were busy and attending to the competing needs of patients. At times I needed to resist the urge to sit with distressed patients and talk with them, as this would have

reduced opportunities to collect data for how staff worked with these patients and made choices for prioritising needs. This was particularly difficult during one observation period where a patient frequently calling out in distress did not receive attention from staff. At other times, there was no choice but to be involved. A late evening observation period resulted in me sitting and talking with a patient with dementia at high risk of falls, as staffing shortages meant no one else could support them. When I left the observation I felt frustrated for the staff that they regularly had to cope with such situations, and sadness for the patients that they were put at risk due to minimal staffing. This experience reinforced the difficult decisions staff had to make, their responsibilities for patient care, and made it clear that there are times when patient needs cannot be met. This also reinforced my feeling that overnight observations were not appropriate for someone without a background in healthcare. While there was an opportunity to highlight the deficiencies in the service, my presence may have been more of a hindrance. Originally, the design of the study had included observations overnight. However, on entering the field it quickly became apparent this would not be practical or welcomed by night staff. Additionally, as situations could not be predicted in advance, it would be unclear if I would have anything to record that would contribute to theory testing, if I would disturb sleeping patients, or if my presence might influence the development of an aggressive and violent situation.

There is some suggestion in literature pertaining to the insider/outsider role that staff are more willing to disclose areas of concern or sensitive material to outsiders (Allen, 2004; Hammersley and Atkinson, 2007). Whether or not I would have elicited the same comments from staff as an insider are difficult to ascertain. However, many staff appeared to provide candid accounts of their experiences, and some would seek me out during visits to discuss further their experiences and annoyances.

## Interviews

Interviews are a popular method for data collection in qualitative studies and are useful for investigating phenomena that cannot directly be observe (Patton, 2002). The purpose of Interviews in qualitative research is varies in relation to the research questions being investigated. They can be used to improve understanding by exploring people's perspectives (Patton, 2002) and, specifically in realist research, to develop and test theoretical propositions (Manzano, 2016).

Traditionally, interviews fall into three categories; structured, semi-structured, and unstructured (Patton, 2002). The choice of category will be driven by epistemological stance of the research (Fielding and Thomas, 2015). Each category has advantages and disadvantages associated with bias, flexibility, and the organisation of data. For example, structured interviews, while reducing the potential for interviewer effect, restricts the opportunity for interviewees to expand on explanations for their answers.

Interviews, while useful for accessing participant feelings, emotions, or testing theories, are subject to potential bias accounts, for example that what someone says they do may differ from what they actually do (Holloway and Galvin, 2016). For some researchers, interviews are considered complementary to other forms of data collection and the robustness of the data collected from interviews can be enhanced with additional methods, such as observation, which can support triangulation during analysis (Hammersley and Atkinson, 2007; Pawson and Tilley, 1997). Interviews aimed to gather data that could inform the context of staff roles, the ward setting, and to explore potential mechanisms that would influence staff and patient outcomes.

When conducting interviews, the qualitative interviewer will often be knowledgeable about the topic area, but to restrict contaminating the data are generally advised to adopt a “naïve” position (Kvale and Brinkmann, 2009) and neutral stance (Fielding and Thomas, 2015). In opposition to this, Pawson (2002) suggests that as realist interviewers are testing a theory, the theory should be made explicit to the interviewee for them to confirm or refute the ideas based on their experience. This has the advantage of being open about the purpose of the interview and allowing an equal exchange of ideas based on a teacher-learner cycle (Pawson, 1996). However, the effectiveness of the cycle will be dependent upon the interviewee’s knowledge and understanding of the theory being tested, and their confidence in challenging ideas that do not reflect their own experiences (Davey et al., 2014).

### *Setting*

The original intention had been to arrange interviews in advance, and to identify a mutually beneficial time and place that would support privacy and confidentiality. In reality, the majority of interviews with healthcare assistants and nurses took place on the wards in the bay they were working during quieter periods in the day. This had an impact on the length of the interviews as often they were paused or stopped for staff to attend to patient and other ward needs. For example, one interview with a healthcare assistant was interrupted three times: once for training in

the use of support stockings, once to answer questions from another member of staff related to a patient, and once to attend to a patient at high risk of falls. Gerrish and Lacey (2013) acknowledge that at times there is a trade-off between the ideal environment for conducting an interview and maximising the inclusion of certain groups. In this case, to involve patients, nurses, and healthcare assistants it was often necessary to perform interviews in the bays. While it is acknowledged this was less than ideal, participants did not appear to be concerned for hiding their feelings. For example, patients described care they had found difficult or upsetting, and some staff discussed dissatisfaction with procedures and roles.

Interviews on the ward might have inhibited some discussions with staff that could be sensitive about their work with colleagues, although most interviews were fairly candid. While this was not ideal, interviews on the wards were appropriate for these members of staff; healthcare assistants and nurses worked long shifts, often 12 hours, with two thirty minute breaks. The additional burden of an interview outside of working hours or during breaks would have reduced the recruitment of these staff members to the study. To counter this, more interviews with healthcare assistants and nurses were conducted to ensure adequate data for theory testing. Additionally, these staff often worked in areas of the ward where observations were being performed, allowing for opportunities to have conversations around theory areas being tested.

Interviews with consultants, psychiatrists, allied health professionals, and dementia leads were planned and took place in their office spaces, allowing for privacy and uninterrupted time. These interviews typically took longer and were more able to explore the theories developed in phase one. With participants' consent, interviews were audio recorded and transcribed verbatim. Two interviewees declined to the recording but agreed to detailed notes being taken and transcribed.

### *The realist interview*

The purpose of the interview was to test elements of the programme theory (Manzano, 2016; Pawson, 1996). As such, interviews took a particular focus depending upon the participant and their ability to contribute to areas of the theory. Pawson (1996) describes the role of the interviewer in the realist interview as that of 'teacher-learner'. In this he suggests that the role of the interviewer is to lay out the theory to the participant and then ask them to comment or provide detail related to this.

Staff were first asked to explain their role at the hospital and experience of working with patients with dementia to establish their personal and professional context, before discussing their use and experience of different resources for supporting patients with dementia, and asking them for their perspective of elements of the programme theory. A guide for interviews was used but adapted to recognise each participant’s insight that would contribute to theory testing and to acknowledge emerging themes during data collection. Interviews broadly covered areas in Table 13.

Table 13: Example interview questions and contribution to theory testing

Question	Function / Contribution to theory testing
Role, length of service, experience of working with patients with dementia	Staff characteristics (context)
What resources do you use (with examples) and what are the benefits to your work with patients with dementia?	Exploratory: Staff use of resources, such as <i>This is me</i> , and how they use them in practice (potential outcomes)
What do you think it is about x resource that supports good care, can you give me an example?	Exploratory: Understanding what is important to staff about a resource that supports their care (potential mechanism)
If x resource was not available, what do you think would be the impact to patients/staff?	Exploratory: looking for negative examples, (potential mechanism)
What are the characteristics of patients who receive this intervention?	Theory testing: Patient characteristics (context), and organisational priorities (context)
When there are competing demands, how do you make decisions for priorities for patient care?	Theory testing: Understanding how staff interpret their role and patient priorities (mechanism)
Testing theory around behaviour: The review suggested that if staff understand behaviour that challenges as an unmet need they would be more likely to address the need.	Theory testing: do staff recognise the concept, why do they think it is important or what do they think is important about it, or not (mechanisms/CMOC)
Testing theory around training: The review suggested that developing empathy for patients with dementia was an important part of training to motivate staff to adapt their care.	Theory testing: do staff recognise the concept, why do they think it is important or what do they think is important about it, or not (mechanisms/CMOC)

Question	Function / Contribution to theory testing
Testing emerging theory: Some of my research suggests that staff have a concern that working with patients with dementia can might lead them to be deskilled in other areas, do you have any thoughts about that?	Testing emerging theory: staff understanding or recognition of the theory to 1) confirm or refute theory, 2) suggestions for emergence and building of theory (mechanism/CMOC)
Anything to add	Opportunity to give information consider important but not covered in the interview

The teacher-learner cycle of the realist interview involves the interviewer explaining the parts of the programme theory being tested to participants and asking them to consider if this matched their experience (Manzano, 2016). Not all staff appeared to have the confidence to engage with this method and some appeared to agree without critique of the ideas suggested. Where I considered this to be the case I asked staff what they thought would be the impact of not having the intervention. Staff were able to engage well with this question and provided rich answers. Other staff engaged well with the teacher-learner principles of the realist interview and were able to dispute claims and put forward examples of why they considered theories to be wrong or incomplete. This was particularly useful around the emerging CMOC for valuing dementia care and preoccupations with losing skills.

### *Patient interviews*

Four patients consented to be interviewed, two at each site. Dewing (2002) describes the importance of the setting of the interview being contextually relevant for people living with dementia to be able to use environmental cues to support the interview. As such, I decided interviews with patients in the ward during their admission was appropriate rather than after discharge. However, this meant there were additional considerations. It was difficult to identify private areas for interviews: site 1 had a treatment room on the ward but this was often in use; at site 2 both patients interviewed needed support to be moved to a private area, for one patient they agreed to be interviewed at their bedside. The other patient was able to make use of the staff room. However, arranging their transfer to the staff room took 45 minutes from the initial agreement to participate as staff were involved in supporting other patients' needs. While there were concerns for privacy and confidentiality, three of the four patient interviews were conducted at the patient's

bedside following agreement of the patients. This may have inhibited some conversations as all three had a level of criticism for the care they had received.

For all patients who participated, there was no need to use additional materials, such as pictures, to support their interviews. The interview explored outcomes related to their care as an inpatient. The interview provided patients with the opportunities to explain what was important to them in terms of hospital care.

### *Carers interviews*

Carers were identified from their visits to see the patient. Recruitment of carers was difficult. Only two carers out of a possible 21 were recruited to the study, one from each site. For those who did participate, one agreed to be interviewed at their home following the discharge of their relative, and one agreed to be interviewed on the ward during their visit while their relative was resting. These carers spoke positively of both theirs, and the patients' experience of care.

### *Documentary review*

Documentary review is a useful data collection method for providing organisational context at the time of the research and for triangulating evidence from other sources (Yin, 2013a). Documents can provide information that it would not be possible to access through interviews or observations (Hammersley and Atkinson, 2007). Pawson and Tilley (1997) highlight that the initial programme theories for interventions may be evident in policy and strategy documents.

Documentary review can include primary and secondary data sources (Hammersley and Atkinson, 2007). For the purposes of this study, documents included for the documentary review (Table 14) are considered secondary data sources, in that the material they contained were not developed for the purposes of the research (Appleton and Cowley, 1997).

While using documents as a data source can have the advantage of being readily available and relatively easy to collect, there are disadvantages related to biases in the information they contain (Appleton and Cowley, 1997). When using documents as a data source, Scott (1990) suggests four domains for determining their quality; authenticity, credibility, representativeness, and meaning. These domains address the intentions of the writer and the document, and support the researcher to interpret the data within the context the document has been written (Holloway and Galvin, 2016).

Table 14: Documents reviewed and their contribution to theory testing

Document type	Description	Contribution to theory testing
Annual report and accounts	Trusts annual reports	Data for Trust context. Information relating to initiatives for patients with dementia
Dementia Strategy	How improvements to care of patients with dementia will be achieved	Trusts approved plan for patients with dementia
Care planning documents	Documents specifically used for the care planning of patients with dementia	Focus of care planning information. How good care for dementia was defined
Referral forms	Referral forms for the ward (site 1) and the 1:1 team (site 2)	Patient characteristics that were service priorities.

In analysing documents, data are coded and categorised as data from interviews (Holloway and Galvin, 2016). The research method will inform decisions for analysis. In realist inquiry, it is recognised that ‘nuggets’ of evidence contribute to analysis (Pawson, 2006a). Unlike grounded theory, where all data within the document would be coded, a realist analysis would only code evidence which contributes to the testing and refining of the programme theory. For example, in this study evidence gathered from the NHS Trusts Annual Reports, only data relating to the provision of care for patients with dementia was entered into NVivo, coded, and analysed.

### Medical notes review

Patient medical notes are a form of documentary analysis that can be accessed with consent from the patient or a representative of the patient (Scott, 1990). For this study the representative was referred to as a consultee (see Patient Recruitment, p55).

While a useful source of information about the patient’s historical and current medical status, the use of data collected in this way as a single method is cautioned. Prior (2003) highlights medical records are highly selective in what information is recorded, with many omissions in regard to a patient’s care, for example in recording exchanges between staff and patients. Whether medical records can be considered a good representation of events during a person’s admission to hospital needs to be considered, as does their importance for organising medical and nursing work (Berg,

1996). As such, it is important to combine data collected from patient records with additional data sources that relate to other aspects of organisational life (Prior, 2008).

A number of studies have suggested that the use of medical notes goes beyond recording activities in patient care to be a mechanism for the provision of particular patient activities. For example, in Zerubavel's (1979) study of time and its influence on hospital activities, he demonstrated how medical notes were key to the organisation of routines, patient priorities, particularly for prompting staff to regularly monitor patients. Berg (1996) found medical records were important for defining staff actions for patient care, for example what medication should be administered and when. In this study, I used medical records to describe the characteristics of the recruited patients, to understand what staff recorded and if the person's dementia was acknowledged, and how that might inform their actions for patient care.

Data collected from medical notes gave an indication of the level of impairment, disability, acute needs, and behaviour that challenges for those recruited for medical notes review at the case study sites. A data collection form (Appendix 11) was used to extract minimum anonymised data from medical notes. Information recorded the reason for admission, dementia diagnosis, health (co-morbid conditions), medication use, care plans and discharge destination. Some areas of the form were difficult to complete, such as evidence of person-centred care, as there was limited recording and reference to this in the medical and nursing notes, and often only referred to known incidents, such as when patients became upset at male carers providing personal care. At both sites there were multiple places for recording care. At site 1, there were medical and nursing notes. At site 2, there were medical notes, nursing notes, separate nursing notes, and notes kept by the 1:1 team. Notes from the 1:1 team were not reviewed as they were not readily accessible and were kept within the team.

### The Neuropsychiatric Inventory

Many tools have been developed to assess the neuropsychiatric symptoms associated with dementia (van der Linde et al., 2014b). Some cover the broad range of behaviours, such as BEHAVE-AD tool (Sclan et al., 1996) and Neurobehavioral Rating Scale (NBRS) (Sultzer et al., 1992), while others focus on one domain, such as the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1986) for agitation. The behaviour and mood of patients is an important factor that influences decisions for care and staff actions, as such it was important to capture this information.

A review of instruments used to measure neuropsychiatric symptoms found the Neuropsychiatric Inventory (NPI) to be the most widely used tool (van der Linde et al., 2013). The NPI has been used in clinical trials to determine responses to treatments (Ballard et al., 2018; Geda et al., 2013; Goldberg et al., 2013) and in research to provide a description of the behaviour and mood characteristics of people living with dementia (Glover et al., 2014; Travers et al., 2013).

Cummings et al. (1994) developed the NPI to assess behaviours and mood in people living with dementia. Originally assessing 10 behavioural domains (delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, and aberrant motor activity), an additional two domains were added (night-time behaviour disturbances, and appetite and eating abnormalities) in recognition of common behavioural changes in people living with dementia (Cummings, 1997). The NPI can be administered quickly through an interview with an informant, often the family carer or healthcare professional involved in the person's care. This confirms the presence of behaviours, their frequency, and severity. The use of an informant to report neuropsychiatric symptoms in the person living with dementia is common for most tools in recognition that self-report of these symptoms may be difficult or inaccurate (van der Linde et al., 2014a). However, a reliance on proxy reports of symptoms was considered to be a limitation of the tool (Geda et al., 2013). In response, the Neuropsychiatric Inventory-Clinician rating scale (NPI-C) (de Medeiros et al., 2010) was developed, allowing the clinician to use their clinical judgement to assess information from both the patient and the informant to score the occurrence and severity of symptoms. Additional versions of the NPI have been developed in recognition of the different settings and uses, for example the Neuropsychiatric Inventory-Nursing Home Version (NPI-NH) (Wood et al., 2000) for use in long-term care facilities, and the Neuropsychiatric Inventory Questionnaire (NPI-Q), a briefer version of the NPI for use in clinical practice and research. For this study I used the NPI-Q.

## Analysis

Data from the Neuropsychiatric Inventory and medical notes were entered into SPSS to provide descriptive characteristics of the patient population at both sites.

## Thematic Analysis

Thematic analysis is a widely used method for identifying and analysing patterns in qualitative data (Clarke and Braun, 2013). It is not tied to a specific epistemology and is, therefore, theoretically

flexible. Both theory-driven and data-driven methods for data analysis adhere to the principles of thematic analysis (Clarke and Braun, 2013). The method for analysis has been used in qualitative studies of people living with dementia admitted to hospital (Brooke and Semlyen, 2017; Lichtner et al., 2015) and in realist evaluations (McConnell et al., 2015; Williams et al., 2013). In realist evaluation, analysis is consciously theory-driven and draws on deductive, inductive, and retroductive strategies. A realist thematic analysis acknowledges the role of existing literature to support the identification of contexts, mechanisms, and outcomes that feed into the explanatory account. Boyatzis (1998) highlights one reason for using theory-driven thematic coding is to extend or refute previous work by the researcher. For phase two of the study, I was testing the programme theory from the realist review (Handley et al., 2017).

The unit of analysis in realist inquiry is the CMOC (Dalkin et al., 2015), however there is no standard approach to how this is operationalised in thematic analysis. Some researchers separately identified contexts, mechanisms, and outcomes before linking these components together (Paré, 2016, July 14). Other researchers have identified dyads or triads of data (combinations of the context, mechanism, and/or outcome elements) as a basis for coding data (Jackson and Kolla, 2012). While not endorsing a specific technique, Pawson and Manzano-Santaella (2012) highlight that analysis should lead to explanations which configure the components of a realist explanation. As such, I used a theory-driven thematic analysis approach influenced by Rycroft-Malone et al. (2016), who mapped interview data onto CMOCs developed during the theory building stage of their review to test and refine the programme theory. Appendix 12 demonstrates a worked example of how data from a transcript was coded to the different areas of the programme theory. Appendix 13 illustrates how NVivo was utilised to organise data.

The analytic process is dependent upon the associations and the connections the researcher makes from the data to test the CMOCs (Jackson and Kolla, 2012). To ensure rigour during data analysis, I wrote memos to record my thoughts and reflections on the data and used meetings with my supervisors to challenge these interpretations and explore alternative explanations. Data were further interrogated and findings discussed, and verified with the Research Network Monitors. Additionally, data from different sources (interviews, observations, medical notes, organisational documents) were used to support the rigour of the analysis by providing means of triangulation (Tolson et al., 2007). To further test assumptions, I looked at negative cases to improve understanding. For example, data from an observation session where there was less staff contact

with patients (OB0209) supported the interpretation of how a preoccupation with risk management was driving staff and patient interactions.

Braun and Clarke (2006) identify five phases in thematic analysis:

- Familiarisation
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes

In this study, I have operationalised these phases using a realist approach as follows:

### *Familiarisation*

This phase, like framework analysis (see Framework Analysis, p42) involved immersion in the data. Familiarisation began during data collection and continued through the transfer of data into electronic documents. Word documents of interview transcripts, field notes from observations, summaries of relevant material from medical notes, such as recordings of written evidence of person-centred care, and relevant data from organisational documents, such as expectations for care standards from the dementia strategies, were entered into NVivo 11.

I deepened my understanding of the data through reading, re-reading, and recording memos of my initial interpretations of how data related to the theory being tested.

### *Generating initial codes*

I used NVivo 11 to support the organisation and analysis of data. Before commencing coding, parent nodes were created from the six CMOCs of the realist review. Two additional parent codes were created, one around the emerging theme of valuing dementia care, and one which classified data as unrelated (Table 15). This ensured all data was initially coded to at least one parent node to support the review and retrieval of data, and refining categories as analysis continued.

Following this deductive approach to coding, data in each parent node were then read and coded inductively to identify themes and patterns within the data. At this stage codes were extensive and the context of the codes were kept, often consisting of one or two sentences.

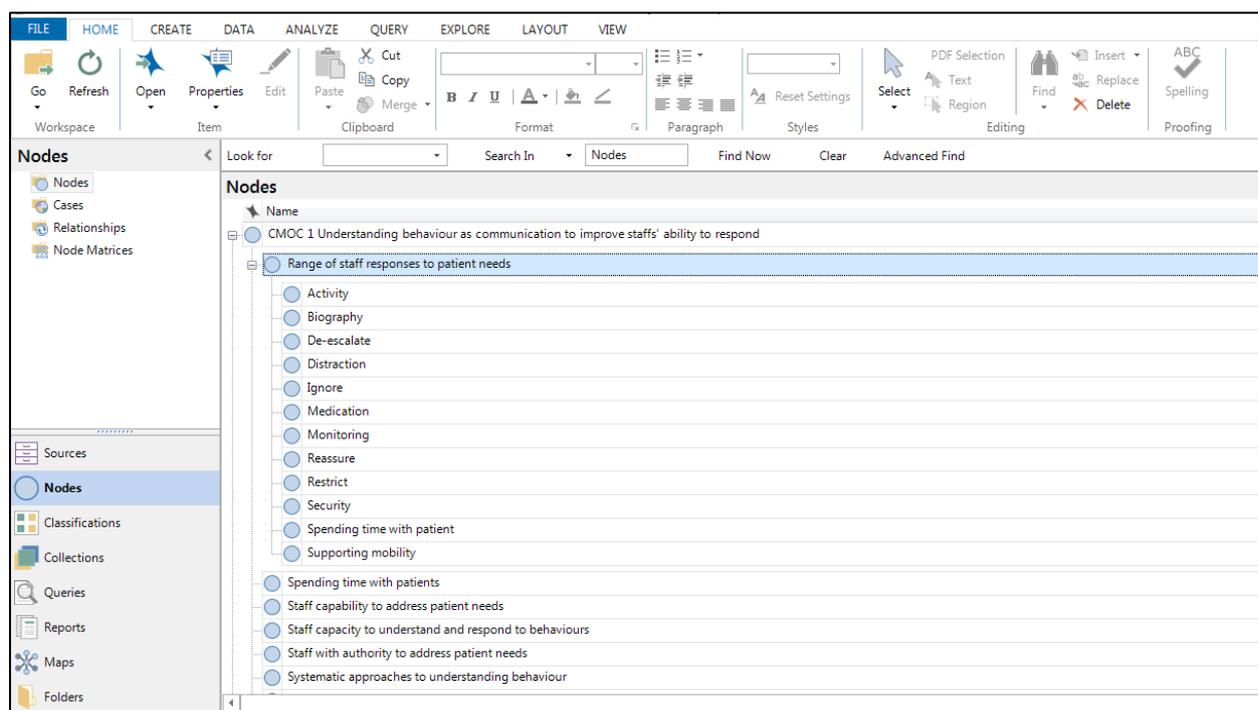
Table 15: Initial parent nodes created for a theory-driven thematic analysis

CMOC 1: Understanding behaviour as communication to improve staff's ability to respond
CMOC 2: The role of experiential learning and creating empathy to encourage reflection for responsibility for care
CMOC 3: Clinical experts who legitimise priorities for care
CMOC 4: Staff with confidence to adapt working practices and routines to individualise care
CMOC 5: Staff with responsibility to focus on psychosocial needs
CMOC 6: Building staff confidence to provide person-centred risk management
CMOC New: Valuing dementia care
Content not CMOC related

### Searching for themes

Time was spent comparing data within and across the extensive child nodes developed. A process of reducing and refining the codes took place where codes containing similar data were merged, combined, and renamed. For some codes, grandchild nodes were used to retain the detail of the themes. For example, while the range of responses staff used to work with patients became an abstracted term for a child node, grandchild nodes were kept to retain the detail of the techniques used (Figure 5).

Figure 5: Example of the use of a coding tree



Memos were used to track of challenges and refinements to coding, as well as expanding information from the data to highlight additional contextual factors that may not be apparent (Table 16).

Table 16: Examples of data with linked memos

Data	Linked memo
<p>Another HCA asks what 9 would like for breakfast. 9 replies that she has already had breakfast and it is approaching lunch time [FN: 9 has not eaten well during her stay, but may have eaten something earlier as had been up since 5am]. The HCA says to her, 'no it is breakfast time, how about some porridge with banana?' 9 smiles at her and nods, the HCA says 'I remember you like that'. The HCA goes and prepares 9's breakfast. [OB0109]</p>	<p>Patient has infection/delirium and is not orientated to time and place. This quote could demonstrate that HCA recognises the importance of nutrition and orientation, or that the HCA is prioritising the task of handing out breakfast.</p>
<p>When the 1:1 is happy that 2 is comfortable she goes over to 5 and checks that she is okay. 5 says that she would like some egg and bacon. The 1:1 says to her that if that's what she wants, then that is what she can have [FN egg and bacon is offered as a breakfast only if it is ordered]. The 1:1 then says to 5 that she thinks tea is at 6 [FN tea on this ward is at 5]. [OB0208]</p>	<p>1:1 does not recognise that this might indicate the patient is hungry, also giving the patient false information. 1:1 has had training in dementia care, so is the ward routine influencing interpretation of patient need?</p>
<p>The job itself I didn't find challenging enough. I'm quite an active person, so the job does consist, I mean it's one-to-one. Or even if you have a bay that you can't leave the bay. You're sitting around, I like to be a little bit more active and I found that I was losing other skills which I didn't want to lose. [Site 2, ST0205, HCA]</p>	<p>HCA spent time on the 1:1 team. Is dementia care recognised as skilled work? What contributes to this?</p>
<p>[ward] It was for dementia, because dementia requires a specific time with patients. Sometimes it's really hard to manage a dementia patient on another ward so when I have been to another ward and the patient is being really difficult because it's hard to manage. Here we are two health care and two nurses and at any time there is someone in the bay. In other wards it is difficult to do that because you have one nurse, one health care, so if one is busy, the other one is busy there is no one who can keep an eye on the patients, they can fall anytime. [Site 1, ST0103, Nurse]</p>	<p>A recognition that working with patients with dementia can be challenging (mechanism?).  Is the context of patient risk key for organising resources and staff time? Does this influence how patient needs are defined?</p>

### *Reviewing themes*

At this stage, I looked for clear, identifiable distinctions between the themes by reviewing all the data in each theme, considering the contribution of the data to that theme, re-coding data where necessary, and refining definitions.

As coding continued, it became apparent that a considerable amount of data had been double coded to CMOCs 4 and 5. Data were reviewed and as a result, CMOCs 4 and 5 were merged and renamed to CMOC 4/5b: Engaging with opportunities to spend time with patients.

### *Defining and naming themes*

A narrative account of the data under each theme was created. Accounts were shared with supervisors for comment and further challenges to interpretation. Themes continued to be redefined and names were adapted to reflect the ongoing analytic process.

## Ethical Considerations

As with all studies, there were ethical considerations that needed to be addressed, these are discussed below.

### Consent

Consent to participate by all participants (patients with dementia, carers, and staff), or assent from their consultees where patients were considered to lack capacity to consent, was informed, voluntary, and ongoing. All participants and consultees were made aware that it was their choice to take part in the study. For patients, they were informed that if they chose not to take part this would not affect clinical care. For staff, they were assured that if they chose not to take part this would not affect their working relationships with colleagues or other aspects of their employment. Participants were also made aware they could withdraw from the study at any point and that their decision would be respected, this was not something that happened after commencing data collection. Additional considerations for consent are discussed below in relation to the participant group.

## Patients with dementia

This patient group is particularly vulnerable due to their declining health, declining cognitive abilities, and age related difficulties. The consent process for patients with dementia complied with requirements of the Mental Capacity Act (Department of Health, 2005) in that capacity to consent was assumed unless there was evidence to the contrary. Patients were considered to have the capacity to consent when:

- the person understood the purpose of the research
- the person understood what their involvement in the study entailed
- the person understood they had the right to not participate and this decision would not affect their care
- the person was able to retain the information about the study and use it to inform their decision of whether or not to take part

Where capacity was lacking, a consultee process was followed (Figure 6).

## Assessing capacity

I was responsible for assessing the capacity of potential participants. This was informed by my observations of patients, conversations with patients, and the perceptions of staff regarding a patient's ability to understand the study information. Staff were also asked if they were aware of information about the patient that would support conversations, such as the person being hard of hearing or personal interests. Eligible patients were assessed to have capacity though:

- initial conversations to explore their communication abilities so information could be adapted accordingly
- introducing and explaining the research and their potential involvement
- checking their understanding and retention of the research and general acceptability of the study

Dewing (2007) suggests that the researcher engages in critical reflection where there is uncertainty regarding consent. The researcher should be confident that the person is consenting before they are considered recruited to the study. For some patients initially thought to have capacity and who were able to engage in general conversations, it became clear more complex discussions around the research were difficult, and clarity to obtain informed consent was uncertain. For example, one patient spoke at length about their family and life experiences, but they had limited ability to

understand and retain information about the study. In this instance, further advice was sought from a personal consultee.

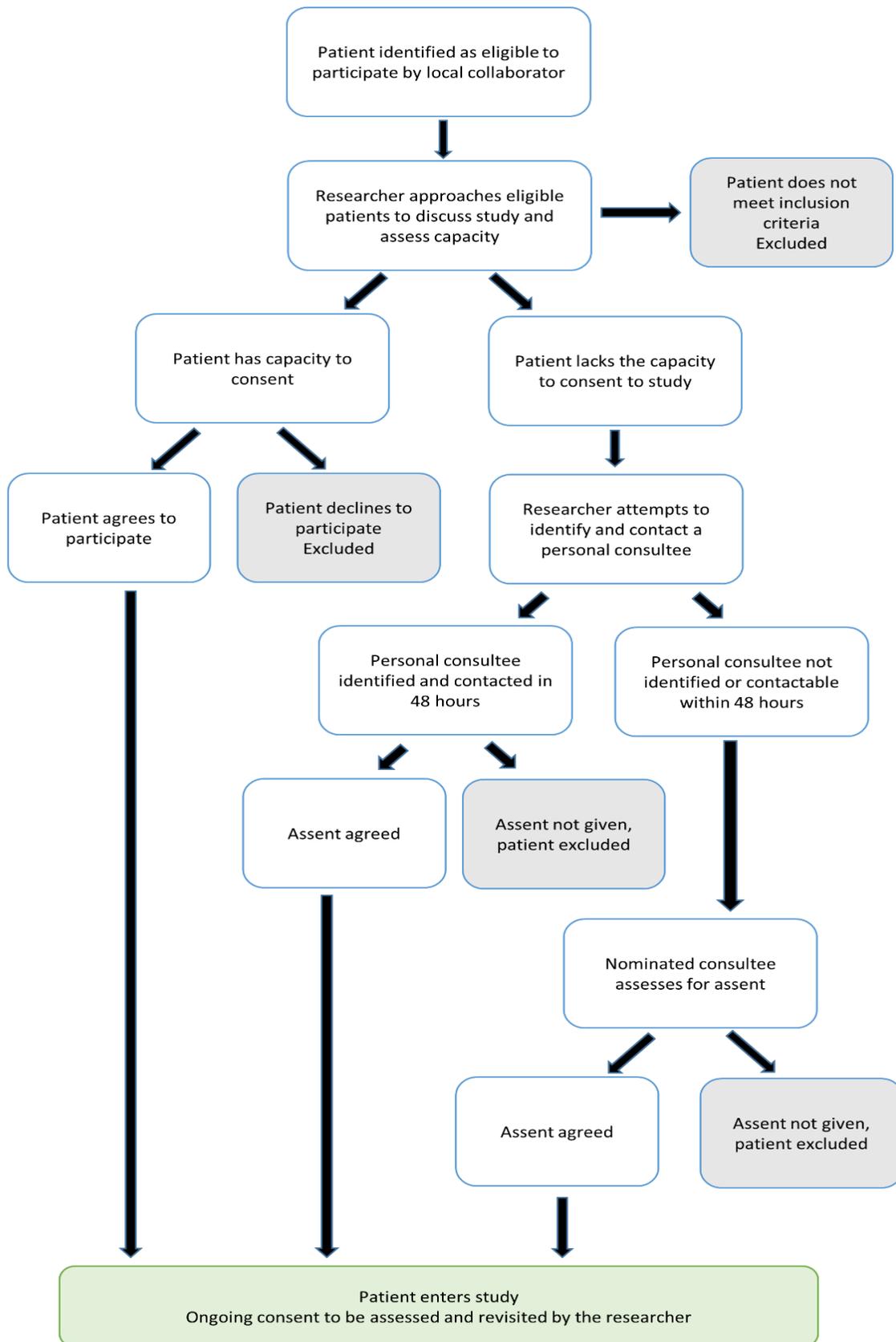
Once capacity and interest in the study were established, I began the formal process of consent. Patients were given an Information Sheet (Appendix 14) which I talked them through page by page. After which, this information was left with patients to have time to consider their participation. Some patients agreed or declined immediately. Where the patient declined this was respected. Where patients agreed, due to the speed of their agreement I spent time confirming their understanding. In some cases this was achieved quickly, in other cases this took more time. For example, one patient appeared to agree to participate quickly and then went on to talk about other topics. Attempts to revisit consent were met with further unrelated conversations. However, at the end of a conversation another attempt was made to confirm consent. The patient said “Yes, yes, yes,” while waving his hand in a dismissive gesture towards the paperwork. This was interpreted as consent but that the patient was more interested in using the opportunity to talk about other subjects. Written consent was later obtained.

For all patients judged to have capacity who consented, this was recorded appropriate to their abilities: either as written consent or as verbal consent that was observed by a member of staff who signed a witness document.

### Consultee process

A large proportion of eligible patients were too ill or too cognitively impaired to be able to provide informed consent. In line with the Mental Capacity Act (Department of Health, 2005), for patients who lack capacity to consent, a personal consultee was identified to give assent to the study (Figure 6). The personal consultee was asked for their opinion, based on their prior knowledge of the person before they lost capacity, whether they would have wanted to participate or not. In one instance a personal consultee was not identified and so a nominated consultee was contacted for assent. A nominated consultee was defined as a senior member of the clinical care team who was not directly involved in the research or patient's care (Scott et al., 2011). In this case, they considered it was not appropriate for the patient to participate in the study.

Figure 6: Process for consenting patients



## Consent in the moment

For people living with dementia consent is not necessarily a single remembered decision and was revisited throughout data collection. For patients who consented to be interviewed, I ascertained ongoing consent in the moment (Dewing, 2007). During interviews I was sensitive to the patient's mood, verbal and non-verbal communication that might suggest a decision to consent had changed. For two interviews, changes in patients' mood or needs related to their acute condition led to my decision to bring the interviews to an end. These patients did not withdraw their consent to use the interview.

## Consent for non-participant observations

Observations on the ward operated an opt-out process for recruitment. Opt-out approaches for non-participant observations have been used in other studies with patients with dementia in hospital settings (Caswell et al., 2015). Patients received written information about the purpose of the study in advance of observations. On the day of an observation period, I aimed to advise patients prior to the start, or during if this had not been possible, because, for example, they had been sleeping, that I would be making notes about their interactions with staff. I informed them that they could choose to participate or not, and that their choice would be respected (Cardona-Morrell et al., 2015). No patients objected to being included in observations. Ongoing consent was used throughout observations. If, during observations, a patient exhibited distress due to my presence, observations would stop. However, the observations did not stop due to general distress, as distressed behaviour can be expected from patients with dementia in hospital wards for a variety of reasons; they may not understand where they are, why they are there, or the need for treatments and care that are being delivered (Goldberg et al., 2014). It was not necessary to stop any observations due to patient distress as a result of the research.

Staff who regularly worked in areas where observations took place received information packs at the start of the study. Included in the pack were participant information sheets (Appendix 15), consent forms for observation, opt-out forms for observation, and a pre-paid envelope. A total of four opt-out forms (two from each site) were returned prior to the start of observations. These staff were reassured that their decision was recognised and that no information would be collected about their work with patients. On the few occasions where these staff were working on the ward, observations took place in other bays. During one observation period one member of staff who had opted-out began working in the bay sometime after the start of observations. I discussed with them that I

would not record information about them. However, after this discussion the member of staff agreed to participate.

Staff affected by observations were informed on the day before the start of data collection and were given the opportunity to opt-out of observations. No staff verbally opted-out.

### Visitors to the ward

Hospital wards are busy places and it was not possible to anticipate all people who may enter an area (Hammersley and Atkinson, 2007; Mulhall, 2003; Pollock, 2012). When observations were taking place, efforts were made to draw attention to my purpose on the ward through posters explaining the study (Appendix 16). No visitors objected to the research.

### Confidence in informed consent

Mulhall (2003) discusses how confidence in informed consent of those being observed is difficult. While every effort was made to inform patients of the purpose of the study and my role, it is acknowledged that some patients would have lacked understanding, or the ability to retain the information. Ongoing consent was used to assess patient consent to observations. Observations were also acknowledged to be a positive experience for patients, there were times where patients actively engaged with the research process. For example in one observation period, a patient chose to sit with me and started to talk through the events going on in the ward, pointing out what was happening with different patients.

Pressure to consent due to concerns about the impact on care were minimised as I was not involved in patient care. However, a few consultees commented that they considered my presence would give them an 'extra pair of eyes' on their family member.

It was made clear to staff that they did not have to participate in the research; that their participation was voluntary and would not impact on their role or the patients that they cared for. It was unclear if there were staff who felt unable to voice their reluctance to participate. A minority of staff did appear avoidant. For example, one staff member approached for interview who initially indicated interest but then maintained a distance from me. After reassuring them they did not have to participate, they confirmed they had felt guilty and had been avoiding me.

## Anonymity

While anonymity was guaranteed for all participants, in some cases this would be difficult. For example, some participants hold positions which are unique in the Trust and represent a small number of professionals across the country. Efforts have been made to ensure participants are not identifiable in the write up of this report by collapsing the categories of staff roles, and when necessary, not providing site information. Participants from the sites were allocated a code upon recruitment to the study and these codes were used to replace their names in any data collected, such as interview transcripts. Additionally, any names of individuals or places mentioned during interviews were anonymised when recordings were transcribed. During data collection for observations no identifiable data was collected. Recording of information in field notes and during transcription ensured this by: staff only being referred to by their role; patients being assigned a number that was used throughout the observation period; and reference to visitors did not record their relationship to patients.

## Confidentiality

Steps were taken to protect the confidentiality of participants. However, it was highlighted in participant information documents that where there were concerns around harm and safeguarding issues, confidentiality could not be guaranteed. Further guidance for the steps to be taken were laid out in the 'Bad Practice Protocol' (Appendix 17) that was reviewed as part of the ethics submission. During data collection, I was informed of a potential incident of harm where these processes needed to be followed. While I did not observe the incident myself, I did seek permission from the informant to raise the issue further. In the literature on nursing research there are few examples of ethical dilemmas relating to addressing concerns for harm. However, Pollock (2012) argues that there needs to be "acknowledgement and acceptance of the intrinsically difficult nature of ethical issues" adding that is not always evident what is the "right thing to do" (Pollock, 2012, p19). She proposes a process that supports the discussion and reflection of the situation to agree the course of action. This process was followed and discussion with my supervisors, informed by guidance in the protocol, led to an agreed appropriate course of action. I raised concerns with a senior member of staff who complied with our protocol requirements and sent written confirmation of how the incident was addressed. This occurred in the first week of data collection at the site, and while I had concerns this would impact access and relationships with key informants, the quantity of data collected was comparable to the other site and it did not appear to inhibit conversations with staff.

## Public Involvement

Members from two public involvement groups were involved in the study; a Research Network Monitor group from Alzheimer's Society and members from the University of Hertfordshire Public Involvement in Research Group. Members from both groups appointed to the study had experience of caring for a family member with dementia. Members from the University of Hertfordshire advised on the initial draft of the study design, which influenced the focus of the study to evaluate interventions from the perspective of those using the service rather than those designing interventions. Members from both groups were involved in discussions about the study's progress and commented on information sheets and interview schedules for use in the realist review (phase one), and the evaluation (phase two), offering advice for improving understanding of the information.

Twice yearly meetings were held with members from the Alzheimer's Society research network monitors to share emerging findings and the progress of the research. They commented on findings and analysis which helped to ensure inferences resonated with their experience and were relevant. For example, at the June 2016 meeting the findings from the realist review were presented to the members. At the time, the context-mechanism-outcome configurations were understood to contribute to two programme theories: 1) reframing of dementia care and the priorities for work; 2) staff responsibilities for psychosocial care and risk management. The research network monitors considered that the two programme theories were not distinct enough to merit being defined separately. This promoted me to revisit the theories and the evidence that had contributed to their development to consider a programme theory which combined the overlapping elements.

The challenge of recruiting carers to the study was potentially limiting. The research network monitors were able to offer insights from their experiences of family members' admission to hospital and provide comment on what they considered important. One member highlighted that although carers were able to visit any time during the day, gaining information about decisions for treatment and care was difficult and required strategies from carers to ensure they were in the right place at the right time.

“[hospital] ward round process meant that they [medical team] could turn up any time between 9am and 4pm, so it really meant camping out during the day (which I did) to make sure that happened.” (Research network monitor, email communication, January 17, 2017)

This member also contributed their thoughts on how they viewed positive and negative aspects of care. The admission of their relative coincided with a meeting to discuss the development of the programme theory following previous comments and the member was able to confirm that the findings were consistent with their experience.

In the final meeting, findings from the evaluation were shared, and there was consensus amongst the research network monitors that the study had produced interesting findings that could inform further research and practice development. For example, they agreed that verbal agitation was a key area of concern for patients, carers, and staff.

### AgeNet Seminar

On 19<sup>th</sup> July 2016, review findings were presented and discussed at an AgeNet Seminar on dementia-friendly healthcare. A total of 75 participants were present and represented a range of academics, the general public, and practitioners from across social care, and primary and secondary health care. Nineteen attendees worked in hospital settings. Attendees were encouraged to comment on the findings and agreed the interpretation of the evidence resonated with their experience. For example, in a discussion around implementing learning from training, attendees confirmed how their reasoning for applying the new knowledge to their practice was influenced by contextual factors such as the priorities of the organisation.

### A critical review of realist evaluation

Realist inquiry is a methodology that is flexible in terms of the methods employed, and has been widely applied to investigate interventions in healthcare research (Marchal et al., 2012). Realist evaluation can draw useful lessons about how particular conditions are more conducive to certain outcomes, although it cannot provide predictive guidance or a simple formula for success it is interested in causality (Pawson and Tilley, 1997). Studies have covered macro, meso, and micro levels of analysis including: evaluating national organ donation policies (Manzano and Pawson, 2014); organisation-wide processes supporting change and good practice (Greenhalgh et al., 2009; Marchal et al., 2010); interventions aimed at service level change, such as the use of protocols and care pathways (Dalkin et al., 2016; Rycroft-Malone et al., 2010); supporting staff development through education and training (Rycroft-Malone et al., 2014; Wong et al., 2010); and understanding patient fidelity to treatment regimens (Clark et al., 2005). The diversity of application of the

methodology is a strength, but has also led to varying interpretations of the key concepts (context, mechanism, outcome) (Marchal et al., 2012) accounted for, in part, by the level of analysis (Byng, 2005).

Previous research has cited limited methodological guidance as problematic in applying realist principles to study design, data collection, and data analysis (Greenhalgh et al., 2009; Rycroft-Malone et al., 2012). Since these earlier studies, reporting standards have been published for both realist review (Wong et al., 2013) and realist evaluation (Wong et al., 2016) to provide clarity in applying realist methodology. Published research continues to evolve the method by describing how processes have been operationalised, providing useful source materials that can be adapted for new studies (Goodman et al., 2017; Rycroft-Malone et al., 2016).

Bias is of concern when using realist evaluation, with key aspects of the research process at risk of introducing bias; specifically during selection of data, analysis, and reporting findings (Greenhalgh et al., 2009; Rycroft-Malone et al., 2014). Data collection involves 'digging for nuggets' of evidence that will contribute to building and testing the programme theory (Pawson 2006). This is a consciously selective process directed by the researcher who must reduce concerns of bias by exploring rival theories and looking for negative instances where the same mechanism or context may lead to different, unintended results. In positivist approaches to research, care is taken to address the potential of researcher introducing bias through activities such as blinding to intervention allocation and controlling for external factors. In realist inquiry, as data collection focuses on theory-testing this could be considered as contributing to the preconceptions of the researcher. For example, the use of the teacher-learner cycle may influence interviewees to replicate what the interviewer has proposed (Davey et al., 2014). However, in explicitly outlining their theory, researchers provide interviewees the opportunity to challenge their assumptions and contribute to refining the theory (Manzano, 2016). Realist analysis is not purely a deductive or inductive exercise, but involves interpretation, discussion, debate, and challenges (Greenhalgh et al., 2009). Triangulation of data and debate within research teams are used to refute or develop explanations for how the interventions lead to outcomes. A transparent account of the process and findings, which explains the decisions taken at each point in the research are used to address concerns of bias (Goodman et al., 2017; Pawson, 2006b).

Realist evaluation has been criticised for its rejection of critical theory as part of the explanatory account (Porter, 2012). Porter (2015b) considers it important that researchers are explicit in their

values, and recognise power imbalances to understand how context can oppress (de Souza, 2013). By underplaying the role of agency and structure and conflating these factors under the rubric of mechanisms, Porter (2015b) suggests realist evaluation has rejected the critical aspect of Bhaskar's (1978) realism, which may lead to a "technocratic interpretations of human problems" (Porter, 2012, p18). This claim is dismissed by Pawson (2015), who cites his endorsement of Archer's (1995) theory of morphogenesis for explaining the temporal sequencing of change as evidence to the contrary (Pawson, 2013). Context-mechanism-outcome configurations provide the explanatory apparatus for how people's choices and capacity for action are influenced by the circumstances they are operating in (Marchal et al., 2012; Pawson, 2015). By investigating what works, for whom, in what circumstances, realist evaluation recognises there will be multiple perspectives and outcomes for how, why, and whether, or not, an intervention works. As such, the conclusions from realist evaluation are often modest and nuanced.

### Difficulties experienced in the application of realist inquiry

I encountered a number of difficulties in applying the concepts of realist inquiry. Through the support of my supervisors, and referring to the literature on realist methods, I found strategies to address them. For example, identifying the elements of the programme theory as their component parts was initially problematic. This is not an unusual problem, and has been reported by others when differentiating elements of the programme theory as mechanisms or contexts (Marchal et al., 2012; Rycroft-Malone et al., 2010). In part, this confusion has been attributed to how practical guidance for operationalising the method from Pawson and Tilley (1997) original text was limited (Porter, 2015a). As an evolving method which is growing in popularity, the terms have been further clarified and guidelines developed to help reduce the confusion (Wong et al., 2013; Wong et al., 2016). However, despite repeated reference to these guidelines and other realist literature, I experienced difficulty in differentiating between the concepts. I was able to resolve this by understanding context as the factors that existed prior to the introduction of the intervention, and mechanism as factors that related to the intervention and staff responses (Marchal et al., 2012). This was of particular importance when clarifying whether "allocated time with patients" was a context or a mechanism. For this study, as allocated time with patients was identified as part of the resources inherent in the interventions and therefore additional to context, it was conceptualised as a mechanism.

Additionally, I explored a number of approaches for understanding mechanisms for developing CMOCs. While approaches recommend further splitting mechanisms into resources and reasoning, which is in keeping with Pawson and Tilley (1997) original concept, they proposed different strategies. Punton et al. (2016) promote the use of intervention-context-mechanism-outcome (ICMO), which can be used to explicitly identify the features of the intervention, separating out the resources it supplies from the reasoning that it generates. Porter (2015b) argues that agency needs to be thought of as separate to social mechanisms. Dalkin et al. (2015) propose that mechanisms can be thought of as the resources an intervention provides, and the reasoning that their addition prompts in people. For operationalising mechanisms in this study, I used Dalkin et al. (2015) formula of  $M \text{ (Resources)} + C \rightarrow M \text{ (Reasoning)} = O$ . This helped me to understand mechanisms as different from context, and identify mechanisms in terms of the cognitive and emotional responses of staff (mechanism reasoning), and the resources inherent in the intervention (mechanism resources).

During the realist review, it became apparent that developing CMOCs with a focus on explaining patient outcomes as a result of staff responses to resources in interventions gave only a partial understanding of the processes that led to patient outcomes. For some CMOCs it was necessary to introduce staff outcomes as an intermediate outcome which could then explain how patient outcomes were generated. For example:

Access to training (context) which promotes empathy towards people living with dementia (mechanism resource) can encourage reflection which identifies deficiencies in current working practices, helping staff to understand their responsibilities for care (mechanism reasoning), **leading them to take more time with patients with dementia (outcome)**, and improving the experience of care for patients with dementia (outcome).

This additional consideration strengthened the CMOCs to explain what staff did as a result of the mechanisms interacting with context to influence patient outcomes.

During data collection and analysis, numerous CMOCs were identified. For example, there were possible CMOCs around staff 'opting-in' to work in dementia care, however this was not developed as a CMOC as it was not considered specific to dementia care. Pragmatic decisions to drive forward the research were important to recognise what could reasonably be investigated within the constraints of the project, while retaining a credible and plausible explanation (Pawson and Tilley, 1997; Punton et al., 2016).

I used realist review to develop an explanatory account of what supports staff working in general hospitals to provide good dementia care for inpatients with dementia, and with what outcomes. Originally, the review had also aimed to test this programme theory. Due to the limits of the available evidence, in terms of the descriptions of contexts and mechanisms and the quality of the evidence, I was only able to build the theory. This was tested and refined in the realist evaluation.

## Chapter summary

Realist evaluation is a useful methodology for investigating complex interventions implemented into complex settings. In considering how context impacts on human volition, it is able to account for multiple outcomes through an explanatory account of how interventions work, or not, in different circumstances, and for whom. Realist inquiry was appropriate for this study as there has been a large amount of activity around improving dementia care in general hospitals, with limited evidence of interventions effectiveness on staff practices or patient outcomes. I have justified how the choice of study sites, participant recruitment, data collection methods, and analysis in relation to the research aims and objectives of this study. While there are methodological issues related to the concepts and application of realist inquiry, I have attempted to minimise these through debate, triangulation, and transparency in analysis and the presentation of findings.

## Chapter three: Realist review findings

In this chapter I will present the findings from phase one of the study, the realist review. The review was complete in three iterative stages which utilised data from interviews with stakeholders and from the current evidence-base. Stage one culminated in the development of three candidate theories based around the work of change agents. The evidence that informed the development of these theories are set out below. The candidate theories refined the search terms and focus of the study. Further evidence collected from the literature challenged and developed these concepts to produce six context-mechanism-outcome configurations, which together make up the programme theory.

The review process (Figure 7) demonstrates how decisions were informed by understanding from the evidence and identification of gaps in knowledge.

### Stage 1: Defining the scope of the review: concept mining and theory development

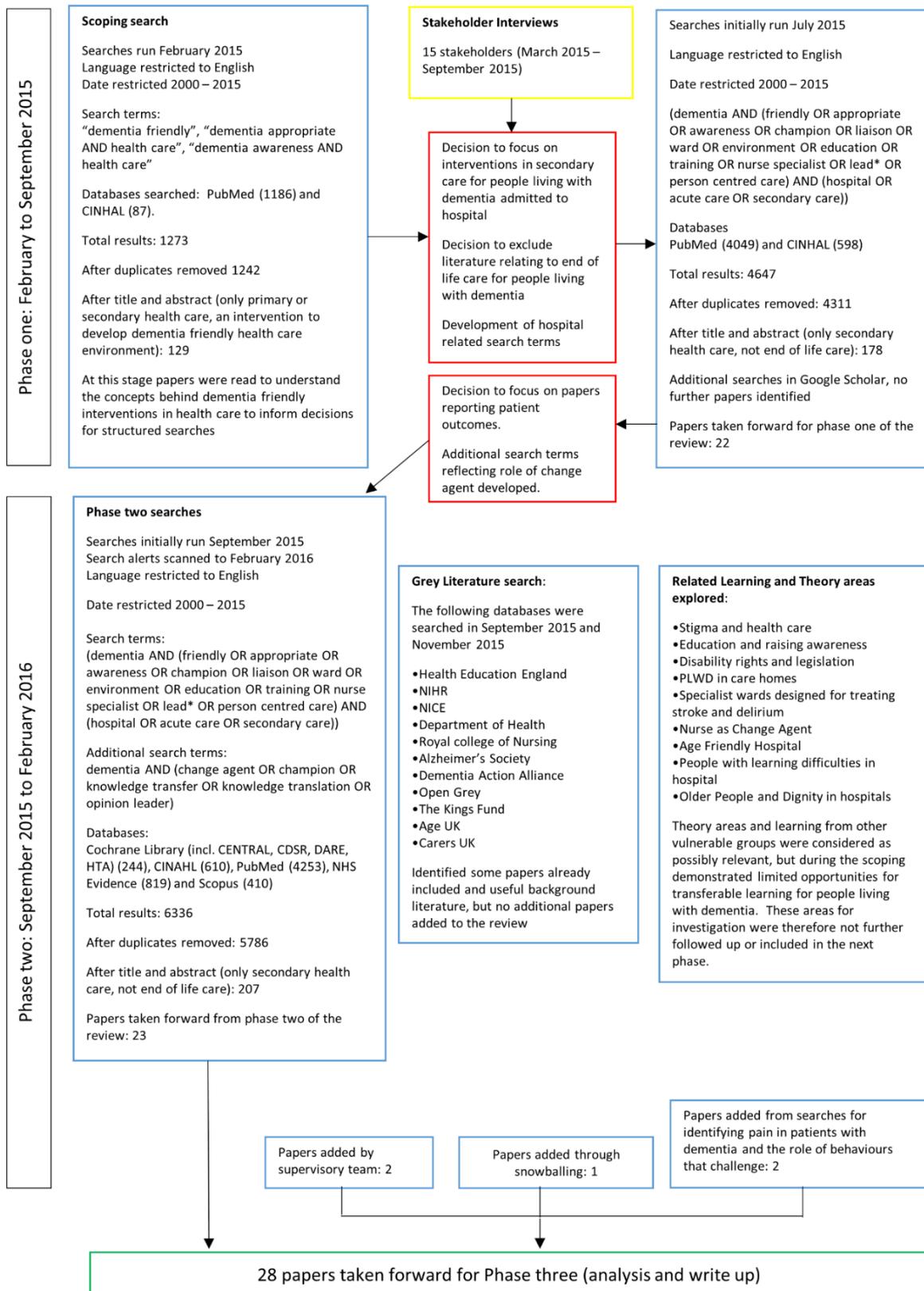
#### Stakeholder interviews

Semi-structured interviews with 15 stakeholders explored their interpretation of dementia-friendly healthcare (Table 17). Interviews lasted an average of 37 minutes (range 19 to 55 minutes). Nine were conducted on the telephone, four were face-to-face, and two were through Skype. Stakeholders discussed their experiences of designing, implementing, and/or receiving initiatives for improving dementia care and services in healthcare, and what they thought was key to supporting the development of dementia-friendly healthcare services and care practices.

Table 17: Stakeholder characteristics

Professional Background	Number
Nursing	6
GP	2
Physiotherapist	3
Social work	2
Education	1
Community	1
	15

Figure 7: The review process



The stakeholders provided insight into how staff practices are likely to affect patient and carer outcomes, how dementia-friendly healthcare is defined, the range of interventions that have been used, and how stakeholders thought they worked, or not. Interviews were not specific to hospital settings at this stage in the review, but cross-cutting themes were identified which were transferable and are reported below.

### *Working in ways that consider the patient with dementia's needs*

All stakeholders highlighted that healthcare staff needed to consider the needs of patients with dementia and adapt their work accordingly. Routine hospital practices, noisy and confusing environments, and staff under pressure to perform care tasks quickly with limited explanation, were all recognised as difficult for patients with dementia. Patients may not understand why they were in hospital and find the experience overwhelming, causing them anxiety which might be expressed in behaviours that challenge staff, as this quote demonstrates:

“you cannot just expect a person, particularly a person with, you know, more advanced changes to simply sit and toe the line and be able to be at the speed and process everything at the speed that needs to happen., A lot of older people without cognitive impairments find the acute hospital experience disorientating... taking them to A&E, then they've gone to medical assessment, then they've gone to a ward, you know, they're moved again at some point during a very short stay, it's challenging for the best willed people, let alone somebody who has got a significant cognitive impairment.” (SK04, Nursing)

Excessive sensory stimulation can overwhelm people living with dementia and lead to difficulties, something that was identified by the stakeholder living with dementia:

“it is a sense of overload, I'm aware of these things now and again, too many lights and things like that, steps, following this, people, noise at times can be overloading, so the awareness, and those are changes [to cognitive processes]” (SK03, person living with dementia)

Being overwhelmed by a situation is one reason that can lead patients with dementia to behave in ways staff find challenging. This might be misinterpreted, leading to practices that address the behaviour rather than the underlying need, such as anxiety or distress. One stakeholder gave a detailed account of the consequences of when a patient with dementia attempts to leave the ward,

leading to them being put on special observation, rather than staff trying to discover why they wanted to leave. They observed:

“these things just are common now and nobody is saying, hang on a minute here, we need to step back and review this and we need to know why have we got into this step in the first place” (SK04, Nursing)

Stakeholders identified ways of working with patients with dementia that would accommodate their difficulties. Two stakeholders (SK05 and SK13) addressed how difficulties with memory were overcome by staff taking responsibility for reminding the patient of appointments and including the carer in the communication. Other stakeholders (10/15) raised the issue of not rushing during interactions:

“so this person who wasn’t aggressive became aggressive in the mornings when he was getting washed and dressed, no surprise there... But she, the nurse went in and spoke to the [care home] staff and did it with them, saying you know, if you do this much more slowly and more carefully and showed them how if they took much more time and didn’t... That he could actually get in and out of bed without becoming aggressive.” (SK02, Education)

This demonstrates how recognising the needs of people living with dementia and providing care in ways which consider those needs can influence patient outcomes of care.

### *Defining dementia-friendly healthcare*

All stakeholders were asked what they understood by the term dementia-friendly healthcare, and how they thought it could be achieved. For eight stakeholders, dementia-friendly healthcare was about an awareness of dementia across the workforce; that staff understood what dementia is, the effect on the person, and the implications for accessing healthcare services:

“to make it dementia-friendly, and I’m talking really frontline here, you need education about what dementia is so you can get staff to understand that they might need a different approach.” (SK01, Nursing)

Linked to awareness was the idea of developing a workforce that had the confidence to work with people living with dementia. It was thought by three stakeholders that this would improve staff ability to manage patients and, therefore, improve the efficiency and effectiveness of the services:

“I think it’s something that we’ve struggled with for a long time in physical healthcare is when you get a person with a physical health problem who has also got a mental health problem, like dementia, it can be a real challenge to manage them really well and I suppose it’s that whole process of everything that we can do to be better at supporting and managing that group of people.” (SK06, Nursing)

Not all stakeholders thought that dementia-friendly healthcare was achieved when staff were aware and confident working with people living with dementia. They saw it as something more ingrained in how the person was perceived. Three stakeholders thought that for healthcare to be dementia-friendly, staff needed to have different values about people living with dementia, to treat them with humanity and to be able to see them as people who had difficulties rather than as a burden:

“I understand this is good because that maybe some quick wins is a good thing, but I think that people on the whole are missing the challenge that they’re talking about here have met just superficial fixes, where, you know, it’s a bit like adding a few accessories to a room and then they’ll be fine, and actually it’s much more substantial than that and it should be connected to our values and beliefs about dementia, people with dementia and what it means to be human and sort of the spaces and places that we all need to flourish.” (SK04, Nursing)

Some characterised dementia-friendly healthcare about addressing the stigma people living with dementia face and the need to challenge assumptions that they do not have the same rights or feelings as people without dementia. Stigma, along with discrimination, was recognised as leading to inequitable access to services:

“they [people living with dementia] get excluded [from services] because of attitudes towards dementia, because of stigma, because of a whole lot of things” (SK01, Nursing)

Negative assumptions about people living with dementia affected the way staff provided care. For example, restricting care choices, failing to properly assess needs, or involve them and/or their

family carers in decision-making about care and treatment provision:

“it’s almost an assumption that that person gets categorised as having dementia, so they’re all going to be having the same problems and immediately that one-to-one supervision is put in place, so as soon as the person gets up, it’s very much sit down again, sit down, what do you want, without actually looking at what they need, what they want, you know, if they want to go for a walk or do they want to go off the ward, just have a chat with them and, you know, it’s those kinds of things.” (SK10, Occupational Therapist)

For these stakeholders interventions needed to address issues of stigma and discrimination by tackling the way people living with dementia were viewed by staff. Promoting an understanding of the abilities people living with dementia had, the difficulties they faced, and not seeing dementia as a reason to exclude them from participating in decisions in care or gaining access to services.

### *Range of interventions*

Stakeholders identified, and were asked about, a range of initiatives that aimed to improve care and services for patients with dementia. The interventions and the way stakeholders understood how they might work are described below.

### *Education and training to improve awareness in dementia and understanding towards patients with dementia*

Stakeholders (12/15) discussed the importance of dementia awareness training and education to help staff understand what dementia is, and how they could improve their communication with patients with dementia. It was seen as necessary to compensate for the lack of focus on dementia care skills during professional training and a shortage of staff with dementia expertise:

“[FN: informed by conversations with colleagues who train nurses] actual input about dementia on a nurse qualifying programme is really actually quite minimal, so people can qualify without knowing a huge amount about dementia, and so you, it then means that you become very, you know, continuing professional development and training opportunities become really important.” (SK07, Social Work)

Training was also designed to help staff understand the difficulties patients with dementia faced, to get them to think about the way they worked with them in an attempt to make their care practices more appropriate; for example that more time was taken, and simple, clear explanations were given. Fast-paced, confusing tasks were used to simulate the experience people living with dementia commonly faced in everyday situations to trainees. They were invited to reflect on this and consider how they might improve completing care tasks with people living with dementia.

The active process of reflection was considered important for deepening the learning experience. However, six stakeholders identified that for training to be effective and used in practice it needed to be supported by managers and dementia champions:

“we can do quite a lot of work around training in dementia awareness, I think that’s got to be one of the big strategies, just about trying to help the staff understand and feel more confident about reaching people with a cognitive impairment but I suppose training is only a bit of the story, that just because somebody knows something is true because they’ve been taught it doesn’t mean they necessarily put it into practice so I think there’s a lot around leadership and around challenging poor practice to try and embed the sort of skills that they’re teaching in the training setting.” (SK06, Nursing)

Linked to this reinforcement of learning from managers and peers was the importance of developing group consensus. One stakeholder’s experience of changing care practices to provide better care for patients with dementia highlighted how there needed to be a shared commitment from all staff for changes to be accepted and sustained:

“I’ve tried to, you know, educate people around me about what person-centred care looks like and I’ve done some training with staff, just what I can, with the new ward team that I had. But I’ve realised very quickly it’s very limited what you can achieve, it has to be a whole culture of change... one person can’t change a whole team ethos. Even if there was somebody who was a really strong leader... it has to be a fundamental commitment to changing the kind of approach.” (SK14, Nursing)

There were differing views on the benefits of dementia awareness training. Some stakeholders felt that it was important for everyone in the hospital to be included while others were more sceptical of

the value of current training, considering it to be too superficial and would not lead to the anticipated changes in practice.

### *Dementia champions to support staff to work well with patients with dementia and role model good dementia care*

Dementia champions were discussed by 11 of the stakeholders. The roles of dementia champions were identified as bridging gaps in knowledge about dementia where training and expertise was lacking, helping to embed new practices, addressing poor practices and role modelling good care, and identifying environmental changes that would be beneficial to patients with dementia.

Stakeholders acknowledged the difficulty faced by dementia champions, that they needed to balance the demands of their paid role with those of the dementia champion role. The dementia champion role required creative thinking about how dementia care could be improved in their locality without receiving any additional support, such as time off the rota, or time to attend group meetings.

Stakeholders conceptualised dementia champions' purpose differently. Some saw dementia champions as proactive, autonomous agents, with a role in streamlining practices for the benefit of patients with dementia:

“I guess that’s what they’re put in place to galvanise things aren’t they, to make things happen, to stir it up a little bit so that the appropriate responses are made, that ward nurses know what to do with the very confused and distressed person with dementia, that medical specialists don’t hang on to them for too long, but transfer their care to somebody who is better skilled to manage the problems that are created and so on, so that I would see the dementia champion as having a political, with a small ‘p’, job of making a system work.”  
(SK13, GP)

Others thought they were a positive way to address deficits in staff knowledge about dementia and help to bring all staff up to a level of knowledge in dementia and dementia care. Two stakeholders described their role as disseminating information and implementing new practices that more senior colleagues had identified as important. This suggested the autonomy and initiative of dementia champions to instigate change is limited, and that their role is to disseminate management plans through peer-to-peer communication strategies:

“Well the dementia champions I have to say are very keen and very good at implementing what is being asked of them at meetings and that kind of thing.” (SK10, Occupational Therapist)

One stakeholder saw them as a negative strategy that created a skills gap in other staff, limiting the probability all staff would take responsibility for working with patients with dementia and isolating the dementia champion from the staff group:

“We found that actually it created a bit of a skills gap between myself, who’s managing things with all of the very, very complex patients with dementia, and the ward staff who were sending the complex patients my way because they didn’t feel that they had the confidence and the skills to manage them and it meant that we had a group of therapists who actually didn’t feel confident and so if I was off for whatever reason those patients weren’t picked up... it’s good to have specialist staff who know what they’re talking about and who can advocate and liaise, but we also have to make sure that there is up-skilling of all of the staff who would be involved with that so that isn’t this culture of ‘Oh that’s not my job because I’m not that champion’.” (SK09, Occupational Therapist)

Another stakeholder felt there were inherent weaknesses in the use of dementia champions if people who volunteered were not in a position of authority, adequately prepared, or had an influence over other staff members to implement changes:

“[dementia champions] they’re expected to be able to work in very complex cultures, work as an insider change agent, or a practice developer when they’re not always in a position of management or leadership position, and implement a huge amount of change as a practice, and routine, and ritual, with people who’ve still... still for the large part still do have a mind-set that they don’t like people with dementia, frightened of dementia, they don’t think people with dementia should be in their service, and these... how can you adequately expect people to change a system, to change ways of thinking, deep rooted values and behaviours with, you know, a half day or one day or a two day preparation?” (SK04, Nursing)

### *The role of leadership in prioritising quality dementia care*

Eleven stakeholders discussed the role of leadership in enabling change and improving provision for patients with dementia. One stakeholder identified that hospital management would need to be

convinced of the problems and solutions for dementia care for dementia to become a priority when set against competing concerns, such as diabetes and cardiac problems within a general hospital. The motivation for hospital management to focus on dementia, either through passionate senior clinical staff or incentive schemes such as CQUINs, was discussed. One stakeholder identified how clinical leaders with a clear vision for the way in which services should be organised for patients with dementia could influence the way training was designed and delivered:

“they [clinical management at hospital] have a real clear view about their community and what they want it to look like and they’ve got a specialist ward in [hospital] so they are doing, I mean they’re approaching this diversity of knowledge problem by deciding what it is they want and then they’re skilling their group up in that way.” (SK02, Education)

A key factor of clinical or organisational leadership was that they could make changes happen; they could access funding or resources for change and set the priorities of care for staff work.

However this top-down approach was not something accepted by all stakeholders. While one stakeholder accepted that resources became available when clinical leadership understood the need for change, they believed that it was only frontline staff who could implement the changes through understanding why they needed to adapt their ways of working. Another stakeholder identified the negative consequences of a top-down approach to change; that staff could become sceptical of the messages and disengage with the process of change:

“I think that there is often a lot of cynicism about management and leadership and that sometimes things that you impose from above, people get angry about.” (SK07, Social Work)

#### *Identification schemes to signal to staff a person has dementia*

Three stakeholders discussed the use of identification schemes, where a symbol is placed above a person’s bed or on the patient notice board next to their name to highlight to staff that the person has dementia. Such schemes are often linked to staff training and resources that gather biographical information about a patient, such as a family carer’s booklet, to help inform care planning. One stakeholder articulated the theory behind schemes, such as the Butterfly Scheme or the use of forget-me-not symbols, was that staff would recognise the person has additional needs and they would be prompted to adapt their typical care practices appropriately.

Another stakeholder explained how the identification scheme made it easier for staff to recognise patients who would benefit from other resources provided by hospitals, removing the need for a lengthy referrals process:

“somebody who’s got a diagnosis of dementia there will be forget-me-not flower [on the patient board] which means it’s easy reference that whether it’s phlebotomist, a security, or a porter, or a volunteer. They can easily see who has got an existing diagnosis of dementia and for the volunteers it means that they can identify who has a dementia diagnosis and they can then identify the correct nurse to speak to.” (SK09, Occupational Therapist)

Computer systems were also being adapted to capture diagnosis status information, share the information with the clinical team, and flag the diagnosis at subsequent admissions.

#### *Volunteers and activities coordinators to provide activity and distraction with patients with dementia*

Seven stakeholders discussed the benefits of using volunteers and activities coordinators for patients with dementia. Benefits included reducing boredom and the onset of behaviours that challenge, improving the patient experience, finding out more about the patient with dementia, and freeing up time for clinical staff to focus on physical and medical needs:

“getting somewhere away from the ward, somewhere where it’s not all medical, where the personality of the patient could come out really strongly. And it was amazing, the quality of what we told was amazing. The amount the patient enjoyed it was lovely to see and how you could see much more people than patient. It meant that people who could get quite agitated really had a place where they could go and be occupied and included and respected, those person-centred things. It meant the nurse didn’t have to do that.” (SK11, Nursing)

When introducing activities for patients with dementia, stakeholders highlighted that biographical information about the person, either through close contact with the family, talking with the person, or use of documents designed to gather this information, would help to ensure activities were appropriate and supported the interests of the person:

“There was, again, another elderly lady on a ward who was quite unsettled and when the staff did the *This is Me* process and talked to the lady’s family, she’d always been a

homemaker this lady, she'd always been very house proud and very busy with her housework and what have you, so they just kept bringing her piles of laundry to fold and it kept her very settled because she was quite happy with the idea that there's half a dozen pillowcases and when they were folded they went away and another half a dozen came." (SK06, Nursing)

However, one stakeholder highlighted how, even with some background knowledge, it was still possible to make mistakes with distraction therapies, highlighting the importance that activities are individualised rather than becoming part of a toolkit that is applied to all patients with dementia:

"I remember being on this ward and I'd been told that this particular patient had been, had been a nurse and so one morning I got her, I tried to get her to make the bed, help me make the bed, and anyway, she didn't really do much, she sort of would pat down, you know, I'd make the bed and then she'd pat it down and sort of check the pillow's plumped up nicely, and I thought to myself 'oh dear, you know, she's obviously forgotten how to make a bed, she's not very good', and then I just discovered that she wasn't a nurse at all, she was an extremely senior midwife and the idea, the idea that she would be making a bed...and I'd just assumed that she couldn't but actually I think it was 'cos she thought it was beneath her!" (SK07, Social Work)

### *Working with family carers in ways that recognise their desired level of involvement and their own needs*

Six stakeholders discussed the role and needs of carers. They recognised the importance of the family carer's knowledge of their relative which could help inform treatment and care plans. One stakeholder discussed the importance of involving carers to help manage their relative's health by including them in the communication for appointments and referrals. Stakeholders discussed the importance of understanding the level of involvement a carer might like, such as assisting with feeding, and encouraging their involvement, while also being aware that the carers had their own needs and were a diverse group. This could be assisted by improving access for carers, although two stakeholders highlighted that staff attitudes to the unrestricted presence of carers might need to be addressed. It was thought that improved relationships between staff and carers could be achieved through better communication and information for carers relating to their relative's care.

### *Biographical booklets to get to know the person living with dementia*

Five stakeholders discussed *This is Me* booklets. They thought they were a good way for staff with limited time to sit with patients, to get a good history about the person and to identify how to support and manage them well, by providing ideas for distraction therapies that might work. Two stakeholders identified that their implementation had been supported by dementia champions. This suggests that for staff to use new interventions they will need to be promoted by colleagues and managers. However, if an intervention is perceived as beneficial to staff their acceptance into practice may develop more organically. One stakeholder identified how they were beneficial to therapists as they complemented their way of working and the goals of their work:

“they’ve [dementia champions] implemented the *This Is Me* initiative, you know, to actually have a booklet and background of who the person is, what they want to do, what their occupation was and all those kinds of things and they, you know, try to bring that into the occupational therapy sessions.” (SK10, Occupational Therapist)

Stakeholders thought interventions such as *This is me* booklets were useful for staff to understand the triggers for behaviour that challenged and strategies to alleviate them or reduce their incidents. One stakeholder suggested that prior to the booklets’ introduction to wards, and staff training in dementia, there was a tendency to treat the behaviour:

“There’s less medication that goes on... I just hear from nurses and from our dementia champions that the visiting doctors will advise say are they involved in any activity during the day, could they go, you know, to the day... what about the family, can they come in and take them out for a walk, you know, that distracting techniques that you’ve got for that person.” (SK10, Occupational Therapist)

### *Specialists wards and dementia specialists to address the mental and physical healthcare of patients with dementia*

Six stakeholders discussed the use of specialist wards for caring for patients with dementia in general hospitals, with five identifying the importance of bringing together expertise in mental and physical health in order to manage people with high levels of physical needs and cognitive impairments. However, they did identify challenges for specialist wards being rolled out more widely; they are expensive, can reduce number of beds available, and have higher staff ratio. One

stakeholder identified the disparity that such wards could cause across a hospital by focusing resources in one ward and not addressing the needs of the wider hospital staff and patient population:

“the fact that one Trust can have one ward that’s this area of clinical expertise and nationally acclaimed, and then there’s nine of the other wards within the Trust, and the patients on the other wards still get I think it’s about 40, 50% of people with cognitive impairment on the normal wards, and they’re receiving a totally different model of care, than that one you’ve worked on where you know what’s needed and you know what works.” (SK14, Nursing)

Four stakeholders discussed the benefits of mental health and specialist dementia care staff. One stakeholder identified that there was access to more information about the patient from a mental health and community perspective. This allowed staff to have a better understanding of the patient’s needs and what provision they had access to in the community:

“we suddenly had a background, information where people asked what point in the process they were, what support they had, what community services had been over to assess them already, so instantly you’ve got information.” (SK14, Nursing)

Specialist staff were also able to role model appropriate care for patients with dementia, providing staff with reassurance they are doing the right thing. Where there were more serious behaviours that challenged, specialist staff were able to use their expertise to de-escalate violent situations.

However, there was a potential for deskilling other staff, as staff with nursing and medical roles were unable to spend the time with patients and had tasks to perform, leaving specialist teams to care for a patient’s psychological and emotional needs. The impact of a time-pressured hospital environment could create a divide in how work was allocated between nursing staff and mental health staff.

#### *Adaptations to the physical environment that support independence and safety*

Seven stakeholders discussed the role of environmental changes in dementia-friendly healthcare, for example using reminiscence rooms or areas that accommodated social interaction. The environment also helped maintain the safety of patients with dementia. This was through locked

doors, removal of clutter that was a potential trip hazard, improvements to flooring and lighting, and noise reduction that made environments calmer.

### Staff motivation to utilise resources from interventions and adopt new ways of working

Stakeholders understood that there were different reasons for staff motivation and engagement with the interventions. Staff who are already persuaded of the need to change practice, regardless of how they arrived at this acknowledgement, would engage well with initiatives. Sometimes staff were already aware of the difficulties that patients with dementia faced when admitted to general hospital and were keen to adopt new practices, such as volunteering to be dementia champions. Enthusiasm was often located in people who had personal experience of a relative with dementia:

[dementia champions] it's the people who've had the personal experience, the people who have volunteered to come (SK02, Education)

Some staff recognised that current practices were not working for patients with dementia and that gave them the impetus to engage with education:

“they [staff] were very receptive to the model of care because they were feeling so deskilled that they, you know, wanted to really know what can we do that's going to help make a difference to the patient and so they were interested to it.” (SK14, Nursing)

One stakeholder suggested that some interventions have a better synergy with particular roles. Where this is the case, staff were thought to be more likely to incorporate the new practices into their daily work. The example below demonstrates how biographical information can inform and individualise the work of therapists who are working to prepare a patient to return to their place of residence:

“the therapy staff I think tend to be kind of leading more on this because they do... I'm not saying they have more time, but they do have the facility when they're doing the rehab to do activities, you know, for instance occupational therapy do some of the activities with all patients, but make sure they encourage people with dementia, that maybe sitting in the bay in some way feeling confused and then that's when they start to wander and get anxious, so trying to do occupational therapy with them really.” (SK10, Occupational Therapist)

However, one stakeholder identified that if staff perceived new ways of working were not of benefit to their work, that it involved more effort, or took more time, then practices already in use would be maintained:

“we’re trying to encourage people to offer everyone and encourage them to come and have dinner in the dining room, so depending on which staff they have on they would be really on-board and they will help us, sometimes they’re too busy and the patients end up having lunch on the chair next to the bed in the room... sometimes some patients they prefer to stay there, but because they haven’t been offered since the beginning, they think that’s the normal thing to have it in the room.” (SK12, Occupational Therapist)

Stakeholders did not discuss how staff who did not understand the effects of dementia and the needs of patients with dementia would respond to the different interventions. There was suggestion from three stakeholders that encouragement from colleagues and line managers would be necessary to push for the use of new resources and ways of working.

### Balancing competing demands

Stakeholders spoke of the choices that healthcare staff had to make regarding the balancing the competing demands of their work. They agreed that medical emergencies and physical needs would take priority over psychological and emotional needs:

“you have a lot of patients to look after as a nurse and you can’t look after everybody so somebody might not be an emergency, might be being ignored and we can’t always meet their needs, you know there are people who call out repeatedly, of which there are a lot in hospital wards, you know they call out ‘help me, help me, help me’ all day and they will be ignored a lot. But there are a whole load of other patients who also have needs, who are critically ill and it’s balancing those needs is very difficult.” (SK11, Nursing)

In the above example, part of the difficulty for staff to address behaviours such as repeated calling out might not just be due to prioritisations of care, but also to a lack of awareness that the behaviour is a communication of some unmet physical or psychological need. If staff recognised that

the person was communicating an important need to be met they might be more inclined to respond.

One stakeholder spoke of how options that might provide comfort for a patient might be viewed as a risk to the ward environment, causing a conflict of meeting the needs of that patient and the requirements of the clinical environment:

“in physical health, in that particular environment whenever you add in dementia-friendly elements you risk compromising the physical healthcare and something as simple as infection control is a really good example of that, so to give you an example, we’ve had a conversation fairly recently about a patient on our bed bays who was really unsettled and we were talking a lot about trying to be very creative about how we better manage this person to make her feel perhaps she’s got more familiar things around her she’d be more settled and someone made, what I thought was a lovely suggestion of she’s got this favourite blanket that she uses at home, can that come in and be on her bed or on her chair and maybe that will give her that familiarity but of course the infection control was, no.”  
(SK06, Nursing)

Where there were concerns of risk, one stakeholder suggested that pragmatic decision-making by staff which was supported by the appropriate assessments of a patient’s needs could lead to a rational appraisal of the risk and subsequent action. However, another stakeholder highlighted this was vulnerable to the fear staff had of getting it wrong, meaning there would be a reliance on protocols which impacted on supporting patient choice and personal preference:

“how much you allow people to walk around and how much they are in bed, but when the staff are worried about their falls they will keep people in bed, they won’t allow them to walk around and I think there is a massive issue about how the whole governance process is going on and how it is stifling, and peoples’ fear of getting into trouble for doing things wrong. Something might be the wrong thing to do, but it won’t go against the protocol.”  
(SK11, Nursing)

The same stakeholder went on to explain how organisational concerns combined with the limited capacity of some patients with dementia to make decisions meant that organisational concerns were prioritised, to the detriment of patient dignity, choice, and their health:

“so we screen for risk of developing pressure ulcers if you have dementia you will be in a risk group for developing pressure ulcers and so then you are having to turn a person every two hours through the night. And so anybody who has capacity can say no I’m not prepared to do that, but if you haven’t got capacity you can’t say that and so your sleep is disturbed and you might get delirium.” (SK11, Nursing)

### Organisational leadership to permit change

For changes to happen to services they needed sign-off at a board level, as implementing change could impact on how staff time was allocated, the way staff roles interacted and the responsibility of the roles. For board level agreement to make the changes, there needed to be recognition at this level that there was a need to adapt services, and that there would be a measurable benefit:

“I think you need to have some kind of buy-in at both those levels, otherwise however good people’s ideas are, if they don’t have some kind of sign-off at a fairly senior level then they’re not really going to have it ‘cos they’ll never be a priority and because there are so many targets to be met in general, unless there’s some kind of strategy or policy in writing I don’t think it can change much really.” (SK08, Social Work)

By gaining organisational support for initiatives, changes to systems and expectations of work could accommodate new practices and models of care, as discussed in this example of implementing daily multidisciplinary team meetings:

“[to implement the daily meetings] we approached the Director [of operations] in this, said if we can get this and we can work towards getting a team together and you support us then we can probably audit and see how we can reduce length of stay and patient experience and getting, and it’s really important for any Trust or any organisation, to get genuine buy-in.” (SK15, Nursing)

Board members of organisations will not always recognise the value of changes suggested by a senior staff member. Further encouragement to make changes comes from national policy and strategies such as incentive schemes have been developed help focus the priorities of organisations. However,

stakeholders were hesitant to suggest such schemes worked in isolation to influence organisational changes, as with frontline staff, the experiences and priorities of board members were also influential:

“[Commissioning for Quality and Innovation (CQUINs, a payment framework rewarding the achievement of quality goals)] I think that can make a big difference, and certainly in the RCN programmes they were working with nine different Trusts from around the country who had applied to take part in this programme, and for them it wasn’t particularly around CQUIN targets, it was about someone within the organisation being a champion I suppose for dementia care, so a lot does come down to, you know, individuals and what their own experiences are, what they want to focus on I guess.” (SK08, Social Work)

### Anticipated outcomes of interventions for staff and patients with dementia

The anticipated outcomes of interventions were mostly discussed by stakeholders in relation to their benefit for staff: that they would develop staff confidence for talking to, and working with, patients with dementia; that they would enable staff to gain an understanding about the person; and that they would help staff to support them. The benefits for patients with dementia were generally implicit; for example, an increase in staff confidence in working with patients with dementia will lead to staff working better with patients by recognising their needs and taking action to meet them.

There were exceptions to this. When stakeholders discussed environmental adaptations, they were largely discussed in terms of the perceived benefits to patients with dementia; they aided orientation and independence which helped to maintain a person’s abilities, allowed patients with dementia to move around the wards safely and without restriction so reducing experiences of distress and frustration, or gave them the ability to control their environment.

With the exception of specialist care wards that addressed both the physical and mental health needs of patients with dementia, which were identified as catering for people in the more advanced stages of dementia, interventions were not discussed in terms of the stage of dementia or particular types of dementia. This question was not asked during the interviews, however within the literature this detail was also absent, suggesting that interventions have been designed to give staff a broad understanding of dementia and its related difficulties, encompassing all dementias and severities within each intervention.

## Summary of stakeholder interviews

In summary, stakeholders agreed that interventions did not work in isolation but that they needed the support of a change agent, who was dedicated to improving the quality of services and care for patients with dementia. For staff to adapt practices to improve care for patients with dementia, they needed a level of awareness of what dementia is, and how it impacted on a person's ability to communicate and engage with their situation. For some stakeholders this awareness needed to be at a deeper level of learning that addressed the values and beliefs staff held about people living with dementia, for them to recognise and treat them with humanity and respect. Stakeholders recognised staff and organisational management would engage and promote interventions differently, depending on whether they had been persuaded of the need for change and if they could identify a benefit to their work. A key theme across interventions was to support staff to recognise behaviours that challenge as a form of communication by the person with dementia, and to interpret and address the underlying need in a way that was not detrimental to the person.

## Scoping Review Findings

### Papers included in Stage One

Twenty-two papers were identified that described interventions that aimed to improve health care for people living with dementia (Figure 7, Table 18, Table 19). Interventions included: schemes for identifying patients with dementia (such as the butterfly scheme), staff training and education, the use of roles such as dementia champions and dementia nurse specialists, specialist teams such as liaison mental health teams, adaptations to the environment, and the creation of specialist units for patients with dementia.

Table 18: Literature by intervention for stage one

Intervention	Papers
Schemes to identify patients with dementia in hospital settings: e.g. use of a symbol, such as a butterfly or forget-me-nots, above the patient's bed for staff to recognise they have dementia. Supplemented with training and resources that record biographical history from the carer	(Williams, 2011)

<b>Intervention</b>	<b>Papers</b>
Dementia champion: healthcare staff (mainly nursing staff) trained to champion dementia care issues with colleagues	(Banks et al., 2014; Crabtree and Mack, 2010; Ellison et al., 2014; Mayrhofer et al., 2014b; Waugh et al., 2011; Wilkinson et al., 2015)
Dementia Specialist Nurse: senior nurse working as a dementia care expert across the hospital to provide advice to staff on treatment, care planning, and liaising with community services	(Elliot and Adams, 2011; Griffiths et al., 2014)
Training and education in dementia awareness	(Elvish et al., 2014; Galvin et al., 2010; Mayrhofer et al., 2014a)
Liaison psychiatry and mental health teams: Complete assessments of mental health, provide advice for staff on treatments and care plans across a hospital	(Baldwin et al., 2004; Holmes et al., 2010)
Environmental adaptations: changes to clinical areas ranging from signage to new furniture, flooring, and lighting	(Waller, 2012; Waller and Masterson, 2015)
Specialist units for patients with dementia: designed to meet the needs of patients through physical adaptations and specialist staff that can address the medical and psychological needs	(Goldberg et al., 2013; Goldberg et al., 2014; Nichols and Heller, 2002; Spencer et al., 2013; Zieschang et al., 2010)
Use of person-centred care: best practice model for dementia care that priorities the needs of the person	(Scerri et al., 2015)

Table 19: Characteristics of papers included in the scoping review

<b>Reference</b>	<b>Intervention/focus of study</b>	<b>Study Type</b>	<b>Setting</b>	<b>Country</b>
Baldwin et al. (2004)	Liaison mental health service	RCT	Hospital wide	UK
Banks et al. (2014)	Dementia champion (training programme)	Evaluation of training	Hospital wide	UK
Crabtree and Mack (2010)	Dementia champion	Description of role	Hospital wide	UK

Reference	Intervention/focus of study	Study Type	Setting	Country
Elliot and Adams (2011)	Dementia Nurse Specialist	Description of role	Hospital wide	UK
Ellison et al. (2014)	Dementia nurse consultants and dementia champions	Mixed method evaluation	Hospital wide	UK
Elvish et al. (2014)	Dementia awareness training	Evaluation of training	Hospital wide	UK
Galvin et al. (2010)	Staff training	Pre-, post- and delayed post-test evaluation	Hospital wide	USA
Goldberg et al. (2013)	Medical and mental health unit	RCT, reporting quantitative findings	Ward	UK
Goldberg et al. (2014)	Medical and mental health unit	RCT, reporting qualitative findings from observations	Ward	UK
Holmes et al. (2010)	Liaison mental health services	Service evaluation	Wards (various)	UK
Mayrhofer et al. (2014a)	Dementia awareness training	Evaluation of training provision	Hospital wide	UK
Mayrhofer et al. (2014b)	Dementia champions	Description of developing a community of practice	Hospital wide	UK
Nichols and Heller (2002)	Acute care dementia unit	Description of changes	Ward	USA
Scerri et al. (2015)	Person-centred care	Appreciative inquiry	Ward	Malta

Reference	Intervention/focus of study	Study Type	Setting	Country
Spencer et al. (2013)	Medical and mental health unit	RCT, reporting qualitative findings from interviews with carers	Ward	UK
Waller (2012)	Environmental adaptations	Discussion of environmental adaptations	Ward (various)	UK
Waller and Masterson (2015)	Environmental adaptations	Summary of Evaluation of environmental adaptations in healthcare settings	Ward (various)	UK
Waugh et al. (2011)	Dementia champion	Description of background to development of Dementia Champions	Ward (various)	UK
Wilkinson et al. (2015)	Dementia champion	Qualitative study	Ward (various)	UK
Williams (2011)	Butterfly Scheme	Description of Butterfly Scheme	Hospital wide	UK
Zieschang et al. (2010)	Special care unit	Pilot study of a dementia specialist care unit	Ward	Germany

## Types of interventions

### *Staff training and education*

Dementia awareness training (Elvish et al., 2014; Galvin et al., 2010; Mayrhofer et al., 2014a) was aimed at staff across disciplines, professional levels, and clinical and non-clinical roles. The three

papers reported a lack of focused dementia care education during training for professional qualifications and from continuing professional development. The papers described training with staff across the workforce, with ambitions to raise awareness across staff from all areas of the hospital who were likely to have contact with patients with dementia, either as patients or visitors. The training addressed what dementia is, what the signs and symptoms might be, the impact dementia has on a person, and ways that staff might better communicate with patients with dementia. Elvish et al. (2014) and Galvin et al. (2010) reported training sessions that used didactic methods, along with group learning activities that were grounded in practice. Evaluation of training was considered successful in terms of increased staff knowledge about dementia and confidence in working with patients with dementia (Galvin et al., 2010; Elvish et al., 2014). These measures were considered important as previous studies had found a link between level of knowledge and confidence. Staff confidence is thought to be an influential factor in the level of effort made, and ability to cope in challenging situations, both useful attributes for working with patients with dementia (Elvish et al., 2014).

However, Elvish et al. (2014) and Galvin et al. (2010) were evaluating training that had been designed as part of the study. Mayrhofer et al. (2014a) reported that the reality of training provision in one area of England was variable in training methods, duration, and quality (defined by a course being accredited and counting towards professional development). Benefits to staff for these courses had not been measured making it difficult to know if training had improved the ability of staff to understand and recognise the symptoms of dementia, and what the implied benefits to patients with dementia might be.

### *Dementia champions*

Five papers reported the use of dementia champions to work as change agents in hospitals (Banks et al., 2014; Crabtree and Mack, 2010; Ellison et al., 2014; Mayrhofer et al., 2014b; Waugh et al., 2011). They described the idea that dementia champions would be trained to have an expert knowledge of working with patients with dementia, to advocate on their behalf, to role model good practice and challenge poor practices, to identify areas within their working locality that could be better and implement changes, to understand the legal implications of addressing capacity issues, and to work as change agents to develop the dementia care skills of staff they work with. Using champions is based on the premise that interventions have limited impact when they are passively implemented into a workplace, they require the support and reinforcement of a change agent. In the case of

dementia champions, Banks et al. (2014) reported that these change agents needed to have a level of authority within their working locality that would allow them to make any changes needed and to be able to influence staff. To help them with this process, dementia champions received an enhanced level of training in dementia care (Crabtree and Mack, 2010; Waugh et al., 2011; Banks et al., 2014; Ellison et al., 2014), and had ongoing support in their role through dementia champion networks and the support of senior colleagues (Banks et al., 2014; Ellison et al., 2014; Mayrhofer et al., 2014).

Reporting of dementia champion roles focused on reporting staff outcomes of the training (Waugh et al., 2011; Banks et al., 2014), the value of a community of practice for dementia champions (Mayrhofer et al., 2014), and the experiences and outcomes of dementia champions in practice (Ellison et al., 2014).

#### *Dementia and mental health care specialists*

Dementia nurse specialists (Elliot and Adams, 2011; Ellison et al., 2014) and liaison mental health staff (Baldwin et al., 2004; Holmes et al., 2010) supported staff to assess patients, develop care plans and address issues around capacity. Again, they were seen as a strategy to compensate for limited dementia care knowledge within general nursing and medical staff. However, this time the strategy was to bring in experts who would complete work that general staff did not understand and then advise them of the way forward.

Literature pertaining to specialist roles, such as nurse dementia specialists, and teams such as liaison mental health teams, were more specific about how particular elements of support provided to healthcare staff, or directly to the patient, had an impact on particular outcomes for patients with dementia. For example, in supporting staff to use pain assessment tools specifically designed for patients with dementia, staff were able to recognise when a person was experiencing pain and administer the appropriate pain relief (Elliot and Adams, 2011).

#### *Dementia specialist care wards*

Dementia specialist care wards (Goldberg et al., 2013; Goldberg et al., 2014; Nichols and Heller, 2002; Spencer et al., 2013; Zieschang et al., 2010) cared for patients with dementia in environments that had been especially adapted to cater for their needs. This included: allowing patients to walk around the ward; access to specialist mental health care staff to address their psychological and

emotional needs; and activities coordinators who provided meaningful activities that were appropriate to their skills level and interests. It was thought that if care was provided in an environment that addressed both the physical and mental health of patients with dementia, this would: improve healthcare outcomes; reduce patient distress; it would be easier for staff to work with patients; and would reduce the length of stay in hospital. While studies demonstrated improvements to patient experience and carer satisfaction, the impact on health status outcomes was less clear, and there was no evidence that length of stay was reduced.

### *Identification schemes*

The Butterfly Scheme (Williams, 2011) used an identification system for patients with dementia. This aimed to make staff aware that the person had dementia and that staff needed to work differently with the person. The scheme was supported with training in dementia care that was specifically tailored for different staff groups across the workforce of a hospital, both clinical and non-clinical. A booklet for gathering biographical information from the carer aimed at providing better care for patients with dementia by identifying the meanings behind behaviours that challenge, ways of working that reduced distress, and knowing about the person to be able to provide meaningful interactions and activities.

### *The use of person-centred care*

The use of person-centred care (Scerri et al., 2015) is promoted as best practice for patients with dementia, but staff are unclear what person-centred care means or looks like. The use of person-centred care improves the experience of care for patients with dementia, and reduces distress and incidents of behaviours that challenge. The paper provides examples of person-centred care in practice.

### *Environmental adaptations*

Environmental adaptations (Waller, 2012; Waller and Masterson, 2015) were designed to accommodate the difficulties patients with dementia experience due to the changes in their brain. Their altered perception, ability to recognise items and their use, difficulties in navigating an environment, and ability to make decisions about an environment were addressed through environmental changes. Improved signage, better lighting and flooring, furniture that supported patient mobility and resting needs, and items that would orientate them in time and place were

thought to improve the safety of patients with dementia, and their experience of a place by being less confusing and maintaining their independence. These changes were suggested to reduce distress and the development of behaviours that challenged, or in the case of 'wandering', allowed for safe mobilisation which did not need to be interpreted as a risk by staff.

Reporting environmental changes focused on benefits for patients with dementia (Waller, 2012; Waller and Masterson, 2015) and participating sites recorded measures to demonstrate improvements. Outcomes for patients with dementia included measures of improved safety (from reduction in falls and reduce use of antipsychotics), and reduction in aggression and violence (measured in number of incidents pre- and post-environmental adaptations).

### Who instigates change

The papers gave information about the way change had been implemented. Some identified a person in the organisation with clinical and organisational authority driving new visions for care, while others identified partnership working with carers and agencies, with an interest in improving care for patients with dementia (such as the Alzheimer's Society and carers charities), in identifying problems in hospital provision and working on solutions for change.

Scerri et al. (2015) stated that person-centred care training had been delivered by the consultant geriatrician in charge. Examples of person-centred practices from interviews with staff working on the wards also suggests that staff influenced each other in the way they work by role modelling good practice to each other, and seeing the differences these practices make to patients with dementia.

In Goldberg et al. (2014) and Goldberg et al. (2013), the specialist unit had been designed from evidence of best practice with patients with dementia and the experience of locating care for people after a stroke within a specialist unit (Harwood et al., 2011). Discussions with Trust management secured funding and additional resources, and a multidisciplinary group met monthly to keep the project on track. The unit was based on units that had been set up by 'enthusiasts' from outside England, as the split of physical and mental health in the NHS system had only led to the development of two such units in England, which had not evaluated their provision.

Carers were highlighted as the catalysts for the development of dementia champions and the related training programme (Crabtree and Mack, 2010; Waugh et al., 2011). Discussions about their

relatives' experiences of hospital care with the User and Carer Involvement charity, and Alzheimer's Scotland, led to the commissioning of the dementia champion programme. The carers contributed to the design and content of the programme throughout the development process, and described their experiences to trainees as part of the training programme (Waugh et al., 2011; Banks et al., 2014). The Butterfly Scheme (Williams, 2011) was developed by a family carer (Barbara Hodgkinson) after observing the experience of her mother's care in hospital.

The King's Fund Enhancing the Healing Environment programme promotes consultation and engagement with patients and carers for designing dementia-friendly healthcare environments (Waller, 2012; Waller and Masterson, 2015). This helped ensure changes met the needs of patients with dementia. Multidisciplinary teams led by senior personnel from the participating organisations implemented changes that met the needs of patients with dementia, while adhering to organisational requirements such as health and safety.

Changes to a hospital ward (Nichols and Heller, 2002) were also driven by involvement of a carer's group in discussions with the Director of Geriatrics. The experiences carers described and their ideas for service improvements were taken forward during the development of the specialist unit.

The role of those instigating change did not necessarily mean that interventions would be successful and the papers were limited in the evidence they provided to demonstrate their impact on practice. Where interventions replicated previous designs, for example the use of dementia champions (Mayrhofer et al., 2014b; Wilkinson et al., 2015) or specialist ward (Goldberg et al., 2014), studies do not report the involvement of people living with dementia or carers. This suggests that once an intervention has been developed and shown to have a positive effect in practice that roll out in other areas does not require the level of input for development; rather it becomes a management decision around implementation. At this stage of implementation, some of the elements may be adapted. In the case of dementia champions, a comprehensive training programme was undertaken by would-be champions (Waugh et al., 2011; Banks et al., 2014), in later incarnations the strategy was more variable with differences in how organisations conceptualised and supported the role (Mayrhofer et al., 2014b).

### Practicalities for change

Elvish et al. (2014) highlights some of the obstacles for implementing dementia awareness training to all staff across organisations. The 'Getting to Know Me' training programme was split across four

sessions, there was an attrition rate of 37% between the first and the last session, this was attributed to difficulties in releasing staff for training. Mayrhofer et al. (2014a) also reported difficulties of dementia champions being released for meetings, impacting on the success of communities of practice programme.

Elvish et al. (2014) found 52% of staff attending training had not received any formal training in dementia care. The authors argue where knowledge in dementia care across staff is limited, a strategy that addresses training needs of the workforce as a whole is likely to be most successful in changing staff practice with patients with dementia. They suggest this is supported with supervision to reinforce learning. The paper did not report whether gains from training were maintained, and if training had impacted on staff practices with patients with dementia.

Galvin et al. (2010) did report that staff training was maintained at 4 month follow up, and that there had been some impact on staff practices. Staff reported that they had organised activity packs for patients with dementia and created a team of volunteers to spend time with patients during their admission to hospital.

### Influencing practices

Elliot and Adams (2011) highlighted that staff in specialist roles that are not based on the wards can have limited impact on ward staff. Holmes et al. (2010) found that staff identified better with liaison staff from the same professional group; this was evidenced through referrals received, for example, from nurses to nurses. Holmes et al. (2010) did find that staff with access to liaison teams were more familiar with conducting mental health assessments, suggesting there had been some transfer of knowledge from liaison staff to general ward staff. However, the influence of liaison staff relied on ward staff being aware of the service, how to access it, and the procedure for referring patients. If staff using the service perceived the provision to be slow to respond, or that the advice and support they offered was not of good quality, this would impact on future use of the service. An additional difficulty was if staff misinterpreted the level of involvement the service offered. For example, if staff anticipated liaison services would support the daily care of patients with dementia they would be disappointed, their role was to assess the person, facilitate access to psychiatric facilities, and support the discharge process.

## Mapping the data

As part of the theory development, potential factors that influenced the acceptance of a dementia-friendly intervention into a hospital environment were mapped from the interview and the literature evidence. This visual representation of the data demonstrated the numerous areas where further investigations could be focused, for example at organisational level, service level, or patient level, and where there were potential gaps in evidence and understanding (Appendix 6). This exercise suggested there was limited understanding of how interventions worked at the point of interaction between staff and patients, but all required extra support from one or more individuals committed to the promotion of a dementia-friendly hospital environment.

## If... then statements

Informed by emerging evidence from the interviews and the literature, 'if... then' statements (Pearson et al., 2015) were developed and refined through discussions with the supervisory team to understand how outcomes were thought to occur (Table 20).

Table 20: If... then statements

If	Then	Evidence / theory
Expert support		
<p>If assessments are conducted for the needs of patients with dementia (nutrition and hydration, pain, falls, delirium), supported by a member of staff with expertise in dementia care (either as a dementia or mental health specialist or as a dementia champion who has received additional training) and a care plan is devised, shared with staff and followed</p>	<p>Then patients will receive appropriate and timely treatment which will relieve their discomfort, reduce the occurrence of adverse incidents, which will minimise the time spent in hospital</p>	<p>Stakeholders: SK09, SK11, SK15</p> <p>Literature: Baldwin et al. (2004); Banks et al. (2014); Elliot and Adams (2011); Goldberg et al. (2014); Griffiths et al. (2014); Holmes et al. (2010); Williams (2011); Zieschang et al. (2010)</p>
<p>If assessments are carried out to understand the person's level of functioning (e.g. activities of daily living)</p>	<p>Then support to maintain their abilities can be planned for with the aim of returning them to their pre-admission status</p>	<p>Stakeholders: SK09</p> <p>Literature: Goldberg et al. (2014); Zieschang et al. (2010)</p>

If	Then	Evidence / theory
Knowledge of patient		
<p>If biographical information is gathered, completed by staff with the family carer and the information is accessible (by being in a convenient place and in a useful format) to all staff and they are aware that the information is of benefit such as providing strategies for working with the patient (e.g. how behaviour represents a need in the person that staff can recognise and address)</p>	<p>Then the information can be used by staff (e.g. occupational therapists) as part of their rehabilitation and the patient with dementia is occupied in an activity that is of meaning to them (has relevance, is something they enjoy). Staff will be able to have conversations that are of interest to the patient</p>	<p>Stakeholders: SK06, SK10,SK12, SK15</p> <p>Banks et al. (2014); Nichols and Heller (2002); Williams (2011)</p>
<p>If family carers are consulted about the patient with dementia (what has led to their admission, normal way of being, decisions regarding care and discharge) and staff work closely to gain a good understanding of the patient (their likes/dislikes, important routines, behaviours in different situations)</p>	<p>Then care will be safer (less adverse events due to accurate history taking) and staff will be able to respond appropriately to the patient's needs (i.e. by recognising pain, being able to comfort them when appearing distressed, understand why they have not eaten)</p>	<p>Stakeholders: SK03, SK05, SK11, SK12, SK15</p> <p>Literature: Nichols and Heller (2002); Scerri et al. (2015); Spencer et al. (2013); Williams (2011)</p>

If	Then	Evidence / theory
Defined roles in patient care		
<p>If patients with dementia are provided with an appropriate activity (something they can do, enjoy) by a person with a role for providing activity (activities co-ordinators, therapist assistants)</p>	<p>Then patients with dementia will have some structure to their day, reduced boredom, reduced daytime sleeping, and increased social interactions, which will then reduce behaviours that challenge, reduce sleep disturbances, and help rehabilitation and recovery</p>	<p>Stakeholders: SK08, SK11, SK14, SK15</p> <p>Literature: Goldberg et al. (2014); Zieschang et al. (2010)</p>
<p>If there is provision for addressing mental health needs in hospitals (liaison mental health teams, mental health staff on ward, dementia champions)</p>	<p>Then emotional and psychological needs of the patients with dementia will be assessed, monitored and appropriate plans made to care for their needs</p> <p>Then staff will feel supported, be able to learn from the way care is role modelled by those with a specialist focus, be able to check their own practices leading to increased confidence and more effective working with patients with dementia</p>	<p>Stakeholders: SK04, SK11, SK12, SK13, SK14</p> <p>Literature: Banks et al. (2014); Elliot and Adams (2011); Ellison et al. (2014); Goldberg et al. (2014); Griffiths et al. (2014)</p>

If	Then	Evidence / theory
If there are clearly defined roles and responsibilities across disciplines and organisational boundaries (through service agreements, job descriptions, protocols, care pathways, care plans)	Patients will receive appropriate, timely care that is not delayed by staff disputes about who has the responsibility and what that responsibility is, leading to quicker treatment and recovery.	Stakeholders: SK13  Literature: Elliot and Adams (2011)
Peer support to embed practice changes		
If there is a dementia champion in place who is working to improve awareness and understanding in staff about dementia and the difficulties patients with dementia have, using training and reinforcing learning by addressing concerns staff express when working with patients with dementia or by addressing negative behaviour they may exhibit towards patients with dementia	Then they can help to breakdown the stigma (assumption patients with dementia do not belong in the service, assumptions that nothing can be done to improve the patient's situation, assumptions that people living with dementia are lesser persons) within staff and help them to see patients with dementia as they see other patients with needs that should be met	Stakeholder: SK04, SK06, SK10  Literature: Banks et al. (2014); Crabtree and Mack (2010); Ellison et al. (2014); Mayrhofer et al. (2014b); Waugh et al. (2011); Wilkinson et al. (2015)
If there is a dementia champion in place to help embed knowledge and practices demonstrated in training	Then learning in staff will be retained and sustained, staff will have a resource to consult, which will lead to best practice in dementia care being used	Stakeholders: SK06  Literature: Banks et al. (2014); Ellison et al. (2014)

If	Then	Evidence / theory
If staff have the opportunity to be reflexive about their work with patients with dementia (discuss things that went well, went wrong, what could have gone better)	Then they will understand what good practice looks and feels like and how it can be achieved leading to an improvement in their skills for working with patients with dementia	Stakeholders: SK04, SK11, SK14  Literature: Banks et al. (2014); Mayrhofer et al. (2014b)
If staff who become dementia champions are empowered through appropriate education (that gives them in depth knowledge about the causes and effects of dementia on the brain and the impact this has on the person and how care practises and services can be adapted to compensate for impairments), and access to experts in dementia (through formal working relationships) and are given time to develop the role during their working day (e.g. time off rota)	Then they will be able to influence their peers in the way they work with patients with dementia, (for example pacing care to a person's needs, ensuring communication is appropriate for the person) and promote empathy	Stakeholders: SK02, SK11  Literature: Banks et al. (2014); Crabtree and Mack (2010); Ellison et al. (2014); Waugh et al. (2011)

If	Then	Evidence / theory
Level of authority for change		
<p>If you have a dementia champion who is motivated (understands why practice needs to adapt for patients with dementia and wants to influence practice in their colleagues), has received adequate training (about dementia and acting as a change agent), has a level of authority (the ability to identify what needs to change and implement those changes), and is supported within the organisation by management (ward management, dementia specialists)</p>	<p>Then they will be able to develop strategies for making changes (training, role modelling, developing tools that fit with current work practices) and persuade staff of the benefits and needs to make the changes.</p>	<p>Stakeholders: SK02, SK06, SK10, SK12</p> <p>Literature: Banks et al. (2014); Ellison et al. (2014)</p>
Dementia awareness and empathy for people living with dementia		
<p>If staff are able to recognise a person has dementia (through their own training in recognising the signs of dementia or from a system that alerts them to someone having dementia)</p>	<p>Then staff will know there are cognitive difficulties and be able to adapt their care to compensate for the needs a person has. E.g. where there are memory difficulties, communication difficulties, behaviour appears unusual</p>	<p>Stakeholders: SK01, SK03, SK06, SK07, SK09, SK10, SK13, SK15</p> <p>Literature: Elvish et al. (2014); Galvin et al. (2010); Nichols and Heller (2002); Scerri et al. (2015); Spencer et al. (2013); Williams (2011)</p>

If	Then	Evidence / theory
If staff have a positive attitude to patients with dementia which respects their personhood (an understanding of what it means to be a person as an individual, as part of relationships and as part of society)	They will better recognise their needs and address them appropriately e.g. will understand that behaviour that challenges is a communication of an unmet need and will work to understand and address the need rather than treat the behaviour	Stakeholders: SK01, SK02, SK04, SK07, SK08, SK11  Literature: Goldberg et al. (2014); Nichols and Heller (2002); Scerri et al. (2015); Spencer et al. (2013); Zieschang et al. (2010)
If staff develop empathy for patients with dementia through training, support from staff with experience in working with patients with dementia or through personal experience	They will be able to see them as the person first rather than the diagnosis, they will consider alternative reasons for particular behaviours and not attribute them to dementia, which will help to ensure health problems are not overlooked by the member of staff (e.g. not recognising pain)	Stakeholders: SK02, SK04, SK10, SK11, SK12  Literature: Banks et al. (2014); Elvish et al. (2014); Galvin et al. (2010); Scerri et al. (2015); Williams (2011)
<b>Trained workforce</b>		
If the majority of hospital staff (clinical and non-clinical) receive dementia awareness training (tier 1)	Then there will be a critical mass of staff able to recognise the signs and symptoms of dementia and offer appropriate support when working with patients with dementia (e.g. helping them find their way, giving them assistance when appropriate to their needs for meals and drinks, taking medical histories, developing a care plan)	Stakeholders: SK01, SK06, SK09, SK10  Literature: Mayrhofer et al. (2014a); Williams (2011)

If	Then	Evidence / theory
<p>If staff increase their confidence in working with patients with dementia and their knowledge about dementia and how it can impact on a person and their care needs through training and team support</p>	<p>Then attitudes towards dementia and patients with dementia will be more positive (i.e. reduce stigma and discrimination), staff will be more competent (be better able to work appropriately with patients with dementia) and better able to cope with situations and behaviours that challenge</p>	<p>Stakeholders: SK01, SK02, SK11, SK12, SK14</p> <p>Literature: Elvish et al. (2014); Galvin et al. (2010)</p>
<p>If staff are trained in appropriate communication skills to use with patients with dementia (pacing, use of non-verbal communication, eye contact, touch, awareness of non-verbal communication, tailored to the patient's individual abilities)</p>	<p>Then staff will develop a therapeutic relationship with patients with dementia which can support their choices, needs, abilities and inform care plans and treatments</p>	<p>Stakeholders: SK02, SK03</p> <p>Literature: Scerri et al. (2015)</p>

If	Then	Evidence / theory
Environment and risk management		
<p>If the environment is adapted to consider the needs of the patients with dementia (decluttered, less clinical, clear signage, use of colour for wayfinding (coloured bays, areas should not to attract attention such as exits are 'disguised', keypad entrance/exit, reduced confusion on notice boards but points of interest such as art, furniture that assists mobilisation such as handrails and seating, clocks for orientation to time and date))</p>	<p>Then patients with dementia will be orientated, able to understand their environment (the purpose of different areas) and move round the environment safely with minimal restrictions from staff. This will reduce distress and foster a calmer atmosphere that can aid patient wellbeing</p>	<p>Stakeholders: SK01, SK08, SK11</p> <p>Literature: Waller (2015); Goldberg et al. (2014)</p>
<p>If patients with dementia are given opportunities to mobilise when they choose in an environment that is safe (e.g. no tripping hazards, ability for staff to observe from a distance)</p>	<p>Then there will be reduced incidents of distress from restricting the patient to bed and functional abilities will be maintained</p>	<p>Stakeholders: SK01, SK09, SK11</p> <p>Literature: Goldberg et al. (2014); Nichols and Heller (2002); Spencer et al. (2013); Waller (2012); Waller and Masterson (2015); Zieschang et al. (2010)</p>

## Candidate theories

Organising findings into 'if... then' statements highlighted the influence of change agents, staff who supported the implementation and uptake of interventions, as a key theory area. As such, three candidate theories based around the work of change agents were developed which incorporated the prominent ideas of what would support the development of dementia-friendly healthcare (Box 3). The theories set out how different change agent roles were thought to support staff and influence patient outcomes. The candidate theories provided a framework to guide subsequent searches of relevant sources of evidence, and a more in depth, theory-driven analysis of the evidence.

### *Box 3: Candidate theories*

If a change agent's activities or resources of an intervention supports staff to understand how to interpret and respond to a patient's behaviour that uses person-centred care approaches, challenges poor practice by using experiential learning and reflection, then staff will be more likely (through mechanisms of confidence, awareness, the ability to prioritise) to engage and assess patient pain or distress and involve patients with dementia and their carer in planning their care

If a change agent has organisational and clinical authority to introduce learning and credible resources that prioritise the identification and care of patients with dementia and addresses concerns around risk and workplace disruption within a person-centred care framework then staff will feel they have permission to do the right thing becoming less risk averse

If a change agent works as a clinical expert to identify and resolve the care needs of patients with dementia then staff will feel supported and be more willing to care for patients with dementia

## Stage two: retrieval and review

The search and selection process was set out in chapter two (see Searching for relevant studies, p48) and is detailed in Figure 7. Twenty-eight papers were included in the review. Their characteristics are described in Table 21.

Table 21: Papers included in stage two of the realist review

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
Baillie (2015)	UK	Published report	Evaluation of training	Qualitative	Written responses and focus groups	Patient satisfaction, patient safety
Baldwin et al. (2004)	UK	Published paper	RCT of mental health liaison team	Quantitative	Validated tools	Depression, cognitive impairment, referrals
Banks et al. (2014)	UK	Published paper	Evaluation of dementia champion training programme	Evaluation	Questionnaires of trainee knowledge and confidence in dementia, qualitative analysis of trainee reports	Staff reported patient outcomes for changes in practice
Bray et al. (2015)	UK	Published paper	The use of bay nursing and activities with patients with dementia	Description of the use of bay nursing and activities co-ordinators	Dementia care mapping, Patient experience questionnaires	Patient experience
Brooker et al. (2014)	UK	Published report	Evaluation of Royal College of Nursing development training programme	Evaluation report	Online survey, site evaluation (including locally determined methods such as dementia care mapping, incident reporting and patient satisfaction survey)	Patient satisfaction, carer engagement, reduced distress
Dowding et al. (2016)	UK	Published paper	Development of pain management tool for patients with dementia	Ethnographic study	Interviews, non-participant observation, medical notes review, documentary analysis	The identification and management of pain
Duffin (2013)	UK	Published paper	Description of interventions to improve care for patients with dementia	Discussion paper	n/a	Patient experience, patient safety

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
Edvardsson et al. (2012)	Sweden	Published paper	Understanding the psychosocial ward environment	Qualitative	Observation	Patient experience
Elliot and Adams (2011)	UK	Published paper	The role of Dementia Nurse Specialist	Discussion paper	n/a	Patient experience, patient safety, needs assessments, patient involvement in decision-making
Ellison et al. (2014)	UK	Published report	Evaluation of Dementia Champions and Dementia Nurse Consultants	Evaluation	Interviews, staff survey	Patient experience, assessment of needs, reduced distress, reduced behaviours that challenge
Enns et al. (2014)	Canada	Published paper	Quality improvement trial to reduce the use of physical restraints in hospital	Step wedged trial	Medical notes review	Use of restraints
Galvin et al. (2010)	USA	Published paper	Evaluation of dementia awareness training programme	Pre-, post-, and delayed post test	Questionnaires of staff knowledge and confidence in dementia, interviews with trainees	Patient experience
Goldberg et al. (2014)	UK	Published paper	Patient experience and care on a Medical and Mental Health Unit compared with care on general wards	Qualitative findings from RCT	Non-participant observation (structured (dementia care mapping) and unstructured)	Patient experience, reduced distress, reduced behaviours that challenge, supporting patient choice (walking about the ward, food outside of mealtimes)

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
Goldberg et al. (2013)	UK	Published paper	Patient outcomes on a Medical and Mental Health Unit compared with general wards	Quantitative findings from RCT	Interviews, medical notes review, used of validated tools, non-participant observation (dementia care mapping)	Days spent at home, health status outcomes, behavioural and psychological symptoms, physical disability, cognitive impairment, carer strain, carer psychological wellbeing, carer satisfaction, patient mood and engagement
Gonski and Moon (2012)	Australia	Published paper	Outcomes of patients treated on a behavioural unit in a hospital	Retrospective review of medical records	Medical notes review, interviews with staff and carers	Carer satisfaction, Patient health care outcomes, behaviours that challenge, mediation, falls

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
Harwood et al. (2010)	UK	Unpublished report	Development of Medical and Mental Health Unit	Discussion paper	n/a	Patient experience, patient orientation to time, supporting patient abilities, patient safety, supporting patient choice (walking about the ward), patient referrals, behaviours that challenge, medication review, carer satisfaction, carer involvement
Luxford et al. (2015)	Australia	Published Paper	Clinician-carer communication tool	Survey	Survey with staff and carers	Acceptability and perceived benefits for patients
Moyle et al. (2011)	Australia	Published paper	Best practice, the use of 'specials'	Qualitative Interviews	Interviews with staff	Patient experience
Nichols and Heller (2002)	USA	Published paper	The development of a specialist dementia care unit	Discussion paper	n/a	Improved communication with carers, improved patient experience
Rösler et al. (2012)	Germany	Published paper	Care of patients with dementia with hip fractures on specialist ward compared with general ward	Matched pair analysis	Validated scales	Functional status, use of antipsychotic medication, length of stay
Scerri et al. (2015)	Malta	Published paper	Person-centred care in hospital wards	Appreciative Inquiry / Qualitative interviews	Interviews	Family carer satisfaction, patient experience

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
Schneider et al. (2010)	UK	Published report	The role of health care assistants in caring for people living with dementia	Ethnographic study	Participant observations, Interviews	Patient experience
Spencer et al. (2013)	UK	Published paper	Family carer perceptions of care on Medical and Mental Health Unit compared with general wards	Qualitative findings	Interviews with family carers	Carer satisfaction, carer perception of care
Upton et al. (2012)	UK	Published report	Multi-component bundle of evidence-based interventions	Qualitative and quantitative findings	Interviews, survey, medical records	Ward moves, infections, weight, catheter use, falls, mobility, place of discharge, use of antipsychotics, patient and carer satisfaction
Waller and Masterson (2015)	UK	Published paper	Dementia-friendly environmental adaptations in healthcare settings	Summary of findings of evaluations	Pre and post audit and locally determined data collection (observations, incident forms and falls data, medication review, interviews)	Behaviour that challenges, falls, patient engagement in activity, reduced agitation and distress, reduced use of antipsychotics

Reference	Country	Type of item	Focus	Method of study or type of paper	Data collection	Patient and /or carer outcomes
White et al. (2016)	UK	Published paper	Management of behavioural and psychological symptoms of dementia in hospitals	Longitudinal cohort study	BEHAVE-AD scale Non-participant Observation Medical notes review	Behaviours that challenge and the use of pharmacological and non-pharmacological interventions for behavioural management
Williams (2011)	UK	Published paper	Development of the Butterfly Scheme	Discussion paper	Staff self-report for use of the scheme	Patient experience, identification and interpretation of behaviours that indicate a need (managing pain and continence), reducing patient distress, patient safety, carer satisfaction
Zieschang et al. (2010)	Germany	Published paper	Feasibility study of dementia care specialist unit	Feasibility study	Staff survey, validated tools	Patient function, patient mobility, behaviours that challenge, length of stay, falls, use of restraints, use of antipsychotics

### Stage three: analysis and synthesis

Data from the papers were extracted using the bespoke data extraction forms (Appendix 7). This evidence was then organised into tables to display the contribution to each theory area and support analysis across studies (Appendix 8). Reoccurring patterns, or demi-regularities, detectable across the studies were identified and debated with supervisors and the research network monitors group. Distinct but related concepts were identified which were expressed through six context-mechanism-outcome configurations (CMOC) (Table 22)

Table 22: Development of theoretical propositions into CMOCs

<p><b>Candidate theory tested:</b> If a change agent’s activities or resources of an intervention supports staff to understand how to interpret and respond to a patient’s behaviour that uses person-centred care approaches, challenges poor practice by using experiential learning and reflection, then staff will be more likely (through mechanisms of confidence, awareness, the ability to prioritise) to engage and assess patient pain or distress and involve patients with dementia and their carer in planning their care</p>	
<p><b>CMOC developed: CMOC 1</b></p>	<p><b>Evidence from</b></p>
<p>Where staff are supported to understand behaviours that challenge as communication of an unmet need (context) through access to experts, training, resources that help to get to know the person (mechanism resource) staff will recognise they have improved capacity and capability to influence the patient situation (mechanism reasoning) making it more likely they will identify and address the need (outcome). <i>However, workload, patient characteristics (context) and staffing resources (mechanism resources) may cause staff to doubt their ability to make a difference (mechanism reasoning) leading to the patient need not being identified, assessed, or addressed (outcome).</i></p>	<p>(Baillie, 2015; Banks et al., 2014; Bray et al., 2015; Brooker et al., 2014; Dowding et al., 2016; Duffin, 2013; Edvardsson et al., 2012; Elliot and Adams, 2011; Ellison et al., 2014; Galvin et al., 2010; Goldberg et al., 2014; Gonski and Moon, 2012; Luxford et al., 2015; Moyle et al., 2011; Nichols and Heller, 2002; Rösler et al., 2012; Scerri et al., 2015; Schneider et al., 2010; Spencer et al., 2013; Upton et al., 2012; Waller and Masterson, 2015; Williams, 2011; Zieschang et al., 2010)</p>

<b>Candidate theory tested:</b> If a change agent's activities or resources of an intervention supports staff to understand how to interpret and respond to a patient's behaviour that uses person-centred care approaches, challenges poor practice by using experiential learning and reflection, then staff will be more likely (through mechanisms of confidence, awareness, the ability to prioritise) to engage and assess patient pain or distress and involve patients with dementia and their carer in planning their care	
<b>CMOC developed: CMOC 2</b>	<b>Evidence from</b>
<p>Access to training (context) that gives staff an experiential understanding of impact of dementia on a person and promotes empathy towards people living with dementia (mechanism resource) can encourage staff to reflect on the deficiencies of current working practices (mechanism reasoning) leading them to take more time with patients with dementia (outcome).</p> <p><i>However</i>, where good dementia care practices (mechanism resource) are not recognised as legitimate working practices (context) staff may interpret dementia care practices as additional to their workload (mechanism reasoning) leading to inconsistencies in care provision (outcome)</p>	(Baillie, 2015; Banks et al., 2014; Bray et al., 2015; Brooker et al., 2014; Duffin, 2013; Galvin et al., 2010; Scerri et al., 2015; Williams, 2011)
<b>Candidate theory tested:</b> If a change agent works as a clinical expert to identify and resolve the care needs of patients with dementia then staff will feel supported and be more willing to care for patients with dementia	
<b>CMOC developed: CMOC 3</b>	<b>Evidence from</b>
<p>Experts with clinical and organisational authority to legitimise the priorities and standards for dementia care (context), and support staff development in dementia care skills (mechanism resource) encourage staff to feel confident they understand the expectations of their role in patient care (mechanism reasoning) and will adapt care practices (outcome)</p> <p><i>However</i>, where the responsibility for dementia care is focused in select staff (context/mechanism resource), this may reduce the sense of responsibility the wider workforce has for dementia care (mechanism reasoning) and reduce embedding good dementia care practices across the organisation (outcome).</p>	(Baillie, 2015; Baldwin et al., 2004; Banks et al., 2014; Bray et al., 2015; Brooker et al., 2014; Duffin, 2013; Elliot and Adams, 2011; Ellison et al., 2014; Enns et al., 2014; Goldberg et al., 2014; Nichols and Heller, 2002; Rösler et al., 2012; Scerri et al., 2015; Schneider et al., 2010; Upton et al., 2012; Zieschang et al., 2010)

**Candidate theory tested:** If a change agent has organisational and clinical authority to introduce learning and credible resources that prioritise the identification and care of patients with dementia and addresses concerns around risk and workplace disruption within a person-centred care framework then staff will feel they have permission to do the right thing becoming less risk averse

<b>CMOC developed: CMOC 4</b>	<b>Evidence from</b>
<p>Where staff are supported to be flexible and autonomous in their role and working environment (context) with clarification of their responsibilities for patient care (mechanism resource) staff will feel confident to adapt care provision (mechanism reasoning) responding to the care needs of the person in a timely, individualised manner (outcome).</p> <p><i>However,</i> considerations of the influence of environmental factors and staff capacity (context) may need to be recognised and addressed by management (mechanism resource) for staff to feel confident a flexible, autonomous way of working is accepted by colleagues and senior staff (mechanism reasoning) for them to provide responsive care (outcome).</p>	<p>(Bray et al., 2015; Goldberg et al., 2014; Rösler et al., 2012; Scerri et al., 2015; Schneider et al., 2010)</p>

**Candidate theory tested:** If a change agent has organisational and clinical authority to introduce learning and credible resources that prioritise the identification and care of patients with dementia and addresses concerns around risk and workplace disruption within a person-centred care framework then staff will feel they have permission to do the right thing becoming less risk averse

<b>CMOC developed: CMOC 5</b>	<b>Evidence from</b>
<p>Where there is provision of activities and therapies for patients with dementia which are designed to support their interests and abilities (context) by staff allocated to this role (mechanism resource), they will take responsibility to address patients social, emotional, and psychological need (mechanism reasoning) and take action to maintain patient functional and cognitive abilities (outcome) which can provide time for other staff to focus on physical and medical needs (outcome).</p> <p><i>However,</i> where staffing resources are limited (context) allocation of staff may be focused on maintaining patient safety (mechanism resource) which requires these staff to prioritise safety concerns over the provision of activities and therapy (mechanism reasoning) limiting how psychosocial needs are met (outcome)</p>	<p>(Bray et al., 2015; Duffin, 2013; Edvardsson et al., 2012; Galvin et al., 2010; Goldberg et al., 2013; Goldberg et al., 2014; Harwood et al., 2010; Moyle et al., 2011; Scerri et al., 2015; Upton et al., 2012; Zieschang et al., 2010)</p>

<b>Candidate theory tested:</b> If a change agent has organisational and clinical authority to introduce learning and credible resources that prioritise the identification and care of patients with dementia and addresses concerns around risk and workplace disruption within a person-centred care framework then staff will feel they have permission to do the right thing becoming less risk averse	
<b>CMOC developed: CMOC 6</b>	<b>Evidence from</b>
<p>Where risk management procedures and expectations are defined through the use of person-centred approaches (context) and ward leadership encourages and reinforces these practices (mechanism resource) staff may feel confident they are supported to address risk proportionately (mechanism reasoning) and they may support the safety of patients with dementia in ways which help maintain their abilities and accept their choices.</p> <p><i>However,</i> resources for risk management will need to be compatible (mechanism resource) with environmental features and staff capacity (context) or staff may feel the changes are inappropriate (mechanism reasoning) making it unlikely they will adapt care practices (outcome)</p>	<p>(Duffin, 2013; Enns et al., 2014; Galvin et al., 2010; Goldberg et al., 2013; Goldberg et al., 2014; Gonski and Moon, 2012; Luxford et al., 2015; Moyle et al., 2011; Nichols and Heller, 2002; Upton et al., 2012; Waller and Masterson, 2015; Williams, 2011; Zieschang et al., 2010)</p>

### CMOC 1: Understanding behaviour as communication of an unmet need to support staff to respond

Awareness in staff that behaviour is a form of communication is an important contextual factor to trigger staff to go on to perform assessments, put in place care plans and treatment regimens, and respond appropriately to better meet the person's care needs. Studies reported where staff understood behaviours that challenge from patients with dementia as a form of communication of an unmet need, rather than as a symptom of their dementia, they were more likely to recognise and respond appropriately; for example by addressing the cause, rather than the behaviour (Banks et al., 2014; Dowding et al., 2016; Ellison et al., 2014; Gonski and Moon, 2012; Nichols and Heller, 2002; Upton et al., 2012; Waller and Masterson, 2015). This improved patient outcomes in terms of reducing patient distress (Baillie, 2015; Bray et al., 2015; Brooker et al., 2014; Goldberg, et al., 2014; Edvardsson et al., 2012; Scerri et al., 2015; Upton et al., 2012) and maintaining independence by

supporting mobility and continence (Duffin, 2013; Rösler et al., 2012; Williams, 2011; Zieschang et al., 2010).

Training in dementia and dementia care (Baillie, 2015; Bray et al., 2015; Galvin et al., 2010; Scerri et al., 2015; Waller and Masterson, 2015), access to dementia care experts, such as dementia champions, dementia nurse specialists, and mental health experts (Banks et al., 2014; Elliot and Adams, 2011; Ellison et al., 2014; Goldberg et al., 2014; Upton et al., 2012; Zieschang et al., 2010), biographical knowledge of the patient (Banks et al., 2014, Luxford et al., 2015; Nichols and Heller, 2002; Upton et al., 2012; Williams, 2011), and assessments of cognitive abilities, and psychological and physiological needs (Dowding et al., 2016; Goldberg et al., 2013; Goldberg et al., 2014; Zieschang et al., 2010) helped staff to reframe how they interpreted behaviours; moving from something to control and manage, to something that could inform how to work with the patient. The negative impact of staff who did not understand the difficulties associated with dementia were identified in interviews with carers (Spencer et al., 2013). They reported staff misinterpreting behaviours that challenge as patients being deliberately difficult. This led staff to respond inappropriately:

“Participants [family carers] felt that staff had little understanding and limited training in dementia care, which carers felt resulted in patients being ignored, shouted at or threatened when staff were faced with uncooperative or challenging situations.” (Spencer et al., 2013, p3)

However, even when staff understood how to work with patients with dementia with behaviours that challenged, their ability and willingness to address these needs were limited by contextual factors. Goldberg et al. (2014) highlighted the impact of conflicting work demands, staff fatigue, long shifts, and difficulty in identifying and resolving patient issues that resulted in staff responding to behaviours by ignoring and disengaging from the patient:

“Staff would try to comfort or distract them...But the calling out would resume once the staff member left the patient and the conflicting demands on time meant staff would sometimes ignore their cries and attend to other patients, staff or documentation.... Delivering care to patients with these behaviours could be exhausting and sometimes, particularly towards the

end of a 'long day' (12 1/2 h shift), staff would ignore patients." (Goldberg et al., 2014, p1338)

Personalisation of practices appeared to occur in pockets of activity rather than as an ethos of care provision that was integral to staff's work. This is discussed further in CMOC 2.

## CMOC 2: The role of experiential learning and creating empathy to encourage reflection for staff responsibilities for care

Interventions to raise staff awareness in dementia and reframed behaviours as communication were considered fundamental to supporting the provision of good dementia care. However, while studies reported improved knowledge in dementia and confidence in staff working with patients with dementia, there was limited understanding of how this influences staff's caring practices or the impacts on patient outcomes (Baillie, 2015; Banks et al., 2014; Galvin et al., 2010; Williams, 2011).

Training strategies which enabled staff to understand the experience of having dementia through experiential learning techniques were reported to help staff empathise with the patient's situation, and consider how they could improve the way they provided care for patients with dementia (Baillie, 2015; Banks et al., 2014; Duffin, 2013). Staff reported suddenly understanding the problems patients with dementia faced which had not occurred to them before:

"Lack of understanding dementia is evident as we ask family, friends or carers to leave while we take the patient through the admission process. Not only is the person with dementia in an unfamiliar environment, but we also isolate them from the people who truly know them."  
(Banks et al., 2014, p724)

Evidence from one evaluation of training found that triggering emotional responses in staff, and supporting them to make personal connections to patient situations, encouraged staff to see patients with dementia as individuals and understand that being in hospital was confusing and caused anxiety (Baillie, 2015). Additionally, the use of examples of good care in familiar situations gave staff a framework for what good dementia care looked like in their own practice. Staff reported that this motivated them to take responsibility for making changes to how they provided care for patients with dementia:

“Staff discussed how their own interactions with patients and behaviour had changed since watching Barbara’s Story, and they often referred to changes they had observed in other staff too. Changes included: giving more time to patients, improved communication, giving more information, and assisting patients who are looking lost. Staff also discussed how Barbara’s Story had highlighted their professional responsibilities.” (Baillie, 2015, p28)

Training that had relevance to staff work was considered important for staff to identify how their role contributed to improvements in care for patients with dementia (Baillie, 2015; Duffin, 2013; Williams, 2011). However, these care practices, such as spending time with a patient to reassure them, were not considered integral to staff responsibilities and were understood as additional to their work:

“Care worker (S33): Not just as part of a chore or duties [but] as part of being really interested in the patient’s needs... Going out of your way, going out of your duty ... because sometimes I go to patients who do not need a speech therapist... but if they ask for something I go out of my way.” (Scerri et al., 2015, p6)

This suggests that, in addition to training in dementia care, staff needed to feel able to spend time with patients without it being viewed negatively by colleagues, or impact on the effective running of the ward (Baillie, 2015; Scerri et al., 2015).

### CMOC 3: Clinical expert who legitimise priorities for care

Staff who were experts in dementia care were employed to support other clinical staff to develop their skills in caring for patients with dementia (Baldwin et al., 2004; Banks et al., 2014; Bray et al., 2015; Brooker et al., 2014; Elliot and Adams, 2011; Ellison et al., 2014; Goldberg et al., 2014; Upton et al., 2012; Zieschang et al., 2010). A number of roles were identified including: supporting the use of assessments and person-centred care plans related to the person’s psychological, social, and functional needs (Baldwin et al., 2004; Zieschang et al., 2010); role modelling how to communicate and work well with patients with dementia (Banks et al., 2014; Goldberg et al., 2014); and providing professional advice for complex situations, such as legal and ethical decisions around best interests (Elliot and Adams, 2011; Ellison et al., 2014). Experts with clinical and organisational authority communicated the expectations for dementia care practices, and were found to legitimise changes at both ward level (Baillie, 2015; Bray et al., 2015; Enns et al., 2014; Scerri et al., 2015; Zieschang et

al., 2010) and across the organisation (Baillie, 2015; Brooker et al., 2014; Nichols and Heller, 2002). Staff concerns about the impact of the changes on their work were addressed in relation to how psychological and emotional needs were prioritised in relation to medical and physical needs, making adequate modifications to ward routines to accommodate patients' preferences, and clarifying expectations around managing patient safety and documentation (Bray et al., 2015; Brooker et al., 2014; Enns et al., 2014; Nichols and Heller, 2002; Zieschang et al., 2010). However, supporting ward staff to adopt and integrate these changes was dependent upon addressing any skills gaps for new care practices, such as supporting and encouraging mobility in patients who are at risk of falls (Enns et al., 2014; Zieschang et al., 2010), and a recognition from managers that this would impact the number of patients staff could be allocated to work with (Bray et al., 2015; Nichols and Heller, 2002; Rösler et al., 2012). The example below demonstrates how an intervention, introduced by a senior nurse with ambitions to improve dementia care, had implications for staffing resources:

“Although the cost of bay nursing is higher because additional nurses had to be recruited to ensure a constant nursing presence in each bay, this has been offset, at least in part, by lower costs as a result of the reduction in one-to-one nursing.” (Bray et al., 2015, p24)

While it was considered support from clinical experts would upskill staff in dementia care practices and influence how they worked with patients with dementia, there was limited evidence to support that new practices were being adopted and embedded into staff's daily practice. Instead it appeared that the experts maintained responsibility for dementia care, either personally or by providing direction. It is possible that a reliance on staff with expertise for dementia care could result in responsibility for the care of patients with dementia being located in a small group of staff rather than creating a culture where dementia care is 'everybody's business'. Evidence from one paper (Goldberg et al., 2014) suggested that while ward staff as a whole were better able to work with patients with dementia, they would direct issues unrelated to medical or physical needs to dementia experts:

“Lisa walks down the walkway. The staff say “Morning Lisa” “Morning” as they walk past. . . Lisa says that this is a strange hospital. The auxiliary says “If you want to go down that way with [the mental health nurse], she's lovely”. Lisa says “You're all lovely”. The mental health nurse then talks to Lisa for some time. MMHU55.” (Goldberg et al., 2014, p1339)

This suggests that the use of experts in dementia care will not, on their own, engage staff to take responsibility for patient needs which staff do not consider part of their role. Other contextual factors and mechanisms that influence healthcare staff to move beyond focusing on physical and medical needs need to be considered and are discussed in the next CMOC.

#### CMOC 4: Staff are confident they are supported to adapt working practices and routines for individualising care

The provision of person-centred care was linked to staff's ability to organise their work around the needs of patients with dementia which, while recognising the constraints of the ward routine, were not restricted by them (Bray et al., 2015; Edvardsson et al., 2012; Goldberg et al., 2014; Rösler et al., 2012; Scerri et al., 2015; Schneider et al., 2010). One study on a rehabilitation ward, where training in person-centred practices had been provided by the consultant geriatrician, explored what made quality dementia care possible (Scerri et al., 2015). Evidence from staff interviews suggested that quality dementia care required staff to recognise the benefit of getting to know patients by spending time with them outside of essential care tasks:

“Results from the interviews with staff denoted that positive experiences could only be possible if staff engaged with dementia patients by spending some time out of their busy schedule to get to know them better. According to a number of care workers, this does not mean solely spending time next to the patient, but engaging with the patient and showing genuine interest. This has been referred to by two members of staff as the provision of ‘quality time’ that sustains this relationship through the use of appropriate communication skills.” (Scerri et al., 2015, p5)

Evidence demonstrated that staff knowledge of the person, combined with the ability to act responsively to patients expressing distress or unmet needs, improved patient wellbeing (Bray et al., 2015; Edvardsson et al., 2012; Scerri et al., 2015; Schneider et al., 2010). Staff with a clear understanding of their responsibilities in patient care was linked to actions which demonstrated their autonomy by responding in timely, creative ways that met individual patient needs (Bray et al., 2015; Scerri et al., 2015; Schneider et al., 2010).

Working practices which were flexible and that prioritised the needs of the patient were suggested to be beneficial for patients' functional outcomes. One study (Rösler et al., 2012) suggested that

improved mobility in patients with dementia were linked to physiotherapists managing their caseload according to the patient preferences. Using professional judgement to take into account patient mood, therapy staff were able to identify optimal times for individual patients to engage with physiotherapy sessions, which reduced the number of sessions that were rejected:

“In the CGU described here, physiotherapists and nurses tried to activate patients more individually by catching the right moment rather than working according to strict time schedules” (Rösler et al., 2012, p401)

There were additional factors supporting staff to work flexibly, including reduced caseloads, training in dementia care, and access to treatment rooms which were located on the ward (Rösler et al., 2012).

#### CMOC 5: Staff allocated to the provision of care focusing on psychosocial needs

The ability of staff to provide good dementia care was influenced by time constraints and the availability of staffing resources. This was addressed through the use of mental health care staff, activities co-ordinators, and volunteers who had specific roles to prioritise emotional, social, and psychological needs. These staff assessed cognitive abilities and psychosocial needs, provided individualised therapeutic activities, supervised mealtimes, and managed risk (Bray et al., 2015; Edvardsson et al., 2012; Galvin et al., 2010; Goldberg et al., 2014; Moyle et al., 2011; Spencer et al., 2013; Zieschang et al., 2010). The reported patient outcomes were improved patient experience (Bray et al., 2015), orientation to time and place (Edvardsson et al., 2012), reduced distress (Bray et al., 2015; Edvardsson et al., 2012; Goldberg et al., 2014), and a reduction in behaviours that challenged staff (Goldberg et al., 2014).

Activities and therapies with patients with dementia were also reported to benefit healthcare staff. By working with some of the ward patients, this provided additional time for healthcare staff to focus on the physical and medical needs of other patients on the ward (Edvardsson et al., 2012; Galvin et al., 2010; Goldberg et al., 2014; Spencer et al., 2013; Zieschang et al., 2010). Studies reported that some activities were deliberately scheduled to cover known times where there would be a high need within the patient population such as supporting mealtimes (Bray et al., 2015; Edvardsson et al., 2012; Goldberg et al., 2014; Upton et al., 2012), or during times known to cause patients with dementia increased anxiety:

“Daytime activities are conducted especially during the afternoon when staffing by the nurses is reduced and the sun-downing phenomenon might occur.” (Zieschang et al., 2010, p144)

The effectiveness of staff providing activities and therapies was linked to patient characteristics. Not all patients could benefit from a programme of activities and participation was dependent on severity of physical illness, level of cognitive impairment, and personal preference of the patient (Goldberg et al., 2014; Spencer et al., 2013). However, these patients may have indirectly benefited as healthcare staff had more time to address their physical and medical needs. This was not explored in any of the papers.

The ability of activities and mental healthcare staff to prioritise emotional and psychological issues was impacted on by ward-wide staffing levels. In this context, ward management prioritised safety and risk management over other non-medical needs and allocated roles accordingly (Bray et al., 2015; Goldberg et al., 2014). While allocation to risk management roles could also incorporate meeting patients psychosocial needs by staff using the opportunity to engage with the patients in conversations and activities, this was not always the case. Moyle et al. (2011) highlight that often risk management is allocated to junior staff members who have not been trained in dementia care, and do not have an understanding of the purpose of their role beyond monitoring the patient. As a result, staff did not engage with patients and their close proximity increased patient distress.

### CMOC 6: Supporting staff to be confident in providing person-centred risk management

Studies reported addressing risk in ways that supported a person’s abilities, choices, and independence improved mobility (Duffin, 2013; Zieschang et al., 2010), reduced adverse incidents (Upton et al., 2012), and improved patient experience and carer satisfaction (Goldberg et al., 2014; Luxford et al., 2015; Nichols and Heller, 2002). To support staff to have confidence to use more person-centred approaches to risk, they received training which developed their skills and helped them understand how different approaches benefitted patients (Enns et al., 2014; Luxford et al., 2015; Zieschang et al., 2010). Environmental factors influenced the way risk was addressed. In wards with locked door access, patients could be monitored at a distance which allowed them to walk around the ward with minimal restrictions (Goldberg et al., 2014; Gonski and Moon, 2012; Nichols and Heller, 2002; Zieschang et al., 2010). This was linked to reductions in behaviours that

challenge, but may also reflect staff reframing behaviours such as ‘wandering’ as no longer problematic:

“The fact that patients cannot leave the unit unaccompanied not only ensures the safety of the patients but also relieves the staff of the necessity to observe them constantly. It also spares patients being repeatedly admonished for not staying in the room, which can evoke aggressive behaviour.” (Zieschang et al., 2010, p143)

In open wards, where patients were at risk of leaving the ward, alternative methods were used to identify these patients, such as the use of wrist bands and different coloured hospital clothing. This helped staff to monitor patients from a distance and intervene as necessary (Baillie, 2015; Duffin, 2013; Galvin et al., 2010):

“People with dementia also wear a blue wristband with their name on. This is another means of alerting staff to patients’ needs, and it can be beneficial if a patient wanders off a ward to walk around other parts of the hospital. It means that staff know the patient is vulnerable and can find out if they need help and also let staff on the older people’s wards know where they are.” (Duffin, 2013, p17)

Staff training and protocols supported staff to use appropriate methods to encourage a patient to return to their ward (Duffin, 2013; Galvin et al., 2010), although there was no detail of what this training involved and who it was aimed at. While the theory for the process was explained, there was no evidence to support how the intervention worked in practice.

## Programme theory

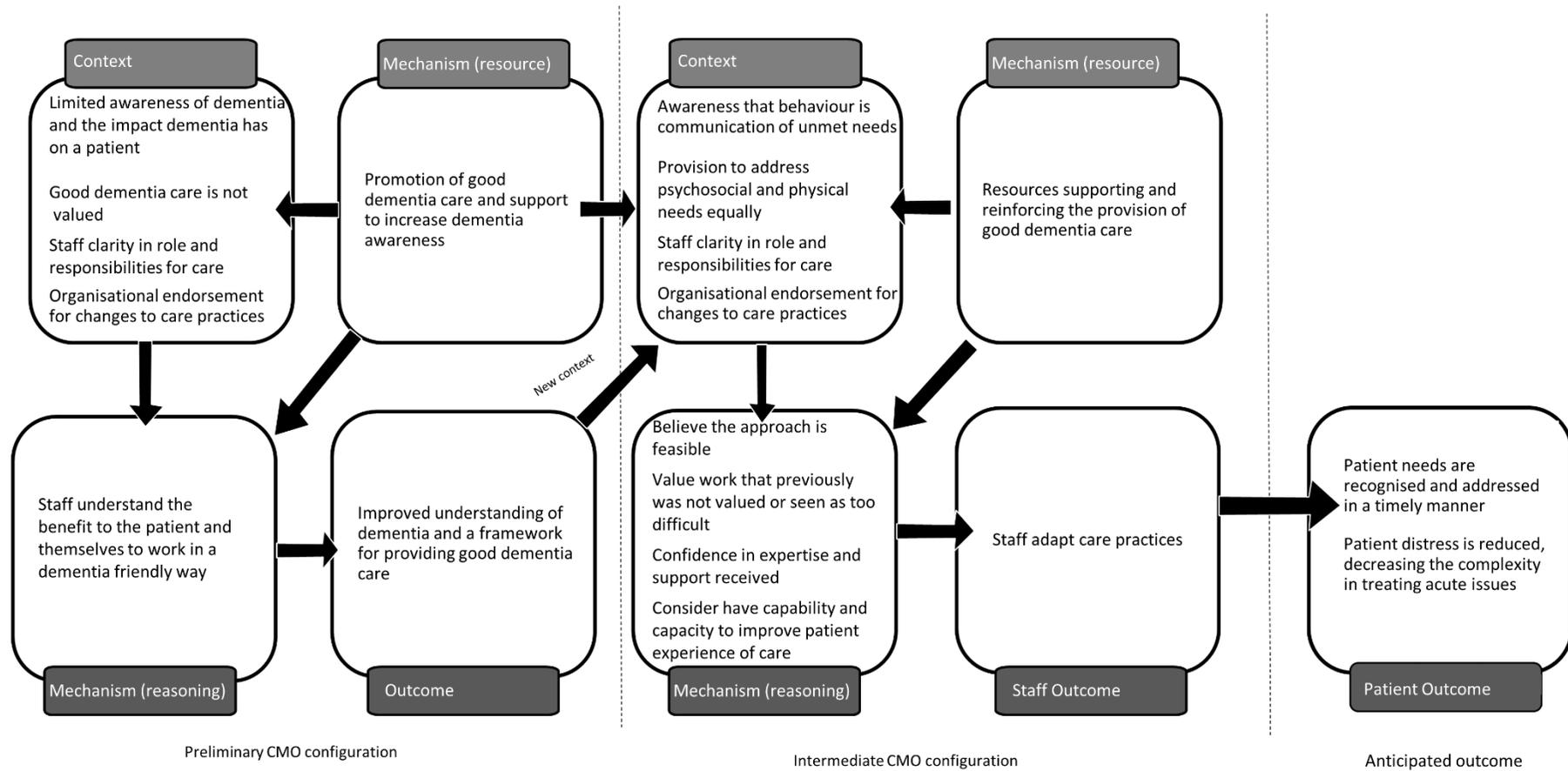
Work in stage one of the review led to the development of three candidate theories. These theories were tested against evidence from 28 papers from CMOCs evident across data from the studies. They suggest that relying on single initiatives, such as a change agent, is not enough to encourage staff to change working practices in ways that are dementia-friendly. There also needs to be attention to contextual factors that will make staff more likely to make use of the resources interventions. Figure 8 presents the programme theory which incorporates the six context-mechanism-outcome configurations. This suggests what needs to be in place to encourage best practice for dementia care in hospitals (Figure 8).

The preliminary CMOC represents a context where staff have limited understanding of what the needs are of patients with dementia, and how care can be provided to meet their needs. It is recognised that resources which promote dementia awareness and an understanding of what constitutes 'good' dementia care are often initially implemented into these contexts. A preliminary outcome of this is that there is a change in the context in that staff can have a common understanding of what good dementia care looks like, and how this is beneficial to their work and for patients with dementia. Additional contextual factors in the intermediate CMOC, such as how organisations and managers legitimise dementia care practices, and the clarity staff have in their responsibilities for patients with dementia, will influence how they engage with resources and make changes to the care they provide. These changes by staff are anticipated to lead to improved patient outcomes, although evidence related to patient outcomes was limited.

## Chapter summary

This chapter has presented evidence from stakeholder interviews and the literature which has contributed to building a programme theory of what supports hospital staff to provide dementia-friendly healthcare, and with what outcomes for patients with dementia. The realist review demonstrated that single initiatives which lack the support of senior hospital staff members are unlikely to change the way hospital staff provide care for patients with dementia. Instead, organisational endorsement is a key context that will influence whether or not staff modify care practices with patients with dementia and draw on resources which can enhance their work, helping them to recognise they have the capability and capacity to improve outcomes for patients with dementia and their carers. A key finding was that hospital staff understand behaviour as a communication of an unmet need in order to assess and address the underlying cause.

Figure 8: Programme theory for supporting dementia-friendly healthcare in general hospitals



## Chapter four: Realist evaluation findings

The realist evaluation aimed to test the programme theory developed from the realist review in two case study sites. In this chapter I report the findings from the study sites, starting with a description of the two sites and participants. I then demonstrate how the findings refined the programme theory with examples of evidence that contributed to developing the context-mechanism-outcome configurations.

### Case study sites

Study sites 1 and 2 were general hospitals in two NHS Trusts in East of England (Table 23). They had taken different approaches to how they used resources to provide care for patients with dementia. Site 1 had a dual-frailty ward with 16 beds. Site 2 had a team providing 1:1 care for patients with dementia across the general hospital. It was not possible to identify the number of patients admitted to each general hospital who had a diagnosis of dementia, as at the time of the study computer systems were not organised to automatically record this information. At admission, patients were recorded as having dementia, or not, but this did not necessarily agree with whether a formal diagnosis had been made. At site 2, the Dementia Lead had a responsibility to cross check diagnosis for patients identified as having a dementia with their primary care and mental health records. Case finding patients recorded as having a dementia was complex. The computer system did not support an automatic search for dementia diagnosis and staff who completed patient records recorded dementia diagnosis across a number of different fields. Additionally, the Dementia Lead had recently joined the general hospital and there had been a gap in recording data related to patient numbers with dementia.

Table 23: Study site characteristics

Site	Number of Beds	Type	Number of emergency inpatients per year* (Trust wide)
Site 1	Over 500	General Hospital	Approximately 40,000
Site 2	Over 700	General Hospital	Approximately 45,000

\*HES data 2015/16

## Observations

A total of 80 hours of observation were completed over three months, comprising of seven weeks at each site. At site 1, 41 hours of observation were performed covering the hours of 7.00am to 10.00pm (see Table 11, p63). At site 2, 39 hours were completed covering the hours of 7.00am to 10.00pm (see Table 12, p64). Observations were carried out in patient bays on the wards. At site 1 they were conducted in one ward, the dual-frailty ward. At site two, observations took place across four wards as follows: Ward A: 25 hours, Ward B: 9 hours, Ward C: 2 hours, Ward D: 3 hours. Observations in Wards A and B looked at the work of ward staff and 1:1 staff with patients with dementia. Observations in Wards C and D focused primarily on the work of the 1:1 team with patients with dementia.

## Staff interviews

At total of 36 staff participated in interviews, covering domestic staff, nurses, healthcare assistants, doctors, allied health staff, psychiatrists (Table 24). Thirty staff participants had English as their first language.

Table 24: Staff interviews by site

Role/Position	Site 1	Site 2
Health care worker	3	7 (2 ward, 5 from 1:1 team)
Nurses	4	3
Allied Health Staff	2	1
Doctors	3	2
Senior Nurse Leads	3	4
Consultant Psychiatrist	1	1
Housekeepers	0	2
Total	16	20

## Patient Recruitment

Across the sites, 28 patients were recruited for medical notes review and the Neuropsychiatric Inventory (NPI) assessment, four of these patients participated in interviews (Table 25).

Table 25: Patient recruitment

Site	Number eligible patients	Capacity to consent	Capacity to consent recruited (interviewed)	Without capacity	Without capacity recruited	Without capacity consultee decline	Without capacity no reply
Site 1	40	9	3 (2)	31	15	5	11
Site 2	29	10	4 (2)	19	6	4	9
Total	69	19	7 (4)	50	21	9	20

## Carers

Across the sites, 21 carers were approached for interview during their visits to the hospital, either through face-to-face discussions or by letter (see Carer recruitment, p56). Only two carers, one from each site, were recruited. Reasons for declining interviews included the burden of a formal interview when their relative or friend was in crisis, other commitments such as looking into alternative living arrangements for their relative or friend, and practical concerns around time spent at the hospital.

## Ward and team characteristics

Ward characteristics differed in the sites, these are detailed below (Table 26 and Table 27). Floor plans for the ward at site 1 and ward A at site 2 show how the physical environments differed (Appendix 18 and Appendix 19).

Table 26: Ward characteristics by site

Site	Ward	Specialism	Beds	Bay/bed	Side rooms	Staff to patient ratio
1	A	Dual-frailty	16	8/2	0	1:2
2	A	Elder care	30	4/6	6	1:6/1:7/1:7
2	B	Orthopaedic	30	4/6	6	1:6/1:7/1:7
2	C	Elder care	30	4/6	6	1:6/1:7/1:7
2	D	Elder care	33	6/5	3	1:5/1:6/1:8

Ward A at site 1 differed from the wards at site 2 by having fewer beds, fewer bays, more beds per bay, no side rooms, and a higher staff to patient ratio (1:2 versus  $\geq 1:5$ ).

Table 27: Ward characteristics for site 1 and 2

Ward Characteristic	Site 1	Site 2
Reason for admission	Physical and mental health need	Ward A, B and D multiple physical and medical needs, Ward C orthopaedic
Environment	Wood effect laminate flooring Locked keypad entrance/exit Temperature locally controlled Red door frames and white doors for toilets and showers TV in each bay Tea, coffee and snack facilities for patients and visitors Tables for patients, staff and visitors in middle and front of bay	Shiny white tiled flooring Locked keypad entrance/exit (Wards A, C, and D) Temperature remotely controlled Red frames, white doors, and photographic signage for toilets and showers Reminiscence room on Ward A and C
Visiting professionals to ward	Psychiatrist, occupational therapist, physiotherapist, specialist nurses (e.g. Macmillan nurse, continence nurse, infection control) mental health team, social worker, pastoral care, dietitian, phlebotomist	Enhanced Dementia Care Team (1:1 team), psychiatrist, occupational therapist, physiotherapist, specialist nurses (e.g. Macmillan nurse, continence nurse, infection control, wound care) mental health team, social worker, pastoral care, dietitian, phlebotomist
Ward rounds	Daily between 9am and 12pm with doctors, sometimes joined by psychiatrist, physiotherapist	(Ward A) Daily between 9am and 10am with doctors, sometimes joined by senior nurse
Multidisciplinary Team Meeting	Daily between 12pm and 1pm Includes doctors, nurses, social worker, discharge nurse, allied health professionals and are joined twice a week by the psychiatrist	Daily between 10am and 11am Includes doctors, nurses, social worker, discharge nurse, allied health professionals

The environment of Ward A at site 1 was noticeably different from the wards at site 2. The bay space was bigger, allowing for tables in the centre that were used for communal dining and activities; often this space would be shared by staff and patients. At site 2, space in the bays was too small to accommodate tables, instead staff used small, portable desks when working in the bays. The bays in ward A at site 1 were well lit and had windows on three sides allowing for plenty of natural light. At site 2, strip lighting in the middle of the ceiling meant that areas were unevenly lit, and at night time this could lead to shadows and dark areas of the bay when curtains were drawn around beds. At site 1, a wood effect laminate flooring had a matt finish which reduced glare, whereas at site 2 floor tiles were shiny. Other wards at site 1 outside of the unit were similar to those at site 2.

There was more focus on assessing and addressing mental health at site 1 than site 2. Staff from the mental health team visited the ward daily, assessment of cognitive abilities and mental health, such as depression, were carried out with all patients, an activities co-ordinator provided daily activities, and the occupational therapist assessed and developed plans for mental as well as physical needs.

### Staff characteristics and responsibilities

Nurses and healthcare assistants at site 1 work 12 ½ hour shifts, either night or day. They had two 30-minute breaks per shift which were timed mid-morning and mid-afternoon to ensure all staff were available at meal times. Each shift allocated four healthcare assistants and four nurses across two eight-bedded bays. A senior nurse was on duty during the day.

At site 2, there were three shifts patterns of early (7am – 2pm), late (2pm – 7pm), and night (7pm – 7am). Staffing numbers differed according to the shift and represented total staff allocation for 30-bedded wards (Ward A, B, C) and a 33-bedded ward (Ward D) (Table 28). A senior nurse was on duty during the day shift.

Table 28: Staff characteristics

Site	Ward	Shifts per 24 hours	Qualified staff by shift	Non-qualified staff by shift
1	A	2	4/4	4/4
2	A	3	5/4/4	4/4/2
2	B	3	5/4/4	4/3/2
2	C	3	5/4/4	4/4/2
2	D	3	5/4/3	4/3/2

## Dementia Enhancement Team (1:1 team) Site 2

The Dementia Enhancement Team at site 2 provided 1:1 care for patients with dementia who were at risk of falls or had behaviour that challenged staff. The team consisted of 17 full-time staff at band level 3, a team manager, and a matron for the team. They worked 12 ½ hour shifts, spending 3 hours with each patient and were generally assigned 4 different patients per shift. They had fixed breaks and shared a staff room with one of the wards. The team used their own care notes and a 'Whatsapp' group to share information on patient interests, activities that have worked, and for general support between the team members.

### Admission to ward

At site 1, patients were not directly admitted to the ward. Transfer to the ward was through a referral process completed by a senior nurse on the admitting ward and assessed by Rapid Assessment Interface and Discharge (RAID) team. Patients were transferred to the ward because they were both medically unwell and had behaviour that challenged due to dementia, delirium, or a combination of the two. When a bed became available, transfer was arranged through the senior nurse on duty. Patients recruited to the study at site 1 (n=18) had a median of 4 (1 – 36) days from hospital admission to being transferred to the dual-frailty ward.

At site 2, patients were admitted and treated in the same way as patients without dementia with the expectation that they remained there until discharge. Some patients with dementia were observed being moved to different beds within the ward according to their, or other patients, level of risk and need to be monitored. The Trust policy for patients with dementia stated that patient moves within or between wards must not occur unless necessary, although there was no guidance where patients with dementia should be admitted to on the ward. However, it was acknowledged by staff that patients with dementia who were at risk of falls were 'cohorted' into the bays that were most visible to the nurses' station.

### Recognising additional staff support needs

At site 1, due to the higher staff to patient ratio on the ward compared to other areas of the general hospital, additional staff support was not available. Staff on the ward provided additional support to patients as required.

At site 2, all requests for 1:1 support went through the 1:1 Team Manager who was responsible for allocation of patients to the 1:1 team and use of agency staff. A referral form set out a Red, Amber, Green (RAG) status for prioritising patients considered to need 1:1 support. Those who presented a high risk to themselves or others from confusion, wandering, and aggressive and violent behaviour were allocated support from the team, and their changing needs were assessed daily.

### Patient characteristics

Across the sites, 28 patients were recruited for medical notes review and NPI (18 at site 1 and ten at site 2). Four of these patients participated in interviews, (see above, Table 25).

At site 1, due to the ward admission criteria, all patients admitted to the ward were eligible for recruitment unless they were identified as end of life. At site 2, identification of eligible patients was supported by the Dementia Lead who was responsible for checking that a formal diagnosis of dementia had been made. This explains the difference between the proportion of patients recruited with a formal dementia diagnosis at site 1 and site 2 (Table 29).

Table 29: Patient characteristics

	Site 1	Site 2
	(n=18)	(n=10)
Median Age years (range)	77 (range 62 – 92)	88 (72 – 99)
Gender Male / Female	11 / 7	4/6
Length of stay days	21 (4 – 106)	23 (12 – 42)
Place of admission:		
Own home	11	8
Residential Home	2	2
Nursing Home	3	0
Sheltered Housing	1	0
Other Hospital	1	0
Place of discharge:		
Own Home	4	1
Residential Home	4	4
Nursing Home	6	3
Sheltered Housing	1	0

	Site 1	Site 2
Hospital (rehabilitation)	0	1
Mental health	2	0
RIP	1	1
Number returning to same place of residence yes/no/RIP	9/8/1	3/6/1
Reason for admission		
Fall	4	3
Confusion	6	0
Infection	5	3
Fracture	0	4
Cardiac/respiratory	3	0
General decline	0	2
Dementia Diagnosis Yes/No	9/9	10/0
Dementia Type		
Alzheimer's Disease	4	1
Vascular Dementia	3	3
Mixed Dementia	0	2
Lewy Bodies	1	0
Unspecified	1	4
Delirium Yes/No	8/10	1/9
Comorbid conditions	Median 5 (1 – 13)	4.5 (1 – 11)
Number of medications on admission	Median 9 (3 – 15)	11 (4 – 26)
Recorded adverse incident during stay Yes/No	12/7	3/7
NPI median number (range)	3 (0 – 7) (n=17)	Median 2 (0 – 5)
Delusions	5	1
Hallucinations	5	2
Agitation or aggression	14	6
Depression or dysphoria	5	2
Anxiety	3	4
Elation or euphoria	0	0
Apathy	1	0
Disinhibition	1	0

	Site 1	Site 2
Irritability or Lability	2	2
Motor disturbance	8	1
Night time behaviours	9	2
Appetite or eating	0	2

The patients recruited at site 1 were younger than those at site 2. Overall, they had a similar length of stay, although nine patients at site 1 did have longer than the median. Nine patients from site 1 returned to their original place of residence, eight had delirium and 12 experienced an adverse incident during admission. The number of incidents possibly reflected the reasons for transfer to the ward, as five of these incidents occurred on other wards and were related to falls or violence. As results from the NPI data demonstrate, patients recruited from site 1 were reported as having a higher number of behaviours that challenged than those at site 2.

### Theory testing

The purpose of the study has been to develop an explanatory account of what supports dementia-friendly healthcare, in what circumstances, and with what outcomes for staff and patients. Evidence from the realist review (see Chapter three: Realist review findings) led to the development of a programme theory consisting of six interrelated context-mechanism-outcome configurations (CMOCs) (Table 30).

### Refined programme theory

The six CMOCs make up the programme theory, which is summarised below.

Table 30: Modifications to context-mechanism-outcome configurations from phase one to phase two

Initial CMOCs developed during the realist review	Revised CMOCs from realist evaluation
1) Understanding behaviour as communication improves staffs' ability to respond	1) Knowledge and authority to respond to an unmet need
2) Experiential learning and empathy encourages reflection on responsibilities of care	2) Role relevant training and opportunities for reflection
3) Clinical experts who legitimise priorities for care	3) Clinical experts and senior staff promoting practices that are patient-focused
4) Staff with confidence to adapt working practices and routines to individualise care	4/5b) Engaging with opportunities to spend time with patients
5) Staff with responsibility to focus on psychosocial needs	
6) Building staff confidence to provide person-centred risk management	6) Risk management as an opportunity for dementia care
	7) Valuing dementia care as skilled work

*CMOC 1: Responding to unmet needs:* Systematic approaches to understanding patient needs are useful for a consistent and continued approach to patient care. However, they are only as useful as the information that is collected; for these documents to support dementia care, staff need to understand what is important to record. A context not identified in the review was the use of tacit knowledge that staff had developed from training and experience. In recognising that staff draw on this knowledge for many of their interactions with patients when responding to their behaviours, providing opportunities that can develop this knowledge could support staff to improve how they interpreted behaviours that were challenging. Important mechanisms were that staff had time to spend with patients, combined with their capacity and capability to engage with the patient, and their authority to approach senior team members. This was thought to influence whether staff believed they could make a difference and take action that would result in the patient's unmet needs being addressed.

*CMOC 2: Relevant training:* Training in dementia care skills that had relevance to staff and could be applied to their work was reported to resonate with them and influence their practice. However, staff were only required to attend dementia awareness training once and the training was delivered in a concise format. Thus, it was important to provide opportunities for staff to share their experiences with other colleagues and develop their ability to work well with patients with dementia. This could widen the range of responses they could draw on in different patient

situations, such as helping to reduce patient distress.

*CMOC 3: Experts and senior staff:* Clinical experts legitimised and defined best practice for dementia care. However, if staff could not identify a benefit to themselves for changing practices they were unlikely to adopt new practices regardless of the benefit to the patient. Credible experts appeared to have less impact on staff practices than immediate line managers, suggesting a need to focus developing dementia expertise at ward manager level, who could then communicate the priorities for patient care to ward staff.

*CMOC 4/5b Time to spend with patients:* Themes from CMOCs 4 and 5 were combined. Biographical knowledge of the patient was used by staff to support their work with patients, but only where information was relevant to their work. Social influences, such as norms for patient care and concerns around contribution of work to the wider ward, could inhibit staff from working well with patients, leading them to focus on their role rather than on the interaction with the patient. Organisational endorsement to spend time with patients, through either policies that required staff to remain in the bay, or the role of a member of staff held in relation to patient care, could encourage staff to work in more person-centred ways. However, this was dependent upon the member of staff engaging with the opportunity rather than resenting and rejecting it. This influenced whether patients and their carers felt they were listened to.

*CMOC 6: Opportunities in risk management:* The ethos of care for managing patient risk did impact on how staff worked with patients at risk of falls. However, this was also influenced by the characteristics of the patient, additional staffing resources, and the ward environment. Organisational concerns and priorities, not patient need, dictated how staffing resources were allocated leading to patients at high risk of falls receiving more time with staff than patients expressing distress who did not pose the same risk. Staff concerns for the consequences of an incident impacted on the way they addressed patient risk, which while supporting patient safety, impacted on patient choice and limited movement. Where dementia care was given a higher priority and understanding of dementia was more consistently reported amongst ward staff, staff were able to approach patient needs calmly, creating an environment where behaviours that challenge were monitored and accepted rather than controlled. This reduced carer concerns that patients should be restricted and reduced patient frustration as behaviours related to understanding the ward were not curbed where they were not a risk to themselves or others.

*CMOC 7: Valuing dementia care:* Whether staff recognised dementia care as skilled work influenced their engagement with resources that could develop their skills. There was limited formal recognition of the expertise in dementia care by the staff (healthcare assistants) who spent the majority of their time with patients with dementia. Time spent with patients attending to needs related to dementia was not considered as worthy as time spent attending to clinical needs. Work with patients with dementia was prioritised according to risk rather than need and influenced the nature of the work staff were involved with, limiting their opportunities to use dementia care skills and leading them to believe they were losing skills. This could impact their long-term commitment to stay in dementia care.

### CMOC 1: Knowledge and authority to respond to an unmet need

Table 31: Evidence informed revisions to CMOC 1

Original CMOC 1 from review	Revised CMOC 1
<p>Where staff are supported to understand behaviours that challenge as communication of an unmet need (context), through access to experts, training, resources that help them to get to know the person (mechanism resource). Staff will recognise they have improved capacity and capability to influence the patient situation (mechanism reasoning) making it more likely they will identify and address the need (outcome).</p> <p>However, workload, patient characteristics (context) and staffing resources (mechanism resources) may cause staff to doubt their ability to make a difference (mechanism reasoning) leading to the patient need not being identified, assessed, or addressed (outcome).</p>	<p>Where behaviours that challenge are understood as communication of an unmet need through staff training, <b>experience</b>, access to experts, <b>and the use of care planning documents to support the assessment of possible causes of behaviour (including medical, physical, psychological, emotional)</b> (Context), <b>shared information about patient care and a range of responses for meeting patient needs</b> (mechanism resource), will support staff to feel they have the capacity, capability, <b>and authority</b> to influence the situation (mechanism reasoning) and will be more likely to identify and address the need (outcome).</p> <p>However, conflicting work demands, patient characteristics, and <b>organisation of the ward</b> (context) <b>will influence how staff respond to patient need, the time they spend with patients</b> (mechanism resource) <b>and if they consider they have the authority to request action from senior colleagues</b> (mechanism reasoning) influencing if patient need is investigated, addressed, <b>or raised with colleagues</b> (outcome).</p>

Findings from the review suggested that staff understanding behaviour as communication of an unmet need is an important context for the provision of good dementia care. Evidence from the case study supports this as an important prerequisite of good care. Staff reported how training and their own experience (CMOC 2), access to expert advice (CMOC 3), and assessment documents were important contexts for developing their ability to identify and respond to patient needs. This was most evident when there were competing demands on staff time. In these situations, it was staff's underlying competence in working with patients with dementia expressing distress and anxiety, and knowing how to respond and take action to address a patient's need, that made a difference. Additionally, a level of authority to raise patient needs with more senior staff and ensure recommendations were acted upon was important for staff to believe they could make difference to the patient, leading them to take action.

The following section explores these elements of the CMOC, drawing on evidence from interviews and observations at both sites.

#### *Methods for identifying and addressing need: the use of systematic and tacit approaches*

Use of systematic approaches for understanding behaviour as communication of an unmet need was identified in the review. Interviews with senior staff identified systematic approaches as key to supporting a thorough assessment of possible underlying causes of behaviour and developing strategies that would address the need. At both sites, staff involved in dementia strategy groups discussed the development and use of dementia care bundles. These set out evidence-based assessments and practices that are considered to improve patient outcomes when used together in a consistent and continuous way, and detailed procedures for identifying causes of distressed behaviour, recommending actions for staff. They were also thought to help staff develop their awareness and help them acquire techniques for addressing patient needs. This quote provides an example of how this learning was supported by ward-based resources to reinforce alternatives to medication for patients with behaviour that challenge:

“And then obviously had some input into the [ward] behaviour chart which has then gone round the hospital. Which of the 17 / 18 interventions listed, only one is medication. You know, one is calling a doctor, one is around one-to-oneing someone, but pretty much there is around 14 interventions on there which are non-pharmacological interventions, which aren't about medicines; do they need the toilet, do they need something to do because it's boring being in hospital, those sorts of things.” (Site 1, ST0116, Psychiatrist)

There was evidence from observations, interviews, and review of medical notes, that doctors, psychiatrists, and allied health professionals were using these systematic approaches to understand possible causes of behaviours that were challenging for staff, although most of this evidence was identified at site 1. Evidence suggested, however, there were limitations to systematic approaches currently in use. The ability to understand and interpret behaviours was linked to what kind of information ward staff recorded. Variability in the recording suggested ward staff awareness for understanding behaviour as communicating an unmet need did not extend to assessment, use of language, and documenting care. While staff spent a considerable amount of their time documenting patients' care in medical and nursing notes, such as their fluid intake and bowel movements, descriptions related to behaviours expressing needs and how staff addressed them were limited and lacked depth or possible explanations. This observation demonstrates how pain was recognised as a possibility for a patient's behaviours but the notes do not explain what had been attempted to improve the situation:

The doctor continues to set out 5's situation; that he is in pain, that he has an infection, and is agitated. They mention that the notes report that he is shouting, but comment that they would want to know why he is shouting, not just that he is shouting. The doctor suspects that it might be because of pain. (Site 1, OB0103)

Motivations for recording behaviours may have influenced what was recorded. For example, staff may have been recording the behaviour to assist assessment, alternatively they may have been recording the behaviour to ensure there was a record of the incident. This might, in part, explain why more disruptive behaviours, such as violence, aggression, or trying to leave the ward, were more likely to be recorded. When information was more detailed, considered possible causes of the behaviour, and documented what staff had done to try and address them, patient records provided opportunities for learning to identify deficits in care provision and how it could be improved:

[FN: 4 earlier reacted badly to being supported with care by a male 1:1 and had hit out. The family member confirmed 4 did not like support from male staff] The HCA ward and the 1:1 are talking about the support needs for patient 4. The HCA ward says to the 1:1 that she will go and update the RN and ward manager **and put it in the patient notes that 4 is not to have male support**. The 1:1 then comes over to me and explains that they now know why 4 cannot have a male 1:1 and that everyone is being updated to change the care plan. (Site 2, OB0202)

Some behaviours, for example calling out, were often not recorded, even though staff recognised this as disruptive and indicative of patient distress. This might have been linked to whether staff considered the behaviour to be inevitable, unsolvable, and to be tolerated by staff and patients, or if they perceived they had the ability to address the cause of the behaviour.

An alternative method of understanding patient behaviour was described by some staff who explained how they drew on knowledge and skills developed from a combination of training and experience. Tacit knowledge led these staff to consider causes, such as pain and hunger, helping them to resolve the patient's need:

She [1:1] then goes on to tell me about how pain is always one of the first things she considers when a person is agitated or aggressive... She said since that training she has been 'on it' looking out for evidence of pain. She then gives the example that 13 has been complaining of headaches since she has been working with him and suggested that possibly it is because he is used to wearing glasses but he does not have them with him. She also explains that 14 had been very agitated this morning and was constantly trying to get out of bed and pulling his catheter, but since he has had the pain relief he has been much calmer. (Site 2, OB0213)

Observations recorded staff checking and clarifying their understanding of behaviours by asking the patient about their needs. Where verbal communication abilities were limited, staff addressed the need based on their interpretation of the behaviour:

The HCA walks back down the bed bay towards the front desk. She looks over at 7 and notices that he is eating the cardboard packaging from the sandwich. She goes over and gently takes it out of his mouth saying to him "7, you don't want to eat cardboard". She then says to him 'would you like a biscuit?' He does not respond, but HCA turns and says 'I'll get you a biscuit'. As she goes to get the biscuit she looks over at 6, 6 does not appear happy with his tea. He sees she is looking and asks about the sugar, HCA replies "there is sugar, it probably just needs a stir, I'll get you a spoon." She goes to get a spoon. (Site 1, OB0106)

However, once staff understood the reason for the behaviour, they would sometimes attempt to address it in ways which might not be reflective of the patient's preference, in part this was linked to

the available resources. For example, where staff recognised patients were hungry but did not have access to patient's food choices, persistent offers of alternatives could lead to increased agitation and frustration:

[FN: 4 has been asking for a particular food, but has run out of her own supply which the family bring in. Staff do not have access to an equivalent alternative and have been offering different options which have been met by anger and frustration from 4.] The agency HCA asks 4 "Do you want a banana?" 4 screws up her face and says in a loud, annoyed voice, "I don't want a fucking banana!" [FN: offers of food continue regularly for two hours and are met with hostility.] (Site 2, OB0211)

The above example demonstrates the limited responses staff had for addressing patient needs. Developing alternative strategies for addressing patient needs depended on being able to attend training, or working closely with other, more experienced colleagues who could reflect on whether strategies were working, provide explanations, and demonstrate alternative ways of how to address a patient's needs (see CMOC 2). At site 1, the layout of the ward and the higher number of staff working in the bay meant there were more opportunities for staff to share how they worked with patients to reduce distress.

#### *Range of responses and time with patients influencing patient outcomes*

An analysis of the types of responses to address different patient behaviours (Appendix 20) demonstrated that while staff were observed as attempting to reduce patient distress, they had a limited range of responses. Some staff were observed to rely mostly on distraction methods, such as offers of drink or food. Other staff were more likely to draw on techniques that had biographical relevance to the patient, such as talking with them about family and jobs. Whether or not these methods were able to address the patient's need depended upon the level of distress the patient was experiencing and the amount of time the member of staff could spend with them. For example, where staff engaged with a patient's distress by making time to focus on their needs, and provide comfort in ways that were acceptable to the patient, this could help calm patients:

The HCA walks over to 9. The HCA asks her if she is okay. 9 looks up at the HCA, she has tears in her eyes. The HCA walks over to her right-hand side, reassures her she is okay and gives her a big hug. She then releases her a little and checks she is okay, 9 nods and smiles. ... The HCA has her left hand behind 9's back and speaks into her ear. 9 looks at her and

nods. The HCA then comes over to the front desk, takes a spare chair, looks at me and says, “she needs a chat”. (Site 1, OB0109)

However, observations recorded a number of occasions where staff spent only brief periods of time with patients expressing distress. These were due to: competing demands which were prioritised over spending time to reduce distress; staff considering that the immediate need had been met, such as observing the patient have a drink; or techniques not being immediately successful in reducing distress. These short exchanges rarely appeared to lead to a reduction in distress, resulting in repeated, brief interactions with staff:

Patient 4 was calling out repeatedly over a three-hour period. Patient 4 expressed discomfort and concern about her drip until it was completed and removed, and feeling hot and uncomfortable requesting to remove clothing. Each time staff explained why she needed to keep the drip in or keep clothes on and then distracted her by encouraging her to have something to drink. After watching her take a sip, they would leave her, returning to other work. (Site 2, Summary of OB0207)

Decisions around whether staff spent time with patients appeared to be linked to whether they had the capacity and capability to reduce distress.

#### *Staff capacity, capability, and authority to request action from senior staff*

Staff capacity to understand and respond appropriately to behaviours were conditional to contextual factors such as conflicting tasks and competing patient needs. Staff at site 1 commented that increased staff support allowed them time to spend with patients who were anxious or distressed. In contrast, in situations where there were reduced staff numbers, staff were less able to respond to behavioural and emotional needs such as anxiety. In these situations, staff attempted to provide comfort to distressed patients through verbal reassurances and, where possible, visually monitoring them:

[FN: 2 has been saying she is lost since the beginning of the observation. The HCA is working with 4 behind curtains] After a moment 2 turns to me and says, “I don’t know my address.” The HCA calls out from behind the curtain “2 your address is on the note, what does it say 2?” 2 looks at the note and says the address. The HCA says, “yes, that’s right”. (Site 2, OB0205)

Addressing patients' emotional needs was secondary at times of conflicting demands, such as other patient needs and ward routines. This appeared to be partly influenced by whether staff considered they could make a difference or were able to stop the task they were involved with to address the patient needs. For example, taking clinical observations, such as blood sugar level readings in the lead up to mealtimes, was prioritised over addressing emotional and psychological needs of patients who were visibly sad or repeatedly calling out:

13 has been repeated calling out for help over the past hour of observations. The bay is not visible from the nurses' station and staff have briefly popped in to see other patients. It is now approaching lunch time and the HCA takes blood sugars for 14 and 15. During this time 13 continues to call out but the HCA does not go over to ask about her needs. (Site 2, Summary of OB0209)

At site 2 the ward culture was more hierarchical and staff appeared to need a level of authority to make requests and follow-up with senior staff. This could impact how patient needs were addressed. For example, when staff recognised patient behaviours as an expression of pain but were not qualified to administer pain relief, they needed to make requests for medication to senior staff on behalf of patients:

The 1:1, in the moments when 2 is not needing support, has been looking around the bay and checking on the other patients. The RN comes in and the 1:1 gets her attention, "sister". The RN goes over to the 1:1, the 1:1 continues, pointing towards 4, "that lady in bed 4 is in a lot of pain". The RN nods and goes over to the medication chart and picks up 4's then goes and stand over to 4's left-hand side. She asks 4 where the pain is. (Site 2, OB0208)

Ward staff who appeared reluctant to make these requests, or follow-up requests, were observed instead repositioning patients and distracting them with drinks rather than approaching the senior colleague. This could lead to a delay in patients receiving pain relief.

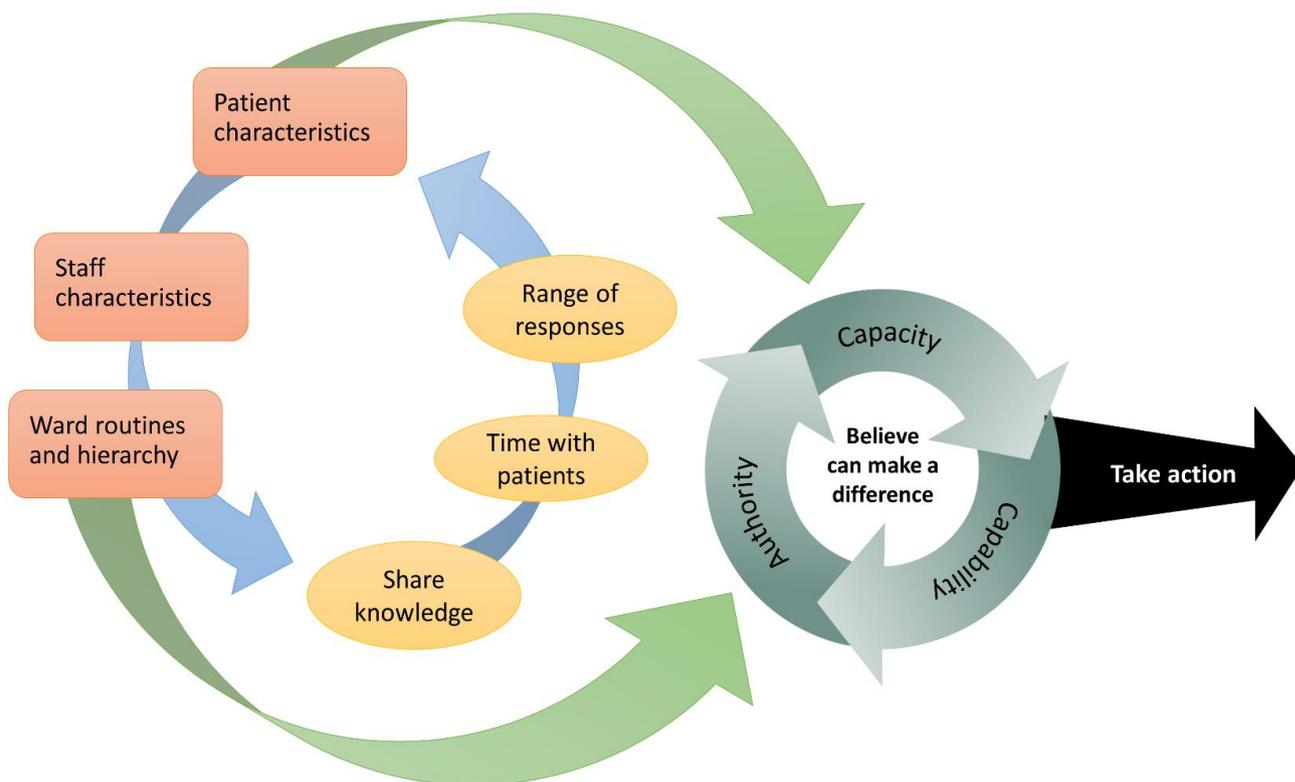


Figure 9: CMOC 1 Knowledge and authority to respond to an unmet need

## CMOC 2: Role relevant training and opportunities for reflection

Table 32: Evidence informed revisions to CMOC 2

Original CMOC 2 from review	Revised CMOC 2
<p>Access to training (context) that gives staff an experiential understanding of the impact of dementia on a person and promotes empathy towards people living with dementia (mechanism resource) can encourage staff to reflect on the deficiencies of current working practices (mechanism reasoning) leading them to take more time with patients with dementia (outcome).</p> <p>However, where good dementia care practices (mechanism resource) are not recognised as legitimate working practices (context) staff may interpret dementia care practices as additional to their workload (mechanism reasoning) leading to inconsistencies in care provision (outcome)</p>	<p>Access to training, support from experts and colleagues with experience in dementia care (context) <b>develops skills and techniques</b> (mechanism resource) <b>that are relevant to staff work</b> (mechanism reasoning) <b>and lead staff to apply the methods in their work</b> (outcome) <b>reducing patient episodes of distress</b> (outcome).</p> <p>However, <b>dementia care is complex and it is not always possible to resolve patient distress</b> (context), <b>staff need to have opportunities to share their experiences to develop their skills</b> (mechanism resource) <b>and be reassured they have tried to make a difference</b> (mechanism reasoning) to improve their ability to cope with patient distress (outcome).</p>

Findings from the review suggested developing empathy and understanding of how patients with dementia experience care was important for staff to recognise why some practices might have a detrimental effect. Evidence from the case study suggests that while staff with a responsibility for training felt this was an important element, staff in receipt of training reported they valued learning specific skills relevant to their daily work. This demonstrates that the priorities for training were different between ward staff and those training staff. Staff ability to implement learning was influenced by previous experience of working with patients with dementia, and concerns for their contribution to ward activities. This evidence will now be discussed.

### *Training that encourages reflection of care practices*

Staff responsible for dementia training discussed using techniques to encourage staff to consider their practice from the patient's point of view. They believed that by understanding how dementia could affect a patient's experience of care, staff would recognise why some approaches might be detrimental. This in turn could help them to consider how to improve their care to meet the patient's needs. For example, by understanding that patients who are confused by their surroundings will be frightened and need reassurance, the staff might be prompted to comfort them:

“And it is looking at things from a very simple point of view, so looking at [consultant] talking about try as hard as possible to put yourself into the patient's position, and if you could see what they were seeing, if you could understand what they were seeing, that sort of thing.”  
(Site 1, ST0116, Psychiatrist)

Staff providing training reported covering a range of topics and skills (Table 33). Mandatory tier 1 dementia awareness training ran at both sites. Additional training was dependent upon staff role and their level of contact with patients with dementia.

The two-hour slot allocated to dementia awareness training suggests there was limited time on the course to reflect on care practices, and the breadth of the course might have led staff to only retain information of relevance to their work. For example, staff who had only received dementia awareness training spoke of how dementia impacted the person from the physical support they might need. This related to how they might adapt care provision but had limited reference to the patient's emotional needs. Staff with additional training and experience in dementia care reported a deeper insight of how care practices might be detrimental, and considered the impact on the

Table 33: Topic areas for training and type of training delivery

Training delivery	Topic area	Teaching format
Dementia awareness	Dementia Aetiology Signs and symptoms Impact on abilities such as eating and balance Person-centred care: seeing the person not the dementia Causes of distress Rights and dementia Communication skills: how to communicate well with people living with dementia Supporting carers: resources in the hospital and the community	Class-based Lecture Facilitated by dementia lead
Ward-based training / case by case advice	Adapting care to benefit the person	Ad hoc Ward-based By senior staff/clinical experts
One day breakaway training (site 1 staff and 1:1 staff at site 2)	How to work with patients who are violent and aggressive in ways that will maintain their safety and staff safety. For example, techniques for getting out of holds and knowing when to call for help	Class-based Hands on Delivered by mental health experts
Ward training (site 1) Enabling patient abilities	Identifying patient abilities and helping patients maintain them e.g. ability to self-care, continence, mobility	Ad hoc, needs based Ward-based By allied health professional
Ward training (site 1) expert facilitating reflection of care practices	Reflection of care practices e.g. examples of what has worked, or not, to encourage someone to be washed when they are refusing care	Planned Ward-based Facilitated by allied health professional
One week induction to 1:1 team (site 2)	Training in dementia care and training from other specialist nurses such as pain and palliative care	Class-based Lectures Group Activities By clinical experts
One day dementia champion training (Site 2)	Use of patient biographical information for care planning. Sharing experiences and reflecting on how would approach situations differently. Carer experiences of hospital.	Class-based Lectures Reflection Activities External educator

patient. For example, these staff spoke of how admission to hospital for patients with dementia was a frightening experience and understood the importance of providing emotional comfort and support:

“When they first come on the ward, it is very frightening, they get very scared. We’ve had people that have been here from, come back from a ward and they are very anxious and scared. And then we tell them and funnily enough so people remember you, you say you’re

on [ward], you say you're okay you're with us, we'll look after you. Once you gain their trust and they feel settled and calm" (Site 1, ST0103, HCA)

Areas staff considered training should cover were linked to their concerns for providing care in the 'right way'. For example, some staff commented that they wanted to develop communication skills for working with patients with dementia. They relayed the importance of having examples for what to do in different situations:

"we had the dementia training. It was a couple of hours, talk, video, which I think is great... I think that it is good to have an insight, watching it, discussing it. The different types of dementia, signs to look out for. I think we could maybe do more. Some people, just how to act around a dementia patient, you know, when they are asking for their parents, you know, just to give them tips." (Site 2, ST0205, HCA)

These comments from staff suggest that the complexity in caring for patients with dementia was recognised. Wanting more examples of how to address patient situations suggests staff were aware that there was more to learn and they were not confident working with patients with dementia. Some staff spoke of the difficulties they faced when providing care for distressed patients with dementia, particularly when they were unsuccessful in their attempts to recognise or meet the patient's needs. This fits with observation data related to the limited range of responses (Range of responses and time with patients influencing patient outcomes, Appendix 20), and indicates that staff had an awareness that they did not always have the right skills. Where staff acknowledged this, they reported a willingness to learn. This suggests an important mechanism for engaging with development opportunities was recognising where knowledge and skills were limited:

"when someone has more experience, and so you can understand how, for example, a colleague is able to manage medication with the patient. It is interesting to learn, something like trying to get more knowledge." (Site 1, ST0102, Nurse)

There were suggestions from staff with more experience that training opportunities were limited in furthering their development:

"[breakaway training] that did help although I think I'd put a lot of those things into practice already so you know even though it was good to have it confirmed professionally, I'd already put that into practice." (Site 1, ST0108, HCA)

“it was a week’s training. I think two of those days were specifically on dementia. But I already knew that training anyway, I didn’t really feel like I learnt much more than I’d already learnt on my previous job.” (Site 2, ST0203, 1:1)

These opportunities were recognised as useful for reaffirming confidence in their professional practices, but they offered little in the way of broadening their knowledge and skills.

### *Access to staff with dementia expertise*

Senior staff with expertise in dementia care were available at both sites. The mental health teams at both sites provided support across the general hospital for adults with mental health concerns which included patients with dementia. The teams were not funded by the Trusts and had their own separate office away from the ward. However, levels of contact varied between the sites. At site 1 these staff worked in close collaboration with the ward team (Figure 10). This included shared ward rounds and multidisciplinary meetings between consultants, psychiatrists, allied healthcare professionals, and nursing staff. Assessments for cognitive abilities and mental health, such as the Mini-Mental State Examination (MMSE) and depression scales, were observed being conducted with patients as a routine part of patient history taking. These staff provided input for patient care planning around supporting patient wellbeing and maintaining functional abilities. They also reported providing ward-based training around care provision, such as providing personal care that met patients’ preferences and abilities.

At site 2 the mental health team and dementia lead were not integrated into the work of specific wards but provided input to patient care as required (Figure 11). The dementia lead made daily visits to wards where patients with dementia were admitted, assessing them and discussing their situation with ward staff and doctors. Advice from the mental health team was on a case-by-case basis for specific concerns, such as assessments of behaviours that challenge to assist their management. Neither the dementia lead, nor members of the mental health team, attended ward rounds or the daily multidisciplinary meetings. Occupational therapists and physiotherapists provided support to wards across the hospital, usually designated to the same ones. They did not provide input on ward rounds but did attend the daily multidisciplinary meetings.

Figure 10: Staff proximity and input with patients and ward at site 1

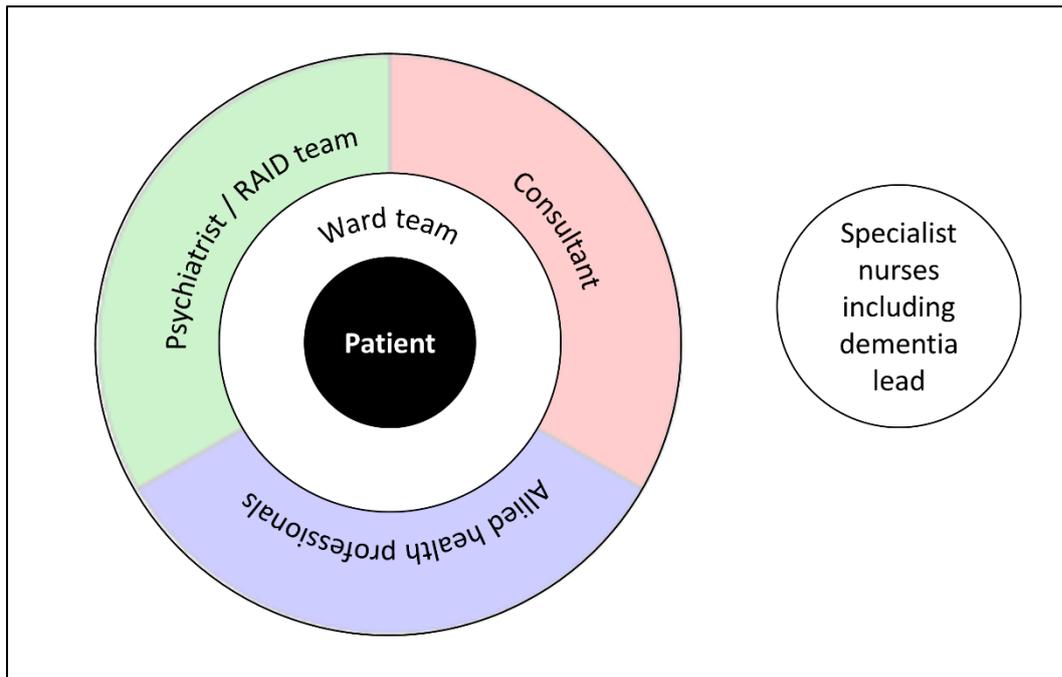
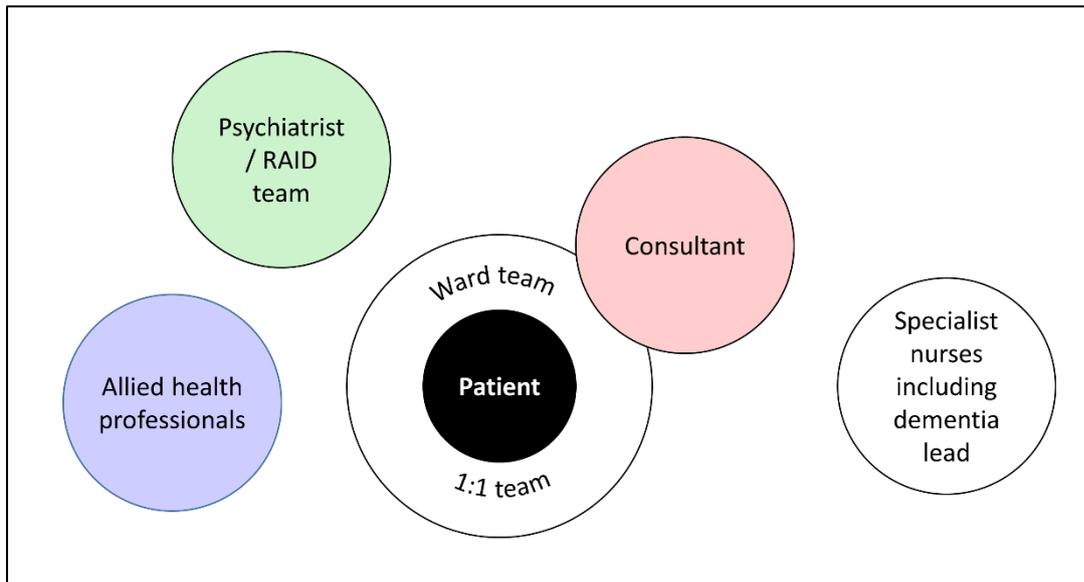


Figure 11: Staff proximity and input with patients and ward at site 2



At site 1, the regular presence of the mental health team on the ward supported informal contact and dialogue with ward staff. Ward staff of all levels were observed being asked about the patients' situation by these professionals during their visits to the ward. At site 2, the dementia lead discussed patient care during visits to patients on the wards with nursing staff. While staff with expertise reported the type of input they provided, it was not possible to track whether different levels of contact with these staff influenced how advice was followed, or the influence on patient

outcomes.

### *Developing skills from peers and senior staff*

At site 1, nursing staff and healthcare assistants reported how their practice was improved by seeing good examples of working from colleagues. This helped develop their knowledge of alternative approaches they could incorporate in their care. Observations of practices demonstrated how staff learned from each other. For example, staff were observed sharing information about patient preferences and abilities, such as patients eating well when given finger food:

An HCA goes over to her [12], “hello 12, how are you today?” They have a brief chat, then the HCA walks away from the bed and speaks to another HCA saying, “I’m going to get her some finger food for breakfast. She ate that well yesterday.” (Site 1, OB0109)

At site 2, the 1:1 management team considered one of the roles of the team was to influence ward staff to provide good dementia care. Staff in the 1:1 team discussed how they had made suggestions to ward staff for the care of some patients, for example by informing them of an activity that helped to calm someone. However, observations suggested that the influence of 1:1 staff on ward staff practices was limited as they often worked in isolation rather than collaborating in patient care. Some 1:1 staff reported times where they had lacked support from ward staff suggesting that their influence on ward staff might be limited:

“When we are looking after somebody, that gives the staff on the ward confidence that they cannot watch over that area so much and they may do all their washes, or their pad changes in the other bays and I kind of, and not just me, the others, sometimes we feel like we are left on our own.” (Site 2, ST0203, 1:1)

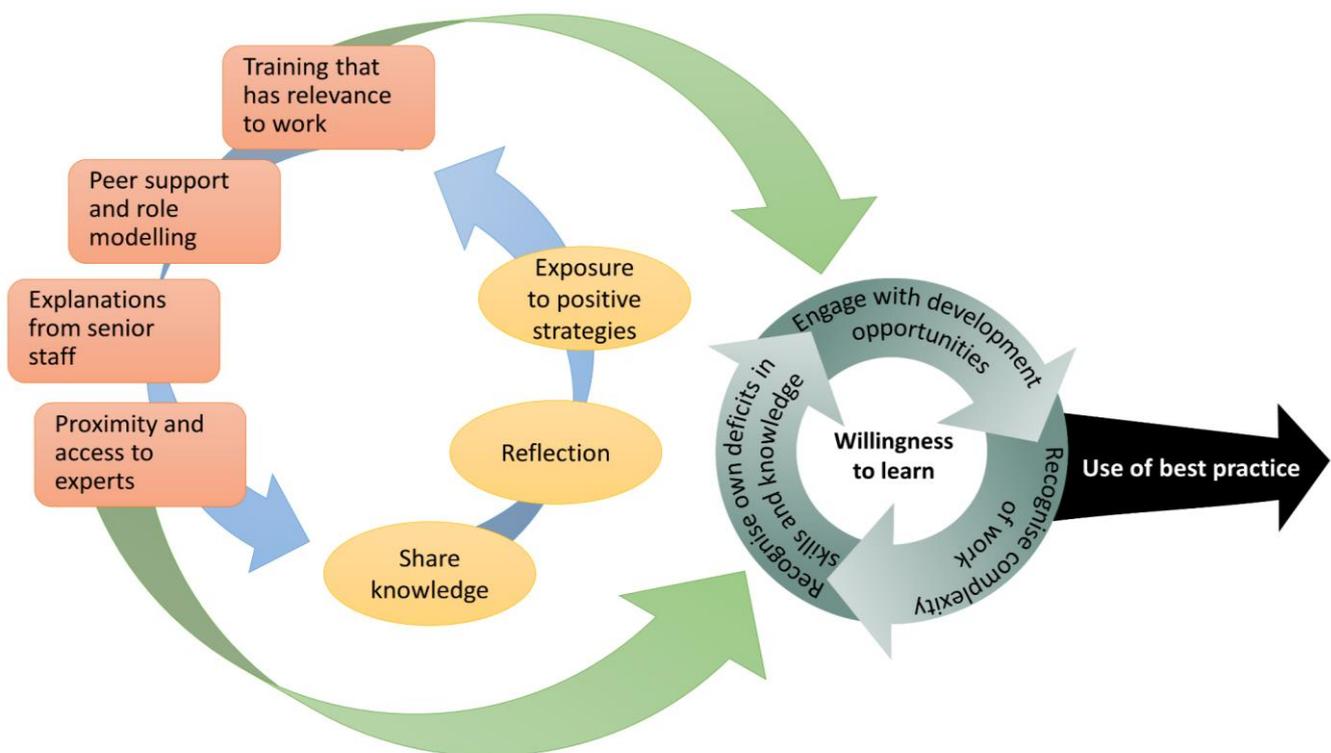
Healthcare assistants and nurses at both sites were observed informally sharing practices that supported patients, although there were more examples of this at Site 1. A more formal approach to sharing practices was used by managers and senior nurses who were observed explaining and reinforcing care practices:

7 had asked to have a cigarette. The HCAs and RNs were discussing this and telling him they were just arranging for someone to take him for a cigarette. Later in the corridor the ward manager was talking to one of the nurses explaining that they did not know if 7 was a

smoker or if he had quit and was using patches. She explained that the previous day he had asked another nurse for a cigarette and the nurse had managed to distract him with conversation while they attempted to contact his family and find out if he was smoking. She told the nurse that the difficulty was that if he had quit smoking six months ago and they took at face value his request to smoke then they would be setting back his giving up. (Site 1, OB0102)

There were few observed examples of these exchanges. Those which were recorded, like the above example, suggest that while there were attempts to inform and develop staff awareness of patient difficulties related to their dementia, the focus was on ensuring the correct procedures and processes were followed.

Figure 12: CMOC 2 Role relevant training and opportunities for reflection



### CMOC 3: Clinical experts and senior staff promoting practices that are patient-focused

Table 34: Evidence informed revisions to CMOC 3

Original CMOC 3 from review	Revised CMOC 3
<p>Experts with clinical and organisational authority to legitimise the priorities and standards for dementia care (context), and support staff development in dementia care skills (mechanism resource) encourage staff to feel confident they understand the expectations of their role in patient care (mechanism reasoning) and will adapt care practices (outcome).</p> <p>However,</p> <p>Where the responsibility for dementia care is focused in select staff (context/mechanism resource), this may reduce the sense of responsibility the wider workforce has for dementia care (mechanism reasoning) and reduce embedding good dementia care practices across the organisation (outcome).</p>	<p><b>Where standards for dementia care are defined through policies and care planning documents which are monitored and reinforced by experts and managers to support implementation of new practices</b> (context) staff will understand what is expected of them and <b>how care is to be prioritised</b> (mechanism resource) <b>and consider the benefits and consequences to themselves for new ways of working</b> (mechanism reasoning) <b>leading them to make choices about the way they provide care</b> (outcome).</p> <p>However,</p> <p><b>A clinical expert’s ability to engage with staff and embed best practice for patients with dementia</b> (context) <b>will depended on their working proximity to staff</b> (mechanism resource) <b>and perceived benefit of new practices</b> (mechanism reasoning) <b>influencing whether staff adopt new ways of working</b> (outcome)</p>

The review suggested that experts helped to legitimise care practices by clarifying expected standards for care and developing linked resources and staff skills to reflect these standards. In the study sites, clinical experts reported their involvement in developing care pathways and care planning documents which set out processes and procedures for the provision of care for patients with dementia. Experts in dementia care provided advice for care practices with patients with dementia and promoted patient-focused care. Senior staff reported that some essential care practices were not recognised as important by more junior staff and required repeated reminders. While some staff considered the credibility of the expert was important, evidence suggested that it

was the proximity of senior staff that influenced care practices, suggesting the importance of senior ward staff having expert knowledge in dementia care. These ideas will now be discussed in relation to evidence from the sites.

### *Developing documents that are acceptable and useful to staff to promote consistency in care practices*

In both sites, standards of practice for dementia care had been developed by strategy groups that involved staff across a range of disciplines who had responsibilities for working with patients with dementia. They contributed to the development of policies, care pathways, and documents for care planning that ensured compliance with national guidance. These documents detailed:

- Use of validated assessment tools, such as the Abbreviated Mental Test Score (AMTS), 4AT assessment for delirium
- Quality indicators relating to dementia screening and follow-up, completion of *This is me* booklets, and patient experience
- Resources available in the general hospital for staff use to identify that the patient had dementia, such as forget-me-not magnets and coloured wristbands
- Options for enhancing patient care, for example use of the Tiptree box which contained materials for activities such as colouring
- Recommended the use of communication frameworks, such as the validation, emotion, reassurance, activity (VERA) framework
- Highlighted paperwork that might need completing, such as Deprivation of Liberty Safeguards (DoLs) or behaviour care plans
- Advice on the use of antipsychotics
- Mandatory expectations, such as Tier 1 Dementia Awareness training, completion of *This is me* booklets.

The collective knowledge of members of the Dementia Strategy Groups had contributed to their development and complied with national guidance. Use of the documents aimed to: ensure consistency in the service by communicating best practice procedures; encourage the integration of biographical information in care planning; highlight resources and practices that might be unfamiliar to staff; and evidence the effectiveness of care practices:

“So we are trying to set up a bundle [document detailing best practice procedures and range of interventions] that can then be carried over to some of the other wards. Something

practical that kind of evidences what they are doing but also gives them tips about what they can do to make that situation better for the person” (Site 1, ST0111, Occupational Therapist)

“I know in the dementia strategy group the consultant was speaking about what was good dementia care, what makes good dementia care. I suppose at the moment **there is no physical, no way to show that we are giving good care.** We have the care plan about the standards we have to follow that could be one of the best ways to measure it.” (Site 2, ST0201, Dementia Lead)

The above quote demonstrates the difficulty for staff to measure good practice in dementia care. Experts in dementia care discussed the principles around good practice in dementia care, giving examples of how these might be applied in practice (Table 35).

*Table 35: Principles of good dementia care described by experts in dementia care at sites 1 and 2*

Area of good practice in dementia care	What it included	Example	By who (site and role)
Addressing both mental and physical health needs	Making provision to support patients’ mental wellbeing as well as physical and medical health needs	History taking and care planning that addresses not just the acute reason for admission, but a person’s abilities and biography to inform care planning.	Site 1: Psychiatrist, Doctors, Allied Health Professional Site 2: Psychiatrist
Maintaining current abilities	Enabling patients to perform personal care appropriate to their abilities, supporting mobility, supporting continence	Allowing patients to shave themselves. Where some support is needed for personal care, staff allow the time to support the patient rather than providing the care because it is quicker. Encouraging mobility to reduce loss of function. Understanding how to support continence related to the person’s abilities and preferences, such as supporting them to find the toilet.	Site 1: Psychiatrist, Allied Health Professional Site 2: Psychiatrist, Allied Health Professional

Area of good practice in dementia care	What it included	Example	By who (site and role)
Use of biography in care and care planning	Using knowledge of patient likes and dislikes, their routine, and things that are important to them	Providing food they like; reducing likelihood of distress from attempts to feed unwanted food, and rejected food being interpreted negatively (e.g. such as patient unable to self-feed, aggression from trying to resist food being treated with medication). Recognising habits, such as bedtime routines, and ensuring care provision and medication administration accommodates these preferences.	Site 1: Dementia Lead, Psychiatrist, Doctors, Allied Health Professional, Dementia Lead Site 2: Dementia Lead, Psychiatrist, Allied Health Professional
Provision of activities	Providing activities that patients can complete by themselves or with support from others	Using activities to stimulate the patient, providing them with opportunities to socialise and relieve boredom which might otherwise lead to behaviours that challenge.	Site 1: Dementia Lead, Psychiatrist, Allied Health Professional Site 2: Dementia Lead, Psychiatrist
Supporting patient identity	Encouraging patients to dress in their own clothes, using the patients favoured name in interactions	Patients are supported to be orientated by things that are familiar to them.	Site 1: Dementia Lead, Psychiatrist, Doctors, Allied Health Professional Site 2: Dementia Lead, Psychiatrist, Allied Health Professional
Involving the carer in history taking	Checking the history of the medical condition and personal needs with the carer	Ensuring that information from the patient is checked with their carer.	Site 1: Dementia Lead, Psychiatrist, Doctor Site 2: Dementia Lead, Psychiatrist, Doctor
Communication with the patient	Staff are aware of their approach, recognise that a patient might have difficulties in understanding and adapt communication to the patient's abilities	Staff use voice tone, body language, eye contact, clear language to support patient understanding of situations and reduce distress during tasks such as personal care or clinical observations. Ensure sensory aids are worn.	Site 1: Dementia Lead, Psychiatrist, Doctor, Allied Health Professional Site 2: Dementia Lead, Psychiatrist

<b>Area of good practice in dementia care</b>	<b>What it included</b>	<b>Example</b>	<b>By who (site and role)</b>
Orientating to environment and situation	Helping patients to navigate the environment	Support for wayfinding. Supporting orientation to time and place for reassurance.	Site 1: Dementia Lead, Psychiatrist, Doctor, Allied Health Professional Site 2: Dementia Lead, Psychiatrist
Managing risk	Using methods of least restrictive practice for managing risk	Managing risk of falls in ways which do not impact on other abilities.	Site 1: Psychiatrist, Allied Health Professional Site 2: Psychiatrist, Allied Health Professional
Involving patient and carer in decisions and care planning	Supporting decisions by offering opportunities for patients and carers to discuss what is important to them and considering the implications of care practices and medication regimens	Understanding what is important to patients when planning how to address care needs, such as knowing when they like to get up. Agree how care is to be provided by understanding the implications e.g. that encouraging mobility might lead to a fall but might be less debilitating than restricting movement.	Site 1: Dementia Lead, Psychiatrist, Doctor, Allied Health Professional Site 2: Dementia Lead, Psychiatrist

While there were similarities in definitions of good dementia care across the sites, site 1 had more alignment across professions (nursing, medical, mental health, allied health) in all areas, whereas in site 2 professionals focused more on areas related to their own responsibilities.

Ward staff at site 1 identified good care practices as related to reductions in anxiety and distress and maintaining a calm atmosphere. Ward staff at site 2 defined good practice in ways that were applicable to all patient groups, few were dementia specific. For example, staff were able to identify actions, such as ways to reduce risk of falls through monitoring patients, and general outcome measures, such as pressure sores. At both Trusts, annual reports detailed objective measures, such as number of falls and pressure sores, as well as reporting improvements to services and patient experience as measures of service quality. However, while service improvement measures, such as training and links with charity groups, were reported, specific patient outcome measures for dementia care were not reported.

Experts at both sites discussed how the complexity of caring for patients with dementia required a holistic approach to ensure that in addressing one area of concern, another of the patient's abilities was not neglected or negatively affected. For example, mitigating one area of risk, such as falls through restricting patient movement, could impact on other abilities, such as continence by not supporting a patient to use the toilet. Care plans were being developed to help staff identify these potential impacts. However, while there was a need to recognise multiple concerns for care, it was recognised documents had to be acceptable and useful to staff. Addressing all issues would result in lengthy documents that risked being rejected by staff.

### *Promoting practices that are patient-focused*

Experts in dementia care reported promoting practices that were patient-focused. At site 1, supporting personal care that recognised the patient's preferences and abilities, and that was not restricted by ward routine, had been encouraged by experts through training and support on the ward. Staff were observed respecting patients' preferences in relation to timings for personal care. However, when staff felt under pressure to provide personal care to patients within a particular time-frame this could lead to care that frustrated and annoyed patients:

Staff normally allow 2 to get up when he is ready. At 7.45am the new HCA approached 2 to get him up for a shower. 2 swore at the HCA. Thirty minutes later the HCA tried again and is advised by other staff to wait until 2 is ready. After another twenty minutes the HCA tries again and is joined by a colleague from the discharge lounge who is providing early morning support. This time 2 gets up and angrily goes to the toilet while the two staff change his bed. (Site 1, Summary of OB0103)

At site 2, experts in dementia reported making ward staff aware of preferences of patients written in *This is me* documents, such as going to bed early. They suggested how these preferences might be incorporated, such as adapting timings of medications to suit patient normal routine. Observed practices that were patient-focused, such as engaging patients in activities and conversations of interest, or ensuring patient comfort, had been instigated by individual members of staff who had experience of working with patients with dementia. This suggests staff insight into dementia influenced how care was provided. Where insight was limited, support from senior staff with expertise was required.

Comments from ward managers indicate staff might not take the initiative to provide care in ways that consider the needs of patients and suggests that understanding how dementia impacts patients was not clear. At site 1, while healthcare assistants and nurses discussed the impact of the psychosocial ward environment on patient experience, this did not appear to influence their use of the entertainment system.

The ward manager said they used to make sure that patients were all in their own clothes in the day time and up and doing activities. She said that standards had slipped and she needed to work on it... Capital radio was playing on the TV and this annoyed her, 'simple stuff' that staff should consider. She then turned to the two patients at the table and asked them what they would like to watch. (Site 1, OB0104)

"We have music that is calm and helps to improve patient experience. Not all the patients will like the music that is being played, but in general it helps to create a calm atmosphere. There are times I have to check that staff have not put on their own music because it is not always appropriate for the patients we are looking after." (Site 2, ST0220, Ward Manager)

Despite their efforts, managers reported little evidence of consistent changes and appeared to concede these practices would require constant reinforcement. Observations of their dealing with these practices showed the ward managers making the change, but not encouraging staff to recognise why attention to these practices was important, perhaps because managers considered them quick to address in the moment.

### *Credibility of Experts in dementia care*

At both sites, experts and senior staff with expertise in dementia care considered how their credibility as an expert impacted on whether they were able to persuade staff to adopt new practices. Credibility and trust were thought to be established through extensive experience, or conveyed when staff could identify with the senior member of staff:

"We did a training session on dementia and challenging behaviour that was run mainly by myself and one of our more experienced nurses who used to run one of our inpatient psychiatric wards. And so, when she's talking [experienced mental health nurse], because again the doctors tend to come along and say, "oh, do this" and then we walk off. The nurses are the ones having to deal with the patient for the next six hours of their shift. So

one of our nurses who has been there and done that as an inpatient nurse, looked after effectively, is telling them, you know that patient you look after who's challenging, imagine the whole ward just of those patients. That's who she was looking after. So when she tells you to do 'X' she is doing it from experience." (Site 1, ST0116, Psychiatrist)

However, clinical experts advising and promoting new ways of working were observed to have variable levels of contact with the wards; at site 1 there was regular support and experts had frequent contact with staff, at site 2 contact was more limited (see Access to staff with dementia expertise, p175). This appeared to influence how staff engaged with their advice. Staff with professional experience, but who were contract-based and provided time-limited input into the priorities for care, might have limited impact for changing practises:

"I think one of the things that I was asked to do was to get the uniform. So again, whether it's hierarchical, and occasionally I do put on a uniform so that people realise that I am a nurse [laughs]. Because there was this general feeling, you know, "who is this person on the ward with a note pad and says these are the stuff you have to do". (Site 2, ST0218, Carer's Lead)

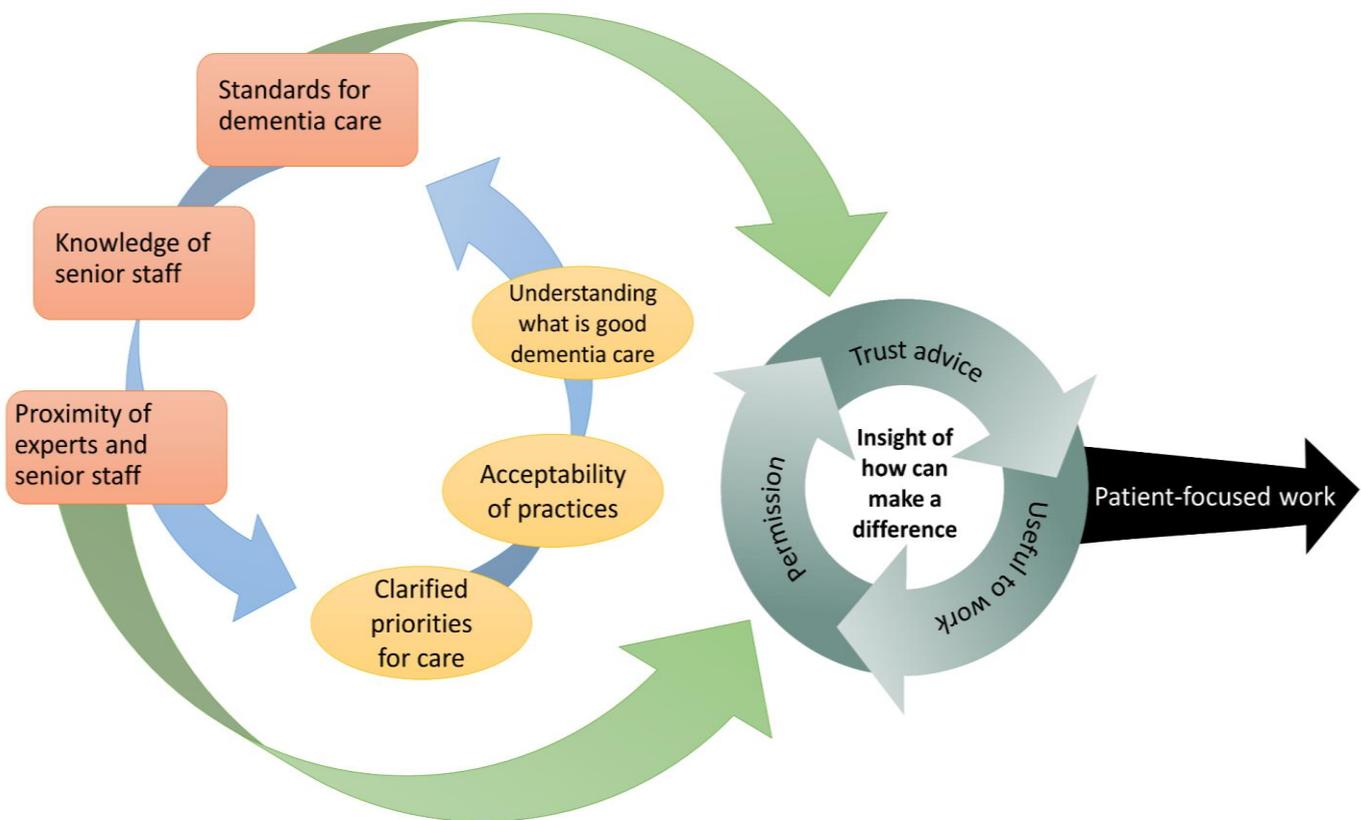
Informal conversations with staff at site 2 suggested the use of 'outside' staff to provide advice that focused on long-term changes to care practices might result in their advice being rejected if it conflicted with advice from senior ward staff, such as the ward manager. This suggests that senior staff proximity plays a part in defining care priorities and has important implications for considering how to organise expertise. Depending upon how much understanding of dementia care senior staff have will influence whether care practices improve. At site 1, the Dementia Lead highlighted the importance of Ward Managers being highly trained in dementia care to influence practice:

"I think the ward managers are people, and people who look after a lot of people with dementia should also be trained up to that level personally, but it is something that we need to look into and make sure that they can then transfer their knowledge down to their staff by practice. Because a lot of dementia I think still needs to be transferred from the top. I feel that very passionately that the ward sisters that are dealing with dementia should be trained." (Site 1, ST0114, Dementia Lead)

While the ward manager at site 1 had received training as part of the development of the ward,

further formal training in dementia care had not been attended. The ward manager was supported with regular input from medical and mental health dementia experts. At site 2 the ward manager had not received dementia care training. This might, in part, explain why knowledge transfer of essential care practices, such as paying attention to the ward environment (see Promoting practices that are patient-focused, p184), were difficult for managers as they were limited in their own understanding.

Figure 13: CMOC 3 Clinical experts and senior ward staff promoting practices that are patient-focused



#### CMOC 4/5b: Engaging with opportunities to spend time with patients

During analysis of evidence from the case study, it became apparent that CMOCs 4 and 5 from the review had a number of overlapping themes. Knowledge of the patient was used by staff in ways that were of benefit to their roles. Staff's experience of working with patients with dementia, and their understanding of their responsibilities for care, influenced how they recognised the contribution of their work and impacted on the focus of care provision. Patients' ability to engage influenced the quality of interactions with staff. Additionally, how staff engaged with service directives that enforced their presence in bay areas, influenced how opportunities to spend time

with patients were utilised. Therefore CMOCs 4 and 5 from the review were combined into CMOC 4/5b (Table 36).

Table 36: Evidence informed revisions to CMOC 4 and 5 to create CMOC 4/5b

Original CMOC 4 from review	Original CMOC 5 from review
<p>Where staff are supported to be flexible and autonomous in their role and working environment (context) with clarification of their responsibilities for patient care (mechanism resource) staff will feel confident to adapt care provision (mechanism reasoning) responding to the care needs of the person in a timely, individualised manner (outcome).</p> <p>However, considerations of the influence of environmental factors and staff capacity (context) may need to be recognised and addressed by management (mechanism resource) for staff to feel confident a flexible, autonomous way of working is accepted by colleagues and senior staff (mechanism reasoning) for them to provide responsive care (outcome).</p>	<p>Where there is provision of activities and therapies for patients with dementia which are designed to support their interests and abilities (context) by staff allocated to this role (mechanism resource), they will take responsibility to address patients social, emotional, and psychological need (mechanism reasoning) and take action to maintain patient functional and cognitive abilities (outcome) which can provide time for other staff to focus on physical and medical needs (outcome).</p> <p>However, where staffing resources are limited (context) allocation of staff may be focused on maintaining patient safety (mechanism resource) which requires these staff to prioritise safety concerns over the provision of activities and therapy (mechanism reasoning) limiting how psychosocial needs are met (outcome).</p>
<b>Revised CMOC 4/5b</b>	
<p><b>Staff with a clear understanding of their responsibilities and the priorities for patient care (context), have knowledge of the patient they can use in their interactions (mechanism resource) and recognise the benefit to the patient (mechanism reasoning) can provide care that enhances patient experience and maintains their identity (outcome).</b></p> <p>However, <b>Organisational endorsement, social norms for patient care, and patient characteristics (context) can influence the time staff spend with patients (mechanism resource) and whether feel they have a level of authority to resist competing demands for their time (mechanism reasoning) influencing how staff prioritise patient needs (outcome).</b></p>	

### *Knowledge of the patient and relevance to staff roles*

Access to biographical information about patients was considered important by staff to support their work with patients with dementia. This information was obtained through discussions with their carer, and from information in *This is me* booklets. It was reported as useful for: supporting conversations and activities of interest to the patient; knowing about their preferences for food and drinks; understanding the patient's routine so that could be incorporated into care plans; and for strategies that might help reduce distress and anxiety.

This information was applied differently by staff according to their role. For staff who had a role in patient care which specified providing occupation through activities and conversations, they valued this information for guiding activities. Drawing on this knowledge to inform activities improved patient engagement and experience:

“I depend upon what the patient's family say about the patients, what they enjoy doing, what their careers were and things like that because I do think it is important for them to remember who they were, remember what they did and it's nice to be remembered by other people and it's nice to be recognised for what you used to do. Because I think when the patients they only see themselves as patients they forget that they were somebody, that they did something to make a difference. For example, we had someone who was an opera singer here and even though she was not mobile, she was very bad, we used to play some of her favourite opera music that she used to actually perform and that made her smile so much and she was singing along and everything. So it was a simple things that you can do for the patient that can really make a big difference.” (Site 1, ST0106, Activities co-ordinator)

Healthcare assistants at both sites reported, and were observed, referring to the information at times of patient distress and anxiety to see if carers had recommended particular strategies. This demonstrates that staff engaged with the information according to how it could support their work with the patient.

### *Experience and responsibility for care influencing capability to adapt to patient needs*

Providing activities for patients with dementia were observed to be complex, requiring a high level of interpersonal skills. Staff needed to: 1) understand the abilities of the patient and provide support appropriate to these abilities, and; 2) be able to interpret the patient's non-verbal

behaviour, recognise their changing needs, and appropriately respond. To do this adequately, staff needed to be able to spend the time engaged with the patient and resist competing demands, or address them while maintaining the patient's engagement:

The HCA looks at 2 and rubs her left arm with her right hand. She then looks at what else is on 2's table and sees a word search book. She encourages 2 to do a word search by starting to look through the book and then sitting close to 2 saying, "let's find this word together". She hands 2 the book and starts to help her look for the word. When 2 finds the word she congratulates her (although not in a patronising way) and helps her to cross the word out to the right point by holding her finger to the end of the word. She continues to sit and help 2 to look for words, talking through the strategies, "this word has a z so we are looking at the letters around the z". 2 and the HCA are both focused on the activity for some time, 2 does not appear distressed at all during this and has a lot of concentration on the activity. (Site 2, OB0205)

However, there were times where staff were not responsive to cues from the patient. This appeared to influence how they engaged with a patient. Their ability to recognise and respond to a patient's changing needs became secondary to maintaining the interaction. This led staff to miss behaviours from the patient that suggested they were becoming tired, or were no longer interested in the activity:

The 1:1 comes back in, picks up the book and starts to go through it again. Initially 17 appears to look annoyed at this but then as the 1:1 picks a page and starts to talk through it 17 starts to smile more. Then 17 puts her left elbow on the left arm rest and rest her head into her fist. The 1:1 continues to point out things of interest in the book and laughs which 17 joins in laughing with. She engages her in a conversation once more and the 1:1 moves closer so she and 17 have their foreheads close and are sharing a moment. But then 17 starts to look round the room a little more and at the bed. While the 1:1 continues to look for more pictures, 17 picks up the menu off her table and looks at that. (Site 2, OB0212)

As the above quote demonstrated, there were times when patients had reduced engagement with activities. At both sites, activities were often observed to continue beyond the patient's initial interest, this was explained during one activity as a strategy to regain a patient's interest:

The activities co-ordinator had set up a painting activity at the middle table. Originally four patients had joined in but after a few minutes all but 1 had left. I was sat painting with the activities co-ordinator and patient 15. 15 had stopped painting for several minutes and said that she had finished. The activities co-ordinator attempted to encourage her to continue. 15 continued to sit at the table but was not painting. The activities co-ordinator continued painting and said to me that sometimes if you continue with an activity it will help the patient to resume their interest. (Site 1, Summary of OB0103)

However, this and other examples demonstrated the difficulty in getting the right balance for the length, level, and focus of activities in ways that would benefit the patient. At times, it appeared staff providing these activities were concerned with demonstrating their contribution to other staff members rather than attending to the patient's changing interest.

#### *Patient ability for engagement and the influence on staff interactions*

Evidence from observations showed a patient's ability to engage with staff could influence the time staff spent with the patient and the quality of those interactions (Table 37). Where the ability of the patient to engage was limited, or their verbal abilities were poor, it was difficult to identify the direction of influence: whether patient's limited abilities influenced staff interaction, or whether the way staff interacted limited patient engagement.

*Table 37: Patient ability to engage and observed interactions with staff*

<b>Patient ability to engage</b>	<b>Types of interactions observed</b>
Good engagement	Conversations that developed around a patient's interest, were enjoyed by patient and staff. Supported in activities. Examples of camaraderie. Reciprocal interactions
Limited engagement; preoccupations of where are and where family members are	Reassured and distracted. Explanations to orientate patient, offers of food and drink. Containing interactions
Limited or no verbal abilities; e.g. reduced communication abilities due to their dementia or not English speaking	Interactions focused around tasks and treatments. Functional interactions

Patients whose abilities to engage appeared lacking, either because they appeared unable to speak or because they spoke another language to the staff, were observed only receiving interactions around task-based care, or to address behaviours around risk, such as attempting to stand up. Staff used body language and hand gestures to support their verbal instructions and question patients about their needs. The few examples of more in-depth, non-task related interactions with patients with limited verbal abilities were from staff with more experience in dementia care. They guided the interactions by involving patients in conversations through their use of body language and props:

One of the HCA's has passed 12 laminated pictures of cities round the world. She starts to talk about her travels to different countries. The other staff sat round the table join in. The HCA continues to talk to 12 making eye contact and using touch to involve her in the discussion. (Site 1, OB0109)

An important element that appeared to determine the success of these interactions was the staff member's ability to maintain the interest of the person with dementia, and to recognise from the person's body language when they were no longer engaged or enjoying the activity. Additionally, during these interactions staff were observed to have the authority to resist other ward demands and devote their attention to the patient.

#### *Policies and strategies that permit staff to work for the patient's benefit*

At site 1, staff were expected to stay in their allocated bay on the ward. This was supported through training and reinforcement from senior staff. An observed outcome of this requirement was that it encouraged patient and staff interactions that were not task focused. Environmental design promoted staff and patients to share spaces, such as tables. This supported impromptu conversations and provide social dining opportunities. While staff did not eat with patients, they did join them to supervise meals and support conversations:

Both 11 and 16 have now moved to have lunch at the middle tables with 9, 12 and 15. Two HCAs are sat at the middle desks. One is supporting 12 to eat (she is not independent with her food), the other is sat next to 9. The HCAs talk to patients in the group, prompt them to eat, and stop patients taking food from each other's plates. (Site 1, Summary from OB0102)

Ward staff at site 2 reported concerns that they did not feel they had time to spend with patients with dementia. In part this appeared to be influenced by social and internal pressures to contribute

to work on the ward, which impacted on their capacity to work with patients and the priority they placed on sitting with patients:

“because they are high risk, it’s the constant vigilance and you are usually given eight patients. And so there’s the dementia team, but they are not always here. They are not here today. So that means that the nurses are put upon, because I’m not free to care for the other patients.” (Site 2, ST0202, HCA)

1:1 staff also commented there were social pressures for them to contribute to work on the ward that was additional to their remit:

“I do want to help out and look after the patients and keep everybody happy and help the ward but you can’t do everything. You are there for a specific job and purpose and that got to, because otherwise once you start doing too much, they [ward staff] will give you other jobs to do.” (Site 2, ST0203, 1:1)

Organising care in ways that addressed organisational considerations for patient safety appeared to counter these concerns, or at least permitted staff to sit with patients. At the time of data collection, a falls prevention policy, involving bay nursing, was being implemented to improve patient safety. Interviews and observation suggested that staff often resented this practice because they felt they were not contributing to the collective care of patients.

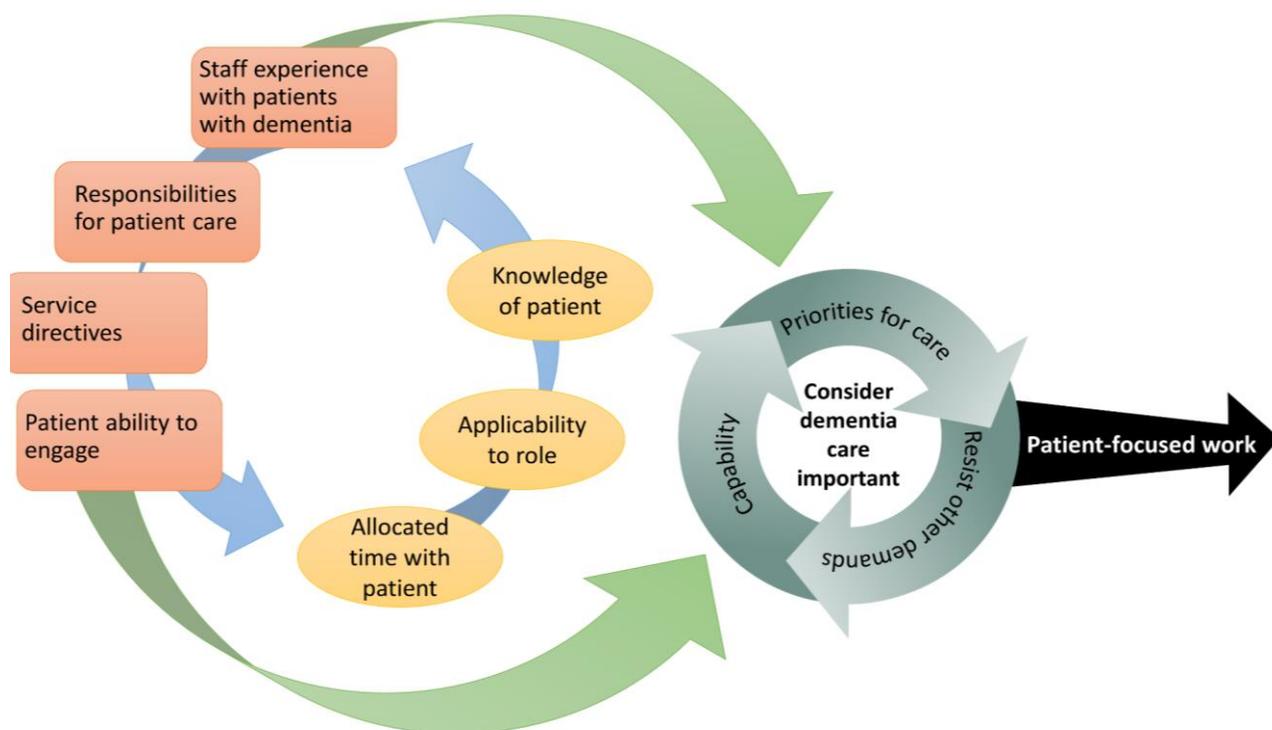
“I’ve got a bay like I’m in today, I can’t nurse other patients in another bay.” (Site 2, ST0205, HCA)

Data suggested that they did not recognise this as valuable work (see CMOC 7: Valuing dementia care as skilled work, p202):

The SN comes in and tells the HCA that one of the other patients had been pulling out their catheter. They have a brief conversation about this then the SN leaves, the HCA then turns to me and explains that normally she would have been assisting with that sort of situation but as 2 is at high risk of falls she cannot leave the bay. (Site 2, OB0206)

Despite staff resistance, the enforcement was observed to encourage more contact with patients that was not task focused.

Figure 14: CMOC 4/5b Engaging with opportunities to spend time with patients



## CMOC 6: Risk management as an opportunity for dementia care

Table 38: Evidence informed revisions to CMOC 6

Original CMOC 6 from review	Refined CMOC 6
<p>Where risk management procedures and expectations are defined through the use of person-centred approaches (context) and ward leadership encourages and reinforces these practices (mechanism resource) staff may feel confident they are supported to address risk proportionately (mechanism reasoning) and they may support the safety of patients with dementia in ways which help maintain their abilities and accept their choices.</p> <p><i>However,</i></p> <p>resources for risk management will need to be compatible (mechanism resource) with environmental features and staff capacity (context) or staff may feel the changes are inappropriate (mechanism reasoning) making it unlikely they will adapt care practices (outcome)</p>	<p><b>Patient abilities, staffing resources, environmental design,</b> and encouragement to manage risk in a person-centred way (context), <b>combined with staff capacity, knowledge for addressing risk</b> (mechanism resource) <b>and their concerns for the potential consequences to themselves and the patient</b> (mechanism reasoning) informed whether staff used more or less restrictive practices (outcome).</p> <p><i>However,</i></p> <p><b>allocation of staffing resources was based on organisational concerns rather than patient needs</b> (context) <b>and gave staff permission to spend time with patients identified as high risk</b> (mechanism resource) <b>reinforcing priorities for patient care</b> (mechanism reasoning) <b>informing choices for how they allocate their time with different patients</b> (outcome)</p>

Evidence supported the review finding that where senior staff promoted risk management approaches that helped maintain patients' functions and abilities, staff would adopt ways of working to support patient choice and identity. Additional factors, such as patient abilities, staffing resources and the ward environment, also influenced how risk was managed. At site 2, a patient's level of risk and the availability of staffing resources influenced how, and if, staff were allocated to individual patients. How staff engaged with these opportunities, their experience of working with patients with dementia, and their concerns for maintaining patient safety impacted on how patient choice and restrictions on movement were addressed. In environments where there was more understanding of dementia amongst staff and family carers, behaviours that challenge and their associated risks were monitored and accepted, rather than controlled. However, learning opportunities for working differently with patients with dementia who had risks were missed.

*Permission to approach risk management in ways that prompted patient choice and the impact of patient dependency*

Clinical staff with expertise in dementia at site 1 discussed how they encouraged staff to approach patient risk differently, for example by supporting and encouraging patients to mobilise around the ward. Ward staff at site 1 also reported that they were comfortable with patients walking around the ward. This was supported by evidence from observations where patients able to mobilise independently walked around the ward, spending time on either bay, or round the nurses' station. Patients who could mobilise with aids and staff support were assisted to walk round when staff had the capacity to help them.

At site 2, no patients appeared able to mobilise without the support of staff. Their level of dependency meant they were more likely to be chair or bed bound. While staff at site 2 were observed supporting mobility with the use of mobility aids, opportunities for patients to mobilise were mostly limited to times where patients needed the toilet. Mobility was sometimes restricted because staff were concerned about the consequences they would face if an adverse incident, such as a fall, occurred. However, as this quote demonstrates being risk averse with frail patients could have unintended consequences:

“What I see again and again is if people come in with a urine infection or a chest infection they are more confused than their baseline and they are brought into a very unfamiliar environment which makes them even more confused.... And if they are at risk of falls you try to restrict them to the bed or the chair, not allowing them to walk very much so they lose

their muscle power very quickly, and we make them bedbound, unfortunately, and perhaps the first couple of days they may have quite significant delirium that they can't walk, but we don't encourage them to walk as quickly as possible and mobilise as quickly as possible because we are struggling with our resources. It's not because people don't want to do it, it's because we don't have the capacity." (Site 2, ST0217, Psychiatrist)

This quote suggests that there was a link between how risk was managed and staff capacity to address the needs of the patients they were caring for. While there was an ethos for encouraging mobility at site 1 which may have influenced staff practices, environmental design, patient characteristics, and a higher staff to patient ratio (1:2 rather than 1:4/1:5) may have also facilitated the different approach to supporting mobility.

Staff capacity and their awareness of patient risk was observed to influence how risk was managed, with unintended consequences for patients. For example, at times where staff ability to monitor patients was limited due to other work priorities, more restrictive practices were observed to ensure patient safety. This could reduce patient movement and lead to frustration and increased distress:

The HCA is about to support 5 with a toileting need. She walks over towards 5 and then turns to me and says that she feels unhappy that 4 is so close to the edge of the bed without the bedrails up. She reports that 4 had said earlier that she does not want the bedrails up and while the HCA understands this is her choice she is still not comfortable with it. She goes over to 4's left hand side, 4 is sleeping, she apologises to 4 but says that she is going to put the bedrails up for safety. She puts them up and then pulls the curtains around 5 to help her.... 4 has woken up and is holding on to the bedrails and shaking them, looking at me and shouting, "will you put the side down for me?" The HCA says, "yes, I will" from next to 5 explaining, "but I just need to be here at the moment". (Site 2, OB0211)

Potential consequences of incidents, such as falls, for both staff and patients were used to justify more restrictive approaches to ensuring patient safety. When incidents had occurred, this appeared to reinforce staff belief that more restrictive practices were better for the patient:

[Summary: Following a patient fall. The patient had been supported to walk around the ward and then continued to stand without support for some time]. As the HCA comes into the room she says to the RN, "that's why I was sat with him". She looks annoyed, and I get

the impression her annoyance is with the other HCA who had not encouraged 3 to take a seat, which might have prevented the fall. (Site 1, OB0107)

Staff ability to consider alternative methods for maintaining patient safety and reassuring patients may have influenced how risk was addressed. Where staff did not have experience of using different methods for maintaining safety, such as allowing the patient to sit with them in a different area of the ward, they might not consider this an option:

“They were too scared do anything different even though it might make it better. Just changing where the patient sits, if they haven’t done that before they might not think about it. They are just worried about the implications of them falling and getting aggressive with them.” (Site 2, ST0201, Dementia Lead)

How staff developed a knowledge of these techniques was not apparent as there appeared to be limited learning at either site following incidents. Senior staff were observed addressing immediate concerns that might have prevented an incident, rather than considering how wider working practices that might have led to different outcomes:

[FN: following a patient fall] The sister asks if he banged his head, the AC replies “no, he did hit his arm though”. The sister turns to the team and says, “this is why the door to the cupboard must be locked”. She then demonstrates that if the door is on the latch it will just open if pushed. (Site 1, OB0107)

However, there was limited evidence that incidents were used as opportunities to assess the environment or staff training needs that might reduce similar situations happening:

(Summary from OB0106) During OB0106 a patient mistook a cupboard as a toilet. For the remaining period of data collection at this site, there were no changes to signage that might improve patient wayfinding. (Site 1, OB0106)

### *Organisational priorities for care influencing how patient need is recognised*

Patients who frequently called out but were at low risk of falls were considered less in need of resources that would support their dementia care. Referral forms at both sites for transfer to the ward (site 1), or 1:1 team input (site 2), highlighted calling out without additional identified risks as a

low priority for allocating additional staff resources, and was considered something that could be addressed or tolerated through current provision:

“...patients get referred because they are shouting out at night and disturbing the other patients, but they are not appropriate for the ward as there is nothing else we can do for the patient that is not already being done on the other ward.” (Site 1, ST0101, Ward Manager)

This suggests that for non-risk related behaviours, despite being a known expression of distress, there were no known strategies for reducing their occurrence, and attempts to understand underlying causes were not valued or supported. Instead other patients and staff were expected to tolerate the disruptive noise, and reasons for the patient calling out were not investigated or addressed. At both sites, a solution to complaints about noise on wards at night from other patients was to offer these patients ear plugs.

Patients who presented with low risk and calling out received less time with staff at both sites in comparison to patients with dementia who had a high risk of falls (Table 39).

*Table 39: How risk and disruption to the ward influenced patient and staff interactions*

<b>Type of disruption</b>	<b>Low risk of falls</b>	<b>High risk of falls</b>
Audible disruption to ward, e.g. calling out	Low levels of staff contact, mostly task focused e.g. mealtimes and personal care	High levels of staff contact, task and behaviour focused e.g. mealtimes, personal care, safety
Physical disruption to ward, e.g. walking about ward, trying to stand up	Mixed levels of staff contact	High levels of staff contact

Patient risk level might also influence how staff interactions took place. Patients at low risk were rarely observed receiving staff attention outside of task or behaviour related interactions. This compared with interactions observed with higher risk patients. Conflicting tasks influenced how staff were able to prioritise patient needs, with the level of risk a patient presented being an important consideration:

“I can stay here looking after the patient. You know, in here they have high risk of falls, so at the same time if my colleagues are changing the patient, on other wards that was impossible.” (Site 1, ST0104, Nurse)

At times where there were no conflicting tasks, staff were observed spending time talking with these patients about their interests and engaging patients in activities. This suggests that how services define patient need influences how staff consider their time with patients should be allocated.

#### *Acceptance of risk and behaviours that challenge reducing patient frustration*

Acceptance of behaviours that challenge and their associated risks and disruptions within the ward were observed at site 1, at site 2 this was less evident due to limited mobility in the patient population. At site 1, staff reported, and were observed, to approach potential risks or conflicts within the patient group in a calm manner that respected patient choice and monitored how situations were developing, rather than immediately restricting patient behaviour or movement. This quote demonstrates how a patient spending time in another patient’s bed area was managed:

[FN: 7 has attempted to leave the ward several times during this observation period using the emergency exit, each time being encouraged to close the door and come back inside as it is cold. 12 is sat at the middle table] 7 is looking around at 12s bed area. The HCA sits in a chair at the end of the bay in front of the emergency exit. 7 continues to look round 12 bed bay area and then sits in 12’s bedside chair. The HCA sits and watches for 5 minutes. 7 then tries to lie down on 12’s bed (12 is sat at the middle table). The HCA gets out of the chair, walks a few steps to the bed, says in a calm tone, “7, that is somebody else’s bed. I’ll take you back to your bed.” The HCA holds out her right hand. 7 walks to the end of the bed takes her hand with his left hand and they walk down the bed bay and back to the men’s bay. (Site 1, OB0102)

Senior staff at site 1 noted that the understanding of dementia amongst staff and relatives allowed for a more accepting environment of patient behaviours:

“I think because all the patients and the patients’ relatives, especially the patients’ relatives, understand dementia and they are not so, “oh Fred keeps interfering with my father’s locker” you know they all sort of know what dementia is like so they are not so tetchy as

they are those who perhaps don't understand what dementia really entails and they don't get quite so cross in a ward setting." (Site 1, Dementia Lead, ST0114)

The carer who was interviewed at this site also expressed appreciation of this. This acceptance was observed when one patient required PRN medication to address their increasing agitation and aggression, and visiting carers and family members supported their relatives' concerns related to the situation:

[FN: 15 has become increasingly agitated and the staff make a decision to administer her PRN of Lorazepam, the atmosphere of the ward changes to a level of distress amongst all the patients] 9 is getting distressed and crying, her husband is with her and talking to her calmly saying that the staff are helping 15, they are going to give her something to make her better. (Site 1, OB0105)

However, while aggressive behaviour was discussed and staff had a level of acceptance of this, there were times where aggressive behaviours were observed to impact on staff and patient relationships, leading patients to feel they were not understood or listened to:

4 had been aggressive overnight and security called. During handover the situation was discussed and the RN stated that he should be discharged today, then mouthed silently "fingers crossed". 4 told me that he had been frightened from visual hallucinations he had experienced and did not feel staff understood. (summary of OB0107)

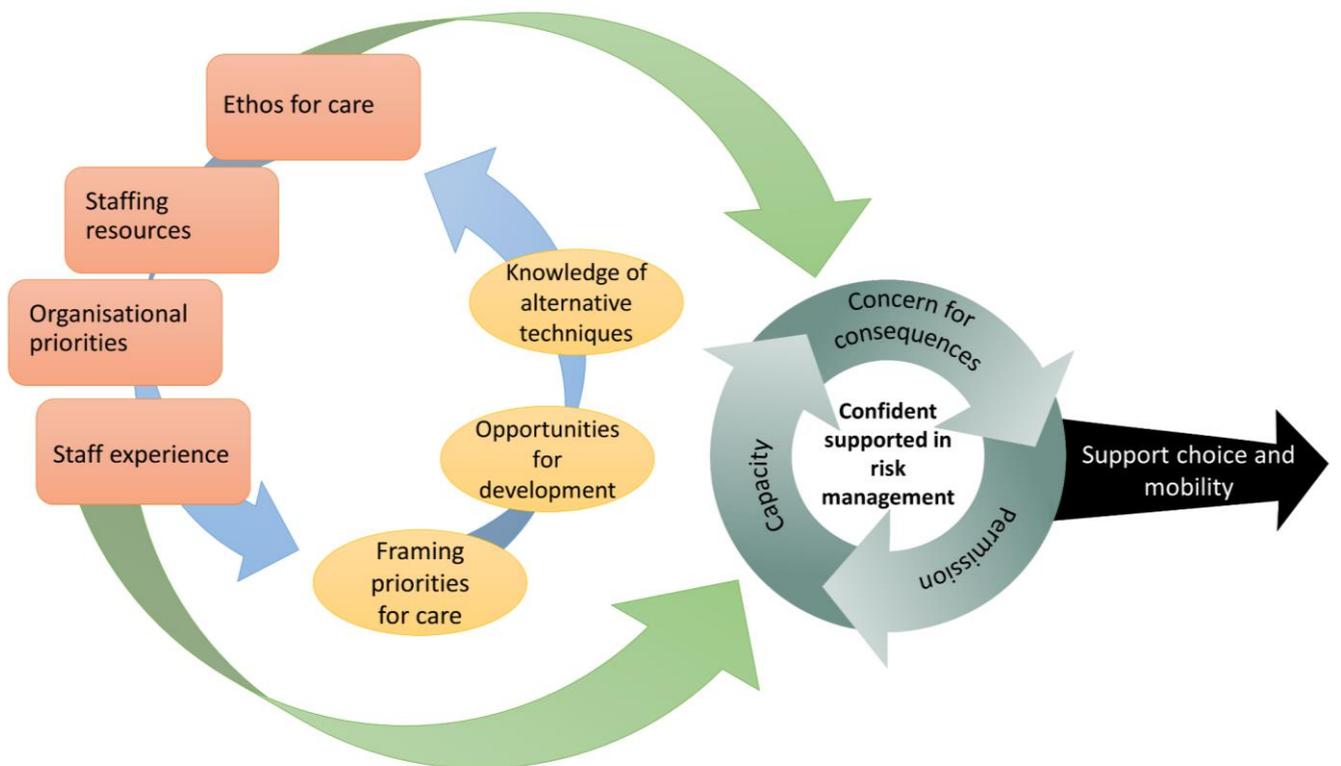
While an expert in dementia was observed in discussion with the staff member affected by the incident, it was unclear how this was addressed in terms of support for the member of staff, and whether the opportunity to develop understanding of the patient's situation was acted upon. Interviews suggested staff anticipated there was a risk of aggressive and violent behaviours, and repeated exposure was acknowledged as a potential factor in staff burnout, but there was no discussion of how this was addressed:

[FN: discussion of the impact of patients with dementia experiencing hallucinations or agitation during the night] "...you hear overnight how awful it's been and staff have been physically hurt by patients. And then you look at them and you think but they're so frail and they are in their late 80s how can they hurt anybody, or they've been absolutely lovely during the day, no bother at all and then obviously they are doing things, really distressing

things, and you can't reason with them, there is no reasoning with them at all and so you are primarily feeling quite useless. So I think when people have worked in the role for a long time that can be quite a burnout for them and that can be quite difficult for them to understand." (Site 1, ST0111, Occupational Therapist)

[FN: discussion of commitment to working on the ward] "... they [patients on the ward] are more physically aggressive which you don't want to come to work and get kicked and punched all the time... depending upon how many patients we have and how physically aggressive they are and that can have me to rethink [about continuing to work on the ward]" (Site 1, ST012, Nurse)

Figure 15: Risk management as an opportunity for dementia care



## CMOC 7: Valuing dementia care as skilled work

Table 40: Evidence informed development of CMOC 7

New CMOC 7
Where staff understand the complexity of working with patients with dementia (context) they will engage with resources that support their development (mechanism resource) and recognise dementia care as skilled work (mechanism reasoning) to continue to develop their skills and expertise in dementia care (outcome). However, where staff do not have opportunities to use dementia care skills and they see dementia care being provided by staff across the workforce (context) this impacts on the way care is prioritised and what staff consider to be skilled care (mechanism resource) they may become preoccupied with concerns around losing other clinical care skills (mechanism reasoning) which may influence their commitment to working in dementia care (outcome).

In phase 1, there were discussions from stakeholders that dementia care skills were not valued. While evidence in the literature touched on this issue there was not sufficient evidence to develop the theme into a CMOC. In phase 2, evidence of this theme emerged during data collection at both sites. Positive and negative examples of the value staff placed on dementia care skills and staff who worked with patients with dementia was gathered. How skills were valued was apparent in discussions of training, decisions for balancing and attending to multiple patient needs, the expectations of their role, career choices, and the priorities of services and the organisations. This evidence is now considered and developed as a separate CMOC.

### *Understanding dementia care as complex and difficult, and how expertise is recognised*

Ward staff at site 1 recognised their work with patients as complex and difficult. Comments from nurses and healthcare assistants acknowledged the physical and emotional effort involved to support anxious and distressed patients:

“You try to stay with them, try to speak with them all the time, because for example that lady, she is quite anxious all the time. You try to sooth her, so she is asking for her husband and she is asking all the time the same question and then you try to explain to her but she forgets in one minute so you try to have some activities for them.” (Site 1, ST0104, Nurse)

Healthcare assistants at site 1 had been supported by experts in dementia care to spend time reflecting and recognising their abilities in dementia care, which led to them contributing to the development of care planning tools. However, it was acknowledged that staff might find it difficult to recognise their contribution as their dementia care skills were additional to expectations of other healthcare assistants in the hospital:

“I think a lot of the time they [healthcare assistants on ward] do a lot of really good work, but they don’t really realise that they’ve got of skills that a lot of other healthcares don’t”  
(Site 1, ST0111, Occupational Therapist)

This comment was also evident for staff in the 1:1 team at site 2:

“And they do the same job as the other care assistants, but they just have that time to do things with them and they’ve probably had a bit more training for how to calm people down, how to talk to people.” (Site 2, ST0204, Matron)

There was no formal acknowledgement of expertise in dementia care for these staff. The difference between staff experienced in dementia care, and those who were not, was most evident when compared with bank and agency staff. While bank and agency staff were observed to be skilled in performing clinical tasks, they appeared uncomfortable or unable to engage with patients with dementia at other times:

The bank staff nurse comes into the room and stands between the middle and the front desk watching the TV. 9 and the HCA come out of the toilet. 9 goes and stands near the bank staff nurse, the HCA goes back to the table and to her notes. The bank staff nurse is stood some distance from 9. 9 says something to him. He looks over at me and raises his eyebrows. 9 continues to talk some more but the bank staff nurse does not respond. (Site 1, OB0105)

#### *Attitudes towards dementia care and concerns about staff contribution to work*

An emphasis on being busy and to be seen to be doing things impacted on the value placed on dementia care work. Spending time with patients to provide reassurance, reduce anxiety and distress, enhance patient experience of care, and maintain safety was understood by some staff at

site 2 as 'just sitting there'. This view of their work could influence how they provided care and responded to patients' needs:

[FN: HCA has been assigned to maintain the safety of a patient with dementia who is at risk of falls] I ask her [HCA] how she is and she nods and says, "okay, I need to stay here with this lady as she is not to stand". As she is saying this the patient tries to stand the HCA puts her hand out to encourage her to sit down. The patient bats the hand away and complains about not being allowed to get up. [FN: the HCA continues to sit with the patient, encouraging her to stay sat in the chair but having no other interaction with her] The patient continues to complain about the HCA and the HCA rolls her eyes. (Site 2, OB0213)

At site 2, concern staff had for their contribution to work on the ward influenced how staff understood the value of their work. Evidence from interviews suggested that 1:1 staff were characterised as 'good' when they contributed more widely, and 'bad' where their work focused on the patient they had been assigned. These characterisations suggest a lack of understanding of their role, and limited insight into good care provision:

"Some 1:1s come on to shift and are very good, they help out with other patients in the bay if the patient they are working with is resting or calm. Other members of the 1:1 team only work with the person they are assigned to." (Site 2, ST0220, Ward Manager)

In site 1, ward staff did not express concern at spending time with individual patients. However, interviews with ward staff and allied health professionals highlighted an awareness that staff working in other areas of the hospital considered working on the ward was easy. This was partly attributed to the increased level of staffing and a lack of understanding of the complexities involved in their work:

"I know that when it's good here it's really good and when it's bad it's horrible and I think that when people see it being good I think that people see it as an easy ward to work on and I think it is that lack of understanding that it takes a lot for the ward to be good. And you do get lots of benefits from it when it is good but it takes a lot of work from the staff for it to be, settled shall we say. And that can cause a bit of ill feeling from my experience of other wards not really understanding that the guys down here work incredibly hard and they have

a lot of challenges with patients which are really poorly from a mental health point of view, not just a physical health point of view.” (Site 1, ST0111, Occupational Therapist)

While staff at site 1 were able to continue their work in ways that were accepted within the ward, these external pressures to be seen to be contributing for staff at site 2 in the 1:1 team may have influenced how they worked with patients.

### *Opportunities to apply dementia care skills and preoccupations with losing clinical skills*

Where staff considered they did not have the opportunity to apply dementia care skills, or did not recognise the care they were providing as skilled work, they express concerns at losing clinical skills:

“I’d been hoping actually that I’d be learning new things, but I feel like I’ve lost a lot of my skills.... for example, in the hospice I changed a lot of stoma bags, and things like that. In fact, it was funny because I did one yesterday. But I’m worried, I’m worried that I’m going to lose my skills.

#### **Do you feel there are different skills that you have learnt with this job?**

No, not really, not really. Maybe to learn how to deal with, I mean I’ve worked with aggressive patients before, but on a different level sometimes. I’ve sort of learnt skills like that, but any practical skills, no.” (Site 2, ST0211, 1:1)

The above quote demonstrates that healthcare assistants valued opportunities to develop skills and become expert in their role. However, for some staff satisfaction in their role was related to evidence they had applied skills and completed tasks. One member of staff who did recognise the value of their role explained:

“Chatting to them, talking to them, giving reassurance. Most of the time it is giving reassurance. They might not know where they are, they might be confused, where’s my husband, where’s my wife. They just want to hear somebody’s voice to say there is somebody on the way, that kind of thing.... You can look after somebody and you’ll think they are asleep and then they’ll put their hand out, feel your hand there and then go back to sleep. So somebody is there, okay. So you think, you may think that you are being wasted by sitting there but actually you’re not.” (Site 2, ST0203, 1:1)

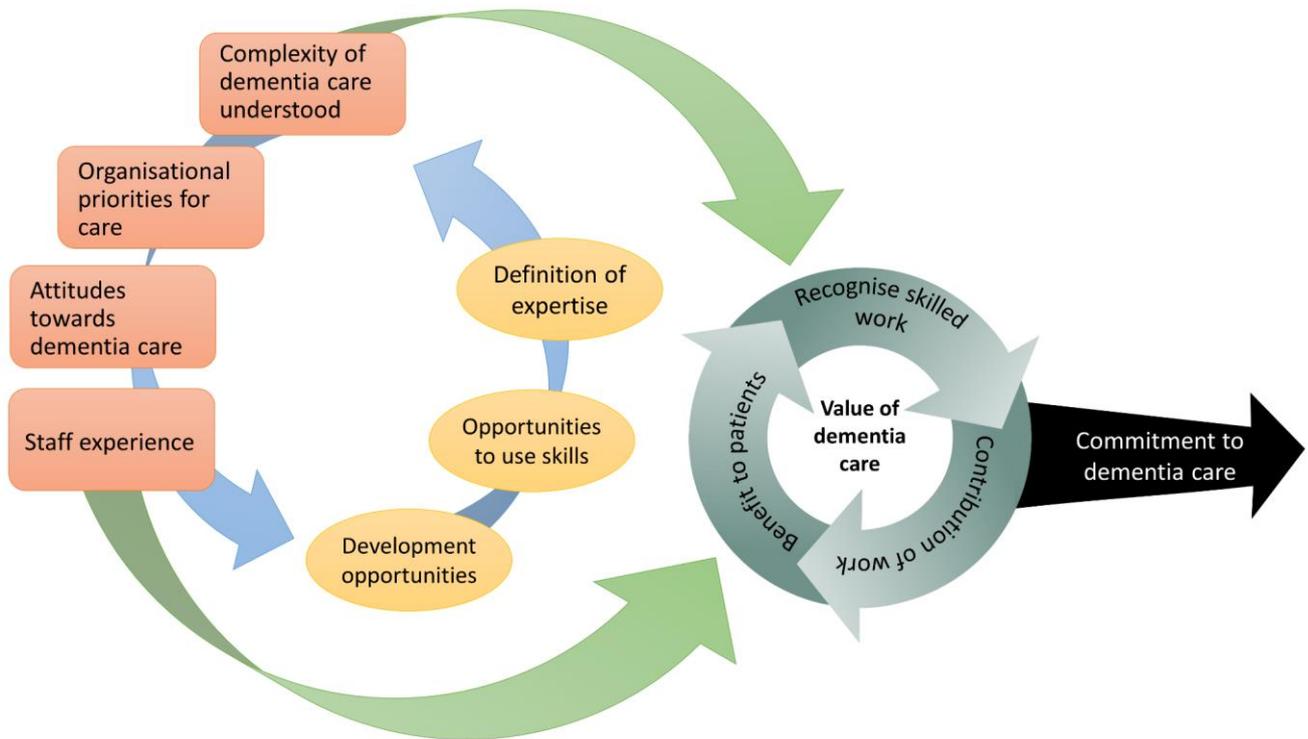
The above quote demonstrates how interpersonal skills can be valued and lead to job satisfaction. However, observations suggest it might be difficult for staff to recognise they were using dementia care skills, which contributed to their concerns for lost skills. At site 2, staff in the 1:1 team's main objective was to maintain patient safety, and patients they worked with were often acutely unwell, who struggled to engage, and were disorientated in relation to time and place. In these situations, staff were mainly involved in retaining the patient in their bed or chair through instruction and persuasion, rather than providing reassurance and occupation through conversation or activities. Where staff spent the majority of their shift in this type of provision, they reported finding the experience unsatisfying and were left questioning their contribution to care.

At site 1, concern of losing clinical skills was not reported by healthcare assistants, but by nurses. Patients were moved to the ward after the initial treatment of their acute condition and many were awaiting care home placements. There were limited opportunities for nurses to be involved in more clinically technical tasks, such as inserting intravenous cannulas. At the time of the study, this was considered to be a factor in a number of nurses pursuing opportunities in more clinically and medically focused departments:

The ward manager sat down with me and said what a difficult time she was having. She was facing losing 7 members of nursing staff by the end of the year, 2 through pregnancy and the others through new jobs. Some were moving to jobs in A&E and the ward manager accepted that for nurses who had recently qualified that they wanted to be in a more clinically focused area so they would not lose their clinical skills. (Site 1, OB0104)

While nurses at site 1 did spend time in conversations with patients and care that were not based around tasks, their role in dementia care appeared unclear as this was predominantly the domain of the healthcare assistants.

Figure 16: CMOC 7 Valuing dementia care as skilled work



## Chapter Summary

Phase two findings support the phase one finding that a fundamental context to developing dementia-friendly approaches to healthcare in general hospitals is that there is an understanding of behaviour that challenges as a communication of an unmet need.

Key mechanisms of allocated time with patients, and knowledge of patients with dementia and dementia care were related to contexts of organisational and staff acceptance of dementia care practices. This influenced whether or not staff believed they were able to make a difference and would go on to take action to address patient needs. Staff responses affected outcomes for patients, for example where staff engaged with patients expressing distress using their knowledge of the patient to talk about topics of interest, this could calm patients leading to positive experiences through inclusion and recognition of their personhood. However, where staff were did not consider addressing the patient's need as important in comparison to other tasks, staff could resent spending time with the patient resulting in generalised interactions, often using methods of distraction. This could lead to more patient frustration.

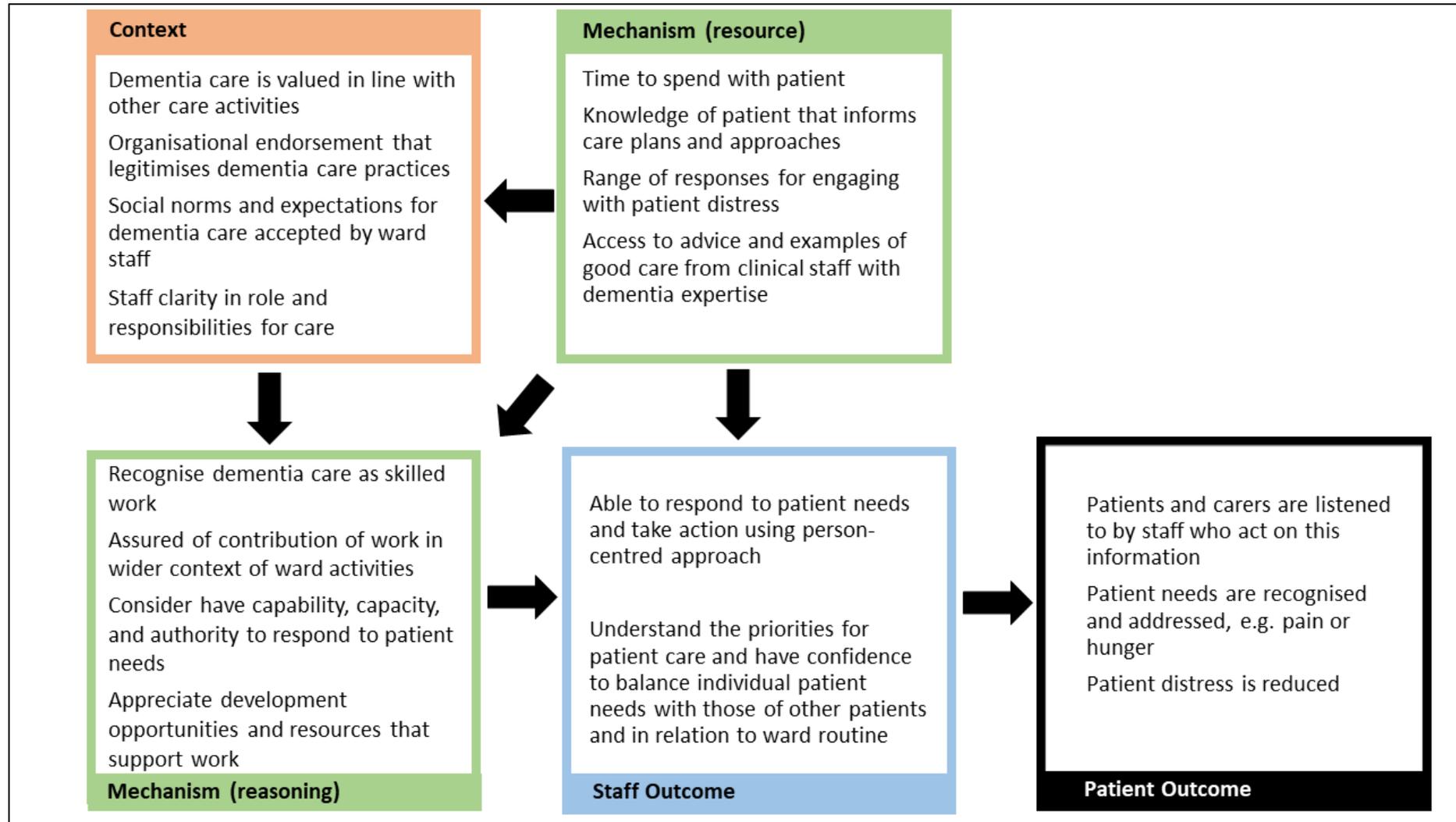
Opportunities for developing staff skills in dementia care were limited and relied on staff engaging with support from co-workers, such as role-modelling or observing colleagues working well with patients. Staff expressed interest in training which would improve their practice with patients, for example achieving patient compliance with medications. However, reference to person-centred approaches was limited to staff who had more personal or professional experience in working with people living with dementia outside of the general hospital setting.

Priorities for care were defined at ward level and influenced by the organisations concerns, such as managing risk. This impacted on how staffing resources were allocated, and which patients received increased staff input. The result of this was some distressed patients who did not pose a risk received less attention from staff. Where there were more staff to support patients, and the environments were designed to encourage mobility and socialising, patients' choices for moving around the ward, options for essential care such as toileting needs and washing, and sitting in different areas were promoted and listened to by staff.

The influence of how dementia care was valued and prioritised was found to be located at ward manager and senior ward staff level. This suggests support and education is needed to develop dementia expertise in these staff, which is important to develop their confidence in communicating and direct changes to practices. Where dementia care was understood as an integral part of staff roles, staff were less likely to express concern about the contribution of their work to wider ward activities and focused more on their contribution with individual patients. Recognising dementia care as skilled work influenced how staff considered the importance of their work with patients with dementia, and their commitment to dementia care.

The programme theory is demonstrated in Figure 17.

Figure 17: Refined programme theory of what supports general hospital staff to provide dementia-friendly healthcare and with what outcomes for patients with dementia



## Reflection on data collection

There were specific challenges I faced during data collection and analysis which related to my personal and professional experiences. I do not have a clinical background and have spent limited time in hospital. As such, I entered the field from a naïve, 'outsider' position. The challenges, how I overcame these, and advantages of this are discussed below.

A recent Guardian article reported findings from a study of the changing roles of those providing care, which includes healthcare assistants, specialist nurses, and registered nurses, led to confusion for patients, visitors, and other staff related to the specific responsibilities of staff in patient care (Leary et al., 2017). This was also my initial experience on entering the field. At first, it was unclear what role different staff played in the delivery of patient care. At times, and particularly in site 1, registered nurse roles and healthcare assistant roles appeared interchangeable. I clarified staff responsibilities by asking different members of the team to explain their role in patient care and their expectations of other members of the team. This helped me to understand that tasks like medication, wound dressing, telephone communication with family members, and contact with service providers external to the hospital were the role of registered nurses. While registered nurses were involved with essential care tasks, this was predominantly the domain of healthcare assistants.

Proctor and Reed (1995) describe how their experience as nurses allowed them insight and understanding in situations which might not always be apparent to naïve researchers. In contrast I did not start with this insight but had to develop it. I did this through asking questions about ward routines and common practices and by joining the morning and evening handovers. This enabled me to gain insight into patient situations and what staff considered the priorities for care. For example, at handover, staff would go through the reasons for admission, treatments, updated on nutrition, hydration, and toileting, and detailed any booked investigations such as CT scans. I was able to ask clinically "stupid" questions. Staff were often willing to provide explanations for different routines, however, there were times where I wondered if my position as an 'outsider' researcher was a surprise to some staff. For example, when asking about the details of an intravenous medication to calm a patient, the member of staff was surprised at my lack of knowledge and my need to clarify the situation. At times such as these, I felt disadvantaged by not having a nursing background.

Practitioner researchers have discussed how decisions during the research process were driven by their experiences in practice (Proctor and Reed, 1995). Conversely, my decisions during the research

were driven by questions related to the theory. For example, I was interested in the influence of risk management on staff resource allocation and staff responses to patients expressing unmet needs. This influenced some choices for the location of observations and interview questions around how patients were identified for needing additional staff input. This may have been an advantage, as a practitioner researcher may not have questioned the allocation of staff to monitor patients at high risk of falls.

An advantage of being a naïve researcher without a professional background in healthcare was that it allowed me to observe situations, without conflicting concerns of my responsibilities for patient care (Allen, 2004). This did not alleviate feelings of discomfort at observing busy staff and patients with unmet needs, but it did allow me to record events knowing that I was not qualified to intervene in while maintaining a duty to report bad practice.

Not having a clinical background or familiarity with hospital settings meant I did not have a view of what good nursing care looked like or how this might differ from good dementia care. This may have meant I was less critical initially of what was being described as good practice than relying on evidence from the data and observed outcomes. As such, feedback and discussions on observation transcripts with my supervisors helped me to consider this. While some practices appeared to be person-centred, further analysis of the data suggested there were times when learnt techniques for interactions that were used across the patient population rather than adapting for each patient.

## Chapter five: Discussion

The aim of this study was to use a theory-driven realist approach to understand how dementia-friendly healthcare in general hospitals works, in what circumstances, and with what outcomes for patients with dementia and their carers. The study comprised of two phases which were guided by the Realist and Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) criteria for realist review (Wong et al., 2013) and realist evaluation (Wong et al., 2016). This chapter will discuss the thesis and its contribution to how dementia-friendly care in general hospitals can be supported by presenting: an overview of the findings from phase one and two; the contribution of the findings to current knowledge; the strengths and limitations of the study; and the implications for further practice and research.

### Overview of findings

This section draws together the findings from phase one and two in relation to the aims of the study, which were:

1. To understand how and why dementia-friendly interventions in hospital settings are thought to achieve the desired patient and carer outcomes
2. To understand how and why context influenced the creation of dementia-friendly healthcare environments
3. To develop evidence-based explanations to understand what it is about dementia-friendly interventions in general hospitals that works for people living with dementia and their carers, in what circumstances and why.

These aims were addressed through a realist review of the evidence (Handley et al., 2017, Appendix 2) (phase one) and a realist evaluation (phase two) that was designed to test the programme theory developed in the review.

In phase one, interviews with stakeholders and an initial scoping of the evidence identified the range of interventions and developed ideas for how dementia-friendly healthcare was conceptualised. From this work, three candidate theories were proposed that described the role of change agents and defined the focus of the review. A structured, iterative review process identified that the majority of evidence reported staff outcomes for interventions, with limited attention to patient and carer outcomes. Evidence from 28 papers contributed to the building of a programme theory,

comprising of six interrelated context-mechanism-outcome configurations (CMOCs). They set out the context-dependent nature of staff responses to resources from interventions which influenced staff and patient outcomes. While the English National Dementia Strategy (Department of Health, 2009) and Royal College of Nursing (Royal College of Nursing, 2013) assert the importance of a skilled workforce, the link between interventions that support this development and improvements to care provision were found to be complex. Single strategies, such as raising workforce awareness of dementia, on their own were limited. Additionally, contextual factors, such as how organisations and managers supported and legitimised practices for dementia care, impacted on how staff prioritised care and if dementia care work was valued. This influenced hospital staff's approach to care and patient outcomes.

This theory, and its component parts, were tested and refined by expanding and challenging the concepts during phase two at two case study sites. To maximise the opportunities for learning and theory development, two sites were selected for applying different approaches to their provision of support for patients with dementia. This study was able to identify common issues in two different cultures of dementia care around: how dementia care skills and dementia knowledge were perceived and understood as a core component of patient care; the resources staff drew on to inform care practices; and how the seniority of staff versus staff experience and interest in dementia care influenced practices and patient outcomes. The programme theory was further refined in light of data collected in phase two.

Evidence from phase two was used to test and refine the context-mechanism-outcome configurations which collectively make up the programme theory (Figure 17). The key features of the programme theory are now considered.

## Context

Understanding behaviours that challenge as communication of an unmet need was found to be a prerequisite context for how resources that support staff to identify and address patient needs were used. Additional contexts were identified that influenced how staff provided care to patients with dementia and the outcomes for patients.

- *Staff experience in relation to dementia care.* This was developed through continuing professional development opportunities, from personal experience in caring for a family member, or a combination of both. Experience gained outside the general hospital

provided staff with a wider understanding of patient needs and implications for dementia care.

- *Organisational endorsement.* Practices were supported by the organisation through staff role or policies which dictated how staff were allocated to patients and their priorities for patient care.
- *The social norms and expectations for patient care.* These were set by ward managers, managers of the 1:1 team, and informally sustained by staff within the ward teams.
- *Clarity in responsibilities for patient care.* Linked to accepted practices for patient care was recognition of who provided what aspects of care, for which patients.
- *Patient characteristics.* Patients' level of risk to themselves or others, their verbal communication abilities, and the onset of behaviours that challenge. These characteristics impacted on care provision and staffing resources, for example patients at risk to themselves or others received more time and attention from staff than those who were not. Similarly, how behaviours that challenge manifested influenced how staff recognised patient needs and prioritised them. For example, staff were more likely to address and record in care notes instances of physical agitation, such as pacing or hitting, than verbal expressions of agitation, such as calling out.

## Mechanisms

Pawson and Tilley (1997) posit that to understand why an intervention works, it is important to understand how mechanisms interact with context. Mechanisms are the resources inherent in interventions and the responses or reasoning of people using the interventions (Dalkin et al., 2015).

Key mechanisms thought to interact with the context and influence patient outcomes were:

- *Understanding dementia care as skilled work.* This was evident in individual staff, within staff groups, and at organisational levels, however often dementia care was not recognised as skilled work by staff themselves and by the wider organisation.
- *That staff consider they had the authority to resist other demands in the ward and to act on behalf of the patient.* This mechanism was linked to contexts of staff experience, organisational endorsement, and social norms.
- *That staff had allocated time to spend with patients.* This was found to be a resource that some organisational interventions around risk management and roles held by staff were able to use as opportunities to focus on the needs of patients with dementia. How staff engaged with this resource was linked to staff experience and knowledge of the patient.

- *Knowledge of the patient and dementia care.* An important mechanism that interacted with the mechanism of time and the context of organisational endorsement to influence how staff interacted with patients.
- *That staff believed they could make a difference to the patient's situation.* This influenced the way staff prioritised care and was linked to patient characteristics and social norms for care.

## Outcomes

Outcomes were identified as staff outcomes that had been influenced by the relationship of the contexts and mechanisms, and patient outcomes as a result of staff actions and outcomes. These are detailed below.

Staff outcomes:

- Whether staff took action to address patient needs using person-centred approaches (outcome) was influenced by their knowledge of dementia care and the patient (mechanism resource), the time they had available to spend with patients (mechanism resource), whether the approach and the importance of addressing the patient's needs was recognised by colleagues and the organisation (context), and whether staff considered they had the authority to address the issue (mechanism reasoning).
- Staff understand the priorities for patient care and are confident in balancing individual patient needs in relation to other patients and the ward routine (outcome). The value of dementia care (mechanism resource) and encouragement from senior ward staff (context) influenced whether staff recognised dementia care as an important part of their work (mechanism reasoning).
- Commitment to work in dementia care (outcome) was influenced by how dementia expertise was valued (mechanism resource), dementia care practices were legitimised by colleagues and the organisation (context), and whether staff recognise dementia care as skilled work (staff reasoning).

The actions of staff influenced patient and carer outcomes.

- Patients and carers considered they were listened to by staff when staff recognised the importance of changes to care plans, and approaches to care that promoted patient preferences. This was evident where patients were supported with essential care and mobility in ways that accounted for their choices and abilities, such as support to use the toilet rather than a commode or bedpan.

- Patient needs, such as pain, hunger, or feeling anxious at being in hospital, were recognised by staff and action was taken to address them.
- Reduced distress was demonstrated when staff were able to balance the competing demands in the ward and engage with patients in person-centred way.

## Implications of findings

This section considers the findings of this study in relation to other research and the contribution it adds to current knowledge. Some reference is made to evidence from care home studies where there is a potential for transferrable learning. However, it is important to recognise that residents in care homes tend to not be in acute crisis, and the focus is to support residents to live well. In contrast, care in general hospitals aims to treat an acute need and discharge patients when they are considered medically fit.

The study findings demonstrated the heterogeneity of people living with dementia admitted to hospital with different acute needs, and needs related to their dementia, corresponding with findings from other research (Glover et al., 2014; Sampson et al., 2009). Site 1 differentiated between patients with dementia who could be supported on the main wards and those who could not. While the admission process was opaque, patients on the ward were not in the acute phase of conditions such as myocardial infarction or stroke, and with the exception of one patient who was well known to the ward, were not surgical patients. It is possible that observations on other wards at site 1 would have been similar to those at site 2. Allocation of resources to support patients with dementia were determined by the concerns of the organisation rather than through a thorough assessment of the patient's needs. For those patients who were not at risk to themselves or others, and were not a physical disruption to the ward, their needs could be overlooked and their behaviour tolerated by staff. Goldberg et al. (2014) reported similar findings in particular circumstances. In situations where the patient's dementia related symptoms, for example repeatedly calling out, did not represent a risk to themselves or the other patients, they were ignored. Where staff were unable to identify the patient's need or reduce the expression of verbal agitation they would focus on other tasks. Evidence from my study suggests this was due to unsuccessful attempts to identify the need, a limited repertoire of responses to draw from, and ranking other needs, such as safety and essential care, as more important.

The review had identified a prerequisite for dementia-friendly healthcare was that staff understand behaviour as communication of unmet need. Behaviours that challenge have reportedly been

recorded in three-quarters of patients with dementia admitted to hospital, with aggression and activity disturbance found to be the most common (White et al., 2016). Assessments of behaviours can support identification of possible causes, promote effective strategies for management, and are recommended as part of national guidelines and best practice documents (Alzheimer's Society, 2011; NICE, 2006). In this study, evidence from observations and medical notes review found inconsistent recording of patient behaviours and few strategies to address them. This was influenced by staff understanding of how the information could be used to improve patient care, a limited range of strategies for reducing patient distress which relied on the individual actions of staff members, and that this information was not valued in the way recording aspects of physical care were. Studies have found limited evidence of systematic monitoring and management behaviours that challenge through non-pharmacological strategies, despite evidence of their use in practice (Inkley and Goldberg, 2016; White et al., 2016; Wilkes et al., 2010). This was influenced by the fact that the information was not used to inform, plan, or review care. Nor was this valued as core work in the same way that aspects of physical care were. Findings from this study suggest information was only recognised as important when related to service concerns such as incident reporting or resource allocation, for example ensuring care was only provided by female staff. However, when this information was recognised as important, changes to care plans were communicated within the team, both verbally and in written notes. This led staff to act on the information to provide care in ways that recognised patients' preferences, and thus reduced patient distress.

Literature pertaining to managing patients with dementia in general hospitals predominantly discusses risk management as a task that is incompatible with person-centred practices (Dewing, 2013; Moyle et al., 2008), by encouraging the prioritisation of physical rather than psychological wellbeing (Goldberg et al., 2014). The allocation of monitoring duties to junior staff who lack training in dementia care, and guidance for their role, contribute to negative patient experiences of these risk management strategies (Moyle et al., 2008). However, managing risk in all patients is an important element of patient care. In managing risk in the everyday lives of people living with dementia, Bailey et al. (2013) highlight how a practice narrative of vulnerability, protection, and concerns for the consequences of adverse events can lead to a strategy of avoidance. Clarke and Mantle (2016) suggest that by refocusing the vulnerability to situations, rather than locating it in the person, can provide a more supportive environment. In terms of applying this to ward settings this might include attending to clutter, and considering how the environment can be improved, for example through signage, to help patients with dementia make sense of their surroundings (Waller and Masterson, 2015). A recent study in Canada with patients with dementia explored their views

for improving ward environments (Hung et al., 2017). Important factors were environments that supported their independence, and that the environment created a sense of physical and psychological safety. Evidence from my study found where environmental adaptations were used to reduce risk, for example through the use of locked doors, this could make a difference to how staff supported patient independence. However, in ward situations where there was constrained space and staffing resources, this could overwhelm attempts to provide choice and movement.

Allocated time with patients was an important mechanism observed at both sites. This supported staff to resist other demands on the ward and engage with the patient, making risk management a positive experience. However, an overriding concern for contributing to work within the ward could impact on how staff interpreted and responded to maintaining patient safety. Staff confidence in applying positive risk strategies, such as encouraging mobility, were influenced by the level of involvement of experts in dementia care at ward level, and the priorities set by senior ward staff. Additionally, the value staff and their ward colleagues placed on providing psychosocial support to patients with dementia influenced how they interpreted their contribution; either as enhancing patient care or 'just sitting there'. The wider nursing literature outside of dementia care recognises that staff measure their contribution in terms of the tasks they complete (Bone, 2002). This has been attributed to the utilitarian nature of nursing in practice, which while staff report a desire to work holistically for the benefit of the patient, they also have to balance this with the reality of providing care that meets organisational concerns for getting the work done, costs, and meeting deadlines and targets (Bridges et al., 2013). This focus for care is not only encouraged by organisations, but also how staff become indoctrinated in to the accepted practices and values within the ward (Melia, 1987). In a study of healthcare assistants on wards caring for dementia patients, Schneider et al. (2010) found staff maintained their professional group identity by efficiently performing care tasks and behaving negatively towards colleagues considered not to be contributing. Such actions were observed during this study and has implications for how the culture of the ward and staff conceptualisations of their role impact on the development of positive dementia care environments.

Phases one and two identified the different elements that need to be in place to support a positive culture of dementia care. While resources were available for staff, how resources were used was influenced by contextual factors. Dewing and McCormack (2017) assert that interventions, such as the use of *This is me* booklets, are not enough for person-centred care to be valued or become the dominant model of care provision. They contend that a person-centred culture needs to be evident

throughout the processes of an organisation, extending beyond specific care activities to include valuing patients, carers, and staff (Brooker, 2007; Dewing and McCormack, 2017). McCormack et al. (2011) argue that the development of person-centred cultures in organisations needs a sustained commitment from experts and managers to facilitate change. Research suggests that person-centred approaches can be cost effective and have positive outcomes for both the patient and their carer (Milne et al., 2011). However, embedding person-centred care as a systemic approach to care requires commitment, understanding of dementia, and processes that recognise the expertise of the person living with dementia, and their carer, related to care needs. Findings from my study demonstrate a current reliance on individual staff who were motivated to work in person-centred ways, with limited acknowledgement of the effort involved. Incentives for staff to provide such care were limited to gaining personal satisfaction from the time spent working with patients and observing the positive effects of their work.

Evidence from this study suggests that staff are keen to develop skills that will support them to work well with patients with dementia, however these may not necessarily adhere strictly to person-centred approaches. Learnt skills for communication and consent for clinical observations and care activities were observed to be broadly applied. A similar finding was reported by O'Brien (2017), who developed an intervention aimed at reducing patient refusal of care by improving hospital staff's communication techniques. There was an observed difference between learning new skills in talking to and working with patients with dementia and adopting a person-centred philosophy. Experts in dementia care raised concerns that the approach may not encourage person-centred approaches to care, but instead provide staff with a way to address refusal that focuses on gaining patient compliance. This criticism can further complicate whether or not staff understand if they are providing care well. An action research study highlighted how staff wanted to know the approach they were using was the right thing to do, demonstrating the uncertainty of staff in working with patients with dementia (Harrison and Brandling, 2009). Training for staff which demonstrates how to work with patients in particular situations, while addressing staff uncertainty, may lead to the application of care practises that ignore the personhood of the patient and lead to situations where dementia care is considered as a series of tasks to complete.

Staff capacity to balance the needs of individual patients with those of other patients on the ward, together with ward routines, was influenced by organisational priorities, and the priorities for care set by senior ward staff. At times where there were conflicting needs, staff prioritised medical, physical and personal care needs. Studies of nurse time with patients has been found to be brief

and often interrupted (Bail and Grealish, 2016). As such, they identify that time-consuming, non-urgent (least life-threatening) care tasks are more likely to be a low priority and overlooked. For patients with dementia these care activities are not straightforward, but as this work may be considered of low importance, there is a risk that their needs will be disregarded and not met (Bail and Grealish, 2016). The literature recognises that patients with dementia often receive care from the least experienced, non-qualified staff (Scales et al., 2017; Schneider et al., 2010) and my study corroborated that. However, some healthcare assistants were observed to be more skilled in dementia care than others. While this expertise was recognised locally, it was not systematically used or developed. The findings suggest there is potential to develop further how non-qualified and qualified staff work and learn together, combining experiential and professional knowledge.

Developing staff's dementia care skills requires opportunities to attend training, have on-going staff development, and exposure to good examples of care practice. Informal opportunities for development were supported by ward environments that allowed for observation of colleagues' strategies for working with patients, and when there was regular guidance from experts in dementia care. At both sites, the implication was staff development was the responsibility of individual staff recognising the limits of their abilities and identifying and engaging with opportunities, rather than being led and encouraged by their managers. As a result, few staff reported exploring development opportunities that consisted of more than building experience on the job. Previous studies found that healthcare assistants were unable to access training to develop dementia care skills and so become reliant on their own experiences to manage patients. This could lead to practices that makes care inequitable, as staff focus on patients they find easier to manage and gain job satisfaction from (Maben et al., 2012; Schneider et al., 2010). Evidence from this study suggests limited development opportunities will lead to a broad application of a small range of techniques used indiscriminately with all patients. An assumption that staff will develop skills through exposure to particular patient characteristics and strategies to address their needs, and through unstructured peer-to-peer support may not build capacity in the dementia care workforce. Where the impetus for development is placed on non-qualified staff who consider they have limited influence in making changes to wider working practices (Schneider et al., 2010), there may be limited incentive to further knowledge.

That dementia care was not seen as important as clinical work had implications for what nurses valued and saw as complex. This impacted on their commitment to remain in dementia care and raises questions about how workforce capacity can be built. It may be that nurses working

predominantly in dementia care who have trained as adult nurses, rather than mental health nurses, find it difficult to define their expertise and technical competence in care when there are limited opportunities to differentiate their work from healthcare assistants. This was particular to site 1 where patients, in general, had less medically acute needs. In nursing literature, there are discussions of how the crossover of roles between nurses and healthcare assistants can cause nurses to feel their role in patient care is threatened (Daykin and Clarke, 2000; Workman, 1996). While some argue these tensions are exaggerated (Kessler et al., 2010) studies have found nurses and healthcare assistants define themselves as part of their professional group in opposition to each other (Kessler et al., 2010; Schneider et al., 2010). An appreciative inquiry study of end-of-life care in care homes found that developing a group identity between all professionals, through common goals in residents' care which recognised the expertise of each group, supported staff to value each professional groups' contribution to care (Amador et al., 2016). However understanding what motivates staff to commit to working in dementia care is complex and needs further research (Chenoweth et al., 2014). In order to build nursing capacity in dementia care, one factor to address will be to clearly define their role and expertise in dementia care.

It is recognised that there were notable gaps in the findings, for example what needs to be in place to involve family carers as partners in care. While family carers were observed with patients providing social interactions and supporting some activities during their visits, such as feeding, a partnership relationship with hospital staff was less clear. For example, biographical information was collected for some patients, however its use in care planning was inconsistent, and at times observed to be underutilised. Previous studies have reported carers frustration that their knowledge of patients is not recognised, listened to, or communicated within the team (Harrison and Brandling, 2009). Jurgens et al. (2012) consider that a recognition of carer needs during the stress of an admission, by providing information and providing opportunities for involvement in care in care activities, would improve carer satisfaction. Interventions such as John's Campaign (2015), the use of *This is me* booklets (Alzheimer's Society, 2013), and guidance from The Triangle of Care (Carers Trust, 2013) aim to improve carer involvement and inclusion during the patient's admission. However, there is a lack of empirical evidence to understand what partnership working in acute settings might look like. Data from this study suggests that while carer input is appreciated, their support is viewed as substituting the work of staff, rather than being understood as a collaborative undertaking. Comments from one of the Research Network Monitors suggested that there was an opportunity for more research with a focus on developing "a best practice for family (or spouse) involvement in patients with dementia, in a way that worked for the medical staff and which didn't

leave the family feeling isolated, uninformed and helpless.” (Research Network Monitor, email, 17<sup>th</sup> January 2017).

## Wider implications for dementia care in hospitals

This study identified how changes to practices to improve care for patients with dementia in hospitals was context-dependent, requiring organisational, ward, and individual staff support. Important mechanisms for change were; allocated time with patients, knowledge of the patient with dementia and dementia care, valuing dementia care as skilled work, and understanding how to balance other work demands. For example, where there was understanding that supporting an anxious patient was as important as other patient needs, such as providing essential care, staff did not express concern at spending time with patients and engaged with their emotional, psychological, and social needs. This was observed at site 1 where priorities for patient care had been defined by experts and embedded in practices as part of the development of the ward, and at site 2 with members of the 1:1 team prioritised the needs of the patients they were allocated to. This highlights the need to address how staff are supported to balance conflicting needs within the ward population, and communication of the priorities in patient care when contending with limited resources.

Contextual factors such as organisational priorities for patient care and staff to patient ratios influenced how staff recognised and prioritised patient needs. Identifying and addressing patient needs not related to medical, physical, or safety concerns were not undertaken in a systematic way. A clustered, randomised trial in care homes, which assessed the use of person-centred care approaches or Dementia Care Mapping (DCM) for improving care processes and influencing resident outcomes, suggested different mechanisms were triggered in staff to take action (Chenoweth et al., 2009). The use of DCM promoted feedback and suggestions for changes to care planning, while the use of person-centred care promoted the autonomy of staff to initiate action. While both approaches recorded reduced agitation in residents, they found the systematic approach of using DCM provided a more comprehensive assessment of resident needs, which were incorporated into care planning. However they recognise that the use of DCM is more expensive than training in person-centred care, which may limit its applicability for general hospital care.

This study has highlighted some of the difficulties in applying the principles of person-centred care when faced with the practical realities of working in general hospital environments. While valuing dementia care is recognised as an important context, it is often at odds with organisational concerns

for reducing costs and risk. However, there was some evidence from this study that it might be possible to align organisational concerns with good dementia care. Opportunities that arise from service directives to reduce patient risk could be utilised by staff to provide care that can address patients' emotional and social needs. To achieve this staff need to understand what good dementia care is and recognise that it is part of their role to provide it.

## Strengths and limitations

A strength of this study is that using a realist approach allowed me to develop and test a theory-driven account of why dementia-friendly healthcare interventions influence patient outcomes. Realist approaches go beyond identifying a list of enablers and barriers to demonstrate the relationship between contexts and mechanisms to describe what works, for whom, and in what circumstances. In this way, the research is able to identify factors that will be useful to address when interventions are designed and implemented into different settings. Interventions for supporting dementia-friendly healthcare are complex, context-dependent, and rely on how staff engage with the resources they provide. By developing the theory from the current evidence base and testing it in two distinct case study sites, the study was able to provide a nuanced account of how shared mechanisms were influenced in different settings and how these impacted on patient and carer outcomes.

This study aimed to identify how and why interventions with a common aim, i.e. improving dementia care in general hospitals, supported staff to provide care that met the needs of patients with dementia (or not). This is useful as interventions are rarely introduced into settings as standalone schemes. Theory was used to understand commonalities across diverse approaches and unpick the relationship between context and mechanism that influenced outcomes. By focusing on patient and carer outcomes, the realist review was able to move understanding beyond evidence that interventions could, for example increase staff confidence and knowledge of dementia and dementia care. Instead it explained how context influenced staff responses to resources from interventions, and how this affected outcomes for patients and carers.

While the realist review was originally designed to test as well as build the programme theory, the available evidence was mostly weak and the contribution of information to the component parts of the CMOCs constrained inferences that could reasonably be made. The decision to exclude papers not reporting patient outcomes might have limited evidence for context and mechanisms in the design and implementation of interventions. However, there has been a focus on staff outcomes for

interventions with limited understanding of how these translate at patient level. The review addressed this knowledge gap to explain how interventions and approaches to dementia-friendly healthcare influence patient outcomes and informed study design and analysis for phase two.

In phase 2, the use of observation allowed for a detailed account of patient experience and their interactions with staff, particularly for patients who were unable to participate in interviews. However, it is recognised that observation data is an interpretation of patient experience and may be limited in the extent to which it reflects patients' reality of their time in hospital. Collecting data at different time points throughout the day and in different ward settings offered a unique understanding of how demands on staff time and the ward routine could influence their interactions with patients and priorities for care to impact on patient outcomes. As data collection at site 1 was confined to one ward, this study was unable to determine how dementia care was applied in the wider general hospital or how focusing resources in one area influenced the support patients with dementia on other wards received.

Recruitment of patients for interview was low. Nineteen patients across the sites were considered to have capacity to consent, representing 28% of eligible patients. Only seven (37%) of these patients agreed to participate, three of whom were discharged before interviews could be completed. From the remaining patients who did not consent, reasons included: they did not consider the study relevant to them (they reported not having dementia despite confirmation of a diagnosis), that it was not something wanted to take part in, or that they did not feel their experience would contribute to the study. As with previous studies (Porock et al., 2015) the additional difficulties of an acute need impacted on patients' ability to participate in an interview; two of the interviews were stopped due to the burden the interview was causing and the effects of their acute illness.

Recruitment of carers was also problematic. Only two carers participated in interviews. Other studies of patients with dementia in general hospital have reported difficulty recruiting carers (Clissett et al., 2013; Closs et al., 2016). As recognised in these studies, competing demands for carers time, emotional distress, and changes to the patient's living circumstances meant that participating in the study, while they considered the study to be a valuable contribution, was not a priority for them. This highlights that when a relative or friend is admitted to hospital, it may be a particularly difficult time to engage carers because of other priorities. Additional insight about the experience of family carers was provided by members of the research network group.

The use of realist interview methods (Manzano, 2016) was challenging in that it asked staff to respond to propositions of how dementia-friendly interventions might work. However, some staff engaged well and contested the assumptions from the initial programme theory providing clear explanations and examples that could be used to test the theory. Other staff appeared acquiescent and may have lacked the confidence to disagree or debate with theories. This has been highlighted as an issue in other realist evaluations (Davey et al., 2014). Additionally, while there were some less positive comments identified in staff at site 1, it was difficult to engage staff who might have provided a different perspective of the negative instances of the way the site had applied dementia-friendly interventions.

The use of a two-phased approach including a realist review and realist evaluation enabled the development of a more robust programme theory. For example, evidence around valuing dementia care and recognising the complexity involved had not been developed as part of the initial programme theory. When this emerged during phase two of the study it was incorporated into the revised programme theory. While consecutive site recruitment was logistically beneficial and supported my gaining a familiarity of the sites, concurrent recruitment would have ensured emerging themes received equal consideration at both sites. However, in this study, early identification of the emerging theme ensured data were collected in both sites to allow for the incorporation of a new CMOC which further refined the programme theory.

## Implications for practice and research

Healthcare assistants' vast contribution to the care of patients with dementia needs to be acknowledged and valued. As the majority of essential care for the most complex and vulnerable patients is provided by this group, proper recognition of the skills required must be a priority. This staff group should have access to ongoing development in dementia care skills, such as communication skills and person-centred care, which is accredited and provides a clear career progression, along with opportunities to reflect with colleagues on what has worked well. There were examples at both sites that healthcare assistants' skills were valued by the healthcare team, although opportunities for discussion and reflection were not routinely scheduled. For example, at site 1 healthcare assistants had worked with allied healthcare professionals to develop a guide for working with patients with dementia who were expressing distress that was distributed across the hospital. This work supported the healthcare assistants to recognise their specific knowledge and skills in dementia care in comparison to other healthcare assistants in the general hospital.

Organisations or senior clinicians need to consider how resources are implemented and discussed with staff to promote their value in supporting good dementia care and to help staff to assimilate them into practice. Ward managers are an important resource for supporting changes to current practices, helping staff to understand the priorities for care, and how to address multiple competing needs in the patient population. Support for ward managers to develop their own understanding of good dementia care practices from dementia care experts is important for developing their knowledge, skills, and confidence in promoting practices with ward staff. Finding ways to encourage closer working of dementia care experts and ward managers will help dementia care become a fundamental consideration for care planning with patients with dementia.

For some time, risk aversion in dementia care has been viewed negatively. However, this study demonstrated that if staff recognise the opportunities to use risk management to engage with patients social and emotional needs, they can improve patient experience while addressing safety concerns. For example, when staff are allocated to monitor a patient they can use the opportunity to initiate conversations or activities of interest to the patient. For this to happen, staff need to understand all patient needs as equally important and be confident that their contribution to work on the ward is recognised. Again, reinforcement from line managers and opportunities to reflect on what has worked well could help staff to move to an improved understanding of this.

Understanding the complex needs of patients and how they might experience admission to hospital needs to be extended beyond focusing on risk and behaviours that challenge. Strategies that have been demonstrated to work in care homes should be tested and adapted to build an evidence base of transferrable strategies in hospitals.

### Recommendations for training and education

Several factors influenced whether or not staff drew on their knowledge of dementia care during interactions with patients, including: how they considered the priorities for patient care within their working environment; how they engaged with opportunities to spend time with patients; and whether staff valued dementia care as core to their role in patient care. As such, this study has concluded that interventions, such as training, will not on their own lead to change. However, training does contribute to improving staff capability and confidence for working with patients with dementia. Evidence from this study suggests that not all staff involved in the day-to-day care of

patients with dementia were confident in their abilities and required confirmation that they were addressing patient needs correctly. Training which addressed the specific difficulties staff encountered and gave them strategies that they could apply in their work was considered beneficial and reportedly used. As such, more targeted training, informed by co-production methods that involve staff, patients with dementia, and carers, will improve the relevance and value of dementia care training to staff. Training opportunities on the ward which are scenario-based and delivered by staff with expertise in dementia care are likely to be most helpful. In this way, experts can role model techniques for specific issues and demonstrate how those techniques can be personalised to meet the individual needs of each patient. This may also improve relationships between experts in dementia care and ward staff where there is limited contact, and increase the likelihood that advice is applied.

A realist review of workforce development strategies aimed at improving standards of care in support workers working with older people identified a number of mechanisms which would improve the outcomes of education and training (Rycroft-Malone et al., 2016). Similar to the findings of this study, they included: training which is relevant and has resonance to staff roles; and the alignment of best practice principles in dementia care with organisational goals and priorities. My study suggested that senior ward staff have a pivotal role in defining the priorities for patient care. Education and training with these staff could lead to a greater emphasis on addressing the psychosocial needs of patients with dementia, permitting staff to spend time with these patients. To support senior ward staff to recognise the value of dementia care as a core part of activities on the ward, they should be encouraged to undertake tier three dementia care skills training (Health Education England, 2015). Through attaining this level of knowledge in dementia and dementia care skills, senior ward staff might better understand the benefit of best practice for patients with dementia and transfer this knowledge to the staff they work with, promoting and reinforcing the importance of these skills.

### Recommendations for policy

This study demonstrated that good dementia care in general hospitals is possible but is often applied inconsistently and is driven by the actions of individual staff members. Regular support from experts in dementia care and a shared ethos which promoted patient choice and support for functional abilities was more likely to influence staff to prioritise dementia care. However, conflicting demands

and the focus on medical and physical needs could lead to preoccupations around losing clinical skills and how staff had personally contributed to the collective workload on the ward. This impacted on the quality of staff interactions with patients. Senior ward staff had a role in directing priorities for care, but additional work will be needed to address what staff define as important work. An alignment of the principles of best practice in dementia care with organisational priorities is one possible option for addressing this. Concerns around patient safety was observed to mobilise staffing resources, however these were not always utilised in ways that benefitted patients or considered their priorities for care. Organisational and service directives that require staff to closely monitor patients with dementia need to be properly supported by: 1) defining the expectations for this work beyond keeping the patient safe; and 2) providing access to development opportunities for staff tasked with this role who are not confident they have the necessary skills to enhance patient experience and wellbeing.

Evidence from care planning documents for patients with dementia suggested that while medical and physical needs are often recorded and may include written strategies for care, needs related to the person's dementia were not consistently documented. One way to address this may be to develop documents that allow for the recording of psychological, emotional, and social needs along with recording physical and medical needs. Collection and recording of this information should be informed by conversations with the patient, observations of their behaviour and mood during their admission, and from information gathered from people involved in the daily care of the person outside of hospital. Reference to this information could inform decisions for how to support and maintain functional abilities and provide care in ways that recognises the patient's preferences. This may help staff to identify strategies for working with patient who's needs can be overlooked, such as patients with verbal agitation. The information could also be used to build an evidence base for strategies linked to addressing patients' needs.

The retention of healthcare staff skilled in dementia care is a key concern, impacting on workforce capacity within general hospitals (Alzheimer's Society, 2018). This study identified whether or not staff recognised dementia care as skilled, valuable work influenced their commitment to stay in the specialism. Finding ways to promote dementia care as complex, rewarding work, and offering career development opportunities across grades and disciplines, could help reframe dementia care as skilled work when considered against other clinical specialities.

## Conclusion

This thesis has addressed an important issue of how general hospitals are using resources to improve care for patients with dementia. Numerous interventions have been implemented with limited empirical evidence of their effectiveness (Dewing and Dijk, 2014). By using theory to understand what works, for who, in what circumstances, this study has provided an account of how causal mechanisms influence staff and patient outcomes. In both study sites common factors impacted on whether patients with dementia were listened to, experienced reduced distress, and influenced how their needs were recognised and addressed. Allocated time with patients, and how staff engaged with this opportunity by drawing on their knowledge of the person and dementia, were important mechanisms that were influenced by organisational priorities and social norms for care. Support from ward managers and experts in dementia care was an important context for how risk management strategies were applied and how patient needs were prioritised. This supported staff to understand how to balance competing needs in the ward and gave them confidence that their work with patients with dementia which was not focused on essential care tasks, ward routine, or physical needs, was important.

Patients with dementia can have complex needs related to the difficulties they experience as a result of their dementia, such as reduced verbal communication abilities and their ability to cope with admission to general hospital. These are additional to the needs that patients without cognitive impairments experience and may require more resources, such as skilled staff with time to spend with patients, to adequately address them (Clissett et al., 2013). Healthcare assistants are a valuable contribution to the care of patients with dementia, but their skills and knowledge of individual patients needs to be recognised and valued, and their professional development supported. To further build capacity in the dementia care workforce, the role and expertise of nurses needs to be clearly defined.

This study has demonstrated that for interventions to have a positive influence on patient and carer outcomes, it is important for staff to be supported to understand the intervention's utility in their work. With guidance from senior ward staff who have themselves received adequate training and support in dementia care, it is possible that dementia care could be valued equal to that of clinical care. By recognising the complexity involved in the provision of good dementia care, allowing staff the time to work with patients with dementia, and asserting the importance of care that uses knowledge of the patient and dementia throughout a person's admission, staff may feel they are

able to make a difference. This can lead to staff to take the appropriate cause of action to address a patient's unmet needs, improving outcomes for patients with dementia and their carers.

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## Appendices

Appendix 1: Published protocol for realist review

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Systematic Reviews

PROTOCOL

Open Access



# Interventions that support the creation of dementia friendly environments in health care: protocol for a realist review

Melanie Handley<sup>1</sup>, Frances Bunn and Claire Goodman

## Abstract

**Background:** Improving health-care outcomes for people living with dementia when they are admitted to hospital is a policy priority. Dementia friendly interventions in health care promote inclusion of patients and carers in decision-making and adapt practices and environments to be appropriate to the needs of people with cognitive impairment. While there has been a wealth of activity, the number of studies evaluating interventions is limited, and the majority focuses on reporting staff and organisational outcomes. By focusing on patient and carer outcomes, this review will aim to develop an explanatory account of how and in what circumstances dementia friendly environments in health care work for people living with dementia and with what outcomes.

**Method/design:** Realist review is a theory-driven method which seeks to produce explanatory accounts of why interventions work and specifically, what combination of components are most effective in producing particular outcomes. Stakeholder interviews, a review of the literature, and an expert steering group workshop will be used to explore the assumptions behind interventions that are designed to enhance health care for people living with dementia to understand the underlying programme theories. The review will focus on studies that report patient and carer outcomes, including involvement in decision-making, length of stay and referral to long-term care, adverse incidents (e.g. patient distress, delirium falls, nutrition and hydration and infection), antipsychotic medication prescribing, evidence of patient-centred care and patient and carer satisfaction.

**Discussion:** The review will provide an explanatory model about how dementia friendly interventions in hospital settings improve outcomes for people living with dementia and their family carers and in what circumstances for future testing and evaluation of future dementia friendly initiatives.

**Systematic review registration:** PROSPERO CRD42015017562

**Keywords:** Dementia, Health care, Dementia friendly health care, Hospitals, Patient outcomes, Realist review

## Background

It is estimated that at any one time a quarter of acute hospital beds are occupied by people living with a dementia, although their reason for admission may not be related to their dementia [1]. Comorbidities for people living with dementia are common and require appropriate attention from a range of health-care services [2, 3]. Inequalities in health-care outcomes for people living with dementia, such as lower use of analgesic medication during hospital admissions and reduced functional ability after discharge,

have been widely reported, and it is acknowledged that these inequalities are detrimental to their health and quality of life [3–6]. A lack of leadership for dementia in secondary care [1], knowledge and training gaps for dementia in health-care staff [7, 8], the use of care practices which do not compensate for the effects of cognitive impairments [9], stigma and discrimination [10, 11] and environments which are disorientating [12] have all been identified as contributing to poorer health-care outcomes for people living with dementia. A number of initiatives have been developed and implemented in secondary health-care settings to address these areas with the aim of creating dementia-friendly health-care environments.

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**Dementia friendly**

The concept of 'dementia friendly' has been used to describe initiatives aimed at increasing the inclusion of people living with dementia in daily life and raising awareness of the issues they face among the wider population [13]. In its application to health-care settings, the concept of dementia friendly aims for the care and treatment of patients to be appropriate to their needs and of an equivalent standard expected by any patient [14]. Dementia friendly health care promotes inclusion of the person living with dementia and their carer in care and treatment discussions and decisions, with the aim of increasing positive outcomes for both [15]. In England, the Prime Minister's dementia challenge [16] identified a number of areas for improvement in health care for people living with dementia and their carers. This included diagnosis rates, access to care, treatment support and information, co-ordination of care, admission and readmission to hospital, admissions to care homes and post diagnosis support. Fundamental to addressing these challenges are multi-component interventions that educate staff in dementia awareness and care, improve health-care environments and increase access to relevant services ensuring people living with dementia and their carers are supported throughout the course of their condition (see Table 1).

**Evidence on problems experienced by people living with dementia and their carers and interventions**

People living with dementia on entering hospital are at greater risk of adverse events, such as falls, poor nutrition and hydration, infections and delirium. If these occur during a hospital admission, they are likely to impact on the length of stay and may result in reduced function for the person [17–19]. Studies indicate people living with dementia admitted to hospital will stay at least an additional 4 days when compared with patients admitted for similar reasons and with similar profiles who do not have dementia [4, 20, 21].

It is also acknowledged that people living with dementia experience exclusion from decisions about their care and treatment [22]. A dementia friendly health-care environment, ideally, promotes and supports decision-making by people living with dementia and, as part of that process, involves their carers [23, 24]. Strategies that address inclusion include communication skills training for staff, the use of tools which document the preferences of the patient with dementia and practices that encourage partnership working between health care professionals and family carers [25–27].

Few studies have evaluated interventions to improve health care for people living with dementia and their carers [28]. Evaluations have mostly focus on staff education, adaptations to models of service delivery and environmental

**Table 1** Dementia friendly health-care environments: anticipated outcomes and ways they might be achieved

Outcomes*	Achieved through
Skilled staff with time to care	<ul style="list-style-type: none"> <li>Staff training focused on dementia awareness</li> <li>Support and reinforcement of skills in dementia care from clinical dementia leads</li> <li>Identifying dementia champions as a resource for staff</li> <li>Attention to staffing levels and staff mix</li> </ul>
Partnership working with carers	<ul style="list-style-type: none"> <li>Awareness and communication tools that include carer knowledge and opinion</li> <li>Flexible visiting hours for carers</li> <li>Assessment of carers' needs</li> </ul>
Assessment and early identification	<ul style="list-style-type: none"> <li>Use of incentives for staff to complete training identify people in need of assessment</li> <li>Screening and assessment tools</li> <li>Protocols and pathways</li> <li>Clinical reviews of medication</li> </ul>
Individualised care (person-centred)	<ul style="list-style-type: none"> <li>Awareness and discussion that focuses on the person's biography, preferences and priorities and retained abilities</li> <li>Activities to support social engagement and inclusion in everyday activities</li> <li>Access to dementia and palliative care specialists who can guide staff in the provision of good quality care</li> </ul>
Environments that are dementia friendly	<ul style="list-style-type: none"> <li>Environments that promote independence by being safe to walk around and navigate</li> <li>Environments that are not confusing to a person living with dementia (e.g. shiny floors can be perceived as water, use of patterns and colour contrast)</li> <li>Having ward moves during admission to minimise distress</li> </ul>

\*Based on [12]

changes to acute settings [29–33]. Primarily, they have reported staff and organisational outcomes, such as improved staff confidence and knowledge of dementia, economic costs, length of admission, readmission rates and place of discharge, with patient and carer outcomes more rarely operationalised or reported.

Approaches or interventions that show promise but have not been empirically tested to assess impact on patient outcomes are those which aim to improve communication between clinical staff and the carer (such as Alzheimer's Society's *This is me* booklet), the introduction of activities coordinators on hospital in-patient wards, and the use of dementia champions as change agents [8, 34, 35]. These are rarely used in isolation and are often adapted to meet the needs of the local context, meaning interventions are multi-component and context sensitive. Understanding the components of interventions that support patient outcomes, such as reduced distress, increased recovery, participation in care and the promotion of independence, can help to develop an explanatory account of what works in what circumstances.

Realist approaches are theory-driven and recognise that interventions themselves are not the cause of change; it is the resources that the intervention provides and reaction to those resources by the people that use them that generates change [36]. The effectiveness of programmes to address the known problems of being a patient with dementia is recognised as contingent not only on specific training (for example) in being dementia aware but also on 'contextually situated decision making' [37].

#### Aims and objectives

The overall aim is to identify features or mechanisms of programmes and approaches that aim to make health-care delivery in secondary health-care settings more dementia friendly, provide a context-relevant understanding of the mechanisms by which interventions achieve different outcomes for people living with dementia and their family carers and make explicit the barriers and facilitators to implementation. Specifically, we will

1. Identify how dementia friendly interventions are thought to achieve the desired patient and carer outcomes
2. Identify the perceived enablers and inhibitors for the creation of dementia friendly health-care environments
3. Identify what is it about dementia friendly health-care interventions that works for people living with dementia and their carers, in what circumstances and why.

#### Methodological approach

This review draws on the assumptions of realist theory [38, 39] and linked ideas of critical realism [40]. Interventions implemented into health care rely on human agency to effect change. The realist approach suggests that the resources provided by the intervention and the context it is implemented have the ability to produce a limited number of potential responses to the intervention which will impact on the outcomes. A knowable, independent reality will constrain the way an individual reacts to an intervention, whether they are aware of these influences or not [41]. It is important to understand these phenomena when seeking to explain why an intervention has worked or not. Interventions in health care are invariably multi-component and complex in design allowing for a spectrum of outcomes to occur under different conditions, from successful to unsuccessful implementation. By focusing on the building, testing and refinement of theory, realist review approaches are able to incorporate the diversity of outcomes to provide an explanatory account of the key features which enable or inhibit the effectiveness of an intervention [36].

Realist review assumes evidence that is relevant and is available from diverse sources, offering a way of synthesising different literature including policy documents, organisational presentations, empirical evidence and editorials, and primary studies which utilise a variety of methods for evaluating complex social interventions [42–44]. It is an iterative process that builds and refines theory throughout the process. This review will follow RAMESES standards [39, 45].

#### Methods/design

Interviews with stakeholders, a review of the literature and an expert steering group workshop will be used to explore theoretical assumptions about why and how interventions that promote dementia friendly health-care work (or not) in secondary health-care settings, how they work with different populations and what are the significant mechanisms for change. There are a number of ways to conceptualise the development of dementia friendly environments in health care, and it is likely that the review will be informed by theoretical work on the following:

- Human rights and social model of disability framework [46–50] that are focused on the adoption of current models of care in order to promote inclusion and engagement
- Organisational theories of change perspectives [51, 52] that focus on the way that values and beliefs defined at a strategic level are embedded across the workforce in order to appropriately meet the needs of people living with dementia and improve the efficiency of services

- Perceptions of the roles clinicians, patients and carers hold [53] and approaches that contribute to breaking down boundaries and barriers to promote shared decision-making for the person living with dementia and their carer, where their insights of living with the condition are valued [54].
- Educational theories for change where increasing the awareness of dementia in the health-care workforce will lead to a critical consciousness that can be further harnessed to transform services [55, 56].

#### Stages of the realist review

There are three overlapping and iterative phases to this realist review (Table 2). These phases do not necessarily follow a linear format. Sources are identified and revisited, new evidence can be incorporated and inclusion criteria can be expanded to include transferable learning throughout the process in order to develop credible theories for how and why an intervention works.

#### Phase 1

##### *Defining the scope of the review: concept mining and theory development*

In phase 1, we will undertake a preliminary scoping of a selection of key literature (e.g. relevant descriptions and evaluations of dementia friendly initiatives in health-care settings). We will map the range of international health-care-based interventions, explore their underlying rationale,

**Table 2** Phases of realist review

<b>Phase 1</b>
<ul style="list-style-type: none"> <li>• Defining the scope of the review: concept mining and theory development               <ul style="list-style-type: none"> <li>interviews with stakeholders</li> <li>scoping the literature</li> <li>Mapping key programme theories</li> <li>Profiling key programme theories</li> </ul> </li> </ul>
<b>Phase 2</b>
<ul style="list-style-type: none"> <li>• Search for primary studies               <ul style="list-style-type: none"> <li>Defining search terms</li> <li>Search strategy</li> <li>study screening</li> </ul> </li> <li>• Selection and appraisal of documents               <ul style="list-style-type: none"> <li>inclusion and exclusion criteria</li> </ul> </li> <li>• Data extraction</li> </ul>
<b>Phase 3</b>
<ul style="list-style-type: none"> <li>• Analysis and synthesis</li> <li>• Dissemination               <ul style="list-style-type: none"> <li>expert meeting group</li> <li>Additional dissemination methods</li> </ul> </li> </ul>

detail the resources, such as training or communication tools the intervention provides and explore how the interventions are supposed to work. This will inform the identification of context-mechanism-outcome configurations that inform the articulation of prominent programme theories and help to refine the search strategy for the detailed review in phase 2.

Key word searches will be performed using PubMed and CINAHL to identify the broad spectrum of work. Google Scholar will be used to identify grey literature. As initiatives may predate recent policy documents (such as the National Dementia Strategy [57], the Prime Minister's dementia challenge [16] and the Alzheimer's Society's dementia friendly communities [13]), search terms will be chosen to reflect the variety of ways in which 'dementia friendly' initiatives might be interpreted or implemented. Potential terms include the following:

'dementia friendly'  
 'dementia friendly AND health care'  
 'dementia appropriate AND health care'  
 'dementia awareness AND health care'  
 'dementia person-centred care AND health care'  
 'dementia champions'  
 'dementia AND liaison'  
 'dementia AND ward'  
 'dementia education'  
 'dementia training'  
 'dementia nurse specialist'  
 'dementia lead'

Searches will be time limited to between 2000 and 2015 to reflect the impact of the work of Kitwood [58] in person centred care. This has become the accepted best practice model of care for people living with dementia and has influenced dementia practice; moving away from a purely biomedical view to one that incorporates the effect of social factors. Searches will be restricted to English language. No other restrictions will apply.

In addition, in order to understand the underlying assumptions or theories that inform dementia friendly initiatives in health care and how effectiveness is defined, we will undertake semi-structured telephone or face-to-face interviews with up to 15 purposively sampled stakeholders. These will include commissioners, clinicians, academics with expertise in dementia care research and people living with dementia and their family carers. Stakeholder interviews will be conducted with a topic guide and, with permission, digitally recorded. Interviews will be analysed with framework analysis using the five steps identified by Ritchie and Spencer [59]: familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation.

Evidence from the literature will be coded and organised into if-then statements to develop a conceptual framework [60]. Data from the interviews and literature

will be used to identify context-mechanism-outcome configurations which can be used to develop possible programme theories for testing in phase 2.

## Phase 2

### Retrieval and review

The inclusion criteria will be refined in light of the emerging data and the theoretical development in phase 1 but are likely to include evidence sources that cover the following:

- People with mild, moderate or advanced dementia of any type, e.g. Alzheimer's disease, vascular dementia, Lewy body dementia, Parkinson's disease dementia, fronto-temporal dementia and alcohol-related dementia
- Studies of any intervention or initiative designed to make secondary health-care settings more 'dementia friendly'. This might include those which promote the inclusion and engagement of people living with dementia and their family carers, which adapt care practices and/or the environment to reduce adverse incidents and promote independence, or which establish roles with the specific remit of improving outcomes for people living with dementia
- Studies that provide evidence on barriers and facilitators to the implementation and uptake of interventions designed to make healthcare environments in secondary care more dementia friendly
- Studies that offer opportunities for transferable learning. For example, studies in hospitals that aim to reduce health-care inequalities in other vulnerable groups, such as people with learning disabilities or mental health issues, or those outside of health care (e.g. Healthy Cities) if they have included older people living with dementia and are drawing on similar principles of engagement and delivery to achieve equivalent outcomes (e.g. inclusion and access).

**Outcomes** The primary aim of dementia friendly health care is to improve the health and wellbeing of people living with dementia and their family carers and to ensure equity of access and treatment [14, 61]. This review, therefore, will only include studies that report patient and carer outcomes. These outcomes will be established by the project team as an iterative process but are likely to include the following: (1) patient and carer involvement in decision making, (2) length of hospital stay, (3) occurrence of adverse incidents (e.g. falls, nutrition and hydration, infection and delirium), (4) use of antipsychotic medication, (5) needs assessment (for patient and carer), (6) patient and carer satisfaction and (7) access to care.

These outcomes are not only important for maintaining health and function for people living with dementia but also for ensuring their choices and rights are respected and supported in an appropriate way.

**Searching for relevant studies** Search terms from phase 1 will be extended to reflect the theories that emerge from the initial scoping of the literature and to ensure we capture the range of potential interventions and theories. If necessary, search terms will be broadened to include groups of patients other than people living with dementia. This would enable us to capture insights from literature pertaining to elements of the programme theory and to build a more refined understanding of the interacting features. While studies will not be limited to the UK, as the international literature will provide important evidence for theoretical understanding, they will be limited to those available in English language and which are likely to be relevant to UK systems of health care.

**Search strategy** An example of the search terms for PubMed is given in Table 3. Search terms will be entered into the following electronic databases: Cochrane Library (including CENTRAL, CDSR, DARE, HTA), CINAHL, PubMed, NHS Evidence and Scopus.

Additionally, databases from disciplines outside health care will be searched to reflect the dominant fields of the theory. For example, if the theory has a focus on organisational change, databases with a focus on education (e.g. Education Research Complete, ERIC) and human resources (e.g. XpertHR) will be searched.

The following extensive lateral search techniques will be used:

- Interrogating reference lists of relevant reviews and primary studies
- Snowballing (forward and backward citation tracking) [62]
- Key word searches in Google Scholar
- Searching of grey literature
- Searching the websites of charities, user groups and patient and carer associations, such as Alzheimer's

**Table 3** Search terms for phase 2

Following the scoping in phase 1, phase 2 search terms will be refined to reflect the theory under investigation. For example, an emerging theory about organisational processes in change management would generate search terms of:

'change agent' OR 'change management' OR 'knowledge translation' OR 'opinion leader' OR 'knowledge transfer'

In PubMed, these would be operationalised using Boolean terms:

hospital AND (change agent OR change management OR knowledge translation OR opinion leader OR knowledge transfer)

Society, Dementia Action Alliance, Age UK and Carers UK.

Searches will continue throughout the synthesis as realist review is an iterative process. Additional studies will be used to refine theory development until theoretical saturation has been achieved [63, 64].

**Study screening and data extraction** Search results will be downloaded into bibliographic software and, where possible, duplicates deleted. Studies will initially be screened by title and abstract for relevance to the research questions by one reviewer (MH). Full texts of potentially relevant manuscripts will be screened for inclusion based on whether they demonstrate both relevance (whether the study has contributed to specific propositions relevant to the programme theory building and testing) and rigour (that the evidence used is of sufficient quality to help clarify the particular proposition it is being used to address) [36, 39]. These decisions will continue throughout the synthesis as their relative contribution to the programme theory is assessed throughout the refinement process. A random subset of papers will be screened by the second reviewers (CG and FB) to ensure that data identified within the documents are relevant, contributing to the appraisal and development of the programme theory. Where there is disagreement about inclusion, decisions will be made through ongoing discussion with debates, and resolutions being recorded and reported.

For studies that meet the test of relevance, data will be extracted by one reviewer (MH) onto a specially designed data extraction form which will enable us to organise the theories of initiatives and patterns that emerge from different context, mechanisms, and outcome configurations. Strengths and weaknesses of the study will be highlighted, which will help inform tests of rigour. Study characteristics such as design, setting, participants and sample size will be included [39].

### Phase 3

#### Analysis and synthesis

After initial characteristics have been extracted, relevant text from the literature will be entered into NVivo and coded by theme by one reviewer (MJ) to assist the refinement of the programme theories [65, 66]. Initial themes and codes will be shared with the team (MJ, FB, CG) to reflect upon the emerging ideas and discuss the resonance of these. Data will be used to corroborate or contradict different parts of the theories, testing the ideas from the earlier stages of the review to build an evidence-based explanation of the relationships between context, mechanism and outcome. Triangulation will be used to adjudicate between and across the findings from studies, highlighting

positive and negative instances. Programme theories will be discussed with the team (MH, FB, CG) and revised to reflect the emerging evidence. Justification for the amendments will be documented. The synthesis will result in a theoretical explanation of what it is about (specific) interventions designed to support the creation of dementia friendly environments in health care that works to improve patient outcomes, in what circumstance, how and why.

#### Dissemination

**Expert steering group workshop** Findings from the full review will be discussed with an expert steering group in a day's workshop. The objectives of the workshop are to check that the findings and recommendations from the review have relevance and resonance with the stakeholders and to highlight any possible alternative interpretations.

**Participants** Stakeholders will be invited using the recruitment strategy employed for the interviews (i.e. identifying a purposive sample from discussions with colleagues, Internet searches and snowballing from other participants) with an emphasis of inviting people living with dementia and practitioners. The workshop will involve up to 20 stakeholders who represent a balanced mix of interests.

**Consent** All stakeholders will be asked to provide written consent or, where this is not possible, witnessed verbal consent will be provided. All discussions will remain confidential to the group. Stakeholders will be asked to respect the views of other members and talk one at a time.

**Data collection** Stakeholders will be asked to participate in activities during the workshop. These will focus on the findings of the review and whether these findings are recognised by the group. Points arising from these small group activities will be written up on flipchart paper by one member of the group or the facilitator and reported back to the whole group. The flipchart paper will be collected by the researcher at the end of the workshop to assist with further analysis. Additionally, the workshop will be recorded to assist with further analysis of the review. This recording will be transcribed, anonymised and entered into NVivo for analysis by one reviewer (MH).

#### Ethics

For phase one interviews, ethical approval was secured from the University of Hertfordshire (HSK/PG/UH/00339). The study will not require NHS ethics approval. The review has been registered with PROSPERO (CRD42015017562).

## Discussion

People living with dementia admitted to hospital need health care services that consider the impact of the patient's cognitive impairment and adapt practices appropriately to provide a standard of care that is equitable to the expectations of other patients. From a range of published and other sources, the review will use a theory-driven evidence synthesis to provide testable causal inferences about what influences effective dementia-friendly interventions in hospital settings, including what enables or inhibits this process. This explanatory account of what it is that supports positive outcomes for people living with dementia and their carers during an admission to hospital will be the basis for future testing in different settings with the ultimate purpose of developing a framework that be used to develop and evaluate dementia-friendly initiatives.

## Abbreviations

CNHL: Consultative Notes to Nursing and Allied Health Literature  
EMBASE: Embase and Medline Evidence for Health

## Competing interests

The authors declare that they have no competing interests.

## Authors' contributions

AW led the design and prepared the protocol as part of her PhD at University of Liverpool, Liverpool, UK. CG and TB wrote the original funding application, supervised the protocol development, critically reviewed drafts and provided substantive topic specific and methodological input. They informed the analysis and interpretation of the review protocol. AW and TB conceived and designed the search strategy. All authors read and approved the final manuscript.

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# BMJ Open Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review

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## ABSTRACT

**Objectives** To identify features of programmes and approaches to make healthcare delivery in secondary healthcare settings more dementia-friendly, providing a context-relevant understanding of how interventions achieve outcomes for people living with dementia.

**Design** A realist review conducted in three phases: (1) stakeholder interviews and scoping of the literature to develop an initial programme theory for providing effective dementia care; (2) structured retrieval and extraction of evidence; and (3) analysis and synthesis to build and refine the programme theory.

**Data sources** PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, NHS Evidence, Scopus and grey literature.

**Eligibility criteria** Studies reporting interventions and approaches to make hospital environments more dementia-friendly. Studies not reporting patient outcomes or contributing to the programme theory were excluded.

**Results** Phase 1 combined findings from 15 stakeholder interviews and 22 publications to develop candidate programme theories. Phases 2 and 3 identified and synthesised evidence from 28 publications. Prominent context-mechanism-outcome configurations were identified to explain what supported dementia-friendly healthcare in acute settings. Staff capacity to understand the behaviours of people living with dementia as communication of an unmet need, combined with a recognition and valuing of their role in their care, prompted changes to care practices. Endorsement from senior management gave staff confidence and permission to adapt working practices to provide good dementia care. Key contextual factors were the availability of staff and an alignment of ward priorities to value person-centred care approaches. A preoccupation with risk generated responses that were likely to restrict patient choice and increase their distress.

**Conclusions** This review suggests that strategies such as dementia awareness training alone will not improve dementia care or outcomes for patients with dementia. Instead, how staff are supported to implement learning and resources by senior team members with dementia expertise is a key component for improving care practices and patient outcomes.

**Trial registration number** CRD42015017562.

## Strengths and limitations of this study

- Applying realist methods enabled a theory-driven explanation of how dementia-friendly healthcare can be supported in hospital settings.
- The process of the review facilitated the development of a new programme theory, which can be used to inform future initiatives that support people living with dementia in hospital environments.
- The involvement of stakeholders from the outset ensured the plausibility and relevance of the findings for hospital environments.
- The extent of evidence to support some elements of the programme theory was limited, especially where interventions lacked specificity about process and patient outcomes.

## INTRODUCTION

There is increasing recognition that hospital staff and services need to understand the complexity of caring for and treating people living with dementia.<sup>1</sup> At any one time, 25% of hospital beds are used by people living with dementia, rising to a higher proportion on some wards.<sup>2</sup> Comorbidities are common and many people are admitted to hospital for reasons not directly related to their dementia.<sup>3-5</sup> Healthcare outcomes for people living with dementia are variable across the country and are inequitable when compared with outcomes for people without cognitive impairments.<sup>5</sup> Adverse incidents occurring during admissions, such as falls, poor nutrition and hydration, infections, and the onset of delirium, contribute to longer stays and reduced functional abilities, which may result in admission to a care home.<sup>6-8</sup>

A number of factors may impact on the disparity of health outcomes for people living with dementia, including a lack of focus and leadership for dementia in hospitals<sup>9</sup>; healthcare staff who have inadequate knowledge and training in dementia and



dementia care<sup>9 10</sup>; difficulties faced by healthcare professionals when assessing the risk and benefits of treatment options<sup>11</sup>; widespread use of care practices that are detrimental to people living with dementia, such as the use of antipsychotics for behavioural management<sup>12</sup>; stigma and discrimination towards people living with dementia<sup>13 14</sup>; and confusing, unsafe environments.<sup>15</sup> The National Dementia Strategy<sup>16</sup> aimed to improve the quality of care for people living with dementia in general hospitals through leadership that addresses quality improvements in dementia care, defined care pathways and the use of liaison mental health teams. It also highlighted the importance of education and training to break down the stigma associated with dementia and to develop dementia awareness within the healthcare workforce. To address these ambitions, interventions have been designed and implemented with the aim of creating dementia-friendly healthcare in hospitals.<sup>17 18</sup>

### Dementia-friendly

The concept of dementia-friendly developed from initiatives to promote age-friendly communities.<sup>19</sup> It was first used to describe physical and social environments that promoted inclusion, acceptance and accessibility for people living with dementia,<sup>20 21</sup> and includes initiatives supporting the independence and safety of people living with dementia.<sup>22</sup> In the UK, this includes the Dementia Friends initiative<sup>23</sup> and the Dementia Engagement and Empowerment Project.<sup>24</sup>

At the patient level, dementia-friendly healthcare is the practice and organisation of care that is aware of the impact dementia has on a person's ability to engage with services and manage their health. It promotes the inclusion of people living with dementia and their carer in treatments, care decisions and discussions, with the aim of improving outcomes for the patient and carer.<sup>16 17 25–27</sup>

Interventions to promote dementia-friendly healthcare environments have been diverse in terms of their design and application in practice.<sup>27–29</sup> This review of the evidence acknowledges that the effectiveness of programmes to address the known problems of being a patient with dementia is contingent on multiple factors, such as staff knowledge and skills in dementia care, the care environment, and the competing demands on staff time and attention. The review objectives were the following:

1. to identify how dementia-friendly interventions in hospital settings are thought to achieve the desired patient and carer outcomes
2. to develop evidence-based explanations to understand what it is about dementia-friendly interventions in hospitals that works for people living with dementia and their carers, in what circumstances and why.

### Realist methodology

Realist review is a theory-led method that applies the principles of realism to evidence review.<sup>30 31</sup> In realism, change is not directly achieved by an intervention, rather change

### Box 1 Glossary of realist terms

**Context:** refers to factors, including but not limited to, personal, social, organisational or policy aspects that influence the way resources are engaged with to generate outcomes. For example, staff's professional focus may influence how they use information about a person's social, rather than medical, history, or an organisation's expectations for dementia care may affect how staff prioritise their work with patients with dementia.

**Mechanism:** includes the resource the intervention provides (such as training, assessments of pain or access to biographical information about the patient) and the reasoning of the subjects, in this case the reasoning of staff (such as recognising the benefit of working differently).<sup>32</sup>

**Demi-regularity:** a semipredictable pattern of outcomes. For example, the provision of meaningful activities for patients with dementia will reduce their boredom and distress in hospital, leading to a reduction in the onset of behaviours that are challenging for staff.

**Outcome:** the intended (or unintended) result. Patient outcomes of interest included patient well-being, medication use (specifically analgesic and antipsychotic), access to assessments, evidence of inclusion in care decisions, reduced distress, adverse incidents (such as falls or hospital-acquired infection), length of stay, reduction in the onset of behaviours that challenge, and maintenance of functions (such as activities of daily living).

**Context-mechanism-outcome configuration:** specifies the relationship between the features (context, mechanism and outcome). It is the unit of analysis that supports synthesis across studies to build and refine the programme theory.

is generated through the influence of intervention resources and contextual factors on human reasoning. A realist approach seeks to explain how the relationship between these elements (context and mechanism) leads to particular outcomes (box 1).<sup>30</sup>

Realist review was appropriate for this study as the evidence base for dementia-friendly interventions is in its early stages. As such, theory building derives from a variety of sources and study types. Complexity is inherent in both design and implementation of the interventions: they are multicomponent and rely on human agency that is influenced by individual, service and organisational pressures. Realist enquiry acknowledges these features and incorporates them to develop an explanatory account of how different aspects influence reasoning and outcomes.<sup>33</sup>

### METHODS

Realist review methods were used to develop a theoretical understanding of what supports effective dementia care in hospital settings. There were three overlapping, iterative phases: (1) defining the scope of the review informed from key literature and stakeholder interviews; (2) structured searches, screening and data extraction; and (3) analysis and synthesis leading to refinement of the programme theory. A fuller account of the review protocol is available in Handley *et al.*<sup>34</sup>

The phases did not follow a linear format, but informed and refined understanding throughout the review,



leading to new interpretations and building of evidence. Sources were identified and revisited, new evidence was incorporated, and inclusion criteria were reconsidered as new theoretical understanding developed. The RAMESES (Realist and Meta-narrative Evidence Syntheses: Evolving standards) publication standards informed the preparation of this report and has been vetted against RAMESES criteria (see online supplementary files 1 and 2).

#### Changes to the review process

One change was made to the review process subsequent to the published review protocol.<sup>34</sup> The expert steering group workshop was not held. However, emerging findings and the refined programme theory were shared with the with Alzheimer's Society research network monitors (RP, JW, PM) who were volunteer representatives with experience of caring for family members living with dementia. They commented on the resonance and relevance of the inferences that contributed to the developing theory throughout the review process. Review findings were presented and discussed at a seminar on dementia-friendly healthcare with 75 participants, 19 of whom worked in hospitals. The findings are being taken forward for testing in a realist evaluation.

#### Phases of the realist review

##### Phase 1: defining the scope of the review — concept mining and theory development

Evidence from interviews with stakeholders and a scoping of the literature were used to (1) identify the range of dementia-friendly interventions in healthcare settings both in the UK and internationally, (2) determine possible theoretical assumptions about how and why interventions were thought to work (or not), and (3) clarify what were understood to be the significant mechanisms for change. Stakeholders, defined as people with experience in designing, implementing and using dementia-friendly interventions, were identified from knowledge within the team, internet searches and dementia-specific conference abstracts. They were purposively sampled from a range of settings (academia, healthcare, commissioning, social work, the community) and backgrounds (nursing, education, physiotherapy, research, person living with dementia).<sup>34</sup> Stakeholders were not further involved in the development of the emerging context–mechanism–outcome configurations (CMOCs) or building the programme theory. Ethical approval for the interviews was secured from the University of Hertfordshire Ethics Committee (HSK/PG/UH/00339).

Data from interviews and the literature were coded using framework analysis,<sup>35</sup> with emerging themes and competing accounts discussed and debated among the authors (MH, FB, CG) and with the Alzheimer's Society research network monitors (RP, JW, PM). Mapping this evidence demonstrated limited understanding at the point of staff interaction with patients and how this influenced patient outcomes. A decision was made to focus the review on how interventions led to patient outcomes.

Data from the interviews and literature were scrutinised for demi-regularities (see box 1, glossary of realist terms) and informed hypotheses set out in the form of 'If... then statements'. These statements were used to define the conditions thought to be necessary to achieve (1) staff outcomes, such as taking action to investigate the cause of patient behaviours and applying best practice with people living with dementia; and (2) patient outcomes, such as reduced distress, reduction in adverse incidents and improved well-being. Discussions among the authors based on these statements led to the development of a conceptual framework.<sup>30</sup> Three overlapping theoretical propositions were generated to explain what supports the implementation and uptake of interventions that promote dementia-friendly healthcare within a ward based environment.

#### Phase 2: retrieval and review

##### Searching for relevant studies

Informed by the theoretical propositions derived from the work in phase 1, search terms were revised. The inclusion/exclusion criteria were refined to focus on studies that reported patient outcomes and provided information about the characteristics and role of change agents (staff who supported the implementation and uptake of interventions).

Searches were limited to 2000–2016 to reflect the impact of the work of Kitwood and Bredin<sup>36</sup> on dementia care practices that recognise the importance of person-centred care and the promotion of personhood. In addition to the electronic database searches (box 2), we undertook extensive lateral searching, including forward and backward citations, and contact with experts. Additional searches were performed as emerging themes around the management of pain and behaviours that challenge became apparent. These were purposive searches that applied the same inclusion criteria. Theory development continued until theoretical saturation was achieved<sup>37 38</sup> (box 2).

##### Study screening and data extraction

Search results were downloaded into EndNote bibliographical software and duplicates were deleted. One author (MH) screened the titles and abstracts identified by the electronic search and applied the selection criteria to potentially relevant papers. Full texts of potentially relevant manuscripts were screened for relevance (whether the study has contributed to specific propositions relevant to the theory building) and rigour (whether they were of sufficient quality to provide credible evidence to help refine specific components of the proposition).<sup>30 31</sup> Appraisal of the contributions and reliability of evidence from papers continued throughout the synthesis through discussion with the other authors.

Data were extracted by one author (MH) using a bespoke data extraction form organised to establish contributions and challenges to the theories, and strengths and weaknesses of the studies. Study

**Box 2 Phase 2 search terms and search strategy**

Searches initially run September 2015, search alerts scanned to February 2016, language restricted to English, date restricted 2000–2016

**Search terms:**

(dementia AND (friendly OR appropriate OR awareness OR champion OR liaison OR ward OR environment OR education OR training OR nurse specialist OR lead\* OR person centred care) AND (hospital OR acute care OR secondary care))

**Additional search terms developed from work in phase 1:**

dementia AND (change agent OR champion OR knowledge transfer OR knowledge translation OR opinion leader)

**Additional search terms reflecting emerging themes in phase 2:**

Searches ran January 2016, search alerts scanned to February 2016 (dementia AND (pain) AND (hospital OR acute care OR secondary care)) (dementia AND (behaviour\* OR BPSD) AND (hospital OR acute care OR secondary care))

**Databases:**

Cochrane Library (including CENTRAL, CDSR, DARE, HTA) (244), CINAHL (610), PubMed (4253), NHS Evidence (819) and Scopus (410)

characteristics such as design, setting, participants and sample size were also recorded.<sup>31</sup> The data extraction form was piloted by MH and shared with the team for comment (see online supplementary file 3). To reduce the potential for bias during data extraction, a sample of the papers and their completed data extraction forms (6/28) were shared with FB and CG to appraise the extraction process and identified data. Information about the role and work of the change agent, the resources provided by the interventions, the contextual features of the settings (eg, workforce, knowledge of dementia), explicit and implicit theories for how interventions were anticipated to work, and patient and carer outcomes were extracted. Coded data from all the papers and their contribution to theory development were shared with FB and CG. Challenges to interpretations were discussed to test credibility. Evidence from the studies was first mapped to capture the complete range of possibilities of how different approaches and resources triggered different responses from patients, family and staff. After discussion among the authors, data were organised into tables to reflect the theoretical propositions they addressed (see online supplementary file 4) and to assist comparison of data across studies.

**Phase 3: analysis and synthesis**

Data synthesis was led by MH and emerging findings were discussed with the team (CG and FB) and the research network monitors (RP, JW, PM). Deliberations assisted the refinement of propositions, ensuring that emerging theories were plausible and clear. Discussions of papers included the key characteristics of members of staff who support the implementation and uptake of

interventions, resources, and new ways of working with people living with dementia (change agents); resources from interventions and how they were thought to influence staff reasoning; the impact of context; and possible undesired outcomes (such as stigmatising practices and broad application of strategies at the expense of individual needs). The focus was on understanding how patient outcomes were achieved through the actions of staff and what had supported the staff to behave in particular ways. Recurring patterns in context and outcome (demi-regularities) detectable across studies were explained by explicit or implicit mechanisms. This led to the development of CMOCs designed to explain what it is about an intervention that works, for whom and in what circumstances. The configurations were used to refine components of the initial theoretical propositions against the evidence.

**FINDINGS****Phase 1**

Evidence from 15 stakeholders was combined with literature on interventions aimed at improving healthcare for people living with dementia (22 papers) to generate three initial propositions for developing dementia-friendly hospital environments. Interventions described in the literature can be seen in table 1.

A key contextual factor to emerge from phase 1 related to the role of change agents, although there were competing accounts of how a change agent might work and the responses they might trigger in staff. There appeared to be three distinct roles for change agents' activities that could lead to improved outcomes, and these were the following:

- ▶ to support staff awareness and learning
- ▶ to possess the authority to institute and sustain changes
- ▶ to be a resource for staff as a clinical expert.

Change agent characteristics (eg, supportive peer facilitator, organisational authority, clinical expertise) were considered to differently influence how staff engaged with interventions, and this in turn would impact on patient outcomes (table 2).

**Phase 2**

Evidence from 28 papers, 12 of which were identified and included in phase 1 of the review (see online supplementary file 5), led to the development of six CMOCs that explored the components of the three theoretical propositions developed in phase 1 (an overview of the selection process can be seen in figure 1). These configurations are interconnected, representing key elements from the theories and how they relate to other factors (table 3). The CMOCs and supporting evidence are discussed below. Illustrative examples of evidence from the literature that guided CMOC development are supplied in online supplementary file 6.



Table 1 Papers included in phase 1

Intervention	Papers
Schemes to identify people living with dementia admitted to the ward: for example, a butterfly symbol above the patient's bed to help identify people who have dementia, linked to a training programme and the collection of biographical history from the family carer	51
Dementia champion: healthcare staff (mainly nursing staff) are trained to champion dementia care issues, providing support to peers	27 39 40 70–72
Dementia nurse specialist: senior nurse working across the hospital as an expert in dementia to advise staff on treatment, care practices and liaise with community services	59 73
Staff training and education: training in dementia awareness and dementia care	9 10 28
Liaison psychiatry/mental health teams: specialist teams working across the hospital to assess mental health of patients and advise staff on treatment and care	74 62
Environmental adaptations: changes to clinical areas, including signage, new furniture and improved flooring and lighting	15 75
Specialist units for people living with dementia: include physical adaptations and specialist staff to treat the medical and psychological needs of people living with dementia	41 45 52 55 58
Use of person-centred care: model of care that prioritises the needs of the person	46

**CMOC 1: understanding behaviour as communication to improve staff's ability to respond**

Studies frequently reported that where staff understood behaviour that challenged as communication of an unmet need, they were more likely to investigate the underlying cause rather than attempting to control and restrict the behaviour.<sup>15 39–44</sup> By addressing the unmet need, staff reduced patient distress<sup>44–50</sup> and maintained independence, for example by supporting mobility and toileting needs.<sup>51–54</sup> Inappropriate and negative staff responses arose from lack of understanding and misinterpretation of behaviours that challenge, for example, interpreting the patient as being deliberately difficult.<sup>55 56</sup>

Strategies employed to reframe staff understanding of behaviours included training in dementia<sup>10 15 46–48</sup>; the use of biographical tools, completed in partnership with informal carers<sup>30 41 44 51 57</sup>; assessments of cognition, pain and psychological needs<sup>42 45 52 58</sup>; and access to experts in dementia care.<sup>39 40 44 45 52 59</sup> Common to these interventions was that they supported staff to consider potential causes of behaviours and provided strategies to address the unmet need, such as the development of individualised care plans<sup>37 59</sup> and personalised strategies for reducing distress.<sup>44 51</sup> Training to recognise behaviours as the expression of an unmet need<sup>47 60</sup> and knowledge of a patient gained through continuity in their care<sup>46 48 60</sup> helped staff become aware that particular care practices were unsuitable and to adapt their work in a way that benefited the individual. However, personalisation of practices appeared to occur in pockets of activity rather than as an ethos of care provision. Even when staff understood behaviours that challenged as communication of an unmet need and were supported to work well with people living with dementia, staff's ability and willingness to address psychological needs was limited. Conflicting work demands, staff fatigue, long shifts and difficulty in identifying and resolving patient issues resulted in staff

responding to behaviours by ignoring and disengaging from the patient.<sup>45 50</sup>

**CMOC 2: the role of experiential learning and creating empathy to encourage reflection for responsibilities of care**

Staff training that improved awareness of the impact of dementia and that addressed negative concepts was found to be a prerequisite for supporting good dementia care. While the literature suggested training had a positive impact on knowledge and confidence for working with people living with dementia, more work is needed to understand how this works in practice.<sup>10 39 47 51</sup>

Training strategies that employed experiential learning techniques and cultivated empathy in staff for people living with dementia prompted reflection on current practices. Evidence suggested these training sessions produced 'lightbulb moments' for staff where they gained a sudden realisation of the problems faced by people living with dementia.<sup>39 47 53</sup> This appreciation for the importance to adapt care practices prompted staff to work in ways that would better support the patient, and improved staff satisfaction with their work.<sup>51 61</sup>

Furthermore, one study reported how staff associated the portrayals of people living with dementia in training materials to their own relatives. This encouraged staff to see people living with dementia as individuals and motivated them to take responsibility to put their learning into practice.<sup>47</sup>

The use of reflection and examples of good care practices in recognisable situations gave staff a framework for working well with people living with dementia and demonstrated the benefit to their own work.<sup>47 53</sup> However, these practices were often referred to by staff as 'going the extra mile' or being additional to their workload rather than being an expectation of their role. Staff needed to be confident additional time spent with patients would not be viewed negatively by colleagues or impact on the



**Table 2** Initial theoretical propositions developed from phase 1

Dementia-friendly interventions in hospitals improve outcomes for people living with dementia and their carers if...	Evidence from stakeholders and preliminary scoping and supporting references
<p>... a change agent supports staff to reframe their understanding of dementia and respond appropriately to people living with dementia through learning and resources that address patient needs in an individual way. <i>Then</i> staff will have increased awareness of dementia and the impact dementia has on a person, and build confidence in their ability to recognise and address distress.</p>	<p>Emphasis on training and education that improve staff confidence in working with people living with dementia; breaking down negative assumptions and supporting staff to see the person rather than the diagnosis; use of resources to get to know the person References <sup>9 10 28 39 40 46 51 70 72 76 77</sup> Stakeholders (SK01, SK02, SK03, SK04, SK05, SK06, SK07, SK09, SK10, SK11, SK12, SK13, SK14) Example quote: "we're starting to do some training with our staff as well just to try and help everyone to know how to approach and how to feel empathy towards these patients who have dementia." (SK12)</p>
<p>... a change agent with organisational and clinical authority communicates the priorities for dementia care and addresses staff concerns around managing risk and workplace disruption in person-centred ways. Staff are supported by training and resources that improve the involvement in decision-making and safety of people living with dementia, <i>then</i> staff will understand they have the permission and encouragement to adapt practices in ways that are beneficial for people living with dementia.</p>	<p>Strategic planning, prioritising good dementia care, providing resources that support staff to work in new ways, changes to systems and processes References <sup>15 40 41 45 46 52 55 58 75</sup> Stakeholders (SK05, SK06, SK07, SK08, SK10, SK11, SK14, SK15) Example quote: "...however good people's ideas are, if they don't have some kind of sign-off at a fairly senior level then they're not really going to have it 'cos they'll never be a priority and because there are so many targets to be met in general, unless there's some kind of strategy or policy in writing I don't think it can change much really." (SK08)</p>
<p>... a change agent with clinical expertise in dementia and dementia care supports staff with assessments and care planning, <i>then</i> staff will identify and resolve the care needs of people living with dementia.</p>	<p>Assessments of cognition, mental health and psychosocial needs; role-modelling good dementia care; supporting staff to perform care in a person-centred way, direct care planning and address complex issues such as decisions of best interest, access to mental and social care information References <sup>45 55 58 59 62 74 78</sup> Stakeholders (SK04, SK09, SK11, SK14, SK15) Example quote: "we had mental health nurses come to work with us and they had a really important part in role-modelling how it looked, how to approach things." (SK14)</p>

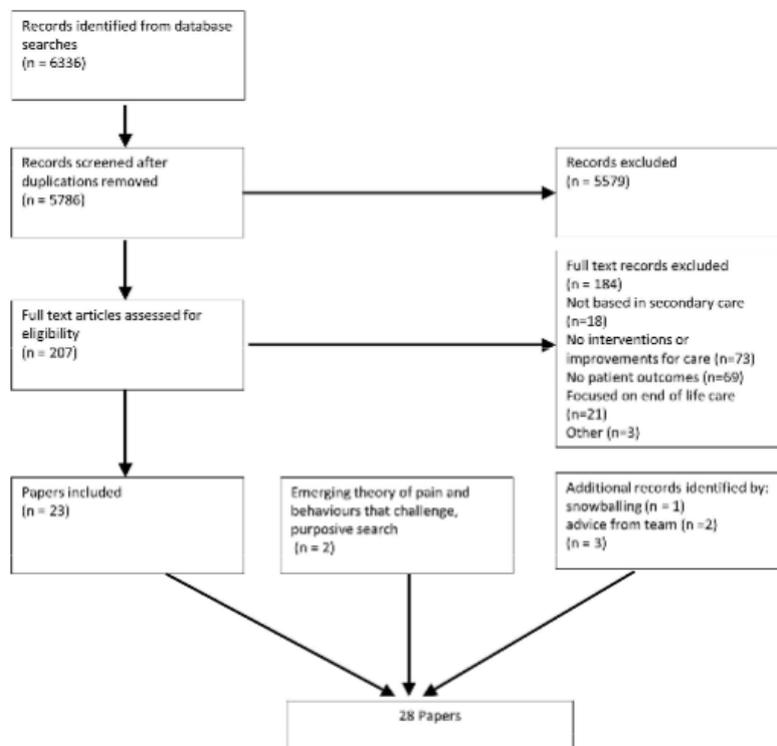
requirements to manage the ward effectively, to support adaptations to care practices.<sup>46 47</sup>

**CMOC 3: clinical experts who legitimise priorities for care**

Change agents influenced staff working practices through clinical expertise and organisational authority.<sup>39 40 44 45 48 49 52 59 62</sup> Experts in dementia care supported staff in the use of assessment tools and person-centred care planning,<sup>52 62</sup> role-modelled appropriate behaviour and communication for working with people living with dementia,<sup>39 45</sup> and provided professional advice for complex situations, such as decisions around best interests.<sup>40 39</sup> Access to experts in dementia care was suggested to reassure and encourage staff to provide good care for people living with dementia. Endorsement of these practices was communicated by clinical experts with organisational authority at the ward level<sup>46-48 52 63</sup> and across the organisation.<sup>41 47 49</sup> They addressed staff apprehensions to adaptations to care practices that previously prioritised medical and physical

needs, ward routines, task-focused ways of working, and organisational expectations for the completion of documentation and risk reduction.<sup>41 48 49 52 63</sup> Our review found that when change agents in authority communicated new expectations for standards of care and changes to procedures, they validated the priorities for care and legitimised staff's adaptation of care practices accordingly.<sup>41 47 52 63</sup> However, the impact of changes to staff's work needed to be recognised and supported.<sup>41 44 45 48 52 54 63</sup> For example, studies reported there was reduced capacity to work with previous levels of patient allocation,<sup>41 48 54</sup> and changes to risk management strategies, such as encouraging mobility in a frail patient population at risk of falls, required staff training.<sup>52 63</sup>

There was limited evidence that new practices were adopted by staff and embedded into everyday practice directly through their contact with dementia experts. Instead, it appeared that the experts maintained responsibility for dementia care, either personally or by providing



**Figure 1** Flow diagram of searches and evidence retrieval.

direction. The use of experts alone could potentially concentrate responsibility for dementia care in a small staff group rather than create a culture where all staff are responsible. Evidence from one paper<sup>45</sup> suggested that even when ward staff as a whole were better able to work with people living with dementia, they would defer issues unrelated to physical or medical healthcare to dementia experts.

#### CMOC 4: staff with confidence to adapt working practices and routines to individualise care

The ability of staff to organise their work around the needs of people living with dementia rather than being restricted to the ward routine was linked to the provision of person-centred care.<sup>45 46 48 50 54 60</sup> Where staff could incorporate getting to know the person, or recognise and respond directly to expressions of distress and unmet needs, patient well-being reportedly improved, evidenced through observations of positive mood.<sup>46 48 50 60</sup> Clarity in staff's responsibility for patient care was an important resource for improving their autonomy and encouraging

them to respond in timely, creative ways to meet individual needs.<sup>46 48 60</sup>

Flexibility in working practices was suggested to be a factor in improving functional outcomes for people living with dementia. One study<sup>54</sup> attributed gains in mobility after hip surgery to therapy staff using their professional judgement to recognise optimal times that a person living with dementia would engage with a physiotherapy session, rather than risk the session being rejected. Additional factors that supported therapy staff to work flexibly included training in dementia care, reduced patient lists and treatment rooms located on the ward.<sup>64</sup>

#### CMOC 5: staff with responsibility to focus on psychosocial needs

Time constraints and staffing resources limited staff capacity to provide good dementia care. This was often addressed by employing staff with a specific role prioritising psychological, emotional and social needs through the use of cognitive and psychosocial assessments, therapeutic activities, supervising mealtimes and managing risk.<sup>10 45 48 50 52 55 56</sup> The use of these staff and the activities



Brief title	Full context-mechanism-outcome configuration	References
<p>Understanding behaviour as communication to improve staff's ability to respond</p>	<p>Where behaviours that challenge are understood as communication of an unmet need (context), through training, resources and support from experts in dementia care (mechanism resource), staff will feel they have improved capacity and capability to influence the situation (mechanism reasoning), making it more likely they will identify and address the need (outcome). However Conflicting work demands, patient characteristics (context) and staffing resources (mechanism resource) may lead staff to feel they are unable to make a difference (mechanism reasoning), meaning patient need might not be recognised, investigated or addressed (outcome).</p>	<p>10 15 39–57 59 60</p>
<p>The role of experiential learning and creating empathy to encourage reflection for responsibilities of care</p>	<p>Access to training (context) that promotes experiential learning and empathy towards people living with dementia (mechanism resource) can encourage reflection that identifies deficiencies in current working practices, helping staff to understand their responsibilities for care (mechanism reasoning) and leading them to take more time with people living with dementia (outcome). However Where good dementia care practices (mechanism resource) are not considered legitimate working practices (context), staff may consider these practices as additional to their workload (mechanism reasoning), leading to inconsistent provision of care (outcome).</p>	<p>10 39 46–49 51 53</p>
<p>Clinical experts who legitimise priorities for care</p>	<p>Clinical experts who have the authority to legitimise priorities and standards for dementia care endorsed by the organisation (context) provide support for staff to develop skills in dementia care (mechanism resource) and can help staff feel confident of the expectations for their role (mechanism reasoning) to adapt working practices (outcome). However By focusing the responsibility for dementia care in select staff (context/mechanism resource), there may be a reduced sense of responsibility for dementia care in the wider workforce (mechanism reasoning), reducing the ability of experts to embed good dementia care practices across the organisation (outcome).</p>	<p>39–41 44–49 52–54 59 60 62 63</p>
<p>Staff with confidence to adapt working practices and routines to individualise care</p>	<p>Staff supported to be flexible in their role and working environment (context), where their responsibilities for patient care have been clarified (mechanism resource), may be responsive or adaptive in their decision-making (mechanism reasoning) to provide care and treatment to a person in a timely, individualised manner (outcome). However Changes to staff capacity or environmental adaptations (context/mechanism resource) may need to be recognised and addressed by management (mechanism reasoning) to support staff to provide responsive care (outcome).</p>	<p>45 46 48 54 60</p>
<p>Staff with responsibility to focus on psychosocial needs</p>	<p>Where there is provision of activities and therapies for people living with dementia that support their interests and abilities (context) by staff with a role to address psychological, emotional and social issues (mechanism resource) and responsibility (mechanism reasoning) for maintaining functional and cognitive abilities (outcome), this can provide other healthcare staff with time to prioritise physical and medical needs (outcome). However Where staffing resources are limited (context), staffing for activity and therapy can be reallocated to maintaining patient safety (mechanism resource), which may require staff to prioritise safety concerns (mechanism reasoning), limiting their ability to meet psychosocial needs (outcome).</p>	<p>10 44–46 48 50 52 53 56 58 61</p>

Continued



Table 3 Continued	Full context—mechanism—outcome configuration	References
<b>Brief title</b> Building staff confidence to provide person-centred risk management	Where procedures and expectations for care are set out to address risk in a person-centred way (context), and are encouraged and reinforced through ward leadership (mechanism resource), staff may feel confident to address risk proportionately (mechanism reasoning) and may support patients with dementia to maintain function and abilities in a less restrictive way (outcome). However Resources will need to be compatible with environmental features and staff capacity (context/mechanism resource) or staff may not feel there is a value to their work or for the patient (mechanism reasoning), making it unlikely they will adapt care practices (outcome).	10 15 41 43–45 51–53 56–58 63

they provided improved patient experience,<sup>48</sup> assisted orientation to time and place,<sup>50</sup> reduced distress<sup>45 48 50</sup> and reduced the onset of behaviours that challenged staff.<sup>45</sup> Studies reported how activities were sometimes deliberately scheduled to cover known times of high need within the patient population, such as during the afternoon when 'sun-downing' might occur,<sup>52</sup> or when staffing levels were stretched, such as during mealtimes. For example, activities coordinators offered social dining opportunities where they could support conversations and prompt patients to eat.<sup>44 45 48 50</sup> Although studies reported improved nutritional intake, this was not formally evaluated.

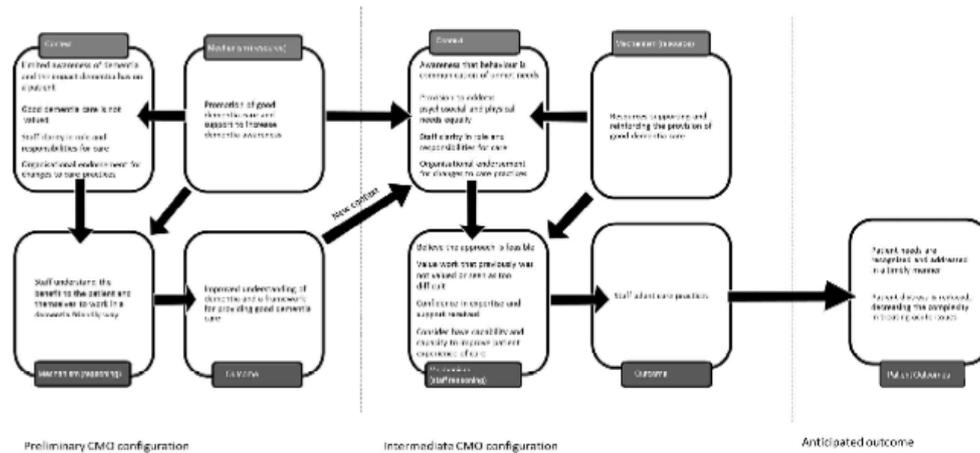
Patients with more severe physical illness or cognitive impairment may not be able to participate in activities,<sup>45 55</sup> although it is possible they may have benefited indirectly as healthcare staff had more time to address their physical and medical needs. While this was referred to in two of the interviews, this was not explored in any of the papers.

Ward-wide staffing levels and skill mix impacted on staff ability to prioritise emotional, psychological and social needs.<sup>45 48</sup> At times of staff shortages, ward management prioritised safety and managing risk over other non-medical needs.<sup>45 48</sup> Risk management techniques, such as the use of 'specials', could be applied in a way that also addressed psychosocial needs. Two studies<sup>45 48</sup> described how staff allocated to monitor patients at risk of falls engaged the patients in games, activities and conversations. However, this was not always the case as staff assigned as 'specials' were often junior team members, had not received training in dementia care and were unclear of the purpose of the role beyond monitoring the patient. This resulted in a lack of interaction with the patient and increased patient distress.<sup>56</sup>

**CMOC 6: building staff confidence to provide person-centred risk management**

We found evidence that addressing risk in a way that supported a person's abilities, choices and independence improved mobility,<sup>52 53</sup> reduced adverse incidents<sup>44</sup> and improved patient and carer satisfaction.<sup>41 45 57</sup> Training, for example, on new skills and procedures for managing risk from change agents with clinical expertise and organisational authority ensured staff understood the benefits to patients and had confidence to implement approved working practices.<sup>52 57 63</sup> Structural factors influenced the way risk was addressed. For example wards with locked door access meant patients could be monitored from a distance without restricting their movement around the ward,<sup>41 43 45 52</sup> and could help staff to perceive 'wandering' behaviours as positive rather than challenging.

In open wards, alternative methods were developed to easily identify patients considered at risk of leaving the ward, such as the use of wrist bands and different coloured hospital clothing, allowing staff to monitor them from a distance and intervene as necessary.<sup>10 47 53</sup> Identification methods were supported by staff training



**Figure 2** Refined programme theory: context-mechanism-outcome configuration (CMOC) for best practice for care of people living with dementia admitted to the hospital.

t the appropriate way to encourage patients to return to their ward.<sup>10 53</sup>

### Refined programme theory

From data in phase 1 we hypothesised that the existence of a change agent was important for improving hospital care for people living with dementia. However, work in phase 2 suggested that a reliance on single initiatives, such as a change agent, was insufficient to change staff behaviour. Additional contextual factors were also necessary in order for staff to make use of the resources interventions provided and use them in their practice with people living with dementia. The six CMOCs have been incorporated into a refined programme theory to suggest what needs to be in place to encourage best practice for dementia care in hospitals (figure 2). Figure 2 presents the programme theory. The preliminary CMOC suggests that resources that promote dementia awareness and an understanding of what constitutes 'good' dementia care are often initially implemented in situations where staff have limited understanding of how to provide care that addresses the needs of people living with dementia. These resources support staff to recognise the benefit of working well with patients with dementia and provide them with a common understanding of what good care looks like. This preliminary outcome then becomes part of the new context. Contextual factors, such as organisational endorsement of dementia care practices and clarity in staff responsibilities to patients with dementia, encourage staff to value resources, reinforcing improvements to care provision. It is anticipated that this will lead to improved patient outcomes, although evidence on outcomes was limited.

### DISCUSSION

Our review demonstrates how consideration of different contextual components in hospitals, hospital staff and patients was fundamental to how the resources of an intervention might influence staff reasoning to adopt good dementia care practices. These changes in care practices may then lead to improved healthcare outcomes for people living with dementia. Developing an understanding in staff of the difficulties dementia presents for people with the condition helped them to recognise the need to approach care differently. Previous reviews of dementia care in hospital settings have identified training as an important strategy to improve staff knowledge of dementia and confidence to work well with people living with dementia, but have provided limited evidence for how this affects patient outcomes.<sup>29 65 66</sup> Findings from this review would suggest that training as a single strategy is not enough to influence staff to adapt the care they provide for people living with dementia. The culture of care within an organisation needs to support staff to provide good care for people living with dementia, legitimising practices so they are valued by staff. This means organisations need to recognise the impact this has on staff workload and roles and the changes that are necessary to ensure care provision can be adaptive to the needs of the patient. Staff needed to have a clear understanding of the expectation for care standards, and be confident that these changes are accepted by colleagues and senior staff if they are to improve the way care is provided for people living with dementia. Managerial endorsement for staff to work flexibly within their role, using practices and resources that enable them to get to know the person, will help staff to recognise and address signs of distress and implement best practice in dementia care.



Turner *et al*<sup>65</sup> suggest that to achieve the type of culture where person-centred care is valued, training in dementia should be aimed at a managerial level. Findings from this review would support their opinion; in the included studies, change agents in senior positions, who understood dementia and the associated impact on patient experience and care of the patient, were reportedly able to positively influence the culture of care.<sup>47 44 46 47 49 52 61</sup> They communicated their vision for good dementia care, addressed processes within and between departments, provided resources that supported staff's work and considered the impact of changes to roles and responsibilities. However, even with this endorsement, there were still times, such as concerns for managing risk and resource shortages, where staff responsibilities were reorganised to prioritise physical over psychological well-being.

Limited time and resources and a preoccupation with managing risk are commonly cited factors that impacted on the ability of staff and organisations to sustain dementia-friendly hospital environments.<sup>29 56 65 67 68</sup> Employing staff who have a responsibility for the psychosocial needs of the patient can potentially improve patient experience of care while also making time available for nursing and medical staff to focus on the physical and medical care needs of the patient. However, it is essential that contextual factors, such as staff awareness in dementia and dementia care, and staff clarification of their role and responsibilities, are addressed before staffing resources are implemented into the setting. Moyle *et al*<sup>66</sup> demonstrated how the use of 'specials' without training in dementia care, a clear understanding of their role and a prioritisation of risk management over addressing psychosocial needs resulted in poor outcomes for patients, such as increased agitation and reduced autonomy. A review on special observation<sup>69</sup> underlined the importance of clarity in the purpose of the role and adequately trained staff to optimise the role's therapeutic potential. Where responsibilities for care are assigned solely by the patient's symptoms, this can lead to a narrow reactive approach to dementia care. Staff will still need to work as a team, rather than creating new tasks to focus on.

The initial aim of the review was to develop, test and refine a programme theory for how dementia-friendly interventions influence outcomes for people living with dementia during hospital admissions. However, testing the theory was problematic; evidence was limited, much was descriptive, and there were few evaluations of interventions and approaches, and limited descriptions of setting and component parts of the interventions which impacted on the development of CMOC. Moreover, most studies included in the review reported little information around patient characteristics (eg, type and severity of dementia), which meant we were unable to establish how the characteristics of people living with dementia interacted with the components of the interventions to influence outcomes. With these considerations, it is recognised that the proposed CMOCs were constrained by the evidence that was available and the inferences that

could be made from the data; further development is needed.

Available evidence clustered around the training for staff and organisational support for changes to care practices. There was less evidence on how the introduction of staff providing activity and therapy for people living with dementia impacted on the practices of other staff. This review does, however, provide a programme theory that can be used as the basis for future evaluations. Our review also highlights the importance of focusing on patient-related outcomes. It was clear from the initial interviews that while there was a shared understanding of the importance of dementia-friendly care, less attention has been paid to how different approaches enhanced patient outcomes. By focusing on outcomes as the basis for inclusion, this review addresses a knowledge gap about how different resources and approaches for dementia-friendly healthcare are effective for patients.

## CONCLUSION

The programme theory that has emerged from this review has the potential to improve how interventions to support dementia-friendly care in hospitals are designed and evaluated. The review highlights what needs to be in place to maximise the impact of training and the key characteristics for staff acting as change agents to influence colleagues to practise good dementia care. Specifically, the elements of interventions need to be relevant to provide ward staff with the awareness, authority and resources to provide personalised care with support from staff with the relevant expertise. Educational interventions should focus on how staff can identify with the experience of being a patient living with dementia, combined with opportunities for staff to share their experiences of addressing behaviours they find challenging and accommodating person-centred practices within ward routines and priorities. This review provides a timely contribution and challenges the assumption that dementia awareness initiatives in acute care settings alone are sufficient to improve patient care.

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**UNIVERSITY OF HERTFORDSHIRE  
HEALTH & HUMAN SCIENCES**

**ETHICS APPROVAL NOTIFICATION**

**TO** Melanie Handley  
**CC** Professor Claire Goodman  
**FROM** Mr. Fraser Heasman, Health and Human Sciences ECDA Vice Chairman  
**DATE** 16/03/15

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Protocol number: **HSK/PG/UH/00339**

Title of study: A Realist Evaluation of interventions that support the creation of dementia friendly environments in health care

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 16/03/15

To: 01/11/15

**Please note:**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

## 1. Introduction and gaining consent:

*Check Information Sheet has been read and consent form completed.*

Thank you for agreeing to take part in this interview. I am interested to find out how different initiatives designed to improve services and care for people with dementia when they access health care have been implemented and received by staff and service users. This will inform the focus and framework of a review of literature that I am conducting of interventions for designed to improve health care for people with dementia.

I would like your permission to record this discussion as it is very difficult to take detailed written notes as we go along. Everything you say will be confidential to myself and my supervisors. The recording will be transcribed and anonymised, ensuring that no one can be identified. I can stop the recording at any time, just say. This interview should take about an hour. Do you have any questions before we start?

## 2. Professional background

What is your background?

- Organisation
- Role
- How long have you worked in x area?

## 3. Experience of dementia-friendly interventions

Have you been involved in any initiatives to improve services for people with dementia? Can you give me some details about how the initiative was implemented.

- Who was responsible for deciding on the initiative
- What was your role in delivering / receiving the initiative
- Why do you think the initiative was implemented – what was it trying to achieve?
- Do you think it achieved its goals
- Why / why not

## 4. How could it work better?

Do you think there were things that might have worked better if the initiative had been different?

- In what way?
- Would more time / different person responsible / different approach /etc. been better / worse?

Do you think there were any barriers, or can you think of any potential barriers to the initiative's implementation?

The initiative was trying to [x], do you think there would have been a better way of achieving this?

Has the initiative worked for everyone that you have worked with (colleagues / patients /carers) if so who and why, if not who and why?

Extract from SK14 from 03.00 to 17.45

(Colour coding denotes where themes change during passages)

Transcript	Themes	Initial thematic framework
<p><b>I was just wondering with the change in the model of care, so was that moving from task focused to more person-centred?</b></p> <p>Yes, yeah, so at first there was people being deskilled and feeling a bit... but they were very receptive to the model of care because they were feeling so deskilled that they, you know, wanted to really know what can we do that's going to help make a difference to the patient and so they were interested to it, but that we kind of we ran these days which had, you know, a strong educational element and like I was saying a vital part of the whole training process was bringing people together as a team and developing a real shared ethos and shared approach to the model rather than saying, this is what it is, this is how to do it, and then it was in addition to the taught element we had mental health nurses came to work with us and they had a really important part in role-modelling how it looked, how to approach things. And so yeah, people were receptive to it 'cos I think that was unique to our ward, I think across... 'cos I work on another ward so I'm on a standard healthcare ward now, and staff are desperate for, you know, so they want the skills to deal with things properly.</p> <p><b>So is it more about just understanding the best ways to approach a person who has dementia and the difficulties that they have, so whether it's learning a better way to communicate with the person or to understand the behaviour they're presenting with might have a meaning behind it?</b></p> <p>Yes, yeah, basically <i>[both laugh]</i>, so it's refocusing your efforts so that your emphasis is on their experience, rather than what you're trying to do to</p>	<p>Unfamiliar with approach, deskilled Feeling deskilled as motivation for engaging with training Importance of training being whole team/shared ethos – addressing culture Experts role modelling approach Not standard across hospital Motivation for change</p> <p>What change was to care practices:</p>	<p>What supports change/Motivation What supports change/Motivation What supports change/Training What supports change/Training What supports change/Shared ethos Range of interventions/Specialist staff What supports change/Conflicting priorities What supports change/Motivation Outcomes/Staff Outcomes/Patients</p>



<p><b>Yeah, so were any people with dementia involved in the development of the ward?</b></p> <p>I don't know what work [PI] did, I know that they've got... a lot of their, and I read about it, did a literature search and things to get an idea what work has been done before to implement what we were going to do and then liaise with people like [other University group], but I wasn't involved in that element.</p> <p><b>No, of course.</b></p> <p>So you know, I'm trying to think, we did... we introduced certain things like <i>[laughs]</i>, you know, about the Alzheimer's, about <i>This Is Me</i> document and we produced our own version for hospital use, and I also worked with one called Caring Together that was focusing on carer involvement and welcoming their involvement, so we involved patients and relatives in that, by just doing this little questionnaire on the ward, so that was the only bit I was involved in that looked at the patients element.</p> <p><b>And did that work quite well then, did they... those documents help the change to a more person focused...?</b></p> <p>The documents we produced?</p> <p><b>Yeah.</b></p> <p>Yeah, definitely, yeah, they were quite fundamental 'cos they introduced information that wasn't clinical, or you know, wasn't medical history taking, it was just about patients' biography, patients' experience, what worked for them, and so it was refocusing you on the importance, to think about the person.</p> <p><b>Yes, so understanding their life outside of a healthcare setting really?</b></p>	<p>Development and implementation of ward</p> <p><i>This is me: involving carer, welcoming involvement</i></p> <p>Importance of biography in changing way work with patients</p>	<p>Range of interventions/Specialist units</p> <p>Range of interventions/biographical booklets</p> <p>Range of interventions/involving carers</p> <p>Range of interventions/biographical booklets</p>
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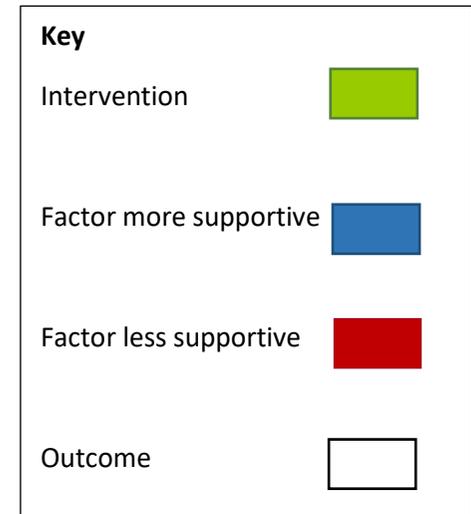
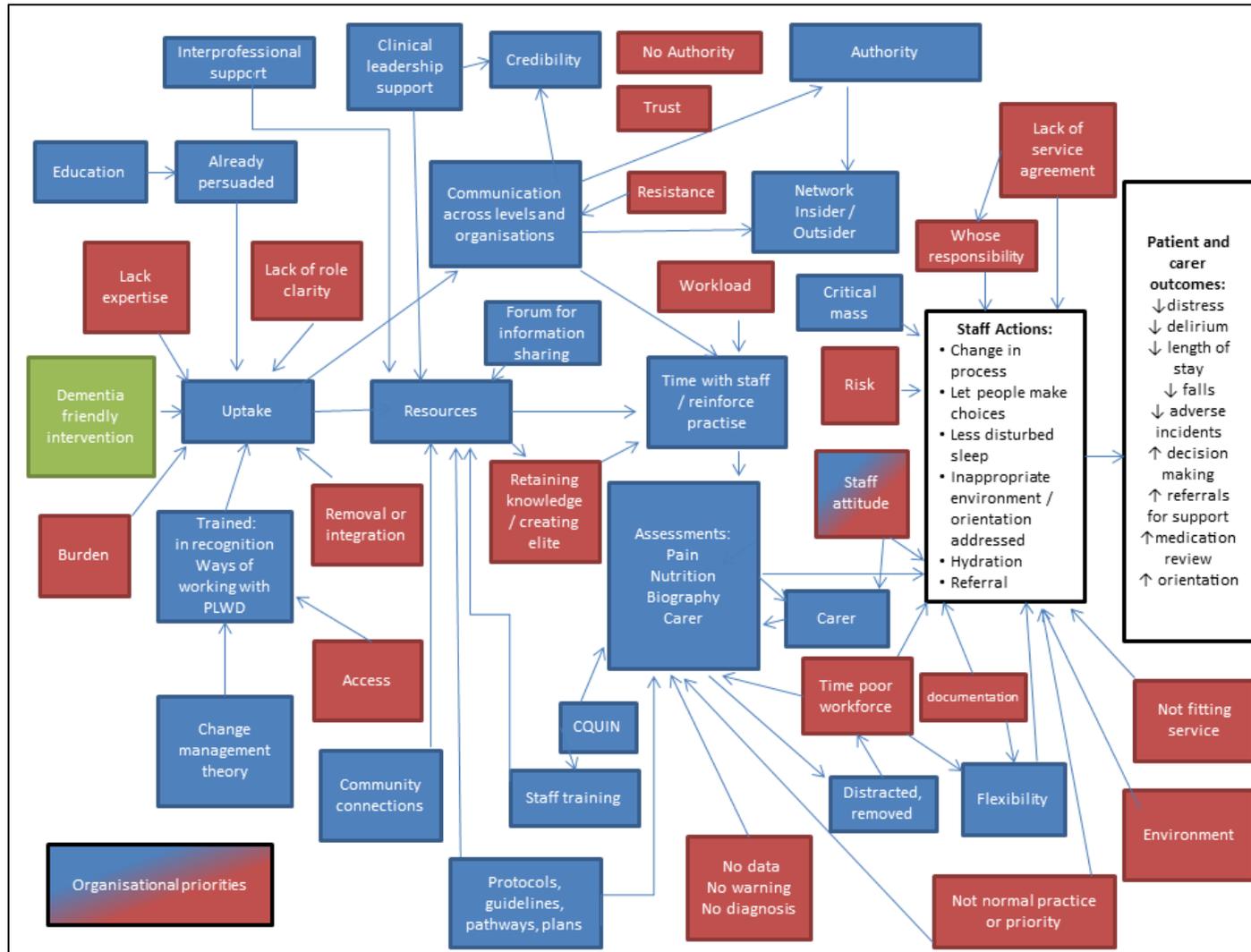
<p>Yes, yeah, and the importance of, you know, maintaining their routines and functions and what works for them and what works for the relatives and recognising that the carer's knowledge and the carer's input, how vital it is in nursing them just as much as the patient.</p> <p><b>Yeah. And with the assistance of the... well the integration of the mental health team, so you say that was quite fundamental as well to the working of the ward?</b></p> <p>Yes.</p> <p><b>What sort of changes did you notice with their input?</b></p> <p>Well massive changes [laughs], they could access mental health records which in physical health like you'd never been able to.</p> <p><b>Yes, not getting the whole story then?</b></p> <p>Yeah, you're feeling, yeah, it's just, yeah, so that was a massive bonus, we suddenly had a background, information where people asked what point in the process they were, what support they had, what community services had been over to assess them already, so instantly you've got information. They were able to role model person-centred care to us, to... a lot of the time we were doing it right but we just needed that reassurance that the approach was the right thing, so they were able to provide that. They had expertise in situations that they're escalating that may have potentially led to, you know, encounters, or violent encounters, and able to do some de-escalation techniques, and that they were also more used to a more person-centred approach and had more time as well, so we still had to plough on with the work whereas they were able to, if you have a situation we're able to come into that situation, just spend time in presence and looking to just be with patients.</p>	<p>Biography to support patient abilities and interests. Carer's expertise, carer's needs</p> <p>Mental health team: access to other patient information</p> <p>Information to understand more about the patient beyond medical need Mental health team role modelling care, reassured in skills Mental health team expertise in patient care, de-escalation, person-centred approach Issue of time to spend with for nursing staff</p>	<p>Range of interventions/biographical booklets Range of interventions/involving carer</p> <p>Range of interventions/Specialist staff</p> <p>Range of interventions/Specialist staff</p> <p>Range of interventions/Specialist staff</p> <p>Range of interventions/Specialist staff</p>
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<p>and in terms of outcome, patient experience improved, there's no cost saving outcomes.</p> <p><b>No, and I think that's quite difficult isn't it to get across to the Board who are making those decisions that actually that's an important factor.</b></p> <p>They pay lip service to patient experience, that's not fair, they value patient experience greatly, but they don't... I don't think there's an understanding of exactly what that means for somebody with dementia, and what that actually takes to make a good experience.</p> <p><b>No, exactly, alright, that's quite hard I imagine, yeah.</b></p> <p>Yeah, it's interesting and it's a challenge, and I don't think I'm going to get very far with it <i>[both laugh]</i>.</p> <p><b>No, I suppose in a way having your experience you could take a role like a dementia champion, and recognise where things might need to change in your ward but you need someone a bit higher up to also push that message.</b></p> <p>It has to be, because I've tried to, you know, educate people around me about what, you know, what the person-centred care looks like and I've done some training with staff, just what I can, with the new ward team that I had and but I've realised very quickly it's very limited what you can achieve, it has to be a whole culture of change. And a massive cultural change took place on [specialist ward] around risk taking and all sorts of things, you have to have a whole momentum and investment and commitment.</p> <p><b>Yeah, so in general do you think the ward staff are quite, would be quite open to it but because they've other focuses that inhibits them a bit to...</b></p>	<p>Outcomes need to demonstrate board level concerns</p> <p>Patient experience What does good look like for patients with dementia?</p> <p>Problems of one person influencing change in team.</p> <p>Needs to be whole culture change</p>	<p>Outcomes/Organisation Outcomes/Person living with dementia</p> <p>Outcomes/Organisation Outcomes/Person living with dementia</p> <p>What supports change/Shared ethos</p> <p>What supports change/Shared ethos</p>
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<p>They were... staff are desperate for their skills and knowledge to help them and I think it's wrong and injustice to the staff that they're not give... well now I know that the tools are available, they're imperfect tools but they're something, to... with, you know, you wouldn't put a nurse to work in ITU and not tell them how to use a ventilator, nurses working with people with dementia are not educated in what they need, so there are training programmes available and the dementia lead runs day, like two day courses and they get very good feedback but it's not enough by any means.</p> <p><b>Yeah.</b></p> <p>It just looks a bit periphery and you have to train people as a whole team.</p> <p><b>Yes, I've seen some educational models where they will take one person and then they diffuse that to the rest of the team, but I don't know how that works with the dynamics of the team and things, it's possibly dependent on who they select...</b></p> <p>Yeah, but it's even if you do that, that it's one person can't change a whole team ethos. Even if there was somebody who was a really strong leader, you've still got to... it has to be a fundamental commitment to changing the kind of approach.</p>	<p>Staff motivation for training (feeling deskilled) Valuing dementia care in comparison to clinical skills Clinical expert lead training. On own not enough</p> <p>Whole team ethos</p> <p>Commitment to change from organisation and team</p>	<p>What supports change/Motivation Range of interventions/Training</p> <p>What supports change/Conflicting priorities Range of interventions/Training What supports change/Training</p> <p>What supports change/Shared ethos</p> <p>What supports change/Shared ethos</p>
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Appendix 6: Mapping of factors that support, or not, the implementation of a dementia-friendly intervention



## Theory Areas

1. If a change agent supports staff to understand how to interpret and respond to PLWD behaviour that uses PCC approaches, challenges poor practice by using experiential learning and patient centred resources and reflection, then staff will be more likely (mechanism confidence, awareness, prioritise) to engage and assess patient pain / distress and involve PLWD and carer in planning their care
2. If a change agent has organisational and clinical authority to introduce learning and credible resources that prioritise the identification and care of PLWD and addresses concerns around risk and workplace disruption within a PCC framework then staff will feel they have permission to do the right thing becoming less risk averse
3. If a change agent works as a clinical expert to identify and resolve the care needs of PLWD then staff will feel supported and be more willing to care for PLWD

<b>Source(ref):</b>	
<b>Author lens</b>	
<b>Country</b>	
<b>Type of study/paper</b>	
<b>Intervention</b>	
<b>Relevance:</b>	
<i>Are the contents of a section of text within an included document referring to data that might be relevant to our mid-range theories? Which ones?</i>	
<b>2. Outcomes of interest</b>	
Are the outcomes of interest referred to in the paper? Which ones?	
<ol style="list-style-type: none"> <li>1) Patient and carer involvement in decision making</li> <li>2) Length of hospital admission</li> <li>3) Occurrence of adverse incidents (falls, nutrition, delirium)</li> <li>4) Use of antipsychotic medication</li> <li>5) Needs assessment</li> <li>6) Patient and carer satisfaction</li> <li>7) Other not specified</li> </ol>	
<b>What are the characteristics of the change agent</b>	

<b>What are the characteristics of person-centred care</b>			
<b>What is the change agent trying to do</b>			
<b>What resources are in place to help them achieve their aims</b>			
<b>To what extent are their aims achieved, what is the evidence?</b>			
<b>In what context is the change agent working?</b>			
<b>3. Interpretation of meaning:</b>			
<i>If it is relevant, do the contents of a section of text provide data that may be interpreted as being context, mechanism (resource/response) or outcome?</i>			
<b>4. Judgements about Context-Mechanism-Outcome-Configurations:</b>			
<i>What is the Mechanism (resource)-Context-Mechanism (response)-Outcome Configuration (CMOC) (partial or complete) for the data?</i>			
<b>Resource/Intervention</b>	<b>Context</b>	<b>Mechanism</b>	<b>Outcome</b>
<b>5. Judgements about mid-range theory:</b>			
<ul style="list-style-type: none"> <li>• <i>How does this (full or partial) CMOC relate to the mid-range theory?</i></li> <li>• <i>Within this same document are there data which informs how the CMOC relates to the mid-range theory?</i></li> <li>• <i>If not, are these data in other documents? Which ones?</i></li> <li>• <i>In light of this CMOC and any supporting data, does the mid-range theory need to be changed?</i></li> </ul>			
<b>6. Rigour:</b>			
<ul style="list-style-type: none"> <li>• <i>Are the data sufficiently trustworthy and rigorous to warrant making changes to the CMOC?</i></li> <li>• <i>Are the data sufficiently trustworthy and rigorous to warrant making changes to the mid-range theory?</i></li> </ul>			

<b>7. Population</b>
<b>Questions raised not captured elsewhere</b>
<b>Notes</b>

Paper	Example Evidence	Key Points and emerging CMOs
Baillie (2015)	<p>“I think the Barbara’s Story made me more aware of them so I go to help them where perhaps I may not necessarily have noticed them before. (Therapists1)” (p26)</p> <p>“After seeing the video it makes those kinds of patients easier to speak with and it also reassures you, so for example in the video it talks about not taking them out of their own reality, and I think that just reassures people that you can distract them and not ‘lie’ to them and that’s okay, and I think that’s reassuring to people that don’t know that much about dementia.” (p46)</p> <p>“Staff remembered Barbara being ‘lost’, ‘confused’, ‘vulnerable’, ‘scared’ and ‘worried’. They engaged with her as a person who could be a family member... Some staff specifically related Barbara’s Story to a family member, which personalised the film’s story... There was also acknowledgement that any of us could find ourselves in a similar situation.” (p24)</p> <p>“Barbara’s Story enabled staff to see her healthcare experience from her perspective and the behaviour shown in the film prompted staff to reflect on their own behaviour and that of colleagues.” (p23)</p> <p>“In most focus groups, staff discussed how their own interactions with patients and behaviour had changed since watching Barbara’s Story, and they often referred to changes they had observed in other staff too. Areas discussed included: giving more time to patients, improved communication, giving more information, and assisting patients who are looking lost.” (p25)</p> <p>Some participants considered that Barbara’s Story had raised the profile of initiatives and other work that was already in place for people with dementia, further reinforcing</p>	<p>Raising awareness to recognise signs and symptoms of dementia</p> <p>Training to improve confidence in working with people living with dementia</p> <p>Reassurance from examples in training of how to work well with people living with dementia</p> <p>Training that developed empathy helped staff relate to people living with dementia as family members</p> <p>Shown experience from patient’s viewpoint to understand how need to adapt care practices</p> <p>Changes staff implemented after training; time for patients, better communication, information, recognising and acting upon distress and confusion.</p> <p>Training supporting and promoting the use of other resources.</p>

	<p>and helping developments to embed in the Trust, such as dementia study days and dementia champions and use of the forget-me-not.” (p29)</p> <p>“Staff related how they listened to patients with a history of dementia, taking their physical symptoms more seriously, rather than attributing them to their dementia: ‘we will now investigate it a little bit more [...] any physical symptoms we will take seriously’ [rather than attributing it to their dementia or mental health condition (Nurse10). Similarly, in relation to behaviour, another nurse said: I think it’s really important for staff to remember not to play a part in that stigma and not to make excuses if they’re upset or aggressive, not to put it down to their condition, sometimes they are just genuinely wanting something or upset. (Nurses8)” (p51)</p> <p>“Those who had used <i>This is me</i> were great advocates for the tool and the difference it made in practice: I saw it once in practice and I thought to myself, this is the best thing that anyone has ever done because it just made the care you gave so personalised and I remember the patient and it said in the notes, loves Coronation Street and EastEnders. So at 7.30pm I’d go and put on Coronation Street, just because I knew about it. (Nurses4) ... It’s nice to know a bit more about them, what they like and don’t like, even if it’s just down to how they like their tea or they don’t like tea. (Nurses6)” p53</p> <p>In one focus group, an example of the benefits of <i>This is me</i> was explained: She [patient with dementia] was in for less than three days, got home, she wasn’t a delayed discharge but my point had been if <i>This is me</i> hadn’t been filled in and she was distressed and constantly calling, they’d have given her [medication], shut her up, then she’d have been over-sedated, she wouldn’t have been eating and drinking, her delirium would have been worse. (Nurses4)</p>	<p>Staff reported changes to practices following training. Understanding behaviours as communication of other needs rather than symptoms of dementia.</p> <p>Use of biographical tool to understand the preferences and routines of the patient.</p> <p>How not knowing about the patient leads to distressed behaviours that might have adverse results such as inappropriate medication, poor nutrition and hydration, and increased severity of delirium.</p>
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<p>Banks et al. (2014)</p>	<p>“<i>This is me</i>] By having this document we have reduced the amount of medication the patient receives in hospital. Staff are much more likely to look into why the patient is behaving this way rather than get them prescribed medication. This in turn has reduced the number of falls during the day, therefore reducing the number of fractures and increased stays in hospital. P727</p> <p>The first change we made was to stop separating the patient with dementia from the relative during the admission process. ... I think the relatives feel more valued as a carer and the importance of their role in looking after their relative with dementia is recognised. The patients are also much more relaxed to have familiar faces around so the admission process has become much smoother for everyone including the staff p727</p> <p>I have tried to take back to the ward with me topics that I have learned and shared with other members of staff. This has been an eye opener as some staff are not keen to accept change and question everything that I have tried to do and don't seem to see the need for change. P728</p>	<p>Resources that support knowledge of the patient reduce adverse events such as inappropriate medication, falls, and increased length of stay. Resources that support knowledge of the patient encourage staff to understand behaviour as a form of communication.</p> <p>Changing processes and procedures that understand the needs of people living with dementia to reduce patient distress and improve carer satisfaction.</p> <p>Difficulty in getting staff to change practices if they do not recognise the need to change practices.</p>
<p>Brooker et al. (2014)</p>	<p>“[Dementia awareness training] It has made a big difference to how staff respond to the behaviour of patients with dementia, as it has increased understanding and awareness. For example, there is now a greater focus on occupying patients with activities to reduce behaviour that challenges, and staff are now seen to be walking around with patients with dementia who are wandering when previously they would have told them to sit back down.” P48</p>	<p>Dementia awareness training improves staff understanding of how to better support people living with dementia. Understand the need for providing activities to reduce onset of behaviours that challenge and adapting way of working.</p>
<p>Dowding et al. (2016)</p>	<p>Participants discussed how pain may be intermittent and fluctuate, often only being present when patients are engaged in certain activities. “often the doctors will go round and they'll ask the patient in their bed or in their chair, “Oh, are you alright? Any pain anywhere?”, “No, I'm fine”. As soon as we [physiotherapists] come, get them up on it, “Oh, oh, that really hurts”.[H1, physiotherapist] p156</p>	<p>Need to understand people living with dementia have difficulty communicating their needs (e.g. pain relief) and will have problems recalling and describing experiences of pain.</p>

	<p>As with other patients, one of the challenges faced by clinicians is the initial recognition of whether or not a patient may be in pain at all; for a variety of reasons patients (including those with cognitive impairment) may not be able to verbally express they have pain, and clinicians often find it challenging to interpret behavioural signals which may be 'atypical' in nature. p157</p> <p>One of the key factors in assessing and managing pain is the ability to build a 'picture' or narrative of the patient case; which is used as the basis for the interpretation of cues, to try and 'make sense' of a situation. Participants highlighted the importance of building patterns of information cues and patient behaviour, to help inform their decision making. This narrative occurred over time (an issue which arose in other themes from the data), trying to link different events over the trajectory of a patient stay, to help test 'guesses' and form the basis of trial and error approaches to management. p157</p> <p>From the observations it appeared that pain recognition, assessment and management was carried out over time, by many individuals. Rather than being under the control of one specific nurse or other health care professional, it could be characterized more as a process of distributed work, which is time dependent. This is reflected in the comments in interviews, which highlight how there is a division of labour in the hospital ward; there numerous people with different professional roles who are all involved in the care of each patient, each with specific duties, responsibilities and powers. In turn, these roles often governed which part of the pain recognition, assessment and management process they participated in, and how they communicated their findings. p158</p>	<p>Challenges for staff to understand patient needs.</p> <p>Getting to know the needs of the patient through time and continuity in their care.</p> <p>Context of ward where responsibilities for the patient's needs are across a number of staff; those who recognise the need may not be able to directly address the need. Importance of communication with colleagues.</p>
Duffin (2013)	'Some people have been moved to tears by the DVDs,'(outcome) says Ms Karasu. 'The films resonate with them. Sometimes you see a look on their face and you can tell they are thinking: "I never thought of that." (reasoning) P16	Emotional engagement with training and realisation of the patient's experiences of care.

	<p>In one training session nurses, doctors and other staff wear specially designed goggles that restrict their vision, and put on a jacket which has small splints inserted in the arms to restrict movement of their upper body. This is to help staff understand the physical constraints faced by some older people. Darlene Romero, a matron across the trust's three older people's wards, who delivers the training, says: 'It's a real eye opener, and makes you realise how difficult it can be to go to the toilet. P16</p> <p>A laminated symbol of a forget-me-not is placed above the beds of all patients with dementia, and a similar motif is put on their casenotes, so that any health worker who comes into contact with them is aware of their condition. Ms Wood says: 'It shows our team that they need to adapt because the person with them has a cognitive impairment. If someone goes to have an X-ray, for example, the team would see the forget-me-not symbol and they would know that this person may not just jump up onto the couch and be ready. They will need to provide more explanation and perhaps to stay a bit calmer than they would with other patients to show extra sensitivity. P17</p>	<p>Experiential learning triggering realisation of patient needs.</p> <p>Identifying a patient has dementia, staff recognising they need to adapt care to be appropriate to the needs of the patient.</p>
<p>Edvardsson et al. (2012)</p>	<p>The subtle initial expression of emerging needs were not picked up by staff as they were absent and the expression of unmet needs could escalate to become behavioural alterations as the need remained unsatisfied. When staff finally came about, they were observed to interpret the behaviour as 'disruptive' or 'disturbing' as they lacked the initial interpretative cues that could explain the behaviour. As a consequence, care became very much reactive, as staff had to come up with acute solutions to full-blown situations for which they lacked the insight and an interpretative framework. P6</p>	<p>Care becomes reactive when behaviour is misinterpreted. Underlying causes not investigated.</p>
<p>Ellison et al. (2014)</p>	<p>Colleagues reported improved skills, knowledge and understanding as well as improved confidence in caring for people with dementia as a result of the training and working alongside a Champion. Colleagues also reported changes in their practice as a result of training, for example:          spending more time with people with dementia on a one-to-one basis to provide more</p>	<p>Training supported by a Champion to improve knowledge and understanding of dementia and confidence to work well with people living with dementia. Staff reported changes to care practices.</p>

	<p>individualised care; more effective communication as a result of a better understanding of the needs of people with dementia; involving carers more proactively; understanding the importance of personal care plans and documentation; being more aware of the impact of the environment on people with dementia; being more proactive in providing additional assistance to people with dementia; being prepared to challenge bed moves involving people with dementia when there was no clinical need; increased awareness of signs of stress and distress and seeking to identify the cause rather than resort to use of sedatives. p51</p> <p>The primary actions undertaken in this respect have been the implementation of person-centred care planning through use of the <i>This is me</i> document initially, and subsequent development and implementation of 'Getting to Know Me'. Many DCs have played a key role in implementing and trying to embed these documents through introducing it to their team and training staff in its application. ... Use of GTKM allows staff to find out more about the patient and their preferences and is generally considered a useful tool in supporting improved person-centred care for people with dementia. Comments from Champions and their colleagues working in acute settings suggest that use of person-centred plans like this represents a departure from the norm for them in terms of the information they are used to collecting and the conversations they are used to having with patients. Examples were cited where staff have used GTKM more effectively minimise stress and distress, reporting how the information they gained about the patient through the assessment had supported them to recognise and respond more effectively to distressed behaviour. p53</p> <p>In interviews DCs frequently cited the role they have played in influencing the behaviour of colleagues, for example by challenging inappropriate use of language when speaking to or speaking about people with dementia. p54</p>	<p>Staff seeking to address underlying need of people living with dementia rather than treating behaviour with medication.</p> <p>Use of biographical tools to support person-centred care practices that reduce distress. Role of champions in supporting implementation of tool.</p> <p>Champions role in addressing negative staff attitudes towards people living with dementia.</p>
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	<p>“Staff’s attitudes have changed hugely in A&amp;E [as a result of DC’s awareness raising of how noise and activity can cause distress] – you used to see someone with dementia and there would be 2 or 3 nurses with the one patient, each doing something else and the poor patient... now you see them going in one person at a time, calmer more quietly.”p56</p>	<p>Champion supports staff to understand difficulties faced by people living with dementia. Staff adapt practices to recognise and support difficulties.</p>
Galvin et al. (2010)	<p>[post training] The staff also recognized the need for improved communication skills with the patient, such as sitting and talking clearly, using nonverbal clues, and asking permission to touch the patient in order to improve care.</p>	<p>Training for staff to recognise the need to change practices.</p> <p>Additional evidence of how training encouraged staff to implement new resources to improve care of people living with dementia (activity packs, volunteers, identification method for patients at risk of leaving the ward).</p>
Goldberg et al. (2014)	<p>Staff also appeared more accepting and understanding of mental health problems and patients on the Unit were more likely to raise concerns about their mental health and these would be responded to by staff. This could be because staff were more aware of mental health needs, because they had more conversations with staff in general (and thus the opportunity to raise such concerns) or it could be because they were cared for on a ward where all patients were cognitively impaired. (p1337)</p> <p>The Unit provided a greater focus on the mental health needs of patients. Staff were more often observed assessing patients’ cognitive abilities (using standardised tools and by questioning) than on standard care. P1337</p> <p>Sometimes, skilled care on the Unit was not evident to observers, as patients who had the potential to exhibited distress behaviour were calm. In this observation Alex has been calmly walking up and down the ward for over an hour. A member of staff has always been walking with him and talking to him. Alex’s aggression was only evident when something unexpected happened. P1337</p>	<p>Awareness and understanding of dementia led staff to address patient psychological and mental health needs.</p> <p>Use of assessment tools to understand patients’ cognitive abilities.</p> <p>Supporting patient choice and independence to reduce distress and the onset of behaviours that challenge.</p>

	<p>Individual attention was given to patients at other times on the Unit with staff getting patients drinks or snacks outside of the meal and drink rounds and using touch when interacting with patients. P1338</p> <p>However, the psychological needs of the patients on the Unit were high and a minority of patients would call out persistently for long periods of time. Staff would try to comfort or distract them... But the calling out would resume once the staff member left the patient and the conflicting demands on time meant staff would sometimes ignore their cries and attend to other patients, staff or documentation... Delivering care to patients with these behaviours could be exhausting and sometimes, particularly towards the end of a 'long day' (12 1/2 h shift), staff would ignore patients. P1338</p>	<p>Staff working outside of ward routine to meet individual needs.</p> <p>Constraints to addressing patient needs when unable to find out the cause, conflicting demands on staff time, and staff fatigue.</p>
Gonski and Moon (2012)	<p>Staff members stated that they were sufficiently trained and a majority (n = 11) were able to confidently manage the behavioral problems. The respondents reported that they were able to build therapeutic relationships with both the patients and the carers and were also happy to provide help for both parties. In terms of communication, the nurses were very confident they could communicate with the patients, and therefore were able to interpret individual's needs. P62</p>	<p>Training supports staff confidence to work with people living with dementia who have behaviours that challenge. Staff ability to communicate well with patients helps them build relationships with patients and understand their needs.</p>
Luxford et al. (2015)	<p>Early in the implementation period, a few clinicians reported difficulty in translating the carers' tips into a workable strategy for the hospital environment as they lacked confidence to write strategies based on 'non-clinical' tips. This issue was addressed through further training and the development of lanyards for clinicians to use which demonstrated how to write an effective TOP 5. P5</p> <p>After implementing TOP 5, the majority of clinicians reported agreeing or strongly agreeing that TOP 5 was easy to use (91%), not time consuming (70%), decreased patient agitation and distress (74%), resulted in decrease use of restraint—physical or chemical (61%)—and made it easier to relate to carers (89%). P5</p>	<p>Use of biographical tool supported by champions, training, and examples of how to implement information into care plan.</p> <p>Use of biographical tool perceived to reduce patient agitation and distress and the use of restraints.</p>

Nichols and Heller (2002)	<p>“We built an interdisciplinary team that looks at the patient and the caregiver as a unit, works with them, and responds to the patient’s behaviour as meaningful behaviour that needs to be understood. We understand that dementia patients have special needs. Using a team approach has allowed us to meet those needs in an acute care hospital.” p186</p>	<p>Working with carer to understand patient’s needs. Understanding that behaviour is a communication of an unmet need.</p>
Scerri et al. (2015)	<p>Care worker (S32): I was thinking about this particular patient who did not need physiotherapy because he was here for respite care. He used to turn to all the staff to ask questions .. So every time I used to engage in a conversation with him and try to first calm him and reassure him because he was panicking and living in a situation as if it is real for him. P6</p>	<p>Recognising patient needs and addressing them to reassure. Understanding from patient perspective.</p>
Schneider et al. (2010)	<p>We found that HCAs continuously ensured that patients were as comfortable as possible, some going out of their way to achieve this. One worker was even known to have sewed and adapted patients’ clothing to maximise their comfort (and staff convenience, because this prevented frequent changes of clothing). Efforts were made to overcome language barriers between staff and non-English speaking patients and, when patients were distressed, HCAs often comforted them with actions as well as words: The male patient who becomes very distressed and cries was comforted greatly by H/CO who warmly cuddled up next to him, whilst on his observation, putting her arm around him and letting him snuggle into her, putting his head on her chest. (Fieldnote, Ward C) p28</p> <p>We concentrate more, as you get to know the patients, the more you know their ways, you know their habits and if they’ve got a bad tummy and things like that and you get to know them; the job comes easier when you get to know them. It doesn’t stop you getting hit sometimes, but you’re aware of, you just get to know them and understand them a bit more. P47</p> <p>“Invoking their practical autonomy, the HCAs also made minor adaptations within routines to suit individual patients. For example, medications were administered to all</p>	<p>Recognising and addressing patient needs to improve comfort for patients and benefit staff workload.</p> <p>Importance of getting to know patients and benefits to workload.</p> <p>Personalising tasks for needs of patients.</p>

	patients at approximately the same times every day on each ward, rather than being doled out individually; this ensured that every patient received his or her medication, as well as conserving staff time. However, within this routine, HCAs who were 'running' the medications would often make small concessions, for example by taking extra time to gain the trust of individual patients." P 49	
Spencer et al. (2013)	<p>Carers of patients with MMHU described staff as being 'well prepared' for dealing with confused patients, displaying patience and compassion. Respondents noted that patients who liked to wander were guided by staff when walking up and down rather than constantly being returned to their bed space, a behaviour observed by carers on standard care wards. p3</p> <p>"Participants felt that staff had little understanding and limited training in dementia care, which carers felt resulted in patients being ignored, shouted at or threatened when staff were faced with uncooperative or challenging situations." P3</p>	<p>Staff who have understanding of dementia and dementia care can meet the needs of patients.</p> <p>Where staff lack understanding of behaviours that challenge they misinterpret them and attribute the problem to the patient, leading to poor care.</p>
Waller and Masterson (2015)	<p>Many of the environmental changes appear to have occurred as a consequence of the training that teams received before they started planning their projects. For example changes in staff attitudes such as investing in table cloths, laying tables, and purchasing coloured crockery, as well as increases in activities for patients such as the provision of newspapers or implementation of therapy hours, were reported; in the words of one team member, it is 'not just about the colour of the paint'. P64</p> <p>Making spaces seem smaller and more familiar, and reducing the numbers of decisions that have to be made by patients in finding their way to places such as the toilet, the dining room or their own bed space, seems to significantly reduce agitation. P65</p>	<p>Staff training helps staff recognise the needs of people living with dementia and make adaptations.</p> <p>Changes that recognise the difficulties of people living with dementia will help reduce distress.</p>
White et al. (2016)	Patients with any form of BPSD during their admission were five times more likely to have an antipsychotic prescribed during the admission (OR 4.99, 95% CI 1.15, 21.70, p=0.032). Antipsychotic prescription was five times more likely in people who	Behaviours that challenge increase likelihood of antipsychotic prescription.

	<p>experienced hallucinations (OR 5.04, 95% CI 2.10, 12.06, <math>p \leq 0.001</math>) or activity disturbances (OR 5.71, 95% CI 2.22, 14.70, <math>p \leq 0.001</math>) and seven times more likely with aggressive behaviours (OR 7.70, 95% CI 2.25, 26.31, <math>p = 0.001</math>). Patients were three times more likely to have an antipsychotic prescribed when they experienced sleep disturbance (OR 3.35, 95% CI 1.45, 7.79, <math>p = 0.005</math>).</p> <p>In total, 55% of participants received non-pharmacological management during their admission. The most commonly used techniques were psychosocial interventions (36%) and staffing (17%) (Table 2). We found no evidence in the nursing or medical notes of ongoing monitoring or review of the effectiveness of these non-pharmacological interventions, or of a systematic way of using these techniques.</p>	<p>Lack of monitor of non-pharmacological management of behaviours that challenge so difficult to know effectiveness.</p>
Williams (2011)	<p>We are testing a REACH education programme for domestic assistants and housekeepers... They had not considered the positive impact they could have in contributing to care and, without exception, were delighted to support the initiative. P15</p> <p>REACH helps all staff to understand the cognitive difficulties experienced by people with dementia. It enables them to contribute in their role and promotes pride in the part they play in care. p15</p> <p>Carers feel relieved that their loved one's condition is recognised and that hospital staff know how to respond to them, while the carers' sheet allows families to pass on crucial information and tips that will keep patients safe and improve their care'. P17</p>	<p>Understanding the problem, knowing how can make a difference to patient experience and being able to take pride in work.</p> <p>Working with carers to get to know the patient and know strategies that work well to improve patient safety.</p>



## Health Research Authority

East of England - Essex Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0207 104 8069

**Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 August 2016

Prof Claire Goodman  
University of Hertfordshire  
College Lane  
Hatfield  
AL10 9AB

Dear Professor Goodman

Study title:	A Realist Evaluation of interventions that support the creation of dementia friendly environments in health care
REC reference:	16/EE/0263
Protocol number:	HSK/PGR/NHS/02368
IRAS project ID:	192294

Thank you for your submission of 10 August 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Helen Poole at [NRESCommittee.EastofEngland-Essex@nhs.net](mailto:NRESCommittee.EastofEngland-Essex@nhs.net)

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### **Mental Capacity Act 2005**

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

### **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	2	25 July 2016
Covering letter on headed paper [Covering Letter]		20 May 2016
Covering letter on headed paper [Covering Letter]	3	04 August 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity 2015-2016]		04 August 2015
Interview schedules or topic guides for participants [Carer interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Staff interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Ward Manager Dementia Lead interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Patient interview schedule]	2	25 July 2016
IRAS Application Form [IRAS_Form_05082016]		05 August 2016
Letter from funder [Alzheimer's Society Research Agreement]		20 January 2016
Letter from sponsor [Letter from sponsor]		19 May 2016
Letters of invitation to participant [Carer invite letter]	1	30 April 2016
Letters of invitation to participant [Family member reply slip interview]	1	30 April 2016
Letters of invitation to participant [Consultee letter]	1	30 April 2016

Letters of invitation to participant [Patient invite letter]	1	30 April 2016
Letters of invitation to participant [Staff invite letter]	1	30 April 2016
Letters of invitation to participant [Consultee letter]	2	25 July 2016
Non-validated questionnaire [Medical Notes Data collection tool]	1	30 April 2016
Non-validated questionnaire [Ward observation schedule]	1	30 April 2016
Other [University lone worker policy]	2	01 December 2014
Other [Bad practice protocol]	2	25 July 2016
Participant consent form [Carer consent form]	1	30 April 2016
Participant consent form [Staff consent form interview]	1	30 April 2016
Participant consent form [Staff consent form observation]	1	30 April 2016
Participant consent form [Witness form]	1	30 April 2016
Participant consent form [Patient opt out reply slip]	1	30 April 2016
Participant consent form [Staff opt out reply slip]	1	30 April 2016
Participant consent form [Nominated consultee declaration form]	2	08 June 2016
Participant consent form [Personal Consultee Declaration Form]	2	08 June 2016
Participant consent form [Patient consent form]	2	25 July 2016
Participant consent form [Patient consent form interview]	2	25 July 2016
Participant information sheet (PIS) [Carer information sheet]	3	10 August 2016
Participant information sheet (PIS) [Consultee information sheet]	3	10 August 2016
Participant information sheet (PIS) [Patient information sheet ]	3	10 August 2016
Participant information sheet (PIS) [Patient information sheet interview]	4	10 August 2016
Participant information sheet (PIS) [Staff information sheet interview]	3	10 August 2016
Participant information sheet (PIS) [Staff information sheet observation]	3	10 August 2016
Participant information sheet (PIS) [Nominated consultee information sheet]	3	10 August 2016
Referee's report or other scientific critique report [Research proposal feedback]		19 December 2013
Referee's report or other scientific critique report [Response letter to proposal feedback]		11 February 2014
Research protocol or project proposal [Protocol]	3	04 August 2016
Summary CV for Chief Investigator (CI) [C Goodman CV]	2	25 July 2016
Summary CV for student [M Handley CV]	2	25 July 2016
Validated questionnaire [Neuropsychiatric Inventory Questionnaire]	1	30 April 2016

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>16/EE/0263</b>	<b>Please quote this number on all correspondence</b>
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With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Alan Lamont**  
**Chair**

Email: [NRESCcommittee.EastofEngland-Essex@nhs.net](mailto:NRESCcommittee.EastofEngland-Essex@nhs.net)

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Mrs Melanie Handley, University of Hertfordshire  
Fiona Smith, West Hertfordshire Hospitals NHS Trust



Professor Claire Goodman  
University of Hertfordshire  
College Lane  
Hatfield  
AL10 9AB

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

26 August 2016

Dear Professor Goodman,

**Letter of HRA Approval**

<b>Study title:</b>	<b>A Realist Evaluation of interventions that support the creation of dementia friendly environments in health care</b>
<b>IRAS project ID:</b>	<b>192294</b>
<b>Protocol number:</b>	<b>HSK/PGR/NHS/02368</b>
<b>REC reference:</b>	<b>16/EE/0263</b>
<b>Sponsor</b>	<b>University of Hertfordshire</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

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procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

#### **HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **192294**. Please quote this on all correspondence.

Yours sincerely

**Miss Lauren Allen**  
**Assessor**

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Mrs Melanie Handley, University of Hertfordshire (Student researcher)*  
*Fiona Smith, West Hertfordshire Hospitals NHS Trust (Lead NHS R&D contact)*

*NIHR CRN Portfolio Applications Team:*

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	2	25 July 2016
Covering letter on headed paper [Covering Letter]		20 May 2016
Covering letter on headed paper [Covering Letter]	3	04 August 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional indemnity 2015-2016]		04 August 2015
Interview schedules or topic guides for participants [Carer interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Staff interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Ward Manager Dementia Lead interview schedule]	1	30 April 2016
Interview schedules or topic guides for participants [Patient interview schedule]	2	25 July 2016
IRAS Application Form [IRAS_Form_05082016]		05 August 2016
Letter from funder [Alzheimer's Society Research Agreement]		20 January 2016
Letter from sponsor [Letter from sponsor]		19 May 2016
Letters of invitation to participant [Carer invite letter]	1	30 April 2016
Letters of invitation to participant [Family member reply slip interview]	1	30 April 2016
Letters of invitation to participant [Patient invite letter]	1	30 April 2016
Letters of invitation to participant [Staff invite letter]	1	30 April 2016
Letters of invitation to participant [Consultee letter]	2	25 July 2016
Non-validated questionnaire [Medical Notes Data collection tool]	1	30 April 2016
Non-validated questionnaire [Ward observation schedule]	1	30 April 2016
Other [University lone worker policy]	2	01 December 2014
Other [Bad practice protocol]	2	25 July 2016
Other [Nominated Consultee Declaration Form]	3	23 August 2016
Other [Personal Consultee Declaration Form]	3	23 August 2016
Other [Statement of Activities]	1	26 August 2016
Other [Schedule of Events]	1	26 August 2016
Participant consent form [Witness form]	1	30 April 2016
Participant consent form [Patient opt out reply slip]	1	30 April 2016
Participant consent form [Staff opt out reply slip]	1	30 April 2016
Participant consent form [Carer Interview]	1	30 April 2016
Participant consent form [Patient]	3	23 August 2016
Participant consent form [Patient Interview]	3	23 August 2016
Participant consent form [Staff Interview]	1	30 April 2016
Participant consent form [Staff Observation]	1	30 April 2016
Participant information sheet (PIS) [Carer Interview]	4	23 August 2016
Participant information sheet (PIS) [Personal Consultee]	4	23 August 2016
Participant information sheet (PIS) [Nominated Consultee]	4	23 August 2016
Participant information sheet (PIS) [Patient Interview]	5	23 August 2016

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Participant information sheet (PIS) [Patient]	4	23 August 2016
Participant information sheet (PIS) [Staff Interview]	4	23 August 2016
Participant information sheet (PIS) [Staff Observation]	4	23 August 2016
Referee's report or other scientific critique report [Research proposal feedback]		19 December 2013
Referee's report or other scientific critique report [Response letter to proposal feedback]		11 February 2014
Research protocol or project proposal [Protocol]	3	04 August 2016
Summary CV for Chief Investigator (CI) [C Goodman CV]	2	25 July 2016
Summary CV for student [M Handley CV]	2	25 July 2016
Validated questionnaire [Neuropsychiatric Inventory Questionnaire]	1	30 April 2016

## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.***

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study: Mrs Melanie Handley ([m.j.handley@herts.ac.uk](mailto:m.j.handley@herts.ac.uk))

### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	There are separate information sheets and consent forms for patient, carer and staff participants and personal and nominated consultee information sheets and declaration forms.  Changes were made to the information sheets and consent/declaration forms following REC favourable opinion to bring in line with assessment standards (e.g. IRAS project ID, consent signatures and copies).
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities and Schedule of Events will act as the agreement between the sponsor and

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			participating NHS organisations.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No funding will be provided to participating NHS organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	The research includes adults who lack capacity to consent for themselves. There are appropriate arrangements for identifying personal and nominated consultees and consultee information sheets and declaration forms have been submitted.
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

## Participating NHS Organisations in England

*This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.*

There is one site type. Interviews, observations and data collection will be conducted at participating NHS organisations. Dementia ward staff at participating NHS organisations will be asked to take part in observations and interviews. Ward staff will also be required to support the research team with identifying potential participants and completing the Neuropsychiatric Inventory (NPI) questionnaire.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). The HRA will work with these organisations to achieve a consistent approach to information provision.

## Confirmation of Capacity and Capability

*This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.*

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

## Principal Investigator Suitability

*This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).*

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A Local Collaborator will be required at participating NHS organisations to facilitate access arrangements for the external research team.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

**HR Good Practice Resource Pack Expectations**

*This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken*

Letters of Access will be required for the external research team to conduct study activity at participating NHS organisations. Disclosure and Barring Service and Occupational Health checks will be needed where the study activity will be conducted in patient care areas of the NHS organisation or involves direct contact with patient participants.

**Other Information to Aid Study Set-up**

*This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.*

- The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

## Understanding what supports dementia-friendly hospital environments

Date: \_\_\_\_\_ Participant Identifier: \_\_\_\_\_.

Age: \_\_\_\_\_ Male / Female

Length of stay: \_\_\_\_\_.

Reason for admission and route of admission (e.g. transfer from A&E, transfer from another ward)

Diagnosis of dementia Yes / no\* If yes state

Current delirium status

Co-morbid conditions (list)

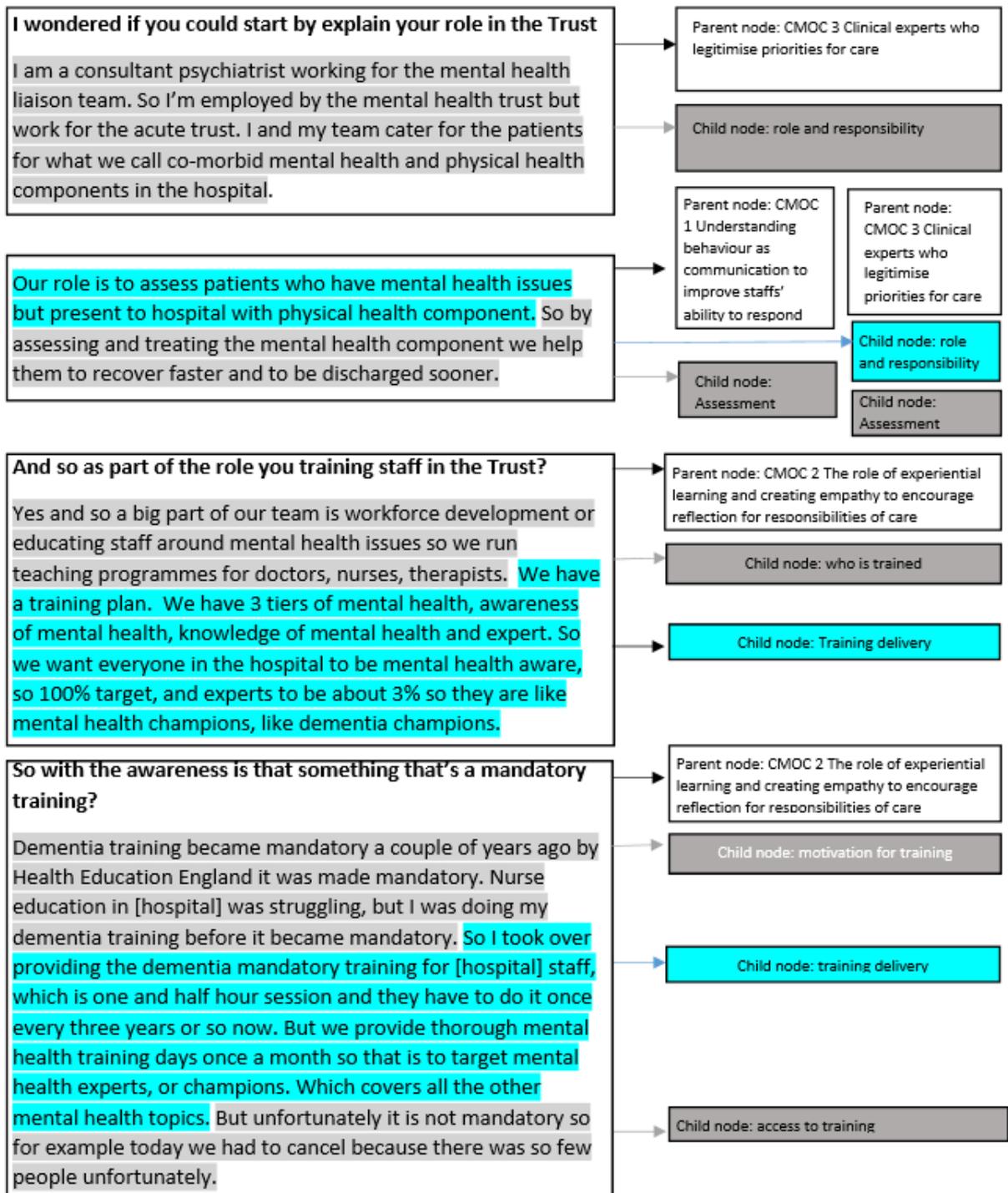
Medications (list)

Evidence of person centred care plan, if yes details

Evidence of adverse incidents in hospital, if yes details

Evidence of pain / treatment for pain

Place of admission and discharge (e.g. home, care home, nursing home)



**Do you also do training on the wards if someone comes in and has particular needs?**

That's right, so what you would probably call bedside training. So whenever there is a difficult situation and we feel we could improve how we approach that situation then we discuss it with doctors and nurses and health care assistants and everyone who is involved. And sometimes, we used to have case based discussions in some of the wards but that has not gone through with changes in the staffing levels and changes in ward sisters, etcetera. So I think that is something we might take up again.

Parent node: CMOC 2  
The role of experiential learning and creating empathy to encourage reflection for responsibilities of care

Parent node: CMOC 3  
Clinical experts who legitimise priorities for care

Child node: training delivery

Child node: advising staff

Child node: access to experts

Child node: access to experts

**With the tier 1 training are there particular areas that you focus on?**

Yeah, so Health Education England have objectives for the tier 1 training, so what dementia is, what are the symptoms of dementia, what types of dementia and what are the basic health services available for people with dementia for diagnosis and treatment and that kind of thing. A bit about the behavioural aspect and psychological aspect of dementia and what kind of treatment is available. But it is a bit of basic knowledge. I think what is more important is for people to understand that it is an illness, it's not normal ageing. To differentiate that and to identify what sort of symptoms they have to look for. So people think that sometimes it is just the memory but it might not be the memory, it might be the language, struggling to find the words or it might be struggling to identify things, or the personality change. Or even initial symptoms could be anxiety and depression because people are aware something's not right and they come up. I've seen it again and again, people presenting with anxiety disorders and six months down the line quite significant memory problems.

So I think it's raising the awareness to be looking for it rather than just waiting until it comes to you. I think actively looking for the possible symptoms and actively asking the questions from the families if you suspect that someone is slightly confused, asking the family is this baseline or is this new confusion. And by that if it is baseline confusion then you have to do something about it. Making sure that you alert the GP and that sort of thing.

Parent node: CMOC 2 The role of experiential learning and creating empathy to encourage reflection for responsibilities of care

Child node: training topics

Child node: addressing stigma/negative attitudes

Child node: addressing stigma/negative attitudes

Child node: knowledge from experience

Child node: intended staff actions

Child node: intended staff actions

So just, you don't have to be a doctor, a nurse, because nurses are the people who do day to day things and observe day to day functionality, so I think that is really important that they pick up those things.

Parent node: CMOC 1 Understanding behaviour as communication to improve staffs' ability to respond

Child node: Assessment

**With your role in the dementia strategy group I understand a care plan for dementia is being developed, can you explain how this will be used.**

So I was involved in the dementia care plan development, and so it's almost there now. But we couldn't meet last month, but we are meeting this Thursday and hopefully we will have a final version to go on a pilot, hopefully. When we first started the care plan it was 15 pages long, and we thought that's not going to be practical, so it's been reduced to 4 or 5 pages. So hopefully we will trail it, pilot it for a few months and see how people feel about it. I think my vision for dementia patients is that if somebody comes with dementia to have a more personalised care plan. Even the care plan we have now is not that personalised, it's just to alert people to what they have to do. But different people may have different needs.

Parent node: CMOC 3 Clinical experts who legitimise priorities for care

Child node: developing policies and plans

Child node: developing policies and plans

Child node: acceptability to staff

Child node: personalised care planning

What I see again and again is if people come in with a urine infection or a chest infection, they are more confused than their baseline and they are brought into a very unfamiliar environment which makes them even more confused. So they don't know where the toilet is invariably they become incontinent not because they, they were continent at home but bringing them into hospital they become incontinent. And if they are at risk of falls you try to restrict them to the bed or the chair, not allowing them to walk very much so they lose their muscle power very quickly, and we make them bedbound unfortunately and perhaps the first couple of days they may have quite significant delirium that they can't walk, but we don't encourage them to walk as quickly as possible and mobilise as quickly as possible because we are struggling with our resources. It's not because people don't want to do it, it's because we don't have the capacity. But I think it's quite sad putting them in the ward for a week, they have lost everything. And often they end up in a care home. I feel so helpless sometimes!

Parent node: CMOC 1 Understanding behaviour as communication to improve staffs' ability to respond

Parent node: CMOC 6 Building staff confidence to provide person-centred risk management

Child node: assessment

Child node: influence of risk on staff actions

Child node: influence of risk on patient outcomes

Child node: staff capacity

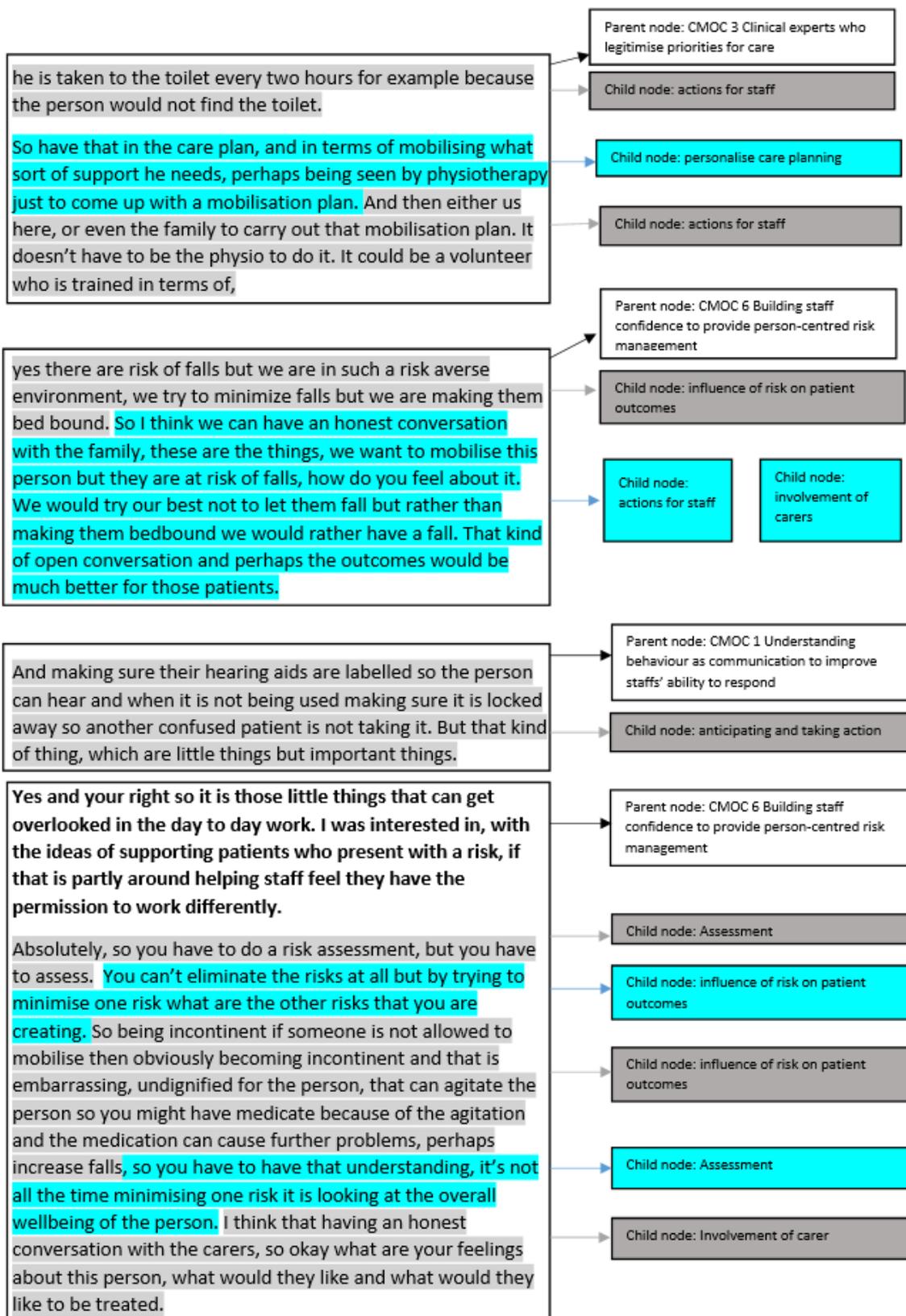
**Of course, because the staffing resources as they are, it's difficult**

It's difficult. In the meetings in dementia strategy what I ask them to do is 'okay in our ideal world what would be our ability to care for a person with dementia.' In my ideal world somebody comes with confusion, we have a personalised care plan and we know everything about this person. So this person wears hearing aids, he can't hear very well at all, he's mobilising very well at home, and continent so make sure that

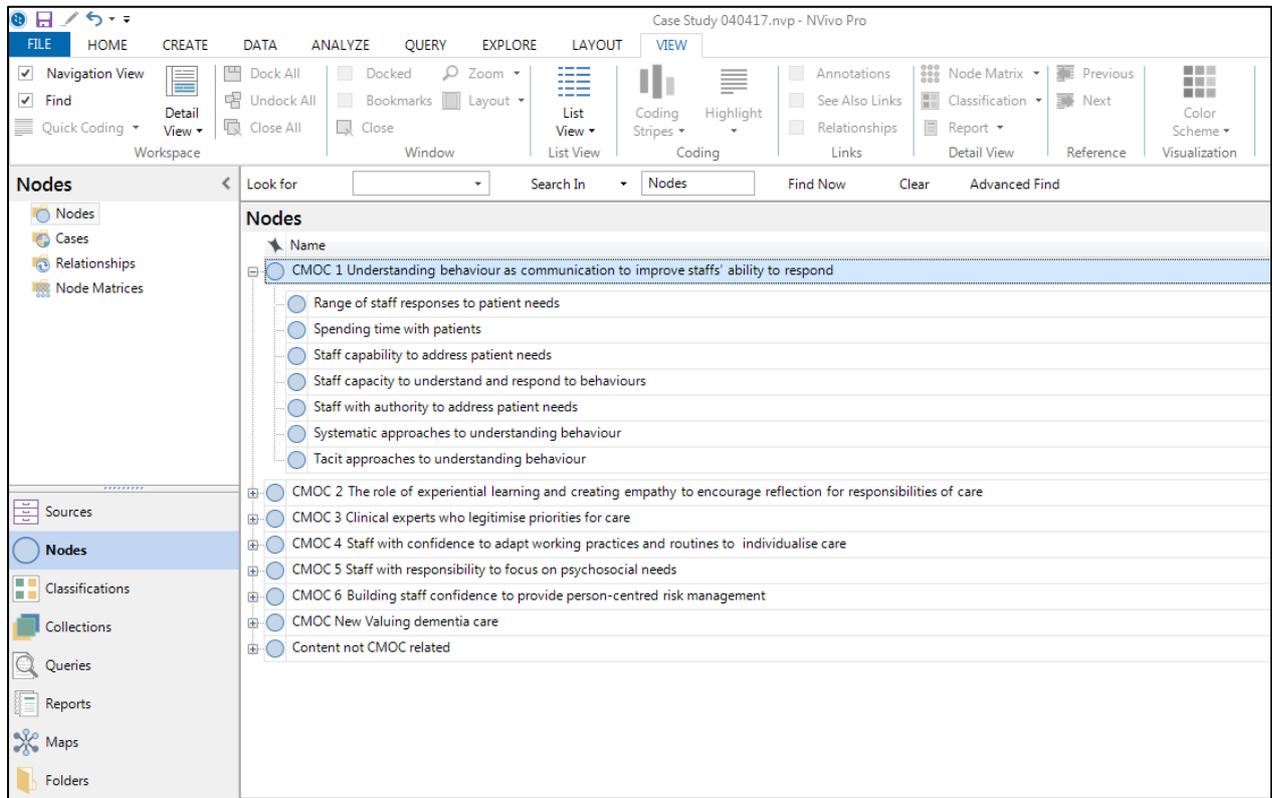
Parent node: CMOC 3 Clinical experts who legitimise priorities for care

Child node: personalise care planning

Child node: knowledge of patient



## Example of CMOC 1: Understanding behaviour as a communication to improve staffs' ability to respond



### Example data in Range of staff responses to patient needs

OB0102

9 has not left the bed bay but is stood in the entrance, she then turns and walks over to the front desk where three patients are sat. She stands at the desk and suddenly shouts “I can’t get out!” The AC enters the room and walks over to 9 and asks if she would like to help wipe down the tables as they are getting ready for lunch. 9 says “no, I must leave”. She walks out of the bed bay with the AC walking with her. The patients at the front desk look bemused. From the corridor I can hear 9 shouting “I can’t get out!” She walks back into the bay with the AC, the AC has her hand placed her right hand gently on 9’s left shoulder. She talks in a calm manner “9, we are having lunch now.” Her hand moves to be supportively round her back. The AC escorts 9 back to the middle table.

OB0104

16 is crying, she has her face in her hands, then she stops, looks up and round the ward and mutters. The HCA is now at 15’s bed on the left hand side taking her blood pressure (FN: early 15 had apparently been aggressive and had been administered some medication to calm her down). The HCA looks over at 16 and says “ah, don’t get upset, you’ve got 15 in the next bed, she’ll look after you.” The HCA has finished taking 15’s blood pressure, looks over at 16 and sees she is still teary, then she walks over to 11 sat at the front desk and turns to me as she does saying in a low voice “I might wait a bit.”

ST0203

I chatted to a gentleman the other day and he looked really bored and a bit restless and I said 'can I do anything to help?' and he said 'my radio's missing' and I said 'okay, I'll look for it and I looked for it and I couldn't find his radio in any of his belongings and I said 'well I haven't got your radio, but I've got the ward radio, can I put the ward radio on?' and he said 'oh yes that would be lovely.' And straight away he calmed right down after the music went on. So he just wanted some music on, he just wanted something to listen to.

OB0206

3 has her head in her hands. The CSW gets up to her, stands to her left hand side and says to 3 'you've got to eat something.' 3 turns to her and has a worried look in her eyes, she asks 'but what about the children?' The CSW says to her softly 'I think they've all been fed, don't you worry' and she rubs 3's left upper arm gently with her right hand. She stands with 3 for a moment.

OB0207

4 is pulling at her pipes and some of the dressing around the cannula and is saying (to no one) can you get this off my wrist please. The CSW has just come back in and goes over to 4. She puts her left hand gently on 4's right hand and says to her firmly 'no, this one we'll take it off when the drip has finished.' She then picks up the cup of tea off the table and says to 4 'have some more tea.'

### **Example data in Staff capacity to understand and respond to behaviours**

ST0116

often what is happening is the patient is frightened, it's what's going on. This is a person who, they are reacting in a way because something is going on, something that is quite scary to them. And if we can make them less scared and less distressed then we can manage them.

OB0103

6 has been walking round the ward. He is back at his bed, the bed rails are up, he is leaning over the bedrails pulling his blankets straight. HCA [1] has pushed the breakfast trolley round to the other side of the room close to 6's bed, he goes over to 6, stands behind him, and asks what he wants for breakfast. 6 answers, still straightening the bedding. The HCA [1] walks back to the trolley and makes up his order. The HCA then places the food on the bedside table and goes to move the table, however instead it block's 6's pathway to his bedside chair (7's curtains are drawn). 6 is currently standing on the other side of the bed, sees that breakfast is ready and he starts to walk round his bed. The HCA [2] goes up to 6 and asks if he would like a cup of tea. 6 smiles at this. HCA [2] goes to get a cup of tea. 6 navigates past the table to his chair. When HCA [2] returns with the cup of tea she sets the cup down on the table and then moves the table into position for 6.

ST0201

### **What makes it difficult for staff to provide good care?**

I think staffing and awareness of dementia and tolerance and people not understanding that they might be able to take it [being in hospital] because of unmet needs; if they've got pain, constipation,

they might be hungry and they might be tired, those areas. So making people aware that it might not be the dementia that is causing these things but it might be these needs. They [patients with dementia] can't express their need, I think that's a big area that needs to be, so some more education needs to be put into the staff.

#### **Example data in Systematic approaches to understanding behaviour**

*ST0107*

We always get briefed every day, in the morning we have handover when we start and at the end of the shift, we always get informed every day of any new plans for the patients and if we have to be careful if any patient is ill or any kind of special foods or things and if they are nil by mouth.

*ST0116*

And then obviously had some input into the [ward] behaviour chart which has then gone round the hospital. Which of the 17 / 18 interventions listed, only one is medication. You know, one is calling a doctor, one is around one-to-oneing someone, but pretty much there is around 14 interventions on there which are non pharmacological interventions, which aren't over medicines, do they need the toilet, do they need something to do because it's boring being in hospital, those sorts of things. So that is the sort of thing we go through with the nurses when we are doing that training. And with the doctors as well, sometimes as well.

*OB0107*

The 2 Dr's are at the middle table discussing the behaviour chart of 4, they are trying to understand the pattern of his aggressive and violent behaviour and mention sundowning as a possible explanation.

*OB0109*

The consultant on the bed gets 9's attention and begins to ask her about her hallucinations. She asks when she started seeing the insects and animals. 9 looks confused for a moment. The consultant continues by asking if it started in hospital or at home. 9 confirms it had started at home. The consultant says to 9 that was what she wanted to know, if she had been seeing them before or after she came to hospital. 9 nods. The consultant then begins to ask her a little about her living arrangements and begins to discuss the possibility of getting her home with some support. 9 nods. The consultant then wraps up the meeting and the doctors go back to the medications table. The consultant talks about the possibility of some sort of dopamine medication.

*ST0201*

I think how dementia patients communicate, making staff aware of how they might communicate through aggression and agitation, that side of communication, make them think it is not the dementia and assuming something is wrong. But then making sure staff are filling out the right charts, so food charts, stool charts, and keeping a record, so they might be constipated, so making sure people fill in the forms and help people communicate. Especially with the turnover of staff, the shift patterns, if it is all documented and the communication will help as well. The hands on of speaking to the patient, and speak the families as well and not communicating, so asking them questions about how they are managing at home, making them more aware of the person for personalised care.

*ST0202*

I mean the dysphasia with dementia, being assessed by the SALT teams, as you know is very common.

*OB0202*

1.20 The CSW ward and CSW 1:1 are talking about the support needs for patient 4. The CSW ward says to the CSW 1:1 that she will go and update the RN and ward manager and put it in the patient notes that 4 is not to have male support. The CSW 1:1 then comes over to me and explains that they now know why 4 cannot have a male CSW 1:1 and that everyone is being updated to change the care plan.

## **Understanding what supports dementia-friendly hospital environments**

### **Invitation: Would you like to take part in some research?**

By research I mean finding answers to questions that can help to improve hospital services for people like yourself.

#### **You do not have to take part in the research**

Before deciding whether to take part, please read this or ask someone to help you read it.

This will tell you what the research is about and what I would like you to do.

I would like to find out about your experience of hospital.

#### **Who is involved in this study?**

The study is part of a PhD that is being funded by the Alzheimer's Society.

The study is based at the University of Hertfordshire.

Claire Goodman and Frances Bunn are supervisors on the study.

Melanie Handley is the student.

#### **What is this study about?**

People living with dementia are admitted to hospital for many reasons.

Hospitals are trying to improve their services for people living with dementia.

I would like to know about your stay in hospital.

### **Why have you been approached about the study?**

As someone living with dementia, I would like you to contribute your experiences so I can understand what is important to you.

### **What is involved?**

I would like to learn from your experiences to improve hospital care for people like you.

With your permission I will

- Make notes of what I see and hear happen between yourself and other people on the ward during mealtimes, clinical rounds, assessments, care, and activities.
- I will talk with staff, patients and visitors about what I see and hear so I understand what is happening and why.
- I will not see personal care or consultations behind curtains, but will I be able to hear what takes place and might make a note of this.
- I will be typed up notes from what I see and hear.
- I will look at your medical notes about why you were admitted, your dementia diagnosis, your health, medication use, care plans and discharge destination
- I will use the Neuropsychiatric Inventory Questionnaire to collect information about your mood and behaviour. This will be completed with a member of staff

- I will interview patients, carers and hospital staff about how care for people living with dementia is provided in ways that recognise the difficulties they experience due to their dementia.

The study will use this information to understand what good care looks like in hospital settings for people like you and how it can be provided.

### **If you are happy for me to make notes about your hospital stay**

I will make notes for between 2 to 6 hours.

I will not write down information that identifies you.

You can decide to stop at any time.

If you decide to take part you will still be free to withdraw at any time and without giving a reason and any information related to you will not be used in this study.

I will type up the notes.

I may use some of the things in a report of the research.

I will not use your name in the report.

### **Will taking part be confidential?**

All data will be stored securely in password protected computers and secure University computer systems.

At the end of the study, anonymised data (data which does not identify any one who has taken part) will be archived for up to 15 years.

You will not be identifiable in any written reports.

Your name will only be on the consent form you sign.

The consent form will be stored in a locked cabinet which can only be accessed by the study researchers.

All information about you for the research will be confidential. But, if, during the observations, you see or am told about something where you, or someone else is at risk of harm I may need to tell someone as required by the rules on safeguarding, and your identity may have to be passed on. I will explain what has happened to [insert name], the Lead Nurse Adult Safeguarding in the Trust, or to another person depending on the circumstances. I may need to complete a form, if advised to do so, or involve others. If this happens I will keep you informed.

### **What will happen to the study findings?**

The study will report its findings to help improve hospital services for people living with dementia and their carers.

### **Are there any risks in taking part?**

There are no risks in taking part in the study.

### **Do I have to take part?**

You do not have to take part if you do not want and need not give a reason.

### **I would like to take part, what should I do next?**

If you wish to take part, please contact Melanie Handley, she will be visiting the ward shortly.

Tel: [x] Email: [\[x\]](#)

### **Who has reviewed the study?**

Research projects are scrutinised by ethics committees whose job is to protect the interests of everyone who takes part.

This study has been reviewed by the East of England – Essex Research Ethics Committee which has made a favourable judgement.

### **How do I contact the researchers?**

You can contact us directly:

**Melanie Handley**, PhD Student

Tel: [x] Email: [\[x\]](#)

**Claire Goodman**, Professor of Health Care Research,

Tel: [x] Email: [\[x\]](#)

**Frances Bunn**, Reader in Evidence Based Health Care

Tel: [x] Email: [\[x\]](#)

Address:

Centre for Research in Primary and Community Care

University of Hertfordshire,

College Lane, Hatfield, Herts. AL10 9AB

## Understanding what supports dementia-friendly hospital environments

### *Information for staff: Observation*

#### **Invitation**

A PhD student from the University of Hertfordshire is undertaking a study to understand dementia-friendly environments in hospitals and identify what factors might lead to positive outcomes for patients and their carers.

Your ward [insert ward name] is participating in the study and as part of the study we will be observing patient and staff interactions on the ward [insert ward name] to understand the patient experience of care.

We would like to invite you to take part in an interview for the study. It is important to understand why the study is being undertaken and what it will involve. This leaflet explains how you can take part, and what this would mean for you. Please read the following information carefully and discuss it with colleagues or family if you wish. You can ask Melanie Handley, the research student, or Claire Goodman or Frances Bunn, the research supervisors, about anything else you would like to know, or for further information if you require it. Contact details for the research team can be found at the end of the leaflet.

#### **Who is involved in this study?**

This study is part of a PhD that is being funded by the Alzheimer's Society.

Claire Goodman and Frances Bunn are supervisors on the study based at the University of Hertfordshire. Melanie Handley is the research student who is conducting the study for the University of Hertfordshire. All members of the team have extensive experience of research in health care with particular focus on issues affecting older people who have cognitive impairment.

## **What is this study about?**

People living with dementia often have multiple health care needs and may need an admission to hospital. Hospitals are recognising the complexity of caring for people with dementia. Interventions have been developed to make hospitals more 'dementia-friendly'. By this we mean that the care provided and the environment are appropriate for people living with dementia. Examples of dementia-friendly initiatives include adaptations to physical environments to assist orientation and engagement, schemes which raise staff awareness of issues in dementia care, staff training, and the involvement of family carers in care discussions. However, research to understand what it is about these interventions that produce successful outcomes for patients and family carers is lacking. The study aims to understand these features and develop a framework to help commissioners consider what kind of service provision and initiatives are likely to be most useful in hospital settings and for which patient groups

## **Why have you been approached about the study?**

As a staff member working on ward [insert ward name], we would like observe the way care is delivered to people living with dementia in hospitals. We would like to understand how care has been adapted to allow for the difficulties they have due to their dementia. This information will help us to highlight the most important features that support the implementation of dementia-friendly interventions in hospitals.

## **What is the study going to do?**

The study is in two parts. In the first part of the study, we looked at the range of dementia-friendly interventions in hospitals and the research studies on their effectiveness. We also talked to commissioners, hospital staff, people living with dementia and carers, and academics, to ask them how different interventions were thought to work and why. We have combined the information from the interviews and research, to highlight different ways that dementia-friendly hospitals can be achieved.

For the second part of the study we have identified hospitals that work in different ways to support people who are admitted to hospital and have dementia. We will test how the different ways of working impacts on patient and carer outcomes. The outcomes are; patient and carer inclusion in decision making, length of stay and destination of discharge, adverse incidents (such as infections, falls), medication use, assessment of needs, patient and carer satisfaction. With the permission from people recruited to the study, we will

- Observe patients and staff in the ward; making notes of what is seen and heard from conversations and interactions during mealtimes, clinical rounds, assessments, care, and activities. The researcher will not see personal care and consultations performed behind curtains, but will be able to hear conversations that take place and these might be included if relevant to the study. During observations the researcher will talk with staff, patients and visitors to make clear her understanding what happening and why. Notes from observations will be typed up by the researcher. Observations will be between 2 and 6 hours.
- Recording information from patients' medical notes about their reason for admission, dementia diagnosis, their health, medication use, care plans and discharge destination
- The Neuropsychiatric Inventory Questionnaire will be completed with a member of staff to collect information about the mood and behaviour of patients
- Interviewing patients, carers and hospital staff about how care for people living with dementia is provided in ways that recognise the difficulties they experience due to their dementia.

The study will use this information to understand what dementia-friendly health care looks like in hospital settings and how it can be provided. This will be used to explain what needs to be in place to support staff to provide good dementia care.

### **What will happen to me if I take part in the study?**

Melanie will observe interactions with staff, patients and visitors on the ward and make notes of what she sees and hears, for example during mealtimes, medication rounds and other times of contact. Melanie will not observe personal care, but will be able to hear interactions that occur behind drawn curtains. She may make notes of what she hears if it is of relevance to the study. Observations will last between 2 and 6 hours.

### **Are there any risks in taking part?**

We do not envisage any risks for staff who agree to take part in the study.

### **Do I have to take part?**

Taking part is voluntary and is entirely up to you. You do not have to take part if you do not want and need not give a reason; the research team will respect your wishes whatever you decide. If you decide to take part you will still be free to withdraw at any time and without giving a reason and any information related to you will not be used in this study.

### **Will taking part be confidential?**

All information relating to you as a result of this research will be confidential. All data will be stored securely in password protected computers and secure University computer systems. At the end of the study, anonymised data (data which does not identify any one who has taken part) will be archived for up to 15 years. You will not be identifiable in any written reports. Your name will only appear on the consent form you sign. The consent form will be stored in a locked cabinet which is only accessible to the study researchers. All information about you for the research will be confidential. But, if, during observations, the researcher witnesses something that suggests someone else is at risk of harm I may need to tell someone as required by the rules on safeguarding, and your identity may have to be passed on. I will explain what has happened to

[insert name], the Lead Nurse Adult Safeguarding in the Trust, or to another person depending on the circumstances. I may need to complete a form, if advised to do so, or involve others. If this happens I will keep you informed.

Although every effort will be made to anonymise published information, there is a small chance staff may be identifiable due to the nature of interactions or their role. To minimise this risk we will ensure:

- Any contribution you make will not be identifiable in the study reports, we will not use names.
- Where staff could be identifiable from their job title, band groupings (e.g. Band 1 – 4, Band 5 – 6, Band 7+) or generic job titles such as ‘Senior Manager’ will be used rather than specific job titles.
- Where necessary, changes will be made to characteristics that might make staff identifiable, for example for a person’s gender.

### **What will happen to the study findings?**

A report will be provided to the Alzheimer’s Society funding the study. All participants will receive a summary of the main findings; they will also be presented to NHS providers, conferences and published in journals.

### **I would like to take part, what should I do next?**

If you wish to take part, Melanie Handley will be your main contact for this study. Please email or call Melanie Handley (contact details below). She will be in touch with you soon to arrange an appointment and to discuss any questions you might have and ask you to complete a consent form.

### **I would not like to take part, what should I do next?**

Enclosed with this information leaflet is a reply slip to opt out of the study, this should be completed and returned to Melanie either by hand or using the enclosed stamp addressed envelope.

**Who has reviewed the study?**

Before they can go ahead, research projects are scrutinised by ethics committees whose job is to protect the interests of everyone who takes part.

This study has been reviewed by the East of England – Essex Research Ethics Committee which has made a favourable judgement.

## **How do I contact the researchers?**

You can contact us directly:

**Melanie Handley**, PhD Student

Centre for Research in Primary and Community Care

University of Hertfordshire,

College Lane, Hatfield, Herts. AL10 9AB

Tel: [x]

Email: [\[x\]](#)

**Claire Goodman**, Professor of Health Care Research,

Centre for Research in Primary and Community Care

University of Hertfordshire,

College Lane, Hatfield, Herts. AL10 9AB

Tel: [x]

Email: [\[x\]](#)

**Frances Bunn**, Reader in Evidence Based Health Care

Centre for Research in Primary and Community Care

University of Hertfordshire,

College Lane, Hatfield, Herts. AL10 9AB

Tel: [x]

Email: [\[x\]](#)

**[Trust]**

# Research Study

## Understanding what supports dementia friendly hospital environments

This poster is to inform you that [Trust] is working with the University of Hertfordshire on the above study to undertake research that aims to understand patient experience.

The study began on [date] and will run until [date].

We would like to find out:

- What good care looks like for people living with dementia and their carers
- How good care is supported by staff and the hospital
- How resources to support good care with people living with dementia are used

During periods of observation, the researcher will be taking notes. Personal information is not being collected and all information that may appear in written reports will be anonymous. If you would prefer that notes are not taken about you, please inform the researcher, Melanie Handley [picture below], who will respect your request.

[picture of Melanie Handley]

**Form more information please contact:**  
**Melanie Handley**  
Centre for Research in Primary and Community Care,  
University of Hertfordshire  
Tel: [x]  
Email: [x]

[Trust] lead for this study is: [staff member and contact details]

This study is funded by the Alzheimer's Society. This study has been approved by [name] Research Ethics Committee, and has R&D approval from [name].  
Information Poster: Poster v2 25.07.16, IRAS project ID 192294

## **Protocol for establishing and dealing with bad practice and concerns for safeguarding**

### **Who is this protocol aimed at?**

- Research staff involved in data collection in hospitals.

### **What is the purpose of this document?**

- The aim of this document is to rationalise a procedure for dealing effectively and sensitively with bad practice or concerns for safeguarding uncovered in hospitals during the research.

### **What constitutes bad practice or concerns for safeguarding?**

- Any concerns a researcher has relating to the care that could impact on the well-being of hospital patients or staff. The research team will be concerned with issues of a serious nature, more specifically issues of abuse, neglect, unreported criminality, unethical practice and serious misconduct. It is essential for the research team to focus on factual information, refraining from becoming emotionally involved in a given situation.

### **When an adult at risk who is making a disclosure (or the person raising the concerns) the researcher will:**

- Assure them that they are being taken seriously.
- Listen carefully to what they saying, stay calm, get as clear a picture as possible but avoid asking too many questions at this stage.
- Not give promises of complete confidentiality.
- Explain that there is a duty to tell the study supervisors and other designated people within the Trust, and that their concerns may be shared with others who could have a part to play in protecting them.

- Reassure the ‘adult at risk’ that they will be involved in decisions about what will happen, wherever possible and providing that it is safe and appropriate to do so.
- Not be judgemental or jump to conclusions.

### **What action should be taken when bad practice is observed and identified?**

- For those issues considered by the research team as bad practice, initial discussions will take place with the Supervisors, Professor Claire Goodman and Dr Frances Bunn. Together a judgement can be made about whether an issue constitutes bad practice and whether action to pursue the issue further is necessary. Where it is considered that the witnessed or reported incident, or suspected incident, is of a serious nature that a patient is at risk of immediate harm, the researcher will raise concerns immediately with the appropriate member of Trust staff, either the Ward Manager or, where this is not appropriate, the Safeguarding Team.

### **Actual or suspected abuse, neglect, risk of harm, or unreported criminality**

Where the researcher witnesses or is told about actual or suspected abuse or neglect, risk of harm, or unreported criminality, the researcher has a responsibility to report their concerns immediately to the Ward Manager, or if this is not appropriate (e.g. the incident involves them) to the Trust Safeguarding team.

- All cases of suspected or actual abuse will be treated seriously from minor to serious incidents. If the researcher has concerns, these will be raised and reported.
- The researcher will act promptly and report concerns. This will allow staff involved in the care of the patient, or the safeguarding teams within the Trust to address the concerns and follow the Trust protocols to protect the patient.

## **Informing the study supervisors, ward manager and/or Safeguarding teams**

- The researcher will inform the study supervisors and, if appropriate, the nurse in charge of the ward/department/shift immediately about the safeguarding concerns. The Trust staff will then follow Trust safeguarding procedures.
- If it is not appropriate to inform the nurse in charge of the ward, for example the concern involves them, the researcher will inform the Lead Nurse for Adult Safeguarding.
- The research team must also request that the hospital provides feedback, stipulating how the issue has been resolved. However, the research team should not allow the organisation to delay or detract them from making a formal complaint if necessary.

### Formal Complaints Procedure

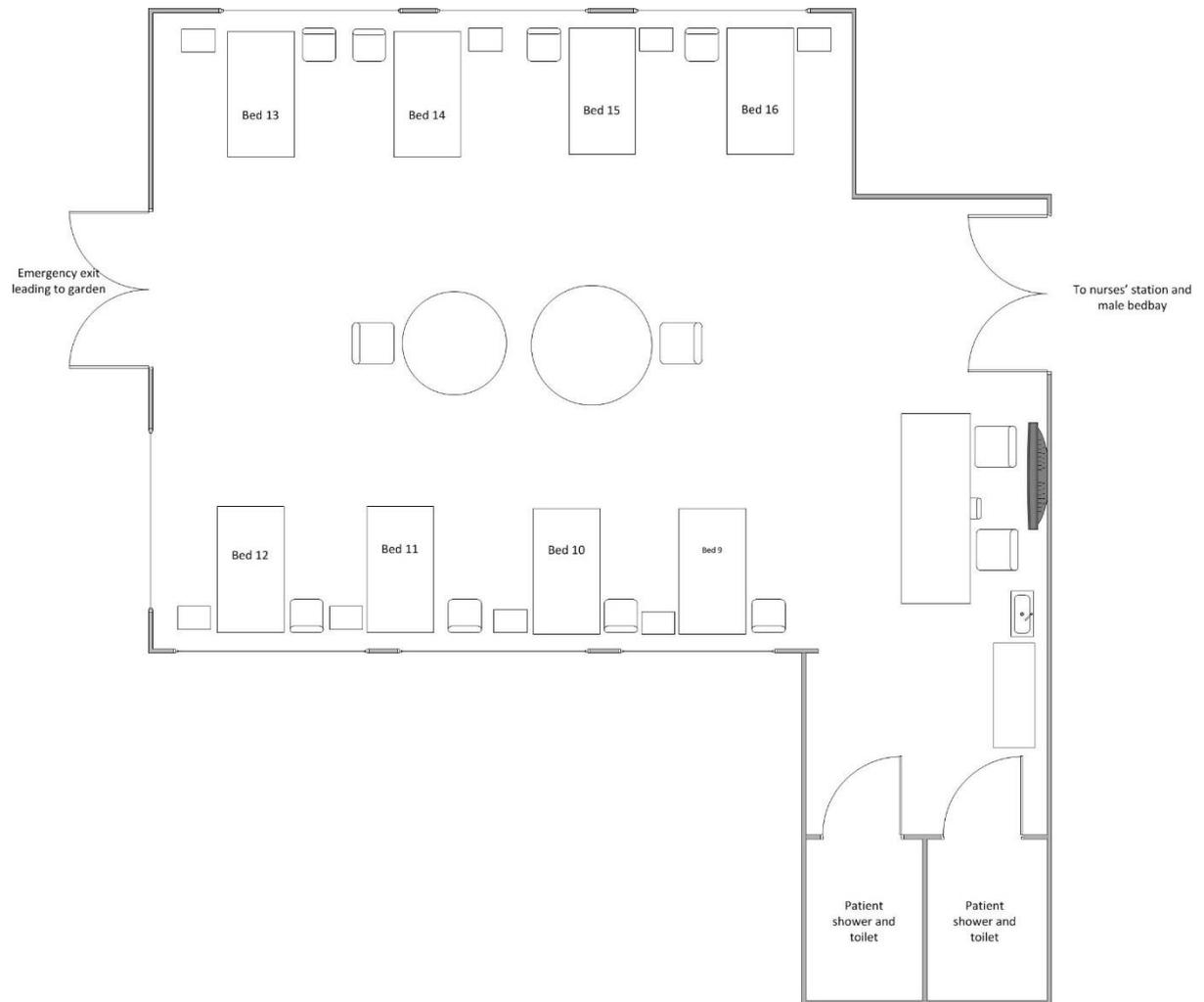
- If the research team are dissatisfied with the way that their concerns have been dealt with they should move to a formal stage. NHS trusts have their own formal complaints procedures and these will be followed accordingly.
- A record of telephone conversations must be kept concerning formal complaints, and information provided to the researcher verbally should also be requested in a written format.

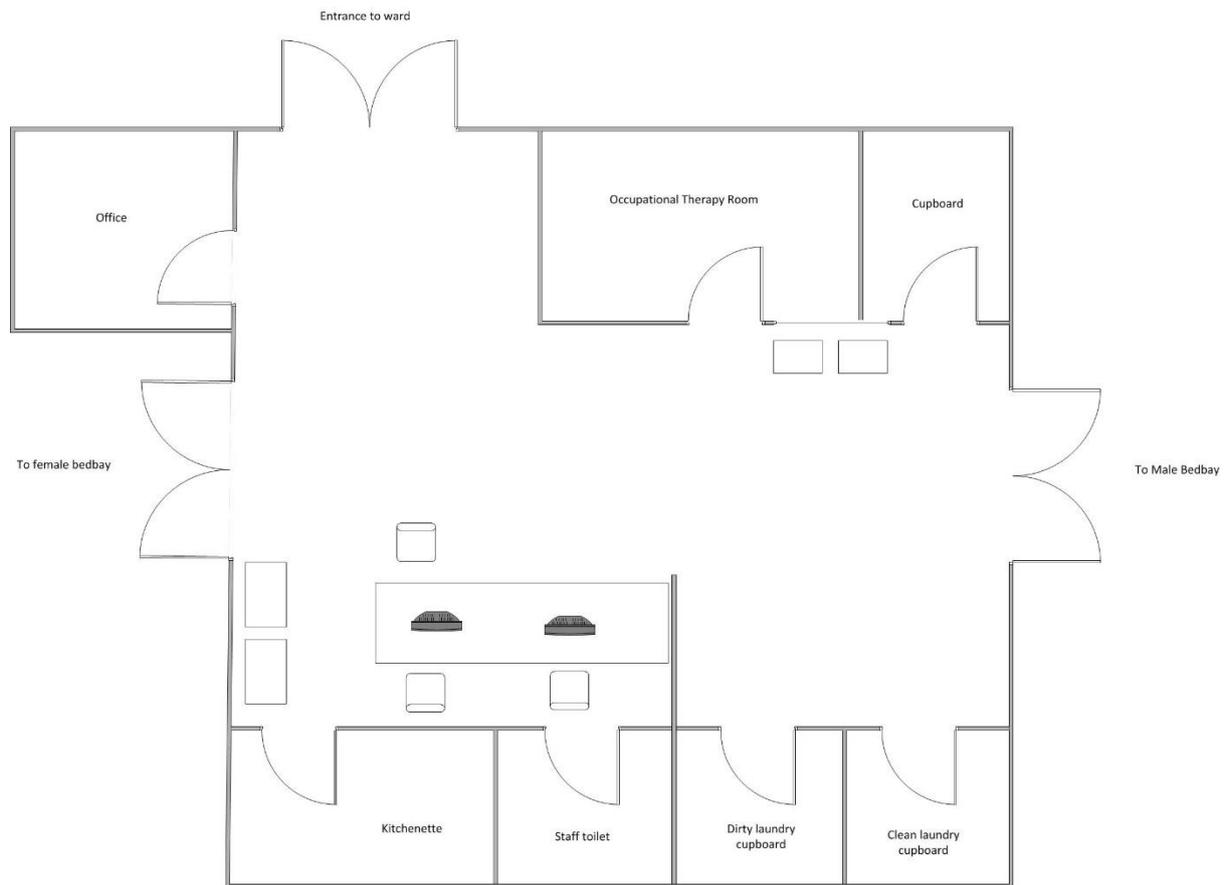
Trust Safeguarding Team Contact details:

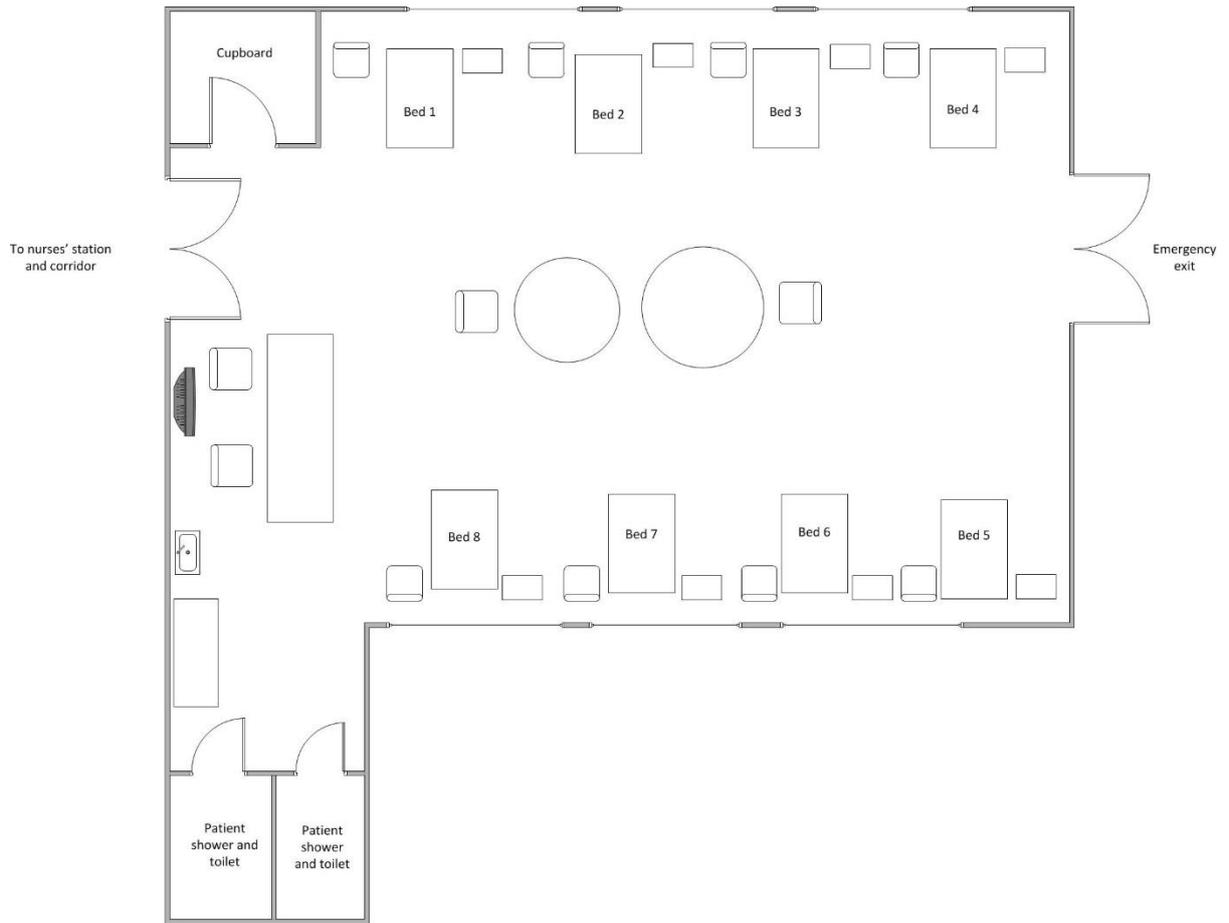
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Contact: [\[x\]](#)

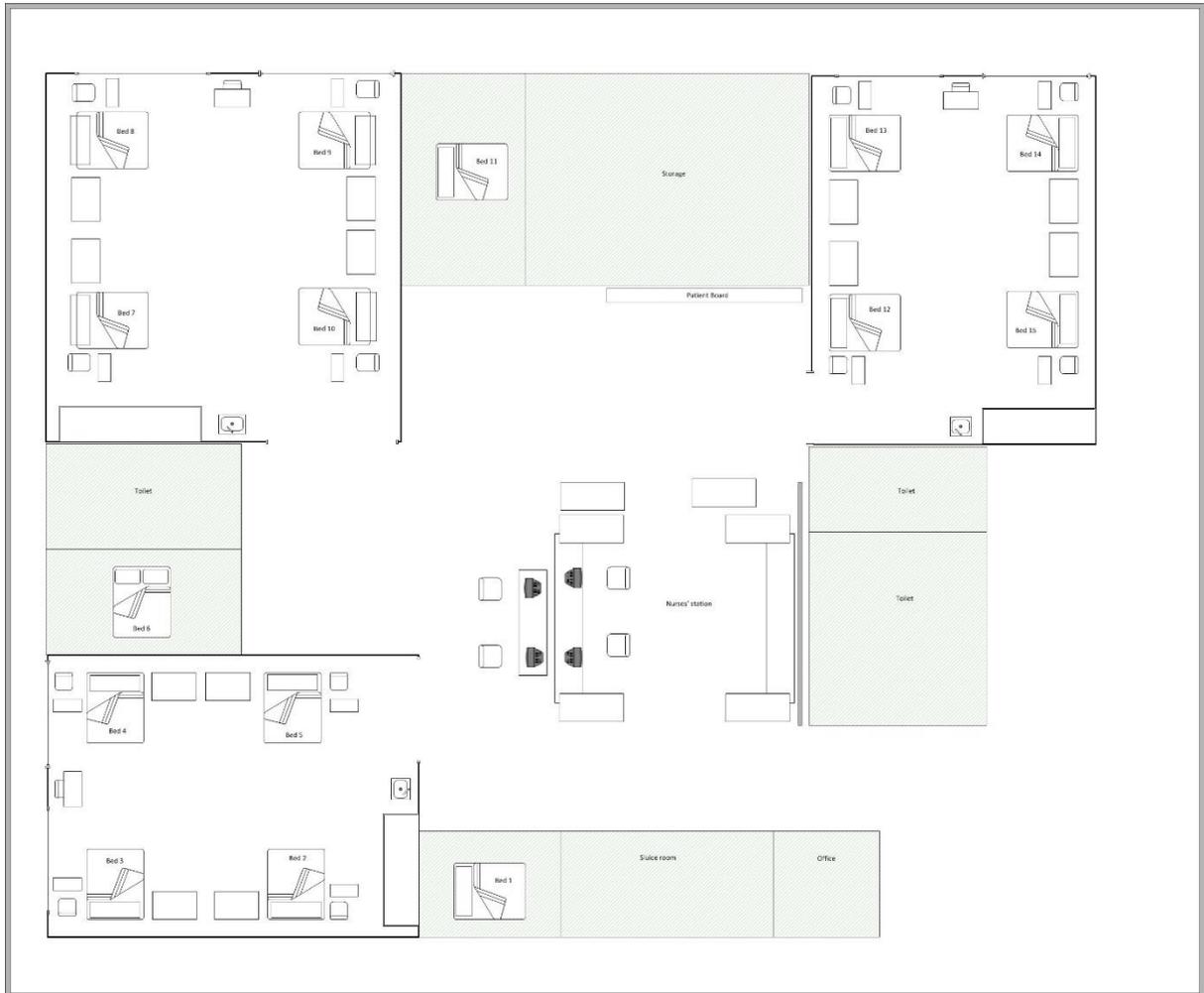
Appendix 18: Floorplan for site 1







Appendix 19: Floorplan for site 2



Appendix 20: Range of responses used by staff

Behaviour / concern	Approach	Types of interactions	By whom	With what affect
Risk of falls	Monitoring	Watching from a distance  Going to patient when attempt to move and asking about need/behaviour	Nurses (site 1), HCA, CSW, 1:1	Variable; calm, compliance, frustration
	Restricting movement	Sitting with patient and explaining where they are and that they need to sit down  Restricting movement using barriers (bedrails, furniture, own body)	HCA, CSW, 1:1  HCA, CSW, 1:1	Variable; compliance, reduced distress, annoyance  Frustration, increased distress
	Supporting mobility	Walking with and talking to Supporting with mobility aid use	HCA, CSW, 1:1	Patient wellbeing, maintaining mobility
	Spending time with patient	Engage in conversation or activity	HCA, CSW, 1:1, AC	Patient wellbeing

Distressed patient / physically disruptive to the ward  (pacing round ward (site 1 only), high anxiety communicated through expressed worries)	Distraction	Distract with offer of food or drink	Nurses, HCA, CSW, 1:1, AC	Variable; brief respite from distress to increased distress
		Visual prompt for distraction (leave something in front of patient)	AC	Brief respite from distress
		Involve in ward activities (such as laying the table)	Nurse (site 1), AC	Variable; calm to no difference
	Reassure	Explain where are and why there	Nurses, HCA, CSW, 1:1, AC	Variable; calm to brief respite from distress
	Biography	Biographical (ask about interests, family, job)	Doctors, Nurses, HCA, CSW, 1:1, AC	Variable; calm and focused to more distress
Distressed patient / not physically disruptive to ward (e.g. calling out from bed)	Find out why calling out	Ask patient about their need	Doctors, Nurses, HCA, CSW, 1:1	Variable; sometimes calm where need identified and addressed, sometimes unchanged when need identified and addressed, sometimes need not identified
	Ignore / not address	Do not go to patient	Doctors, Nurses, HCA, CSW, 1:1, AC	Calling out continues
Physical aggression and violence	De-escalate	If patient and staff safe, step away from interaction and monitor at distance	Nurses, HCA	Reduced patient distress

	Security	If patient dangerous security called	Nurses, HCA, CSW	(not observed but reported) Unclear
	Medication	If patient aggression not reducing, staff use of PRN medication	Nurses	Reduced distress
	Assess (following incident)	Refer to patient notes, consult with patient and other staff	Doctors and psychiatrists	Attempt to understand causes and ways to reduce incidents
Verbal aggression	Ignore	Where not directed at anyone	Nurses, HCA, CSW, 1:1, AC	Variable; could reduce, could continue
	Address	Explain to patient behaviour is unacceptable	Nurse	Stops, length of time variable
	Diffuse	Use humour to diffuse	HCA	Stops one off verbal aggression, unclear in persistent
	Empathise and explain	States understands why patient is angry and explains options to help	1:1	Variable
Sadness	Concern and comfort	Touch, eye contact, hug	Nurse, HCA, CSW, 1:1, AC	Variable
	Biography	Distract with interests	Nurse, HCA	Brief respite
Expressions of concern for family (who may or may not be alive)	Distraction and deception	Explain they will be in later (without knowledge if they will) and offer drink	Nurses, HCAs, CSWs, 1:1	Brief respite, but may return to asking
	Validate and comfort	Explain family know they are	HCA, CSW, 1:1	Some respite, but may return to asking

		being looked after by staff and comfort with touch/hug		
	Biography	Ask or engage in chat about family member	HCA, CSW, 1:1	Dependent upon time spent
Walking round ward (site 1 only)	Restrict to area	Keep in a bay, return to seat	Nurse, HCA, AC	Patient safety but may cause frustration
		Walk and talk with patient	Nurse, HCA, AC	Patient wellbeing
Trying to leave (site 1 only)	Distract	Offer drink or food	Nurse, HCA	Limited affect, might stop briefly
	Monitor	Observed from a distance and intervene if necessary	Nurse, HCA	Maintains patient safety
	Stop from leaving	Speak to patient calmly, encourage to return to ward	Nurse, HCA	Returns to safer area, may try to leave again
		Block path	Nurse	Returns to safer area, may try to leave again