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Improving Care for People with Dementia in NHS Continuing Care Facilities: Enhancing the Mealtime Experience for Older Patients, their Relatives and Staff

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for the degree of Doctor of Philosophy
in Social Policy

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ABSTRACT

The study focused on mealtimes in two NHS Continuing Care facilities for people with dementia. The overall aim of the study was to collaboratively develop and implement small-scale interventions to improve the tone and nature of meals on the ward, enhance service user, relative and staff experiences of meals and mealtimes, and improve service user nutrition and hydration levels. It was predicted that interventions collaboratively developed with service users, relatives/carers and staff would likely be adopted and effective. In order to evaluate mealtimes and their change over time, the study employed mixed methodologies and measured physiological (e.g. nutrition and hydration), environmental (e.g. mealtime set-up) and psycho-social (e.g. engagement and emotion) dimensions of mealtimes. The study found that while all stakeholder groups on both wards generated a high volume of ideas for improvement, organisational and micro-cultural factors adversely affected implementation. Also, the chosen interventions successfully addressed physiological aspects of mealtime experiences (overall, patients on both wards gained weight, which was in contradiction to both research and practitioner expectations; see Abbasi & Rudman, 1994). However, social aspects of mealtimes were often overlooked by ward staff and did not show substantial improvement. Additionally, comparisons of research sites revealed that micro-cultural processes within the wards determined both the way mealtimes were experienced and their potential for change/improvement. The study, therefore, demonstrated that while enhancing mealtime experiences on Continuing Care wards is possible, it is also a highly complex and multifaceted process, often not taken into account by organisational and national-level policies and care guidelines.

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DECLARATION OF ORIGINALITY

This is to certify that to the best of my knowledge, the content of this thesis is my own original work.

- This thesis has been composed solely by myself.
- The intellectual content of this thesis is the product of my own work and all the assistance received in preparing this thesis and sources have been acknowledged.
- This thesis has not been submitted for any other degree or purposes.

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ACKNOWLEDGEMENTS

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ABBREVIATIONS

BMI	**Body Mass Index**
CC	**Continuing Care**
CQC	**Care Quality Commission**
DOH	**Department of Health**
EdFED	**The Edinburgh Feeding Evaluation in Dementia Scale**
HCA	**Healthcare Assistant**
IPA	**Interpretative Phenomenological Analysis**
LA	**Local Authority**
LTC	**Long-term care**
LTDC	**Long-Term Dementia Care**
MNA-SF	**Mini Nutritional Assessment (Short Form)**
NHS	**National Health Service**
PWD	**People with dementia**
QoL	**Quality of Life**
UK	**United Kingdom**
USA	**United States of America**
WHO	**World Health Organisation**

Chapter 1
INTRODUCTION

Dementia currently affects around 850,000 people with dementia in the UK; a number predicted to rise to over 1 million by 2025 and over 2 million by 2051 (Alzheimer's Society, 2014). One in three people with dementia (PWD) live in long-term care facilities and 80% of long-term care residents have dementia or severe memory problems (Alzheimer's Society, 2014). Despite its prevalence and increasing policy interest in dementia (Department of Health, 2012) it remains significantly under-researched. For every million pounds in health and social care costs, dementia receives under £5000 of research investment (more than 26 times less than investment in cancer research; Alzheimer's Research UK, 2013).

Mealtimes are an important part of all people's lives (Larson et al, 2006), but have a heightened importance for people with dementia. For people faced with deteriorating cognitive abilities, mealtimes can provide a structure to the day, be a meaningful activity where other activities and interests can no longer be practiced, provide sensory enjoyment and social opportunities, and, of course, ensure adequate nutrition and hydration (Berg, 2006).

Literature on mealtimes in long-term dementia care, however, suggests that the aforementioned potential of mealtimes is rarely utilised. Instead, malnutrition is common in long-term care for older people with or without dementia (Abbasi & Rudman, 1994), while undernutrition / low food intake is associated with higher mortality and morbidity rates (Janssen, Katzmarzyk, & Ross, 2005). Specifically for PWD in LTC, being at risk of malnutrition is associated with eating/swallowing difficulty (Edahiro et al, 2012), severity of dementia (Chang & Roberts, 2011; Lin et al, 2010), not receiving feeding assistance (Lou, Dai, Huang, & Yu, 2007), difficulty beginning a meal (Edahiro et al, 2012), shorter amount of time devoted to eating (Chang & Roberts, 2011) and fewer family visits (Lou, Dai, Huang, & Yu, 2007). The importance of family visits further suggests that malnutrition (and mealtimes in general) are related not only to physiological, but also relational processes.

Research literature has also demonstrated that food intake for people with dementia (PWD) in long-term care settings can be improved by changing food composition (e.g. high-calorie, high-protein meals; Keller, 2003), use of high-calorie oral supplements (Hanson et al, 2011), specially-composed music (Ho et al, 2011), making the mealtime environment more homelike (changing table dressings, food setting, seating arrangements; Nijs et al, 2006),

person-centered staff approach (validation, connecting, inclusion, empowerment, relaxed pace; Hung & Chaudhury, 2011) and 'Integrity Promoting Care' (supporting autonomy, stimulating patient initiative, improving communication; Mahmidir, 2007).

Despite the accumulation of findings, notable knowledge gaps remain. Literature is dominated by quantitative medical research, focussing almost exclusively on (mal)nutrition and (de)hydration (Hanson et al, 2011). Even when environmental, psychological or social aspects of mealtimes are taken into account, existing research tends to focus on a singular and predetermined interventions to improve meals or mealtimes (Aselage, 2010). Also, while there is a small number of ethnographic studies, which explore mealtimes in long-term care settings more holistically and incorporate multiple dimensions of mealtimes (Hung & Chaudhury, 2011), there are no UK-based studies to date. Also, within studies with a holistic approach, limited focus is placed on *both* investigation and improvement.

To address these knowledge gaps, the research project discussed within the thesis aimed to explore mealtime experiences on NHS Continuing Care wards and collaboratively develop small-scale interventions to improve meals and mealtime experiences for people with dementia, their relatives, and ward staff in two NHS Continuing Care facilities.

The thesis starts with discussing what dementia is, along with the types, distribution of dementia care. long-term dementia care is covered in more detail, with a specific focus on NHS Continuing Care. Chapter 2 then continues to explain why the setting within which dementia care is delivered matters, with an emphasis beyond the type of facility and importance of distinct micro-cultures within each setting.

Chapter 3 reviews the literature on mealtimes in dementia care, but starts with elucidating the importance of mealtimes in general, as well as the importance of mealtimes for people with dementia, regardless of whether the mealtimes take place in the community or in long-term care. The chapter then discusses what is known about the three aspects/dimensions of mealtimes: the physiological aspects (involving (mal)nutrition and (de)hydration, as well as eating and eating assistance/feeding), physical aspects (food and the wider mealtime environment) and psychosocial aspects (covering topics such as mood or social opportunities, and reflecting both on experiences of PWD and care staff approaches). Intervention to improve mealtimes will also be discussed, separately covering academic, practitioner and policy literature.

Chapter 4 discusses the current research project, including its rationale, aims and hypotheses, while Chapter 5 covers the methodology, covering site and patient characteristics, participant and researcher profiles, methodological approach and measures, as well as procedure and design. Ethical considerations, especially (but not limited to) patient consent, will also be discussed, as well as providing information on the research timeline.

Due to the use of multiple and mixed methodologies, the Results chapter (Chapter 5) first covers exploratory findings from staff-initiated quantitative assessments, quantified structured observations, and qualitative methods: focussed ethnographies and interviews. The chapter then goes on to discuss action research and mealtime change, separating it into group-based outcomes that compare patterns of change between the research sites, and individual outcomes, that present patient vignettes. Catalysts and barriers to facilitating change are also covered.

Chapter 6, in turn, brings together the diverse findings of the study, situating them within mealtime literature and highlighting their distinct contributions to the knowledge base. Chapter 6 also discusses limitations within the study (both in methodological and practical terms) and reviews implications for research, care practices and policy, while Chapter 7 offers a summary and concluding remarks.

Chapter 2
DEMENTIA IN CONTEXT(S)

The purpose of this chapter is to set the context for the research project, both in terms of statistics trends, and policies. The chapter starts by providing a brief overview of dementia, through an exploration of dementia's aetiology, typology, symptomatology, prevalence and personal impact. Instead of providing comprehensive knowledge of dementia, this chapter aims to illustrate the experience of dementia may mean to a person and also how the illness(es) are understood from the medical/clinical perspective. Next, the chapter discusses the care destinations of people with dementia in the UK, with a particular focus on long-term dementia care and its breakdown. The purpose of the subsequent sections is to explain why the setting where a person with dementia resides and receives care is important – generally and in terms of current research; and the distinctiveness of dementia care provided in NHS Continuing Care facilities. The chapter ends with consideration of why location/setting where dementia care is received matters and an introduction to the concept of micro-cultures, which determine a distinctive milieu of each institutional care setting beyond its typology.

2.1 Dementia: Aetiology, Typology, Symptomatology, Prevalence and Impact

Dementia as a term represents a group of more than a hundred progressive neurodegenerative diseases, which affect the brain and cause the deterioration of mental and (later) physical functioning (Alzheimer's Association, 2017). Dementia is particularly characterised by memory, behaviour and thinking impairments. It encompasses a number of conditions, such as Alzheimer's disease, vascular dementia, frontotemporal dementia or dementia with Lewy Bodies, which differ in their aetiology, symptomatology and overall prevalence, as well as the likely age of onset and rate of progression. A substantial number of individuals also experience two or more types of dementia at once; for example, an estimated 19% of people with dementia (PWD) experience a 'Mixed Type Dementia', which includes both Alzheimer's Disease and Vascular dementia (Alzheimer's Society, 2017a).

Despite the diversity of conditions, all types of dementia are characterised by a global cognitive impairment which results in the decline of previous functioning and can be presented as a psychiatric or behavioural disturbances (Alzheimer's Association, 2017). A

person with dementia is likely to experience a combination of symptoms such as memory loss, language and communication difficulties, disorientation in time and/or place, difficulties with abstract thinking and judgment, difficulties performing everyday tasks (i.e., procedures), changes in taste and smell perception, depth perception and coordination, visual and/or auditory hallucinations, difficulties concentrating, changes in mood and/or personality and loss of initiative/appetite (Ghent-Fuller, 2002). Some symptoms are more common or tend to start earlier in the progression of some dementias. For example, Alzheimer's disease is marked by memory loss and language difficulties (MacDonald *et al*, 2001), pronounced changes in mood and personality are common in people experiencing frontotemporal dementia, and visual hallucinations and changes in depth perception often appear early in the development of Lewy Body dementia (Harding *et al*, 2002).

The aetiology of dementia is not entirely understood (especially in terms of *why* the illness develops; NHS Choices, 2017a), and it differs depending on type. For example, Alzheimer's disease is caused by formation and accumulation of protein 'plaques' and 'tangles' in the brain which are responsible for the loss of brain cells and brain shrinkage (Hardy & Higgins, 1992). However, Huntington's disease, which is another form of dementia, is a genetic (inherited) condition, which damages nerve cells in the brain (Panov *et al*, 2002). Moreover, Vascular dementia is caused by interruptions to the blood supply in the brain or brain bleads that lead to cell death (Konno et al., 1997), meanwhile Lewy Body dementia results from small circular lumps of protein (called Lewy Bodies); although it is not yet clear what causes Lewy Bodies to appear or how exactly they affect the brain; the illness is prevalent among people diagnosed with Parkinson's Disease (Kramer & Schulz-Schaeffer, 2007). Due to the difficulties establishing a clear cause of dementia, the types are commonly separated not by cause, but rather by the brain areas that are most affect by the illness (thus resulting in different symptoms). For example, Alzheimer's disease is known to particularly (but not exclusively) affect the hippocampus (and the rest of the temporal lobe), which helps new memories form (Hoozemans *et al*, 2009), and areas of the parietal lobe responsible for language production and comprehension (Price et al., 1993). Frontotemporal dementia tends to affect the frontal and temporal lobes (McKhann *et al*, 2001). As the function of the frontal lobe particularly affects reasoning and impulse control, frontotemporal dementia is particularly characterised by profound changes to a person's character (ibid). Unclear aetiology of dementia does, of course, raise both sociological and philosophical questions about the explanatory models used to understand dementia (Downs & Clare, 2005), but as this chapter serves more as an overview of the current understanding of dementia.

Each type of dementia is progressive (Alzheimer's Society, 2017b). Some types of dementia, such as those which are caused by hypoxia or bleeds in the brain (i.e. stroke or transient ischemic attacks) may progress in a step-like fashion, with sudden deterioration followed a long period of no change, then another abrupt change, etc. (Ballard et al, 2001). Others, like Creutzfeldt-Jakob disease, tend to progress steadily yet rapidly, while Alzheimer's and some other dementias progress steadily, but relatively slowly (Geschwind et al, 2008). Despite some discernible patterns, the progression itself is highly individualised and is often hard to predict; for two people diagnosed with the same type of dementia may experience very different patterns and speed of illness progression (Alzheimer's Society, 2017b).

Clinically, dementia is widely viewed as a 'staged' condition divided into mild, moderate, severe and (in some cases) 'end' stages (e.g. Hughes *et al*, 1982). In the early/mild stage of dementia, the person is expected to do most things independently with minimal assistance (Razani *et al*, 2007). This is also the stage when the differences between the distinct types of dementia are most discernible (e.g. Mathuranath *et al*, 2000). In severe and particularly end-stage dementia, the damage to the brain affects not only cognitive and sensory functions, but may impair swallowing (Easterling & Robbins, 2008), breathing (Pond *et al*, 1990) and ability to mobilise (Kovach, 2013). However, the boundaries between the stages are difficult to establish and often depend on (widely critiqued) mental state examinations (Perneczky, 2006; Wind *et al*, 1997). The assessments of dementia severity often struggle to accommodate differential progression of separate symptoms. For example, one person's short-term memory may be profoundly effected, meanwhile their procedural memory remains largely intact, on the other hand another may experience extensive difficulties with reasoning and logical thinking with their visuospatial processing uneffected (Robinson *et al*, 2008). The categorisation of dementia into stages of severity is mostly used as a tool to assess the level of need for support / ability to live independently (Debettignies *et al*, 1990), rather than providing insight into the experiences of people with dementia. As mentioned previously, experience of dementia is highly diverse and individualised, with experiences of the illness transcending type or severity of the dementia, or a mere accumulation of symptoms (Kitwood, 1997). Statistically, however, the world average of life expectancy following a dementia diagnosis is around 4 years for men and 4.5 years for women (Xie et al, 2008).

It is currently estimated that there are around 850,000 people living with dementia in the UK (Alzheimer's Society, 2014). This amounts to one in every 79 (or 1.3%) of the entire UK

population, and 670,000 people in England (Department of Health, 2013a). Due to issues around timely and accurate diagnosis in addition to the fact that dementia develops slowly, as well as cultural factors where some people are cared for at home by their relatives without their condition being formally identified, this figure is likely to be a significant underestimate (Vernooij-Dassen *et al*, 2005). Due to the increase in the 'oldest old' population (people over 80; Corrada *et al*, 2010), as well as other factors, such as diet or drug and alcohol misuse, the effect of which on the likelihood of developing dementia is still being investigated (e.g. Engelhart, 2002), the incidence of dementia in the UK is projected to increase at a faster rate than in the previous decades and exceed 1 million by 2025. Although dementia might present in people of any age (Harvey, 2003), 'late-onset' dementia (i.e. dementia affecting people over 65 years of age) is more common. The probability of acquiring dementia rises significantly with age, from 1-2 in 100 for people aged 65-69 to nearly 1 in 4 for individuals aged 85 or over.

Up to the present day, there is no available 'cure' for dementia which would reverse the effects of the disease or prevent it from occurring, although research and clinical trials of some pharmacological as well as non-pharmacological therapeutic interventions have shown that the progress of dementia can be delayed (e.g. Diniz *et al*, 2009), or that despite the impairments in the brain, levels of functioning might be increased or kept stable for longer (Woods *et al*, 2012).

Apart from the difficulties caused by the symptoms of the disease, people with dementia suffer from stigmatization (Burgener & Berger, 2008), especially prominent in developed western societies which are highly ageist and attribute high value to conventional, 'up-to-date' intellectual capabilities and the ability to survive independently (Angus & Reeve, 2006). Katsuno (2005) demonstrates that at least in the mild stages of the illness people with dementia are aware of negative public views and that this affects their psychological and social well-being as well as increasing the likelihood of *felt* social exclusion. Participants of the above study (ibid.) talked about feeling devaluated, isolated and stigmatised by others and reported loosing important friendships as a result of the diagnosis. Due to findings that dementia has not only physiological, but also social implications, activists experiencing dementia (see Weaks et al, 2012), as well as an increasing number of scholars and practitioners (e.g. Gilliard et al, 2005) suggest adding a social perspective of dementia rather than solely viewing the condition clinically, concentrating on its effect to the brain and on functioning. The social model of dementia, alongside the 'new culture of dementia care'

advocated by Kitwood (1997), emphasise that difficulties or disabilities people with dementia experience are not intrinsic to the condition itself, but is largely an outcome of social processes and circumstance, and material factors. The model also advocates seeing the person 'behind' their dementia (ibid). It focuses not only on the lost skills and capabilities, and developing strategies to compensate for them which would allow the person to function/continue living, but also seeks to fully understand the individual with dementia, their emotions and experiences. Furthermore, it focuses on their unique identity with emphasis on the retained capabilities, and aims to provide care that is aimed not at survival, but at maintaining a positive Quality of Life (QoL) from the person with dementia themselves (Lyman, 1989). As such, health and social care services in the UK are presented with a wide range of physical, psychological and emotional needs of people with dementia (Woods, 2001) and their family carers (Rosa *et al*, 2010) coupled with the task of providing high quality and effective support.

2.2. Dementia Care: Types, Distribution and Policy

The extent, multiplicity and complexity of needs, especially physical ones, of people experiencing dementia often requires extensive care. In the majority of cases (66%) where a person with dementia develops care needs – usually in the later stages - care is provided (Dementia Care, 2015). by family members or friends of the person with dementia (ibid); this will usually be the person's spouse and/or their adult children. According to the Carer's Trust (2017) 770,000 of people in the UK are family carers for someone with dementia. Informal family care may become impossible due to the health of the family carer (e.g., in cases where the main carer is a spouse of similar age or older), or as a result of financial reasons (e.g. a necessity to leave one's job to care for somebody with dementia; Carers UK, 2014). Where and/or when the care needs become very intensive e.g. double incontinence (see triggers below) Where family care is unavailable or insufficient, people with dementia may still remain in their own homes if they are able to access reliable regular visits - or live-in support - from professional carers (Dementia Care, 2015).

Once their dementia progresses and in order to receive a sufficient level of assistance, a considerable proportion of people with dementia relocate to 24-hour care facilities such as care and nursing homes (although a small proportion of people already reside in care homes when dementia symptoms appear; Denning & Milne, 2013; see Figure 1). It is estimated that

a third of people with dementia live in long-term care (LTC) facilities (Alzheimer's Research UK, 2014). Most people enter a care home because they can no longer live independently. 'Triggers' or causes of admission to a long-term care Facility are usually assessed for the entire LTC population, with no specific data for people with dementia. However, given the high estimated incidence of dementia in LTC facilities, the general findings are likely to be applicable. According to Taylor and colleagues (2010) the most common triggers for admission are incontinence, falls, depression, and presence of dementia *per se.* Importantly, the admission is usually fairly sudden and often follows a 'crisis' situation. Denning and Milne (2013) stress that many individuals about to enter an LTC facility do it under pressure to make a quick decision, and when they are feeling ill or frail (Livingston et al, 2010).

The decision to relocate to a 24-hour care facility may be made by the person themselves or by their family member on behalf of the PWD, especially if care is privately funded (Miller et al, 2013). If a community based care package is funded by the Local Authority, however, the decision to relocate may be (partially) driven on financial grounds (i.e. if it is cheaper to for the local authority to fund a place in a care home than an intensive home-care package; Jarrett, 2016).

Figure 1: Types of Dementia Care
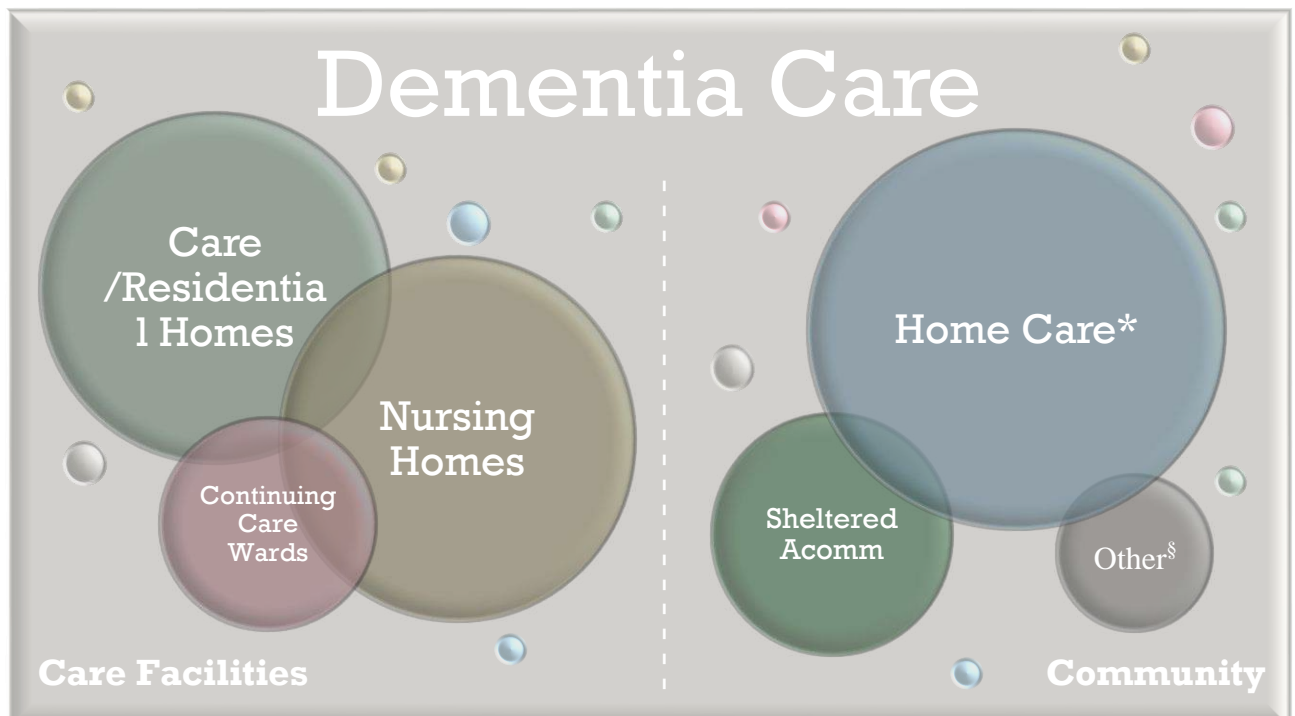
* including paid care (live-in care, hourly care, day care, telecare) and unpaid care delivered by relatives/fiends/neighbours

§ e.g.: respite care, and retirement villages

Regardless of who makes the decision, over half of the admissions to care homes come from hospital (Bebbington et al., 2001) rather than a person's own home; this rises to about two-thirds for nursing home admissions. For people with dementia this may specifically mean a prior legal detention for assessment or treatment at a mental health hospital (often under Section 2 or Section 3 of the Mental Health Act, 1983)). It is also important to note that PWD move between care homes, too: about a tenth of 'new admissions' are moves from one home to another (Laing and Buisson, 2010). Once a person with dementia is admitted to a long-term care facility, it is likely to be their place of residence for the rest of their lives; the average period between admission and death is 2 years and 2 months (Forder & Fernandez, 2011).

2.2.1. Long-Term Dementia Care

Long-term care facilities in the UK can be broadly divided into care homes and care homes with nursing (a relatively new, official term for nursing homes; CQC, 2017). Both types of facilities provide accommodation, supervision from staff 24 hours a day, meals and help with personal care needs. This means that they can provide care for people with more complex needs and those who need regular nursing interventions benefit from registered nurses who are on duty 24 hours a day (Carers UK, 2017). Of the 18929 registered care facilities in the UK, roughly 28% are residential nursing homes and 27% are care homes (carehome.co.uk, 2017; the remaining types were Extra Care Housing, Adult Day Care Centres and Mental Health Hospitals). However, it is increasingly the case that the distinction between the two types of home is blurred.

It is also important to note, that the care/nursing home population has remained almost stable since 2001 with an increase of just 0.3%, despite growth of 11% in the overall population aged over 65 (Office for National Statistics, 2014), while the overall proportion of people with dementia in long-term careCare has increased (Alzheimer's Society, 2014), suggesting that care and nursing facilities increasingly provide higher intensity and complexity support.

While the care/nursing home population has remained stable in numbers over the last decade, there were other significant historical changes in long-term care in the UK. The most notable change was a shift out of publicly-provided settings to privately-provided settings, and from public provision of care to private-provision (Denning & Milne, 2013). Care home services have transformed from a predominantly public sector activity in the mid-1970s to a

predominantly private sector activity now. In 2010 the private sector accounted for 76% of all long-stay bed capacity; 14% was provided by the voluntary sector and just 10% by the public sector (Laing and Buisson, 2010), with the trend away from public provision likely to accelerate in the future (Denning & Milne, 2013). The care/nursing home market has also become more corporate (e.g., the four biggest care home providers supply 23% of the beds; Laing and Buisson, 2010).

According to the Alzheimer's Society (2015) approximately 283,000 people with dementia live in care/nursing homes. However, it is also estimated that 80% of care/nursing home residents in the UK have dementia or severe memory problems, even if it is not (yet) diagnosed (Matthews and Dening, 2002). The proportion of people with dementia in the older care home population is also increasing (Office for National Statistics, 2014). Currently, over 42% of care/nursing homes in the UK are registered as providers of specialist dementia care, but it is widely acknowledged that 'non specialist' care homes also provide care for residents with dementia (Alzheimer's Society, 2014). The prevalence of dementia is fairly consistent across different types of care home, so even homes that are not registered as 'dementia care homes' have a majority of residents with significant cognitive impairment (Macdonald *et al.,* 2002). Dementia care is undoubtedly one of the principal functions of long-term care for older people and the costs of care for people with diagnosed dementia are estimated at £8 billion (out of a total of £14 billion; House of Commons Committee of Public Accounts, 2010).

Long-term care for people with dementia is also costly on an individual level. Although regional variation exists and there is no specific data for people with dementia, in the UK individuals can expect to pay on average around £29,270 a year in residential care costs, rising to over £39,300 a year if nursing care is necessary (Laing and Buisson, 2015). Overall, 45% of Care/Nursing home residents self-fund, while 44.6% are Local Authority funded placements and around .05% placements are funded by the NHS (Miller *et al*, 2013). Whether the Local Authority funds care home placements (and what proportion of care/nursing home fees they cover) depends on a means test of income and capital (Age UK, 2016). Also, if the Local Authority does provide funding, the Person with Dementia or their family are likely to pay top-up fees if the home costs more than the local authority is prepared to pay (Alzheimer's Society, 2017). Somewhat in line with variable costs, services and facilities provided by different care/nursing homes also differ; for example rooms with en-suites, single-occupancy rooms and rooms on the ground floor tend to cost more (ibid).

However, as a 'setting' some commonalities of living in long-term care are shared between setting types . Academic and practitioner literature alike acknowledges, that in terms of experience and set up, institutional care for older people with or without dementia significantly differs from community based living (e.g, see Aneshensel *et al*, 2000). Despite policy calls for long-term care facilities (LTC) to be more 'home like' and to be 'part of the community', most retain at least some of, the key features of 'a total institution' (Department of Health, Social Care & Public Safety, 2010; Goffman, 1961). They tend to be impermeable and separate; considerable restrictions are placed upon residents (especially those living with dementia); opportunities to leave the facility are limited (Atwal *et al.*, 2003); and visitors who are not professionals or next-of-kin are rare (Landau *et al.*, 2013).

A number of other features of LTC for people with dementia mark it out as distinctive. Most residents are very old and frail (Rockwood *et al.*, 1996). The roles assigned to people in LTC are uni-lateral and asymmetrical (i.e. care providers vs care receivers) both in terms of reciprocity and authority (Charras & Gzil, 2013). The asymmetry of the relationship is further reinforced by staff wearing uniforms; the difference in dress denotes who is the 'doer' and who is the 'done to'. Life is co-lived with strangers. Residents live what Falk and colleagues (2013) term a 'semi-public life'; whilst only some share bedrooms and bathrooms, residents always share lounges and dining areas. If residents do have interests, histories or tastes in common this is coincidental (Bergland & Kirkevold, 2008). In LTC facilities specialising in (or at least incorporating) dementia care, residents also often live alongside people whose advancement of dementia is very different from their own; both in terms of quality (i.e., the type of dementia and/or the types of symptoms experiences), and of quantity (i.e., the severity of their dementia). Living in LTC often means abandoning one's home and most of one's belongings and adapting to imposed routines e.g. when meals are served. For those who are married, admission to an LTC facility may often mean having to live apart from their spouse (Lundh *et al.*, 2000), as institutional cohabitation of spouses, one whom has dementia while the other one does not are practically unheard of in the U.K. (Balcombe Care Homes, 2017). Giving up a pet and only seeing visitors at specific times are also common; some facilities for people with dementia do not allow visits from young children citing risks of unpredictable behaviour (Gaugler, 2005).

In terms of the specific profile of residents with dementia many have behaviour disturbances, especially activity disturbances (agitation), aggression, psychosis, and depressed mood, with reported prevalence of such behaviour problems as high as 80 or 90% (Brodaty *et al.,* 2001;

Cheng *et al.,* 2009). Self-harming behaviours are also prevalent and may be active, such as scratching oneself or punching objects (De Jonghe-Rouleau *et al.,* 2005), or passive, e.g. refusal to take food or drink (Draper *et al.,* 2003). Use of anti-psychotic medication is often used to address these behaviours, with a large-scale longitudinal study by Szczepura and colleagues (2015) showing that approximately 1 in 5 residents is prescribed antipsychotics (a number that has not changed despite policy drives to decrease prescribing; see the National Department of Health (2009).

Most 24 hour care facilities, even if their stated vision of care is of a person-centred approach are reported to prioritise physical care needs (Bowers et al, 2001). As many of these facilities are understaffed this often results in residents being supported only when they require assistance to perform an activity of daily living (ADL); many suffer from a lack of occupation and very limited social contact for considerable lengths of time (Brooker, & Latham, 2015). Also, many people with dementia may be placed under Deprivation of Liberty Safeguards (DoLS; Mental Capacity Act, 2005), where "[t]he person is under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements" (Alzheimer's Society, 2017e).

2.2.2. NHS Continuing Care

For people with dementia in England and Wales receiving NHS Continuing Care usually denotes the type of funding the person receives, but does not specify the location or facility where care is provided. In other words, NHS Continuing Care is about funding and provision, rather than setting or service.

The Department of Health defines NHS continuing healthcare (DOH, 2012, p.10):

> '[A] package of ongoing care that is arranged and funded solely by the NHS
> where the individual has been found to have a 'primary health need' as set out
> in this guidance. Such care is provided to an individual aged 18 or over, to
> meet needs that have arisen as a result of disability, accident or illness.'

The assessment looks into behaviour (e.g., presence of aggression or lack of inhibition), cognition (e.g., difficulties reasoning or making decisions), psychological/emotional needs (e.g., distressing hallucinations or anxiety), communication (e.g., difficulties in conveying needs and wishes to others), mobility (e.g., risk of falls or inability to bear their own weight),

nutrition (e.g., difficulty swallowing), continence, skin condition and tissue viability (e.g., pressure ulcers), breathing (e.g., emphysema or chronic pulmonary infections), drug therapies and medication for symptom control (e.g., if a person is prescribed anti-psychotic medication or if administering medication requires covert approaches), altered states of consciousness (e.g., coma) and any other significant care needs (Alzheimer Society, 2017c). It also measures 'any significant care needs' in each domain based on their nature, complexity, intensity and unpredictability, although not all domains have identical ratings (DOH, 2012).

Figure 2. Increasing Intensity of Care per Setting & Percentage
of PWD Receiving Care in Each Type of Setting

It is widely noted that people with dementia find it more difficult to qualify for NHS continuing care than some other groups of patients both because of their dementia and because of their age (Alzheimer Society, 2014). For example, psychological, emotional and communication needs – very common among PWD – do not have a 'severe' rating in the NHS Continuing Care Assessment, so in the absence of severe needs in other domains, a person with dementia is unlikely to receive NHS Continuing Care funding (ibid). Due to this, people with dementia receiving NHS CC funding are likely either have a high co-morbidity of physical illnesses as well as dementia, or exhibit behaviours that are perceived as challenging (Boyce, 2014). Also, if the person's needs are judged to be *social care* needs rather than *health care* needs, they would not be eligible for NHS continuing care and would be expected to pay for, or at least financially contribute towards this provision. Social care provision includes home care, day care and other non-health related services. Due to a combination of the structural separation of health and social care in the UK (Royal College of Nursing, 2014) a lack of a

clear boundary between what constitutes a 'health care need' and a 'social care need', embedded ageism in the care system and the fact that dementia is usually 'assessed' as not requiring health care support older people with dementia are less likely to qualify for NHS CC compared to their younger counterparts (NHS Choices, 2017b). As dementia is more prevalent among older individuals, PWD experience a double jeopardy in NHS CC assessments, both because of the dementia and because of their age. This has been considered structural ageism and there is widespread confusion about why dementia is not viewed as a 'primary health need'. Due to the above, PWD who do qualify for NHS CC funding are also the ones to receive the most intense care and support compared to individuals with different funding arrangements.

If a PWD does manage to gain access to NHS CC funding they are likely to retain this until they die. While each individual's Continuing Care status is re-assessed every 3 months, the progressive nature of dementia (DOH, 2012), an increasing likelihood of nursing care needs (Alzheimer's Society, 2017b) and developing symptoms means that loosing Continuing Care funding post-qualifying is uncommon (Alzheimer's Society, 2017c).

If a person with dementia meets the assessment criteria, they may receive NHS CC funding whether they live in their own homes or care/nursing facilities, although the former is very unusual in practice. The NHS provides only the funds required to meet the individual's healthcare needs. If a person requires 24 hour care the NHS usually pays for that care to be provided in a care home. As noted above, as the majority of care homes are now privately run, this most often means that the NHS is paying for most, or part, of the care home fees. In a small number of cases however, NHS Continuing Care (NHS CC) is provided directly by the NHS (i.e. by NHS staff within NHS facilities).

While commonplace several decades ago, this model of care – termed long term geriatric or psychogeriatric care in hospital – it is now very rare (Denning & Milne, 2013).As previously mentioned, the NHS pays only 0.5% of long-term care fees for people with or without dementia (Miller et al, 2013), usually provided in care/nursing homes; the dementia-specific NHS wards providing NHS CC are even rarer. While no reliable statistics exist, it is estimated that NHS CC wards provide care for less than 0.01% of people with dementia in the UK (Culverwell, 2014; see Figure 2).

In the majority of cases, an individual with dementia would be admitted to an NHS ward following 'sectioning' under the Mental Health Act (1983) for assessment (Section 2) or for

assessment and treatment (Section 3). Their stay on the wards is temporary (meant to last 28 days if under a Section 2) and it is expected that at discharge the person will either return to their previous place of residence, or relocate to more suitable accommodation. NHS Continuing Care wards, however, provide long-term dementia care. While the minimum period of stay is 3 months (NHS Choices, 2015), for most individuals, a CC ward will be their place of residence for the rest of their lives.

While no formal guidelines exist about who is 'eligible' for NHS CC ward admission (vs. NHS CC in care/nursing homes), personal communication with professionals involved in admissions to NHS CC wards (e.g., consultant psychiatrists and ward managers) revealed that aside from presence of physical co-morbidities that require intense nursing input, most PWD are admitted into NHS CC wards if they are refused by Care/Nursing Homes. This is usually because of behavioural needs. Therefore, PWD on NHS CC wards tend to be very physically unwell and/or exhibit behaviours (e.g. aggression) that others find challenging (Brown, 2013). Younger PWD (i.e. under 65 years of age) are also more likely to reside on NHS CC wards, as they do not meet the admission criteria in many care/nursing homes, who specialise in care for older adults (Hayes, 2013).

NHS CC wards function largely the way Nursing Homes do. However, they are also subject to NHS guidelines and procedures. For example, following the Mid Staffordshire NHS Foundation Trust Public Inquiry (Francis, 2013), mandatory nursing levels have been introduced for all NHS wards. Due to the integration of the wards in the wider NHS infrastructure, access to other professionals, such as consultant psychiatrists, psychologists, occupational therapists and music or art therapists (Pinner *et al*, 2011) are also available. NHS settings also determine practical aspects of running CC wards. For example, visiting hours and items relatives can bring to the wards may be more limited and controlled than in care/nursing homes (Department of Health, 2013b). Finally, due to high complexity of needs, co-morbidity of illnesses and a high prevalence of behaviours that challenge, CC wards are likely to be more hectic and noisy compared to other LTDC facilities (Cole et al, 2000).

2.2.3. Beyond the Type of Facility: The Importance of Micro-Cultures

As the sections above illustrate, long-term dementia care and specifically NHS Continuing Care possess some common characteristics that distinguishes it as *a setting* from care homes and them from community based care. However, there is clear evidence the the milieu of

each setting, even if they fit within the same category, differ (Berglund, 2007). In other words, while NHS CC settings are distinctive, aspects beyond the type of the setting further differentiate the experiences of long-term dementia care and its specific aspects (e.g. mealtimes).

A concept that helps to encapsulate site-specific differences is that of the micro-culture. In institutional settings a micro-culture has been described as, ".... a system of knowledge, beliefs, values and behaviours shared by the members of an interacting group to which the members can refer and which serves as the foundations for new interactions" (Fine, 1987, p. 125). They tend to be resistant to change; new 'members' are expected to conform to the existing micro-culture rather than the culture adapting to them (Lalueza, *et al.*, 2008). Also, rather than regarding the micro-culture merely as a situational backdrop, members recognise that they share experiences and expect those experiences to be understood by all. It is this accepted 'understanding' (ibid), together with a shared physical space and the daily routines, that distinguishes the micro-culture of LTC (Edvardsson *et al.*, 2012).

Micro-cultures exist around socio-cultural groups who share an identity such as ethnicity or sexuality (e.g. Wulff, 1988, and Albro & Tully, 1979); and interest groups e.g. British horse-racing enthusiasts (Fox, 2002), or online Emo groups (Rickman & Solomon, 2007). They may also develop as a consequence of sharing a space or setting, e.g. an office or a school (Lopez & Allal, 2007; MacLeod, 1998). Micro-cultures are a product of a shared context, setting and/or identity (Schein, 2010). Research exploring micro-cultures of 'institutional living' and how these influence the experiences and wellbeing of the people within these institutions tends to focus on orphanages (MacLean, 2003), psychiatric units / asylums (Wing, 1962), prisons (Sandhu, 1964), and the military (Soeters, *et al.*, 2006); there is even work exploring 'life aboard ship' (Zurcher, 1965). However, as demonstrated in a scoping review by Mikelytė & Milne (2016), there is very little work on micro-cultures in any LTC setting type for older people (with or without dementia). This absence of research on the topic is particularly interesting given that the largest group of individuals living in institutions in the UK - and who live there on a permanent basis - is older people (see Section 2.2 for statistics). There are, after all, ample LTC settings to investigate the construct of micro-cultures in; more than there are orphanages or long-haul ships.

Despite the current lack of knowledge on micro-cultures in LTC facilities, institutional care for people with dementia lends itself particularly well for micro-cultures to exist, and for them to be studied. Due to relative impermeability of LTC (see above) – especially within

hospital settings like NHS Continuing Care Wards – micro-cultures are likely to differ starkly from macro-cultures and should be amenabale to both capture and study.

2.3. Summary

The way people with dementia experience life and living with their illness is complex and individualised. It depends on the interplay of causes, affected areas, and symptomatology of the illness, as well as societal stigma and social exclusion, and it is hard to predict even if the aforementioned factors can be ascertained/measured. The setting within which a PWD lives and receives care, is another factor that significantly influences quality of life and life experiences. Around a third of PWD (mainly with advanced dementia) live in long-term care facilities, which differs significantly from community living in multiple respects. Further differences exist between the different kinds of LTDC settings, with NHS Continuing Care wards making up a small and unexplored, yet particularly distinctive dementia care setting. It is noteworthy that whilst LTDC settings share some common features they also differ significantly. The concept of micro-cultures may offer a way of exploring experiences of PWD in a holistic manner, while also acknowledging the impact of each 'nesting doll' level of the care setting (see Figure 3).

Figure 3. Dementia Care Settings
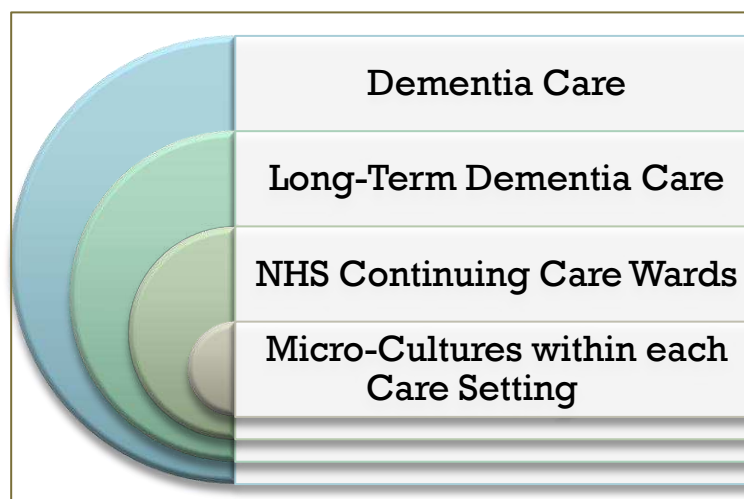
Chapter 3:

LITERATURE REVIEW: MEALTIMES IN LONG-TERM DEMENTIA CARE

This chapter reviews literature on mealtimes in LTC settings for older people with dementia. It briefly locates this review in the wider mealtime literature. The review also aims to foreground the reasons why mealtimes in long-term dementia care are important and why more research on this as an issue is needed. The organisation of the Literature Review reflects existing divisions in research literature (for an overview, see Figure 4). The first section will consider existing research around the *physiological* aspects of mealtimes: namely nutrition and hydration (simultaneously with mal-/under-nutrition and dehydration), as well as eating ability and eating assistance / feeding. The following section will explain the *physical* dimension of mealtimes will be discussed, with specific regard to food and drink, as well as the mealtime environment (e.g., the way meals are served and the set-up of the dining environment). The *psycho-social* aspects of mealtimes will be discussed in the next section of the chapter and include the sub-dimensions of communication, quality of life, engagement (with people and objects), activity and emotion. A separate section will also be dedicated to discussing literature that outlines and/or reviews policies and strategies to improve mealtimes for people with dementia living in long-term care facilities.

Figure 4. Mealtime Dimensions
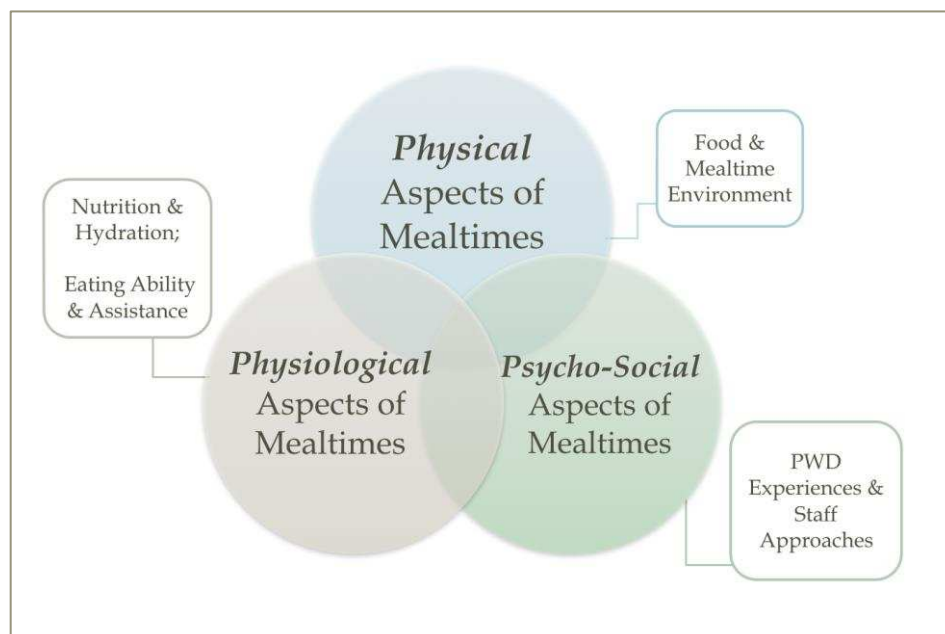
As will be discussed in detail later in this chapter, few studies to date have considered mealtimes from a holistic perspective and attempted to incorporate multiple aspects of mealtimes. Instead, the majority of existing literature tends to focus on one aspect or dimension of mealtimes. It should be stressed that the three mealtime dimensions are neither finite nor reflective of valid boundaries within mealtimes. Instead, mealtime dimensions should be seen as co-existing, overlapping and flexible. The somewhat rigid and divisive structure of the literature review is therefore reflective not of clear-cut boundaries that exist among the different dimensions of mealtimes, but rather of existing division in literature on the topic of mealtimes in long-term dementia care.

As literature is drawn from a number of different countries, where definitions of long-term care and patterns of health and social care differ considerably, references will only be made to long-term care (LTC) throughout this review. Further specificity is not possible without creating confusion and/or lengthy explanations of country and cultural distinctions. Also, as noted in Chapter 2, long-term dementia care in the UK can be divided into (broadly) three subtypes (care homes, nursing homes and NHS Continuing Care wards; see Figure 1 above). While conceptual and practical distinctions between the care settings exist, there is also considerable overlap; as a consequence the review will discuss long-term care settings overall, without separating material by setting type.

Finally, it is important to note that the majority of the review will focus on academic, (mainly peer-reviewed, literature. Given the importance of the issues to policy makers and practitioners such as nurses, practitioner related publications, national and local/site-specific policies, and other grey literature (e.g. voluntary sector reports) is also included.

3.1. Mealtime Matters: The Importance of Mealtimes in Dementia Care and Beyond

Theoretical and empirical literature incorporates a large variety of perspectives on the significance of meals and mealtimes in different settings with topics ranging from those suggesting that mealtime routines can be an indicator of family structure and adolescent 'risk behaviours' (Levin, Kirby & Currie, 2012) to those trying to ascertain the function and meaning behind final meal choices by prisoners awaiting the death penalty (Collins, 2009; Wansink, Kniffin, & Mitsuru, 2012).The range of interests within meal and mealtime research (which some authors regard as a separate discipline; Fjellstrom, 2004) is not only a

reflection of the widespread interests of the researchers, but also of the universality and importance of mealtimes.

Relevant literature has been drawn from a wide area and the review specifically includes material from the four 'areas' or groups outlined in Figure 5. This is important to appreciate as it illustrates the extent of the reach of the topic and the challenge of carving a path through the material. Nonetheless, the due to topic of current research (namely mealtimes in NHS Continuing Care wards), particular focus will be placed on people with dementia living in Care Facilities.

Figure 5: Intersections Between Dementia Status and Living Circumstances
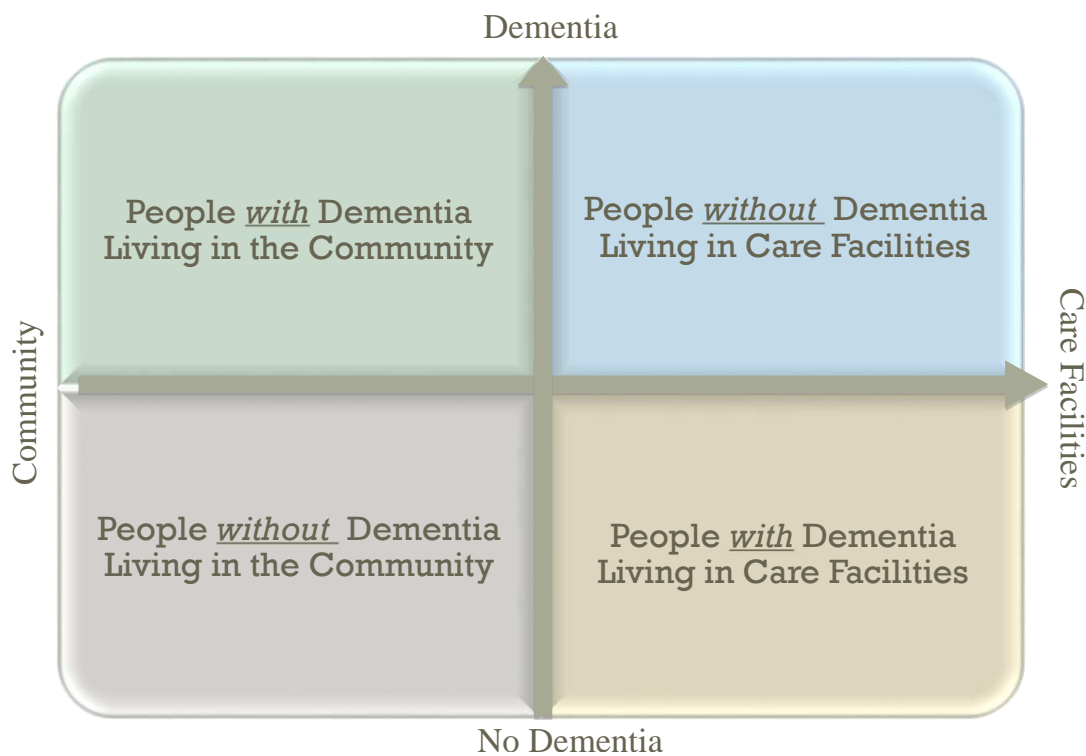
3.1.1. The Role and Function of Mealtimes

3.1.1.1. In the Community

At ' face value', the role of meals - and often mealtimes too - are viewed rather narrowly as 'providing sustenance' (Larson, Branscomb, & Wiley, 2006). In fact the Oxford English Dictionary (2013) describes both meals as 'regular occasions in a day when a reasonably large amount of food is eaten' and mealtimes as 'time[s] at which a meal is eaten'. It therefore appears that overall meals and mealtimes are considered primarily through the lens of food consumption, often excluding other (especially social) dimensions of mealtimes (Fjellstrom,

2004).

The wider role and meaning of mealtimes is one of the foci of mealtime research. It looks at the role of mealtimes beyond eating and sustenance by comparing meals and other types or occasions of food consumption that people do not regard as a meal or a mealtime. Wansik, Payne and Shimizu (2010) have surveyed 122 staff and students at an American university about what constitutes a meal - and what is merely a snack - and found that the distinction depends on physical factors such as portion size or perceived food quality as well as the time food takes to prepare. But wider environmental and social factors surrounding eating were also shown to feature in this distinction. Presence of family members or friends, the effort in setting up the meal (use of napkins and quality of plates) and eating style (e.g. sitting at a table) were all influential situational cues for perceiving an eating occasion as a *mealtime*. Wansik and colleagues (2010) therefore demonstrate that environmental and social factors (and not eating food alone) are crucial in turning an occasion of food consumption into a 'meal'.

The social and psychological roles of mealtimes have been commonly identified within research literature, especially around building/maintaining bonds among (groups of) individuals, as well opportunities to express and (re)affirm one's identity (Fiese, Foley, & Spagnola, 2006). For example, Casotti (2005) has interviewed 29 young-to-middle-aged women about the meaning of celebratory meals, who identified mealtimes as essential in uniting family and establishing/strengthening social bonds of those participating the meal. Moreover, the aspect of 'bringing people together' and sharing a meal with persons important in ones life was identified by Cassotti's (2005) interviewees as the driving force behind mealtime practices and choices. In addition to this, Possick (2008) talks in detail about the different functions of family meals, ranging from affirming the family membership, relationships and roles, as well as identities, providing a space to express and negotiate beliefs and 'ritualistic coordination' of the family. Possick (2008) also explains that the 'meal' can be used as a form of therapeutic intervention, whereby the ritualistic nature of the mealtimes allows for expressions of ethnicity and culture, as well as the family bond. The role of mealtimes to perform a function, he argues, extends beyond the physiological and into the social and psychological. .

Even when considered purely as 'events', mealtimes are not confined to eating or sharing a meal. Cooking, - Bundgaard (2005) - argues can also be seen as an expression of individual and group identity, as well as manifestations of love and caring. It has been suggested that

cooking practices contribute significantly to people's identity or 'sense of self', especially if the person routinely took part in meal planning and preparation in the past. Locher et al (2010) found that cooking was a considerable tension for both cancer patients and their family carers (often spouses) given the change in abilities and circumstances since the cancer diagnosis; however, the source of tension was different depending both on gender and on whether the person was a patient or a carer. Female patients felt a loss of self-identity, while male carers were frustrated and felt guilt for not providing adequate food.

Aside from identifying the range of important dimensions that construct mealtimes (some of which are mentioned above), research literature also emphasises inter-culture and inter-individual differences in the way meals are understood and negotiated (Martini, 1996). For example, using secondary data from a Flemish time-use survey Daniels et al (2012) found that meaning and importance placed upon home cooking differed greatly among individuals and depended on factors such as cohabitation or living with children. Gender, however, did not significant differentiate the perceived meaning of cooking, despite an uneven division of labour. Crucially, while situational differences were influential, the variability of perspectives remained great in each group even when taking these differences into account. There was a considerable variability in respondent opinions, ranging from those who saw home cooking primarily as an affirmation of their cultural identity, to those who regarded it as an expression of care and affection, to people who saw home cooking purely as an obligation, a task and a necessity. Daniels et al (2012) has effectively demonstrated that along with the multiplicity of roles that mealtimes can assume, the individual differences in perceived meaning and importance of mealtimes must also be considered in assessing and acknowledging the complexities of mealtimes.

However, prominent issues regarding mealtime research exist and should not go unmentioned. While the research focus is to explore the role and meaning(s) of mealtimes in people's lives, it can also (perhaps inadvertently) impose an 'expectation' on what mealtimes *should* encompass. The most prevalent area of peer-reviewed literature in which mealtimes are discussed is that of child and adolescent development (e.g. Evans & Rodger, 2008). Here, mealtimes are approached from a deterministic and prescriptive standpoint, suggesting that failure to provide a fairly specific structure of family mealtimes (e.g. eating together at a table, or availability of home-cooked meals, Sweetman et al, 2011) is likely to result in negative outcomes for children and adolescents (e.g. Larson, et al, 2006). The emphasis on what 'good' family mealtimes should look like has also resulted in development and validation of

measures of mealtime practices, which assess the merit of mealtimes on factors such as having a 'clear plan' for the mealtimes (e.g. Kiser et al, 2010; Scholderer et al, 2004).

These research trends, therefore, demonstrate, that mealtime research often incorporates values and bias specific to the researchers. Mealtimes are commonplace and (as mentioned above) numerous inter-individual differences exist in relation to the perceived meaning and importance of mealtimes. It is, therefore, unsurprising that researchers' perspectives affect conceptualisations of mealtimes. However, a greater attempt within mealtime research should be made to ensure that research values are reviewed and multiple perspectives and constructions of what a 'good' mealtime is are incorporated in research considerations. Finally, while the prescriptive nature of mealtime research is concerning, it can also be see as an expression or affirmation of the importance of mealtimes for most people.

3.1.1.2. In Long-Term Care

The role, function and experiences of mealtimes are influenced by a number of factors, including situational ones. The setting within which the mealtime is situated shapes mealtime experiences.

The majority of existing mealtime literature within LTC focuses on perspectives and experiences of older adults *without* dementia. Compared to the general, community-dwelling population, older adults living in LTC tend to identify similar perceived mealtime roles and functions (Carrier, West, & Ouellet, 2009). However, there are a number of areas within institutional care that do not allow for the important aspects of the mealtimes to manifest. For example, sharing a meal with family is no longer a routine and is rarely commonplace during family visits. Opportunities to cook a meal for oneself or others become very rare (Palacios-Cena et al, 2013). Choice of food can also be limited in institutions, although considerable variability exists across settings (ibid.). In line with this, Fjellstrom (2005) investigated the different mealtime opportunities older persons have depending on their living contexts and concluded that people in long-term care experience reduced choice of food/meals, reduced flexibility of mealtimes and reduced company compared to their community-dwelling counterparts. As Sidnevall (1999) proposes, there is a clash of personal and institutional culture, where older persons coming to LTC "with their individual meal customs [are] met by caregivers with an institutionalised culture" (p. 319). The change in meal culture, therefore, often results in some aspects of the mealtime becoming more salient in LTC. One way in which this manifests is through loss. For example, losing the ability to cook

might make cooking an often thought about aspect of mealtimes – and become important due to its absence. However, aspects of meals in LTC can become prominent because of their presence, as well. For instance, as sharing a meal with family members is unusual within LTC, it is likely to be particularly appreciated whenever occurring within the setting.

In line with this, Palacios-Cena et al (2013) interviewed 26 older adults without dementia living in LTC in Spain. The interviews have revealed that nursing home residents saw meals as an important reference point providing structure to the day. Moreover, where choice of food was provided, the meal was seen as an indicator of autonomy and personal identity. Conversely, while mealtime routines were not altogether absent from narratives of community-dwelling participants (e.g. Daniels et al, 2012), they were rarely the focus. As people living in LTC have little-to-no influence on when meals are served, the emphasis on and attempts to explain the positive aspects of imposed mealtimes routines could be seen as a way of adapting to life in LTC (Palacios-Cena et al, 2013). Similarly, having (or being granted) an opportunity to choose ones meal was also specified by a large proportion of persons in LTC as a sign of autonomy and an important facet of identity expression. Choice within mealtimes, both of *when* and *what* meals are served, is a highly prominent topic in LTC.

The social aspects of mealtimes within institutions also differ from those available to community-dwelling individuals. In some cases, it has been suggested that mealtimes in LTC provide more opportunities for socialization. For example, Curle and Keller (2010) found that mealtimes in retirement homes generally provided opportunities of social interaction for the residents, although such interactions varied greatly in nature and valence.

Increased opportunities for eating together, however, do not always result in greater ability (or desire) to socialise. For example, Sidnevall (1999) mapped out pre-retirement employment areas for 60 patients within an LTC facility in Sweden and found significant variability in past experiences. In relation to this, it was suggested that finding common interests and shared experiences is not straightforward within long-term care settings, and should not be automatically expected. The latter, Sidnevall (1999) suggests, stems from assumptions of resident homogeneity within LTC settings. Residents' integrity and personhood is, therefore, undermined both by lack of options and by present expectations.

The importance of social interactions with people significant in ones life (rather than random interactions with other LTC residents) were also demonstrated by Walton et al (2013), who

found that presence of visitors improved residents' dietary intake. This research, of course, does not suggest that interactions between residents have no merit, only that a mere presence of others is not sufficient and depends on finding commonalities with others and gradually building friendships.

Furthermore, the quantity of (or opportunities for) social interactions during institutional mealtimes is only one side of the issue, and the qualitative aspects of the interactions are also significant. In relation to this, Dube et al (2007) conducted mealtime observations in a Canadian LTC unit (observing each participant for the average of 46 meals) and found that the types of interaction between patients and care providers influenced nutritional intake and that patients who were able (or enabled) to be more dominant in these interactions ate more. However, it must be stressed that aforementioned studies considered the benefit of (qualitative) interactions based on the increase in dietary consumption, rather than looking at participant satisfaction or quality of life.

However, aside from specific restrictions in choice and/or opportunities that stem from the practical issues within institutions (e.g. cost implications of cooking individual meals), institutional culture itself seems to have a negative impact on the way mealtimes are experienced by people living in LTC. In their descriptive study of mealtimes in an LTC facility for older people Xia and McCutcheon (2006) found that addressing nutrition was not seen as a priority by the nursing staff in comparison to other nursing care activities. This resulted in patients not receiving sufficient assistance at mealtimes, frequent interruptions of mealtimes and commonplace neglect of social interaction, as well as around a third of patients routinely leaving more than 65% of their meals. The perception of mealtimes as a 'non-nursing duty' to be completed as quickly as possible was also found by Pearson, Fitzgerald and Nay (2003) during their observations and staff interviews in 10 nursing homes. The authors further argued that such perceptions of mealtimes resulted in staff's failure to recognize and accept the mealtime issues that were identified by the residents and the researchers. This also coincides with Sidnevall's (1999) findings that despite a relatively homely atmosphere within an LTC facility, both residents and staff were susceptible to the institutional culture. Residents tried to conform to the cultural values and expectations of 'appropriate' behaviour in hospital settings while nursing staff tended to reinforce that expectation. This was found to be particularly detrimental to residents' identity and dignity, as they were both deprived of their individual preferences and values (e.g. ability to serve food) and were also made aware of 'failing' to conform to the expectations of the hospital setting (e.g. by not coming to

the dining room on time or not eating quick enough). Thomas and Mor (2013) argue that mealtimes within institutional settings are commonly regarded only as means to sustaining life. Equally, the main focus is placed upon maintaining independence in eating ability. Even then, independent eating is not seen in relation to quality of life or identity and integrity, but only as a process that contributes to the functioning of the institution (i.e. independent eating is encouraged because it reduces demands on staff). Residents' social and psychological mealtime needs, however, fade into the background and are overshadowed by institutional mealtime needs.

Institutional micro-cultures, however, are not inevitable in long-term care. Bundgaard (2005) researched the meaning of mealtimes for older persons residing in 'Living Units' (a novel way of organizing nursing homes that is not commonplace in the UK). These units are often arranged to mirror family units, with 6-8 people living in private rooms connected by a shared lounge, dining area and kitchen. According to the residents, mealtimes within the Living Units provide a shared place and a shared event (including opportunities to co-arrange meals), meaningful occupation, opportunities to feel familiarity and proximity, as well as chances of 'ordinary' communication and ability to show understanding and caring about others. Having the ability to make decisions around mealtimes and maintain previous likes and dislikes was also seen as highly important in strengthening the sense and expression of self, as well as "connecting self to former life activities" (p. 96).

Overall, institutional mealtimes are not only qualitatively different from mealtimes experienced by people living in the community, but also more restrictive of options and opportunities within mealtimes. In addition to this, the institutional structure itself can devalue mealtimes within the setting. It is therefore that mealtimes within institutions deserve particular research attention.

3.1.2. Mealtimes for people with dementia

Barratt (2004) estimates that the cost of providing adequate nutrition makes up approximately 25% of the health and social care costs of dementia care in the UK (and thus 1.4% of the overall healthcare costs). The author arrived at the estimate by including not only the cost of food provision, but also accounting for time spent by carers to help people with dementia eat and drink and overcome difficulties such as changes in perception and attention, deterioration in motor coordination, and food refusal. The cost of providing

adequate nutrition in dementia care, together with statistics, trends and policy considerations regarding long-term dementia care (discussed in Chapter 1), as well as the importance of meals in people's lives and specifically within institutions justifies a distinctive focus on mealtimes in long-term dementia care. However, because of the impact of institutions on the experience of mealtimes, it is also of interest to explore what mealtimes mean for people with dementia who live in the community, thus separating the influences of dementia, from the influences of LTC settings.

3.1.2.1. Overall Findings

Berg (2006) suggests a number of reasons why mealtimes are of particular importance for people living with dementia. He argues that mealtimes can provide structure to the day, especially for people who might experience some disorientation regarding the time of day (Day, Carreon & Stump, 2000). Mealtimes can also provide a meaningful activity. As people with dementia have identified activities as meaningful if they address their psychological and social needs (Harmer & Orrell, 2008), mealtimes have a potential to provide if they reflect the person's own beliefs and choices. Cooking especially has been evidenced as a therapeutic and meaningful mealtime activity, which has been shown to reduce apathy and alleviate distress for older people with dementia (Fitzsimmons & Buetter, 2003). Berg (2006) also reflects on the sensory pleasure/enjoyment people with dementia can experience from food. In fact, practitioners involved in Dementia Care Mapping (a method for assessing and improving care practices for people with dementia; Bradford Dementia Group, 2010) often report that a significant proportion of people with dementia exhibit highest levels of enjoyment while eating (Clover, 2009). As already mentioned, mealtimes can also provide social opportunities within institutional settings if wider environmental, social and cultural factors enable and encourage social interaction (Manthorpe & Watson, 2003).

3.1.2.2. Comparison between LTC and Community-Based Settings

Differences between mealtimes experienced by people with dementia residing in long-term care facilities and those dwelling in the community are also of interest. Johansson, Christensson, & Sidnevall (2011) interviewed people with dementia in their own homes and found that they did not report struggling with mealtime tasks and identified and attributed

this to routines and habits, as well as new coping strategies around mealtimes. Moreover, PWD took pride in mealtime independence and saw it as a way to reaffirm the continuity of their identity (i.e. that despite dementia, they were still the same person). Interviews with family caregivers also demonstrated that despite a recognised and stressful decline in meal planning and preparation abilities experience with the progression of dementia, mealtimes were seen as an important and satisfying 'social times' by the caregivers. Interview studies with PWD within LTC are absent from mealtime research to date; arguably because of greater average severity of dementia. However, observational studies (while still few in number that focus on experiences beyond nutrition and hydration; Manthorpe & Watson, 2003) suggest less positive experiences of mealtime. For example, Hung & Chaudhury (2011) demonstrate that mealtimes for people with dementia in LTC can (and on a significant number of instances do) undermine personhood; this takes place due to staff outpacing PWD, withholding opportunities, resources or choice, around mealtimes, a lack of sensory stimulation, a lack of respect, invalidation of emotions and experiences, staff distancing themselves from PWD, disempowering and/or ignoring residents.

Amella (2002) observed 53 nursing home residents living with dementia and suggested that resistance to eating assistance was at least partly dependent on quality of interactions between the carer and the resident. Home-like meals in a French LTC facility (with a comparable setting serving as a control site), where staff shared meals with residents and did not wear uniforms was shown to result in resident weight increase, improved eating ability, improved participation in setting up before and cleaning-up after meals, improved quality of resident-resident and staff-resident interactions, greater staff satisfaction and greater staff understanding of resident's nutritional needs (Charras & Fremontier, 2010).

Carrier, West, and Ouellet (2009) have assessed the quality of life for 395 residents in 38 Canadian LTC facilities and found that more mealtime autonomy and more dining companions was associated for a better quality of life (QoL). Importantly, Carrier et al (2009) also compared people with and without dementia within these facilities. People without dementia related presence of specialised meals (e.g. diabetic), as well as use of china to mealtime satisfaction, while these factors were not significant for PWD. Conversely, PWD experienced better QoL if they were able to eat independently and if the menu was revised more frequently.

While literature specifically investigating the mealtime experiences of people with dementia living in long-term care facilities is lacking, existing evidence suggests that qualitative

differences might exist both because of the resident's experience of dementia (as different mealtime aspects are associated with QoL of people without and people with dementia in institutional care) and because of aspects within dementia care facilities (as people with dementia living in the community seem to experience mealtimes differently).

3.1.3. Summary

To sum up, meals and mealtimes are universal for all people, but the roles, meanings and functions people attach to mealtimes differ between individuals and depend on a number of factors. For people living in long-term care setting, practical aspects of institutional care, as well as institutional cultures can affect the way residents experience mealtimes; both in terms of changes in mealtime aspects that gain/lose their relative importance and in terms of changes that directly affect enjoyment of mealtimes. Further differences in function of and contribution of mealtimes is present for people with dementia living in long-term care facilities, where mealtimes have the potential to fulfil needs not characteristic for other populations (e.g. orientation to time of day), but also a potential to cause more pervasive negative outcomes (e.g. refusing food). While mealtimes are opportunities to achieve adequate nutrition and hydration, especially for people with dementia this often depends not only on the food provided and capabilities of the person with dementia (Edahiro et al, 2012; Lin et al, 2010a), but also on optimal environmental (Chang & Roberts, 2011) and social (Lou et al, 2007) factors. This, therefore, further justifies the need for research which specifically concentrates on mealtime experiences of people with dementia in long-term dementia-care facilities.

3. 2. Physiological Aspects of Mealtimes

Meals and mealtimes in long-term care (LTC) are often seen purely through the lens of physiological function to restore energy and sustain the body through eating (Kagansky, 2005). The majority of academic, as well as practitioner literature around mealtimes in LTC has focused on the physiological/biological aspects of meals, namely nutrition, hydration and the eating ability of people with dementia (see review by Hanson et al., 2011, also Chang & Roberts, 2011; Lou, Dai, Huang & Yu, 2007). The section structure follows the main divisions within existing literature into mealtimes in long-term dementia care and begins with findings related to the physiological aspects of mealtimes. However, while such divisions exist both in research publications and the current chapter, the overall interdependence of the physiological, physical and psycho-social factors of mealtimes should be acknowledged.

3.2.1. Nutrition and Mal-/Under-nutrition in Dementia Care

3.2.1.1. Findings

Broadly defined, nutrition encompasses an adequate intake of protein, energy and nutrients (Kokkat, Dharmarajan, & Pitchumoni, 2004) to enable optimal functioning, while malnutrition means inadequacies in such intake, including both under- and over-nutrition (Reuben, Greendale, & Garrision, 1995). The exact amount of energy, protein and nutrients required for individuals, however, fluctuates depending on a wide range of fairly static factors such as gender, (Blaak, 2001) or ones that change temporally e.g. recovering after a surgery (Willcutts, 2010).

It is widely agreed, that nutritional needs change with age (De Castro & Stroebele, 2002; Heilbronn & Ravyssin, 2002). However, there is far less consensus on the precise change in requirements to achieve an adequate nutritional status. For example, there are conflicting accounts as to the desired protein intake in older age. Whereas Garry, Rhyne, Halioua and Nicholson (1989) observe that healthy older adults' protein intake decreases with age, Wurtman (1988) shows no absolute change in amount of consumed protein, yet a proportional increase in protein consumption, as less carbohydrates are eaten with age. Furthermore, Nordstrom and colleagues (1988) observe no absolute change in protein consumption, but a proportionate increase in consumption of fat. Undoubtedly, fluctuations in protein consumption of individuals is highly susceptible to personality, social, cultural and

multiple other factors (Brijnath, 2012). Nonetheless, the multiplicity of research outcomes in the area demonstrates a need for future research to uncover the precise change in nutritional requirements in later life.

Equally, some studies suggest that target BMI for healthy older adults is the same as that of younger adults (Cook et al., 2005), while other sources suggest that the upper parameter should be wider (e.g. BMI that is considered too high for younger adults might be within the healthy range for older adults over 70 years of age; Crawley & Hocking, 2011).

Age, however, is not a factor that singularly determines the change in nutritional needs. Illnesses such as dementia, which are associated with old age, are also independently predictive of metabolic and nutritional changes (e.g. Wang, 2002). What is more, the pathway of influence (i.e. whether dementia influences nutrition or if nutritional indicators can impact on the likelihood of developing dementia) is complex and multidirectional, with research evidence simultaneously supporting both predictions. For example, in their longitudinal study Scarmeas and colleagues (2006) demonstrate that adherence to Mediterranean diet was associated with a lower risk of Alzheimer's disease, while Roberts et al (1988) show that compared to healthy volunteers, people with dementia absorb more aluminium from a 'normal' dietary intake. While both aspects of the link between nutrition and dementia are undoubtedly important, for the purposes of the current literature review and the research project, however, the association between nutrition and dementia is only considered in instances where a person is already experiencing dementia.

The severity of dementia has been linked to under-nutrition in a number of studies (e.g. Chang & Roberts, 2011; Magri et al, 2003); and some studies also suggest that at least a third of people experiencing dementia are likely to eat an increased quantity of food at some stage of their dementia (Morris, Hope & Fiarburn, 1989). In addition to this, there is some evidence that a proportion of people experiencing dementia develop an increased preference for sweet and/or spicy food (Hope et al, 1991; Morris et al, 1989). Multiple investigations have been carried out to explain the increase in under-nutrition and to a lesser degree over-nutrition experienced by people with dementia living in the community, as well as in long term dementia care. Some factors, such as declining appetite, changes in taste, difficulties with chewing, swallowing and/or motor dexterity have been suggested to appear with ordinary ageing, but become amplified due to neuro-degeneration in dementia (Keller, 2006). Other causes of changed nutrition, such as inability to recognise food, inability to express or

recognise hunger, fear of food and difficulties in maintaining attention, however, have been specifically associated with dementia symptomatology (Aziz et al, 2008; Reimer 2012).

Specifically in relation to long-term care for people with dementia, the risk of malnutrition is associated with difficulty in beginning a meal (Edahiro et al, 2012), not receiving feeding assistance (Lou et al, 2007), eating/swallowing difficulty (Edahiro et al, 2012), shorter amount of time devoted to eating, higher dependency in activities of daily living, difficulties with assisting the person to eat, a greater number of medication taken (Chang & Roberts, 2006) and fewer family visits (Lou et al, 2007). The prevalence of under-nutrition/low food intake for people in long-term dementia care settings has also been assessed and a review by Abbasi & Rudman (1994) detected a range between two and 83 percent. While such a wide range suggests that there might be unaccounted factors that influence the prevalence of malnutrition (e.g. availability of a dietitian consultation or oral nutritional supplements), it also indicates that while common, under-nutrition in long-term care settings is almost entirely preventable. Further investigation in the differences between settings with high and low malnutrition rates is, therefore, of primary importance in researching mealtimes.

Alongside potential predictors and associates of malnutrition, potential outcomes of experiencing malnutrition are of associated importance. A large longitudinal study by Janssen, Katzmarzyk and Ross (2005), which involved a 9-year follow-up of 5200 participants over the age of 65 has demonstrated, that lower Body-Mass Index predicted higher mortality and morbidity rates, and an increased likelihood of falls, infections and depression. In addition to this, a number of smaller-scale studies have also linked under-nutrition to slower wound healing (Harris & Fraser, 2004), higher incidence of falls and fall-related fractures (Dawson & Hughs, 2008), increased infection rates (High, 2001), and a lower health-related quality of life (Kuikka et al, 2009). Given the multitude of associated negative outcomes of experiencing under-nutrition for older persons, and particularly for people with dementia living in long-term care settings, it is perhaps unsurprising that (mal)nutrition in institutionalised dementia care has attracted a disproportionately large amount of research interest.

3.2.1.2. Prominent Issues

However, there are a number of significant issues surrounding research on (mal/under) nutrition. As can be seen in the Findings section above, conflicting research accounts exist in multiple areas, along with a lack of attempts to find out what and how additional factors within the settings, different participant groups and/or diverse measures contribute to

conflicting evidence (Brijnath, 2012). In addition to this, it is important to note that the factors investigated in relation to (under)nutrition are largely physiological in nature and address physical well-being. Only a few studies relate nutrition to psychological well-being and/or social factors for older adults (Kuikka et al, 2009), with no studies to date doing so for participants who are experiencing dementia.

Among the aforementioned trends, a dominant issue in researching under-nutrition in people experiencing dementia, is the way (mal/under) nutrition is measured. In the vast majority of studies (including those described earlier in the chapter), the indicator of adequate nutrition or under-/over-nutrition is either weight or Body-Mass Index (BMI). For example, Lou and collegues (2007) aimed to find out if changes in nutritional status are related to changes in health outcomes for older people with dementia living in LTC. However, the nutritional status within this study was equated to, and measured solely by, Body Mass Index. BMI was also equated to nutritional status in a nutritional intervention study for people with dementia living in community assisted housing (Faxen-Irving, et al, 2002).

A considerably smaller number of researchers have applied multidimensional assessments to investigate nutrition (e.g. Barone et al, 2003). Probably the most commonly used and widely validated tool is the Mini Nutritional Assessment Short-Form (MNA-SF; Kaiser et al, 2006), which takes into account not only BMI (or calf circumference when BMI cannot be obtained), but also looks at changes in food intake, weight loss, mobility, psychological stress and acute disease, neuropsychological difficulties and changes. In doing so the assessment allows a more sensitive assessment of nutrition. For example, someone who is overweight by the BMI criteria, but is rapidly loosing weight will not be considered at risk of malnutrition in terms of BMI for as long their BMI remains in the 'overweight' or 'normal' ranges. Conversely, MNA-SF allows the identification of the individual as 'at risk of malnutrition' or even 'malnourished' depending on the rate at which weight loss has occurred and food intake declined (Guigoz, 2006). In relation to this, researching malnutrition in Taiwanese older adults living with dementia in Long-Tern Care facilities found the incidence of malnutrition to be at 19% when the World Health Organisation BMI cut-off points were used, but rising to 90.4% when MNA-SF was ustilised to identify residents at risk of malnutrition (Chang & Roberts, 2010). Importantly, while the above research demonstrates that specialised nutritional assessments can provide greater sensitivity of the information on a person's nutritional status than weight or BMI, the latter remains a dominant measure of (mal)nutrition.

Nonetheless, both BMI and nutritional assessments like MNA-SF (Kaiser et al, 2006) remain focused on food/calorie/energy intake, rather than *nutritional* intake. As mentioned at the outset of the findings section, mal-/under-nutrition does not equate to calorie intake. Adequate nutrition also encompasses sufficient intake of nutrients (i.e. consuming an appropriate quantity of proteins, carbohydrates, fats, vitamins and minerals; Kokkat, Dharmarajan, & Pitchumoni, 2004). To assess nutrition in a more comprehensive way, the nutrient content in food available for people with dementia in LTC facilities should be evaluated. This is especially important as the 'correct' amount of food in terms of energy intake might not be sufficiently balanced to meet the need for various nutrients. In relation to this, Lengyel, Whiting & Zelllo (2008) found that among Canadians living in long-term care Facilities consuming regular amounts of food over 70% lacked key micronutrients. Similarly, the research exploring nutrient content of food served to people with dementia in long-term care found that meals lacked recommended amounts of vitamins D and E, as well as folic acid (Suominen et al, 2004).

Furthermore, while nutrient content in food is to be considered, an equally important aspect to look into is the consumption of food. For example, during a 1-year follow-up of community-dwelling people with dementia, researchers have found that people with dementia had poorer dietary intake compared to matched controls (people without dementia; Shatensten, Kergoar & Reid, 2007). In support to this, Sueminen and colleges (2004) have also demonstrated that in addition to the sub-optimal nutritional content of served food, people with dementia long-term care Facilities on average consumed only 72% of the food available.

While the above research stresses the importance of looking at nutritional, as well as food intake, it should also be acknowledged, that measuring nutrient intake is a complicated and time consuming process, which, even if practically possible, can prove highly intrusive and ethically inappropriate at mealtimes (i.e. carrying out measures required to assess nutrient content and intake might in itself detract people with dementia from eating as much as they would ordinarily). It is, therefore, perhaps not entirely surprising and somewhat justifiable, that the majority of studies in the area limit their scope to shorter, more achievable and less intrusive assessments of nutrition.

Nonetheless, the discussed issues with research findings in the area of (mal-/under-) nutrition demonstrate that the problem of malnutrition in long-term dementia care is a complex, multifaceted issue. Moreover, as most existing research fails to take into account these complexities, both the true extent and difficulty in addressing malnutrition in long-

term care is partially masked. In other words, research communities are likely to inadvertently exacerbate the significance of malnutrition due to the dominating research focus.

3.2.2. (De)Hydration in Dementia Care

3.2.2.1. Findings

While (mal)nutrition is often the focus of literature on mealtimes, this is not the case for (de)hydration. Only a few studies look specifically at dehydration in older adults. Bennett, Thomas and Riegel (2004) show that from older adults visiting an emergency department, 48% suffer from chronic dehydration (which, among other factors, is associated with increased mortality and morbidity; Benelam & Wyness, 2010). Most importantly, however, Bennett and colleagues (2004) have demonstrated that chronic dehydration in older adults was highly under-assessed and/or under-recorded. Despite high association with illness and death in the community (ibid.), as well as in long-term care facilities (Weinberg, et al, 1994) dehydration remains largely unnoticed. A notable exception in this case is a UK-based long-term care survey carried out by the Royal Society for the Promotion of Health (2003), which suggests that older people residing in care homes consumed less than half of the recommended daily fluid intake for older adults.

Overall, there is a considerable lack of research linking dehydration and dementia. For example, as malnutrition in people with dementia is associated with difficulties in swallowing (Edahiro, et al, 2012; Lou, et al, 2007) it is reasonable to assume that ability to swallow will also have an impact on dehydration levels. However, this association is rarely mentioned and seems to appear mainly in practitioner literature (e.g. Curfman, 2005). There is also some evidence suggesting that people with dementia might be insensitive to thirst and not react to the sensation of thirst by attempts to obtain fluid (Alber et al, 1994).

Hydration is also rarely the focus of interventions or even assessments. The aforementioned studies that measure food intake (Edahiro, et al, 2012; Suominen et al, 2004) do not simultaneously assess fluid intake and its impact on overall functioning. Therefore, considerably more research is required in establishing the determinants and outcomes of dehydration for people living dementia, as well as strategies to reduce dehydration in long-term dementia care.

3.2.2.2. Prominent Issues

Aside from an overall lack of research on (de)hydration, a prominent bias/issue is noticeable within existing research. In the majority of instances when dehydration is associated with dementia, it is often perceived as a "natural endpoint of dementia" (Raymond et al, 2006, p.350). Here dehydration is seen as a primary cause of death for people who live until the final stages of dementia. Dehydration is, of course, an important topic within Palliative and End of Life Care (ibid.). An issue, however, arises from seeing (de)hydration purely from the perspective of End of Life Care, as addressing dehydration within this area is shaped by ethical considerations and care goals specific to end of life issues. Using research from Palliative Care to inform (de)hydration in long term dementia care is, therefore, likely to be more problematic than beneficial.

3.2.3. Eating and Eating Assistance for people with dementia

3.2.3.1. Findings

Within research literature, nutrition (and hydration, when discussed) are usually viewed as statuses or indicators of individuals' physiological wellbeing (e.g. Sandman, 1987; but see Hakel-Smith & Lewis, 2004 for an alternative conceptualisation). Conversely, a person's eating ability is almost always constructed as a process within literature on physiological aspects of mealtimes (e.g. Morris, Hope, & Fairburn, 1989). In other words (mal)nutrition and (de)hydration represent the 'what', and eating/feeding represent the the 'how' of the biological aspects of mealtimes, while the two constructs are mutually influential (see figure 6).

Food availability is relatively easy to address when compared to strategies on improving eating ability, and have subsequently attracted less attention. Changes to the nutritional content of food, as well as physical properties (e.g. texture or colour) are, of course, common in attempts to improve nutrition when eating ability is affected by the dementia processes (e.g. Crawley & Hocking, 2011), but represent physical/environmental factors of the mealtimes and will be discussed later in the chapter.

Figure 6. The Structure of the Physiological Aspects of Mealtimes
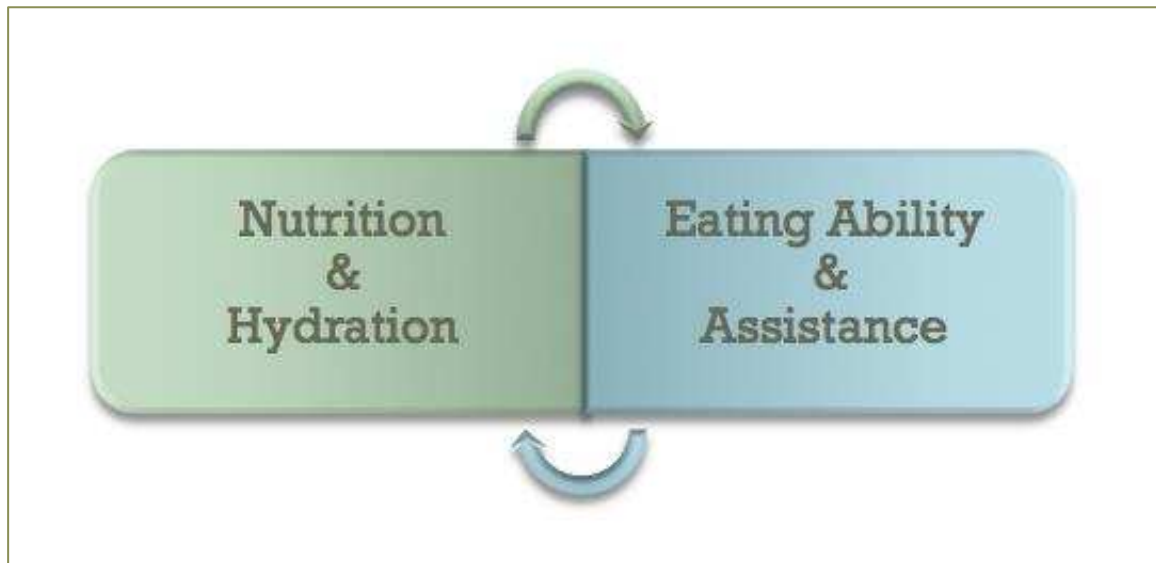
Due to close conceptual ties with nutrition and research focusing predominantly on the physiological aspects of mealtimes, eating ability has *de facto* become regarded as the main determinant of adequate nutrition, while eating difficulties - the main contributor to under-/malnutrition. As a result, eating ability and eating difficulties have attracted considerable research interest and resulted in particularly large-scale studies. For example, in their study of 477 people residing in 9 LTC facilities in Taiwan, Lin et al (2010) found that low food intake was associated with eating difficulty and not receiving feeding assistance, while Chang and Roberts (2011) found that feeding difficulty was also linked to malnutrition. A Japanese study (involving 324 participants with dementia from 16 LTC facilities) was also the first to demonstrate that in addition to signs of dysphagia (difficulty in swallowing), difficulty in beginning a meal due to inability to recognise food or perceive a need to eat, is a highly significant factor in malnutrition (Chang & Roberts, 2008; Edahiro et al., 2012). Finally, much like under-nutrition, eating difficulties were found to be highly prevalent in long-term dementia care populations, with Dey (1997) estimating that approximately 45% of LTC residents need assistance with eating.

Studies have also attempted to explain why eating difficulties are common among people experiencing dementia. Hanson and colleagues (2011), for example, suggest that a deterioration in eating a ability might result from changes in smell and taste functions (which remain poorly understood from the research perspective; Piwnica-Worms et al, 2009), apraxia (inability to perform purposive motor actions) attention deficits and dysphagia (difficulty or discomfort in swallowing) might all cause food avoidance.

In addition to this, there is some evidence, that aside from making adjustments in the environment to accommodate the changing eating ability and need for assistance (Crawley & Hocking, 2011), eating ability itself can be improved. For example, a Randomised Controlled Trial (RCT) in Taiwan showed that people with dementia in long-term care who received one of two types of 'training' ate more and had fewer difficulties in eating than the group that did not receive the training (Lin, et al., 2010; Orsulic-Jeras, Schneider, Camp, Nicholson & Helbig, 2001). Systematic reviews, however, tend to favour physiological interventions that aim to improve eating ability. For example, Hanson, Ersek, Gilliam, and Carey (2011), in their review of oral feeding enhancers assigned the highest quality rating only to the studies that are randomised, double-blind, and placebo-controlled. Therefore, studies on high calorie supplements and oral interventions (which allow a placebo intervention) were regarded as 'quality studies', while complex studies requiring multiple simultaneous changes (like Lin, et al., 2010 study described above) were not mentioned at all or placed in the lowest quality category. A review by Watson and Green (2006) also found that narrow-scope environmental changes (especially introducing specific music during mealtimes) show promise in improving acceptance of eating assistance/feeding; these will be discussed in the subsequent section.

Other researchers have extended the concept to 'mealtime difficulties', to incorporate aversive eating, feeding, and crucially mealtime behaviour, but also social and environmental factors such as noise levels and opportunities for communication (Aselage, 2010). Aselage and Amella (2010), argue for a change in the way eating and feeding is conceptualized; from seeing eating/feeding as an isolated phenomenon to regarding it in societal, historical and cultural context, acknowledging complex, multifactorial nature of mealtime difficulties. However, studies following the publication of Aselage and Amella (2010) recommendations continue to conceptualise eating in isolation (e.g. Hung & Chaudhury, 2011).

3.2.3.2. Prominent Issues

Similarly to nutrition and mal-/under-nutrition research, studies looking into eating ability and eating difficulties present with a number of issues. Moreover, a significant proportion of these issues are related to how eating ability and eating assistance are assessed and measured.

Systematic reviews of literature, the aim of which is to establish which tools are most suitable to assess mealtime difficulties serve as a good example of inherent biases in choosing (and potentially developing) ways to assess eating difficulties. While a number of reviews have been conducted in the area, the majority expose a similar set of issues affecting the process of ascertaining the best assessment tool. Due to this, an iterative review by Aselage (2010) on strategies and tools via which eating difficulties are assessed, will be used to exemplify the dominant issues.

Firstly, there is a clear preference for peer-reviewed literature in selecting assessment methods. In Aselage's (2010) review a total of 12 articles were selected, all of which were extracted exclusively from peer-reviewed journals. Practitioner literature or publicly available dissertations and theses, however, were not included despite potential contributions to the topic (e.g. see Way, 2011). Furthermore, only existing assessments were reviewed, ignoring theoretical proposals on what should be included in assessments of mealtime difficulties (e.g., suggestions made by Lopez & Amella, 2011) – an issue that was highlighted in a commentary (Lopez, 2010) on Aselage's (2010) review. The lack of integration of academic and practitioner research, as well as theoretical approaches in evaluating eating ability is widespread and seems to create a less-than-ideal separation, where researchers aim to draw practical, feasible and clinically applicable assessments from purely academic literature.

The narrowly focused search area for eating/feeding assessments, however, reveals only one part of the issue on how eating ability is commonly assessed. An associated issue is the perceived quality of assessment tools. As the Aselage (2010) example demonstrates, a number of tools were not selected for review, if the research publication did not have enough information to determine quality or clinical feasibility of the instrument. This not only involved lack of validity and reliability testing, but also aspects such as a number of items within an assessment tool which are relatively easy to determine. However, no attempt was made to contact the authors for additional information even in cases when the authors researching the assessment tool were also its developers.

Furthermore, Aselage (2010) actively excludes instruments if "their purpose was solely to measure […] global functioning" (p. 623). However, some assessments of global functioning, like Cambridge Behavioural Inventory (Bozeat, Gregory, Ralph & Hodges, 2000) are found to successfully measure changes in eating behavior (Piguet, et al., 2011). While Piguet and colleagues study was published after the Aselage (2010) review, it shows that more generic

assessments of Activities of Daily Living or Behavioural Inventories should not be automatically eliminated as potential instruments to assess mealtime difficulty. Edahiro et al. (2012) suggest that attention should also be paid to measures that are not combined into an assessment tool *per se.* However, both strategies of assessing eating ability that are not formalised into a 'tool', as well as more holistic assessment tools that incorporate items on eating ability are often ignored in the selection of clinically feasible means to assess mealtime difficulties.

Perhaps the biggest issue, however, comes from Aselage's (2010) analytic conclusions, whereby she suggests that there is only one clinically feasible assessment method. Nine out of 12 reviewed assessment tools are excluded due to unreported reliability, validity or both (the shortcomings of which are discussed above). Furthermore, two of the remaining 3 studies were excluded due to perceived impracticality, which was based on the number of items in each assessment. However, the excluded McGill Ingestive Skills Assessment (MISA; Lambert et al., 2006), is psychometrically tested with reported reliability greater than the favoured EdFED (although it is not clear whether this difference is significant) and, although MISA includes more items, it is fairly easy to administer during a single meal. Exclusion of MISA therefore further suggests that exclusion, both due to lack of psychometric testing, and especially due to perceived difficulty to administer seems rather unfounded particularly as the latter seems to be based predominantly on the number of items in each tool rather than a more complex review of ease of use.

There seems to be an overall preference for short, extensively researched and validated assessments of eating ability and eating assistance, which, in practice should prove advantageous. Little effort so far has been made to look at mealtimes in a holistic way, acknowledging the impact of micro-cultures. However, by prioritising short, highly validated assessments, the more qualitative holistic studies, which are broader in scope (and thus more time-consuming) and give greater regard to mealtime dimensions beyond the physiological, are bound to be perpetually judged as inferior. In the same vein, assessments of sensory pleasure derived from food (which is both physiological and psychological in nature) also seems to be excluded from the preferred medicalised assessments. For example, EdFED items (Watson 2006) while trying to establish difficulties in eating or feeding (e.g. seeing the spitting out of food as indicative of eating problems), does not account or attempt to assess if spitting of food occurs simply because the food is not enjoyed.

Such shortcomings, as pointed out, are not in any way restricted to review articles or to the specific publication of Aselage (2010). Instead, these are commonplace practices that guide the selection of tools to assess eating ability, thus constraining the types of findings that can be derived. Similarly to issues in assessing (mal)nutrition, assessments of eating ability can have an impact on what information is drawn from the research and what aspects of eating ability remain invisible (or proportionally understated or exaggerated).

3.2.4 Summary of Physiological Aspects of Mealtimes in Long-Term Dementia Care

Physiological aspects of mealtimes tend to dominate research and practitioner literature and focus predominately on (mal)nutrition and (de)hydration as physiological statuses, and eating ability as well as eating assistance as physiological processes. Nutritional needs seem to change with age (De Castro & Stroebele, 2002) and dementia processes appear to be predictive of mal/under-nutrition (Chang & Roberts, 2011). However, the precise patterns of change and its causes remain complex and largely unknown, while various situational factors further shape these relationships. As well as the complexity of existing contributions and interactions, explanations exploring the high prevalence of malnutrition and dehydration are further complicated by multi-level issues around assessments measuring malnutrition and dehydration. In contrast to malnutrition, little is known about the prevalence, causes and outcomes of dehydration in dementia care, and more research is needed.

Physiological eating and drinking ability is often regarded as the most important contributor to adequate nutrition as well as a capability posing the greatest risk of malnutrition if lost. The research on assessing, maintaining and/or improving eating ability, however, almost exclusively focuses on physiological and cognitive factors and lack regard for wider environmental, societal and cultural antecedents. In addition to this, further issues exist around biases due to which certain types of strategies on avoiding the loss of eating ability are valued disproportionately.

Because of current gaps in knowledge and given existing biases, more information on the physiological aspects of mealtimes is needed despite its current dominance in mealtime research. However, particular attention should be concentrated towards research that incorporates a multiplicity of dimensions and sub-dimensions and approached mealtimes in a holistic manner.

3.3. Physical Aspects of Mealtimes

Despite the aforementioned disproportionate focus on the physiological aspects of mealtimes, mealtime literature is becoming increasingly aware of the importance of physical aspects of mealtimes. These, in turn, can be broadly categorised into literature on food, and that on wider mealtime environments (e.g. the layout of dining rooms). The following sections will therefore discuss research these research areas separately.

3.3.1. Food and Drink

Food/diet and dementia has been a specific and growing research area for a number of decades. However, the apparent abundance of studies predominantly looks at the role of food and drink in preventing or developing dementia (Engelhart et al, 2002). For example, fruit and vegetable consumption in midlife is suggested to prevent dementia (Loef & Walach, 2012), as does dinking coffee (Panza et al, 2015). Moderate intake of unsaturated fats at midlife is protective, whereas a moderate intake of saturated fats may increase the risk of dementia (Laitinen et al, 2000). Food manufacturing industries appear to have given rise to studies on the benefits and disadvantages of some products in particular; for example, alcohol. Considerable disagreement also exists, with some studies suggesting that wine can protect from developing dementia (e.g. Pasinetti, 2012), others suggesting a detrimental effect (e.g. Farcnik & Persyko, 2005) or even causing alcohol-related dementias (Moriyama et al, 2006); with the research controversies generating news headlines such as "Red wine could help slow dementia onset (but you'd have to drink 1,000 bottles a day)" (Osborne, 2016).

In contrast to the multiplicity of studies on the impact of food before the onset of dementia, literature on the food and drink *per se* (versus nutrition and hydration) for people who are already experiencing dementia is lacking. Nonetheless, the following section attempts to summarise existing findings.

3.3.1.1. Findings

The importance of food and drink in dementia is often seen through the lens of solution to changing eating abilities and tastes. For example, PWD experiencing swallowing problems may be served soft-textured or pureed diets, changes in appetite lead to offer of different foods to either boost or reduce calorie intake, changing food preferences (such as increased

preference for sweet foods) would result in altering food flavours, and change in food habits, such as eating with hands would lead to serving finger foods (Ikelda et al, 2002; Ragdale, 2014). Food, therefore, is not seen in its own right, but rather solution to a problem. Nonetheless, research on food in dementia has produced an interesting array of findings.

Empirical research, for example, has demonstrated that food preferences change as a result of dementia processes. People with dementia do not always maintain the same preferences in food and drink that they had before the onset of dementia and this can be manifested in several ways. For some, new things may be tried and enjoyed. For others, changes in food preference can include expressing a dislike for and avoiding what may be considered to be a healthy diet, and people with dementia may develop a preference for snacks and foods that are easily eaten (Watson et al, 2000).

Change in taste has been documented in a number of studies. Keene and Hope (1997) have demonstrated that the proportion of sweet food eaten was higher in people with dementia and even higher in people with dementia who were hyperphagic (i.e. eating an increased quantity of food). The same change was not observed in older (over 50 years old) and younger (under 50) control participants who did not have dementia. The authors did, however, acknowledge that small sample sizes (17 people with dementia with and 14 without hyperphagia) may have affected the results, and that - despite some speculation of hormones the levels of which generally reduce in Alzheimer's disease - the cause of preference for sweet foods is not yet known. Equally, PWD were found to prefer foods with stronger flavours. A study by Pouyet and colleagues (2015) recruited 104 French LTC residents who had severe, moderate or no cognitive impairment (the former category in particular being indicative of dementia) and offered them appetisers typical to French cuisine, as well as measuring food intake and food liking. The appetisers fell within 3 categories - neutral (i.e. non-enhanced), enhanced with olive oil, and enhanced with seasonings, but offered similar nutritional intake. It was found that regardless of cognitive status, nursing home residents consumed significantly more flavour-enhanced food. Also - and perhaps unsurprisingly - food liking was significantly correlated with food consumption regardless of cognitive status, showing that liking of food can partially explain how much is eaten. 'Fixation' on particular foods has also been noted. In her commentary regarding Hoffer's (2006) article on the metabolic perspective on tube feeding in advanced dementia, Ansell (2007) pointed out the change in taste as dementia progresses, specifically referring to narrowing of appealing options (e.g. where a Person with Dementia eats only one type of

food or meal for extended periods of time). The aforementioned studies, however, aim for food to meet the (changing) preferences for PWD.

A larger proportion of food-related research in LTDC, however, focuses on meeting nutritional needs and avoiding or reversing under-nutrition, rather than addressing preferences. The challenges in this arena are eloquently summarised by Keller and colleagues (2007), by the term "shrinking plate" which incorporates people with dementia "no longer preparing or choosing own foods; limited preferences; and limited ability to feed oneself, use utensils, or chew and swallow some foods" (p. 435-436). Energy-dense foods have received particular research interest, as a beneficial way of increasing weight in someone who has lost their appetite (Caroline Walker Trust, 2004). This can be achieved simply through adding high-calorie ingredients such as full-fat milk, cream, cheese, butter, oil, mayonnaise and yoghurt to meals (Crawley and Hocking, 2011). Leslie and colleagues (2013) ran a cluster randomised controlled study on the impact of energy-enriched foods on dietary intake in 445 under-nourished LTC residents. Despite adequate food provision and the intervention, energy and macronutrient intakes were below UK dietary reference values. Nonetheless, providing usual meals enriched with standard quantities of energy dense foods (e.g. double cream added to cereal, porridge, soup and desserts, butter added to potatoes and milky drinks offered each evening) resulted in a significantly higher energy intake among participants in the intervention condition.

Nonetheless, needs and preferences seem to be interlinked when it comes to 'fortified' diets. Young and colleagues (2005) demonstrated that receiving meals that differ from ordinary ones only in higher amount of carbohydrates resulted in increased food intake in 20 out of 32 participants with dementia. However, greater intake also related to greater carbohydrate preference, which in turn was related to a more severe dementia. This suggests that to consume more 'adapted' food PWD first need to like that type of food, and that the preference for particular adaptations (like sweet foods in Keene and Hope (1997) study) may develop due to the progression of dementia itself. Preference and need, however, does not always interact in a positive way, and can be a source of tension. Keller and colleagues (2007) demonstrated that informal carers experienced a tension between providing nourishing food, versus food that was pleasurable and desirable for the person with dementia. The tension arose predominantly from equating nutritious food with good care, and while Keller et al (2007) spoke to informal carers, the same tension may exist among LTC staff. In addition to this, Caroline Walker Trust (2004) has stressed that while intake of 'inappropriate foods'

(e.g. eating only sweet foods) is problematic, it is important to keep weight issues in perspective, as intervention to reduce 'inappropriate' eating could be counterproductive if the person eats well, is active and their weight is stable.

Aside from food composition, changes in food and drink texture have also been researched. Both in cases of dysphagia (swallowing difficulties) and poorer eating ability *per se*, soft or liquidised meals are often made available (Lee & Song, 2015). Logemann and colleagues (2008) found that aspiration on thin liquids among PWD was eliminated with honey-thickness fluids, followed by nectar-thickness fluids and a chin-down position while drinking. Introducing a variety of finger-foods were also found to have a positive effect on the eating experience, maintaining independence at mealtimes, and increasing food intake of those residents with dementia who are prone to walking during meals (Zgola & Bordillon, 2001).

Food composition and texture, however, provide a clinical way of conceptualising and measuring food within long-term dementia care. New research is emerging, where food is conceptualised not by how pleasurable or nutritious it is, but rather by the meaning it hold for people with dementia in long-term care. Hanssen and Kuven (2016) conducted in-depth interviews of family members and nurses experienced in dementia in South Africa and among ethnic Norwegians and the Sami in Norway to explore the meaning of traditional food in dementia care. The authors found that traditional foods created a feeling of belonging and joy. Familiar tastes and smells awoke pleasant memories in patients and boosted their sense of well-being, identity and belonging, even producing words in those who usually did not speak. In persons with dementia, dishes remembered from their childhood may help maintain and strengthen cultural identity, create joy and increase patients' feeling of belonging, being respected and cared for. Hanssen and Kuven's (2016) research, in fact, goes further than addressing cultural needs of first-generation immigrants, but instead illuminates the positive effect of 'traditional' foods familiar from childhood (the period of time PWD may remember the longest). It suggests that beyond the most suitable flavours, textures and content of food, what may matter is the familiarity and meaning of food, and that 'suitability' of food meaning should be considered as much as its physical factors.

Finally, while food has long been researched in its capacity to prevent or contribute to the development of dementia (Engelhart et al, 2002), some sporadic examples of medical influence of food in dementia. For example, Perry and Greig (2002) have considered the impact of a glucagon-like peptide (hormone secreted in response to nutrient ingestion) as a potential treatment for Alzheimer's disease. While consideration of bio-chemical properties

of these peptides is beyond the scope of the thesis, the findings do suggest that the process of eating may be beneficial to the experience of Alzheimers *per se,* and not just in terms of nutrients and energy required for functioning.

3.3.1.2. Prominent Issues

One of the obvious shortcomings of research on food in mealtimes for PWD in LTC is lack of scope. While research does address different aspects of food, such as flavour, composition and texture, not all aspects of food are covered. For example, while it is known that flavour preferences change with the development of dementia, sweet foods and enhancing flavour with olive oil and spices is not the only possible flavour adaptation. Therefore, while it is known that the previously mentioned flavour adaptations result in better food consumption, it is not known if some other flavour adaptations may be even more advantageous and preferred by PWD.

This, in turn, leads to considerations on how to best target food research in dementia care. Random selection of food adaptations is unwise both because of funding constraints ('fishing expeditions' are rarely favoured by funding bodies), and because this approach would constrain potential changes by the imagination of the research team. What is lacking, instead, is investigative (vs interventionist) research, aiming to find out more on how food preferences change with dementia and how changes in eating ability are experienced by PWD themselves.

The above approach may also account for the varied nature in food preference changes (both per type of dementia and per individual) that have so far been largely unaddressed by empirical research. A notable exceptions is Ikelda and colleagues (2002) conducted a caregiver questionnaire on swallowing problems, appetite change, food preference, eating habits, and other oral behaviours (e.g. indiscriminate eating) of PWD in the community and LTC, and compared the results based on the type of dementia the participants experienced: frontotemporal dementia, semantic dementia or Alzheimer's disease. The authors found that appetite change, food preference, eating habits, and other oral behaviours were more pronounced in people with frontotemporal and semantic dementias compared to Alzheimer's disease, while swallowing difficulties were equally common in all groups. The authors also found a clear pattern for eating difficulties in semantic dementia: a change in food preference, followed by appetite increase and altered eating habits, then other oral behaviours, and finally swallowing problems. Altered eating habits and appetite increase

were the initial symptoms in frontotemporal dementia, with less clarity about the sequence of subsequent symptoms, while no clear patters emerged with Alzheimer's disease. However, the authors relied on caregiver accounts, rather than attempting to include PWD.

Therefore, the prominent issues of food research in dementia care are threefold: current research lacks scope, investigative (vs interventionist) approaches, and individual perspectives of people with dementia themselves.

3.3.2. Mealtime Environment

Food and drink, however, is only one part of physical aspects of mealtimes in dementia care. It is situated within a wider mealtime context (see Figure 7), which involves how and where food is served, both in terms of table set-up and dining spaces.

Figure 7. Physical Aspects of Mealtimes

3.3.2.1. Findings

The importance of mealtime environments has prominently emerged in large-scale studies looking at factors influencing food/fluid intake and eating ability. For example, Lee and Song (2015) investigated factors that influence eating ability among 149 PWD in Korean LTC facilities. Aside from physiological influencers of eating ability, physical factors were also significant. Eating in a public space, such as a living room or a dining room versus own room, and eating an ordinary meal (versus soft or liquidised meals) were related to better eating ability. Similarly, Reed and colleagues (2005) observed 407 PWD living in 45 LTC facilities in the USA and found that among a wider array of factors related to low food intake,

environmental characteristics were particularly prominent. Participants were likely to eat more if they lived in smaller facilities (under 16 residents), if they ate in communal dining rooms instead of their own rooms, and if the communal rooms had less institutional features (e.g. not eating off a tray). Less institutional features and eating in the communal dining room was also associated with absence of low fluid intake. However, similarly to research on food in dementia care, most empirical knowledge of mealtimes comes from intervention research. Some of the findings are, therefore, very specific to a particular mealtime aspect.

Lighting, visual and auditory stimulation, and visual contrast has received substantial research interest. Brush and Calkins (2008) stress that environment can be both a barrier and a solution to positive mealtimes in dementia. Their commentary outlines that mealtimes may be negatively affected by visual overstimulation and auditory confusion in busy and noisy areas, poor lighting, and lack of visual contrast in food and tableware. To improve mealtimes the authors suggest increased lighting and avoiding shadows over the tables, increasing visual contrast with use of colours, and improving acoustics by introducing noise-absorbing by use of soft furnishings and acoustic panelling. Increasing lighting and controlling glare and improving contrast was shown to facilitate independence, improve oral intake and functional abilities in people with dementia (Brush et al., 2002). However, some unresolved contradictions exist, with Barrick and colleagues (2010) showing that ambient bright light did not reduce agitation in dementia compared to standard lighting and did, in fact, exacerbate agitation (Barrick et al, 2010). Further complications were uncovered by Tanaka and Hoshiyama (2014), who provided visual and auditory stimulation by using tablecloths and flower vases on tables, and playing background music over lunch in LTDC in Japan. 20 PWD were asked if they knew what meal it was both before and after lunch. The recognition of lunch significantly improved with stimulation, while pairing both auditory and visual stimuli worked better than visual stimuli alone. Together, the research demonstrates that mealtime outcomes may be influenced by very specific environmental stimuli and their combinations.

More refinement has been successfully achieved in research on tableware contrast in dementia. The use of warmer, stronger colours in dining rooms was shown to encourage conversation and interaction, with coral, peach or soft yellow colours encouraging eating (Brawley, 1997). Despite a small sample (N=9), Dunne and colleagues (2004) also found that use of red tableware (versus white) resulted in a significant increase in food and liquid consumption. However, in a follow-up study using high- and low-contrast plates of different

colours, the authors clarified that rather than the colour per se, increased food and fluid intake resulted from using pates that contrasted highly compared to food. Marsden and colleagues (2001) also demonstrated that colour-contrast between food, crockery, place mats and floor covering can provide support in the eating experience for people with dementia (Marsden et al, 2001).

The impact of music at mealtimes has been researched particularly extensively, uncovering complex and at times contradictory findings. For example, Thomas and Smith (2009) found that playing music at mealtimes for people with moderate dementia resulted in residents staying in the dining room for longer and consuming 20% more calories. In contrast to this, McHugh and colleagues (2012) found that pre-meal singing slightly decreased the amount of food eaten. Although the findings were affected by a small sample size (N=15), and 2 'outlier' participants in the experimental group, the study demonstrated the growing interest in the role of music on mealtime outcomes.

Interestingly, a high proportion of mealtime research is interested in aggressive or agitated behaviours at mealtimes, rather than food and fluid consumption. Chang and colleagues (2010) played 41 residents with dementia background music during mealtimes. The authors found that music at mealtimes significantly reduced physical and verbal aggression. Similarly, Ho and colleagues (2011) found that researcher-composed music (including a smooth rhythm, minor tonalities, smooth melody lines and no dramatic changes, and played only at mealtimes at a volume slightly higher than the average noise levels) resulted in a significant decline in agitated behaviours both during and outside mealtimes. While agitated behaviour was measured comprehensively: over a 24 hour period 7 days a week and across 29 behaviours, it is surprising that mealtime-specific outcomes such as food consumption or mood during mealtimes were not observed. It is therefore unclear in decreased agitation in turn increased food intake or wider mealtime experiences, and requires further investigation.

Other, specific aspects of the dining environment and their impact on mealtimes in LTDC have also been investigated. For example, Namazi and Johnson (1992) demonstrated that PWD's ability to independently select snacks from visible and accessible refrigerators, while Simmons and colleagues (2008) showed that snack delivery between meals significantly improved intake. In relation to this, Hung and colleagues (2016) interviewed staff in two LTC facilities in Canada (one for PWD and another for residents without dementia) on the influence of physical environment renovations in the dining rooms for the residents and for

the staff themselves. The renovations involved creating a dining room with two open kitchens - one for staff to prepare some of the food and wash up, and another for the residents which offered facilities such as a microwave, a fridge, and cabinets with cutlery and crockery. Staff focus groups positively viewed the independence and autonomy afforded to the residents by the resident kitchens. However, managing risks was also prominent; while the open staff kitchen encouraged PWD to enter the area wishing to take a more active role in mealtime activities, staff members used a considerable amount of time taking PWD out of the staff kitchen. Square tables that clearly define eating territory were also shown to support a positive eating experience for people with dementia (Marsden et al, 2001), while Cleary and colleagues (2008) investigated the impact of routine seating plans on improving mealtimes for people with dementia. Three PWD in LTC participated in the study, which involved measuring food and fluid consumption, length of time waiting for meals and time taken to complete the meals via retrospective video analysis. The introduction of a seating plan (where each participant as encouraged to sit at the same place at each meal) led one of the participants to eat and drink more during the intervention, but not once it was withdrawn, another to eat and drink more both during and after the intervention, and the last participant to first eat and drink more during the first round of intervention, but near-baseline on the second round. Niche studies also exist, from finding that aquariums in dining rooms influence weight gain in people with dementia (Edwards & Beck, 2013) to humming as a way to facilitate feeding people with dementia (Engström & Hammar, 2012). A large clock and a large-print sign identifying mealtimes in the dining area as a low cost intervention was also found to help reduce confusion about mealtimes (Nolan et al, 2004). The above studies show that specific aspects of mealtime environment do impact mealtime outcomes, but more investigation is needed to understand the full scope of influencers and their complex effects on mealtimes.

Nonetheless, the largest proportion of research on mealtime environments has looked at the distinction of institutional/artificial versus home-like mealtimes in long-term care. Some comparative studies have focused on singular aspects of homeliness, such as how food is portioned and delivered. For example, Shatenstein and Ferland's (2000) evaluation found that food consumption and energy intake (and intake of most other nutrients) increased significantly when meals were portioned in the dining room, rather than brought in already portioned. The authors argued that the differences were due to food portioning in the dining room simulating a more home-like atmosphere. A pleasant aroma of baking or cooking food in the dining spaces has also been shown to promote food intake (Abbott et al, 2013).

Bringing food choices as close to the resident as possible with food delivery models, such as "restaurant style" was also shown to promote food intake (Douglas & Lawrence, 2015; Vucea et al, 2014).

However, a particularly notable study by Nijs and colleagues (2006) has taken home-like mealtimes in a wider sense. The authors ran a cluster-randomised trial with 178 residents in 5 Dutch LTC facilities (each of which had 2 wards to provide experimental and control settings) to investigate family style mealtimes' effect on quality of life, physical performance and body weight. Family-style mealtimes involved table dressings (presence of a table cloth, drinking glasses, ordinary plates, full cutlery, napkins and flower arrangements), food served in dishes on the table with several menu choices available, staff sitting and chatting with the residents at the table and not changing during the mealtime, resident choice of when food is served and if to serve themselves, and no other activities such as drug rounds. Ordinary mealtimes involved no table cloths, plastic cups, sectioned plates, residents wearing bibs, pre-plated meals chosen two weeks in advance and ready-to-eat sandwiches available, staff handing out food and medication, but not sitting down with the residents, no choice or availability of a change during a meal, a pre-determined beginning of the meal (depending on food delivery), and diverse activities (such as cleaning and doctor's rounds) taking place during the meal, with family and friends walking in and out of the dining room. Compared to the control group, family-style mealtimes prevented a decline in Quality of Life, physical performance (both gross and fine motor functions) and body weight. Importantly, family-style meals did not improve any of these aspects, but instead prevented a deterioration seen in the control group.

Overall, the importance of home-like dining environments is seen as important for two main reasons. Firstly, complex relational ties between the operational, managerial, and environmental features of home-like settings affect residents' ability to find meaning and satisfaction in their mealtime experiences (Roberts, 2011); meaning which is absent when – in institutional settings - individuals collect together to eat food they have not planned or served, and which they will take no part in clearing (Manthrope & Watson, 2003). Secondly, that meaning is drawn from the generational familiarity of a homely mealtime, since – as Warde and Martens (1998) argue – eating among the current generation older people has been commonly restricted to intimate family settings. Homely mealtimes, therefore, provide a chance to connect to place in LTDC facilities (Manthrope & Watson, 2003).

Finally, some notable 'offshoots' of environmental research also remain. For example, some research has considered the temporal aspects of mealtime environment. Dyer and colleagues (2001) emphasized the importance of time of day when the meal takes place and the importance of breakfast in LTDC, which is often anecdotally reported by staff. The authors found that for most of the 19 participants breakfast was the least variable meal in terms of energy intake, but also the meal where energy intake was the lowest. In addition to this, some researchers have suggested that mealtime environment is conceptualized too narrowly; namely, that it is not only present when food is placed on a table (Zgola & Bourdillon, 2001). According to Zgola and Bourdillon (2001) it involves planning the menu, getting a recipe, help in the preparation of food, setting the table, planning the menu, cleaning up after the meal – and even growing herbs in pots - are all opportunities for a person to be involved in different aspects of making the eating experience for someone with dementia.

3.3.2.2. Prominent Issues

Despite considerably more research on wider mealtime environments than on food, similar issues remain. As can be seen from the research described, the majority of empirical evidence comes from intervention studies, where the focus is pre-determined rather than exploratory. Furthermore, the studies are often small-scale and site-specific, making generalisations difficult. Inability to partial out site-specific features in small-scale studies may also contribute to some of the contradictory findings.

Current research also has not yet delved into multiple tensions around mealtime environments. For example, while a home-like dining appears advantageous, it arguably sends mixed stimuli to people with dementia in long-term care, as some institutional features are unavoidable (e.g. presence of relative strangers in terms of both other residents and staff). Also, apart from studies on time of day (the temporal aspect of mealtimes) and food described above (See Dyer et al, 2001, and Simmons et al, 2008), insufficient attempts have been made to explain the way food and wider mealtime environments interact.

Finally, despite numerous attempts to investigate aspects of mealtime environments and their impact on PWD living in institutions, a coherent understanding on how these factors interact is also lacking.

3.3.3 Summary of Physiological Aspects of Mealtimes in Long-Term Dementia Care

Physiological aspects of mealtimes in dementia care cover food and drink, and the wider mealtime environment. Food-related research shows that food preferences change, with many PWD preferring sweeter foods, or foods with more enhanced flavours. Another line of food research considers nutritional needs rather than preferences, and considers high-calorie and high-nutrient foods, as well as adapted-texture food and drink. Nonetheless, food preference seems to impact on how much adapted food is consumed. Research on wider mealtime environments is wider in scope. Lighting, visual and auditory stimulation, as well as visual contrast at mealtimes appears to positively impact food and drink intake, although some contradictory research is also present. The impact of music both before and during mealtimes has also been investigated. However, the impact of home-like features at mealtimes has received the most attention and seems to show universally positive results on a variety of mealtime outcomes. Nonetheless, some prominent issues remain in relation to research on physiological aspects of mealtimes. Current research lacks scope, is almost exclusively based on intervention studies, site-specific factors are rarely controlled for and the voices of people with dementia remain marginal.

3.4. Psycho-Social Aspects of Mealtime

Compared to literature on physiological and physical aspects of mealtimes, where literature can be dichotomized (either 'two sides of a coin' like with nutrition/hydration and eating ability, or a smaller factor within a wider arena like food/drink and mealtime environment respectively), research on psycho-social aspects of mealtimes are harder to categorise. The separation presented within this section is, therefore, made not on the basis of the precise topic (e.g. communication versus mood), but instead along the passive-active continuum. As will be demonstrated below, literature on psycho-social aspects of mealtimes in dementia care can be separated into studies considering what people with dementia experience during mealtimes (which is often told by caregivers serving as a proxy) and studies that look into what staff *do to* PWD during mealtimes (see Figure 8). The implications of conceptualising people with dementia as passive recipients and staff as actors are, of course, problematic, and will be discussed later in this section.

Figure 8. Continuum of Literature on Psycho-Social Aspects of Mealtimes
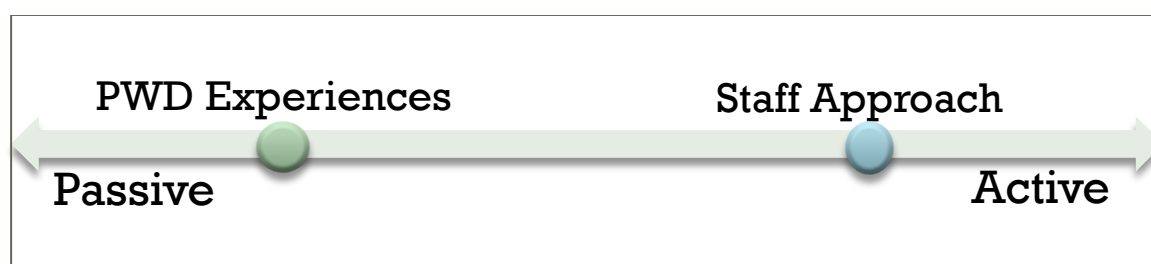
Psycho-social aspects are also difficult to narrow down to specific constructs, but includes inner processes of the individual (such as personhood, identity, or mood) and interactions with the outside world though activity, engagement and communication, as well as Quality of Life in general. As will be illustrated in the 'Findings' sections, literature to date has not yet attempted to conceptualise a holistic understanding of psycho-social aspects of mealtimes in dementia, and often tends to measure a single and more specific construct such as mood or interaction.

3.4.1. Psycho-Social Experiences at Mealtimes

Within each category (i.e. PWD Experiences versus Staff Actions) the studies can be more readily divided not by what is known, but rather how this knowledge is obtained. Because psychosocial mealtime aspects are addressed by a large proportion of qualitative studies - unlike research on physiological and physical aspects - clear themes or topic clusters are

harder to discern. Instead, methodologically-divided studies show that the knowledge of psychosocial mealtime aspects is drawn from interviews with informal carers, mealtime observations, mealtime interventions and larger-scale exploratory studies that look for factors influencing negative outcomes in dementia care.

3.4.1.1. Findings

A lot of what is known about psycho-social experiences of mealtimes in long-term care results from either direct comparison with mealtimes of people living within the community. On the one hand, these comparisons reveal the artificiality of social interactions within LTDC, while on the other examples on how changing mealtimes are managed within families or spousal dyads reveal the social and psychological opportunities that mealtimes afford. In relation to the latter, Keller and colleagues (2010) looked at the meaning and experience of mealtimes in families living with dementia in the community. Eating together was seen by PWD and by their 'partners in care' as way of being connected and honouring identity (thus meeting both psychological and social needs). Importantly, mealtimes were seen as facilitators of connection between the person with dementia and their carer. This, according to the author's thematic analysis from 26 PWD-carer dyad interviews, particularly revolved a guaranteed time of being together and facing each other during mealtimes, which promoted connections, participating psychologically, including conversations with one another and engaging emotionally, and getting and giving support from one another. In terms of support, mealtimes provided specific opportunities to express and/or identify needs, which in turn built and strengthened connections. Once dementia progressed, carers identified mealtimes as near only occasions of building connections with one another. A previous study by the lead author involving interviews with 23 informal caregivers also revealed that mealtimes were predominantly seen as a social activity (Keller et al, 2007), re-enforcing the notion that mealtimes are not only the space where social and psychological processes occur, but in fact a particular opportunity to meet psycho-social needs.

Research does, of course, acknowledge the social and psychological challenges of changing mealtime abilities for both the person with dementia themselves and for their families. Papachristou and colleagues (2013) interviewed 10 male and 10 female informal carers of PWD. Their narratives indicated a set pattern of decline, with food shopping being the first ability to decline, followed by food preparation and the ability to eat. While adaptations were necessary and seen as stressful, they were also perceived as rewarding as 'food care' was

seen as an important social time. Similarly, Wong and colleagues (2015) performed narrative enquiry on interviews with a single family living with dementia in relation to mealtime change and mealtime resilience. The authors found that while decreased capabilities during mealtimes proved challenging, reminiscing, incorporating humour, hope and optimism in mealtimes, and establishing social support proved to be positive strategies to adapt to mealtime change. This, therefore, further reinforces the idea that in terms of psycho-social aspects functional change in mealtimes is both a challenge and an opportunity.

A crucial aspect of discovering and negotiating challenges and opportunities is, however, its complex nature and gradual pace. This is evident in the Atta-Konadu and colleagues (2011) grounded theory study, involving 3 years of interview data with 9 dyads involving a male spousal carer and a female who experiences dementia. The authors found that food-related familiar roles change over time (from the wife occupying the majority of roles around cooking and serving food, to husbands taking over when, due to their advancing dementia, the wives can no longer fulfill this role), and that this process is one of 'sliding into food-related roles' in a gradual way, navigating change and working things out together. Crucially, spousal carers were shown to find this 'sliding' less challenging when they were successful in promoting each other's self-worth and preserving identities throughout the process. This raises some prominent issues around relocating to long-term care facilities. Once entering a LTC environment, no such 'sliding' or negotiating is possible. The change is abrupt and dictated by institutional policies and frameworks, and usually takes the person completely out of most food-related tasks (e.g. procurement, preparation or serving) regardless of how involved in these tasks the residents were before admission. It is hard to envisage, therefore, how an institutional role-change around mealtimes and food would promote self-worth and preserve identities; instead, the opposite is likely.

The findings Herkusens and colleagues (2014) are of particular interest in relation to relocation. The authors have analysed interview data of seven families who participated in a larger qualitative study for at least 4 consecutive years, specifically investigating how relocation to a LTC facility affected mealtime experiences of families living with dementia. The 5 themes emerging from the interview data have particularly demonstrated that meals in LTC were highly organised and did not resemble a relationship-focussed, more relaxed meals at home. Relatives of PWD also reflected on task-orientation in communication with staff, and spoke of observing their loved one's nutritional, but not social needs being met. Specifically, families mentioned lack of interaction and staff attention to enhancing the

mealtime experience. At the same time family members spoke about 'over-adherence' to and a 'fixation' on rules and procedures around the mealtime, commenting on the lack of flexibility and spontaneity present in mealtimes with the PWD while they still lived at home. People with dementia also spoke about the process of adjusting to dining with relative strangers, and considered it a 'big change', especially if they could not choose whom to sit with. Some participants with dementia discussed difficulties in making conversation with tablemates and running out of topic to talk about, which resulted in unnatural and forced interactions. Declining abilities of eating and related aspects such as vision was also a source of difficulty, both in terms of self-awareness and shame about own abilities and adjusting to and accepting behaviours of others. Nonetheless, having someone to share a meal with was also seen as positive and fostering new social connections. PWD and their relatives also spoke about holding on to home and using strategies to retain familiar mealtime experiences. Going out to eat outside of the LTC facility was particularly important as a way of maintaining family dining. Loss of mealtime roles, such as cooking and nurturing others though food, were also frequently discussed. However, while some role loss was meaningful and distressing, other roles were willingly relinquished with a sense of relief. Role negotiation also took place; while no longer able to 'host' a meal in a traditional sense (e.g. engaging in cooking and serving activities), PWD spoke about being a 'host' at the table when their family were visiting. Although the only one of its kind to date, Herkunsen and colleague's (2014) study demonstrates illuminates some of the impact of abrupt mealtime change when PWD relocate, as well as showing that positive opportunities still remain.

Gathering views of informal carers, however, has not been the only way to find out about PWD experiences of mealtimes their psychosocial aspects and involved large-scale exploratory studies. For example, Orrell and colleagues (2000) studied 60 PWD recently admitted to an NHS Mental Health ward, following up on the cases 3 years later. The authors found that, among other factors, lack of social support both within and outside of mealtimes (e.g. having support from relatives, receiving meals-on-wheels, and attending a day centre) was a predictor of whether the participants was still alive at the 3-year follow-up point. In a large-scale (N=477 PWD) Taiwanese study Lin and colleagues (2010) found that low food intake was associated not only to physiological factors, but also to social ones; namely not receiving attention/assistance from staff and fewer visits from family.

Observational studies have also illuminated psycho-social aspects of mealtimes in LTDC. In terms of social actions around food Silver and Albert (2000) observed 79 residents with

dementia and 32 without in the dining areas of a large US-based LTC facility, and recorded food sharing among residents. PWD were more likely to take food from others than residents without dementia, while food-giving patterns did not differ between groups. Food taking was shown to be non-mutual in all observed cases (i.e. only one person took), while food-giving appeared reciprocal. Lack of social engagement, in turn, was observed to have negative effects. Older adults (without dementia) eating alone or without social engagement were shown to exhibit decreased food intake (Beck & Ovesen, 2003), while Reed and colleagues (2005) observed 407 PWD living in 45 LTC facilities in the USA and found that participants consumed more food if they ate in communal dining rooms rather than their own rooms. However, it is unclear how much lack of socialisation *per se* impacted on intake, and what role was played by negative emotions related to isolation (Steptoe et al, 2013). In realtion to this, Paquet and colleages (2003) demonstrated that older people without dementia living in LTC experiencing emotions such as anxiety, mild depression, and anger consume less food. Family-style dining involving residents serving themselves has also been shown to increase in participation in mealtime activities by 65% and communication at meals among residents increased by 18% (Altus, Engelman, & Matthew, 2002), suggesting that mealtime environment and chances to be actively involved in mealtimes may have a positive psychological (e.g. a role or a sense of achievement and autonomy) and social (e.g. a reason to communicate) impact.

3.4.1.2. Prominent Issues

While knowledge about social and psychological experiences of mealtimes in Dementia Care is collected in a diverse manner, notable gaps remain. Crucially, while primary research concern is the experiences of PWD, these are often investigated either by using family carers as a proxy, or conducting observations. Where PWD own accounts are collected, they involve people with mild levels of dementia, often still residing in the community, with accounts of people experiencing a more advanced stage of dementia largely missing. Equally, while the potential of mealtimes to meet psycho-social needs of PWD are researched in community settings, similar investigations in long-term care settings are considerably fewer in number.

As noted above, the studies – especially those conducted in LTC settings – also lack a holistic view of psycho-social aspects of mealtimes. Instead, constructs of higher specificity, such as food sharing, communication and participation in mealtime activities, are investigated. This means that synthesising research findings on the topic remains difficult.

Another notable issue is that specific psycho-social aspects are often included in larger qualitative studies (e.g. Lin et al, 2010) that attempt to look for factors associated with low food intake more as an afterthough, with most investigated factors being physiological in nature. This raises two issues: (1) the investigated factors are pre-selected and there may be other psycho-social aspects that influence mealtime experiences to a greater extent, and (2) as an addition to studies that look predominantly at physiological factors psycho-social factors end up insufficiently discussed or do not fit in the largely physiological narrative of the studies.

Altogether, this reveals a particular need to investigate psycho-social aspects of mealtimes in LTC facilities by seeking first-hand accounts of people with dementia and conceptualising psycho-social aspects in a holistic, exploratory manner.

3.4.2. Staff Approaches

In the same way that food (physical aspect) mirrors eating difficulty (physiological aspect), staff involvement in mealtimes mirrors - but goes beyond - eating assistance. Assistance is not mere movement of food to mouth, but instead a social, interactive venture that goes beyond physical meals. In fact, as will be discussed below, studies that look at psycho-social aspects of mealtime assistance, see it not as a physical intervention (i.e. feeding people who are less able to help themselves to receive enough sustenance), but instead as a psychological one, prioritising independence and autonomy at mealtimes with less direct assistance. Staff's impact on PWD psycho-social experiences of mealtimes are researched by investigating the influence of staff opinions and perceptions, as well as behaviours, and by modifying staff behaviours within interventions studies.

3.4.2.1. Findings

Staff opinions and perceptions of mealtimes and mealtime assistance are important in their psycho-social effects on the residents. Due to the necessary dependency of some individuals in LTDC, staff perceptions are, in fact, disproportionately important. Kuehlmeyer and colleagues (2015) measured 131 staff perceptions of nonverbal behaviour of PWD in response to hand and tube feeding. Most nurses and nursing assistants considered residents' behavior during hand or tube feeding to be important, but their interpretations are heterogeneous. 53% of the staff interpreted residents' expressions of pleasure while eating

as a will to live, while when residents did not open their mouth during hand feeding, 41% of the staff inferred a will to die. Although ethereal (i.e. tube) feeding is highly uncommon in LTDC in the UK (Manthorpe & Watson, 2003), suggesting limited applicability of Kuehlmeyer and colleagues' (2015) study, it does show that perceived meaning of feeding behaviours was therefore shown to directly inform care choices, including that of taking no further action in cases of PWD refusing to eat. Studies focussing on staff perceptions of resident mealtime behaviour have also corroborated the importance and potential impact of staff perceptions. For example, Namazi and Johnson (1992) demonstrated that PWD's ability to independently select snacks from visible and accessible refrigerators was hampered by staff perceptions of excess disability (i.e. staff assuming the resident is unable to help themselves and thus not encouraging independence). Similarly, Silver and Albert (2000) found that staff labelled food exchange among PWD as a problem and intervened in around a quarter of the changes, instead of conceptualising food sharing as a social aspect of mealtimes. While the body of studies in the area remains sparse, it demonstrates that staff perceptions and opinions around resident abilities and behaviours may substantially impact on the way PWD in LTC experience mealtimes.

As well as perceptions, behaviours (e.g. staff-resident interaction patterns and staff's behavioural responses to the residents) have also been shown to impact on resident mealtime outcomes. Amella (2002) investigated mealtime resistance in 53 PWD-staff dyads (where staff completed assessments and psychometric questionnaires about the residents with dementia and themselves). The author divided the sample into PWD who did resist assistance at mealtimes and those who did not, finding that people in the resisting category were more likely to appear bothered, inflexible, agitated and resistant on a behaviour scale. Interestingly, staff feeling bothered and being inflexible themselves also related to 'resistive behaviour' among residents. PWD who resisted assistance at mealtimes did not differ from the accepting group in terms of cognitive impairment or BMI, but showed more deterioration in global functioning, consumed less food and took longer to assist with meals. Overall, the study demonstrated that to understand mealtime resistance, the dynamic between the person being fed and the assisting member of staff should be investigated as a two-way process, rather than seeing resistance only as a product of dementia. Unsurprisingly, however, perceptions and behaviours are closely interlinked. In an earlier study Amella (1999) also observed 53 PWD-staff dyads in a large US LTC facility during breakfast and provided staff with psychometric scales on power, empathy and interaction. The quality of the resident-staff interaction accounted for 32% of the variance in the proportion of food

consumed. Staff ability to allow another person to control a relationship (e.g. in terms of pace or addressing a refusal to eat) were most predictive of the variance in the proportion of food consumed. Despite severe cognitive impairment, residents were able to engage others in an interaction that promoted feeding. Due to these reciprocal behaviors, residents were fed a larger amount of food. Staff did show high attention to the *task* of feeding (not being distracted or engaging in other activities), but did not attend to the *process* of feeding. Staff did not interact using banter, centering behaviours and conversation around the concerns or interests of the resident, and did not exhibit behaviours that involved showing concern and a willingness to change approach if required by the resident. Beliefs related to institutional mealtimes and their purpose therefore led to particular staff behaviours, in turn affecting the experiences of PWD.

Aside from looking at staff behaviours, however, Amella's (1999) study also touched on wider, institution level factors that impact on mealtime experiences; particularly, the author spoke about the focus on task rather than process. A number of other studies also looked at the psycho-social experiences stamming from LTC environments. For example, some studies on family-style mealtimes (see Section 3.3.2.1) have measured psycho-social elements. A cluster randomised trial by Nijs and colleagues (2006; discussed above) demonstrated that family-style mealtimes involving staff sitting at the table and chatting with the residents prevented a decline in Quality of Life. Interestingly, however, despite the family-style setting, family and friends were not allowed to take part in the mealtime; while a questionable practice overall (XX), this demonstrated that maintaining Quality of Life was achieved by change in staff's interaction with residents. Additionally, Charras and Frémontier (2010) conducted a 'natural experiment' of sharing meals with people with dementia in two LTC facilities in France. Staff within one of the facilities ate together with the residents. Compared to the control group, resident weights in the experimental group have increased. Staff also observed that during the intervention some residents started to eat independently again. They were also happy to assist with setting up and clean-up, while some of the residents served food for themselves and took or asked for seconds. Resident-to-resident and staff-to-resident interactions increased, staff learnt more about resident likes and dislikes, shared mealtimes offered a space for reminiscence, due to which staff learnt more about resident biographies. Staff also observed food sharing and helping between residents. Before the meals were shared residents were often seen asking for the bill or refusing food because they did not have money to pay for it. However, this behavior ceased once meals were shared. Staff also reported more satisfaction with mealtimes and more positivity at the end of shift. The

latter study is particularly beneficial in capturing the psycho-social benefits of shared and interactive mealtimes, corroborating the aforementioned studies on mealtime potential for PWD living in the community. It also re-enforced the idea that staff assistane at mealtimes transcends ensuring adequate nutrition via feeding. Instead, it suggests that interactions can bolster independence and prevent overtaking. The latter can be avoided through tailoring assistance to compensate only for deficiencies (Bonner, 2005), which can be achieved through prompting, placing cutlery into the individual's hands and offering assistance, possibly by cutting up food (Hargreaves, 2008).

Other intervention studies have approached staff interaction patterns more directly, specifically aiming to enable independence and autonomy. Mamhidir and colleagues (2007) conducted an integrity-promoting care training programme for staff in an LTC facility for PWD. The staff were asked to consider how to promote PWD integrity by creating trust, supporting autonomy, stimulating the patient's own initiative, helping the patient be industrious (e.g. feel competent to eat independently), feel like a person with his own identity and achieve intimacy and stimulate an experience of wholeness and meaning. A model of interaction was also taught with a stressed importance of being attentive, respecting turn-taking and responding in a manner understandable to the patient, while the mealtime environment was made calmer, more homelike and easier for PWD to interpret. Mealtimes were seen not only as an opportunity to eat enough food (task aspect), but also as an opportunity to promote integrity (relational aspect). 18 patients from the intervention ward and 15 from a control ward were assessed for changes in weight, motor performance, and intellectual and emotional impairment. 13 of 18 patients in the intervention ward experienced weight increased, compared to two of 15 patients in the control ward. Similarly, Beattie and colleagues (2004) conducted a multi-case study to determine the effects of behavioural communication intervention to decrease table-leaving during mealtime. The intervention involved systematic reinforcement of sitting-at-table behaviour using two communication strategies: focused conversation about the meal, eating and social comments related to the mealtime experience, and specific elements of social behaviour (smiling, eye contact). While the body weight of the 3 participants remained stable, the intervention increased time spent at a table and food (but not fluid) intake. These studies demonstrate that staff behaviours and interaction patterns have an impact both on the experiences of PWD and on mealtime success, as well as showing that more positive psycho-social experiences of mealtimes in LTC are indeed possible.

3.4.2.2. Prominent Issues

Studies on the way staff approach towards PWD impacts on mealtime experiences is subject to similar issues as is research on psycho-social experiences of PWD. The scope of staff actions is often narrow and pre-determined, rather than holistic, with investigative research lacking. First-hand PWD accounts on how staff approaches influence their experiences are also missing, and the existing research body is both sporadic and diverse in focus, making a consolidation of findings difficult.

Another issues stems from perceived passivity of PWD versus staff agency. As is demonstrated by the separation of research in the psycho-social section into PWD Experiences and Staff Approaches, studies on the topic tend to focus either on PWD or on staff. In itself, this is not problematic, but the notable lack of studies that simultaneously explore PWD and staff positions may be explained by a differential understanding of roles within mealtimes. Staff are the *doers*, with few studies looking at the psycho-social impact mealtimes have on staff experiences. Conversely, PWD are the *receivers* of care, whose communications to staff and/or mealtime activities towards staff (e.g. offering staff food) are rarely investigated. Although some research has already related mealtime success with perceived reciprocity in staff-PWD mealtime dyads (Amella, 1999), most research ignores reciprocity. Psycho-social *processes* within mealtimes, that occur bi-directionally between staff and PWD are therefore insufficiently understood or even acknowledged.

Finally, most research focuses on either staff or PWD at mealtimes, excluding the role of visitors (e.g. family or friends). It is not known, for example, if spending mealtimes with familiar individuals improves mealtime experiences and outcomes. Also, as already mentioned, if relatives are included in research, it is often in the role of a *proxy* for PWD experiences. Investigations on how being part of (or even observing) mealtimes in LTC impact on relatives of PWD themselves as lacking.

3.4.3 Summary of Physiological Aspects of Mealtimes in long-term dementia care

Overall, research on the psycho-social aspects of mealtime experiences of PWD demonstrates that while mealtimes present a particular set of challenges once dementia develops, they are also distinctly social events, offering both the person with dementia and the caregiver distinct opportunities to interact and connect. However, managing mealtime change occurs via

careful and gradual renegotiation of roles around mealtimes; while common among PWD and their informal caregivers in the community, relocating to LTC means a gradual change is not possible. Role-loss and rigidity within institutional mealtimes therefore often results in negative mealtime experiences. Staff perceptions and behaviours also impact on the way mealtimes are experienced in LTDC. Due to this, some intervention-based studies focussed specifically on changing staff behaviours and interactions with PWD, showing positive influence on mealtime experiences. Mealtimes in LTDC, therefore, can be particularly challenging in the way they affect PWD psychologically and socially. However, while psycho-social mealtime needs are complex and insufficiently investigated, interventions studies also demonstrate that mealtimes may be particularly conducive for meeting these needs.

3.5. Mealtimes Policies & Interventions

As has been discussed in Sections 3.2-3.5 a considerable proportion of studies on mealtimes in long-term care for people with dementia are interventionist in nature. Instead of investigating how mealtimes are experienced and what factors influence mealtime outcomes (e.g. food intake), this set of studies specifically aims at improving the outcomes via use of physiological, environmental or psycho-social interventions. In addition to the prevalence of intervention-based empirical research, practitioner literature around mealtimes almost exclusively looks at ways to improve mealtime outcomes (rather than investigating mealtime experiences). This shows that improving mealtimes in dementia care is a cross-professional concern. In addition to this, it is a national-level concern with policy documents and national guidelines touching on the topic. Due to this, the current section will discuss academic, practitioner and policy-led interventions to improve mealtimes in dementia care. Importantly, this section does not intend to re-produce previously mentioned research. Instead, the aim is to summarise current research and comment on trends.

3.5.1. Academic Literature

Academic literature on interventions to improve mealtimes in long-term dementia care can often be categorised along the physiological, physical and psycho-social dimensions of the mealtime intervention. Physiological interventions involve feeding assistance, physical interventions – modification of food or mealtime environments and use of oral supplements, and psycho-social interventions – training/education programs for LTC staff (Alzheimer's Disease International, 2014; Liu et al, 2012). Nature of the interventions, however, has already been covered in previous sections of the literature review. An equally important aspect of intervention studies is intended outcomes. While it does matter whether the intervention itself attempts to change psychological, physical or psycho-social aspects of mealtimes, the target of the intervention reveals the main areas of concern around mealtimes and their nature (i.e. whether the interventions aim to improve physical, physiological or psycho-social outcomes – or their combination). As can be seen in Table 1, intervention outcomes can be categorised into clinical indicators (e.g. food intake or BMI), behaviours, food liking / appetite, participation in mealtime activities, independence and autonomy at mealtimes, cognitive function, Quality of Life, eating time, communication and staff outcomes (e.g. knowledge and satisfaction).

Table 1. Summary of Mealtime Interventions (Academic Literature)

STUDY	INTERVENTION	INVESTIGATED OUTCOME	*
Shatenstein & Ferland (2000)	Decentralized bulk food portioning	• Food consumption • Nutrient consumption • Anthropometric markers • Biochemical markers	1 1 1 1
Ho et al (2011)	Researcher-composed music	Agitated behaviours	2
Pouyet et al (2015)	Flavour-enhanced food	• Food liking • Food intake	3 1
McHugh et al (2012)	Pre-meal, vocal re-creative music therapy	Nutritional intake	1
Hung et al (2016)	Dining room physical environmental renovations	• Person-centered staff practices • Resident independence and autonomy	X 5
Edwards & Beck (2013)	Aquariums in the dining room	Body weight	1
Young et al (2005)	High-carbohydrate foods	• Food intake • Body mass index • Behavioral function • Cognitive function	1 1 2 6
Nijs et al (2006)	Family style mealtimes	• Quality of life • Physical performance • Body weight	7 2 1
Chang & Lin (2005)	Feeding skills training programme	• Staff knowledge • Staff attitudes • Staff behaviours • Resident eating time • Resident eating difficulty • Resident food intake	X X X 8 1 1
McDaniel et al (2001)	• Improving lighting • Decreasing noise in dining rooms	Nutritional intake	1
Altus et al (2002)	Family-style dining	• Participation in mealtime activities • Communication at meals among residents	4 9
Brush et al (2002)	• Increasing lighting • Controlling glare • Improving contrast	• Resident independence and autonomy • Food intake • Functional abilities	5 1 2
Chen et al (2016)	A multi-level intervention on mealtime assistance	• Resident independence and autonomy • Food intake • Swallowing • Nutritional status • Eating ability	5 1 1 1 2
Beattie et al (2004)	A behavioural-communication intervention	• Time spent at the table • Food intake	8 1

Mamhidir et al (2007)	Integrity-promoting care training	• Body weight • Motor performance • Cognitive functioning • Appetite	1 1 6 3
Cleary et al (2008)	Routine seating plans	• Food intake • Meal duration	1 8
Logemann et al (2008)	Different fluid thickness	Aspiration of fluids	1
Leslie et al (2013)	Energy-enriched food	• Food intake • Nutrient intake • Energy intake	1 1 1
Tanaka & Hoshiyama (2014)	Visual and auditory stimulation	Resident recognition of mealtimes	6
Chang et al (2010)	Background music	Aggressive behaviours	2
Simmons & Schnelle (2004)	Trained and graduated eating assistance	Food intake	1
Charras & Frémontier (2010)	Staff and residents sharing meals	• Body weight • Resident independence and autonomy • Staff satisfaction • Resident participation in clean-up • Residents asking for seconds • Resident-to-resident interactions • Staff-to-resident interactions • Staff knowledge of resident food preferences • Staff knowledge of resident biographies	1 5 X 4 4 9 9 X X
Thomas & Smith (2009)	Background music	Energy consumption	1
Dunne et al (2004)	High-contrast tableware	Food and fluid intake	1
Desai et al (2007)	Decentralized bulk food portioning	Nutrient intake	1
Simmons et al (2008)	Snack delivery between meals	Food intake	1
Barrick et al (2010)	Ambient bright light	Agitated behaviours	2
Brush et al (2002)	• Improving lighting • Increased contrast	• Energy intake • Functional abilities	1 2
Laque et al (2004)	Oral supplements	• Body Weight • Fat-free mass • Level of dependence • Cognitive function • Fractures • Pressure Ulcers • Hospitalisation	1 1 1 6 1 1 1
Planas et al (2004)	• Oral supplements • Micronutrient enhancement	• Energy consumption • Triceps skin fold thickness • Mid-upper-arm circumference • Biochemical parameters (serum magnesium, zinc, selenium, vitamin E and serum cholesterol) • Feeding/eating behaviour • Cognitive function	1 1 1 1 2 6
Young et al (2004)	Oral supplements	• Energy consumption • Protein consumption	1 1

		• Carbohydrate intake	1
		• Cognitive function	6
		• Behavioural disturbances	2
		• Behavioural function	2
Salas-Salvo et al (2005)	Whole formula diet	• Body weight	1
		• Biochemical parameters (albumin, haemoglobin and serum ferritin)	1
		• Energy intake	1
		• Nutrient (protein, carbohydrates, fat) or alcohol intake	1
		• Nutritional status	1
		• Cognitive performance	6
Wouters Wesseling et al (2006)	Oral supplements	• Body weight	1
		• Energy intake	1
		• Mid-upper arm muscle circumference	1
		• Triceps skin fold thickness	1
		• Calf circumference	1
Kamphuis et al (2011)	Medical food	• BMI	1
		• Activities of Daily Living	4
		• Cognitive function	6
Suominen et al (2007)	Feeding skills training program for staff	• Staff knowledge	X
		• Staff attitude	X
		• Staff behaviours	X
		• Resident eating time	8
		• Resident feeding difficulty	1
		• Food intake	1
Lin et al (2010)	• Spaced retrieval • Montessori-based activities	• Energy intake	1
		• Protein/calcium/folic acid intake	1
		• Nutritional status	1
		• BMI	1
Lin et al (2011)	Montessori-based activities	• Eating ability status	1
		• Self- feeding frequency and time	1
		• Physical assistance	9
		• Verbal assistance	9
		• Nutritional status	1
		• Eating time	8
Richeson & Neil (2004)	Music at mealtimes	• Agitated behaviour	2
		• Aggressive behaviour	2
		• Food intake	1
Hicks-Moore (2005)	Music at mealtimes	Agitated behaviour	2
Wong et al (2008)	• Food service and routine change • Feeding assistance • Music at mealtimes	• BMI	1
		• Calorie intake	1
		• Mid-upper arm muscle circumference	1
		• Nutritional status	1

*Outcome categories
1=Clinical indicators
2=Behaviours
3=Food liking / Appetite
4=Participation in Mealtime Activities
5=Independence & Autonomy
6=Cognitive function
7=Quality of Life
8=Eating time
9=Communication
X=Staff outcomes
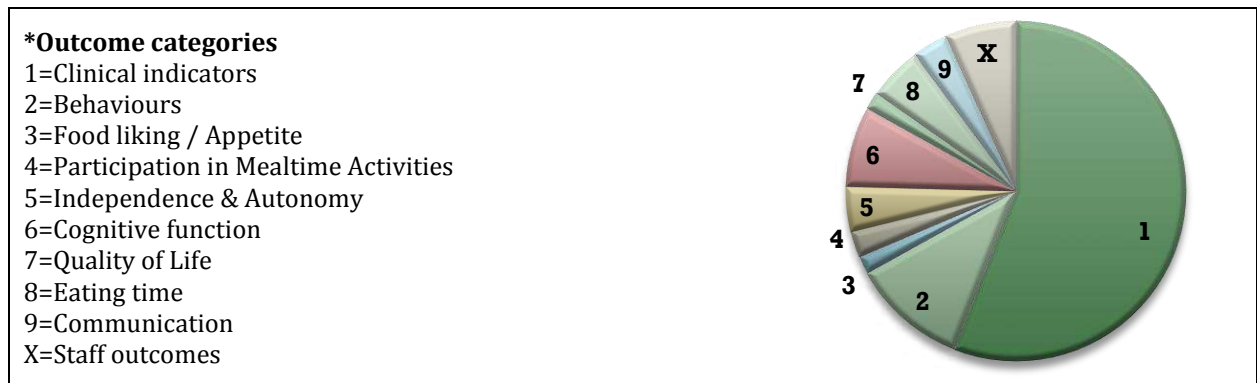
As demonstrated in Table 1, over half (55%) of assessed outcomes are clinical indicators. This suggests that physiological improvement is the dominant research concern. Reduction of behaviours that challenge are also frequently assessed (11%), while non-problematic or positive behaviours (e.g. participation in mealtime activities) are rarely measured. While studies frequently assess how much food is consumed, only two studies (Mamhidir et al, 2007; Pouyet et al, 2015) looked at pleasure in eating. Increase in autonomy and ability to eat independently – while an important psycho-social aspect of mealtimes (Hung et al, 2016) – is also under-researched, as is communication at mealtimes. Also, while mealtimes in long-term care involves not only people with dementia, but also staff, only 4 studies measured staff outcomes.

Altogether, this suggests that intervention success is mostly considered as physical health. Little attention is paid to whether people with dementia enjoy mealtimes, draw sensory pleasure from food/drink/mealtime environment, and whether particular interventions may 'unlock' the potential of mealtimes to meet social and psychological needs.

3.5.2. Practitioner Literature

Practitioner literature on mealtime intervention is also ample. While it rarely assesses or aims to quantify the impact of particular mealtime interventions, mealtime interventions are nonetheless suggested and often based on practitioner knowledge (e.g. Crawley & Hocking, 2011). This knowledge is often collected from informal observations and ad-hoc management of mealtime difficulties. Due to this, practitioner-produced documents on mealtimes and dementia care simultaneously discuss multiple interventions and/or aspects of mealtimes (see Table 2) and, unlike an often specific focus of research literature, offers a more holistic view of mealtimes.

As practitioner literature covers a wider area of interventions, it also uncovers some interventions that have not yet been empirically measured. For example, the benefit of finger foods is frequently addressed in practitioner literature (Ashford & St. Peter's NHS, 2014; Northern Health & Social Care Trust, 2015; Royal Devon & Exeter NHS, 2014; South Essex NHS, 2015) but only one research study approaches this topic (Ikelda et al, 2002). Other aspects of mealtimes that may require an intervention, such as food temperature, have not been considered in academic research at all. The reverse can also be true. While some mealtime aspects – such as background music or lighting – are often discussed in academic research, they are rarely mentioned by practitioners.

The primary aim/purpose of practitioner literature is to inform the intended audience about potential strategies to improve mealtimes (74%). A small proportion of documents also offers assessment tools for nutrition status or eating ability (6%), while the remainder provides specific checklist and toolkits for dementia care settings or illustrates best practice. This shows that the primary concern of practitioner literature is to offer the audience a wide array of possible interventions.

Table 2. Summary of Mealtime Interventions (Practitioner Literature)

STUDY	CONTENT / INTERVENTIONS	PURSPOSE	AUDIENCE
Crawley & Hocking (2011)	• Strategies to help PWD eat • Maintaining independence in eating • Eating/drinking assistance • Managing various eating difficulties • Texture of food • Eating patters • Meal planning • 'Special' diets • Portion sizes • Encouraging to eat • Examples of 1-week menus of different food textures	Strategies to improve mealtimes	Anyone caring for PWD (informally or formally) across community and institutional settings
Dementia Care Matters (2011)	• Mealtime atmosphere • Eating ability and nutrition status assessment • PWD mealtime skills • Quality of food and food provision	A checklist to consider how far a Care Home is implementing quality care re the mealtime experience	Long-term care facilities
South West Yorkshire NHS (2011)	• Encouraging people with small appetites to eat • Overeating • Not eating enough • Preference for sweet foods • Practical aids • Eating assistance • Managing various eating difficulties • Meal planning and recipes	Strategies to improve mealtimes	Family (informal) carers

NHS Dumfries and Galloway (2012)	• Avoiding or preventing problems with eating and drinking • Preparing for mealtimes • Mealtime environment • Oral hygiene • Posture for mealtimes • Insufficient eating • Helping to feed • Compensating for problems with eating and drinking • Alternatives to high risk foods	A toolkit based on the experience of clinicians	Anyone caring for PWD (informally or formally) across community and institutional settings
Norfolk & Norwich NHS (2015)	• Constipation • Anaemia • Swallowing difficulties • Mouth problems • Visuoperceptual difficulties in dementia • Obesity • Weight loss • Supporting a person with dementia to eat and drink	A dietary advice sheet	Family (informal) carers
Ashford & St. Peter's NHS (2014)	• Constipation • Common difficulties with eating and drinking • Preparing for a meal • Mouthcare • Taste Changes • Mixing food together • Spilling food • Struggling to complete meals • Wandering or becoming easily distracted • Mealtime assistance • Modified food textures • Adding extra energy and protein • Finger foods and nourishing drinks • Overeating • Constipation • Problems with fluids • Swallowing difficulties • Hospital stay • Nutrition in Later stages of dementia	Strategies to improve mealtimes	Family (informal) carers
The Caroline Walker Trust (2004)	• Food preparation • Diet and health • Nutritional requirements • Food preparation • Menu examples • Nutritional assessment • Exciting the appetite • Sources of nutrients • Portion guide	Nutritional guidelines	Professionals working with PWD within institutional and community settings
Bedford Hospital	• Malnutrition universal screening tool 'must' • Care planning points to consider	Assessment tools & strategies to improve mealtimes	Long-term care facilities

NHS Trust (2012).	• 100 calorie boosters • Example nutrition care plans • Nutritional supplements • Special diets • Food & fluid chart • Referrals to a dietician • Keeping hydrated • Tips for accurate weight & height • Food & palliative care • Diabetes • Recipes • Dealing with dementia (& meal time behaviours that affect food intake) • Constipation • Diarrhoea • Mouth problems		
Helps (2010)	• Providing palliative care in dementia • Meaning and purpose of food • Nutritional issues at end of life • Options and outcomes of nutrition and hydration • Dehydration • Process of dying • Care planning	Strategies to improve nutrition in end of life care for PWD	Professionals working with PWD within institutional and community settings
University of Western Sydney (2004)	• Understanding weight loss in advanced dementia • Medical problems that cause weight loss • Artificial feeding	Informational booklet to assist decision-making	Family (informal) carers
BAPEN (2011)	• Measuring BMI including alternative procedures • Measuring weight loss • Measuring acute disease effect • Management guidelines	Screening Tool	Professionals working with PWD within institutional and community
SCIE (2013)	• Reasons for food avoidance • Significance of food • Changed body weight • End of life care • Strategies to increase food intake • Involving PWD in consultation • Involving other professions in nutritional care	Explanatory information & strategies to improve mealtimes	Social Care professionals working with PWD within institutional and community
SCIE (2015)	• Problems using cutlery • Problems seeing and recognising food • Decision-making difficulties • Help with choices • Timing menu selections	Strategies to improve mealtimes	Social Care professionals working with PWD within institutional and community
Clarke (2009)	• Restoring service users' interest in food • Providing PWD with a choice • Stimulating the desire to eat • Ensuring a healthy and balanced diet	Best practice example	Long-term care facilities

	• Encourage participation in the social and practical activities surrounding preparing and serving meals		
Evans et al (2009)	• Choosing oral supplements • Tube feeding • Practical feeding & fluid administration strategies • Medication administration	Strategies to improve nutrition, hydration and medication in advanced dementia	Palliative Care professionals working with PWD
Leicestershire NHS (2014)	• Maintaining independence in eating • Food refusal • Preference for sweet foods • 'Wandering' at mealtimes	Strategies to improve mealtimes	Family (informal) carers
Mid Cheshire NHS (2010)	• Initial assessment • Clinical prognostic indicators • Initial management and support of oral intake • Transient vs permanent problems • Enteral tube feeding	Clinical decision-making guidelines	Speech and Language Therapy practitioners working with PWD
Coventry & Warwickshire NHS (2014)	• Oral care • Swallowing problems • Eating & drinking issues: Refusing to swallow; Pouching food in the mouth; Cramming too much food in the mouth; Biting down hard on feeding utensils	Patient information & strategies to improve mealtimes	PWD & family (informal) carers
Alzheimer's Association (2016)	• Nutrition tips • Make mealtimes easier • Encourage independence • Minimize eating and nutrition problems	Strategies to improve mealtimes	Family (informal) carers
Alzheimer's Society (2016)	• The importance of eating and drinking • Common problems • Problems with mental abilities • Motor difficulties • Sensory difficulties • Behavioural difficulties • Eating environment • Meal preparation • Living alone • Useful organisations	Strategies to improve mealtimes	Anyone caring for PWD (informally or formally) across community and institutional settings
Alzheimer's Resource of Alaska (2012)	• Medical or physical reasons for mealtime difficulties • Environmental reasons for mealtime difficulties • Task difficulty • Communication	Strategies to assess and improve mealtimes	Family (informal) carers
South Essex NHS (2015)	• Size & shape of finger foods • Temperature • Moist fillings • Serving fruit • Carry-bags and waist pouches • Example finger foods	Strategies to improve mealtimes with finger foods	Family (informal) carers
Northern Health & Social Care	• Effect of dementia in food intake • Managing eating difficulties	Strategies to improve mealtimes	Family (informal) carers

Trust (2015)	• Professional input (dietician, occupational therapist, speech and language therapy) • Eating environment • Eating assistance • Finger foods • Increasing calorie and nutrient intake • Preference for sweet foods • Diabetes and dementia • Mouth and dental care		
Stone (2014)	• Causes of people with dementia experiencing difficulties with eating and feeding • Consequences of eating and feeding difficulties in people with dementia • Reasons why the aging process can have a negative effect on nutritional intake • Predictors for eating difficulties and risk of weight loss among people with dementia living in care homes • Environmental strategies in reducing eating/feeding problems in residents with dementia • Resources for improving the physical and social environment of dining areas in care homes	Explanatory information & strategies to improve mealtimes	Long-term care Facilities
Alzheimer's Australia (2005)	• Loss of appetite • Overeating or insatiable appetite • Preference for sweet foods • Mouth, chewing and swallowing problems • Difficulties at the table	Strategies to improve mealtimes	Family (informal) carers
Nutrition & Diet Resources UK (2014)	• Common Eating and Drinking Challenges • Preparing for a Meal • Eating Habits • Adding Extra Energy and Protein • Overeating • Constipation • Difficulties with fluids • Mouth Care	Strategies to improve mealtimes	Family (informal) carers
Rotheram, Doncaster and South Humber NHS (2011)	• Outcomes of dysphagia • Signs of dysphagia • Available help	Patient information & strategies to improve mealtimes	PWD & family (informal) carers
Airdale NHS (2015)	• Changes in dietary behaviour • Increased energy requirements • Dehydration • Medications • Stress • Difficulty Swallowing • Nutritional needs in dementia • Practical tips for carers	Patient information & strategies to improve mealtimes	PWD & family (informal) carers

	• Assisting with eating • Social eating		
Carers UK (2016)	• Weight loss in dementia • Weight gain in dementia • Eating well on a budget • Strategies to encourage eating • Strategies to improve nutritional intake • Medical nutrition	Strategies to improve mealtimes	Family (informal) carers
South Tees Hospitals NHS (2016)	• Eating difficulties in dementia • Common causes of eating difficulties and potential solutions	Patient information & strategies to improve mealtimes	Family (informal) carers
Alzheimer's Society (2012)	• Person-centered approach to mealtimes • Effect of dementia on ability to eat • Mealtime strategies for the person with dementia • Mealtime strategies for caregivers • Mealtime challenges and strategies to address these by stage of dementia	Strategies to improve mealtimes	PWD & family (informal) carers
Royal Devon & Exeter NHS (2014)	• Senses • Swallowing • Changes in Behaviour • Finger foods • Variety of foods • Frequency of meals • Extra time for eating • Drinks	Patient information & strategies to improve mealtimes	Family (informal) carers
Dementia End of Life Practice (2015)	• Mealtime challenges and strategies to address these by stage of dementia • Ceasing to eat at end of life	Patient information & strategies to improve mealtimes	Family (informal) carers
Epson & St. Hellier NHS (2011)	• Factors Affecting Oral Intake • Dysphagia in Dementia • Nutritional Implications of Dementia • Aims of Nutritional Therapy • Nutritional management of dementia • Nutrition and Artificial Feeding • Summary • Further Reading	Strategies to improve food intake and swallowing	Dietetics and Speech and Language Therapy practitioners working with PWD

Purpose
1=Strategies to improve mealtimes
2=Screening Tools
3=Other
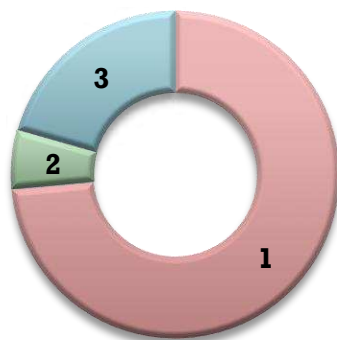
Intended Audience
1=Family (informal) carers
2=Healthcare specialists
3=PWD & family (informal) carers
4= Anyone caring for PWD (informally or formally) across community and institutional settings
5=Long-term care Facility Staff
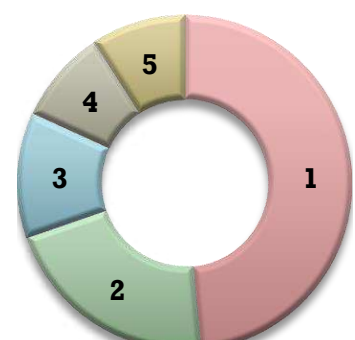
Notably, the majority of practitioner documents are produced by Speech and Language and/or Dietetics departments within the NHS, while a smaller, yet significant, proportion comes from voluntary sector organisations (e.g. The Caroline Walker Trust). The intended audience, however, is often family (informal) carers of PWD rather than other practitioners; 48% of documents are explicitly intended for carers, while another 21% includes carers in the wider target audience. A further 21% of studies are aimed at healthcare specialists (e.g. Dietetics and Speech and Language Therapy practitioners working with PWD). Only 9% of documents are specifically written for staff in LTC facilities, with a further 9% aimed at anyone caring for PWD (formally or informally), which includes LTC staff. As discussed in section 3.4, mealtimes in LTDC present a distinct set of challenges and opportunities, making the lack of practitioner literature aimed at LTC facilities particularly noteworthy.

Another target audience that is often excluded from practitioner literature are people with dementia themselves. Only 12% of documents imply that the content could be read by at least some PWD themselves, and not only their informal caregivers (often despite the 'Easy Access' format). In this sense, PWD are viewed as passive recipients of suggested interventions, rather than active consumers of literature; a trends also observed in academic literature (see Section 3.4). Here, it is important to note that the same passivity is not perceived within other areas of practitioner literature. For example, PWD themselves have been the intended audience of a considerable proportion of practitioner-produced literature on memory strategies in dementia (e.g. Alzheimer's Society, 2014).

Overall, practitioner literature is distinct from academic literature not only in their rigour and the application of scientific methods and principles, as well as author profession, but also in its scope, aims, intended outcomes and target audience.

3.5.3. Policy Documents & National Guidelines

Government policies are a "deliberate intervention by the state" (Baldock et al, 2007, p. xxxi). In other words, policy documents and their accompanying national guidelines are a macro-level of intervention; they are therefore therefore included in the section on interventions related to mealtimes in LTC for people with dementia.

In recent years the detection, management, care and support of people with dementia has become a prominent issue for health and social care services in the UK (Department of

Health, 2009, 2012). Policy initiatives include a call to improve the quality of service provision within long-term care settings including in-patient NHS facilities (Pinner et al, 2011), with stakeholder consultations on 'how' to improve care in such settings have led to a number of specific priorities being set. For example, The National Dementia Strategy sets out the Department of Health's goal for people to be helped to live well with dementia, regardless of their stage of illness or where they receive care (DOH, 2009). However, while dementia has become a policy priority, nutrition or mealtimes in dementia care have not been specifically addressed within policy literature on dementia. Neither the 'Quality Outcomes for people with dementia' report (DOH, 2010), 'Prime Minister's Challenge on Dementia 2015' (DOH, 2012), 'Dementia: A State of the Nation' reports (DOH, 2013), nor The Care Act (2014) mention nutrition, eating, dining, food or mealtimes. Interestingly, Regulation 14 of the Health and Social Care Act (2008; now replaced by The Care Act, 2014) required the registered person (e.g. nurses) to ensure that service users are protected from the risks and complications of inadequate nutrition and hydration, suggesting that mealtime aspects in dementia have lost some of their prominence in policy documents.

'Prime Minister's Challenge on Dementia 2020' (DOH, 2015) mentions poor nutrition and hydration only once, and only as a potential cause of behaviours that challenge. Similarly, the National Dementia Strategy (DOH, 2009, p. 52) only states that "[p]oor care can lead to malnutrition and dehydration for people with dementia" as one of its 'Cases for Change' and points out that "[m]any examples were cited during the consultation on the National Dementia Strategy of people with dementia being left without assistance to eat or drink". The document also refers to the Nutrition Action Plan (DOH, 2007) produced as part of the Department of Health's Dignity in Care campaign. While the Nutrition Action Plan sets out the five key priorities for action around nutrition in care provision, no specific reference to dementia is made. The same is true for 'The Hospital Food Standards Panel's report on standards for food and drink in NHS hospitals' (DOH, 2014), with not a single mention of dementia throughout the document.

This demonstrates that while UK policy considers Dementia and long-term care Provision (overlap labelled as '2' in Figure 9), and Food and Nutrition in Social and Health Care provision (including long-term care, overlap '3'), food/nutrition and dementia are not considered together (overlap '1') and no attempts to combine all 3 areas (overlap '4') have been made so far.

Figure 9. Policy Intersections
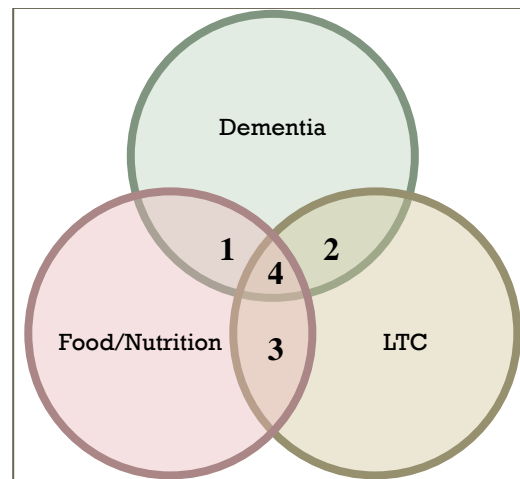
Regulatory bodies in the UK have paid more attention to food/nutrition/mealtimes in LTC for PWD to a greater extent, but notable issues remain. Care Quality Commission (CQC, the independent regulator of health care and adult social care in England) has included 'Meeting Nutritional Needs' in the 16 Essential Standards most directly relating to the quality and safety of care (CQC, 2011). After the commencement of the study, the 16 Essential Standards have been replaced by 13 fundamental standards "below which [one's] care must never fall"; the standard for 'Meeting Nutritional Needs' was replaced by a 'Food and Drink' standard, stating that "[one] must have enough to eat and drink to keep [them] in good health while receiv[ing] care and treatment" (CQC, 2016). While it is notable that having enough food and fluid does not guarantee nutritional needs are met (assistance with eating may also be crucial), thus suggesting that the new standard is somewhat reductionist compared to its predecessor. Nonetheless, food and eating has remained a prominent aspect of essential care. In addition to this, inadequate provision of food and drink in care facilities has been persistently identified as a key area of public concern; at the point the current research project commenced, it was a priority for CQC particularly in long term care settings supporting people living with dementia (CQC, 2010). However, the 'Position Statement and Action Plan for Older People, Including People Living with Dementia 2010-2015' has since been withdrawn and not replaced by an updated/current version.

In 2012 CQC carried out 'Dignity & Nutrition themed inspections' in NHS hospitals (CQC, 2013b) and care homes (CQC, 2013c). 'Meeting nutritional needs' was one of 5 standards, presenting 3 subthemes: "Are people given a choice of suitable food and drink to meet their nutritional needs?"; "Are people's religious or cultural backgrounds respected?"; and "Are people supported to eat and drink sufficient amounts to meet their needs?" (CQC, 2013b, p. 11). 86% of wards/units that cared for PWD met nutritional standards, compared to 100%

of wards that do not care for PWD, while hospitals that had a dedicated dementia care unit met nutritional needs slightly better than hospital without dedicated dementia units (88.2% and 87.9% respectively). Similar trends were observed in the care home report (CQC, 2013c). 82% of homes caring for PWD met nutritional standards, compared to 86% of homes that did not. A difference in meeting nutritional needs also depended on type of care provider, corporate providers met nutritional needs better than non-corporate providers (86% and 82% respectively).

In 2013 CQC also published 2 Care Update reports (reflecting state of care on 31 December 2012 and 21 March 2012). 19,058 current adult social care locations that CQC (2013a) had inspected since the start of the new regulatory system, 15,160 (80%) were meeting the national standards CQC had checked at each location. This compares with 8,451 out of 11,808 locations (72%) at 31 March 2012. In contrast to this, 92% of inspected NHS hospital-based services met nutritional needs (an increase of 7% since March 2012). No further 'Care Update' reports have been produced, while the most recent 'State of Care' report (CQC, 2016) has mentioned nutrition only once in its 144 page content, reporting that approximately 75 inspected adult social care provider have been rated inadequate in meeting nutrition and hydration needs, resulting in imposed requirements, warning notices, civil action or cancellation of registration.

The Care Update as well as Dignity and Nutrition reports demonstrate that Care Quality Commission has been successful in monitoring cases of where nutritional needs are not met, imposing requirements for improvement and intervening if progress is not made.

The National Institute for Health and Clinical Excellence in collaboration with the Social Care Institute for Excellence have also produced clinical guidelines for Dementia (NICE-SCIE, 2006). In relation to food/nutrition, the guideline document remains sparse, but states that "health and social care staff should identify the specific needs of people with dementia and their carers arising from [...] problems with nutrition [and] poor oral health [and that] care plans should record and address these needs (Principle of Care 1.1.1.4; p. 12). The document also refers to palliative dementia care, stating that "Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity" (Principle 1.10.1.4, p. 42).

Unlike government policies and reports, national and independent Health and Social Care regulators do consider nutrition/food specifically in long-term care for people with dementia. However, the guidelines remain broad and fairly abstract.

3.5.4. Commentary

Overall, academic, practitioner and policy literature related to mealtime interventions shows distinct trends in scope of both suggested intervention and selected outcomes (see Figure 10). Academic literature tends to be specific and narrow down to particular interventions and outcomes that are easier to conceptualise and measure compared to a more holistic focus. Practitioner literature often offers a broad array of interventions, but conceptualises outcomes in an equally specific, often clinical manner. While the majority of academic literature looks at nutritional status and weight, sufficient food intake is often the focus of practitioner literature. In contrast to this, policy documents – if they do address the intersection of mealtime needs and dementia – tend to be abstract in defining intended outcomes. Particular interventions are rarely outlined at all, and the documents *per se* serve more as an intervention (i.e. a way of enforcing care objectives or guidelines).

Figure 10. Predominant Intervention and Outcome Trends by Source Type

Academic Literature	• Narrow Intervention • Narrow Outcome
Practitioner Literature	• Broad Intervention • Narrow Outcome
Policies & Guidelines	• Broad Intervention (if specified) • Broad/Abstract Outcome (if known)
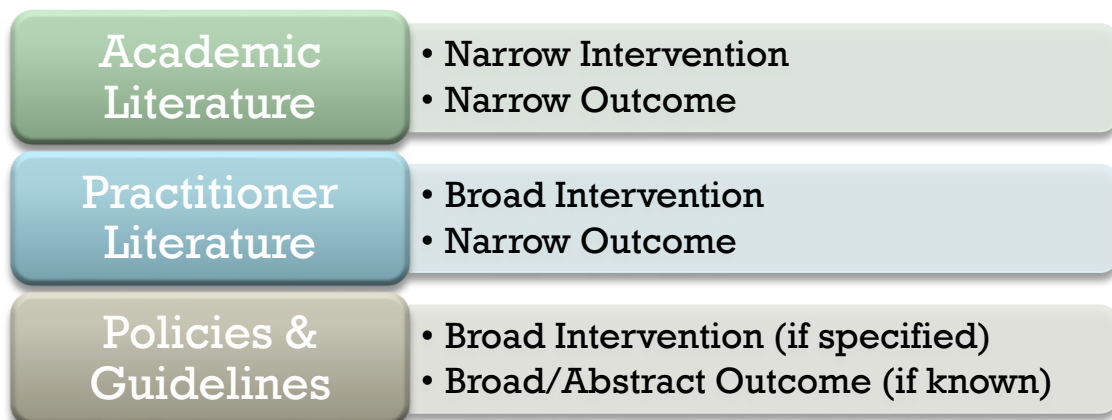
As stated above, practitioner literature on mealtime interventions in dementia care provides a wider scope of acknowledged mealtime difficulties and potential solutions compared to academic literature. However, the distinction goes beyond simply providing a broader scope. Instead of subsuming academic focus, practitioner literature does not cover some topics addressed by academic research (and *vice versa*); the cumulative focus of practitioner literature does not fully overlap academic focus. Usually produced by healthcare specialist, practitioner literature is most often targeted at informal carers. Due to the lay audience, however, documents produced by speech and language or dietetics specialists are often less

focussed on clinical aspects and outcomes of mealtimes than research/academic literature. Although often broad and abstract, policy documents tend to conceptualise good dementia care beyond clinical outcomes and include Quality of Life / Wellbeing. Therefore, academic literature (as discussed further in section 3.6) is the most physiologically-oriented in nature. This may also be due to the intended audience; academic literature is aimed at professionals with some specialist knowledge of dementia (either academics or health/social care practitioners), practitioner literature – predominantly towards informal carers, and policy literature – towards care providers. Notably, while all intervention-related literature is intended to impact on mealtime experiences of people with dementia, almost none of the documents are aimed at people with dementia (although policy documents increasingly involve PWD in their consultations; Joseph Rowntree Foundation, 2012).

3.6. Critique of Literature

Academic and practitioner literature stresses the importance of multiple dimensions when mealtimes are considered (e.g. Nijs et al, 2006, Watson & Green, 2006). The complexities of mealtimes in institutionalised dementia care, as well as the importance of the physical (e.g. the mealtime environment) and social/cultural (e.g. opportunities to relate to others during mealtimes) dimensions have long been acknowledged as factors that should be taken into consideration when researching mealtimes (Manthorpe & Watson, 2003). This is true even in cases where the overall aim of the research – to improve residents'/patients' nutritional status – remains physiological in nature (e.g. Osborn & Marshall, 1992; Sidnevall, Fjellstrom & Ek, 1994). The commonplace regard for the multifactorial nature of mealtimes is perhaps best reflected by Synder and Fjellstrom (2005) who propose that mealtimes constitute a time when biological needs meet social/cultural needs and habits, thus pointing out that the different dimensions of mealtimes do not only co-exist, but also overlap, intersect and interact in their contributions to the overall mealtime experience. Therefore, the lack of a more evenly distributed literature across the different dimensions of mealtimes (i.e. research dominated by physiological concerns) cannot be solely due to the lack of academic regard and importance ascribed to the multiple aspects of mealtimes.

The majority of existing research around mealtimes for people with dementia in care is produced by researchers from medical professions (nursing staff, psychiatrists and nutritionists; e.g., see review by Watson & Green, 2006) and/or published within medical/clinical journals (e.g. Asellage & Amella, 2010; Chang et al., 2010a, b; Kaiser et al., 2009; Lin et al., 2010; Lou, Huang & Yu, 2007). At the same time, while notable exceptions exist (Chang et al, 2010; Ho et al., 2011) medically oriented/affiliated authors are focused more on the issues of (mal)nutrition (Chang & Roberts, 2011; Lou, Dai, Huang & Yu, 2007), food (particularly its nutritional composition; Lin, Watson, & Wu, 2010; Suominen, Laine, Routasalo, Pitkala & Rasanen, 2004) and ability to eat / need for assistance with feeding (Aselage, 2010; Chang & Roberts, 2008; Watson & Green, 2006). Therefore, it is perhaps not surprising such research trends result in a considerably larger volume of literature that concentrates on (mal)nutrition and eating or eating difficulties. It is difficult to say, whether such an imbalance exists due to research funding preferences, different research interests of scientists depending on their faculty affiliations, an interaction of both, or any other (combination of) factors.

Instead of discerning the causes, however, it is arguably more important to assess the impact of such differences on strategies to improve mealtimes. Mealtime research produced by social scientists, for example, focuses more on social and relational aspects of mealtimes (Charras, & Fremontier, 2010) as well as their influence on maintaining and changing identities (Atta-Konadu, Keller, & Daly, 2011; Genoe, et al., 2010; Hung & Chaudhury, 2011). Cross-disciplinary partnerships including social scientists, while not commonplace, do occur (e.g. Mahmidir, et al., 2007). However, even if involving social scientists in mealtime research could offer the best route to developing holistic mealtime approaches, it rests on the assumption that both types of approaches (social and medical) are equally valued by the academic community, and (perhaps more importantly where interventions are concerned), equally valued by the practitioners who are directly involved in long-term dementia care and play an active role during mealtimes.

Research affiliated to medical professions either via faculty alignment or as being practitioner-led, centres around topics which are more concrete, narrowly-focussed, easier to define and - crucially - easier to measure in a systematic manner. For example, defining and measuring signs of dysphagia (difficulty swallowing) is easier than measuring relational experiences in patient-carer dyads during feeding assistance which might be necessary due to the aforementioned dysphagia (see Edahiro et al., 2012, and Sidnevall, 1999, for medical vs social sciences' perspectives on comparable issues). It is, therefore, perhaps unsurprising that narrowly-focused (and thus usually medically-based) research into improving mealtimes for people with dementia is more favoured.

A bias towards the medical viewpoint is clear in research practice. A review by Hanson and collegues (2011), looking into feeding options/interventions for people with dementia, has judged oral supplements to be the best intervention to alleviate malnutrition. This decision was largely due to the quality ratings assigned to different types of research. Hanson et al. (2011) clearly favour systematically measured Randomised Controlled Trials (RCTs) and statistically established reliability and validity, which is undoubtedly easier to achieve when research questions are particularly narrowly focussed (e.g., Galante, Venturini & Fiaccadori, 2007). Even if it was ethically unproblematic (Edwards et al., 1998), it is hard to imagine how one could attempt to systematically control relational experiences in patient-carer dyads in order to achieve counterfactuality. Regardless of this, Hanson et al. (2011) review assigned the lowest quality rating to studies that involved either a wider range of simultaneous interventions (e.g., Keller, 2003) or a more holistic evaluation of effects (e.g., Chang et al,

2010), and indeed studies that did not have a control group. Similarly, Keller's (2016) review of successful mealtime interventions in LTDC, frequently made claims about the studies lacking rigour and quality, and invited more randomised-controlled trials. Preferencing the already disproportionate body of literature focusing on controllable clinical/physiological aspects of mealtimes, therefore, perpetually disadvantages studies that look at non-physiological aspects of mealtimes or take a more holistic/multidimensional approach.

The quality-rating ascription involved in Hanson and colleagues' (2011) review, therefore, exemplifies a three-fold problem with emphasis on physiological aspects of mealtimes within research in long-term dementia care. Firstly, because long-term dementia care settings are often medicalised (e.g. Daker-White et al, 2002), research into mealtimes disproportionately attracts and accommodates medically-affiliated researchers. This, in turn, produces more research that focuses on the physiological dimension of mealtimes, than on any other factors. Because there is more research into nutrition, and eating ability than any other aspect of mealtimes, this also has an influence on what criteria is used for systematically analyse and compare research in the area. Due to this, there is a further preference for narrow-focus, controlled research, which is arguably easier to achieve when looking at physiological indicators of mealtime success, than social or environmental factors (or a combination of these). As there is no way for social science research into mealtimes in dementia care to meet the quality demands of systematic reviews that utilise evaluation tools designed for randomised controlled quantitative research, this arguably results in a relative discouragement of social science research in the area of mealtimes (in terms of funding, prestige, publication opportunities, etc.; a broader debate on these issues can be found in the field of criminology by Buckler, 2008). In other words, a disproportionate amount of research that focuses on physiological aspects of mealtimes in dementia care is not a problem itself, but it can cause a further impediment for development of studies that look into other aspects of mealtimes, as well as those that combine multiple dimensions and explore mealtimes more holistically.

Another issue, that stems from using a research 'path of least resistance' centers around a disproportionate amount of intervention-based studies. As stated by Beatie and colleagues (2004), within the complex environment of LTDC, a greater potential exists for manipulating consequences of behavior than for identifying a multitude of factors that may produce the behaviour. While this view is constrained to mealtime actions of PWD (e.g. spitting of food), it applies to mealtime research as a whole. Because of the complexity of multiple interacting

and overlapping factors, investigative studies, unearthing the full scope of influential factors and the processes of influence is difficult; especially considering the preference for scientifically rigorous, controlled, quantitative studies. In contrast to this, the 'effect' of a particular intervention is easier to capture quantitatively, and the process of pre- vs post-intervention and experimental vs control group comparisons allow for controlling of at least some of the mealtime factors. Exploratory studies are, therefore, rare.

Nonetheless, a notable exception exists. A study by Hung and Chaudhury (2011), exploring personhood in dining experiences of PWD in LTC facilities. The authors used an ethnographic approach and directly involved (i.e. recorded conversational interviews with) residents with dementia, as well as care staff. Instead of applying and intervention to improve personhood, the authors investigated and discovered hitherto undiscussed care practices that either enhancd or diminished person hood (outpacing/relaxed pace, withholding/holding, stimulation, disrespect/respect, invalidation/validation, distancing/connecting, disempowerment/ empowerment, and ignoring/inclusion). Knowledge of these processes then led to considerations of ways in which staff can improve their care practices and interactions with PWD.

Hung and Chaudhury (2011) study possesses other exceptions that illustrate the issues with the mealtime research with PWD in LTC. It has already been discussed, that while mealtime research directly impacts on experiences of PWD (especially if the research is intervention-based), it is usually carried out without the direct involvement of PWD. Instead, mealtime knowledge comes from reports of caregivers (both formal and informal), observations of PWD or measurement of clinical outcomes (e.g. BMI), while PWD are seen as passive recipients of mealtime care. Exploring opinions and perceptions of PWD via interviews of conversations is particularly uncommon, yet - as discussed above - successfully employed by Hung and Chaudhury (2011).

Similarly, while the majority of the mealtime research looks at specific mealtime constructs or outcomes (e.g. background music and its influence on aggressive behaviour), few studies to date approach mealtimes holistically (simultaneously including physiological, physical and psycho-social factors), and consider the sum-total of complex and interacting factors that determine mealtime experiences of everyone within the setting. The influences of the specific setting and its micro-cultures (see Chapter 2) is also overlooked. Hung and Chaudhury (2011), however, have acknowledged that "[a]lthough staff approaches seemed to have the

greatest impact on residents' experiences, the physical environment and organizational milieu were also responsible for hindering and facilitating" (p.1).

The aforementioned issues with the emphasis on the physiological aspects of mealtimes, lack of exploratory research, holistic approaches including complex and overlapping mealtime aspects, not actively involving people with dementia and overlooking the potential influences of LTC setting micro-cultures within research on LTDC does not, however, invalidate the need for investigating physiological aspects of mealtimes. It merely suggests that notable disproportions in mealtime knowledge and knowledge gaps remain (Asellage & Amella, 2010; Chang & Roberts, 2008). However, it is equally important to acknowledge that the self-reinforcing preference for clinically-oriented research is making other types or mealtime research – and its funding - *increasingly* difficult to achieve. In addition to this, while studies that look into all aspects of the mealtime simultaneously are very valuable, especially in designing ecologically valid strategies to improve mealtimes (Malloy, 2011), there is still space for studies that separate different factors within mealtimes and inspect their influence of one another (e.g. Miyoshi et al., 2008). The latter type of studies, while often of less immediate application, can help to better conceptualise complex factors and their processes of mealtimes (e.g. Piwnica-Worms, Omar, Hailstone & Warren, 2009). Beyond specific criticisms of the current state of mealtime research in LTC for PWD, more research of any type or focus remains needed.

Chapter 4:
CURRENT RESEARCH

4.1. Rationale

Dementia affects 850,000 people in the UK and the prevalence is expected to rise to 1 million by 2025 (Alzheimer's Research UK, 2014; Alzheimer's Society, 2012). In addition to this, it is estimated that a third of people with dementia live in long-term care (LTC) facilities, making up approximately 80% of the LTC population (ibid.). Despite this, there is a widely acknowledged lack of research funding for work on dementia and on long-term care, leaving both arenas significantly under-researched (Alzheimer's Research UK, 2013). One of the opaque and rather marginalised areas of dementia related research is meals and mealtimes in LTC.

Mealtimes are universally important for all people (Larsin et al, 2006). However, both the significance of the meal and the meaning of mealtime varies from person to person (Fiese et al, 2006); it is both a reflection of individual variation and situational influence (Wansik et al, 2010). Both living with dementia and living in LTC influence the experience of mealtimes (e.g. Carrier et al, 2009; Fjellstrom, 2005). As the research reviewed in Chapter 3 shows meals and mealtimes for people with dementia (PWD) have particular significance. Not only do they ensure nutrition and hydration, but also provide structure for the day, a meaningful activity, sensory pleasure and social opportunities (Berg, 2006). These aspects become even more prominent within LTC facilities, where residents' choices and opportunities are often restricted. Paradoxically, rather than focusing on the multiple significance of mealtimes for PWD, institutional structure and processes often default to a rather reductionist focus on only the physiological aspects of mealtimes (Chang & Roberts, 2011).

Similarly, the existing literature on mealtimes in long-term dementia care is dominated by quantitative medical research, focusing almost exclusively on (mal)nutrition (and, to a lesser extent, other physiological aspects of mealtimes; Hanson et al, 2011). The focus on physiological aspects is 'medically' justified, as the rate of malnutrition in long-term dementia care has been estimated to be as high as 83% (Abbasi & Rudman, 1994). Further, Barratt (2004) estimates that the cost of providing 'adequate nutrition' makes up approximately 25% of the health and social care costs of dementia care in the UK. However, the physiological aspects of mealtimes are interrelated with environmental and psycho-social aspects of mealtimes in ways that are often unrecognised and they may jointly contribute to improving or undermining nutritional outcomes (Aselage & Amella, 2010).

A few studies in the area of dementia care investigate environmental and social aspects of mealtimes (e.g. Altus et al, 2002; Baur & Abma, 2011) and fewer yet draw on these aspects in developing interventions to improve nutrition and hydration (Lin et al, 2010). However, even when environmental, psychological and/or social aspects of mealtimes are taken into account, existing research tends to focus on singular and predetermined interventions to 'improve' meals or mealtimes (Aselage, 2010). For example, while Ho and colleagues (2006) acknowledge the complexities around mealtime needs, their research focuses specifically on effects of researcher-composed music at mealtime on a specific outcome – agitation.

There is a small number of ethnographic studies (e.g. Baur & Abma, 2011; Gibs-Ward & Keller, 2005; Pastman et al, 2003), which look at the importance of the setting in long-term care settings and incorporate multiple dimensions/aspects of mealtimes (Hung & Chaudhury, 2011). However, all studies to date are based outside of the UK and little is known about the mealtime experiences of people with dementia living in long-term care in the UK. Moreover, even when ethnographic methods are used to investigate mealtimes in LTC the aim of these studies is to do just that - investigate mealtimes, rather than simultaneously investigate and improve. Intervention studies, on the other hand, are often qualitative and reductionist in scope (e.g. Brush et al, 2002).

Very few studies combine the two approaches. While ethnographic methods allow a detailed and multi-dimensional investigation of mealtimes, they do not simultaneously collect quantitative data on nutritional outcomes. Only one study to date has adopted an approach that combines evidence about the impact of an intervention on well-being and quality of life alongside data on nutrition & hydration levels (e.g., Nijs, Graaf, Kok & van Staveren, 2006). Nonetheless, this study was not only non-NHS, but also non-UK based.

Almost no research has been specifically conducted in the NHS continuing care facilities and none focus on mealtimes. This setting is of particular research interest. Compared to other forms of LTC for people with dementia (see Chapter X), NHS Continuing Care settings are characterised by higher levels of complex multiple needs and are located in a hospital environment governed by institutional structures and goals (DoH, 2012).

4.2. Research Study

The current study is unique in that it aims to collaboratively develop small-scale interventions that will improve meals and mealtime experiences for people with dementia, their relatives, and ward staff in two NHS Continuing Care facilities. A mixed methods

approach will be used and incorporate a wider focus of ethnographic methods, as well as a more targeted focus of interviews and structured observations, and quantitative assessments of nutritional outcomes (Creswell, 1999). The study will also employ action research methodology with participatory elements, with a goal to collaboratively develop mealtime interventions by a involving all stakeholders who are affected by the issue being studied (i.e. people with dementia, their relatives and ward staff). An action research design was chosen as it allows for immediate impact, encourages cooperation and partnership between researcher and participants and ensures that research findings are practice relevant and situationally applicable (Bate, 2000).

Furthermore, by taking account of the nature of the facility's micro-culture, interventions are much more likely to be tailored to both the needs of the individuals living - and visiting and working - in each setting but also to be meaningful, nuanced and effective. Such an approach also embraces notions of involvement and operationalises co-production with users, relatives and staff in designing and evaluating interventions. As the research is led and owned by the aforementioned groups, it is expected to result in a more effective implementation and retention of the developed interventions.

The first phase of the project will focus on collecting baseline measures on nutritional status, mealtime difficulties, emotional and relational experiences, wellbeing and quality of life, etc. will be collected to enable systematic comparisons across the phases. Findings emerging from this phase will be shared with all three participant groups in order to collaboratively develop feasible small-scale interventions intended to improve mealtime experiences for people with dementia and their relatives. Phase two of the project will involve putting the interventions in place along with collection of quantitative and qualitative data to (1) assess the characteristics of this phase and (2) to allow systematic comparisons with other phases. During phase three the impact of the interventions will be assessed by repeating measures on service users' emotional and relational experiences of mealtimes and beyond, as well as their mood, interactions, Quality of Life, and nutritional and hydration outcomes. Interviews will also be conducted to explore the experiences and views of staff and relatives in relation to the interventions and their impact, alongside with ethnographic observations investigating if and what changes in micro culture have taken place.

It is often assumed that interventions, which lead to a more positive experience of mealtimes, automatically result in greater consumption of food (e.g. Charras & Fremontier, 2010;

Crawley & Hocking, 2011) and reduce the risk or effects of malnutrition. The current researchwill critically explore this relationship.

4.3. Research Questions

The main research questions are:

1. How do service users, their relatives and ward staff experience mealtimes in NHS continuing care facilities for people with dementia?

2. Can small-scale interventions aimed at improving meals and mealtime experiences within continuing care facilities be collaboratively designed and implemented with users, relatives and staff?

3. Will these interventions:

   a) Have an effect on service users experiences of meals and mealtimes at the time of the meal and beyond (including nutrition and hydration levels; communication/socialisation/engagement; and mood)?

   b) Have an effect on relatives and staff experiences of mealtimes?

4.4. Hypotheses

The study's hypotheses are that:

1. Interventions which lead to a more positive experience of mealtimes are also likely to show greater consumption of food and drink (see Charras & Fremontier, 2010; Crawley & Hocking, 2011) and lowered risk of malnutrition and dehydration.
2. Interventions that are collaboratively developed with users, carers and staff are likely to be adopted and effective.
3. The impact of the interventions will extend beyond nutritional indicators and impact on activity, engagement and mood of the users.

Chapter 5:
METHODOLOGY

5.1. Overview

The research took place in 2 NHS Continuing Care Units (Wards) for people with dementia in Kent and involved patients, relatives and staff as participants. Action Research Methodology was applied alongside a Mixed Methods design. Ethnographic observations and stakeholder interviews allowed a detailed and deep analysis of collective and individual experiences of meals and mealtimes and understanding of the nature and influence of the micro-culture of the facility on mealtimes. This approach also offered the opportunity to assess what individuals think could improve meals and mealtimes and allowed the researcher to collaboratively develop small-scale interventions in partnership with patients, relatives and staff. Assessments of patients' emotional and relational experiences of mealtimes, behaviour, mood, eating ability and mealtime difficulties, and nutrition and hydration status were conducted using observational methods. These measures were used throughout the study period to allow a comparison of 3 research stages: before, during and after small-scale interventions were implemented. Interviews were also conducted with relatives, staff and, where possible, patients. It is important to recognise that for some interventions e.g. a change to layout or style of mealtimes, when the intervention 'ends' was not always clear. When the intervention has become 'part' of the meal/mealtime it was considered an 'end' even though is some cases small alterations to the implementation continued.

5.2. The Settings

5.2.1. Setting I

Setting 1 was one of two wards located in a specialised Continuing Care NHS unit in Kent. The research ward accommodated patients of both genders and had 20 beds. The organisation (NHS Trust) and the ward itself officially identified as providing "care outside of the traditional hospital environment and over an extended period of time [...] for people who have a diagnosis of dementia and associated complex needs" (*reference not available due to patient confidentiality*). The ward was staffed by a multidisciplinary team including Mental Health and General Nurses, Health Care Assistants, Occupational Therapists, Physiotherapy Technicians, Art and Music Therapists, and Therapy Technicians; a visiting GP and Consultant Psychiatrist also supported the ward. Use of agency staff was frequent. The unit (i.e. both wards) also had a dedicated housekeeping and maintenance team. The unit was open to

visitors 365 days per year, between 10am and 8pm, however children were not allowed to visit due to safety concerns. The Care Quality Commission (CQC) assessment concluded that the service was meeting all Care Quality Comission's national standards (CQC, 2010, 2013), with a report addressing both wards simultaneously.

5.2.1.1. Site Characteristics

The ward where the research took place was located on the ground floor and 'L-shaped' in layout. Historically, the 2 wings were separate, independently staffed and run wards. While a single ward today, it retained some of the original aspects, with staff assigned to work on a particular wing at the beginning of each shift. As can be seen in Figure 11, the ward had 20 single-occupancy en-suite bedrooms. Each wing also had a large communal room with a kitchenette area. While officially one was labelled as a 'Sitting Room' and another a 'Dining Room' both rooms were used during mealtimes and outside of them, thus simultaneously serving as sitting and dining rooms. Both rooms had identical half-wall kitchen areas, equipped with cupboards, a fridge, a microwave, a hot water urn and a specialized serving station that kept food warm; no oven or hob were provided. At the outset of the study, the furniture in both dining rooms were very similar (each including a sofa, several armchairs and dining chairs), the dining room had a single large table at the centre of it, while the sitting room had 3 small circular tables located on one end of the room. Tray tables were also present in these rooms and routinely used by some of the patients. The ward had 2 therapy rooms: one, entitled 'The Parlour', was designed to resemble a homely sitting room, whereas 'The Pamper Room' was styled as a beauty salon with a hair washing chair and sink and a salon hair dryer. The corridors were decorated to look like a street, including wallpaper resembling house exterior and decal stickers on patient room doors that looked like traditional front-of-house doors. The foyer (which was used as a sitting room, TV/music room and activities area) and many of the patient rooms had custom-painted floral murals. The unit's garden has recently been re-modeled into a sensory garden with gazebos, sitting areas, fountains and a herb area. Patients access was restricted to some areas of the ward (see Figure 11), while other areas (e.g. the garden and therapy rooms) could only be accessed when accompanied by a member of staff. The half-walled kitchen areas in both dining rooms did not have doors, but patients were not allowed to enter the areas during dishing up (serving trolleys were often placed in the way); the area could be entered outside of mealtimes, but patient presence in these areas was generally discouraged.

Figure 11. Site 1 Layout

The unit where Research Site 1 is located, was built in 1994 and run by a General Health NHS trust. Until 2007 the two ground floor wards (i.e. the current research site) operated as 'Respite Homes' for older people, but, following reports of abuse, it was taken over by the Mental Health NHS trust currently running the unit. The ward was then re-structured to a Continuing Care Ward. The patients on the ward at the point of the 2007 re-structuring remained on the ward. The Respite Home policy promised a life-long place on the ward, should it be needed, which was at odds with the Continuing Care eligibility. The latter included a review every 3 months and a requirement to leave the ward should ones Continuing Care eligibility be withdrawn. After the re-structuring, the decision was made to honour the life-long stay guarantee for patients admitted pre-restructuring, which partially

accounts for the patient diagnostic status. Of the patients who did not have a diagnosis of dementia, two thirds were also the ward's longest occupants (some patients lived on the ward since 2001).

5.2.1.2. Patient Characteristics

As suggested in the eligibility criteria (see above), most of the patients on the ward had a diagnosis of dementia and along with complex physical and/or mental health needs. Co-morbidity of illnesses and/or presence of 'behaviour that challenges' were characteristic of all patients, including a small number who did not have a diagnosis of dementia. The additional health needs included loss of mobility, personality disorders, schizoaffective disorder, learning disability, Type 1 diabetes, and Chronic Obstructive Pulmonary Disorder. The ward was also occupied by a relatively high proportion of younger adults living with dementia (10% on the ward compared to 4.8% in the general population of people with dementia).

Ward patients were subject to a quarterly assessment of their needs and eligibility for Continuing Care. On one occasion during the research project, a patient (who did not have dementia) had to re-locate after not qualifying for continuing care, but re-qualified and came back to the ward moths later. Despite the reviews, most patients' the stay on the ward was likely to be permanent due to the progressive nature of dementia.

In principle, the ward was expected to admit patients who could not be adequately cared for in Care or Nursing homes due to behaviour that challenges or complex physical and mental health needs. In practice, however, the ward would occasionally decline a referral on the basis that potential patient was perceived as 'too challenging' (see Chapter 6 for further detail).

5.2.1.3. Occupancy

The patient numbers in Research Site 1 (RS1) were almost always kept to full occupancy. On the majority of occasions, an unoccupied room was filled within 2 weeks and on one case where a room was unoccupied for over 2 weeks, this was due to repair work. Over the period of the research project, 12 patients left the ward. Usually (5% of cases), this was due to death of the patient – a rate does not exceed predicted mortality rates in long-term dementia care

facilities (see Bebbington et al., 2001). On two occasions, patients were re-allocated to an all-male NHS Continuing Care Ward within the same building. Once this was done to allow an admission of a female patient and on another instance the 'swap' was to enable a more physically frail patient to re-locate to the mixed-gender ground floor ward (i.e., RS1). Another patient lost their Continuing Care status and was re-allocated to a Residential Care Home, but came back to the ward 5 months later (the patient was also a participant in the study both before the move and following their return). Finally, one patient was moved out of the ward on the request of the family – it is unknown to the researcher where the aforementioned patient lived after the move. The patient participated in the study until the move.

5.2.2. Setting II

Site 2 was one of four wards within an Integrated Care Centre in Kent. While the other three wards were run by the local council as social care facilities, Site 2, while owned by the council, was run by the same NHS trust as Site 1 and provided "NHS continuing healthcare [...] outside of the traditional hospital environment" (*reference not available due to patient confidentiality*). The ward – commonly referred to either as a 'wing' or a 'unit' in official documents - was staffed by a multidisciplinary team, including Mental Health and General Nurses and Health Care Assistants. Unlike in Site 1, Site 2 did not have dedicated Therapy Technicians (or equivalent). A music therapist visited weekly, while Nurses and HCAs were responsible for offering activities. Compared to Site 1, Site 2 access to a consultant psychiatrist and a visiting GP was rarer and formal; drop-ins were not possible, as these professionals were not located in close proximity (i.e. the same building). The centre (i.e. all 4 wings) also had a dedicated housekeeping and maintenance team, as well as on-site catering. Cleaning and catering services, however, were subcontracted private providers, instead of local council or NHS staff. The unit was open to visitors 365 days per year. Visiting hours to the unit were not clearly imposed, but visitors could not walk into the centre without ringing the doorbell and first speaking to the staff before 8am and after 8pm. Unlike Site 1, Site 2 allowed children and babies to be brought onto the unit if supervised by an adult and two patients on Site 2 received regular visits from children and newborns. The Care Quality Commission (CQC) assessment concluded that the service was meeting all CQC national standards (CQC, 2011, 2013), with a report addressing the entire Care Centre simultaneously.

5.2.2.1. Site Characteristics

The ward where the research took place was located on the ground floor and rectangular in shape. The entire Integrated Care Centre was purpose built in 2007 on the site of a disused tram shed, and research Site 2 has performed the same function of providing Continuing Care since. As can be seen in Figure 12, the ward had 15 single-occupancy en-suite bedrooms. However, at the point of research commencement, only 10 of the 15 rooms were occupied (in Figure 12, unoccupied rooms are shaded in either grey, green or red). This was due to staffing level and occupancy ratio (a requirement imposed on all NHS wards following the Francis (2013) Public Inquiry Report). Towards the end of the research period, however, the occupancy was extended to 12 patients (who then occupied the rooms shaded in green). The unit had a sitting room with a television set and armchairs, which led to a large garden area. The large area in between the rooms was used a small sitting room space at one end, and a dining room with 5 circular tables at the other. The dining area backed onto a half-wall kitchen area, equipped with cupboards, a fridge, a microwave, a hot water urn and a specialized serving station that kept food warm; no oven or hob were provided, but staff often used a small electric grill for food preparation. The aforementioned sitting room was also used for dining, with tray tables available for the residents, while a small proportion of the residents routinely ate in their own rooms also using tray tables. The interior of the unit was not altered for residents with dementia like in Site 1, and was hospital-like. However, staff have decorated the walls and ceiling with objects (e.g. planes and air balloons) to provide sensory stimulation for the residents. The garden was standard for care units (in comparison to the sensory garden in Site 1), but staff have purchased plants and lights for some sensory stimulation. At the beginning of the research period the ward also received a donation of a large garden table and chairs, which was often used another space to eat both during and outside of mealtimes. Patient access was never fully restricted to any of the ward areas, with the exception of an unoccupied patient bedroom that was used a stock room and routinely locked (see room shaded in red in Figure X). The garden could be accessed at all times in the warm season (not only under staff supervision as on Site 1), but was locked when raining or during the cold seasons. The half-walled kitchen areas did not have a door, but a long piece of wood was at times used as a barrier. The periods of inaccessibility were not clearly defined; there were occasions when residents could access the area during the mealtime, and times when the barrier was up outside of mealtimes; accessibility depended more on which staff members were present, than on the time of day. The residents had full access to all other spaces; some routinely resided – and ate – in the staff room and were not escorted out despite

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of ward events (e.g. handover meetings). Resident's rooms were never locked, including rooms that were either temporarily or permanently empty (shaded in green and grey respectively on Figure X). However, the patients could not exit the ward without supervision; only staff who had key cards could enter and leave freely.

Figure 12. *Site 2 Layout*
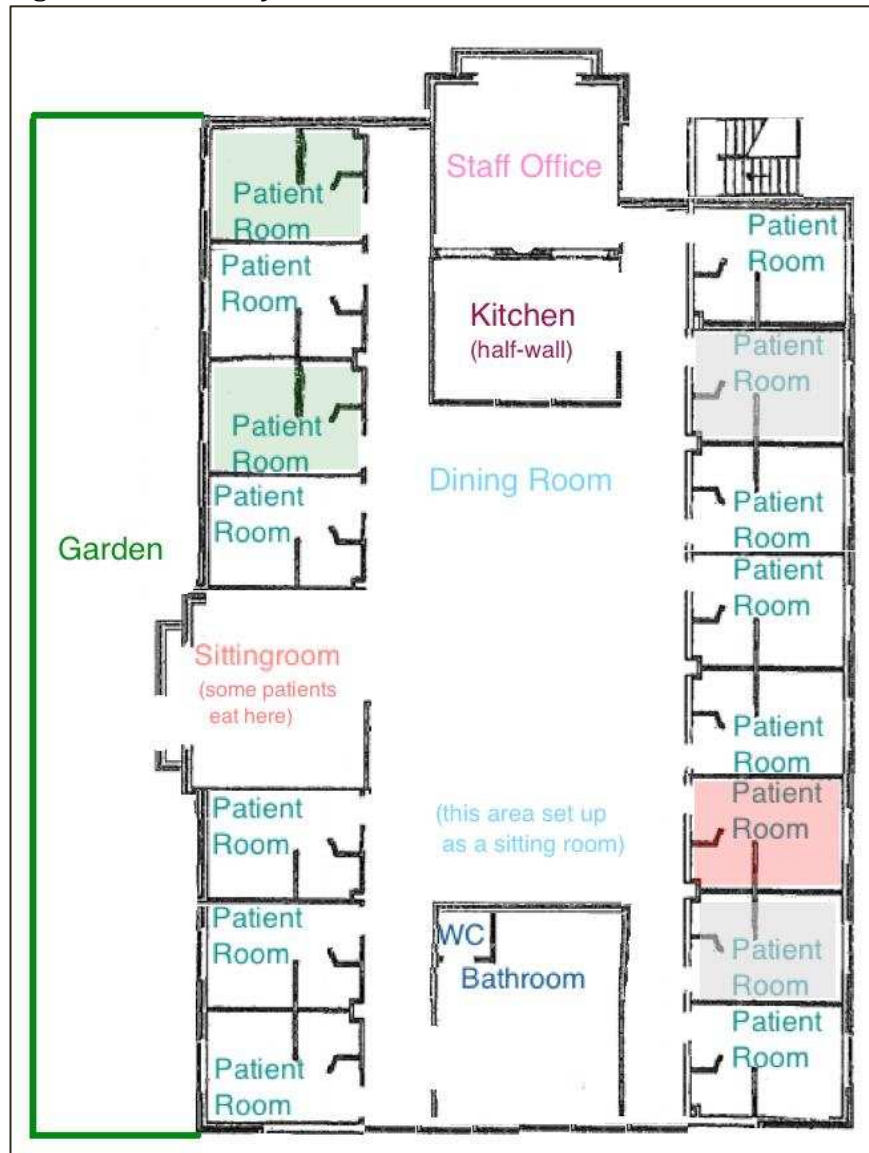
5.2.1.2. Resident Characteristics

Most of the residents on the ward had a diagnosis of dementia and along with complex physical and/or mental health needs; only one of the residents did not have a formal diagnosis of dementia. Co-morbidity of illnesses and/or presence of 'behaviour that challenges' were characteristic of all patients. The additional health needs included loss of mobility, personality disorders, cancer and severe edema, and chronic obstructive pulmonary disease. One person on the ward was a younger individual with dementia (making

up 10% of the ward population compared to 4.8% in the general population of people with dementia; the same proportion as on Site 1).

While the ward patients were subject to a quarterly assessment of their needs and eligibility for Continuing Care, no one lost their eligibility in the research period. Only 3 admission to the ward happened during the research period, and to the researcher's knowledge no referrals were refused as 'unsuitable' for the ward.

5.2.2.3. Occupancy

As mentioned above, during the majority of the research period the ward occupancy was kept at two thirds, increasing to 80% in the last 3 months of the research. Rooms were left empty intentionally, due to staffing levels, rather than lack of referrals. No one died during the research period, and only 1 resident was relocated to a different care facility following an extended stay in a general hospital. In the latter occasion, the unoccupied room was filled within a week. Two individuals were also admitted to the ward once the intended occupancy rose from 10 to 12, with both admissions taking place within 2 weeks since the confirmation of occupancy increase.

5.3. Participants

Ward patients, their relatives and ward staff took part in the study. Due to the intricacies of fluctuation in participant numbers, all three participant groups are described separately.

5.3.1. Setting 1
There was a total of 60 participants, of which 16 were ward patients, 37 were staff and 7 were relatives/friends of the patients.

5.3.1.1. Patients

The numbers of participating patients ranged from 3 to 13 within the formal part of the study; the first 2 months of the study were spent obtaining consent, familiarising with the setting and introducing the study to potential participants (see section 5.9.1 for information on gaining consent). As can be seen from Figure 13, participant numbers varied over time. More importantly, the make-up of the participant group varied beyond the overall numbers; while some patients' participation ceased, others have joined the study. Overall, 16 ward patients took part in the study. Only 2 participants took part in the study from beginning to the end,

whereas the majority participated for a period between January 2014 and December 2014 weeks.

A total of 3 participants died during the study, which made up 50% of participant dropout. Three participants were moved out of the ward; one was transferred to an all-male NHS Continuing Care Ward, one lost their Continuing Care Status and was moved to a local Care Home and another patient was moved out of the ward on the request of their family. The patient who lost their Continuing Care status later regained it, came back to the ward and provided consent to take part in the study again.

Figure 13. Change in Participant Numbers (Patients Only) throughout the course of the study; Site 1.
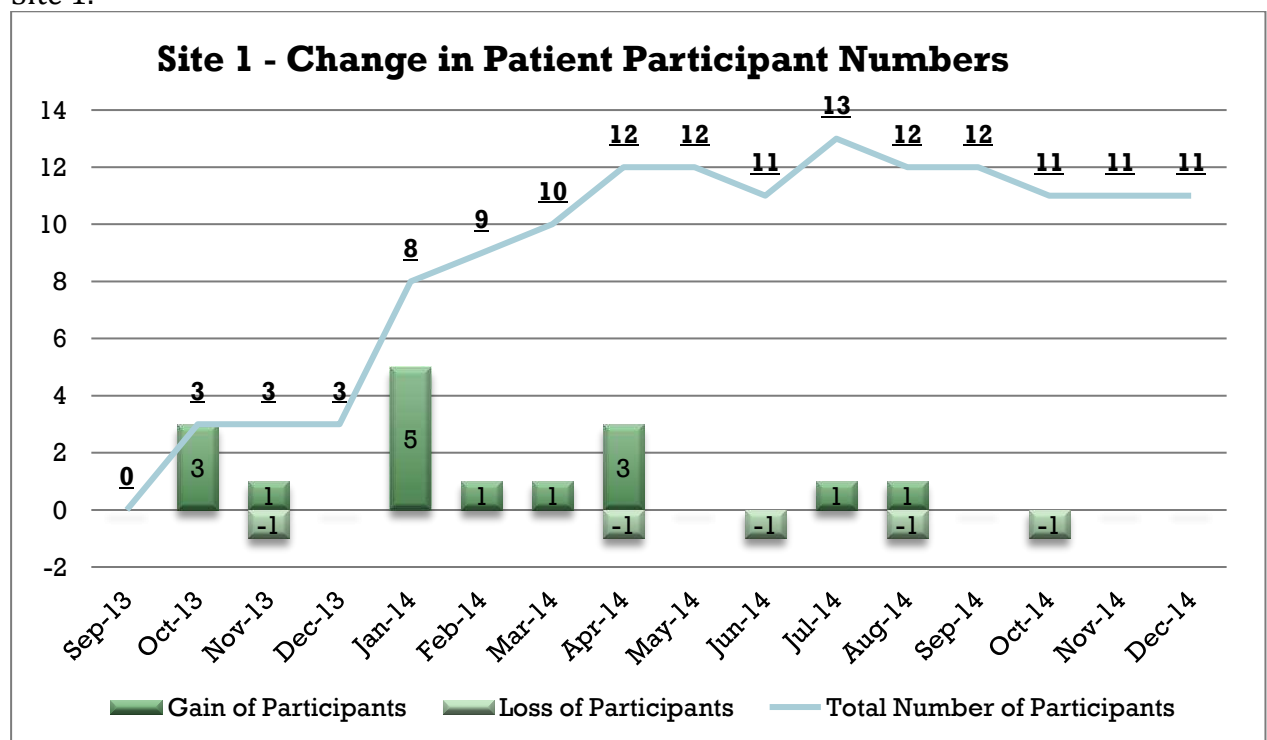
N.B.: Sept-Oct 2013 was a pre-study period to secure initial consents.

Among the total pool of participating patients, 50% were male and 50% were female. The majority of participating patients were White British, and 1 was Black British. Other demographic details (e.g. age) could not be systematically collected due restrictions imposed by the Social Care Research Ethics Committee; the researcher did not have access to patient records).

Figure 14. Participant Timeline (Patients only) throughout the course of the study; Site 1.
N.B.: Sept-Oct 2013 was a pre-study period to secure initial consents.
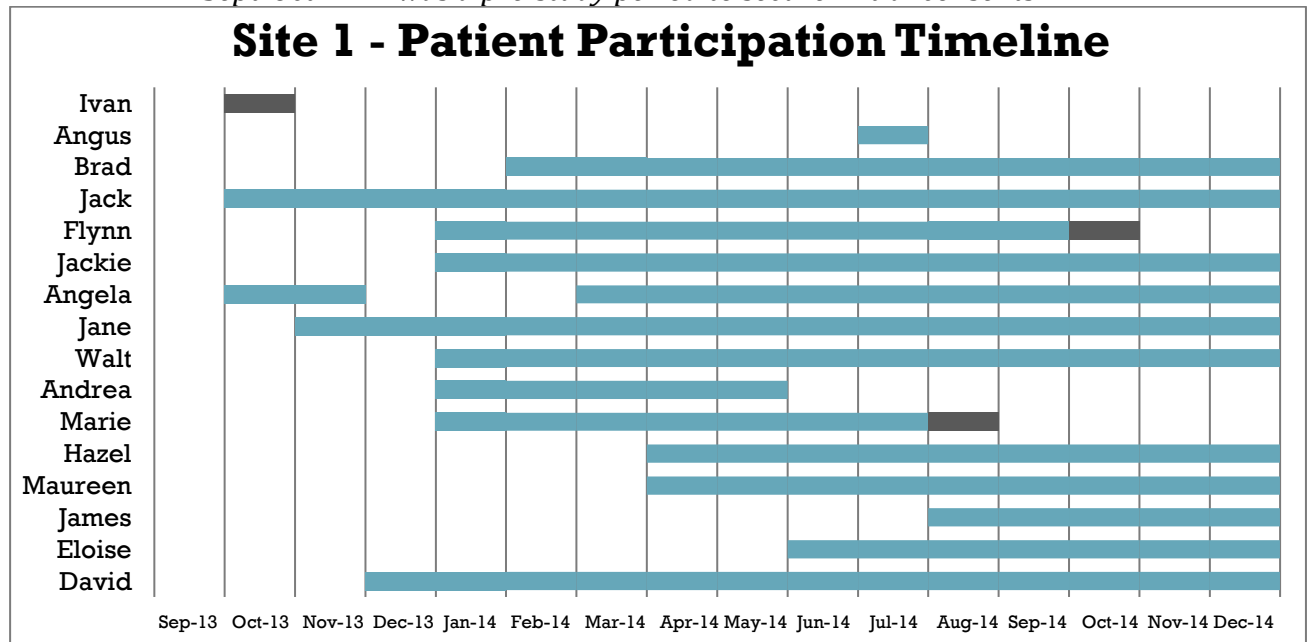
Out of the overall pool of participating patients, 14 (88%) had a formal diagnosis of dementia (all in severe stages). Two participants did not have a diagnosis of dementia, but were admitted to NHS Continuing Care due to complex needs arising from conditions such as Bipolar Personality Disorder or Schizoaffective Disorder. These patients were included in the study in order not to put them at an unfair disadvantage concerning potential benefits of taking part. Also, while a formal diagnosis was lacking, both of the participants had some degree of memory difficulties as reported by ward staff.

31% of participating patients experienced severe loss of mobility (i.e. unable to mobilise independently), 31% experienced significant mobility difficulties, but were able to mobilise with use of aids or minimal assistance and 38% had no mobility issues. Comorbidity of mental and physical illnesses was high among the patient population; however, due to the limitations of the Research Ethics approval, this information could not be systematically extracted from patient records.

5.3.1.2. Staff

37 members of staff took part in the study, with some fluctuation in numbers throughout the study (between 24 and 30 ward staff participating at any one point). In total, 9 participants from the staff group dropped out; in 6 cases this was due to staff terminating their employment on the ward, 1 participant started their maternity leave and 2 were nursing

students on placement whose participation ceased at the completion of their 12-week placement. Due to organisational factors, not all staff vacancies were filled. Due to this, the loss of overall staffing numbers resulted in a smaller number of participants towards the end of the study. Only 15.5% of the staff participants were male. No other demographic information (e.g. age or ethnicity) was collected as it was beyond Research Ethics clearance. However, a significant variation was present in staff participants' age along with considerable ethnic and cultural diversity.

The majority of participating ward staff were permanent members of the ward team, with 82.9% (29 persons) of the permanent ward staff taking part, 8.6% (3 staff members) declining participation and another 8.6% not responding to the invitation (all 3 staff worked exclusively on night shifts). The breakdown of permanent ward staff roles is displayed in Figure 15.

Figure 15. *Job Roles of Participating Ward Staff; Site 1*
figures include only permanent ward staff
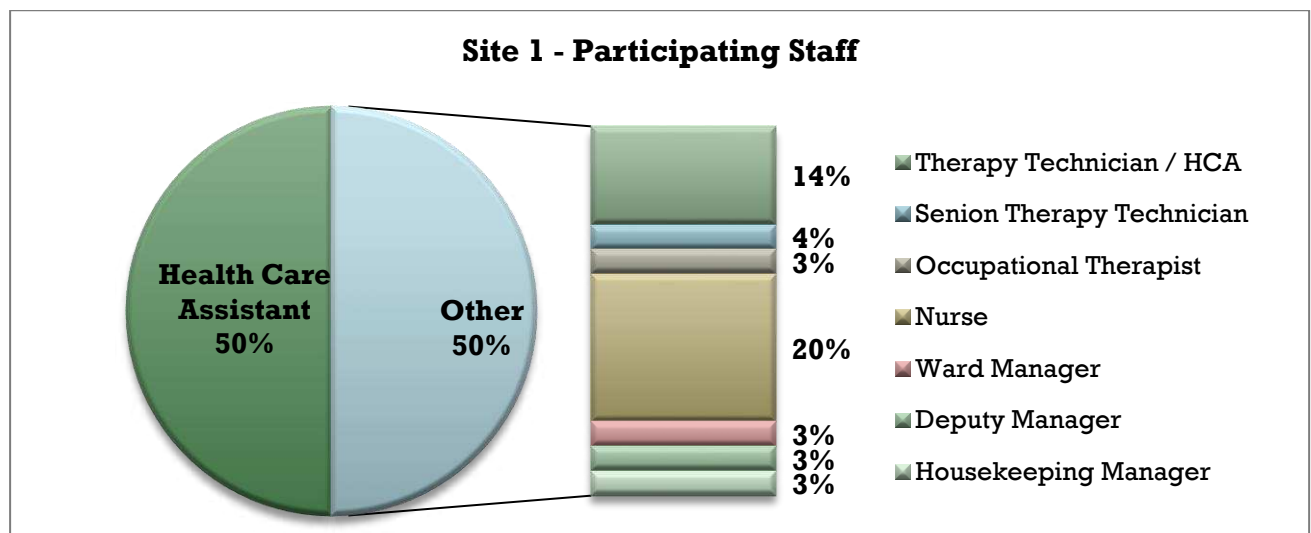
A number of non-permanent ward staff and non-ward-based staff also took part in the research. The original research plan excluded agency staff from people eligible to take part in the study, as it was anticipated that they would not be working on the ward often enough or know enough about the patients or mealtimes on the ward. However, due to cost-saving intentions, the organisation did not fill all staff vacancies, resulting in significant reliance on agency staff. Therefore, agency personnel, who regularly worked on the ward over a 3-month period were also invited to take part, resulting in 3 participants (60% of the eligible population). In addition to this, 2 nursing students who were on placement on the ward also took part for the duration of their 3-month placements, making up 67% of the eligible population. The Locality Manager (i.e. manager of all Continuing Care wards within the trust)

also took part in the research, as did the Head Chef from another NHS trust who ran the food service provided to the patients on Site 1.

Members of the ward team, who never took part in mealtimes on the ward in any way were excluded from the study; these were arts and music therapists, a physiotherapy technician, general practitioners and housekeeping staff (who were only involved in washing up after mealtimes). The consultant psychiatrists and General Practitioners regularly visiting the patients ware fully informed about the study. However, as they were also the nominated consultees for some of the ward patients, it was decided to exclude them from taking part in order to avoid any conflict of interest (based on DoH (2013) guidelines).

5.3.1.2. Relatives/Friends

Although relatives could be located for every patient, only 4 relatives fully took part in the study (2 of which dropped out following the death of the patient they were related to). The low numbers could partly be attributed to the consent process. After the ward staff sent identified relatives information about the study, only 57% returned the study slip with contact details (for more information, see section 5.9.2). If the relative did not return the reply slip (43%) or indicated that they did not wish to be contacted about the study (13%), the researcher could not contact them with further details or invite them to relatives meetings. Of the 13 relatives who did express interest in the study and could be contacted for further information, 4 signed the consent form. An additional small group of relatives (N=3) did not complete the consent form, but expressed interest in the research and attended relatives meetings regarding the research. Due to this, it was decided to seek event-based consent (i.e. relatives who did not sign study consent, but came to meetings were asked to provide consent for each meeting they came to). This enabled the researcher to record their contributions and inform them of research progress.

Of the 7 participating relatives 75% were female. Three participants were adult children of the patients and four were patients' spouses. No other data (e.g. age or ethnicity) were collected about the relatives, as they this was beyond Research Ethics clearance.

5.3.2 Site II

There was a total of 42 participants, of which 9 were ward patients, 27 were staff and 6 were relatives/friends of the patients.

5.3.2.1. Patients

A total of 9 participants took part in the study, with 8 participants taking part in the study from February to September 2015. As can be seen from Figures 16 and 17, participant numbers remained stable over time. Only one of the participants joined the study at a later point and no participants died or drop out f the study for any other reasons.

Figure 16. *Change in Participant Numbers (Patients Only) throughout the course of the study; Site 2*
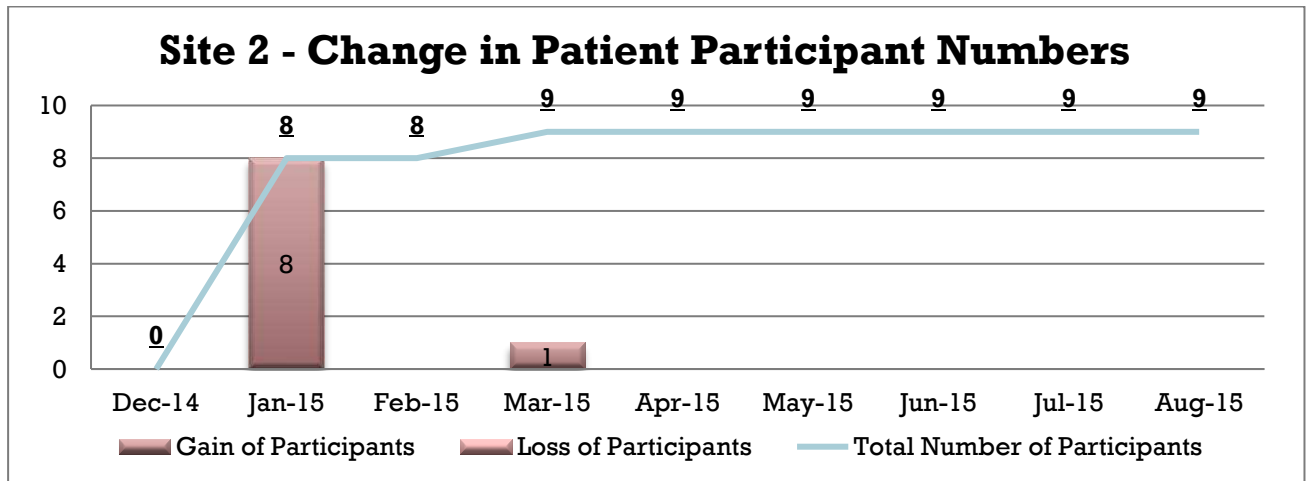
Figure 17. *Participant Timeline (Patients Only) throughout the course of the study; Site 2.*
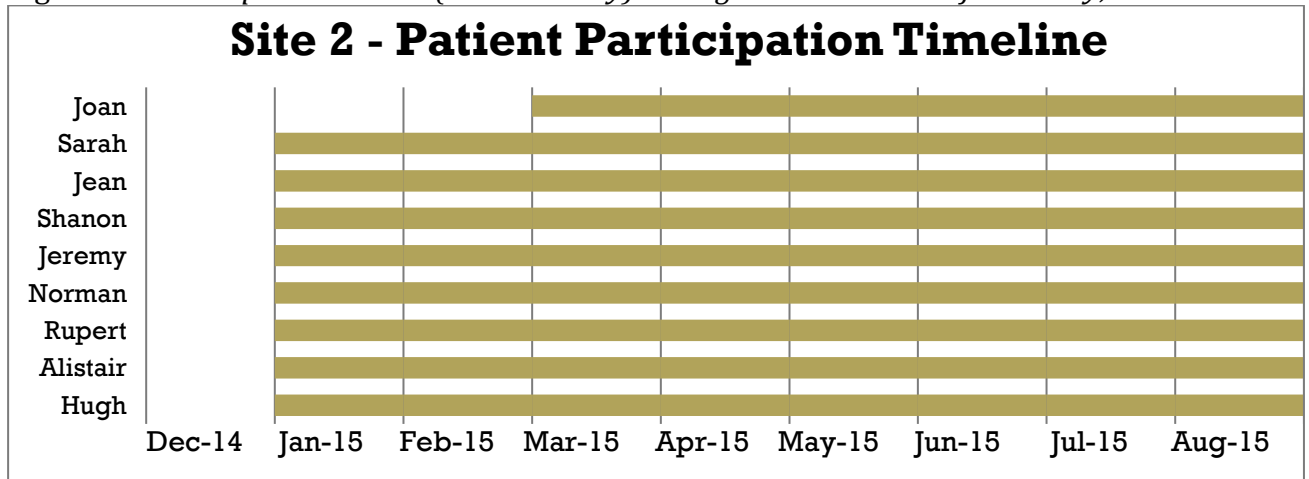
Among the total pool of participating patients, 44% were male and 56% were female. All of participating patients were White British. Other demographic details (e.g. age) could not be systematically collected due restrictions imposed by the Social Care Research Ethics Committee; the researcher did not have access to patient records).

Out of the overall pool of participating patients, 8 (89%) had a formal diagnosis of dementia (all in severe stages). Once of the participants did not have a diagnosis of dementia, but was

admitted to NHS Continuing Care due to complex needs arising from aggressive behavior and physical health comorbidities. The aforementioned patient had suspected frontitemporal dementia, but the diagnosis was not formalised during the research period.

22% of participating patients experienced severe loss of mobility (i.e. were unable to mobilise independently), 34% experienced significant mobility difficulties, but were able to mobilise with use of aids or minimal assistance and 44% had no pronounced mobility issues. Comorbidity of mental and physical illnesses was high among the patient population; however, due to the limitations of the Research Ethics approval, this information could not be systematically extracted from patient records.

5.3.2.2. Staff

27 members of staff took part in the study, with some fluctuation in numbers throughout the study (between 22 and 25 ward staff participating at any one point). In total, 5 participants from the staff group dropped out; in 3 cases this was due to staff terminating their employment on the ward, 1 participant started their maternity leave and 1 was a nursing student on placement whose participation ceased at the completion of their 12-week placement. 26% of the participating staff were male. No other demographic information (e.g. age or ethnicity) was collected as it was beyond Research Ethics clearance. However, a significant variation was present in staff participants' age along with considerable ethnic and cultural diversity.

The majority of participating ward staff were permanent members of the ward team, with 96.4% of the permanent ward staff taking part and 3.6% (1 staff member) declining participation. Three agency staff members also took part in the study, as they all worked on the ward for over 3 months at the point of study commencement. The wards' designated cleaner expressed an interest in the study and was included. Also, one nursing student signed up to the study for their 12 week placement. The breakdown of ward staff roles is displayed in Figure 18.

The Locality Manager (i.e. manager of all Continuing Care wards within the trust) also took part in the research, as did the Head Chef who ran the privately-owned food service provided to the patients on Site 2.

Figure 18. *Job Roles of Participating Ward Staff; Site 2*
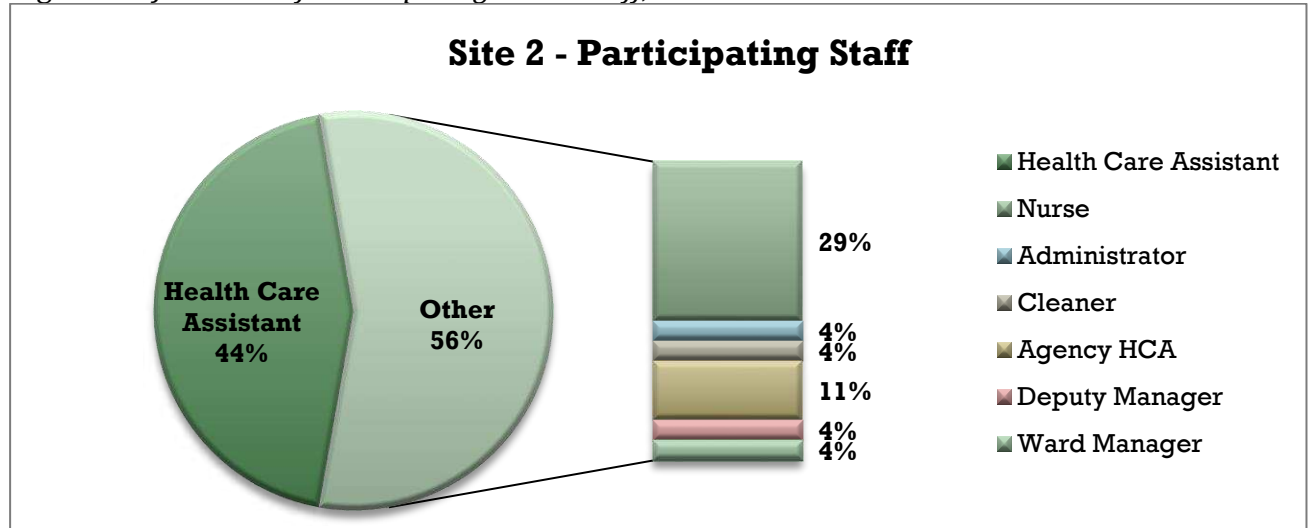
All ward-based staff took part in mealtimes; none of the ward staff were therefore excluded. The consultant psychiatrists and General Practitioners visiting the patients ware fully informed about the study.

5.3.2.2. Relatives/Friends

Six relatives took part in the study (and none dropped out as the study progressed). One patient did not have any known relatives. 9 relatives were contacted and 6 (67%) returned the study slip with contact details and subsequently signed the consent form.

Of the 6 participating relatives only a third were female. Five participants were patients' spouses and one was an adult child of a patient. No other data (e.g. age or ethnicity) were collected about the relatives, as they this was beyond Research Ethics clearance.

5.4. Researcher

At the onset of the study the researcher had 6 years experience of working with people with advanced dementia in both the NHS and private care facilities and has completed training on Mental Capacity Act (2005) as part of her NHS work. This included care work, as well as conducting research. Due to her previous employment, the researcher previously and strictly professionally knew 2 members of the ward staff (1 in each research site), 1 patient as well as their spouse, and the Locality Manager. The researcher was a Caucasian female in her mid-twenties.

The researcher's role within the study was dual due to the study's Action Research nature. I simultaneously adopted the stance of an observer, impartially documenting mealtime experiences on the ward, and acted as a facilitator of collaboration and co-creation, as well as being the lead for some of the small-scale interventions.

Figure 19. *Researcher's Role*

While balancing ones own role and involvement, the researcher also attempted to maintain the balance of perspective. Given the aforementioned lack of relative/friend participation coupled with participation barriers for people with dementia and large numbers of staff participants, the study was in danger of disproportionately representing the wishes of the staff. To avoid such disproportion and evade further disempowering patients – a participant group who are seldom granted agency - the researcher was tasked with maintaining equal 'power of action' among the participant groups despite the discrepancy in amount of contributions from each group. Maintaining the balance included not only researcher's own observations and recommendations, but also taking steps to ensure that all groups are equally represented in the collaborative decision-making process (see Chapter 6 for further information).

5.5. Methodological Approach

5.5.1. Action Research

Action research methodology was chosen to underpin the study's methodological approach. It was felt that the majority of existing research on people with dementia in long-term care was exploratory, lacking direct impact to the participants of past research. Dementia is a complex disease that profoundly affects the lives of people living with it. It also impacts on the wellbeing of families and friends and caring for a person with dementia both informally (i.e. family carers) and professionally (i.e. paid carers) is often a physically and psychologically demanding task (see Chapter 2). Given the aforementioned demands and stressors on people living with dementia, as well as their families and care givers, adding further demands of taking part in research becomes ethically problematic. In other words, it must be considered whether the requirements of taking part in a research study (however minimal) can be outweighed by the potential benefits of participation.

Action Research methodology proved ideal to address these considerations. Firstly, it aims to deal with topics/issues that are seen as problematic *by* the studied population (Dold & Chapman, 2012; Levin, 2012; Schneider, 2012). During the current project, all stakeholder groups (patients, relatives and ward staff) were informed about the research focus and aims, and asked if mealtimes were an important issue within the setting and if it required some improvement. The project could commence only if the majority of the stakeholders expressed an interest in contributing towards the improvement of mealtime experiences.

In addition to personal relevance and perceived importance of the research topic to the stakeholders, action research principles allow for ad hoc change of intervention/action as new knowledge emerges (e.g., McDermott, Coughlan, & Keating, 2008) thus ensuring that research findings are applied in practice (Bate, 2000). However, traditional action research usually involves the researcher generating ideas on what action/intervention should be taken and handing over to the stakeholders to implement it. This, too, was seen as ethically problematic for the current project. Previous research shows that within dementia care PWD are often stripped of choice and agency, which results in oppressive practice (e.g. Martin & Younger, 2000). Once a Person with Dementia is placed in a long-term care facility, relatives and friends also express a significant reduction in agency (specifically regarding how much they could be involved in and/or advise on the delivery of care; Herkunsens, 2013). Staff working in long-term care facilities have also been shown to feel that they are seldom empowered to make decisions about care provision, but rather 'handed down' instructions from higher management with little regard for care staff's expertise (Young et al, 2017). In fact, qualitative research in long-term dementia care facilities has revealed that "the most striking theme from all groups [residents, relatives and staff] was the need for choice" (Train et al., 2005, p. 119).

In relation to this, the current project aimed to incorporate aspects of Participatory Action Research (PAR) within its methodological approach. The *participatory* part in PAR signifies a goal to involve all stakeholders who are affected by the issue being studied (and thus being studied themselves as participants) in the research process and collaboratively developing the research (Levin, 2012). Action Research at large is also characterised by the involvement of participants - Brydon-Miller and colleagues (2003) state that Action Research is based on "[a] respect for people and for the knowledge and experience they bring [...], a belief in the ability of a democratic process to achieve positive social change, and a commitment to action"

(p. 15). PAR, however, strives to extend beyond consultation and information sharing towards equitable collaboration and participants afforded the role researchers.

While complicated and challenging, PAR has proven successful in other Mental Healthcare settings. For example, Schneider (2012) involved research stakeholders in every step of the research practice, including planning the research, data collection and interpretation, and choosing where and how the findings were disseminated, as well as giving talks and presentations on the findings. However, due to the restrictions of Research Ethics clearance a definitive research plan was required prior to the commencement of the study which resulted in inability to involve stakeholders in research planning. Most of the data was also collected exclusively by the researcher, with only 2 types of patient assessment completed by the ward staff (see below). Greater stakeholder involvement in data collection was also deemed unfeasible due the aforementioned complexity of demands of living with or caring for someone with dementia and the aim to keep research demands on the stakeholder as minimal as possible. However, whenever possible stakeholders were invited to contribute to data interpretation.

The major PAR feature within the current re-search was stakeholder cooperation in co-creating interventions to improve mealtime experiences on the ward (thus also bringing the 3 distinct groups together). The stakeholders were encouraged to take ownership of and lead on the interventions, where the researcher acted as an informant and facilitator rather than the creator of ideas and interventions.

Finally, Action Research Methodology was selected as its specificity to the studied setting allowed for a simultaneously broad (i.e. covering a multitude of aspects related to mealtimes) and in-depth (i.e. investigating micro-cultures within and across settings) research focus. In doing so, the research focussed on the 'Here and Now' of the participants lived experiences. This was in accordance to the suggestions that dementia research should steer away from evaluating intervention success by its long-term effect (e.g. maintaining independence for longer post-intervention, which might not be feasible given the progressive nature of dementia), but rather focuss on its benefits while the intervention is in place (see MacPherson et al., 2009).

5.6. Measures

As well as following the framework of action research with participative aspects, the current project involved mixed measures. A multi-method approach, involving qualitative, as well as quantitative measures was chosen to tap into the stakeholder mealtime experience in a holistic way, simultaneously exploring physiological, physical and pasycho-social aspects of mealtimes. Importantly, the measures were not selected expecting that they will corroborate each other in terms of findings; instead, it was expected that (as discussed in the literature review) the chosen method will influence the likely findings, which may not coincide with findings from other measures. For example, more positive emotions observed during mealtimes were not expected to automatically go hand-in-hand with greater food intake or increases in BMI. The measures were intended to complement one another and aimed to capture different dimensions and elements of meals and mealtimes. A multi-method approach was particularly impoirtant as it provided an opportunity to examine the complex relationship among different mealtime aspects.

5.6.1. Qualitative Measures

Focused Ethnographic Observations. Focussed Ethnographic Observations were conducted during the entire study period and alternated with other measures. The ethnographic approach (Hammersley & Atkinson, 1995) was used to investigate how the micro-cultures of the long-term care facilities e.g. social interactions, care practices, environment, intersect with the mealtime experiences of patients, staff and relatives. *Focused* ethnographic methodology was chosen as it is widely considered to be appropriate for research that focuses on specific - largely unexplored - questions in specific environments (Knoblauch, 2005). Furthermore, focused ethnography has been successfully applied within other long-term care settings for people with dementia (see Stephens, et al., 2012). Together with semi-structured interviews this allowed for an in-depth understanding of the nature of micro-cultures and structures and ensured that the collaborative development of interventions were relevant to the lived experiences of people living in, working in or visiting the facility and addressed areas that were perceived to be most in need of improvement. During the intervention and post-intervention phases, ethnographic observations also facilitated the holistic capture of how the interventions are experienced and what their impact is.

Semi-structured Interviews. Semi-structured interviews were conducted with staff, relatives and, where possible, patients to explore mealtime experiences and scope for interventions. All interviews were informed by the topic guide (see McNamara, 2009) and differed depending on the interviewed participant group and phase of the study. A semi-structured interview format was chosen as it allowed for focused yet conversational communication between interviewer and respondent (Diefenbach, 2009). However, some variation across participant group occurred and due to patient needs interviews were often more unstructured (yet still following a topic guide) and much more conversational, as the patients often brought up unrelated conversation topics. Due to difficulty in recruiting relatives/friends and event-based participation of some of the relatives (see section 5.3.1.2), relatives' interviews were carried out as semi-structured group interviews. The interviews were also used to encourage collaboration in the development and implementation of interventions. Specific strategies were used to enable the involvement of people with dementia in interviews (e.g. adjusting pace, volume and tone of voice, and choosing an environment with minimal distractors; Reid et al, 2011; Williamson 2012). Interviews were conducted throughout the study period and also allowed capturing staff, relatives and, where possible, patients' opinions on the effectiveness of interventions.

5.6.2. Quantitative Measures

Weight and BMI. Patients' weight and Body Mass Index were (recorded by staff) were utilised in the current study to assess whether the interventions had an effect on both. They have been used in other studies involving people with dementia (Hanson et al., 2011).

Mini-Nutritional Assessment Short-Form. Nutritional status was assessed by ward staff using Mini-Nutritional Assessment Short-Form (MNA-SF; Kaiser, et al., 2009) during Stages 1 and 3 of the research. MNA-SF is a widely used and highly reliable and valid measure of nutritional status (Bleda et al, 2002; Gulgoz, 2009); it is also quick and simple to administer and is familiar to nursing staff. Inter-rater reliability was checked using an interclass correlation coefficient (see Wuensch, 2010).

Edinburgh Feeding Evaluation in Dementia Scale. The Edinburgh Feeding Evaluation in Dementia Scale (EdFED; Stockdell & Amella, 2008; Watson, 1993) was used by the ward staff during Stages 1 and 3 of the research to evaluate feeding/eating abilities and responses to food. EdFED is a widely used (self-)feeding assessment, which, according to a review by

Aselage (2010) is the best currently available feeding assessment in term of its psychometric properties, reliability and validity, as well as being widely used in the UK and validated cross-culturally (Lin, Watson, & Lou, 2013).

Mealtime Observations. In addition to nutrition and feeding assessments conducted by ward staff, the researcher also observed people with dementia utilising a composite of measures used by Edahiro, et al. (2012), which looks at amount of food eaten, duration of the meal, presence of dysphagia signs, difficulty in beginning a meal, difficulty in proper use of utensils, difficulty in scooping the proper amount of food, difficulty in recognising the total amount of food provided, difficulty in maintaining attention while eating, and difficulty in maintaining alertness while eating (see Appendix A). The observations were conducted with a single participant at a time and in relation to a single meal. While Edahiro and colleagues' (2012) measures are new and therefore not widely replicated, it is one of few available observational methods that encompasses both nutrition and feeding/eating ability. While it is not a part of Edahiro et al. (2012) measures, the type of food served to service users will also be recorded. Unobtrusive observations will also be used to monitor mood, participation and social interaction of people with dementia during and around mealtimes (Brooker, 1995). Systematic observation and recording of participants' activity closely followed the principles of Dementia Care Mapping (DCM; Innes & Surr, 2001), which is widely applied in long-term settings with people with dementia; it is also routinely used in the continuing care facilities where the research will be carried out. DCM shows high reliability and validity (Brooker, 1995) and it has been successfully utilised in the principal investigators previous research (Hirst, Lane & Mikelyte, 2011; see Appendix B).

Well Being and Quality of Life. At the outset, the study intended to measure patients' Quality of Life. As the majority of patients on the continuing care wards are expected to have advanced dementia, the assessment of their wellbeing and quality of life would not allow for self-reported assessments, as these have been found suitable only for people with mild or moderate dementia (see Ready & Ott, 2003). Due to this, an observational measure was used. The Quality of Life in Late-Stage Dementia (QUALID) scale was employed as it was demonstrated to possess good levels of validity and reliability (Weiner, et al., 2000) and is advantageous in terms of its brevity and relying on informants who know and have regular contact with the patients. QUALID is an 11-item instrument based on direct observation of people with dementia over a period of 7 days. While QUALID encompasses items on mood and interaction, these were not deemed sufficient sole indicators of these constructs.

Therefore, observational data on mood and interaction was also collected (see above). However, once the study commenced, it became apparent that ward staff were either unwilling or unable to complete the scale (both due to time constraints or being unsure about the answers). QUALID scale was therefore withdrawn from the study.

5.6.3. Overall Structure

Multiple qualitative and quantitative measures were employed within the study to holistically measure the 3 dimensions of mealtimes: physiological, physical and psycho-social. Each dimension, in turn, is assessed by measuring particular phenomena within that dimension. For example, within the physiological dimension of mealtimes specifically measured were Nutrition and Hydration (see Figure 20 and refer to Chapter 4 for further details). Figures 21, 22, and 23 show further the breakdown of specific measures per dimension.

Figure 20. *Meal & Mealtime Dimensions with Corresponding Constructs*
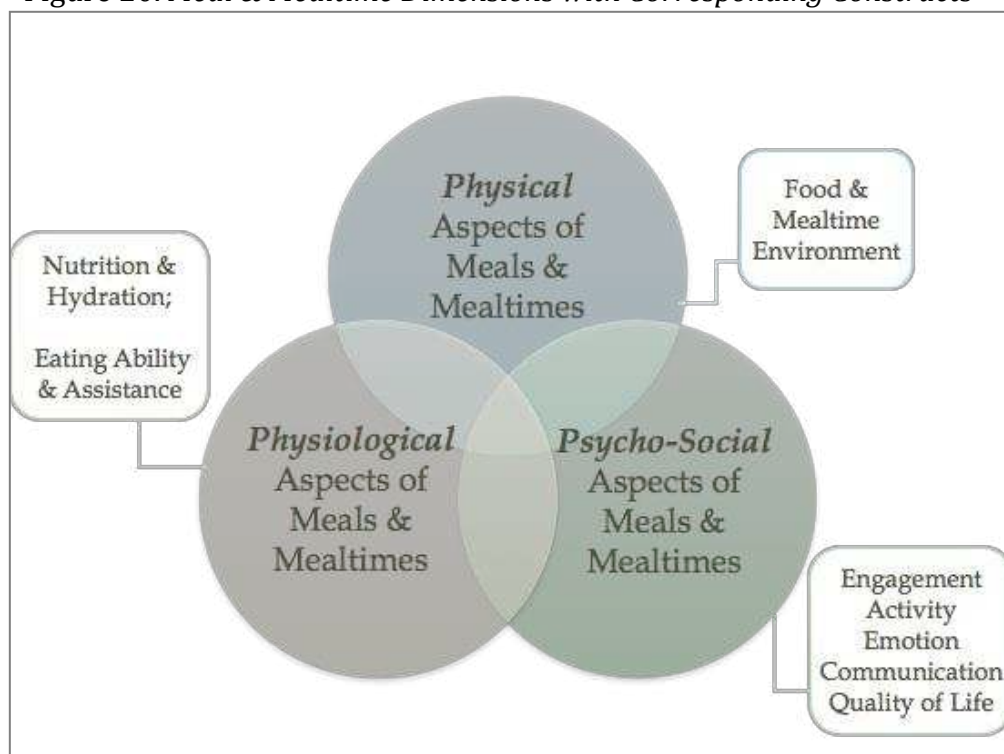
Figure 21. *Measures Associated with the Physiological Dimension of Meals and Mealtimes*
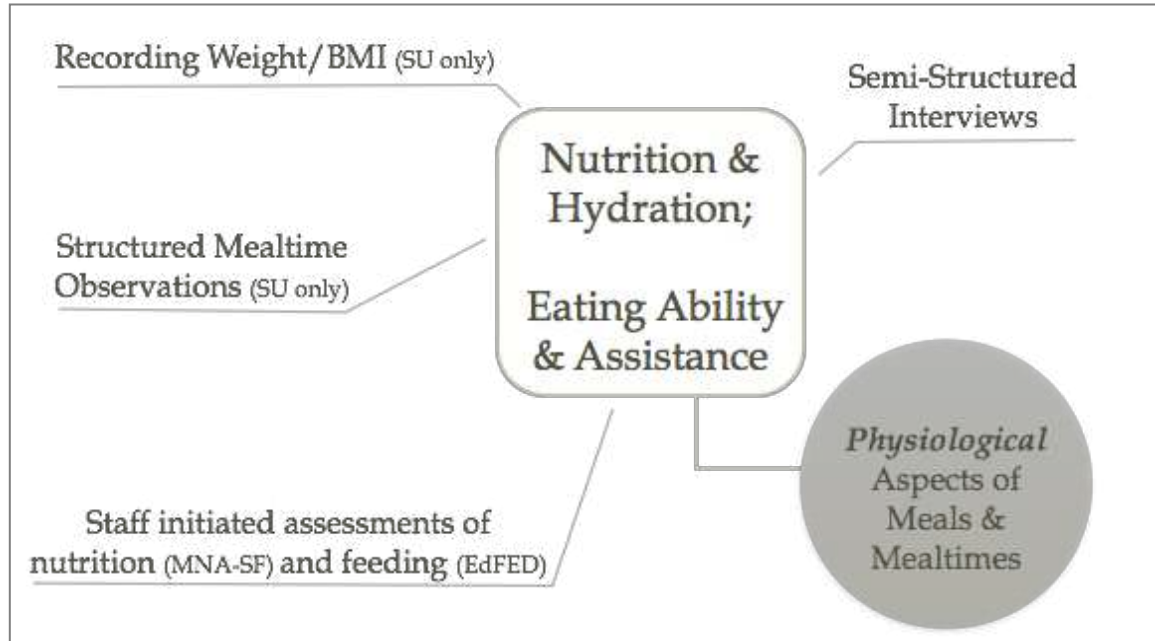
Figure 22. *Measures Associated with the Physical Dimension of Meals and Mealtimes*
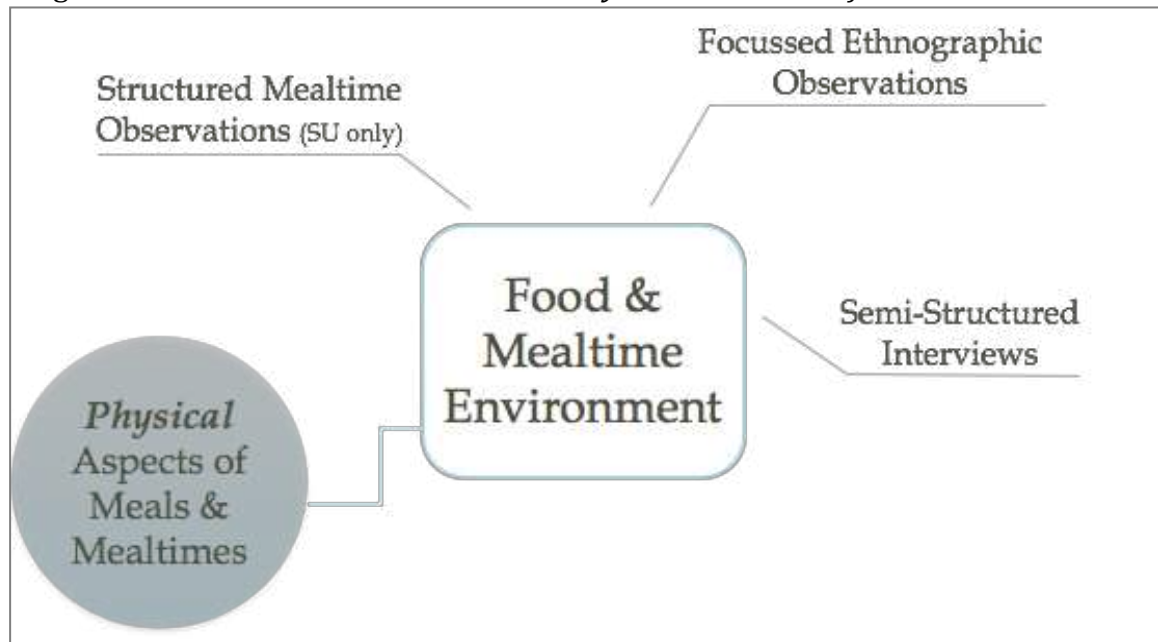
Figure 23. *Measures Associated with the Psycho-Social Dimension of Meals and Mealtimes*
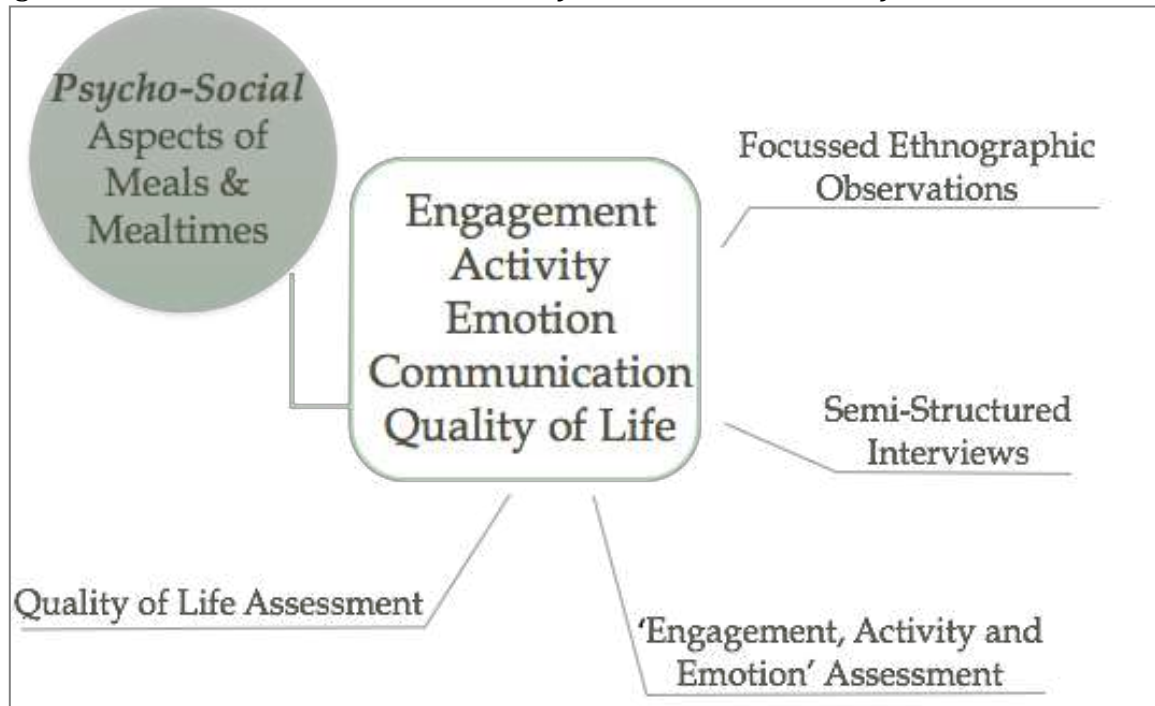
5.7. Procedure

The study was conducted in three phases: Phase/Stage 1 - Pre-Intervention, Phase 2 - Intervention and Phase 3 - Post-Intervention (Figure X). During Phase 1 of the study, baseline measures around food, nutrition, and mealtime experiences were collected with the aim of exploring the micro-cultures of the ward environments and the factors that influence mealtime experiences of people in the continuing care facilities. Particular attention was paid to those issues that negatively impact on meals and mealtimes, which informed the development of interventions. Phase 2 saw the findings from Phase 1 discussed with stakeholders, who then collaboratively developed and implemented site-specific small-scale interventions to improve mealtime experiences on the ward. Data collection continued during this stage to evaluate the implementation process. Finally, Phase 3 of the research investigated whether the interventions improved mealtime experiences, which aspects of the mealtimes improved and how the changes affected patients, relatives and/or staff (for more detail see Figure 25). Findings from all stages were routinely shared with stakeholders during informal conversations, newsletters and ward meetings.

Figure 24. *Research Structure*
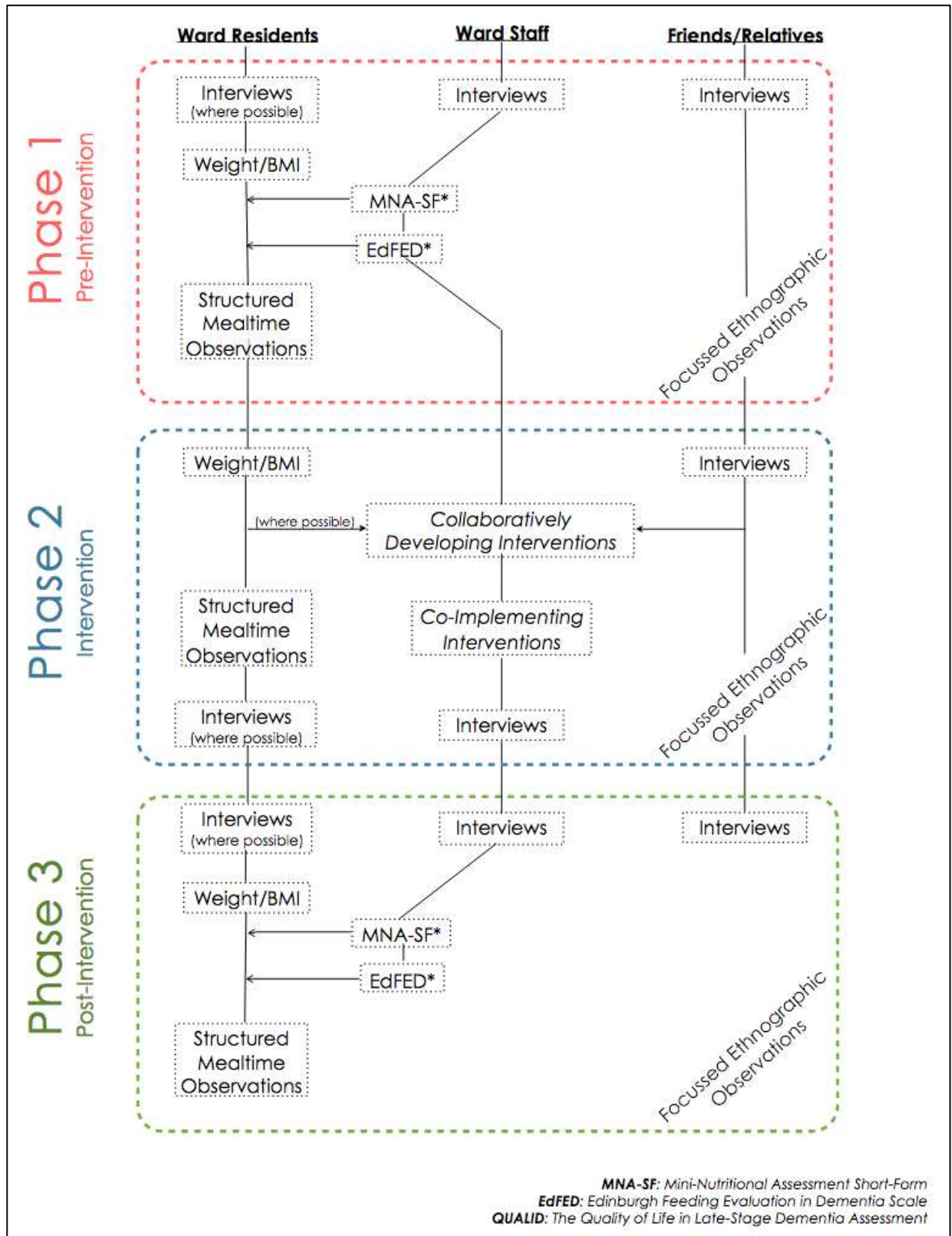
Most measures (ethnographic observations, semi-structured interviews, mealtime observations, and weight/BMI) were used to collect data throughout the study period (i.e., before, during and after the interventions). Data on nutritional status (Mini-Nutritional

Assessment Short-Form) and feeding/eating abilities (Edinburgh Feeding Evaluation in Dementia Scale) was collected before and after the intervention period. As these tools (i.e. MNA-SF and EdFED) were used by staff, it was not considered feasible to conduct the assessments during the period of intervention implementation when staffnwere already performing additional tasks. Repeating of all measures utilised in the study allowed to systematically investigate if and what kind of differences occur as a result of the interventions.

5.8. Design

A single-subject design was used to assess significant change in any of the quantitative measures from pre-intervention to intervention and post-intervention stages. Single-subject designs are designs that can be applied when the sample size is one or when a number of individuals are considered as one group. These designs are typically used to study the behavioural change an individual exhibits as a result of some treatment. In single-subject designs, each participant serves as her or his own control, similar to a time-series design. It is considered the most appropriate method for studies that involve an application of an intervention and where the participant pool is relatively small and is therefore methodologically suitable to the current study. Visual representation of the analysis will be provided.

5.9. Ethical considerations

Ethical considerations were paramount to the current research due to the potential vulnerability of people with dementia taking part in the study (Protection of Freedoms Act, 2012) and as a large proportion of PWD residing on wards were deemed lacking capacity to consent to their own participation (Mental Capacity Act, 2005). Approval for the study was obtained from the Social Care Research Ethics Committee prior to its commencement (REC reference: 13/IEC08/0018).

5.9.1. Consent

Those providing consent were informed of data confidentiality and use of data in the future, their right to discontinue their participation at any point of the study or withdraw their data without any penalty.

5.9.1.1. Patients

As described in Sections 5.2.1.1 and 5.2.2.1 the majority of the ward patients had a diagnosis of dementia. Three patients who did not have a formal diagnosis of dementia lived with (often multiple) mental and/or physical illnesses. Due to this, all patients were assessed for their capacity to consent to taking part in the research project.

Based on the Mental Capacity Act (2005, Section 2(1) "*a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter, because of an impairment of, or disturbance in the functioning of, the mind or brain*".

Following official guidelines for researchers seeking to recruit participants who might lack capacity to consent (The British Psychological Society, 2008), the researcher used a formal framework to establish if the patient had capacity to consent. The patient was first approached by the researcher, who (upon the patient's agreement to speak to them) briefly verbally explained who she was what the research was about. Written information sheets, prepared to the requirements of the Research Ethics Committee proved too complicated for the patients to read and understand. Instead, to enhance decisional capacity, the researcher relayed research information verbally, and in an 'accessible' and concise manner. To ensure the process was free from coercion, a member of staff often oversaw the Capacity to Consent Assessment and the consent itself. Two individuals were deemed able to provide their consent, were given a hard copy of the Patient Information Sheet (see Appendix C) as well as verbal summary, and completed the Participant Consent Form (See Appendix D; large-print copy provided in 1 case). If the person was unable to provide informed consent, a personal or a nominated consultee was located to provide advice about their participation (see Section 5.9.2).

The researcher was responsible for routine assessment of the participants' mental capacity status in relation to their ability to consent to research. In addition to this, 'inclusionary' consent was sought (i.e., consent of those people who are unable to provide consent in traditional terms and where the personal or nominated consultee has already expressed a favourable opinion; Dewing, 2008). Ongoing inclusionary consent was ensured by observing visual and/or verbal cues indicating continued - or withdrawal of - consent (see Kelly, 2010). For example, if the individual seemed uncortable by being observed or moved away from the researcher for any reason, the observations would cease.

5.9.1.2. Staff

Ward staff were initially approached during hand-over meetings and informed about the research and given a chance to ask questions. Flyers about the research were also left on the ward (see Appendix E). Once the majority of the ward staff expressed their interest in taking part in the research, each staff member was given a letter containing a leaflet about the study, Staff Information Sheet and Consent Form (see Appendices E, F and D respectively). The letters were left in staff pigeonholes along with a labeled tray/drawer (depending on research site) for returned forms. Staff joining the team after the commencement of the study were also spoken to about the study and then given the aforementioned documents. To allow potential participants to ask questions about the research or any of the forms, the researcher was often present on the ward and came to handover meetings.

For staff interviews only a voice recorder was used to capture responses. Staff who agreed to be recorded during the interview had to sign a separate consent form (see Appendix G).

5.9.1.3. Relatives/Friends

All relatives invited to take part in the study were also invited to act as Personal Consultees for the patient whom they were related to / friends with. Due to rules around contact initiation with personal consultees, the first contact was made by the ward team (see section 5.9.2 and Appendix H for details). Only those relatives/friends who returned the Study Reply Slip (see Appendix I) and indicated that they wanted to take part in the research themselves (a total of 17 relatives on Site 1 and 6 on Site 2) were sent a letter with a leaflet about the study, Relatives' Information Sheet and Consent form (see Appendices J, K and D respectively) along with a stamped and addressed envelope to return the consent form. Researcher's contact details were provided, so that relatives could contact the researcher if they had any questions about the study or the forms.

A number of relatives who indicated an interest in the study and provided their contact details, have also informally expressed their opinions about mealtimes on the ward, but had not signed the consent forms. These relatives were still sent newsletters and invited to Relatives' Meetings (see Appendix L) throughout the course of the research. In order to be able to record their informal contributions, it was decided to ask for event-based consent (see Appendix M) where prior to the start of the meeting relatives consented to the researcher taking notes about their contributions.

Figure 25. *Decision-tree for researchers in assessing capacity to consent to participate in research. Reproduced from BPS (2008, p.15)*
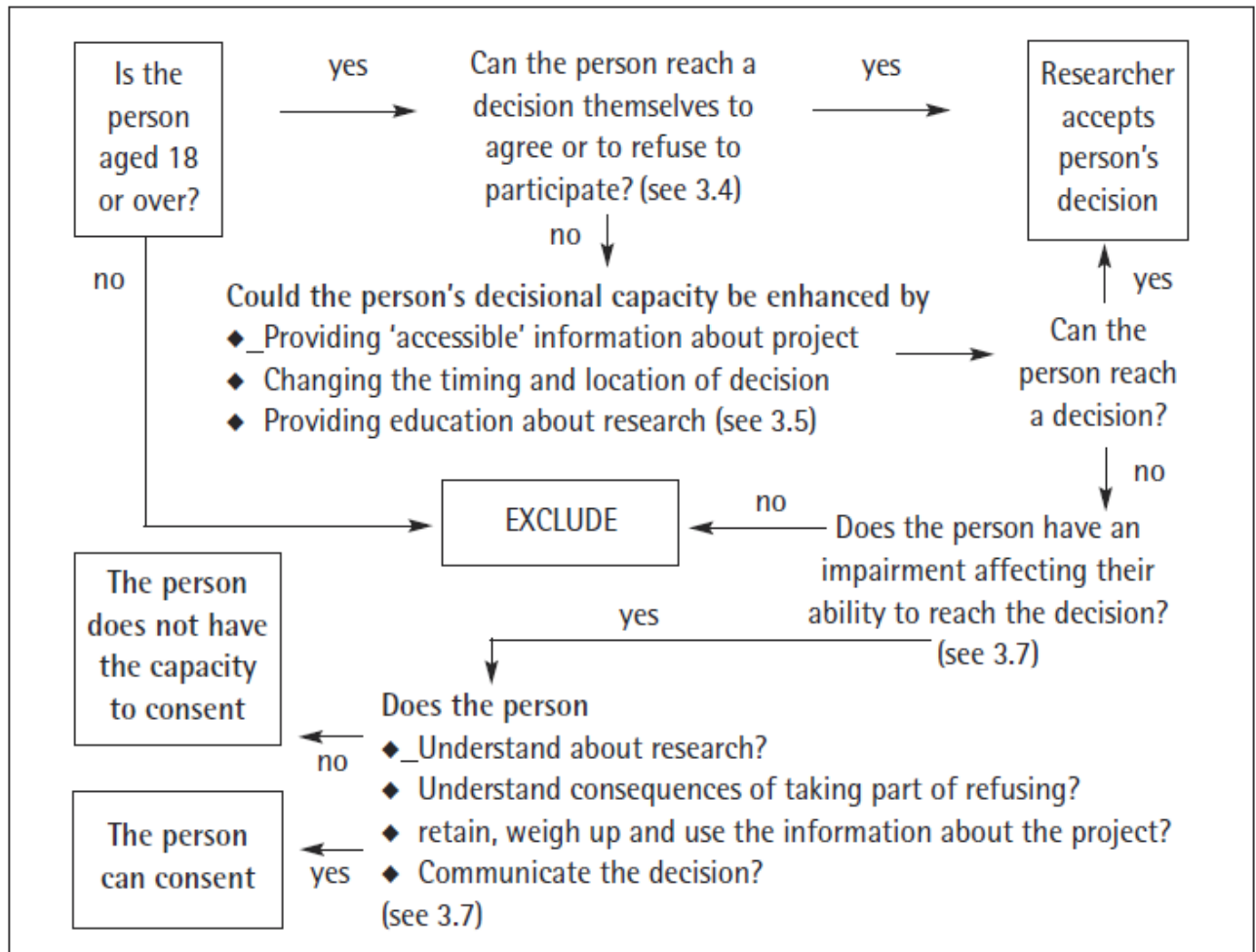
5.9.2. Consultee Advice

5.9.2.1. Personal Consultees

Based on the requirements of the Mental Capacity Act (2005), if a patient lacked capacity to consent to research, a Personal Consultee (someone the person knows and trusts with important decisions about their welfare, but who is not paid to provide care, e.g. family members and frieds; The British Psychological Society, 2008) was contacted by the ward team. The Mental Capacity Act (2005) outlines that the researcher cannot initaite first contact with the personal consultee. A letter was sent by the clinical team informing personal consultees about the research project taking place in the ward and inviting them to express their interest in the research. A leaflet about the research and two Reply Slips were sent to the personal consultees (one asking if they could be contacted regarding their own

participation - see Section 5.9.1.3 - and another asking if they were willing to provide an opinion about their relative's participation). 15 (50%) of identified Personal Consultees from Site 1 and 6 (66%) from Site 2 returned their reply slips indicating that they were willing and able to provide an opinion about their relative's participation.

Those who have indicated willingness to act as a Personal Consultee for their relative were then sent a Consultee Information Sheet and Consultee Form along with a cover letter (see Appendixes N and O) and a stamped and addressed envelope to return their consultee forms. 40% of Personal Consultees from Site 1 gave favourable opinion regarding their relative's participation, while the remaining 60% did not return the Consultee Form. The response rate was considerably higher on Site 2; 83% of Consultees gave favourable opinion regarding their relative's participation and 1 Consultee provided unfavourable opinion, with the overall return rate at 100%. Researcher's contact details were provided, so that relatives could contact the researcher if they had any questions about the study or the forms.

5.9.2.2. Nominated Consultees

Under the Mental Capacity Act, if a family member / close friend does not respond to an invitation from the clinical team to act as a personal consultee (i.e. provide advice about a family member with dementia who cannot legally consent), this role defaults to a 'nominated consultee'. A nominated consultee is usually a health or social care professional who knows the person in question to some degree.

In cases where a personal consultee could not be identified, did not reply to the invitation or if they specifically expressed their preference for the clinical team to make this decision, a nominated consultee was sought. If the potential personal consultee refused to act in this capacity without expressly 'handing over' the role to the clinical team, the patient could not take part in the study.

As the DoH (2013) guidelines stress that a nominated consultee should be someone who has "no connection with the project" (p. 8), it was decided to avoid the potential conflict of interest by not assigning the role to any of the ward staff (as they either took part in the project or, even if they did not, could potentially benefit from the positive outcomes of the study). On Site 1 the Consultant Psychiatrists who visited the ward regularly and knew the patients well was invited to act as nominated consultees and provided favourable advice

regarding the participation of 10 patients. The dedicated Consultant Psychiatrist visited Site 2 very infrequently, and was judged to not know the patients well enough to serve as a consultee. Instead, a ward nurse who did not wish to take part in the study volunteered to serve as the Nominated Consultee (thus avoiding the issue of conflict of interest) and provided favourable advuce regarding the participation of 3 patients. Appendixes N and O include the Consultee Information Sheet and Consultee Form.

5.9.3. Privacy, Confidentiality and Data Protection

A list of participant names and corresponding pseudonyms was securely stored on the ward, not taken outside of the ward at any time and securely destroyed following the completion of the study. The original list was only be required to match data from repeated measures (e.g. changes in weight) to the correct participant. Personal data (a list of participant names and corresponding pseudonyms) was stored on the ward in a locked cabinet accessible only to ward staff (the researcher had to get staffs' permission to access the list). The storage and secure destruction of the list was in compliance to the host NHS Trust's policies on confidentiality of personal data and safe disposal of confidential information. No personal identifiable data was ever be used outside of the ward.

As the researcher's presence on the ward was not part of their routine care, to ensure any risk to privacy is minimised, the researcher offered to conduct interviews and complete measures in the communal areas. However, if participants wished to be interviewed in private this will be respected. Mealtime observation only took place in communal areas and patients eating in their own rooms were excluded from any type of observations. Inclusionary consent was routinely sought from participants with dementia; if a participant exhibited any signs of distress, data collection ceased immediately.

5.10. Research Timeline

Figure 26. *Research Timeline*
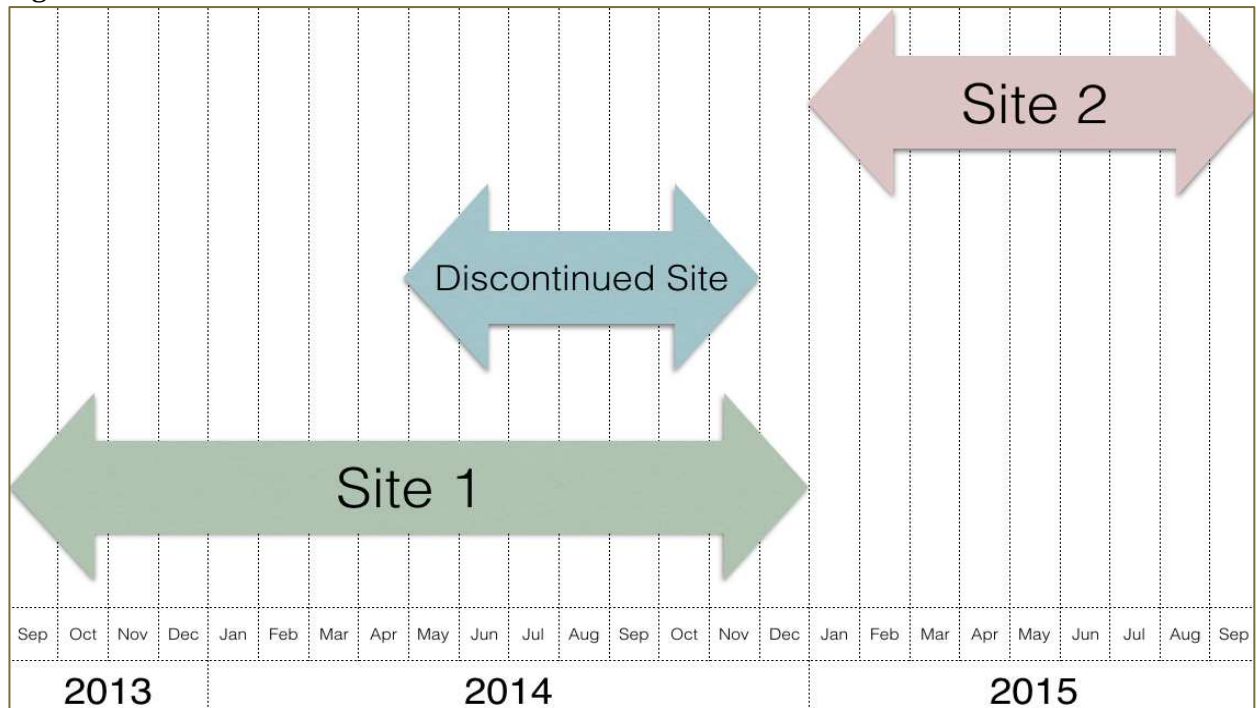
The research project was conducted between September 2013 and September 2015. Research on Site 1 lasted between September 2013 and January 2015, whereas research on Site 2 started in July 2014 and was completed in September 2015. Each phase on Site 1 suffered delays and was extended beyond the allocated 3-months (see Chapter 6 for more detail). Another site (i.e. Continuing Care ward) was approached between May and November 2014. Phase 1 of the research was completed, but the research was discontinued due to concerns regarding patient wellbeing (which were passed on to officials within the NHS trust running all 3 sites). A Care Quality Commission inspection in March 2015 "identified poor practice and unsafe care" (CQC, 2013), corroborating research findings (see Section 7.2 for more details).

5.11. Funding and Costs

This research project was sponsored by Kent Health; funding covered tuition fees and a maintenance grant for the PhD student / researcher. Project supervision was shared between the University of Kent and Kent and Medway NHS and Social Care Partnership Trust.

Chapter 6:
RESULTS

6.1 A Brief Overview of Structure and Content

Given the multi-method and multi-phase nature of the project (see Chapter 5) a large amount of data has been collected. Within the current chapter the findings are treated as 'pieces of the puzzle', allowing the researcher to gain a holistic understanding of mealtimes on the two research sites. However, it was felt unfeasible to present all the findings simultaneously and in a clear manner. Instead, the findings were conceptualised along research dimensions outlined in Figure 27, which informed the organisation of the Results chapter. Findings were first divided into qualitative and quantitative findings and looked at how mealtimes are *experienced*, while later considering action research and mealtime change*.*

Figure 27. *Intersecting Research Dimensions*
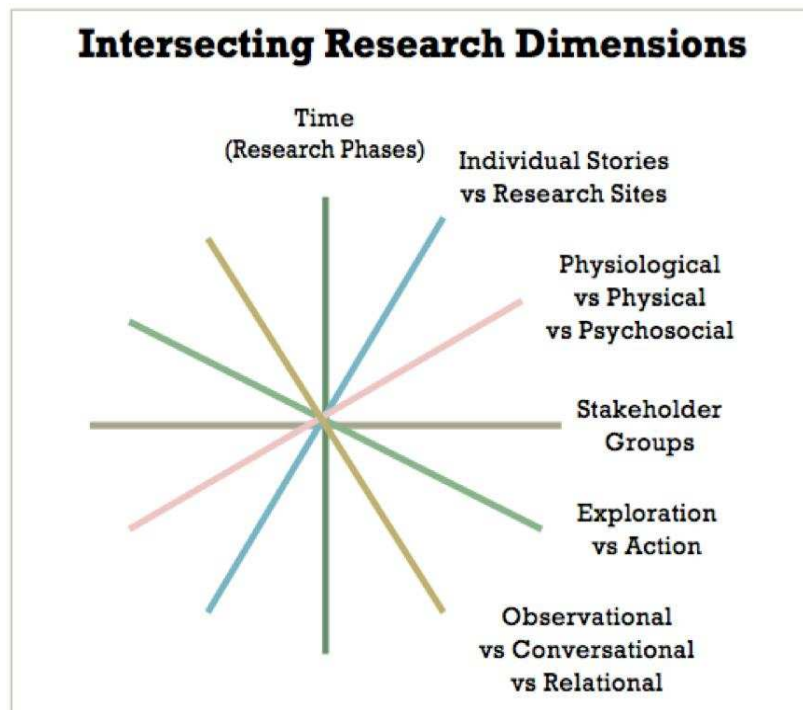
The chapter starts by Quantitative and Qualitative findings presented separately and further devided into distinct data collection methods. Where applicable, the findings within these sections are also separated per Research Site. The majority of the sub-sections are not separated by the stakeholder group that the findings relate to. However, interview analysis is presented for patients/residents, relatives and staff separately. Also, while the chapter is not organised by which mealtime dimension – physiological, physical or psychosocial - the findings relate to, their position within the conceptual mealtime framework (see Figure 28) is stressed when relevant.

Figure 28. The Organisation of Research Findings

Quantitative Findings	Qualitative Findings	Action Research: Evaluating Interventions
•**Staff-Initiated Assessments** •BMI •MNA-SF •EdFED •**Quantified Observations** •Eating and Eating Ability •Activity, Engagement & Mood	•**Focussed Ethnographies** •**Interviews and Informal Conversations** •People with Dementia •Relatives •Staff	•**Mealtime Changes** •**Group-Based Outcomes** •**Individual Outcomes** •**Catalysts and Barriers**

Sections 6.2 on quantitative findings and 6.3 on qualitative findings present research findings in a static way, with the overall focus on exploring how mealtimes are experienced on the wards. The sections also show the specific contributions of each method employed, as well as discussing the distinct contributions of qualitative and quantitative approaches in understanding mealtimes. In comparison to the exploratory approach of Sections 6.2 and 6.3, Section 6.4 addresses the Action Research aspect of the current study and describes as well as evaluates creation, implementation, retention and impact of mealtime interventions. The section on Action Research is further divided into Group-Based findings, that discuss mealtime change separately for each research site and separates the findings per method and Individual Findings, which present 6 patient vignettes. Individual stories are drawn out from the data as summarizing data per site tends to obscure individual nuance. The chapter also discusses catalysts and barriers to carrying out Action Research within NHS Continuing Care wards and facilitating mealtime change.

However, before intersecting the research findings by methodology, specific methods, exploratory or evaluative aims, stakeholder groups and research phases, a brief illustration of the research settings is presented, to provide a context to the research findings.

6.1.1 The Context

The Continuing Care wards within which the research took place operate like the smallest nesting doll in a set. They are embedded in the wider society, but are largely invisible and hard to access for those without legitimacy (someone who is neither a service provider nor

a relative/friend of people resisting on the ward, could not enter the wards without official permission). The wards are also part of an NHS Trust and the NHS as an overall service. Hierarchical and organisational factors within the NHS also define who is affiliated with the ward and thus who could enter it on frequent or occasional bases. While some permeability exists, it is unusual to see an unfamiliar place on the ward. In this way, the ward can be seen as a microcosm in its own right. As will be illustrated throughout the Results chapter, despite belonging to the same NHS Trust and broadly governed by similar policies, the two research sites are very different.

Nonetheless, an 'outsider' would find many similarities within these environments (i.e. the two wards), at least in contrast to the world outside of them. The doors are locked; accessible either with a key code or an entry card. This means that while staff can leave and enter the ward with ease, residents/patients cannot - it is not unusual to see a resident trying to open the door or banging on it to no avail. Outings are possible to many of the residents, but they are structured and supervised. No resident can exit the ward whenever they choose, unless accompanied by a member of staff or with a relative; not even those residents who are not experiencing dementia. Outside visitors, whether they are family members / friends or external staff (e.g. occupational therapists, chaplains, and consultant psychiatrists) have to formally sign in and would often have to ring the doorbell to be let into the ward.

Inside the wards, there is a division of private and communal spaces. While each patient has a private bedroom and shower room, sitting rooms and dining rooms are shared and accessible at all times. Along with private en-suites, there also are shared bathrooms and toilets and these are usually closer to communal areas. Other spaces, like gardens or kitchen areas are communal, but access is periodical. Residents are rarely permitted to enter these spaces if unaccompanied. There are also clinical rooms and stock rooms that are always locked and not accessible to the residents. The bedrooms have a single bed, a wardrobe, a desk and a chair; personalisation is only achieved via wall art and small personal belongings like soft toys, statuettes or toiletries. Communal spaces are open and large, with seating and dining furniture, as well as media devices. Most surfaces are clear of decorative objects, apart from pictures on the walls.

The ward follows routines, some of which are implemented more rigidly and follow stricter time frames (e.g. mealtimes) than others (e.g. getting up). Nonetheless, no one is left in bed throughout the day (apart from a minority of very frail individuals) and everyone is expected to get up at some point in the morning. Residents who do not require extensive physical

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assistance with mobility can leave their rooms and enter communal spaces whenever they wish to do so, while those in need of more assistance are often dependent on staff availability and are subjected to the ward routine in stricter ways (it is important to note, however, that Site 2 was more flexible regarding the ward routine). Nevertheless, there is a set notion of acceptable time to get up and get dressed or go to bed, clear meal*times*, scheduled baths and activity times. Staff breaks and handover periods are also clearly allocated. Relatives are encouraged to visit with certain timeframes, although the precise indications differed between the wards.

Of all structured ward activities, mealtimes are particularly regimented - the meals are delivered at a set time and both wards are allowed 45 minutes for lunch and dinner each. Breakfast and snack times are more flexible and more likely to be staggered than simultaneous (i.e. residents are likely to have breakfast at different times to one another, rather than as a shared event). Food is delivered to the residents already plated and in individual portions with limited possibilities for sharing. While some patients are encouraged to the table, this fluctuated over the research period (as well as being part of the interventions). The majority of patients, however, frequently receive their food in locations where they were prior to the meal. A small number of patients choose to receive their meals in their rooms and another minority of very frail individuals stay in bed at all times.

The unusual nature and operation of the research sites compared to communal living and mealtimes in the community should be held in mind throughout the Results Chapter to put research findings into context.

6.2 Quantitative Findings

Quantitative findings are divided into two subsections: Staff-Initiated Assessments and Structured Observations. Staff-Initiated Assessments are further divided into findings on Body Mass Index, the Edinburgh Feeding Evaluation in Dementia Scale and Mini-Nutritional Assessment, followed by reflections and limitations related to the staff-initiated measures. The subsection on Structured Observations is further divided into observations on Eating and Eating Ability as well as Activity, Engagement and Mood, also followed by reflections and limitations.

6.2.1 Staff-initiated assessments

As indicated in the Procedure section, staff-initiated assessments were originally intended to be performed twice: once during Phase 1 and again at Phase 3, so changes in nutritional status and eating ability after implementation of small-scale interventions could be measured. However, on both research sites the staff did not find Eating Ability and Nutritional Status assessments – or repeating them – beneficial. According to the staff, the assessments not only failed to provide new information or insigts, but were portentially misleading and required qualitative comments to clarify why, for example, a patient requiring a lot of support would appear as relatively independent on an assessment form. Due to this, only data for Phase 1 were collected. Also, on both research sites the collected data did not include all participating patient/residents. Despite the limitations of the nutrition and eating ability assessments in providing a comparison between the sites and/or research phases, the measures did provide valuable insights into the assessments themselves, which will be discussed later in the section. Patient Body Mass was the only staff-initiated assessment available for all research periods. However, on Site 1 the staff did not regularly weigh the patients, resulting in a large proportion of missing data.

6.2.1.1 Body Mass Index

Patient weight was measured by the ward staff and converted to Body Mass Index. Patient/resident BMI changes are displayed in Figures 29 and 30 for Sites 1 and 2 respectively. The charts track individual changes in weight on monthly basis and maps them against Older Adult cut-offs (Caroline Walker Trust, 2011) for undernourishment/malnutritition (BMI under 22), healthy weight (BMI between 22 and 30) and being overweight (BMI above 30). As can be seen from the un-shaded blank cells in Figure 29, Site 1 did not weigh patients routinely, and a comprehensive account of weight

change is not available. Also, as a result of missing weight data, results for Site 1 are displayed from January 2014 only (Phase 1 started in November 2013).

Due to taking part in the study for under a month each, Ivan and Angus were not included in the weight chart for Site 1. As can be seen from Site 1 chart, some patients' BMI was routinely measured before admission and the records were made available to the ward staff. Equally, not all participants took part in the entire research project due to death or relocation and one patient relocated and subsequently came back to the ward, rejoining the study (these periods are indicated by shading in Figure 29). Once pre-admission and exit periods are taken into account, however, a considerable amount of BMI data is still missing for Site 1 and some patients (e.g. Brad and Andrea, both of whom were visibly thin and likely underweight) have not been weighed throughout the entire study period. In comparison to Site 1, missing BMI data for Site 2 was infrequent. Due to small sample sizes and missing data, creating averages or comparing sites was not meaningful.

Despite missing data and small samples, the data for Site 1 has demonstrated that of those patients whose BMI was measured, 38% were underweight, 46% patients were of healthy weight (with 1 of the 6 becoming overweight as the study progressed), and 16% were overweight. Overall, 61% of the patients showed weight increase, while 39% lost weight as the study progressed. However for some the change pattern was not straightforward; for example, Flynn showed steady BMI increase initially, but lost weight in the last month before his death. Equally, Maureen's BMI grew steadily during Phases 1 and 2, but dropped and started increasing again in Phase 3. Three individuals experienced considerable BMI change (of 3 points or more); Angela's BMI increased from 22.5 to 29.0, Jeremy' BMI rose from 26.7 to 31.5, and Hazel's weight dropped from 28.6 to 22.7. The lowest recorded BMI was 15.4 (Maureen), while the highest was 38.9 (Jackie), showing a highly diverse range of weights on Site 1.

BMI measures on Site 2 demonstrated that 33% of patients were underweight (rising to 44% in Phase 3 as one more patient became underweight), 56% were of healthy weight and 11% were overweight. Overall, 66% of patients gained weight, 22% lost weight and 1 participant's weight dropped and then rose, eventually coming back to baseline levels. None of the patients experiences BMI gain or loss of 3 points or over. Compared to Site 1, Site 2 did not show as much variability in BMIs, with the lowest BMI at 18.9 (Jean) and the highest at 32.7 (Hugh).

Figure 29. *Weight Chart for Site 1*

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Brad												
Jack		30.0	30.0						32.8	32.9	32.3	
Flynn	17.5		18.5						21.5	19.1		
Jackie	36.3		36.6	36.5	36.5	36.5			38.0	37.8	38.9	
Angela	Away from Ward			22.5		23.2	23.3	26.0	29.1	27.3	29.0	
Jane		26.1		25.7					24.1	23.7		
Walt			23.7						24.3	23.9	24.5	
Andrea												
Marie		21.6							No Longer on the Ward			
Hazel			28.6						26.1	22.7		
Maureen	15.4	15.7	15.7	15.8	16.3	16.6		17.5	17.9	16.9	17.5	
James	Pre-Admission		26.7					31.3	31.2	31.4	31.5	
Eloise									17.8	20.1		
David									22.6			

Figure 30. *Weight Chart for Site 2*

SITE 2 - Resident BMI Changes

	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug
Joan	22.6	22.4	22.3	22.2	22.0	21.9	22.1	21.6	21.3
Sarah	28.3	28.5	29.1	29.2	29.5	29.6	29.6	29.7	29.8
Jean	19.1	18.9	19.1	19.3	19.6	20.1	20.7	20.3	20.4
Shanon	21.4	20.9	20.3	21.8	21.9	21.7	21.8	21.6	21.5
Jeremy	R	27.4	28.0	26.8	26.7	26.6	27.2	25.9	25.6
Norman	26.4	25.8	27.8	28.6	28.9	29.0	29.1	28.8	27.7
Rupert	19.6	19.3	20.2	20.6	20.8	20.9	21.3	21.4	21.6
Alistair	R	R	23.6	24.4	25.2	25.8	26.1	26.0	26.0
Hugh	pre-admission			31.5	32.0	32.0	32.6	32.2	32.7

Overall, BMI findings have demonstrated that weight loss can be avoided for most patients/residents, and weight gain is achievable for many.

6.2.1.2 MNA-SF

Data on Mini Nutritional Assessment (Short Form; see Appendix GG for the form) was only available for Phase 1 of the research and involved only 7 (44%) patients in Site 1 and 3 (33%) of participants on Site 2. Due to this, summarizing the findings for each site was not meaningful. Each individual was rated by more than one rater, resulting in 17 ratings on Site 1 (2-3 ratings per person) and 15 ratings (5 per person) on Site 2. The findings are displayed for each assessed individual (see Figure 31), by averaging the findings across all raters for each participant. All of the patients on Site 1 and 1 out of 3 patients on Site 2 were categorized as malnourished.

Figure 31. *Mini Nutritional Assessment Scores for both Sites*
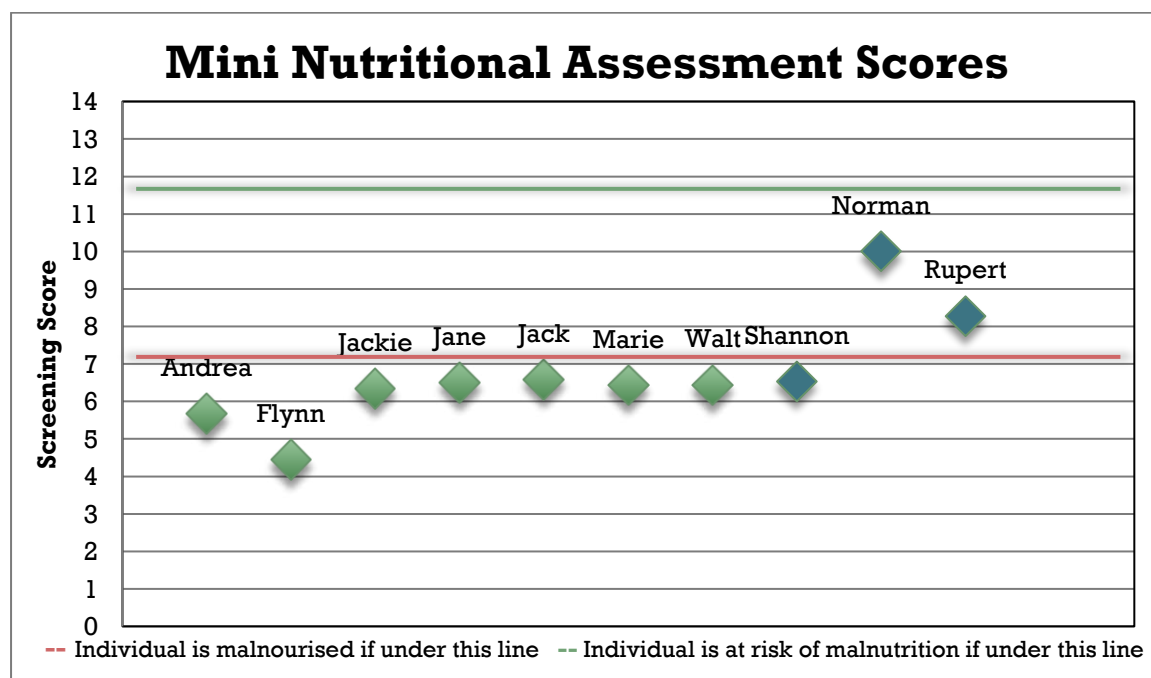
6.2.1.3 EdFED

As MNA-SF and EdFED (Edinburgh Feeding Evaluation in Dementia; see Appendix FF for the form) data were collected at the same time, the same issues with response rates and the number of participating patients applied. Data was only available for Phase 1 of the research and involved only 7 (44%) patients in Site 1 and 3 (33%) of participants on Site 2. Due to this, summarising the findings for each site was not meaningful. Each individual was rated by more than one rater, resulting in 16 ratings on Site 1 (2-3 ratings per person) and 15 ratings

(5 per person) on Site 2. Instead, the findings are displayed for each assessed individual (see Figure 32), by averaging the findings across all raters for each participant. All of the patients on Site 1 and 1 out of 3 patients on Site 2 were categorized as malnourished.

Figure 32. Difficulties in Independent Eating for both Sites
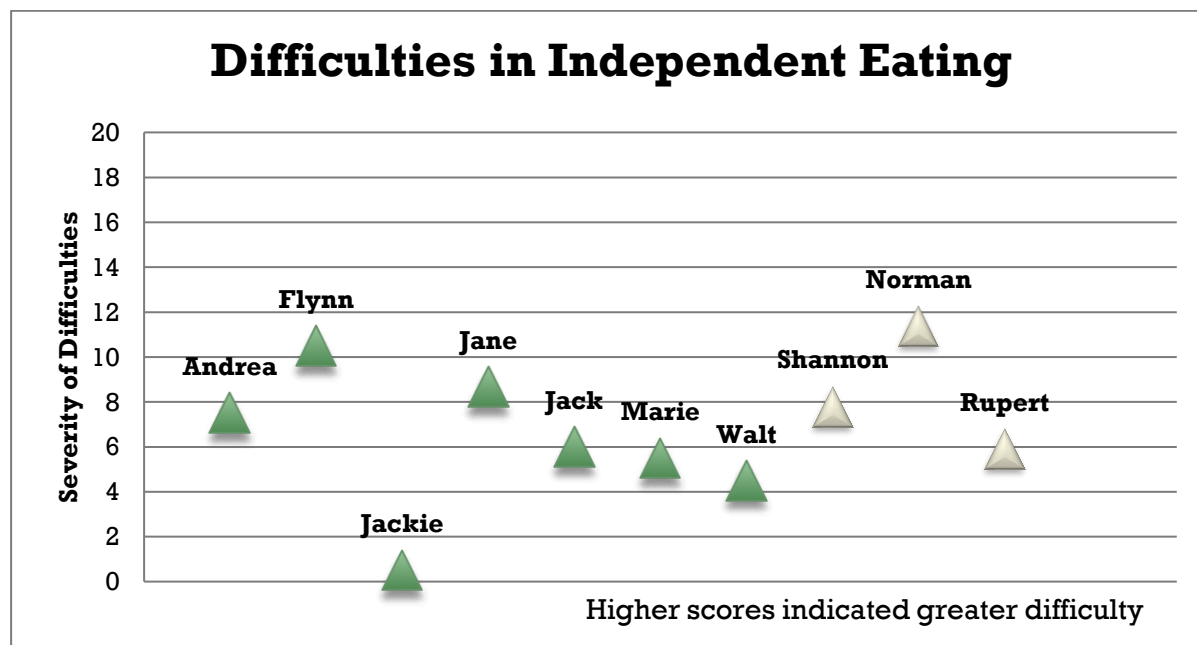
EdFED does not categorise eating difficulties, instead offering a score from least to most serious level of difficulty. According to staff most individuals experienced moderately serious eating difficulties (Jackie was an exception and did not experience mealtime difficulties). If nutritional status went hand in hand with eating difficulties (i.e. a higher level of eating difficulty resulting in a poorer nutritional status) the scores in Figures 31 and 32 would be mirror images of one another. This, however, does not appear to be the case, suggesting no straightforward link between eating ability and nutritional status. For example, Norman was rated as least at risk of malnutrition, yet experiencing the highest degree of eating difficulties (observational data shows this to be correct; while Norman could not eat independently and required feeding on all occasions, he ate well when assisted). Despite a high BMI, Jackie was rated as malnourished on MNS-SF, yet experiencing almost no eating difficulties. BMI also did not show a clear link to eating ability. Flynn was considerably underweight and – as could be expected – experienced a relatively high degree of eating difficulties. However, while Norman experienced an even higher degree of eating difficulties, his BMI was healthy.

The complexity of findings shows that body mass, nutritional status and eating ability are not closely related and tap into different mealtime aspects/outcomes. However, lack of a

discernible relationship between the variables also raises questions about the suitability of these measures.

6.2.1.4 Reflections and Limitations

As an additional measure, inter-rater reliability was assessed. However, there were too few cases to calculate the Intra-Class Correlation Coefficient, or produce Bland-Altman's plots on limits of agreement for either MNA-SF or EdFED ratings. Instead, illustrative scatterplots were produced to show rater scores on each measure for some of the participants.

As can be seen from Figure 33, there was little agreement between Rupert's five raters in terms of his MNA-SF scores. While they all agreed that Rupert was bed bound (rating C), a lot of disagreement was present for weight loss during the last 3 months (rating B); 1 rater said he experienced no weight loss, 1 said Rupert lost between 1 and 3 kilograms, and 3 said he experienced weight loss greater than 3 kilograms. Norman's ratings, however, were identical among the 5 raters (see Figure 34).

Overall, disagreement was common for individuals on both sites (see Figure 35), but for most of the patients overall ratings were similar (i.e. while the actual total scores differed, the degree of difference between them was usually within 2 points).

Figure 33. MNA-SF Rater Consensus for Rupert
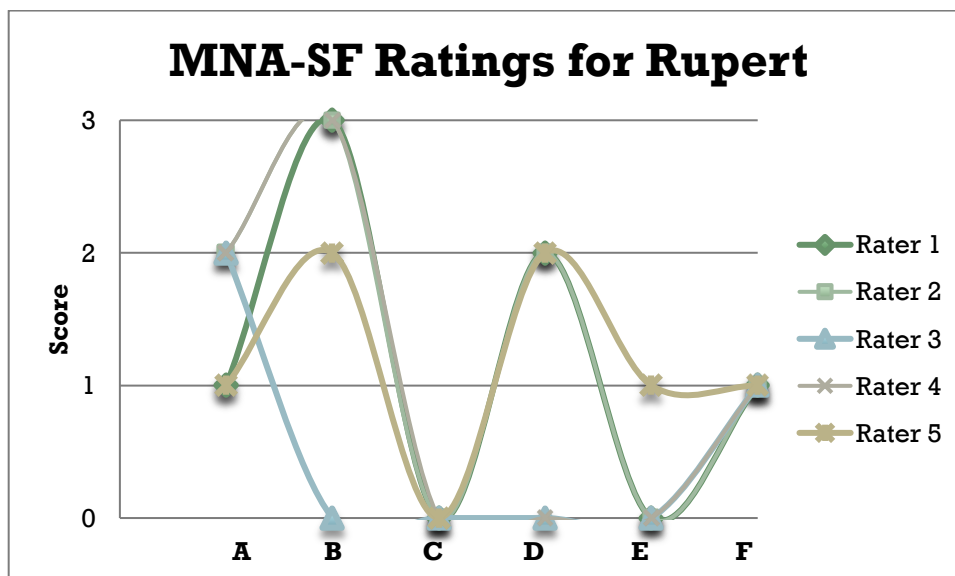
Rater agreement, however, depended on rated area. Most raters agreed closely on mobility status, but disagreed when rating recent changes in food intake and (particularly in Site 1 where patients were not routinely weighed) weight loss. This demonstrated that staff were better able to evaluate current status, than change over time.

The EdFED assessment revealed even less agreement between raters. For example, Flynn's two raters disagreed radically on most of the questions, by each choosing 'never' and 'often' for the same questions (see Figure 36). No EdFED ratings showed complete rater consensus as in the MNA-SF care for Norman (although Jackie's ratings were close), and the 40% of the rates had been assigned EdFED total scores that differed by more than 5 points (i.e. over a quarter of the available scale; see Figure 37).

Figure 34. MNA-SF Rater Consensus for Norman
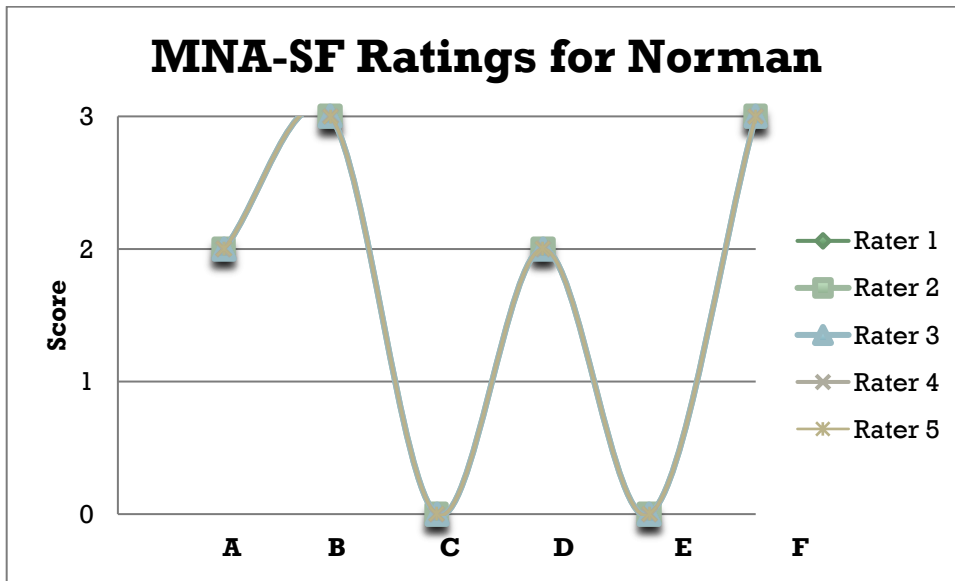
Figure 35. MNA-SF Rater Consensus for Overall Scores
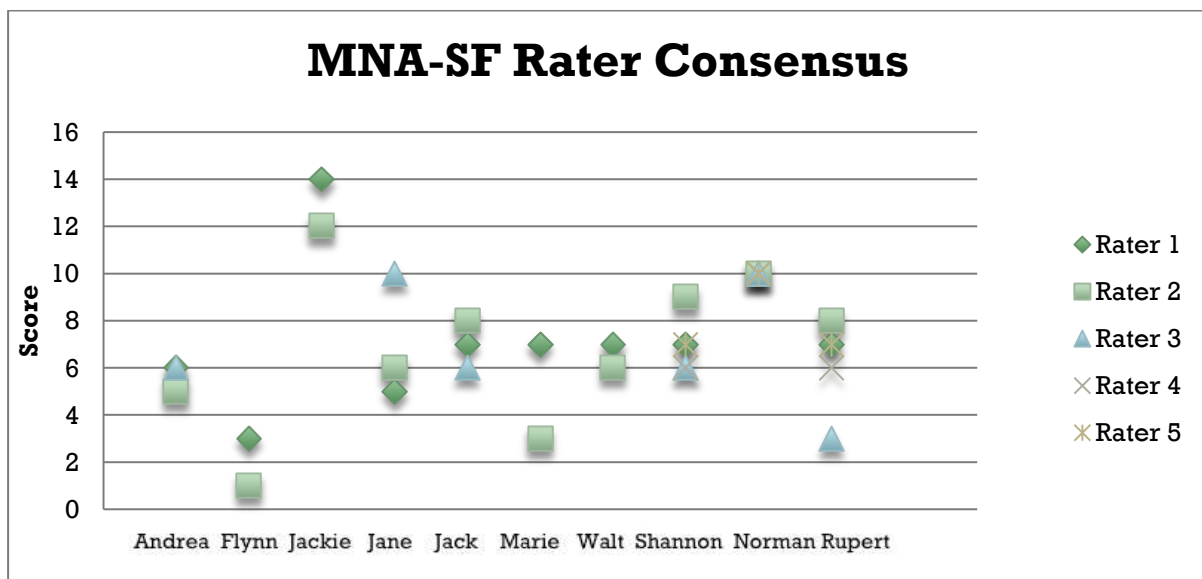
Figure 36. EdFED Rater Consensus for Flynn
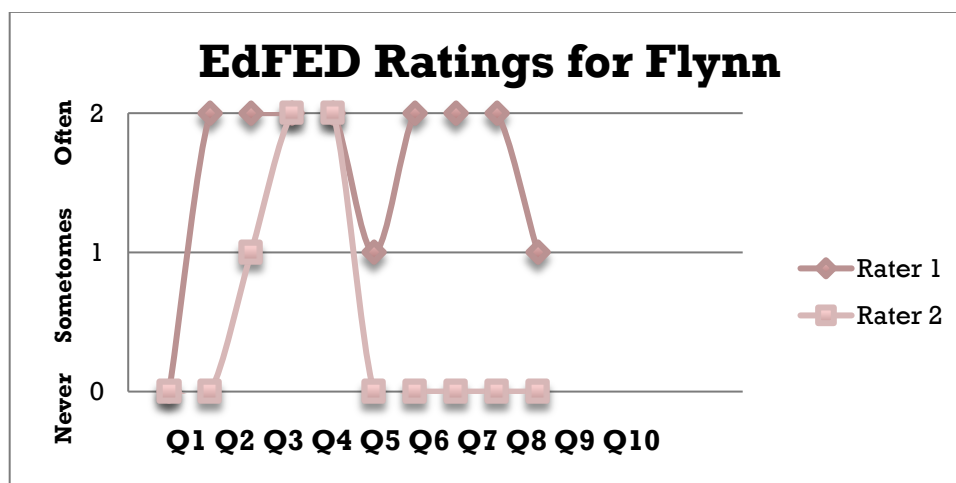
It is important to note that all raters were permanent staff on the ward (both nurses and HCAs) who have worked with the patients for a long period of time and were familiar with their patient notes (e.g. if the person was recently admitted to the ward). While it is, of course, possible, that raters lacked knowledge about the patients in relation to the specific questions of MNA-SF and EdFED forms, and while both the participant and ratings-per-participant numbers were low, poor inter-rater consensus gives cause to consider the suitability of these assessment in measuring mealtime outcomes.

Suitability of MNA-SF and EdFED assessments is particularly questionable due to a much higher consensus in qualitative information about the patients. On the form where the raters provided MNA-SF and EdFED scores, a space was left for 'any other comments'. While not all raters provided additional information, those who did demonstrated very high agreement. For example, while Rupert's MNA-SF scores particularly lacked consensus, comments about his mealtime experiences and needs among the 3 raters who did give additional comments were nearly identical. They all mentioned that Rupert has recently been prescribed pureed meals and since then ate much better, that he needed feeding at all times, and that he enjoyed food, often finishing the portions. The staff also mentioned that Rupert was fed lunch by his wife, who visited at least three times a week.

The questionable suitability of EdFED and MNA-SF assessments stemmed not only from low inter-rater agreement. The raters themselves reported not finding the forms useful, which significantly contributed to low rates of completing the assessments in Phase 1 and discontinuation in Phases 2 and 3.

Figure 37. EdFED Rater Consensus for Overall Scores
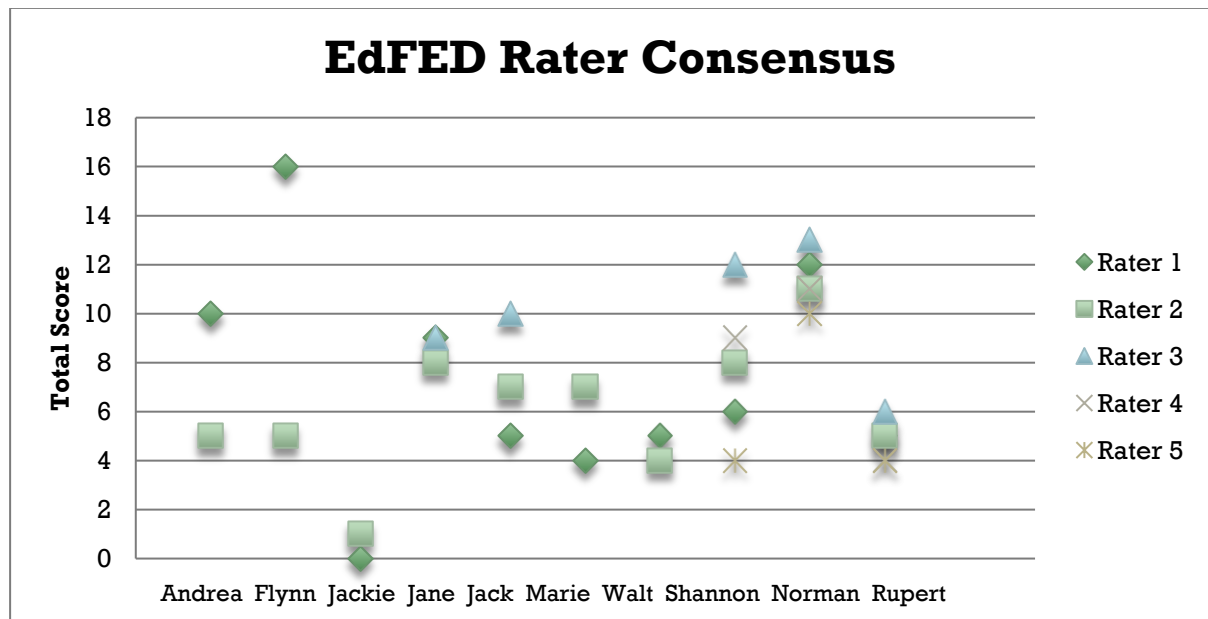
While the forms are of limited application in helping staff understand patients' eating ability and nutritional status, and track change over time, it is also unclear on how well these assessments capture mealtime outcomes. The lack of a clear relationship between body mass, eating ability and nutritional status suggests that these measures should not be used in isolation, while the usefulness of these assessments as an empirical measurement also remains unclear.

The above is particularly noteworthy, as a large number of studies use MNS-SF (Charlton et al, 2010; Persson et al, 2007, Vischer et al, 2010) or EdFED (e.g. Amella et al, 2008; Chang, 2012; Watson & Deary, 1997) as one of or the only assessments of mealtime outcomes.

It is also important to mention, that the suitability of Body Mass indicators within older adult populations has also been questioned, due to likelihood of underestimating the amount of body fat and muscle loss (Kwok et al, 2001) and not acknowledging that higher weight is beneficial for people in later life, serving a protective function in case of illness (Newman et al, 2001). Only benefits of higher weight are reflected in the older-adult cut-offs used to measure BMI within the current study (Caroline Walker Trust, 2011), while issues with fat and muscle levels remain.

6.2.2. Quantified Observations

As well as collecting quantitative data from staff-initiated assessments, the researcher also conducted lengthy structured observations during mealtimes, measuring patients eating ability and eating difficulties (along with staff assistance), as well as patient activity, engagement with others and mood during mealtimes. While eating ability measures tapped into physical and physiological aspects of mealtimes (e.g. the amount of food consumed and rates of independent eating), mood, engagement and activity measures largely tapped into the psycho-social aspects of mealtimes (e.g. how often patients communicated to one another and how their moods changed during mealtimes). The following sections are organised around these measures, each describing patterns of data collection and analysis, outlining the findings and providing some explanation for the results, as well as offering reflections and limitations. While findings are conventionally explained within the Discussion section, due to the size of the thesis it was deemed important to provide some context to the findings in the Results.

6.2.2.1 Eating Ability and Assistance

Patterns of Data Recording and Analysis

Structured mealtime observations included an adapted version of a composite of measure used by Edahiro, et al. (2012), which looks at amount of food eaten independently and with assistance, number of eating/feeding cycles, frequency of prompting, presence of dysphagia signs, difficulty in beginning a meal, difficulty in proper use of utensils, difficulty in scooping the proper amount of food, difficulty in recognising the total amount of food provided, difficulty in maintaining attention while eating, and difficulty in maintaining alertness while eating (see Appendix A for the data collection form).

A total of 179 observations were made, 120 in Site 1 and 59 in site 2 (Site 1 accommodated twice the number of patients, thus explaining the difference in number of observations per site). A total of 26 participants were observed, at different mealtimes throughout the day (see Table 3) and in different locations within the wards (see Table 4). The 'targets' of observations were chosen randomly, with intent to equalise the number of observations per participant; however, this was not always possible due to new participants joining the project at different phases and because patients ate in different rooms (including their own rooms

that could not be observed due to ethical concerns) that could not be observed simultaneously. Balancing the number of observations depending on time of day, room or any other factors was not practically feasible and would have resulted in considerable research delays. Also, processes within the ward meant that some times of the day or locations could not be observed as frequently; for example, Site 2 frequently offered patients breakfast in bed, while the foyer in Site 1 did not always have people eating in it.

Table 3. Number of observations at different mealtimes per Research Site

Site 1					Site 2		
Breakfast	Breakfast Club	Lunch	Teatime	Supper	Breakfast	Lunch	Teatime
23	16	50	26	5	3	31	25

Table 4. Number of observations at different mealtimes per Research Site

Site 1			Site 2		
Dining Room 1	Dining Room 2	Foyer	Dining Room	Lounge	Office
54	57	9	35	13	11

For the purposes of the analysis, new variables were computed. Rate of Independent Eating (RIE) was computed by dividing the number of Self-Feeding Cycles (e.g. a patient lifting a fork with food to their mouth and eating the food off the fork) by the total number of cycles that included Assistance cycles for all the courses within one mealtime. The Total Percentage of Food Eaten was also calculated by averaging the percentage of food eaten across each course within a mealtime. Information on whether patients were served finger food, ate with hands, did not use cutlery for non-finger-foods and if they were given extra food was also systematically recorded (although these were not part of Edaghiro and colleagues (2012) composite of measures) and were then translated into separate variables. Finally, a variable was created to demarcate the different phases of the research (pre-, during- and post-intervention).

Findings

Despite small sampling frames and an uneven number of observations, the results on all measured variables were compared across sites to find out if the research sites differed significantly from one another. Independent-samples t-tests were conducted to compare Physical Prompting, Verbal Prompting, Self-Feeding Cycles, Fed-by-Others Cycles, Rate of Independent Eating, Total Percentage of Food Eaten, Signs of Dysphagia (difficulty

swallowing), Difficulty Initiating Eating, Difficulty Using Utensils, Difficulty Scooping, Difficulty Recognising Total, Difficulty Maintaining Attention, and Difficulty Staying Alert in Site 1 and Site 2 (see *Table 5*).

Table 5. A T-Test for Research Sites

	Site 1		Site 2		Difference[a]			
Variable	*M*	*SD*	*M*	*SD*	*M*	*SE*	*t*	*p*
Physical Prompting	1.07	2.03	1.98	3.06	-.92	.39	-2.38	.02*
Verbal Prompting	1.98	2.93	1.90	2.63	.09	.45	.19	.85
Self-Feeding Cycles	35.29	20.19	16.05	19.90	19.24	3.20	6.02	.00*
Fed-by-Others Cycles	4.88	12.86	24.10	25.30	-19.22	2.86	-6.73	.00*
Rate of Independent Eating	.87	.31	.47	.44	.40	.06	7.05	.00*
Total Percentage of Food Eaten	91.02	39.06	74.15	30.57	16.87	5.83	2.90	.00*
Dysphagia	1.16	.45	1.09	.28	.07	.07	1.14	.26
Difficulty Initiating	1.19	.56	1.70	.92	-.51	.14	-3.78	.00*
Difficulty Using Utensils	1.48	.68	1.62	.81	-.14	.17	-.83	.41
Difficulty Scooping	1.64	.78	1,90	.72	-.26	.19	-1.35	.18
Difficulty Recognising Total	1.08	.39	1.07	.25	.02	.08	.24	.81
Difficulty Maintaining Attention	1.43	.69	1.88	.80	-.45	.12	-3.85	.00*
Difficulty Staying Alert	1.32	.68	1.58	.86	-.26	.12	-2.18	.03*

Note: [a]Difference scores were calculated by subtracting Site 2 scores from Site 1 for each variable; *p* < .05

There was a significant difference in the scores between Sites 1 and 2 in Physical Prompting (more prompting in Site 2), Self-Feeding Cycles (greater number in Site 1), Fed-by-Others Cycles (greater number in Site 2), Rate of Independent Eating (participants in Site 1 ate more independently), Total Percentage of Food Eaten (participants in Site 2 ate more), Difficulty Initiating, Difficulty Maintaining Attention and Difficulty Staying Alert (participants on Site 2

found it more difficult to initiate the meal, maintain attention and stay alert). No significant differences between sites were found in terms of Verbal Prompting, Dysphagia (difficulty swallowing), Difficulty Using Utensils, Difficulty Scooping, and Difficulty Recognising Total.

It was also investigated if the Time of Day (Breakfast, Lunch and Teatime) would have an effect on the outcome variables. A one-way between subjects ANOVA was conducted to compare the effect (See Table 6).

Table 6. A One-Way ANOVA of Time of Day (IV)

	Breakfast		Lunch		Teatime			
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*F*	*p*
Physical Prompting	1.04	2.25	1.54	2.66	1.16	2.11	.61	.55
Verbal Prompting	1.88	2.64	2.16	3.33	1.65	2.09	.51	.60
Self-Feeding Cycles	34.38	19.14	27.33	23.14	28.96	23.46	.95	.39
Fed-by-Others Cycles	8.04	22.07	15.03	20.17	10.10	21.49	1.50	.23
Rate of Independent Eating	91.25	28.14	72.02	44.74	77.78	42.04	1.88	.16
Total Percentage of Food Eaten	93.90	42.93	86.00	32.47	76.76	38.79	2.06	.13
Dysphagia	1.12	.33	1.15	.42	1.16	.47	.10	.91
Difficulty Initiating	1.09	.42	1.34	.68	1.37	.77	1.45	.24
Difficulty Using Utensils	1.35	.67	1.55	.69	1.53	.18	.63	.53
Difficulty Scooping	1.70	.87	1.76	.77	1.50	.61	.88	.42
Difficulty Recognising Total	1.00	.00	1.17	.54	1.05	.22	1.81	.17
Difficulty Maintaining Attention	1.28	.54	1.63	.74	1.76	.85	3.46	.03*
Difficulty Staying Alert	1.42	.76	1.53	.84	1.33	.65	.98	.38

*Note: *p < .05*

The time of meal only had a significant effect on Difficulty in Maintaining Attention at the p<.05 level for the three conditions [$F(2, 152) = 3.46$, $p = .03$]. Post hoc comparisons using the Bonferroni test indicated that the mean score for Breakfast (M = 1.28, SD = .54) was significantly different than Teatime (M = 1.76, SD = .85), suggesting that patients found it more difficult to maintain attention at mealtimes towards the end of the day. However, lunch (M = 1.63, SD = .74) did not significantly differ from breakfast or teatime meals in terms of Maintaining Attention.

As both Research Sites and the Time of Day had a significant effect on Maintaining Attention, a 2 (Location) x 3 (Time of Day) ANOVA was performed. The analysis yielded a significant main effect for location, F(1, 149) = 8.89, p < .05 and for Time of Day, F(2, 149) = .54, p < .05. However, the interaction effect was not significant, F(2, 149) = 1.43, p = .24.

Figure 38. Total Percentage of Food Eaten per Time of Day on Site 1
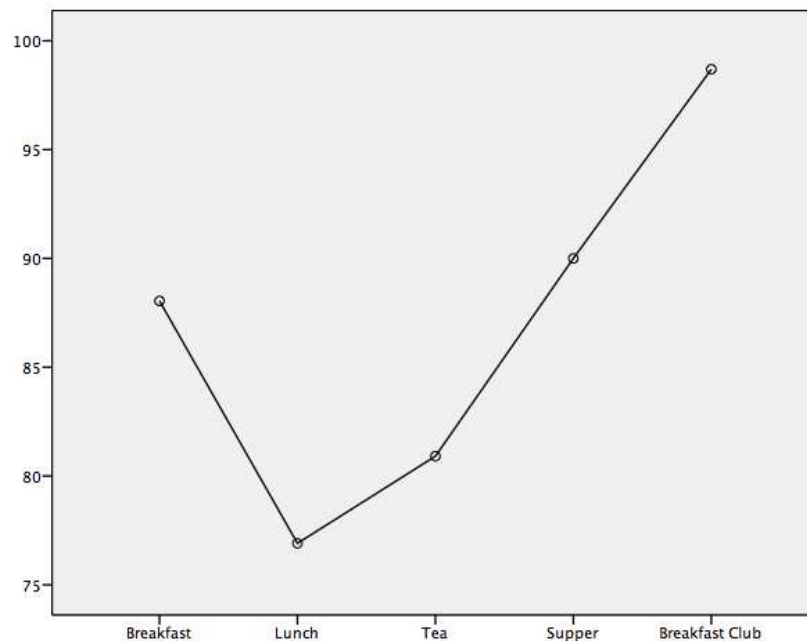
Although the Total Percentage of Food Eaten or the Rate of Independent Eating did not differ significantly depending on the time of day, the results for each site demonstrated interesting trends. As can be seen in Figure 38, on Site 1 patients ate nearly all food during Breakfast Club, while the rate dropped to the average 76% at lunch.

Conversely, Breakfast Club was the time when most assistance with eating was provided (see Figure 39).

The patterns of independent eating and proportion of food consumed on Site 2 were more straightforward. Patients ate nearly all food during breakfast, with the rate dropping steadily as the day progressed (see Figure 40).

Figure 39. Rate of Independent Eating per Time of Day on Site 1
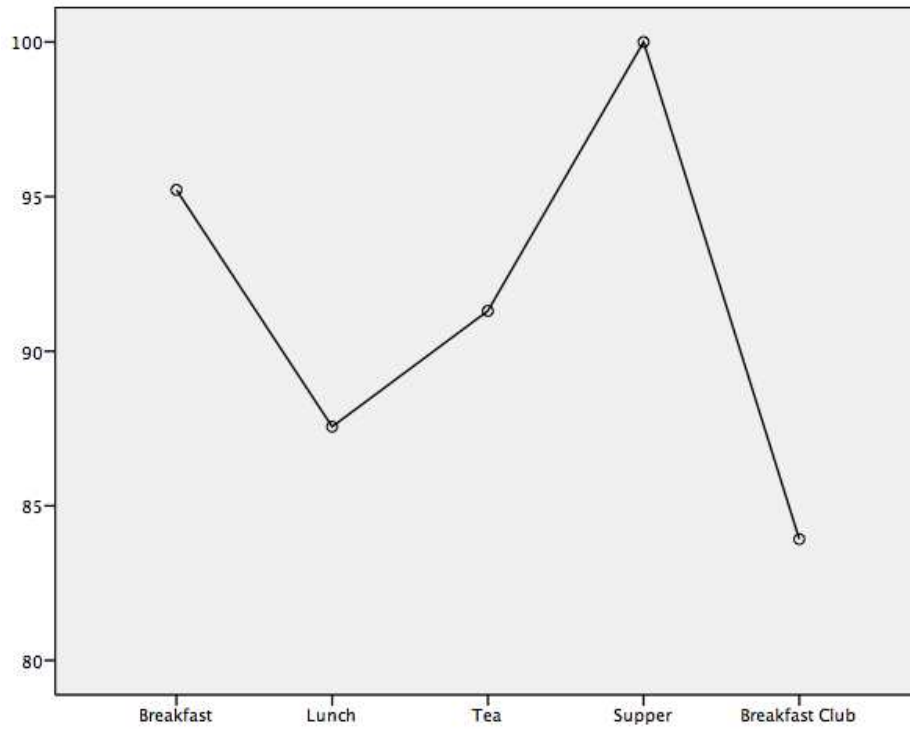
Figure 40. Total Percentage of Food Eaten per Time of Day on Site 2
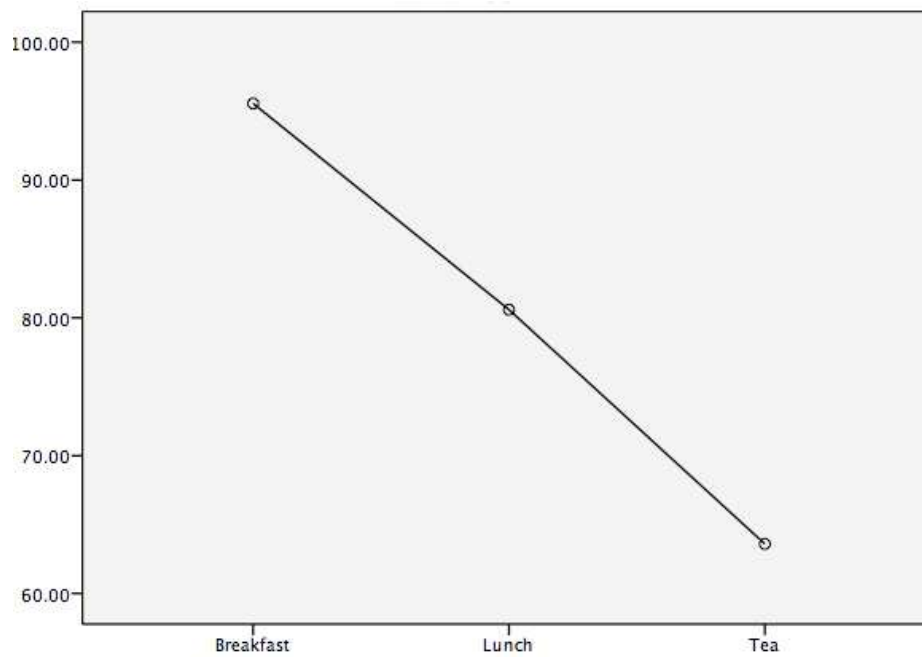
Figure 41. Rate of Independent Eating per Time of Day on Site 2
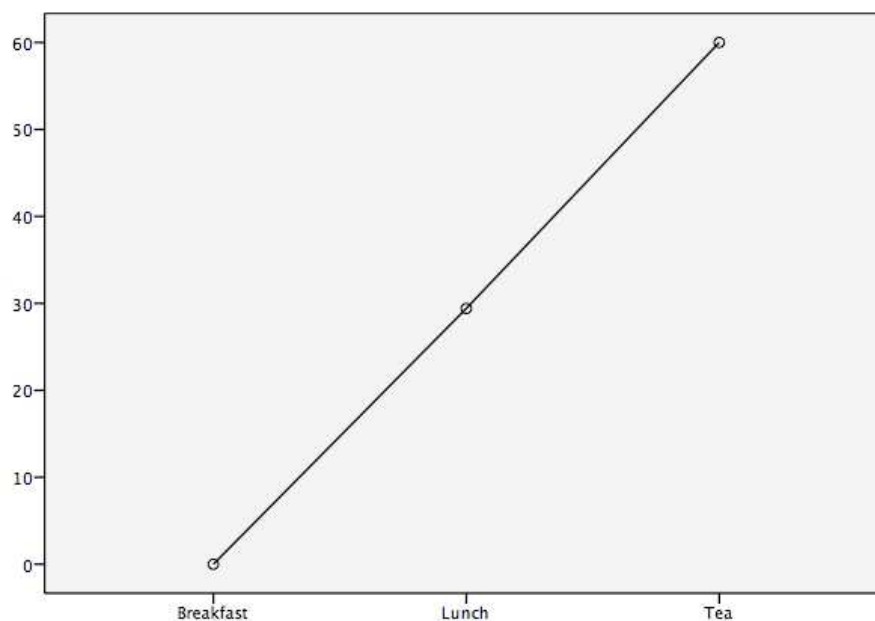
How much food was eaten on Site 2 at different times of day seemed to relate to independence in eating, as Rate of Independent Eating scores increased as the day progressed (see Figure 41).

Regression analyses were also run to investigate if any of the eating ability variables (i.e. Physical Prompting, Verbal Prompting, Rate of Independent Eating, Total Percentage of Food Eaten, Dysphagia, Difficulty Initiating, Difficulty Using Utensils, Difficulty Scooping, Difficulty Recognising Total, Difficulty Maintaining Attention, and Difficulty Staying Alert) together or independently of one another could predict Rate of Independent eating. The overall model was significant ($R^2 = .32$, $F(10, 89) = 4.11$, $p < .001$). Only Difficulty Recognising the Total Amount of Food ($\beta = -.13$, $t(99) = -3.82$, $p < .001$) and Difficulty Maintaining Attention ($\beta = -.06$, $t(99) = -2.94$, $p < .01$) could predict Rate of Independent Eating independently from other variables. The more the patient struggled to maintain attention at mealtimes or to recognise the total amount of food served to them, the less independence in eating was observed.

Another regression analysis was performed to find out if any of the aforementioned variables (including Independence in Eating) could predict the Total Percentage of Food Eaten. The overall model was significant ($R^2 = .29$, $F(10, 89) = 3.65$, $p < .001$), but only Difficulty Initiating the meal ($\beta = -16.44$, $t(99) = -2.06$, $p < .05$) and Difficulty Maintaining Attention ($\beta = -12.40$, $t(99) = -2.43$, $p < .05$) could predict Rate of Independent Eating independently from other predictors. The more the patient struggled to maintain attention at mealtimes or to initiate the meal within the first 5 minutes of being served, the less food they ate independently.

Given the intervention-based nature of the study, the observations were also divided into Phase 1 (pre-intervention), Phase 2 (during-intervention) and Phase 3 (post-intervention). However, to avoid duplication, the results are discussed in Section 6.4.2.

Reflections and Limitations

Due to the complex and potentially confusing nature of the findings, the context – and limitations of the data – require discussion. While it is entirely possible that any of the observed trends and patters are coincidental, due to small data samples, the changing make-up of the participant pool in Site 1 and variable numbers within each data cross-section (e.g. data divided per time of day or per setting), qualitative observations collected on both research sites may also provide valuable explanations.

Overall, the data supported that, despite identical purpose and function of the research sites, geographical closeness and being part of the same NHS Trust, the Research sites differed significantly in terms of patient eating ability and eating difficulties. This demonstrated that the overall profile of the patients (at least those participating in the study) differed across sites. However, it is impossible to say whether the amount of assistance given to individuals (i.e. feeding) and the rate of independent eating was significantly different between sites due to differences in patient needs, differences in the way staff provided assistance, or a combination of both.

A clearer explanation can be provided for a significant difference in ability to maintain attention at mealtimes as the day progresses. It goes in line with a substantial body of literature that shows attention – and other cognitive capabilities – tends to worsen for individuals who experience dementia as the day goes on (e.g. Khachiyants et al, 2011). This, however, clashed with data on eating assistance, which also seems to reduce (rather than increase) towards the end of the day. Qualitative observations have demonstrated that this occurred due to lower staffing levels at teatime and further related to lower proportions of food consumed. This suggested that, despite needing the most help at teatimes, the patients received the least assistance, likely impacting on how much food was consumed.

6.2.2.2 Activity, Engagement & Mood

Patterns of Data Recording and Analysis

Structured mealtime observations also included measuring patient activity, engagement and mood during mealtimes (see Appendix B for the data collection form), as observational methods are considered reliable and most appropriate in institutional dementia care (Brooker, 1995). Participants within a selected room (e.g. Dining Room 1 on Site 1) were observed in a consecutive fashion, for approximately 20-30 seconds each time, and notes were taken to reflect the aforementioned categories. The data was converted to rates of category incidence prior to analysis.

A total of 1533 observations were made, 815 in Site 1 and 718 in Site 2 (on average 55 observations were made per each mealtime). The participants were observed at different mealtimes throughout the day (see Table 7) and in different locations within the wards (see Table 8). The 'targets' of observations were chosen randomly, with intent to equalise the number of observations per participant; however, this was not always possible due to new participants joining the project at different phases and because patients ate in different rooms (including their own rooms that could not be observed due to ethical concerns) that could not be observed simultaneously. Balancing the number of observations depending on time of day, room or any other factors was not practically feasible and would have resulted in considerable research delays. However, it is important to note that absence of breakfast observations on Site 2 were a result of breakfast often being served in bed; the researcher did not have ethical permission to conduct observations in patients' own rooms.

Table 7. Number of observations at different mealtimes per Research Site

Site 1				Site 2		
Breakfast	Breakfast Club	Lunch	Teatime	Breakfast	Lunch	Teatime
131	106	326	252	0	392	326

Table 8. Number of observations at different mealtimes per Research Site

Site 1		Site 2		
Dining Room 1	Dining Room 2	Dining Room	Lounge	Office
361	457	511	100	107

Findings

Activity and Engagement data was recorded as categorical variables. The categories for Activity variable were: Eating, Being Fed, Eating & active with an inanimate object, Eating & walking, Not eating, engaged in a different activity, Not eating & walking, Alert, but disengaged (no visible activity) and Sleeping/Napping. In turn, the Engagement variable was categorized as: Interacting with another resident (self-initiating), Interacting with another resident (other-initiated), Interacting with staff (self-initiated), Interacting with staff (other-initiated), Interacting with a relative (self-initiated), Interacting with a relative (other-initiated), Verbalising, but not interacting, Intently observing other interact, Interacted with, but does not respond, Interacting/verbalising, but not responded to, Does not socialise (opportunity present) and No opportunity to socialize. Conversely, Mood was recorded as a continuous variable, ranging from -5 (Strongly negative mood) to +5 (Strongly positive mood). Subsequently, engagement patterns were analysed.

Due to substantial differences across research sites, it was deemed unsuitable to combine the results. The findings are therefore displayed separately for each site.

As can be seen from Figure 42, the most common mealtime activity was eating independently (42%). When combined with being fed, eating while walking and eating while engaging in another activity, consuming food took up only 50% of the of all activity observations. Not eating while being engaged in a different activity was observed on 23% of occasions and 8% of the time participants on Site 1 were sleeping during mealtimes.

Figure 42. Activity Breakdown for Site 1
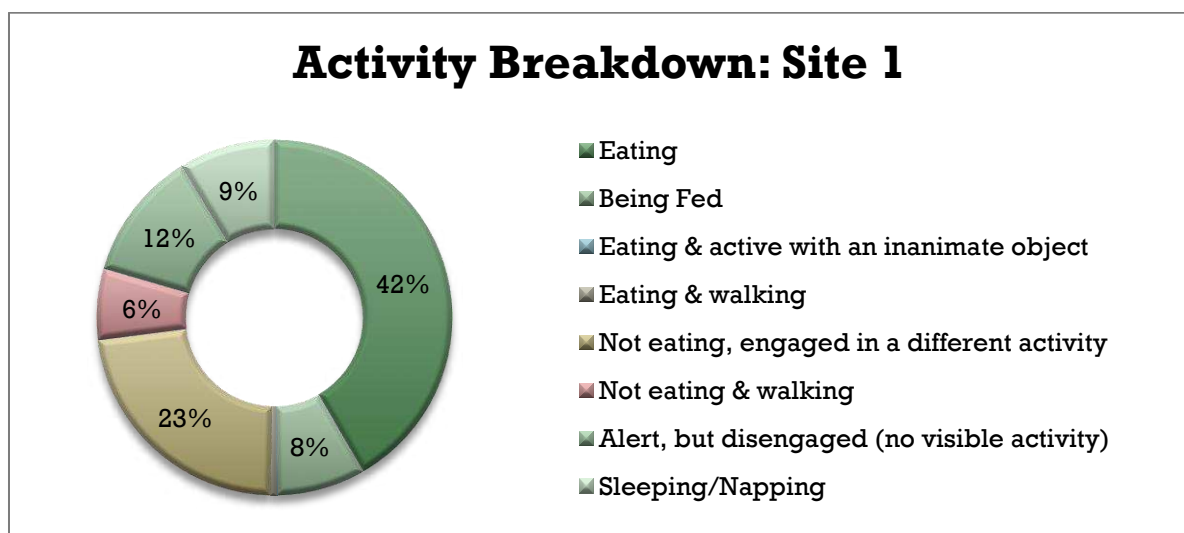
Figure 43. Activity Breakdown for Site 2
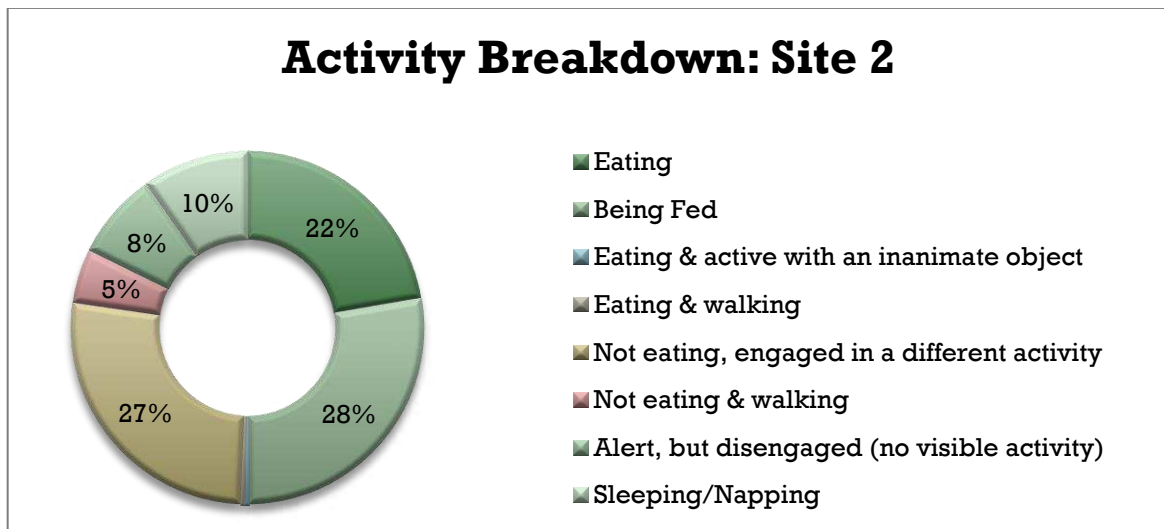
Eating activities were also observed 50% of the time on Site 2 (Figure 43), but, as can be seen from Table 9, residents on Site 1 ate independently twice as often as participants on Site 2, while being fed was more than 3 times more prevalent on Site 2. Activities not involving eating, however, demonstrated a very similar breakdown between the sites.

Table 9. Activity Breakdown compared for Sites 1 and 2

	Site 1	Site 2
Eating	41.6%	22.3%
Being Fed	8.1%	27.6%
Eating & active with an inanimate object	0.1%	0.4%
Eating & walking	0.5%	0.4%
Not eating, engaged in a different activity	22.6%	26.6%
Not eating & walking	6.5%	5.0%
Alert, but disengaged (no visible activity)	11.8%	7.9%
Sleeping/Napping	8.7%	9.7%

Eating breakdown for both sites (Figures 42 and 43) was in line with ethnographic findings in demonstrating that not socializing was more common than engaging socially at mealtimes (53% and 54% for Sites 1 and 2 respectively). Crucially, around half of each of these figures involved having no opportunity to socialize (i.e. no one close enough to interact with), while the remaining half reflected no interactions when other people were nearby. Overall, interacting with staff was more common than interacting with other residents/patients, while the majority of resident-staff interactions were initiated by the member of staff. Along with high incidence on not interacting when opportunities are present, the findings suggest

that PWD may not always be able to initiate interactions themselves, thus emphasizing the importance of staff approaches.

A comparison of Engagement breakdown between sites (See Table 9), however, has demonstrated some notable differences. For example, as Site 1 excluded relatives from mealtimes no interactions with relatives were recorded. Conversely, although relatives were not present at all mealtimes for Site 2 and only 3 of the participants had frequent mealtime visits from their relatives, interactions with relatives accounted for over 5% of engagement data. Also, interactions with staff were proportionately lower on Site 1.

Figure 44. Engagement Breakdown for Site 1
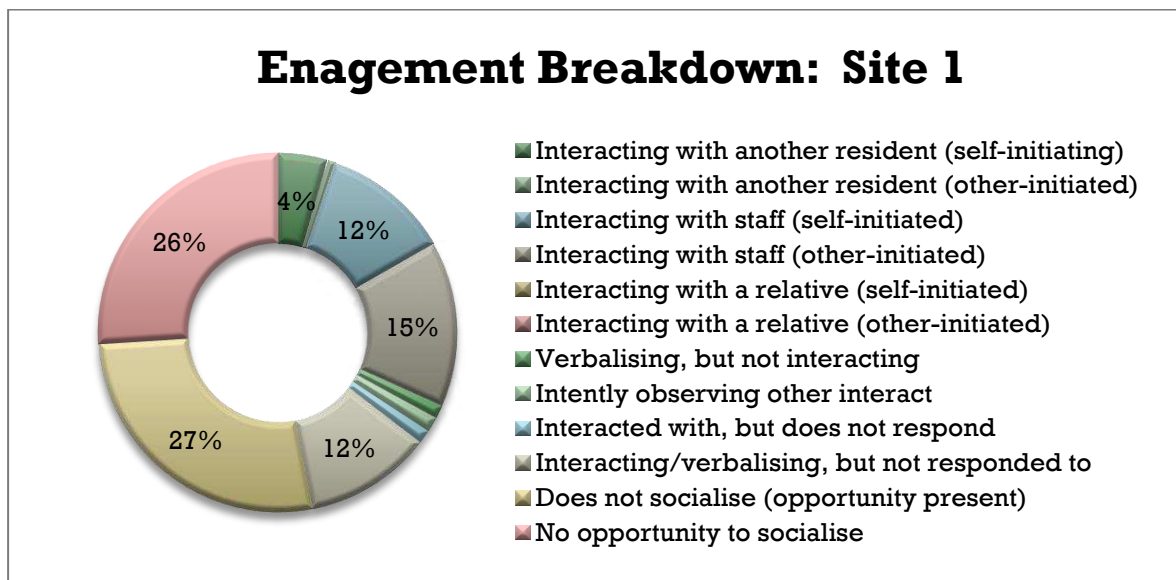
Figure 45. Engagement Breakdown for Site 2
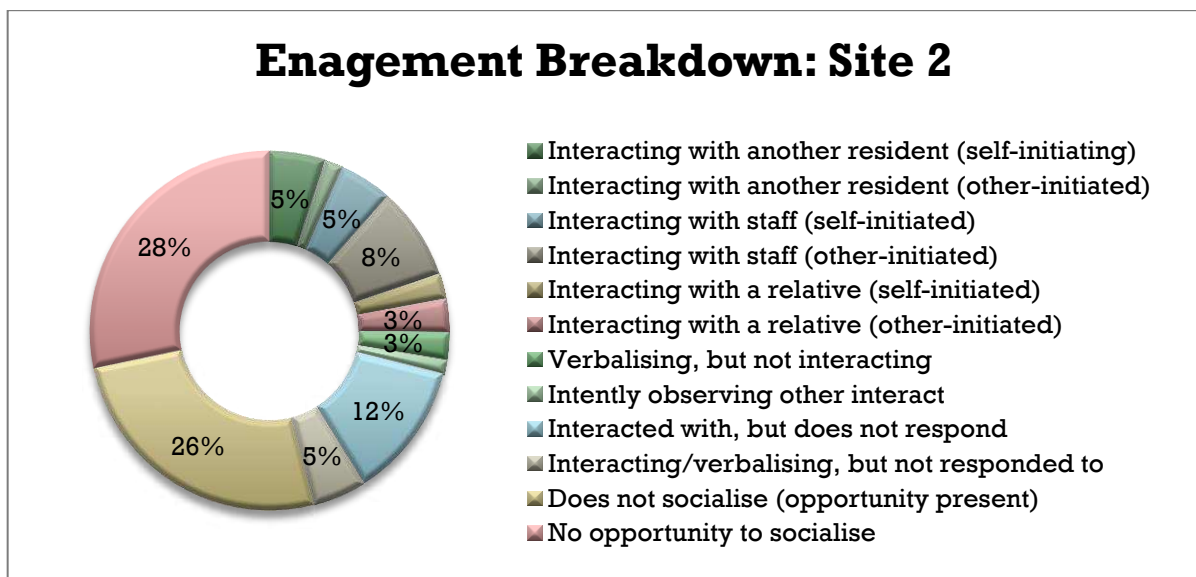
Aside from not interacting or a two-way interactions with others, a proportion of interactions from the patients remained unanswered; more than double the incidence on Site 1. Conversely, being interacted with but not responding was over 10 times more common on Site 2, suggesting lower capacity to interact among patients on Site 2.

Mood breakdown has further demonstrated that residents overwhelmingly experienced neutral mood during mealtimes; more than ¾ of the time on each site. Highly positive or negative moods were uncommon, nearly ¾ of non-neutral moods on both Sites were only slightly positive or negative.

Table 10. Engagement Breakdown compared for Sites 1 and 2

	Site 1	Site 2
Interacting with another resident (self-initiating)	4.4%	5.0%
Interacting with another resident (other-initiated)	0.7%	1.7%
Interacting with staff (self-initiated)	11.6%	4.8%
Interacting with staff (other-initiated)	15.0%	8.3%
Interacting with a relative (self-initiated)	0.0%	2.3%
Interacting with a relative (other-initiated)	0.0%	3.0%
Verbalising, but not interacting	1.2%	2.4%
Intently observing other interact	1.3%	1.4%
Interacted with, but does not respond	1.2%	12.3%
Interacting/verbalising, but not responded to	11.5%	4.8%
Does not socialise (opportunity present)	27.1%	25.7%
No opportunity to socialise	26.0%	28.3%

Overall, the Activity, Engagement and Mood measure has demonstrated that participants ate only around half of the observed times, did not interact with anyone on the majority of occasions and experienced predominantly neutral mood. This was corroborated by qualitative observations.

Figure 46. Mood Breakdown for Site 1

Mood Breakdown: Site 1

2% — Strongly negative mood
2% — Moderately negative mood
7% — Slightly negative mood
— Neutral Mood
9% — Slightly positive mood
1% — Moderately positive mood
1% — Strongly positive mood

78%   22%
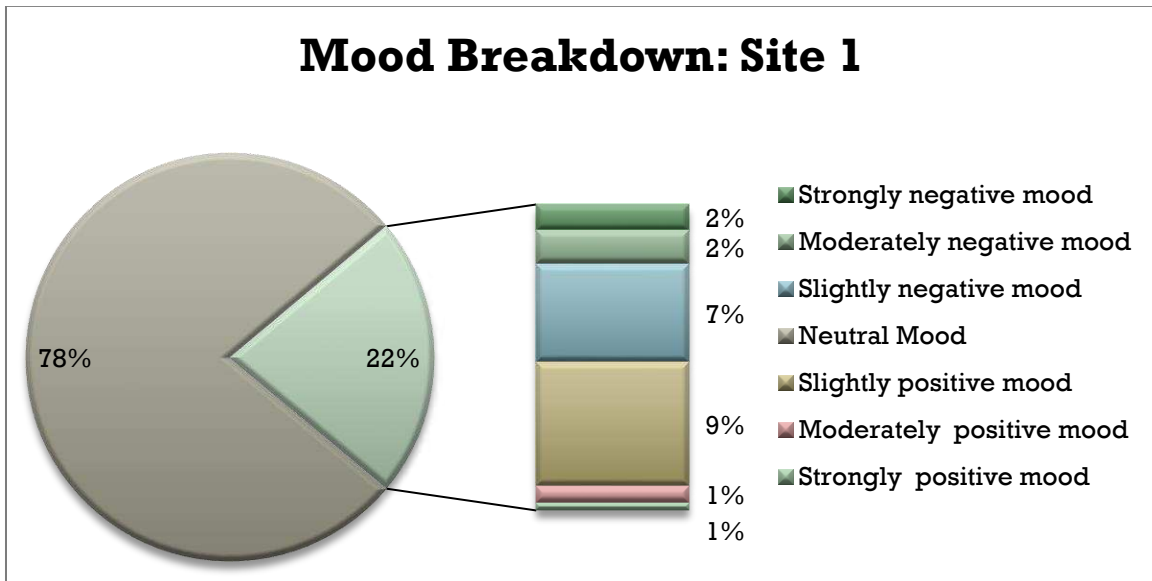
Figure 47. Mood Breakdown for Site 2

Mood Breakdown: Site 2

3% — Strongly negative mood
2% — Moderately negative mood
9% — Slightly negative mood
— Neutral Mood
8% — Slightly positive mood
2% — Moderately positive mood
0% — Strongly positive mood

76%   24%
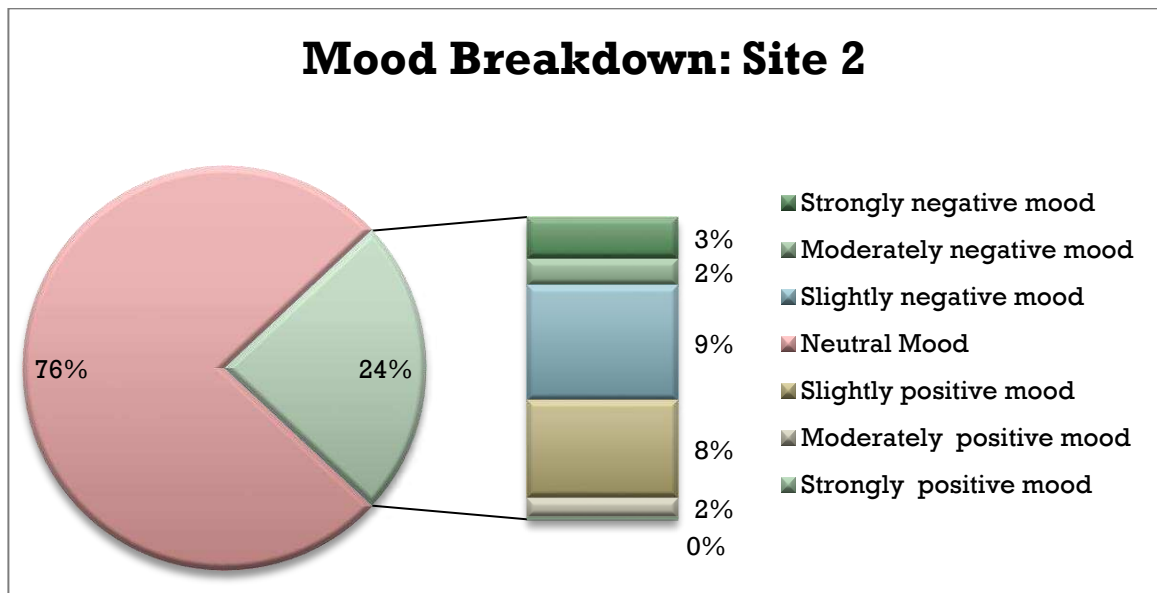
Reflections and Limitations

While there were discernable differences in terms of patient activity, engagement and mood, it is unclear whether these differences reveal true distinctions between the wards, or are coincidental due to a non-matched nature of who was observed, at what time of the day and

in which location. Also, while qualitative data appears to support the notion that many of the differences stemmed from either different running of the mealtimes (e.g. involvement of relatives), or different staff approaches (e.g. a higher proportion of patients not responded to on Site 1), these differences may have also resulted from different capabilities of the patients themselves (e.g. a much higher incidence of patients not responding when interacted with on Site 2). The different levels of ability were further corroborated by more feeding observed on Site 2. Lack of ability/willingness to interact with others, however, was highly similar between sites, suggesting either that capabilities for independent eating and interacting with others did not go hand-in-hand, or that the presumption of more dependence on Site 2 is incorrect.

6.3 Qualitative Findings

Qualitative findings on mealtimes in NHS Continuing Care were collected via use of Focussed Ethnographic observations within the research settings and Semi-Structured interviews with relatives and staff, as well as informal conversations with patients/residents. The current section is organised according to each method, with the interview findings further split by stakeholder group. As well as discussing findings *per se,* each section also provides information on patterns of data recording and data analysis, as well as reflections and limitations on the findings.

6.3.1 Focussed Ethnographies

Patterns of Data Recording and Analysis

Ethnographic data was collected and analysed following the guidance of Cruz and Higginbottom (2013), and Higginbottom, Pillay and Boadu (2013), which suggests a clear focus of research topic and a discrete community/population. The focus of the ethnography was to understand what factors affected the experience of mealtimes on the ward. However, in contrast to the suggestions made by the above authors, data collection within this project was not only time-intensive, but also time-extensive and included long-term field visits. The visits have produced over 3,000 fieldwork hours, which included observations during weekends, late evenings and overnight, to ensure that collected data reflected all aspects of life on the wards. Of those hours, approximately 700 were spent directly observing mealtimes, such as breakfast, lunch and supper. The remaining time included observations of eating outside the instituted mealtimes, such as snacking or holding parties, along with more general observations of ward life and conversations with patients/residents, staff and relatives. At times, other types of data (e.g. eating ability) were collected simultaneously, but it was ensured that at least a third of direct mealtime observations would be purely ethnographic in nature.

The initial set-up of the research methodology indicated that the research should assume the role of Observer-as-Participant (i.e. including more observation than participation, seePearsall, 1970; especially during mealtimes). However, in an environment characterised by spontaneous movement and interactions between participants an Observer-as-Participant approach was impossible to achieve and proved to be ethically problematic. As the researcher was physically present in the observed environment, she would frequently be

spoken to by the patients/residents. Refusal to maintain an ordinary interaction could have been confusing or distressing to the patients and therefore unsuitable and unethical. Moreover, there were numerous instances when the researcher actively assisted during mealtimes, helping with serving of meals, encouragement/prompting of some patients or feeding of others. This was deemed appropriate for two reasons. Firstly, at times of staffing shortage or any unexpected disruptions on the ward mealtime assistance was paramount to ensure that patient's nutritional needs were met as well as possible under the circumstances. As stated by Higginbottom and colleagues (2013, p. 7), when carrying out a focussed ethnography "within [a healthcare] context there becomes a heightened need for ensuring maintenance of respect for human dignity [...] and for demonstrating genuine concern for [patients'] welfare and justice". Secondly, participating in mealtimes proved important for facilitating action. It was particularly needed to demonstrate to the ward staff that a researcher understands the complexity of mealtimes in dementia care, and the reasons why a person with dementia may not be eating; this legitimised both the sharing of knowledge from the observations and making action-related suggestions. In some cases indirect modeling (i.e. the research trying a new approach first to demonstrate its suitability) was also employed. Due to this, the stance of the research in both field sites became Participant-as-Observer, involving active participation and active membership (Baker, 2006).

The data was collected by taking notes shortly after the mealtime observations as well as at the end of each fieldwork day. Semi-structured interviews were considered as a distinct method and therefore analysed separately (see Section 6.3.2), but casual conversations on the ward were treated as part of the ethnographic data and included in note-taking. As shown by Coffey and Atkinson (1996), data analysis should not be a distinct or final stage of an ethnography. This was particularly important in the current project, as simultaneous analysis was necessary to provide research feedback to the stakeholders (patients, staff and relatives) and generate action. It also helped to target observational focus. For example, following analysing the first 4 weeks of ethnographic data on Site 1, the topic of identities and how these are negotiated in mealtime interactions became a sub-focus. The data was also revisited once the data collection was finalised on both research sites.

Ethnographic data was analysed thematically. According to Ryan and Bernard (2003, p.83) "themes are abstract (and often fuzzy) constructs that investigators identify before, during and after data collection". The researcher therefore engaged in systematic classification of ethnographic data, which led to the emergence of abstract generalisations of processes and

patterns related to mealtimes (Higginbottom et al, 2013). The process was both iterative and self-reflective (Pope et al, 2000), however, at the same time a clear focus was maintained. Emerging themes had to contribute to the research question and thus reflect factors or processes that impact on how mealtimes (and mealtime change) are experienced on the ward. Therefore, while the analysis process was largely iterative (driven by the data itself), features of theoretical analysis (driven by the specific, theoretically-informed study interest) were also present (Ball, 2006).

Due to the action-based nature of the study (see Section 6.4), the ethnographic data reflected both the experiences of mealtimes on the ward and the experiences of mealtime change. While Section 6.4 evaluates the success of mealtimes changes on the wards and contrasts pre-, during and post-intervention stages, it was decided to analyse and present ethnographic findings as a whole (without making phase-based distinctions). The goal of ethnographic research was to gain a holistic understanding of mealtimes on Continuing Care wards for people with dementia, providing observational data that other methods may not pick up. Mealtime change was therefore seen as an effective research process as it challenged the status quo (Ejimabo, 2015) and allowed the researcher to investigate mealtimes in a more in-depth way.

Thematic Analysis

The analysis has revealed 5 themes that explained the way mealtimes were expressed and experienced. All themes were relevant to both research sites, although this was not a criterion for abstract generalisations to become a theme. Also, despite application to both sites, the themes were at times expressed in different ways within each site. While a direct comparison of sites can be found in Section 6.4, incidental references to differences between sites will be made when relevant.

It is also important to note that while data analysis resulted in distinct themes, there is both overlap and processual interaction between the themes.

Theme 1. *Knowing Your Place*: Hierarchical and Authority Structures on the Ward

The strength of institutional hierarchies and the way in which these were enacted had a profound influence on the status and progression of mealtimes. While both sites had a similar structure and differentiation of roles (apart from absence of Therapy Technicians on Site 2),

the salience of these roles diverged. For example, the tasks of Nurses versus Health Care Assistants (HCAs) were more distinct on Site 1. It was unusual for nurses to assume an active mealtime role, apart from times of low staffing, as mealtimes were (rightly) perceived as non-clinical activities. However, this also meant that mealtimes were assigned less importance than other ward-based events. Therapy Technicians were also absent during ordinary mealtimes; their breaks were scheduled during lunchtime and shifts ended before teatime. Therefore, mealtimes were also excluded from therapeutic activities.

A notable exception to this was a weekly-held Breakfast Club where Therapy Technicians would prepare a full English breakfast, lay and decorate the tables, and encourage communal eating. Structured observations on eating ability and eating assistance have demonstrated that these were the most positive mealtimes on Site 1 (see Section 6.2.2.1). However, precisely because of the differentiating hierarchies, HCAs were not substantially involved in Breakfast Club and therefore did not apply similar principles to everyday practice; there were no naturally-occurring opportunities to transfer best practice between 'routine' and 'therapeutic' mealtimes. Therefore, the therapeutic nature and aspects of mealtimes themselves were not appreciated or encouraged on a daily basis. Celebratory mealtimes, where enjoyment of food and the event itself were a priority (over sustenance), were therefore seen as an 'extra' activity (also first to be 'cut' due to staff shortages).

An added aspect of the way staff hierarchies interacted with mealtimes meant that staff with the highest level of training and education were not sufficiently present during mealtimes to observe shortcomings with the process or institute change (this also meant that some staff on Site 1 found research feedback surprising).

> **S1D150911E3:** *Today I have been speaking to staff [on Site 1] about the study, encouraging more people to either refuse or confirm participation and sign the form; the majority agreed although a couple of individuals asked for an extra consent form as they have misplaced the original and signed it immediately. As I was talking about the research on a more individual basis this time, many staff have shared their initial impressions of mealtimes. I was particularly struck by a number of nurses, the lead Therapy Technician, the ward manager and the housekeeping manager all saying they were rarely involved in mealtimes and being unsure if they "can be of use for the project". It became clear that the individuals least likely to be part of mealtimes were also the ones most likely to be in charge and also the ones with highest levels of expertise. [As research*

progressed it became apparent that the same individuals would be involved in / oversee clinical activities].

The function of hierarchical role differentiation went beyond task division and mealtime status. It also affected mealtime-related decision making processes and enactment of mealtime change. Soon after the data collection on Site 1 commenced, the researcher found out that the opinion of nurses could override majority consensus. One instance when this was salient was during the first feedback meeting, where the researcher shared collated suggestions from the stakeholders on the ward (patients, staff and relatives).

> **S1D1011E2:** *[…] I have mentioned that Flynn remains underweight and often refuses to eat, but also often asks for a strawberry milkshake. I have suggested part-replacing it with an oral supplement to increase Flynn's nutritional intake (as has been successfully achieved by some HCAs). Fist Kelly [HCA] said; "Yes, we could do that", and some other staff nodded. Then Sally [nurse] said she has already tried this and it did not work, as Fred did not like the taste of strawberry-flavoured oral supplements. I then explained about making half a cup of ordinary milkshake and topping it up with oral supplement drink, which worked on multiple occasions in the past. When I asked staff if they were willing to try this, no one answered, but several people looked at Sally.*

More explicitly, an HCA who had since moved on to a new role in a different service has spontaneously shared with me that prior to the commencement of the study the ward ran a meal-based group, where HCAs met to discuss ways to improve mealtimes. According to her, the group ran well until *"Sally joined and took over",* which later led to the dissolution of the group.

Importantly, having to prioritise nurses' opinions on mealtime or other non-clinical matters was never explicitly communicated among staff, but rather resulted from the implicit role differentiation and pay-grade hierarchies. Nonetheless, HCAs often expressed frustration with their opinion being less valued, whereas some nurses mentioned feeling under pressure to generate solutions, instead of being part of a collaborative process.

Although the staff on Site 2 belonged to the same organisation and followed the same organisational structure, hierarchies were less visible. Paradoxically, this was largely driven by the ward manager (the highest position within the inter-ward hierarchy). The manager made an explicit effort to regard all her staff equally when it came to making suggestions,

sharing opinions and solving problems. Also, all staff were expected to engage in the mealtime; even the manager and the ward administrator voluntarily took part in assisting residents who chose to eat in the office. This lead to a greater and shared awareness of mealtime difficulties. Also, individual suggestions on improving mealtimes were considered regardless of whom they came from.

> **S2D0403E2:** *[...] Joan [a former school headmistress] stayed in the office since breakfast [this was usual for Joan and she rarely left the office for any length of time]. The staff served her lunch on a tray table, but had to leave her to eat independently while assisting patients who needed more input [Joan would rarely allow someone to actively feed her, but was often unable to feed herself due to attention and motor difficulties]. Nina [the ward's administrator] was sitting with her back to Joan, typing. She would, however, look over to Joan from time to time and verbally encourage her to eat. She also occasionally tried to give Joan the spoon or scoop some food on the spoon and leave it for Joan to pick up. None of that seemed to work very well with the main course, and Joan was getting increasingly frustrated, [unintelligibly] verbalising louder and louder. This lasted for over 5 minutes, at which point Nina opened her lunch bag and put some crisps from her packet on Joan's plate. Nina also proceeded to eat the crisps remaining in the bag at the same time facing Joann and asking her to try some. Joan did. She ate almost all the crisps from her plate, independently feeding herself [finger-foods were noticed to help previously]. Afterwards, she (mostly) independently ate a bowl of sponge and custard with some encouragement and assistance from Nina [similar to assistance provided with the main course].*

While hierarchies were expressed differently around mealtimes in each site, a hierarchical structure of the ward *per se* proved to be problematic for research goals. The project aimed at providing agency to the stakeholders, whereby patients, staff and relatives would decide on mealtime changes that are most relevant to the given setting. However, ward managers payed a disproportionate role in enabling and facilitating change. Management (both ward-based and service-based) had to approve any change, especially in cases where funds were being used (which resulted in long delays). If any management members were away, this usually resulted in no progress taking place for that duration; even with small-scale changes many staff felt it important to inform the manager. This, in turn, removed the perception of

collaboration, raising questions on how suitable participatory action methodologies are within hierarchy-based organisations.

Theme 2. "*Forget What You Have Done Before*": Roles and Role Negotiation

Identities on the wards were clearly defined and boundaried. The uniforms have clearly defined staff members, whereas the majority of the patients were visually defined by their age (tensions were visible in cases where the staff were either older adults themselves or of similar age to the patients/residents with early onset dementia). These became the predominant, visible roles that were actively imposed and maintained to separate staff from patients. Any form of liminality or deviation from those roles also created tension and was often brought 'in line' with the dominant role differentiation, as in Angela's case.

Angela did not have dementia, but lived on the ward due to bipolar disorder. She has often spoken to me about her former job as a caterer and expressed pride in it. Due to this, she took an active interest in the food and mealtimes on the ward and would at times make comments about meals lacking seasoning. She also spontaneously shared her wishes to have an active role in serving of the meals on the ward, which she spoke about as a way to express care to other patients and "gratitude" to the organisation. It was also not unusual for Angela to come up to the kitchen area and have the 'first look' at what was being served that day.

> **S1D2203E3.** *At teatime, once the food was delivered, Angela came up to the kitchen area, looked over the wall and at the trays of food and started talking to Stella [HCA serving food] about the meal and what she liked. Stella responded by shouting loudly for Angela to sit down: "Sit down, Angela. You will be served at the same time as everyone else!". Angela complied and came back to her seat, while Stella (loudly) expressed her frustrations with Angela being "impatient", when another member of staff came to collect the meals for Dining Room 2. Angela spoke little during the rest of the teatime and did not look over to me as often as she usually did during observations.*

This was one of the many examples on the asymmetries of roles during mealtimes. The staff were exclusively the 'givers' and residents/patients - the 'receivers' within mealtime processes. The latter role was partly defined by declining independence and abilities for people experiencing dementia, as well as food-related procedures (e.g. food hygiene).

However, these asymmetries were both maintained and exacerbated beyond the above factors. This was particularly visible when observing patients on Site 1 who did not have dementia, as they were treated in much the same way as someone with advanced dementia. Many were not asked what they would like to eat, but served the meal chosen by the staff (especially if they never protested not having a choice), there was little attempt to encourage socialising at mealtimes and sometimes an active discouragement of interactions, whereas sharing of food among residents was often actively prevented.

Another mealtime division centered around ways of eating. Staff used ordinary (breakable) crockery for their drinks and meals, whereas all patients, regardless of ability or 'aggressiveness' were given plastic plates and cups. Suggestions about purchasing more aesthetically pleasing, ordinary crockery for everyday meals, while suggested by numerous staff, patients and relatives, was quickly vetoed over safety concerns (e.g., someone throwing a cup at someone else or cutting themselves on broken shards). Interestingly, all crockery was non-break-resistant during Breakfast Club (see above) and in the 12 month period of observations no incidents of breaking crockery or injury to self or others occurred. Also, during a large proportion of mealtimes all/most patients regardless of their ability and preference were only provided with spoons for ease of eating. The above process were less pronounced on Site 2. While some variation was present, overall, residents' ability determined choice of crockery (e.g. plastic cups were given to residents who found ordinary cups heavy). However, role negotiation and actively separating residents/patients from staff around mealtimes were evident in both research sites.

Unlike on Site 1, staff on Site 2 ate their food together and did not leave the communal spaces of the ward. After residents were assisted to get up (unless they did not wish to do so) and served breakfast, the staff would push together several tables, bring chairs and have breakfast as a group. These were overwhelmingly positive experiences, including conversation, laughing and sharing of food. Due to this, more able residents often gravitated towards the breakfast table and were often offered food.

> **S2D1905E1.** *I was invited to join the staff at the breakfast table. Staff purchased their own bread and had their own toast toppings (a much wider selection than one available to residents). Sheila [who was not on shift that day] had previously brought in some homemade cherry jam, which the staff shared around encouraging one another to try if they haven't done so previously. Everyone sat round the table and most food was shared (Celia had her own cream cheese*

topping, but offered it around). Topics both relating to the ward, but also to staff's personal lives were discussed. Most of the residents were up and dressed, and have already had breakfast, but many remained in their own rooms. Sarah, however, was walking around and would at times come to the table. Sally [the ward manager] got her a chair and fed Sarah some scrambled egg, although she has already had breakfast, after which Sarah walked away again.

In several feedback meetings the researcher has remarked on how positively the post-breakfasr period was experienced by all taking part and asked whether it could be extended to most of the residents (where appropriate); encouraging those who are able to come to the breakfast table with staff for a second breakfast or simply an interaction. Although staff were open to trying this during the meetings, minimal changes occurred. When spoken to at later points, some staff remarked on the importance of "protecting" these events as staff breaks, where staff can relax and be free of care tasks. Therefore, communal meals between staff (at breakfast and after tea) remained ward-based and permeable to the residents - it was common for staff to share their own food with residents if they have expressed interest in it - but no overt attempts were made to include the residents in these events.

Overall, staff on both wards also legitimated and maintained their identities (of authority) by wearing uniforms. The researcher, too, was often regarded as 'staff' by staff members, and the issue of her not wearing a uniform came up on many occasions.

> **S1D1310E3.** *[...] I was called a 'part-timer' by two members of staff today, referring to me being on the ward 3 days a week. This also demonstrated I was seen as a staff member [...].*

> **S1D2504E1.** *[...] Maureen [patient] has wiped her hand on my cardigan sleeve after eating a jam sandwich I gave her. Sue [nurse] saw this and remarked that I needed a uniform, to which I said that either item of clothing would need washing. Sue then proceeded to say: "But you don't want <u>that</u> on your normal (sic.) clothes" [...].*

> **S2D1801E1.** *This was my first visit to Site 2, where I have spoken to the ward manager about the research taking place here [...]. The manager said she has spare uniforms and could get me one, which I politely declined. A member of staff who was in the room at that point, seemed to have agreed with the idea, as they*

nodded when the offer was made. It seemed important for the staff that I 'take a side' from the start [...].

The use of uniforms in general appeared to clash with the idea of 'pleasant' mealtimes as expressed by patients, relatives and staff, where homeliness and a friendly/familial atmosphere were stressed. However, once, reflecting on these ideas, the researcher have spoken about a mealtime project (Charras & Fremontier, 2010) which involved staff taking off their uniforms for non-clinical activities, the staff did not express willingness to try this approach and some overtly expressed anxiety about loss of authority.

Identity differentiation and negotiation were in fact so strong, that the labels of patient vs staff eclipsed all other aspects of identity. As mentioned above, gender roles were specifically investigated around mealtimes, as food and meals are a gendered arena (Neuhaus, 2003). However, within mealtime interactions on the ward, gender played a minimal role both among staff, among patients/residents and across these groups. It was not a significant factor in the way food was prepared, served or consumed. In contrast, the giver/receiver dichotomy in the staff versus patient identities was so strong, that the minority of patients who did not have dementia were treated in the same way as those who did both during mealtimes and on multiple occasions outside of them.

Relatives occupied a liminal, outsider-insider role, which resulted in tension on both wards, although the approach to these tensions was markedly different between sites. On Site 1 staff expressed unease with some of the relatives knowing the code to the ward and being able to let themselves in, with one member of staff using the word "intruders" to refer to the relatives. Many relatives were excluded from communal spaces (especially at mealtimes) and either advised to avoid mealtime visits altogether or encouraged to go to the patient's room with them and eat there. Having to wait until the mealtime finishes before seeing a relative was also a common practice (see below on beliefs around 'protected mealtimes'). When the researcher asked staff about reasons behind this, many have spoken about the communal spaces being an area for all the patients and that presence of relatives was colliding with the right to privacy of other patients. The researcher proceeded to ask if any of the patients ever opposed visitors' presence on the ward and if a similar rule applied to staff presence, which appeared to challenge such enactment of role differentiation and often resulted in hostile or defensive reactions.

Unlike Site 1, which often opted to exclude the "outsiders" (term used by one of the staff), Site 2 involved relatives within mealtimes as an asset. A quarter to a third of residents (depending on total occupancy) had daily or near-daily visits from their spouses, who also assisted during one mealtime. On the majority of occasions this worked very well and was highly appreciated by staff. However, tensions arose whenever mealtime approach by the relatives clashed with what the staff believed to be the correct approach and if the relatives made any complaints about mealtimes. In most cases, the staff attempted to resolve such issued by justifying their approach / care decisions and attempted to reach a common ground, but one relative was asked to temporarily stop visiting at mealtimes due to the distress mealtime interactions between her and her husband were causing to both of them and other individuals on the ward. She was later allowed to resume visiting at mealtimes, but asked to modify her approach.

> **S2D2207E2.** *[...] Today I learnt that Muriel [wife of a resident, Rupert] has been asked to step out during lunch. She was feeding Rupert and getting increasingly anxious and frustrated about him not eating, but continued to insistently feed him (I was told about this rather than actively observing the occurrence, but the description was in line with previous observations). Rupert started to shout quite loudly and with decreasing intermissions, which upset / increased anxiety in other residents and resulted in them eating less. It was the manager who asked Muriel to 'step out', but at the time of my arrival some hours later the staff were still affected by this. Many expressed not wanting to do this, but feeling that asking Muriel to stop feeding Rupert was in his best interest - and that of other residents. Because this was a "mealtime issue", I was asked to meet with Muriel and talk to her about a less stressful approach in feeding Rupert or other ways in which she could engage with Rupert while staff would takeover feeding. While well-intentioned and thought-out, this process revealed the power differentials in staff vs relative roles; Muriel knew her husband for over 50 years and initially provided dementia care for him, but within this situation her familial knowledge was trumped by clinical knowledge.*

Such relative-staff interactions have further demonstrated that staff held a privileged role of 'knowledge holders' when it came to dementia care and more specifically mealtime approaches. When opinions clashed, such specialist knowledge was regarded as more important than the greater knowledge of the individual, their personality, likes and dislikes

that was possessed by the relatives. The relatives therefore were more powerless during mealtime interactions and often did not voice their opinions (which they shared in individual interviews) and/or sought permission for even minor changes to the mealtime routine (e.g. giving their relative a cup of tea at lunch instead of squash). Mealtimes, as a predominately social, casual family/friends event, therefore, offered a unique clash on the wards, where the (public) institutional regime collided with the (private) familial ideology.

Another important way in which roles and identities were negotiated on the ward via '**rites of initiation**', was that newcomers to the ward were (often explicitly) expected to conform to the norms of the ward and assume the identity ascribed to them. Any challenge to role differentiation was met with resistance. It has already been explained above, how patients/residents were expected and even coerced into assuming a receptive role, and attempts to actively help during mealtimes was discouraged even in cases with minimal risks. A similar process was applied to new staff.

> **S2D2508E2.** *During today's team meeting that welcomed a new member of staff, he briefly spoke about his experiences in private care and in services for people with Learning Difficulties. The manager then remarked: "You must forget the way you worked in the past - we do things differently here"; which was met by some other staff nodding and no one mentioning the importance of his previous experiences and knowledge in bringing something new to the ward life.*

Therefore, identities within the ward did not simply depend on the sum total of identities already possessed by the individuals within the setting, but were actively negotiated to fit the setting itself.

Theme 3: *Can you say 'no'?* Status Quo Maintenance

As explained in Theme 2, everyone who came into the ward, either as a patient/resident or a new member of staff was expected to conform to the norms and processes of the new setting. While this undoubtedly affected the way identities were experienced and negotiated, the norms and processes went beyond influencing individuals and created a self-maintaining culture. This transcended routine or policy (e.g. on hand hygiene) that is expectable in a health care setting for people with dementia, and involved behaviours and justifications which appeared irrational to an 'outside' observer. In other words, it was not individual self-

serving beliefs, but rather institutional self-serving beliefs that were enforced and maintained.

Both wards seemed somewhat 'at ease' with underweight and undernourished individuals, but, as will be discussed later, the settings also highly problematised weight gain and being overweight. Upon investigation, this 'ease' appeared to stem from a widely held belief that "*weight loss is normal in dementia*". While unsubstantiated in scientific literature (see Chapter 3), this notion could be found in some practitioner material (e.g. Norfolk NHS, 2013). It appeared to be a logical fallacy, whereby following an observation of weight-loss as frequent among people with dementia in institutional care, the weight loss was assumed to be 'normal' and an inherent process of dementia. However, this belief was, to a degree, self-serving within the wards, as it allowed for less concern and less active intervention to maintain or increase patients' weight.

> **S1D1607E1.** *I saw Sam's wife today [it has been at least a month since our last conversation]. We briefly spoke about Sam recovering after an illness, but now needing a 'profile' chair. I remarked that he has lost quite a bit of weight since falling illd, but that hopefully, now he is better, Sam can start gaining it back again. Celia [wife] immediately responded that "The staff are very good here. It is Sam's dementia, you know..." [Sam did not take part in the research, but Celia did]*

This showed how widespread the belief was, and that it was likely transferred from staff to relatives (given the clinical content of the topic). The relatives were therefore incorporated into the belief system of the wards.

In fact, raising awareness about the problem (and avoidability) of undernutrition was often met with dismissive or even confrontational manner. It took the researcher several months and a contribution from two consultant psychiatrists to ensure that Site 1 weighed patients on a monthly basis (despite this being an explicit policy requirement; Trust's Nutritional Standards For Inpatient Services Policy, 2012). While speculative, such adamant avoidance of weighing patients despite requirements would suggest that this helped to avoid acknowledging the issues of undernutrition and dangerously low Body Mass Indexes.

Furthermore discussion of processes that result in weight loss for someone experiencing dementia (e.g. inability to identify hunger) and possible solutions did not successfully address the overall belief. Some feedback meetings in Site 1 were spent discussing with staff

and sometimes relatives why someone with dementia may lose interest in food or not eat what is being given to them, along with overview of often very simple solutions. While relatives were receptive to these explanations, staff were less so. Even if they agreed that some individually-tailored interventions may help, it was seen as somewhat futile given the terminal nature of dementia. The belief in the normalcy of weight loss did not change even when the weight of the majority of participating patients started to increase as the project progressed.

Beliefs about weight-loss in dementia were intersected by the clinical emphasis within the settings, in turn affecting mealtime experiences. Firstly, the main focus of mealtimes (especially from the nurses) was around nutrition and weight, rather than a wider experience of mealtimes and its positivity. However, the intersection meant that only overweight individuals were monitored; within both research sites staff designed specific strategies and to reduce the weight of the few overweight or obese individuals. This was explained as the best interest for the patient's health, considering the risk associated with high BMI. However, staff did not factor in the life expectancy of these patients and did not weigh up the disadvantages against the sensory pleasure that eating may have. At the same time, and despite indications that being underweight is more dangerous for older adults than being overweight, no specific interventions were applied to undernourished and underweight individuals.

The generic understanding of health also influenced the perceptions of acceptable food. While many stakeholders (patients, relatives and staff) have suggested offering individually favoured and/or high calorie foods, some nurses on Site 1 also expressed that they "don't feel comfortable giving patients unhealthy foods" such as pork pies or sausage rolls. Healthy food was therefore seen as more important, even if it meant insufficient consumption.

Theme 4. "*They Won't Care*": Infrahumanisation

Infrahumanisation is a "tacitly held belief that one's ingroup is more human than an outgroup, which is less human" (Cortes et al, 2005). The process of infrahumanisation also involves the perception that one's outgroup is less able or unable to experience secondary emotions such as shame, guilt, disappointment, enthusiasm or satisfaction, while the primary, more animalistic emotions (e.g. fear, anger or joy) remain possible.

Processes of infrahumanisation were observed on both wards. This was particularly evident when looking at the importance social aspects of mealtimes were ascribed. Both during individual interviews (see Section 6.3.2) and casual conversations all staff have identified social aspects and important or even the most important part of enjoyable mealtimes. However, this knowledge was not applied on the wards. On Site 1 it was observed that calm and quiet settings were prioritised and, importantly, interactions between patients discouraged during mealtimes. This manifested both passively (by not inviting individuals to eat at a table and no opportunities to share food) and actively (by positioning chairs in such a way, that patients did not face towards anyone to engage in eye contact with).

> **S1D1211E3.** *At teatime Maureen sat down next to Jane, who at that point had not started eating her yogurt. They smiled at one another and seemed to exchange some pleasantries. Jane then pushed her yogurt pot towards Maureen, who happily accepted it and started eating. This was met with disapproval from staff, who loudly told off Maureen for taking Jane's pudding (no one saw Jane give it to Maureen and assumed Maureen had taken it). They forcibly took the yogurt pot from Maureen, who then became upset and attempted to retrieve the yogurt pot from Sally's [HCA] hand. Therefore, she was put in Hold 2 [restraint technique] and escorted to her room. No replacement pudding was offered to Jane and Maureen was too distressed to eat at this point.*

However, sharing of food was a positive experience for many patients/residents and encouraged eating.

> **S1D2702E3.** *Today I observed people eating in the foyer. At that point, the space was occupied by Walt and Hazel, sitting on opposite sofas with food served on tray tables. Maureen was going in and out of the room. Staff were busy in the two dining rooms and feeding patients in their rooms, so no one was supervising the foyer or encouraging Walt or Hazel (previous structured observations have shown that both these patients benefitted from verbal prompts and occasional physical prompting, but did not require feeding). During one of her 'visits', Maureen came in with a corned beef sandwich [sliced into 4 triangles] and sat down next to Walt who at that point was not eating from the plate in front of him. She proceeded to pass one of the triangles over to him, which he ate and she continued to eat hers. Often restless, Maureen walked away for a while, but then came back to give Walt another piece of the sandwich, which he ate. They both*

chatted and smiled and the half of the sandwich was the only food Walt ate that evening.

In comparison, there was little active discouragement on Site 2, but spontaneous social interactions were not encouraged and their potential benefits not appreciated.

S2D2007E3. *Before the mealtime started both Alistair and Jeremy [residents] were angry. Alistair was displeased with the work he believed his building crew failed to do, while Jeremy was periodically raising his voice since receiving personal care. The staff looked apprehensive when Alistair joined Jeremy at the dining table in case their proximity resulted in a fight (Alistair continued to repetitively point at Ken [HCA] and angrily berate him). They were both served tea despite Alistair proclaiming that he was "too annoyed to eat". They both continued to talk past each other rather angrily and neither touched their food at first. However, instead of escalating, their anger seemed to diminish and while Alistair continued to talk about builders' failures, he was much calmer, whereas Jeremy would laugh at times. They both looked at each other and spoke towards one another more as the teatime progressed. [Alistair's appetite was always good, but Jeremy struggled to focus and maintain attention on food, and would often endlessly portion it into smaller units never starting to eat; at the same time Jeremy would rarely allow staff to assist/feed him when feeling angry or agitated]. Jeremy started by positioning his sandwiches around the plate and occasionally licking his fingers. However, as both Alistair and Jeremy continued to calm down, and after watching Alistair eat his sandwiched, Jeremy proceeded to do so, as well. By the end of the mealtime, they had both eaten full portions and have shared an extra piece of chocolate cake (eating all the food at teatime was unusual for Jeremy).*

Moreover, while the staff downplayed the importance of social interactions at mealtimes, lack thereof was overtly distressing to some of the patients.

S1D1706E2. *[Marie has expressed to me on numerous occasions how important eating together with family was to her. She has spoken about always eating at a table with family - first her parents and siblings, then her husband and children. Her wish to eat at a table was often respected, but she was usually the only one there, with other patients seated on the sofas or the armchairs in Dining Room*

2]. At lunchtime today Marie was the only person sitting at a table. A few patients and a number of staff kept walking around the table (e.g. serving food) and Marie kept looking around, not eating. After a while, she started shouting in distress, saying "What have I done?", "Why am I left on my own?" and other similar expressions. This was not met with any assistance or anyone joining the Mavis at the table; she was simply told not to "be so loud" and "start eating". At the end of the mealtime, two members of staff sat at the opposite end of the table discussing their favourite types of pie, but did not include Marie in the conversation. She continued to shout in distress and did not eat her meals. While she did attempt to drink some tea, the tremors in her hands were made worse by anxiety/distress and she could not get the cup to her mouth. [...] I found this situation highly distressing and went for a walk outside the ward after the mealtime.

Social aspects of mealtimes, however, were not the only manifestation of infrahumanisation. Lack of regard for choice and preference were also significant. While both wards kept a list of patients'/residents' preference for tea vs. coffee and the number of teaspoons of sugar they liked (Site 2 had another such list for staff), these preferences were only considered within the restraints of routinely provided food and beverages. Interviews/conversations with patients/residents themselves and their relatives revealed extensive lists of preferences which, especially in terms of beverages were never catered for. Conversations with staff showed that both sites did wish for other food and drink items to be available, but this depended on what they thought would be appreciated, rather than any knowledge of individual likes/preferences; patients were often thought about as a group and choices were guided by what would suit the majority.

One of the more extreme examples where a patient was deprived of choice was Angela. Being of Nigerian dissent, Angela often found food on the ward bland. However, she never asked for spice or sauce, or different meals. The only item of food she did, however, repeatedly request was boiled rice instead of potato mash. The ward policy alone dictated that ethnicity or religion-based dietary needs should be catered for, but no notable attempts to ensure this were made by the staff. Instead, Angela eventually arranged for her family to bring rice to the ward and the staff appeared pleased with such a solution.

In relation to Theme 3 (maintaining the Status Quo), infrahumanisation was also used against the researcher once she challenged the norms on the ward.

S1D0310E2. *After lunch I was standing in the kitchen area chatting with 2 HCAs (they were the only staff in Dining Room 2 as the rest were undergoing handover in the staff room. Walt (patient) joined us in the kitchen area, at which point one of the HCAs loudly remarked: "It smells of shit here, must be Walt". Taken aback by the nature of the comment, I nonetheless did not want to overtly confront the staff about Walt's dignity and need for respect. Instead, I decided to show the inappropriateness of the comment in a more humorous fashion, asking said HCA: "How do you know it's not me?". After a momentary pause, Kayleigh (HCA who made the comment) walked behind me, lifted up my dress and pulled down my tights and underwear (thus exposing my behind in the dining room area with 6 residents and 2 staff present). "It's not you!", she remarked. I did feel affected by this event, but have chosen not to show any such reaction and continued a conversation with both HCAs. [Throughout the research process this was probably the starkest, but not the only example, of infrahumanisation being employed to show 'if you're not with us, then you're with them' type of dichotomy]. At the same time, this 'incident' showed how ingrained infrahumanisation on the ward was; Kayleigh did not seem apprehensive of her behaviour and did not seem to worry (enough) about a possibility of a complaint. This may have also taken place because she knew my ability to carry out the research on the ward depended on none of the stakeholders objecting to my presence; it is therefore hard to separate the influence of infrahumanisation from that of power.*

Overall, instances of infrahumanisation, while often used towards people with dementia, were also a coping mechanism common in many healthcare settings. Given institutional pressures and limitations affording patients less humanity allowed staff to deal with procedures that often compromised dignity and personhood (e.g. lack of choice at mealtimes). This, in turn, relates to Theme 5 on mealtime proceduralism.

Theme 5: *Policy before People: The Paradox of Proceduralism.*

What happened or did not happen during mealtimes heavily depended on institutional policies and procedures, as well as restrictions. However, as will be explained later this process was not straightforward or uni-directional.

On Site 1 the priority of procedure was primarily characterised by a lack of catering contract between the Mental Health NHS Trust Site 1 belonged to and a General Health NHS Trust that provided catering for the entire hospital, including the ward. In practice, this meant that the NHS trust that Site 1 belonged to did not pay for the food they received from another trust and therefore higher management were delaying the set-up of the contract as much as possible. The only way the trust providing food was pushing for a contract, was by refusing to consider any menu- or food-related requests from Site 1 that were outside what they were already providing.

> **S1D0410E2.** *I have interviewed the head chef earlier today, who showed me around the kitchen [...] Each time I asked about the possibility of providing different textures and types of food, as indicated by the patient's care plans [e.g. soft-textured food, high-protein/calorie meals and rice for Angela], I was told this was not possible without the contract. The food could only be provided within the framework by which food is provided to short-stay general hospital wards. The chef did acknowledge, that older people with dementia, who stay on Continuing Care wards for at least 3 months have different needs, but told me that any requests could only be considered after the contract has been established [...]. The only time when [the head chef] spoke to me openly about feeling frustrated with his trust's pressures regarding the contract, he asked me to switch off the recorder [...]*

On Site 2, catering was provided by a private company based on the same site. A strong relationship between the catering manager and the ward manager meant that requests were often accommodated, even if they were outside of the approved remit. However, funding issues and proceduralism also affected mealtimes in a profound way.

> **S2D2306E2.** *I have spoken to the catering manager about the project and the suggestions that came from staff. We came to talk about the benefits of finger foods and the staff and relatives' keenness to try this at teatime with some of the residents. Sarah [catering manager] agreed with the importance of food and its variety in texture, flavour and availability. She also agreed about the benefits of finger foods. But throughout the conversation, she related to me on a personal, rather than a professional level; talking about her family members and their experiences and needs around mealtimes. The stance she chose to take was that of a relative (albeit not of anyone currently on the ward), rather than in her*

professional role. She offered to consider the possibility for finger foods outside of sandwiches (and acknowledged the absurdity of each patient being allowed only 3/4 of a sandwich), but warned about budgetary constraints. [A few days later, we were told that the meal budget could not accommodate for finger foods, as they are more expensive than the alternatives available now].

Due to budgetary constraints, both wards have experienced poor food quality. Moreover, both care and catering staff often spoke about this being the case not because of lack of skill, but rather use of the cheapest ingredients.

Policy imposed on the mealtimes from outside-bodies was often seen and explained as constraining and unhelpful. For example, due to Fire Safety regulations the 'Breakfast Club' on Site 1 was not allowed to purchase a grill, which negatively affected staff enthusiasm towards any other mealtime changes (interestingly, Site 2 did have and frequently used a grill). However, policy was also (mis)interpreted and constructed in a way that suited the ward routines. Both sites had to operate 'Protected Mealtimes' which, in policy terms meant "[p]rotected mealtimes are periods when all activities (where appropriate) stop to enable nurses, housekeeping staff, catering staff and volunteers to serve food and give support and assistance to patients" (p. 29; full reference cannot be provided for purposes of confidentiality and identification). The policy also stated, that "visitors who wish to support or assist a patient with eating are encouraged to do so, in line with the principles of protected meal times" (p.29). However, both wards constructed the policy to mean that relatives were not allowed to be present during mealtimes. Site 1 allowed mealtime visits only if the patient was escorted to their room. There were also occasions, where relatives had to wait up to an hour to see their relative, if they came to visit once the mealtime has already started. Discussions about the policy during staff meetings revealed a lot of resistance to allowing (or encouraging) relatives to join in at mealtimes. As described above, Site 2 considered relatives as assets and in the majority of the occasions supported mealtime visits. However, the interpretation of protected mealtimes as instructive of excluding relatives persisted; the staff described themselves as operating contrary to policy for the benefit of the patients.

There were no policies specific to each ward (i.e. created from within), but ward routine was sometimes elevated to the status of policy; especially if it justified practices that were easier. This also made changes to routine unexpectedly difficult. On Site 1, observations demonstrated the difficulties with the serving pattern for the 2 dining rooms; the room where the food was dished out got their meals last. This resulted in patients becoming irritable and

often leaving the table/room in the approximately 15 minute period when they could hear the clatter of the dishes and smell the food. Changing the pattern around and serving food in Dining Room 1 first was both simple to achieve and of minimal impact to the staff, but instituting this change took nearly a month, required physical presence from the manager and often defaulted back to the original routine. Similar reluctance in other areas (see Section 6.4) was common and required intensive input for minor changes, while staff predominantly explained adherence to these patterns because "[they] have always done things that way".

The influence of procedure was therefore bi-directional, crossing both external and internal rules. The staff therefore often found themselves in a conflicting position on the intersection of agendas. Navigating these conflicts often resulted in a symbiosis between staff and procedure (and therefore loss of focus on the patients/residents), as it was protective of staff's roles and identities. Most staff indicated frustration with restrictions and rules and acknowledged the ways in which they negatively impacted on the patients, and their own self-image and integrity when interviewed, but in practice prioritising procedure helped to deal with the conflicts and tensions both around mealtimes and in institutionalised dementia care generally.

Reflections and Limitations

As can be seen from the themes, they show a high degree of intersection, while field-note examples can be illustrative of several themes at once. This permeability, however, was not considered to be a limitation, but rather a reflection of the complex microcosms of ward-life.

Moreover, upon reflection both during fieldwork and data analysis, the field notes from both sites tended to become more fact-/event-based over time. Both post-hoc reflections and instances of ethnographic reflexivity remained present, but numerically fewer, as were inquisitive notes, pointing out the need for further investigation of events or beliefs. Overall, this was considered as an index of data saturation. However, the researcher acknowledges that intensive and prolonged data collection may have resulted in "going native" (Fuller, 1999). While this process is not problematic *per se* and may result in ethnographically desirable 'human intersubjectivity' (Jules-Rosette, 1975), it is important to acknowledge that this was not the intended stance of researcher (i.e. the position of observer-as-participant). As such, it may have influenced collected fieldwork data in an unintended manner.

Another important reflection relates to the way ethnographic data was presented in this subchapter. Comparisons between research sites were often employed to explain and illustrate the themes. However, it should not be taken as a demonstration of a complete dichotomy between the wards or one ward being superior to / better than the other in most respects. As mentioned above, all themes were present in both sites and both revealed tensions / problems around mealtimes, even if the exact expression of the theme differed. While these contrasts may present a limitation, it is also a strength in storytelling and conveying the diverse ways in which the themes manifested.

Finally, it is important to acknowledge the ambiguous role of the researcher during the research process and the impact this had on the ethnography. The researcher was simultaneously a participating observer, and a facilitator of change. While the decisions regarding the change came from the patients, relatives and staff, finding ways to enact the changes (e.g. securing funding or proposing routine changes) was often the role of the researcher. This conflicted with the purposes of the ethnography, which relies on challenging beliefs and asking difficult questions to explore the processes behind the actions. However, confrontation - while helpful for the ethnography - was often consciously avoided in order not to jeopardise the action research 'side' of the study.

6.3.2 Interviews and Informal Conversations

The overall purpose of collecting interview and conversational data within the research project was dual. On the one hand, it was important to capture participants' inner experiences beyond what could be recorded via ethnographic observations. The aim was therefore to tap into beliefs and constructions held about mealtimes, about dementia and the way these intersected. The second role of the interviews and conversations was to elicit directions for action. Interviews therefore collected individuals' ideas on what worked well and how mealtimes could be improved, getting a wider range of opinion as a platform for discussion. This section, however, will only discuss the findings from the former purpose of the interviews, while the latter can be found in Section 6.4 which reflects on the progression of the Action elements of the research.

The interviews were also collected at different times of the research, with a general aim to interview all 3 participant groups (patients, relatives and staff) repeatedly, over the pre-, during, and post-intervention stages of the research. While only a small fraction of

participants were interviewed at 3 different times and some attrition in participant numbers was noted throughout the stages, overall representation from the 3 groups was achieved.

Section 6.4 of the results will be looking particularly at longitudinal cross-stage change combining all the methodologies and therefore including interview data. The current section, however, will focus on the cumulative interview data separating it only for the 3 participant groups. It is acknowledged that beliefs and inner experiences may have changed over the course of the research, but the current section is looking particularly at *what* those worldviews were rather than *how* or *when* they were expressed.

Patterns of Data Recording and Analysis

The interviews/conversations collected during the research project were designed to look at the way stakeholders experienced mealtimes on the ward, as well as what aspects of mealtimes they wanted to change and how they reflected on implemented interventions. To avoid repetition, however, a summary of findings on interventions and their perceived success is discussed in Section 6.4. Instead, the current section focuses on the way stakeholder groups *experienced* mealtimes.

To investigate this, Interpretative Phenomenological Analysis (IPA; e.g. Smith & Osborn, 2003; Smith et al, 2009) was chosen because as a method of data analysis it allows to explore the way participants "are making sense of their personal and social world" (Smith & Osborn, 2003, p. 53). The approach places emphasis on the meanings and the worldview, rather than themes or repetitions. It allows the researcher to get close to the participants' personal worlds, adopt an active role within a dynamic process and engage in interpretative activity (Smith et al, 2009). IPA is also a suitable method for interviews involving people with dementia (especially later stages of dementia where communication becomes more difficult; Alzheimer's Society, 2015). The method has previously been successfully used in research with people living with dementia (e.g. Frazer et al., 2012) and allowed the researcher to be reflexive and arrive at the meanings of participants' social constructions, while simultaneously attending to their own personal and professional reactions to the experiences of participants (Smith & Osborn, 2008, p. 679).

The analytic process followed the strategies outlined by Smith and colleagues (2009). The analysis started with transcription of the interviews and immersion in the data (re-living the interviews by attentively listening to the recording). Initial noting and coding then took place. While numerous software packages assisting with qualitative analysis exist, it was deemed

more beneficial to code and take notes manually, the result of which was producing themes – first within, and then across cases. Once the themes were extracted and conceptualised, the results were written up.

It is also important to note, that while IPA was used with all stakeholder groups, the patterns of data collection and the justification for using IPA at times differed. These differences are discussed below.

Patients. IPA is also based on idiographic analysis (ibid); it examines objects of interest in considerable detail, thus allowing small sample sizes. This was considered ideal for the current research, as other analysis methods may have led to the worldview and opinions of the patients with dementia being lost in the more comprehensive and higher in number accounts from other stakeholder groups, especially staff (few consistent themes were present across patient accounts if their contributions were taken literally). Ethically, it was important to afford the worldview of people with dementia an equal status compared to other stakeholder groups, at least in terms of the depth of interpretation. IPA methodology acknowledges the importance of *hearing* what people with dementia have to say. It is an interpretative process, that involves knowing the person, their history, and how it is embedded in the current context, working out what is being said and why, what the meaning and purpose is, rather than focussing on the literal and the dissonance with reality.

The importance of the role and stance of the interviewer is also addressed within IPA (Smith & Osborne, 2008). Ability to relate to the interviewees, analyse their contributions and possess self-awareness of one's impact both on data collection and data analysis. Again, this was deemed particularly important in conversations with people with dementia. In relation to his, at the point of data collection the researcher had 8 years of professional experience in different services for people with dementia, including dementia care. Interpretative communication skills were therefore already within the research capabilities and assisted in both collecting and analysis often unclear or convoluted contributions.

As stated above, formal interviews were deemed inappropriate with the patient population and, therefore, interview data was collected by carrying out casual conversations. On-going consent was sought from the patients/residents at all times. Conversational data was collected by making notes during the conversation and writing down quotes, but it is acknowledged that important information may have been lost due to this process and due to the need to primarily focus on the conversant, rather than the notes. Permission to audio-

record conversations could not be obtained from the National Social Care Research Ethics Committee as it was deemed inappropriate given participants' lack of capacity to provide an informed consent.

Relatives. Interpretative Phenomenological Analysis of interview data was also deemed suitable for interviews with relatives, as it allowed to capture their experiences of mealtimes. In terms of procedure, however, it is important to point out that as relatives were excluded from mealtimes on Site 1 and visited the ward comparatively rarely, individual interviews could not be carried out. Instead, three Relatives' Meetings were held on the ward where participating relatives provided consent for their contributions to be recorded. On Site 2, however, the interview process with Relatives was identical to that with Staff.

Staff. IPA techniques were also used to analyse interview data from staff. Semi-structured interviews were carried out in private settings with only the interviewee and the interviewer present. There were occasions when the interviewee had to leave the room to attend to an emergency call or to carry out a scheduled activity. In those cases, the interview was resumed at the earliest possible time.

Findings

Interview findings within this section are initially divided by the stakeholder group (which also mirrors the analytic processes). Once findings emerging from patients', relatives' and staff interviews have been discussed in 3 separate sections, an overall commentary, comparing the views of the stakeholder groups, will be offered.

6.3.2.1. People with Dementia

Not all of the patients participating in the overall project could take part in informal conversations. While every attempt was made to capture and interpret all spoken contributions, however unrelated to interviewer questions, some of the patients could not converse at all due to severe aphasia (inability to produce and/or comprehend speech). Only 10 (63%) of the patients on Site 1 could take part in conversation, with 1 out of these 10 patients never expressing an interest in conversing with the research. With severe aphasia more common on Site 2, only 4 (44%) of the residents could converse with the researcher. Where the conversations did take place, they sometimes involved very short utterances or, in case of longer conversations, deviated away from the topic of mealtimes. Following the

principles of IPA, attempts were made to analyse these contributions beyond their literal meaning and interpret what the individual intended to communicate. Most conversations took place during or just after mealtimes; due to memory difficulties retrospective accounts were impossible to obtain. However, in cases where the topic of the conversation was mealtimes in general or mealtimes from the patient's early life (a period that is more likely to be remembered for people with dementia than recent events), these conversations intentionally took place outside of mealtime periods. Due to the informal, situation-specific nature of these conversations conversation topics or questions were never predetermined, but broadly focussed on the *experiences* of and *wishes* related to both meals and mealtimes.

Overall, the patients/residents were very willing to talk to the researcher about food and mealtimes and appeared to particularly appreciate being consulted about mealtime change. As will be discussed in Section 6.4., despite the advancement of their dementia, patients not experiencing advanced aphasia were able to make suggestions and provide astute observations. This section, however, focuses on how patients *experienced* mealtimes.

It is also noteworthy, that when spoken to about mealtimes, the patients often talked about food or the mealtime environment, rather than the physiological aspects of mealtimes that were the focus of many staff contributions. However, while food was talked about directly, the way food mattered was mostly due to the psychosocial aspects of eating and mealtimes. In relation to this, 3 themes were discovered. These themes focussed on the function of food in either meeting patients own psychological needs, or by providing opportunities for social interactions and social giving.

Food as Identity. Patients often spoke about food and its importance. However, this was rarely in terms of taste, or flavour, or sensory pleasure. Instead, food was spoken about as an extension of identity. For example, while Shannon was eating a sponge and custard pudding with visible gusto, the researcher asked her if she liked it. Shannon answered: "*My daughters like this. [a reflective pause] They ask it for afters (sic.)".* Shannon's contribution therefore demonstrated that the reason this particular meal was enjoyed by Shannon was not simply because of nice flavours of her preference for sweeter foods, but because this particular dish related to her identity as a mother, and reminded her of her daughters. In fact, it was clear from a wider conversation that Shannon thought she had cooked the meal, which in part accounted for her expression of pleasure. Shannon also reinforced her identity of a wife via food. She would often refuse her teatime meal, but insist on keeping the plate with food; staff

explained to the researcher that this was because Shannon was waiting for her husband to return from his late shifts to eat with him.

Alistair, too, spoke about food in terms of his identity and relation to others. When Alistair was asked if he liked his food on an occasion when he appeared to be particularly enjoying the meal, he replied: *"I can't fault my missus. She's a bloody good cook!"* This reinforced the notion that the meaning of food is derived from the psychological and relational, rather than physiological experiences.

There were also strong reflections on both a loss of identity around food, and - more accurately - a deprivation of identity. On these occasions the staff's focus on the physiological needs around food collided with the importance of social, emotional and sensory needs that the patients (often indirectly) expressed. The staff-dominated mealtime processes therefore not only failed to enhance a sense of identity, but also detracted from it, instead encouraging a more universal identity of un-wellness or deficiency.

One such example came from a conversation with Angus, whose current situation as well as personal history helped to interpret conversational contributions. Angus was a major in the British military. Respect afforded by others was something he was used to in the past and he reacted painfully when deprived of it. His frustration and occasional verbal aggression / shouting were seen by many staff purely as a manifestation of his dementia (i.e. frontotemporal brain damage resulting in poor emotional regulation). However, Angus' reactions were not arbitrary and would often manifest at mealtimes. He was fed pureed meals, although soft-textured food (not provided due to lack of catering contract) would have sufficed. While Angus could eat independently - yet slower and often in a 'messy' manner with frequent spillages - he was spoon-fed very quickly, with 3-course meals sometimes taking less than 5 minutes. It was at these times that he often got frustrated, as his independence (and thus sense of identity) was actively removed.

The researcher has spoken to Angus on several occasions about mealtimes on the ward and the way he used to / preferred to eat. *"They never give me salt and pepper… or sauce […] it's not very hard"*. Angus was therefore reflecting on the unnecessary removal of choice during mealtimes. On the same occasions he also spoke about his wife's cooking and missing German food (his wife was German and he was stationed in north Germany for several years at the beginning of his military career). Talking about German food (and on other occasions teaching the researcher German words) was Angus's way to resist some of that institutional

habitus and identity erosion and a way to contribute in a space where all options for his contribution were removed. In fact, lack of choice and lack of option was mentioned often across both wards and particularly by male participants (possibly because lack of choice particularly threatened masculinity).

Food as Social Giving. The importance of giving food to others was another prominent theme. As part of the interventions on both sites included the wards purchasing food that was enjoyed by and meaningful to the patients, the researcher spoke to the patients to find out about their preferences. However, those contributions provided more than a mere list of foods the patients enjoyed, and instead illustrated the wider role of food for the patients.

For example, the researcher interviewed Jane not long after lunch during which she did not eat a lot and was periodically distressed, banging a spoon on the tray table. Jane and the researcher ended up speaking for over half an hour. The researcher explained why she was there and that she wanted to find out what food Jane likes so the ward staff could buy some for her; Jane enthusiastically agreed to talk on the topic, spoke to the researcher for just under half an hour and provided a very long list of desired items. As the conversation progressed, however, it became clear that Jane's understanding of the topic changed to that of planning a party. As she observed the researcher writing (taking interview notes), she kept reciting food items or ingredients as if it was a shopping list. It also became clear that Jane was not just planning for herself or a family dinner, as she kept saying "*people like that sort of thing*" after coming up with yet more food ideas. *"You need to get cake… <u>That's</u> important"*. Within this conversation, food for Jane was a form of relating to people and the way of making others happy; she smiled throughout the conversation and appeared genuinely excited about the plans she was making.

Food and drink was equally important as a form of *giving* to men on the ward, although male participants spoke about food preparation somewhat less and referred more to serving or consuming food. In a conversation with a similar aim to that with Jane, Alistair told the researcher: *"I want to have a bottle of ginger beer and lemonade, but I have no money and my legs are bad [meaning he knew he could not get to the shops]".* Once the researcher asked him if those were his favourite drinks, he said: *"I like ginger beer. I want to have some in case my friends or my daughter comes to visit".* Once the aforementioned items were purchased for Alistair, he was often observed offering other individuals on the ward to have some (even though he was rarely given the bottle and usually served a single glass).

Also, when participants refused food (but did not appear to experience difficulties with maintaining attention, recognizing the food or chewing it), it was usually because they intended to give it to someone else. If asked why they are not eating, instances of disliking taste were less common than an intention to share. For example, James on Site 1 would often eat only crumbs or small bits of the food he was served (suggesting he did like the food), but not touch the majority of the meal. When asked why he was not eating, he would often say that he was saving the food "*for [his] sisters*". From wider conversations it became clear that James was an older brother of twin sisters in a poor household in East London, where food shortages were common. He was therefore forgoing his own hunger to make sure that his sisters had enough to eat and often required reassurance from staff that there is enough food to go round before starting the meal.

Food as Social Interaction. Several participants also mentioned wanting to share food and eat together with others (some talked about family and some referred to other residents). Angela, a former caterer, often said she wished she was *"allowed to cook in here"* and when asked why it was important (i.e. if it was because she did not like the food provided on the ward), she instead spoke about wanting to show her appreciation to the staff and care towards other patients in what she perceived was utilization of her best capabilities *("I'm a good cook, you know"*), capabilities that were not given any chance to manifest and contributed to Angela feeling that others did not appreciate her because they did not know who she was and what she could do. On other occasions she also spoke about a consultant psychiatrist, whom she felt a lot of gratitude towards for bringing her back on the ward from another placement, by saying she was hoping to visit him and bring him some of her homemade food.

The emphasis of food as a catalyst for social interactions was also visible when the potential for interaction was removed. This following monologue from Marie was recorded during the lunch hour, when she was the only person sitting at the table in Dining Room 2 (Site 1). The researcher was performing structured observations and already had on-going permission from the residents to do so. However, due to the distressing context of what Marie had disclosed, the researcher asked her after lunch had finished if she could keep the notes of what Marie said; Marie agreed.

Marie: *"They separated me; they made me different. I don't like eating like this! I want to eat with everyone else. Why do they sit me separately? [...] I used to like eating with my family... It was happy... It's not happy now [short pause] Where's my mum?! [shouted loudly] I'd rather not eat at all than eat like this. Why did they separate me? Why did they sit me away from other people? They made me different!"*

This, again, demonstrated that the role of food and the mealtime in general was not physiological sustenance or physical pleasure. Instead, it food was about social/relational opportunities, which in turn had a psychological/emotional effect (what Marie described as being "*happy*").

Overall, while food was at the forefront of the majority of conversations with patients, sustenance or feeling hungry were rarely mentioned (apart from Maureen, who was often hungry due to diabetes and staff feeling overly anxious about giving her food outside of official mealtimes and pre-set portions). Otherwise simply eating was not the primary purpose of having a meal; the content of the collected data was more about what food – and mealtimes - represented. Patients spoke about sensory pleasure, a sense of event and togetherness.

Overall, contributions of participants with dementia have demonstrated a great level of insight into mealtimes and ability to express their own mealtime needs. Many of the contributions resonated well with general observations and with reflections of some of the staff, suggesting an overall consensus. Also, conversing with participants most of whom were experiencing severe or moderate-to-severe dementia confirmed that phenomenological research with this population is feasible, useful for the research goals and potentially empowering – or at least pleasant - for the participants.

6.3.2.2 Relatives

Due to the aforementioned lack of involvement during mealtimes of the relatives in Site 1, it proves unfeasible to carry out one-to-one interviews with this group. Instead, several group meetings to discuss mealtimes in a wider forum were organised, which also served as a peer support space. These meetings did not attract large numbers of participants, but provided continuity, as the participants coming to these meetings remained fairly constant throughout

the project. Some informal conversations with relatives also took place on Site 1, while on Site 2 longer, more structured individual interviews were the most prevalent and no group interviews took place.

Five relatives took part in group interviews on Site 1 as part of the relative's meetings and another 5 participated in individual interviews in Site 2. The interview schedules for relatives can be found in Appendix S. A similar strategy of IPA analysis was employed as for patient interviews.

The nature of most relatives' contributions was around suggesting strategies on improving mealtimes for patients with dementia, along with providing insight into individual preferences of their family member who now resides on the ward (see Section 6.4). However, for the purposes of this section only results that relate to *experiences* of mealtimes were analysed.

A clear difference arose when relatives were asked what good, enjoyable mealtimes mean to them and what the experiences – and needs – of their family members residing on the wards were. When describing personal experiences or past mealtimes with a patient before they experienced mealtimes, the relatives spoke predominantly about social and relational aspects of mealtimes. For example, Jane's daughter told about childhood meals with her mother by saying "*we always ate at the table, always together […] You wouldn't dream of not coming or eating in your own room. It was nice that way*", stressing relational aspects of mealtimes, while Jean's son spoke about food as care and giving "*We didn't have much after dad died, you know… but mum never saw us kids go hungry. I don't know how she did it half the time*". As the collaborative decision was made to get soft fruit for the patients, Jean's son started bringing in large amounts of strawberries and blueberries on the ward, stressing it was not only for his mother and alluding several times that he enjoyed getting fruit for the residents, as it was his way of reciprocating the food-related care he experienced from his mother in childhood. Food was also used to express the identity of the patient/resident, in relatives' recollections of their family member. Jerry, Shannon's husband, stressed Shannon's prowess as a cook several times throughout the initial interview, yet this concerned less the quality of meals Shannon produced or her skills *per se* and was more around relating to others though cooking, and cooking as facet of identity of being a mother: "*Shannon had Wendy [daughter] cooking from little […] very good with cooking she was*".

When relatives spoke about current mealtimes with the patients, they also stressed their own social needs. Muriel, Rupert's wife, has told the researcher that feeding Rupert was "*the only time we connect… I don't know if he recognises me anymore, but he responds… smiles… when I give him food".* Jerry also spoke about coming in near-daily to spend lunch together, because he felt that Shannon responded to his encouragement the best (a trend found to be true from mealtime observations). Jerry said that: *"[Shannon] is hard to encourage… [the staff] try, but she isn't easy… not good with food anymore… but when I say "you need to eat this" - she does".* Similarly, relatives on Site 1, who were discouraged from participating in mealtimes, spoke about wishing there was a space on the ward where they could share a meal with the patient. For example, Brad's son said that: "*if there was a paying café here, we could take dad down… come the whole family (sic.) […] it would be turnover for the ward, too",* while Jack's wife, who often brought her husband fish and chips to the ward, spoke of "*not enough seating"* in the bedrooms, as a reason why she only brought food for Jack, instead of sharing a meal with him.

However, when asked their thoughts on how their family members was experiencing mealtimes on the ward, and how their experiences could be improved, relatives spoke predominantly of food quality and variety, and the wider mealtime environment, in terms of sensory experience. For example, Jerry spent a long time naming the types of food and cuisines Shannon liked in the past: "*Chinese she liked… Italian food, Spanish food",* while Muriel stressed physical attributes of a meal: *"they [the residents] don't have serviettes. Just a little square of fabric would make it quite nice".* The lack of sensory pleasure (both in terms of taste, smell, and visual set-up of mealtimes) was a particular concern to relatives with some (especially on Site 1, where food quality was lower) repetitively making statements similar to Brad's son saying that tasty, enjoyable food "*is all they've got going for them".* To further illustrate this, Jerry was also recorded saying "*Shannon has a very strong sense of smell… if she don't like the smell, she won't eat it. Now I lost my sense of smell completely… so I don't know what smells she likes".*

In contrast to sensory pleasure, once social interventions were brought up, such as eating together, many of the relatives remained sceptical of both the feasibility and – importantly – the benefit of such interventions, with Jack's wife saying "*I don't think it would work*" and other relatives nodding during a group interview on Site 1. Overall, therefore, relatives appeared to perceive the primary role of mealtimes and **food as sensory pleasure.**

6.3.2.3 Staff

A total of 29 ward-based staff (17 on Site 1 and 12 on Site 2) took part in semi-structured interviews, some participating more than once. A disproportionately large number of interviews were conducted in Phase 1 (65%). The participation in the intervention phases has dropped as staff already felt under pressure to implement the changes and reported to not have the spare time. As Phase 3 had to be discontinued early on Site 1 (see Section 6.4.), only one interview was conducted. Interview data on mealtime change, however, can be found in Section 6.4.2).

When mealtime *experiences* were investigated among staff, three lines of enquire were followed: staff experiences of mealtimes on the ward, staff experiences of mealtimes in their personal lives (i.e. outside of the ward), and staff's perceptions on how patients/residents experience mealtimes.

In terms of own experiences of mealtimes, staff (particularly on Site 1) spoke about a busy, often loud and overwhelming nature of the mealtime. Kelly's [HCA; Site 1] first utterance after being asked what her impressions of mealtimes on the ward were was: "*Chaos. Organised chaos*". These reflections from staff suggested that the more unpredictable and nature mealtimes and a relative lack of a structure challenged the sense of order and routine that appeared to be desirable by many staff. However, while some staff found mealtimes insufficiently structured, others (mostly on Site 2 where mealtimes were already less structured), found too much structure a challenge; Martin [HCA; Site 2] said that: "*Mealtimes are the most structured thing of the ward*", before reflecting on the benefits of a 'rolling' breakfast. Overall, however, mealtimes were rarely anticipated and usually perceived as one of the most difficult and hectic activities on the wards (Jean [nurse; Site 1], for example, said that mealtimes are "*a necessity part of the day; got to be done*" . Instead of focussing on the positivity of experiences, the focus was either physiological (seeing mealtimes as opportunities for sustenance) or risk-based *("I don't like the hot plate being in the same room where the patients are eating […] when you've got your back turned, you don't know what they're taking*).

The views of mealtimes on the ward were starkly different to staff's reflections on what they considered a positive mealtime in their own lives. Much like the relatives (see above), they spoke about mealtimes not only as a time for sensory enjoyment, but a predominantly social event. Sue [HCA; Site1] described a good mealtime as "*good food, good company… having a*

pleasant conversation over food", while others stressed the importance of giving/sharing a meal (*"I love it when the whole house smells of the food and the kids come down to check on what I'm cooking… Seeing them eat and enjoy it"* ; Debbie, nurse, Site 2].

However, the importance of social experiences was not carried over to the perceptions of how patients on the ward experience mealtimes. Overall, this question resulted in longest pauses and most hesitation, showing that adopting the patients' perspective was not routinely practiced on the wards and potentially uncomfortable as an exercise. Again, many of the interviewed staff remarked on an overstimulating nature of mealtimes for the patients (*"Busy. Exasperating. Chaos. Confusing";* Sheila, HCA, Site 1). Other staff saw mealtimes as a challenge to the staff, but neutral experiences for the residents ("*I think the majority of the patients feel okay during mealtimes. It's just the 'walkers' who walk off, it's hard to sit them down"* , Sue, HCA, Site 1). Sue's comment is noteworthy also because it illustrates the aforementioned difficulty to perspective take, and infrahumanisation (referring to patients as 'walkers') operating as a defence mechanism from acknowledging that mealtimes were distressing to some of the patients and did not meet their needs.

Both in terms of own perceptions of mealtimes on the ward and taking the perspective of the patients, the main function of the mealtimes was seen as meeting physiological needs and sustaining life, rather than providing sensory pleasure or opportunities to relate and socialise that staff identified to be of prime importance in their own lives.

Limitations and Reflections

Overall, interpretative phenomenological analysis of interview data from different stakeholder groups revealed that the lenses through which mealtimes were viewed and experienced differed by stakeholder group. However, a number of potential limitations should also be acknowledged.

While interview findings provide a compelling account on differing mealtime foci, the limitations of interview methodology on understanding mealtimes should also be discussed. Firstly, it is acknowledged that the difference in interview processes may have contributed to the differences in findings across the sites, but it was felt important to adapt to the needs of the setting and of the participating relatives, especially given that they were overtly put in a powerless position by the institutional setting. The staff dictated the rules and the way their loved ones were cared for, with minimal choice left for the relatives. It was therefore

important to maintain the data collection process as flexible as possible, to enable all willing participants to share their opinions and worldviews.

It is also important to note that the interviewer/researcher had an active role in both the collection and analysis of the data, and thus had an impact on these processes. It should first be acknowledged that while explicit efforts were made to avoid researcher's own ideas and beliefs about mealtimes from impacting on the interview process, completely avoiding personal influences is unrealistic. Beyond the researcher's own beliefs and knowledge, the multi-method nature of the study and multiple roles of the researcher was noted to impact the interview process. Reflexive practice during the interviews has revealed that the structured, fairly artificial nature of formal interviews was hard to maintain as the researcher and the participants (in this case either relatives or staff) had an informal relationship outside of the interviews. The process of the interview itself was hard to 'guard' from veering into a symmetrical conversation or a discussion. Staff in particular would often ask the interviewer for her opinion on the topic after answering the question, and the researcher found it difficult to retain the asymmetrical nature of the interviews not let the interview become a two-way conversation.

The analysis process also impacted and was impacted by the experiences of the researcher. The researcher found data analysis of patient contributions emotionally difficult, more so than during data collection. Contributions that revealed unmet mealtime needs or any form of distress were difficult to analyse in face of complex emotions of anger and guilt, when considered in conjunctions with intervention success; a retrospective view particularly emphasised that some of the needs and sources of patient distress remained unaddressed. Strategies were put in place whereby the researcher attempted to externalise her emotions and sought additional clinical supervision before performing data analysis. However, despite the measures put in place to minimise researcher impact on the data analysis, some influences may remain.

Despite the potential limitations, the interviews have demonstrated that the different participant groups - patients, relatives and staff - had different outlooks on mealtimes (see Figure 48). The staff's lens on mealtimes was restrictive and unilateral; interview analysis revealed that mealtimes were seen predominantly as a quasi-clinical need and means to achieve health via adequate nutrition and hydration. Physiological needs were seen as a priority and while some staff did acknowledge sensory and social needs, these were seen as peripheral or of secondary importance. Conversely, while the relatives did acknowledge

physiological needs, they laid more emphasis on the sensory aspects of food. Sensory pleasure in tasty, preferred food, as well as a pleasing mealtime environment (nice crockery, attractively laid tables) and the overall enjoyment of food and eating were seen as the most important. Social needs were not prioritised, however, and when asked about the way their loved one enjoyed eating in the past from the social perspective (e.g., alone or with company, round the table or while watching television with a lap tray) many interviewed relatives postfixed it with saying that this is no longer relevant or that this changed since their loved one's dementia progressed. Therefore the aforementioned sensory pleasure was understood as drawing pleasure from food or other individual interactions with inanimate objects (e.g. cups and saucers) rather than the pleasure drawn from social interactions around mealtimes. Here, it is important to note than when asked what was the most important aspect of mealtimes for themselves, both staff and relatives mentioned social interaction most frequently (even over the taste of the food).

Figure 48. *Mealtime Foci by Stakeholder Group*
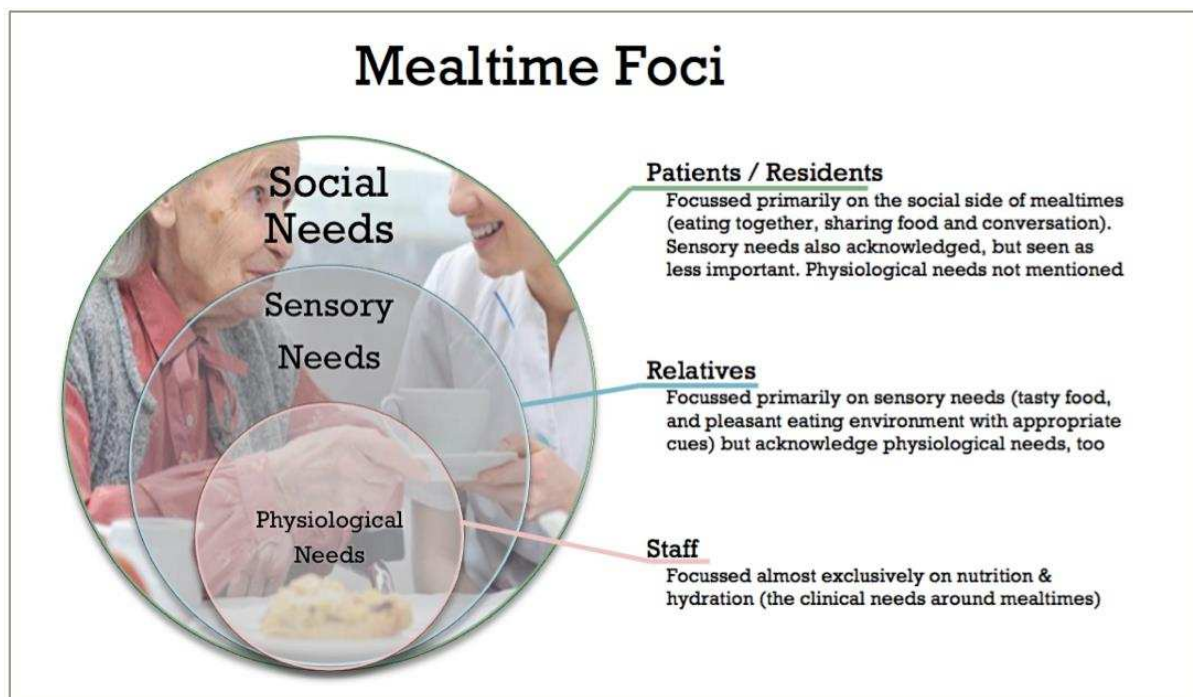
While both staff and relatives seemed to (often indirectly) communicate the diminished importance of social interaction at mealtimes, especially that between patients rather than in patient-staff/relative dyads, residents/patients not only expressed the continued need for and enjoyment of social aspects of mealtimes, but focussed on social needs over any other need category. It is hard to comment on whether such focus on social need was due to lack of social opportunities available on the wards, or whether it was the 'highest-order', most

frequently thought of need for the patients as it was for relatives and staff when they were asked about their own mealtime experiences outside of the ward.

Overall, the interview process has revealed that in their phenomenological understanding of mealtimes in dementia care both relatives and staff applied narrower lenses/foci (both in relation to the focus of the patients/residents and to the way these groups spoke about their own mealtimes). Analysing conversations with the patients has also shown that such narrowing of the scope was not adequate, as social needs within mealtimes remained important - and acutely unfulfilled - for the patients.

6.4 Action Research: Evaluating Interventions

6.4.1. Mealtime Changes: A Summary

The process of the mealtime changes on both research sites started with data collection. Interviews with staff, a meeting with relatives (individual interviews proved difficult to set up on Site 1) and conversations with PWD allowed collection of stakeholder ideas for improvement. Ethnographic and structured observations were also employed to investigate aspects of mealtimes that did not work well at baseline and could be improved. Some ward staff exclusively worked night shifts, only a proportion agreed to participate in interviews and some relatives visited infrequently (e.g. only on some weekends, with the researcher present on Site 1 only on two weekends in Phase 1), 'Suggestions Boxes' were left in staff rooms and the foyer along with slips of paper where the respondents indicated their mealtime ideas and whether they were staff members or relatives. The boxes were enclosed, with only a narrow opening at the top (i.e. ballot-box style) to ensure the anonymity of the contributions. The researcher was also invited to sit a number of staff handovers, where (time permitting) she could discuss arising ideas and share observational results with the staff. Staff who did not take part in the study itself were still able to have a say via the 'Suggestions Boxes' and during the staff meetings/handovers.

In Site 1, due to larger participant numbers in the staff group compared to patients and relatives, a much more frequent staff presence on the wards (vs. relatives) and greater cognitive abilities to actively make suggestions (vs. patients), ward staff made a disproportionately large number of suggestions. In addition to this, a large number of suggestions was also problematic due to the ward's capacity to implement all the changes simultaneously. Due to this, once the staff suggestions were collated, the staff and relatives filled in a survey choosing which 10 changes should be prioritised (see Appendix V). A total of 19 staff and relatives completed the survey, and survey results were weighted equally for staff and relatives' suggestions. The suggested interventions were then ranked (see Appendix W) in order, but frequency with which staff and relatives mentioned them. While the full list can be seen in Appendix W, the suggestions tended to fall either physical category; with most interventions targeted either at food and drink (e.g. 'better quality food') or a wider mealtime environment (e.g. a separate kitchen on the ward). Due to a smaller number of contributions and – crucially – because mealtime changes would affect them most directly, the suggestions made by the patients on the ward were not ranked, and automatically prioritised (see

Appendix W). Food quality, again, was the main area of designed change. Notably, however, one patient (Marie) mentioned feeling left out and disliking having to eat on her own.

As Site 2 did not exclude relatives from participating in the mealtimes, the relatives were on the ward more often and knew about current mealtimes more, and thus provided more ideas. Staff, on the other hand, contributed less than on Site 1; both due to lower participant numbers, but also because – as demonstrated by mealtime observations – there were considerably less mealtime shortcomings (and thus potential for improvement). In fact, during interviews, some staff expressed worry that the project would negatively affect some of the current mealtime features the staff considered particularly beneficial (e.g. 'rolling' breakfast) and required re-assurance about the collaborative nature of mealtime change. Fewer residents could actively express opinions or wishes about mealtimes, but the small number who did spoke mostly about food and social aspects of mealtimes (see Section 6.3.2). Both because of a smaller number of ideas, and due to a less formal approach to mealtime change on Site 2, no surveys took place to prioritise change.

Observations on both sites (both ethnographic and structured; see Sections 6.2.2 and 6.3.1) uncovered additional issues and areas of potential improvement. The issues were shared with staff and relatives on the ward during casual conversations and formal meetings (meetings with staff and relatives were always separate, partly due to the preference of both groups, and partly due to potential difficulties of staff numbers outweighing that of – much smaller in numbers – relatives' group). During these meetings, staff and relatives suggested potential strategies of addressing mealtime issues. The researcher was also able to make suggestions regarding mealtime improvements, but these had to be agreed on by the staff.

The already formal process of coming up with potential interventions on Site 1 was further formalised by the production of a 'Mealtime Action Plan' at the request of the ward and service managers. The plan was organized into 3 general areas. Firstly, staff and researcher assessments demonstrated that the majority of patients are undernourished. Especially for patients experiencing under-nutrition (but also for everyone on the ward) current food provision is inadequate; food availability, quantity and variability, as well as food composition are not optimal for patients' needs. Secondly, there were little or no changes made in the dining rooms before the mealtime. In other words, there were no indications or cues to the patients that the mealtime was about to start. Thirdly, observations demonstrated that while most of the time patients did not experience distress or become unhappy in direct relation to the mealtimes, enjoyment and positive emotions were also lacking. Each area was

divided into 8 detailed findings with associated recommendations for change (see the full action plan is included in Appendix X), and the ward team then proceeded to implement (many of) the pre-determined changes.

While fewer issues relating to mealtimes were present on Site 2, ethnographic and structured observations also uncovered additional aspects of mealtimes (i.e. ones not mentioned by the stakeholders) and served as a platform to stimulate discussion on potential interventions (see Appendix CC). The process of deciding on change, however, was less formal on Site 2. Stakeholders often brainstormed and chose 'leads' for particular interventions 'on the spot', and while most such discussions happened among staff, and no active attempt was made by the staff to involve relatives and residents in the same meetings, collaborative creation of ideas between staff and relatives during casual conversations – often after mealtimes – did take place.

The success of change implementation and differences between the sites. Following the production of the action plan on Site 1, the staff on the ward implemented a sizeable proportion – although not all – of the changes. Appendix Y demonstrates that of 31 agreed changes, the staff implemented 17 (55%). Compared to recommendations that were not taken up, the implemented ones were likely to be more clinical in nature (e.g. regularly weighing patients) or relatively boundaried/concrete (e.g. tasting food and reporting praise, as well as issues, back to the caterers; see Appendix EE or purchasing and using more serveware). Broader interventions, especially if they were psychosocial in nature (e.g. changing mealtime seating arrangements for people with limited mobility so they have a chance to socialize) or required more input from staff that currently provided (e.g. encouraging patients to eat independently where possible and feeding more slowly), were less likely to be implemented.

Not all the implemented interventions were retained after Phase 2 of the research has ended. As can be seen in Appendix Y, only 47% were retained, although at times the retention was partial. For example, fruit was now routinely purchased for the ward, but there were times when the patients did not have access to it. Compared to the implemented and retained changes, the not retained interventions were likely to involve more effort from the staff (e.g. because snacks had to be purchased by staff in their own time (see Appendix JJ), re-ordering of extra food became considerably more sparse and snacks could no longer be offered daily) or because no immediate benefit was observed (e.g. food tasting had ceased two weeks after implementation, as no improvement was noted after compliments and issues were relayed

to the catering staff at the end of Week 1). A wider summary and explanation of change implementation and retention (or lack thereof) can be seen in Appendix KK.

The patterns of implementation and retention of mealtime change were similar on Site 2. Notably, however, Site 2 was better at implementing environmental changes (purchasing new, non-plastic crockery, table cloths and other soft furnishings to make the mealtimes more homely and retaining the homely set-up in Phase 3). Otherwise, changes that required effort or were about meeting psychosocial needs, were less likely to be implemented and retained. Nonetheless, it is important to mention that Site 2 successfully implemented some of the social changes (e.g. introducing the role of a waiter that allowed staff assisting residents with food to stay with the resident throughout the mealtime) and Engagement data (see below) has demonstrated an improvement in social interactions – particularly with aphasic residents – on Site 2.

It is also important to note that some of the measures / collected data for research also became the interventions. As can be seen from the Weight Chart for Site 1 (Figure 29), initially, Site 1 did not weigh the patients at intended frequency (i.e. at least monthly, or weekly if the patient was underweight). Staff-initiated assessments also demonstrated, that many staff did not know if and how participant weight has changed in recent months. Creating a weight chart that showed BMI changes over time, included all patients at once, demonstrated how often patients were weighed and indicated at a glance whether the patient was underweight, of healthy weight or overweight therefore served as intervention *per se.* It also encouraged other interventions in order to help undernourished patients reach healthy weight.

Similarly, some of the occurring changes around mealtimes were not a part of the research study or overtly agreed upon by the staff and/or other stakeholders. For example, the study increased the overall awareness of mealtimes. At the time of the research both sites had newly-established access to externally-provided training packages on a variety of topics and it was noted that a high proportion of chosen packages were around nutrition and hydration.

As discussed above, overall mealtime changes were collaboratively decided by patients (who could express opinions or wishes), relatives and staff. Staff, however, were the principal and often sole implementers of the change due to role and power division on the ward. Both due to the power asymmetries (further discussed in Chapter 7) and roles, they were therefore at

a position to either implement or not implement changes that may have been proposed by patients, relatives or other staff; i.e. changes they did not necessarily agree with or wish for. Due to the participatory principles of the project, implementation of changes therefore remained at staff's discretion. Some changes on Site 1, however, were needed to meet the Trust's Nutritional Standards For Inpatient Services Policy (2012) requirements. In cases where the necessary changes were not implemented (e.g. routine weighing), the ward manager, service manager and the visiting consultant psychiatrist requested change, rather than leaving it at the staff's discretion. The researcher also produced 10 small posters reflecting specific sections of the Nutritional Standards For Inpatient Services Policy (2012; see Appendix HH) to encourage policy compliance.

There were also other ways in which the researcher facilitated some of the change. For example, due to time constraints the staff chose what equipment or serveware they needed to improve mealtimes, but the researcher was asked to compile the list of items and their costs before the procurement process was carried out by administrators (example list provided in Appendix Z). At times the researcher also modelled interventions, before they were taken up by staff. For example, during team meetings some staff expressed doubt about whether added-calorie and added-protein drinks (e.g. milk-based coffee with added cream and powdered milk) would be liked and consumed by the patients. Due to this, the researcher facilitated the first few times when the drinks were used and demonstrated that the residents did indeed consume fortified fluids. Due to the multitude of unresolved mealtime difficulties at the end of the project, the researcher also compiled a resource pack of practitioner-produced literature on strategies to improve mealtimes (see Appendix R) as a source for potential ideas.

The change in mealtime outcomes and experiences pre-, during and post-implementation of interventions was measured utilising all of the measures used in the project; namely ethnographic methods, interviews with stakeholders, tracking weight change and structured mealtime observations (see Sections 6.2 and 6.3). Section 6.4.2 combines these methodologies to provide a more holistic view of mealtime change, specifically focusing on change over the three phases of the research and comparing research sites.

Finally, it is important to note that research findings, progress and implementation as well as success of interventions was communicated to the stakeholders in quarterly newsletters (see Appendixes AA and BB for Sites 1 and 2 respectively), as well as casual conversations. This was a way to inform the stakeholders of progress (or lack thereof) and find out their opinions

and perceptions regarding the change, but also served as encouragement to continue implementation and retain changes.

6.4.2. Group-Based Outcomes: Comparison Between Sites

Given that the proposed and implemented interventions were site-specific, the outcomes were investigated separately for each site. Importantly, due to the co-emergent nature of the changes, it was not feasible to track or measure how each intervention affected mealtime outcomes. Instead, the accumulation of direct and indirect changes was measured across the research phases. It is acknowledged that the phases of pre-, during- and post-implementations were rarely clear-cut for each intervention, and that different integrations within a site started and ended within somewhat uneven time-frames. However, for the purposes of evaluating the overall success of the project, data analysis followed the pre-determined framework.

6.4.2.1. Ethnographic observations

Ethnographic observations provided a broad, holistic view to capture the nature of mealtime changes, their implementation and success. Data collection and analysis is already described in Section 6.3.1. Instead of repeating the overall themes emerging from ethnographic observations, this section aims to provide a summary of ethnographic findings comparing Sites 1 and 2. It is through comparison of settings with the same remit, similar set up and within the same NHS organisation that micro-cultures influencing intervention success become visible.

As expected, many of the mealtime interventions differed across sites; often due to the differences between settings. For example, while Site 1 often talked about not having enough food, especially at teatime, Site 2 considered smaller portions at teatime and distributing the courses across a longer period of time. Similarly, Site 2 discussed the need for and subsequently implemented a role of a 'waiter' to distribute food, so staff assisting residents to eat do not have to periodically leave the person they are assisting. Also, to celebrate food and mealtimes, Site 2 adapted activity time to incorporate food, and created three weekly food-related afternoon activities (see Appendix DD). Where the 'issue' was the same or similar on Site 1 and Site 2, the solution/intervention was often different. For example, in attempts to increase independent eating, Site 1 prioritised assistive equipment (e.g. specially-shaped spoons for people with hand-dexterity issues), while Site 2 focused on finger foods. Overall, as can be seen from Appendixes P and X, Site 1 not only had fewer

suggestions and interventions, but was also more individualistic; while both wards made changes to mealtimes overall (i.e. changing experiences of PWD as a whole), Site 2 looked more at meeting individual needs of each resident.

A small proportion of changes were near-identical across both sites. Nonetheless, the reasons driving the intervention and/or its outcomes were often different. For example, the same weight chart was used to evaluate weight changes, but the reasons for using the chart differed. Unlike Site 1, Site 2 was already weighing residents at a greater frequency than required by policy (all patients were weighed on weekly basis). The reason for using the chart was more to demonstrate change, increase interventions if the person was losing weight and encourage change retention by demonstrating cases of BMI increase. Similarly, both sites decided to collect information on residents' past mealtime preferences (e.g. favourite drinks and eating habits) by consulting relatives (see Appendix S) and producing Mealtime Profiles for the patients (see Appendix MM). The use of the mealtime profiles was different. While both sites used mealtime profiles to inform food purchase choices, Site 1 included frequently mentioned items on their list and offered these items for everyone (e.g. staff bought lemonade if it was a commonly mentioned drink across Mealtime Profiles and then offered it to all patients), and Site 2 treated each profile individually and purchased items regardless of how frequently they were mentioned and saved them for residents who liked them specifically.

Another notable difference on Site 2 was the involvement of the relatives not only in suggesting, but also implementing change. Relatives on Site 2 contributed by buying equipment and bringing in food. For example, on several occasions Jean's son brought in soft fruit not only for his mother, but also for other residents and staff to share. As some relatives frequently assisted residents to eat, they were also keen to try new approaches to encourage independence or increase food/fluid/nutrient intake. For example, aside from often bringing his favourite foods, Rupert's wife bought him a divided dish in order to prevent the flavours of his pureed meals from mixing and successfully changed pace and turn-taking of feeding to decrease Rupert's distress when being fed.

Overall, these differences between sites demonstrate that despite identical function of the wards, their specific micro cultures influenced what mealtime changes were seen as necessary. However, they have also affected the process of implementation and retention. Site 1 struggled to implement and retain change, whereas Site 2 implemented efficiently and promptly, but also found it difficult to maintain some of the changes. The difference may have

stemmed from a larger number of intended changes; considering workload and staffing pressures on the ward, staff may have become overwhelmed by the magnitude and requirements of change. The nature of the changes also impacted implementation and retention. Physiological/clinical interventions, as well as labour-nonintensive physical/environmental changes were implemented the best, while social change was lacking. However, it is also notable that Site 2 were used to instituting prompt change once difficulties were noticed. For example, long before the start of the research Site 2 had identified lack of staff during lunch and changed shift patterns in relation to this, so 2 groups of staff (i.e. morning and afternoon shifts) assisted with handover. Although this impacted on handover time, the staff felt that mealtime benefits were more important. Site 1 experienced the same difficulty, with staff self-identifying the need for more staff at lunchtime and potential to use both sets of staff if handover and/or lunch times are changed (in other words, staff were aware of both the issue and the solution prior to the research process). The solution, however, was not spontaneously implemented. Importantly, even once the issue and solution were 'formalised' within the action plan, the change did not take place; involving both sets of staff at lunchtime on Site 1 was one of the non-implemented changes.

As clarifie by ethnographic observations, implementation of changes and its success also depended on practical and financial factors that differed across the wards. For example, an established petty-cash flow and access to NHS procurement via Housekeeping management on Site 1 meant that money for additional food purchases was readily available and equipment/serveware could be bought via an official process, using the ward's budget. As Site 2 was located on a site that belonged to a Local Authority, rather than being part of a large NHS site (e.g. with NHS Housekeeping team) meant that funds were much harder to obtain and NHS procurement systems could not be used to buy equipment/serveware. Relatives and staff on Site 2 personally funded some of the purchases, and a small NHS research grant available to the researcher was used to fund initial changes. Once positive impact was demonstrated, a small amount of weekly funds was secured from service management. However, funding complications and delays negatively impacted on the rate and promptness of implementation.

Nonetheless, the quality of relationships and interactions across services often helped to mitigate – or exacerbated – practical issues. For example, Site 1 received meals from a different NHS Trust (located on the same site), but did not have a contract. This meant that the NHS Trust Site 1 belonged to was not paying the Trust providing catering for the services.

Due to this, catering services often refused to meet the requirements from Site 1 (e.g. catering did not provide soft-textured meals requested by Site 1). Provision was further impacted by the animosity between ward staff and catering staff. As discussed above, while all stakeholder groups often complained about food quality and variety among themselves, this information was rarely communicated to caterers. An interview with the Chef in charge of food provision for Site 1 revealed that while some modifications of provision required a contract, some flexibility was possible upon request. However, the intervention of tasting food and communicating criticisms as well as complements to the catering staff on a weekly basis ceased after only 2 weeks (i.e. only one event of providing feedback). The staff reported no change after the first set of feedback was communicated to the catering team and were adamant that no change was possible; thus the intervention was perceived as "pointless".

Officially, Site 2 had even less influence on food provision, as on-site catering was privately-provided. As such, the private providers were not subject to some of the NHS nutritional policies and were not obligated to meet as many requests or demands. For example, despite requests for a variety of finger foods at teatime to improve independence in eating for some of the residents, catering could not provide these options aside from sandwiches due to higher costs (however, the catering manager fist attempted to calculate costs and considered a variety of options). A positive relationship between ward and catering staff – especially the ward manager and the catering manager – meant that small-scale routine requests could be met, even if they were outside of the remit of official policy. For example, officially, the ward could not request extra food, outside of official provision. However, if the ward ran out of bread or a resident asked for a fried egg, ward staff were able to ask catering staff for (and receive) these items. This demonstrated that while practical aspects could interfere with change implementation, relational factors could either mitigate or further exacerbate the issues.

Overall, the comparison of ethnographic findings on change creation, implementation and retention demonstrated that despite the wards being part of the same organisation and performing the same function, change heavily depended on ward micro cultures. Many of the interventions were different between the sites. In the majority of cases where both sites experienced the same mealtime issues, the solution/intervention differed. Even if the intervention was the same or very similar in Sites 1 and 2, the reasons (i.e. issues behind it), as well as the outcomes differed. Site 1 approached mealtime change in a much more formal way than Site 2, while the overall patterns of change implementation and retention differing

between sites (retention rates in particular were much lower on Site 1). External factors such as funding also impacted mealtime interventions, but the impact was often exacerbated or mitigated by relational factors.

6.4.2.2. Stakeholder Interviews

Given the advancement of memory difficulties in the patient/resident population, PWD could not evaluate mealtime change; they could not remember previous ward mealtimes and could not offer comparative reflections. Nonetheless, conversations with PWD proved a useful method of assessing intervention success. While ethnographic methods provided *observed experiences*, interviews were a form of collecting *communicated experiences* of the 'here and now'.

All stakeholder groups (patients/residents, relatives and staff) were particularly positive about being asked about their experiences of mealtimes and when provided a chance to contribute ideas. people with dementia in particular were both capable and very willing to share ideas about change, and exhibited excitement when doing so. When asked for ideas on food items to be purchased for the ward as additional snack, PWD provided more than a 100 suggestions across both wards, which were then used to inform purchasing choices (see Appendix JJ).

The process of change itself was frustrating for staff, both in terms of delays or complications around implementation and in relation to additional effort required. Although this was rarely shared in formal interviews, informal conversations revealed frequent hesitation about suitability or success of interventions. For example, Sally [nurse, Site 1] was recorded saying: "*It's not worth it. They will only get messed up*" when talking about use of tablecloths. In terms of verbal communication, patients did not express being affected by the intervention process, but some specific interventions were commented on positively. For example, on Site 2 several participants commented about liking the apron (mimicking a tuxedo) that the dedicated waiter of the mealtime, delivering food to the tables, was wearing. Relatives on Site 1 were excluded from mealtimes and, due to this, could not name observable mealtime changes. On Site 2, however, relatives appeared more positive than the staff about the changes. Rupert's wife Maureen, for example, said: "*It's much better. We don't all gather by the kitchen now*", referring to the aforementioned introduction of a 'waiter', which meant that relatives no longer had to leave the patient when collecting meals from the server in the kitchen area.

Overall, the interviews revealed that staff and relatives were more positive about mealtimes on Site 2 during all research phases, which was corroborated by observational data. However, it should be taken into account that the interviewer also acted as a facilitator of mealtime change on both sites. It is therefore unclear how much bias the duality of researcher role introduced to the interview findings; it is possible that due to an established rapport and the facilitator role, both staff and relatives were inclined to provide exaggeratedly positive reflection.

6.4.2.3. Staff-Initiated Assessments

As pointed out in section, the majority of staff-initiated assessments were only carried out in Phase 1 and therefore are not discussed in this section. However, despite a large proportion of missing data and changing participant population on Site 1, attempts were made to compare BMI categories between Phases and across Sites.

While data on Site 1 should be treated with extreme caution due to irregular weighing of patients (especially in Phase 2), available data shows a slight decrease in the proportion of underweight participants from Phase 1 to Phase 3, a drop in healthy BMIs and an increase in overweight individuals (see Table 11). However, it is important to note that individuals missing recorded weights, were often the ones who were visually emaciated, suggesting that figures for Site 1 are misleading.

In comparison, Site 2 saw an increase in underweight individuals and a decrease in individuals of healthy weight. Again, however, small sample numbers should be kept in mind when considering these trends.

Table 11. BMI Category Breakdown per Research Phase and Research Site

		Phase 1	Phase 2	Phase 3
Site 1	Underweight	3 (30%)	1 (25%)	3 (27%)
	Healthy Weight	5 (50%)	1 (25%)	5 (45%)
	Overweight	2 (20%)	2 (50%)	3 (27%)
Site 2	Underweight	3 (38%)	3 (33%)	4 (44%)
	Healthy Weight	5 (63%)	5 (56%)	4 (44%)
	Overweight	0 (%)	1 (11%)	1 (11%)

6.4.2.4. Eating Ability & Eating Assistance

Eating Ability and Assistance observations were also divided into Phase 1 (pre-intervention), Phase 2 (during-intervention) and Phase 3 (post-intervention). It is acknowledged that these timeframes are somewhat artificial, as not all interventions started and ended at the same time. Instead, the division into Phases followed the pre-determined research framework (see the Method section) dividing the data into roughly equal timeframes.

Table 12. Number of observations at different mealtimes per Research Site

Site 1			Site 2		
Phase 1	Phase 2	Phase 3	Phase 1	Phase 2	Phase 3
45	32	43	12	24	23

Research Phase did not significantly predict any of the outcome variables. However, a marginally significant effect of research phase was found on Self-Feeding Cycles [$F(2, 175) =$ 2.49, $p = .09$]. Post hoc comparisons using the Bonferroni test indicated that the mean score for Phase 1 (M = 32.98, SD = 25.21) was significantly different than Phase 2 (M = 23.93, SD = 19.13), suggesting that patients received more assistance during Phase 2 than Phase 1. However, Phase 3 (M = 29.65, SD = 20.76) did not significantly differ from Phases 1 or 2 in terms of Self-Feeding Cycles.

While the results did not show a significant difference, some of the change patterns are particularly noteworthy. While physical prompting (e.g. helping a patient hold a fork or moving the plate closer, instead of feeding them) was more common on Site 2, the patterns diverged as research phases progressed. As can be seen in Figure 49, physical prompting decreased in Phase 2 on both sites. In Phase 3 however, it continued to decrease on Site 1 and increased above initial levels on Site 2.

Table 13. A One-Way ANOVA of Research Phase (IV)

	Phase 1		Phase 2		Phase 3			
Variable	*M*	*SD*	*M*	*SD*	*M*	*SD*	*F*	*p*
Physical Prompting	1.84	2.92	1.07	1.74	1.22	2.50	1.62	.20
Verbal Prompting	2.58	3.43	1.71	2.46	1.62	2.48	2.08	.13
Self-Feeding Cycles	32.98	25.21	23.93	19.13	29.65	20.76	2.49	.09[§]

Fed-by-Others Cycles	10.70	21.52	12.45	20.39	10.71	18.67	.14	.87
Rate of Independent Eating	80.87	38.14	74.90	43.71	81.25	38.54	.39	.68
Total Percentage of Food Eaten	85.72	40.23	84.77	41.22	85.49	31.00	.01	.99
Dysphagia	1.16	.46	1.13	.39	1.12	.38	.13	.88
Difficulty Initiating	1.33	.73	1.40	.78	1.20	.54	.94	.39
Difficulty Using Utensils	1.51	.72	1.40	.65	1.56	.73	.40	.67
Difficulty Scooping	1.74	.79	1.60	.82	1.70	.74	.26	.77
Difficulty Recognising Total	1.11	.44	1.05	.22	1.08	.39	.29	.75
Difficulty Maintaining Attention	1.54	.76	1.64	.80	1.56	.71	.31	.74
Difficulty Staying Alert	1.40	.70	1.45	.81	1.37	.74	.16	.85

*Note: *$p < .05$; $^\S p < .1$

Figure 49. Estimated Marginal Means of Physical Prompting Across Research Phases
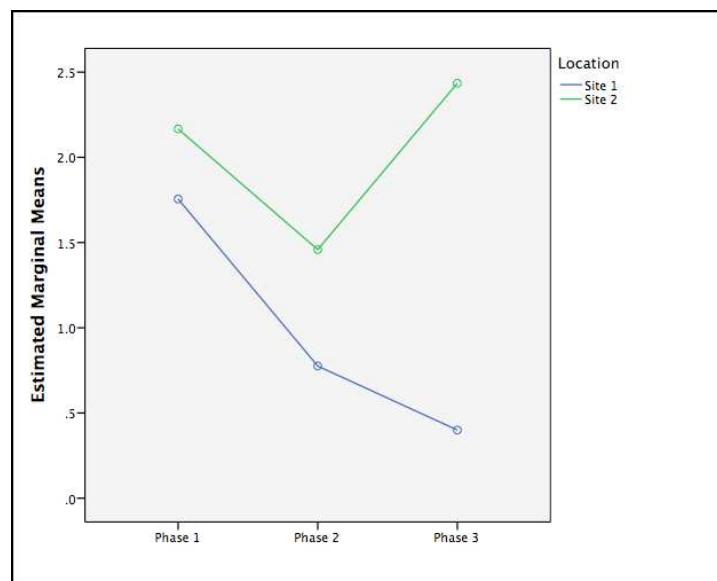
The patterns for verbal prompting also showed a starkly different pattern across sites (see Figure 50). While higher on Site 1 initially, it decreased as research progressed, while the reverse pattern was seen for Site 2.

Figure 50. Estimated Marginal Means of Verbal Prompting Across Research Phases
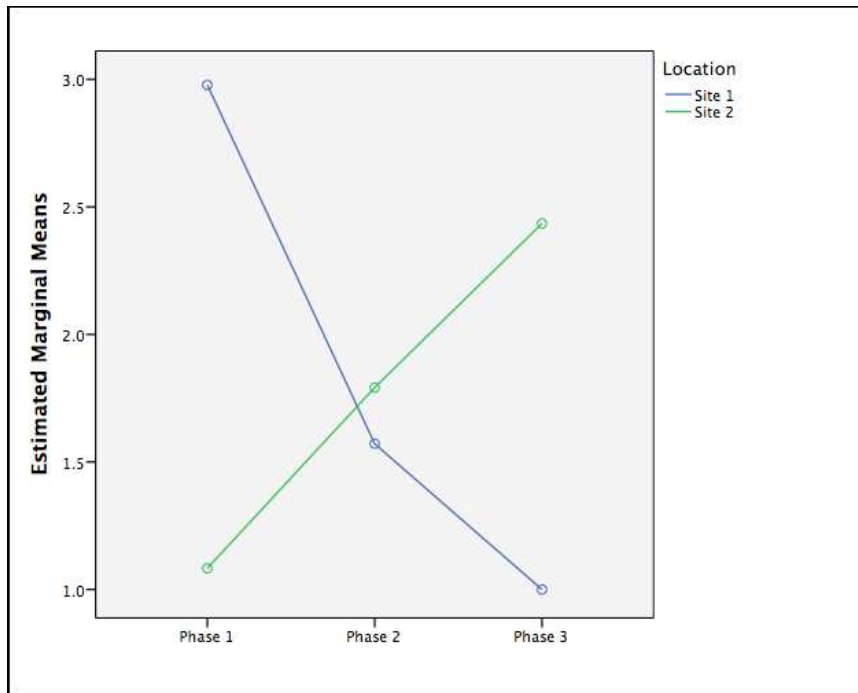
Figure 51. Estimated Marginal Means of Total Amount of Food Eaten
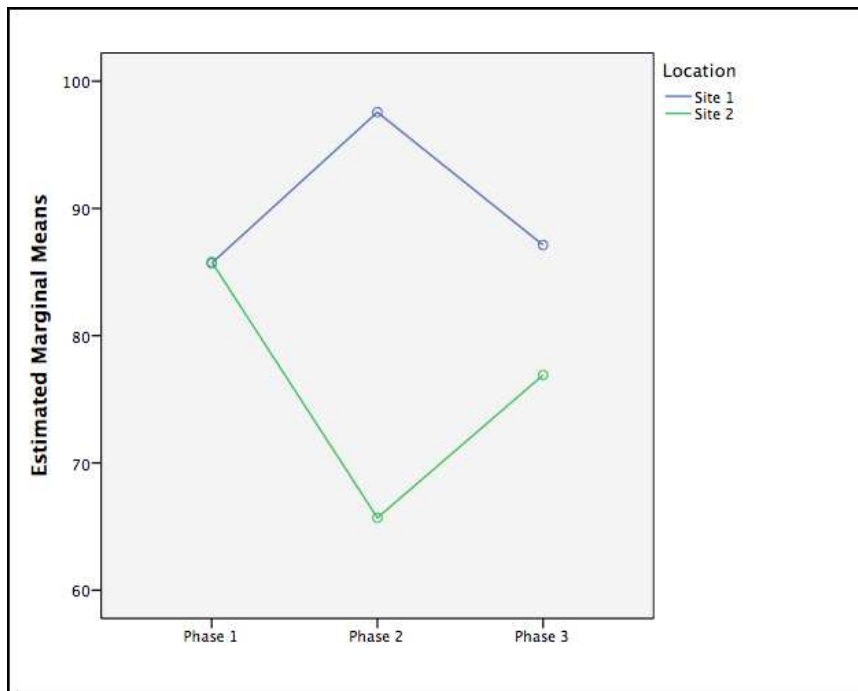
Also, while in Phase 1 both sited showed a near-identical average amount of food eaten (86%), in Phase 2 this percentage dropped to 66% on Site 2, yet rose to 96% on Site 1. In

Phase 3, however, the percentages of food eaten moved back nearly to the initial levels (87% on Site 1 and 77% on Site 2).

All this data should be treated with caution due to differences in number of observations per research phase, as well as the changing patient profile on Site 1. Overall, Phase-based comparisons in Eating Ability and Eating Assistance suggested no significant improvement or deterioration during the research phase. For example, there was no significant deterioration in mealtime difficulties (e.g. significantly more issues with patients maintaining alertness at mealtimes). Food intake also did not improve. However, a marginally significant result showed that independent eating near-significantly decreased during the intervention phase of the research, compared to baseline, but increased again post-intervention. This suggests that proportionally more assistance was provided during Stage 2. This goes in line with qualitative data, which shows that while mealtimes did improve initially, many of the changes were not retained.

The pattern of assistance, however, was more complicated when compared between the wards. On Site 1 physical prompting (such as handing someone a fork) decreased as the research progressed, and decreased on Site 2 during intervention, increasing above baseline in the post-intervention period. A clear explanation for these differences is hard to establish and is particularly speculative, but it might be that the additional workload of implementing changes in Phase 2 reduced staff ability to provide physical prompts, although this does not explain the differential change in Phase 3 between the wards. However, the findings may also be related to staffing levels or any other factors not captured by the research, and it is important to note that while the pattern was observed the differences were not significant. It is equally difficult to explain why verbal prompts decreased on Site 1, yet increased on Site 2.

However, the differential pattern of the amount of food eaten per research site and its change during the research phases could be explained in relation to qualitative observations. As discussed above, Site 1 experienced more mealtime issues/shortcomings than Site 2. It is therefore possible that the relatively more optimal mealtimes on Site 2 were disrupted by the interventions, but improved on Site 1. This would go in line with the Social Facilitation theory, which suggests that presence of others or being observed (as indeed the staff were by the research) would improve performance on simple tasks, but decrease performance on difficult tasks (Bond & Titus, 1983). Considering the level of shortcomings, improving

mealtimes beyond the baseline on Site 1 was not difficult (i.e. simple task), while Site 2 were already operating many approaches to mealtimes needed on Site 1, making their interventions more difficult and thus decreasing performance. Improved or decreased staff performance at mealtimes could then have impacted on amount of food eaten by the patients, as reflected in Figure 51. However, this explanation should be considered as speculative and merely as a platform for future research.

6.4.2.5. Engagement, Activity and Mood

Engagement, Activity and Mood observations were also divided into Phase 1 (pre-intervention), Phase 2 (during-intervention) and Phase 3 (post-intervention). These timeframes, however, were somewhat artificial, as not all interventions started and ended at the same time. Instead, the division into Phases followed the pre-determined research framework (see the Method section) dividing the data into roughly equal timeframes.

Phase-based comparisons of Activity data on Site 1 (Figure 52) have demonstrated minimal change throughout the research phases. While eating slightly decreased towards Phase 3, feeding dropped in Phase 2 and regained baseline incidence at Phase 3. A small but considerable increase was also seen in not engaging in any activity while being alert, and napping, as well as sleeping.

Site 2 (see Figure 53) has seen a cross-over in independent eating and feeding over the researchers; while eating on one's own decreased, the incidence of feeding increased. While the makeup of participant pool was steady on Site 2, the crossover depicts a change in either patient capability or the staff approach (or – likely – both). Patients tended to be awake more often as the study progressed, but not necessarily engaged, as demonstrated by the data. Finally, not eating, yet engaging in a different activity has increased, potentially accounted for by the introduction of tablecloths and serveware on Site 2.

Engagement data on Site 1 (see Figure 54) has revealed several mirror patterns. The drop in having no opportunities to socialise in Phase 2 was mirrored by an increase in staff-initiated interactions with patients, although neither of the change was sustained in Phase 3. Similarly, the drop in having no opportunities to socialise in Phase 2 was mirrored by being interacted with, but not responding, suggesting that staff started interacting more with aphasic patients. However, the change was once again not retained in Phase 3.

Engagement on site 2 (see Figure 55) did not show a clear mirrored pattern, but some trends emerged. Having no opportunities to socialise increased in Phase 2 coming back to near-baseline levels in Phase 3. Interacting with another resident dropped slightly in Phase 2, but rose 3-fold in Phase 3 (once a more homely set-up of the mealtime environment was established). Being interacted with, but not responding also rose nearly 4-fold from baseline to post-intervention, suggesting that at least in terms of engagement, staff on Site 2 successfully implemented interventions.

Figure 52. Activity Patterns Across Research Phases for Site 1

Activity Patterns: Site 1

	Phase 1	Phase 2	Phase 3
Eating	43%	44%	39%
Being Fed	9%	4%	9%
Eating & active with an inanimate object	0%	0%	0%
Eating & walking	1%	1%	0%
Not eating, engaged in a different activity	23%	24%	22%
Not eating & walking	8%	5%	5%
Alert, but disengaged (no visible activity)	10%	10%	14%
Sleeping/Napping	7%	11%	10%
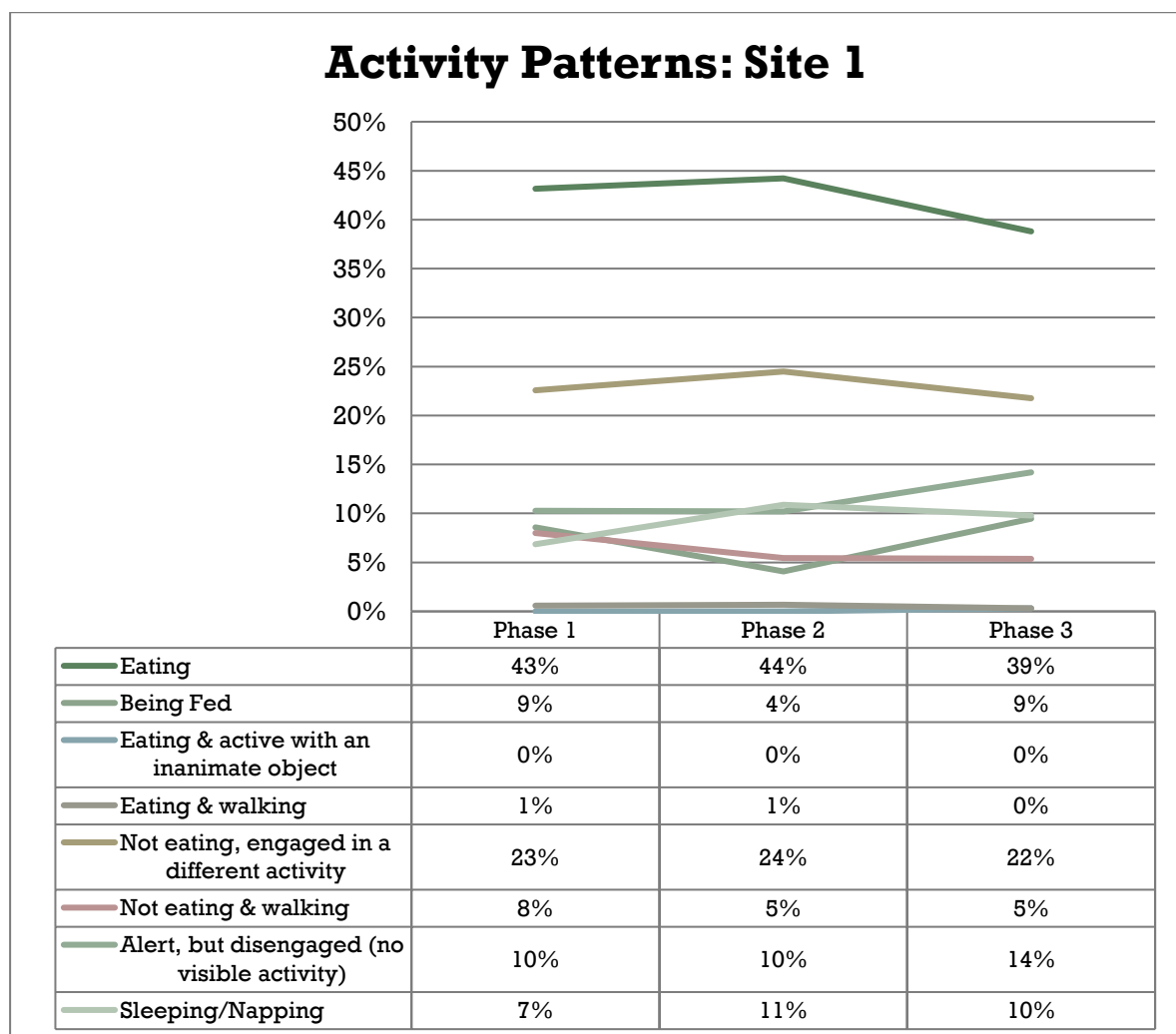
Figure 53. Activity Patterns across Research Phases for Site 2

Activity Patterns: Site 2

	Phase 1	Phase 2	Phase 3
Eating	28%	20%	22%
Being Fed	17%	31%	28%
Eating & active with an inanimate object	1%	0%	0%
Eating & walking	0%	1%	0%
Not eating, engaged in a different activity	32%	25%	23%
Not eating & walking	5%	5%	6%
Alert, but disengaged (no visible activity)	5%	7%	16%
Sleeping/Napping	13%	10%	5%
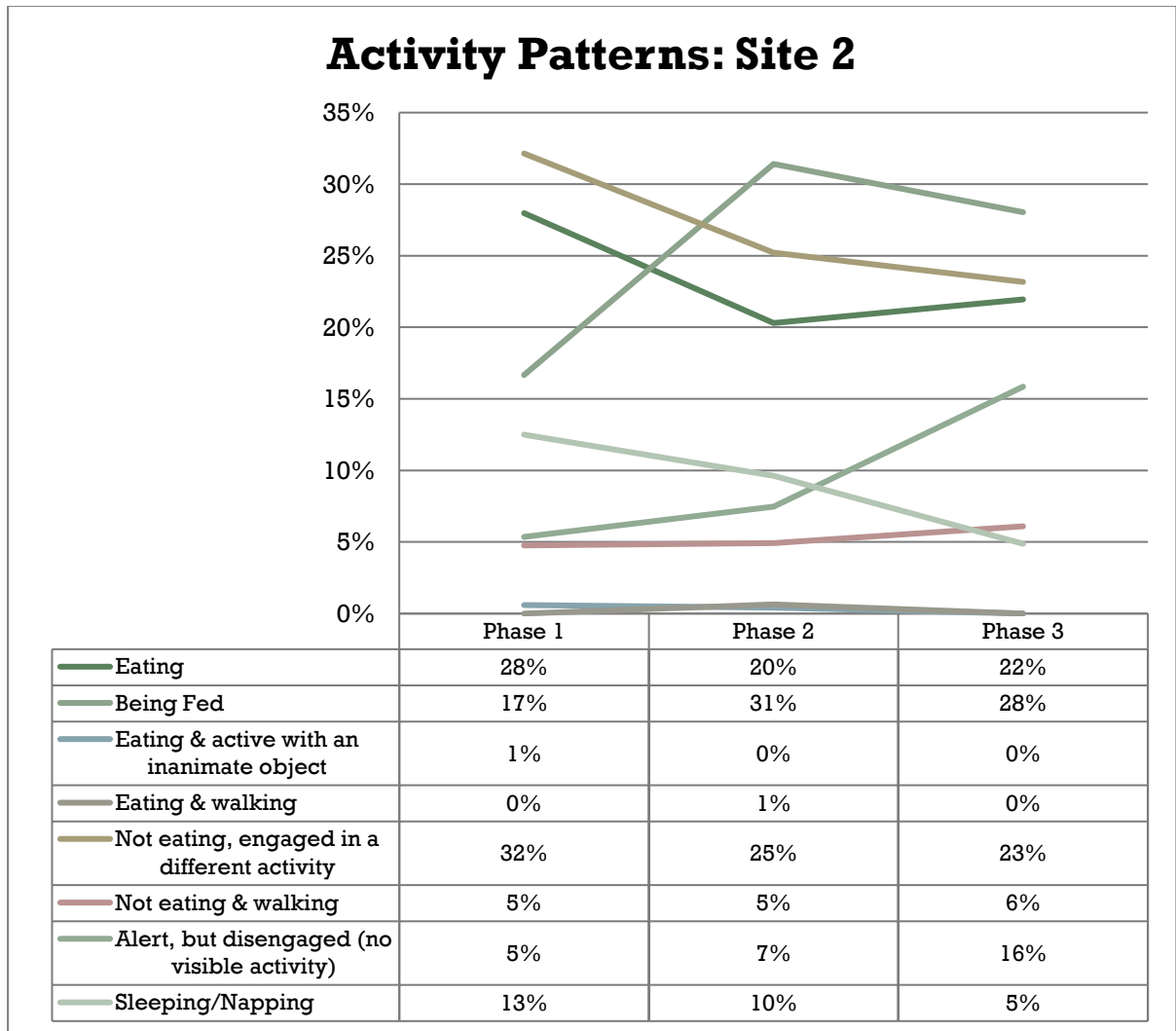
Figure 54. Engagement Patterns Across Research Phases for Site 1

Enagement Patterns: Site 1

	Phase 1	Phase 2	Phase 3
Interacting with another resident (self-initiating)	4%	5%	5%
Interacting with another resident (other-initiated)	0%	1%	1%
Interacting with staff (self-initiated)	12%	14%	10%
Interacting with staff (other-initiated)	13%	21%	14%
Interacting with a relative (self-initiated)	0%	0%	0%
Interacting with a relative (other-initiated)	0%	0%	0%
Verbalising, but not interacting	2%	2%	1%
Intently observing other interact	1%	2%	2%
Interacted with, but does not respond	2%	0%	1%
Interacting/verbalising, but not responded to	11%	11%	12%
Does not socialise (opportunity present)	29%	22%	27%
No opportunity to socialise	26%	25%	26%

Figure 55. Engagement Patterns Across Research Phases for Site 2

Enagement Patterns: Site 2

	Phase 1	Phase 2	Phase 3
Interacting with another resident (self-initiating)	6%	4%	18%
Interacting with another resident (other-initiated)	6%	1%	1%
Interacting with staff (self-initiated)	6%	5%	2%
Interacting with staff (other-initiated)	6%	9%	9%
Interacting with a relative (self-initiated)	6%	1%	1%
Interacting with a relative (other-initiated)	4%	3%	0%
Verbalising, but not interacting	6%	2%	0%
Intently observing other interact	2%	1%	0%
Interacted with, but does not respond	5%	13%	18%
Interacting/verbalising, but not responded to	6%	5%	2%
Does not socialise (opportunity present)	24%	25%	26%
No opportunity to socialise	22%	31%	23%

Finally, as mood was recorded as a continuous variable, a 2 (Location) x 3 (Phase) ANOVA was performed. The analysis yielded no significant main effects for location, $F(1, 1397) = 1.03$, $p = .31$ or for Research Phase, $F(2, 1397) = .02$, $p = .99$. However, the interaction effect was significant, $F(2, 1397) = 6.87$, $p < .01$.

Figure 56. Estimated Marginal Means for Mood Across Sites and Phases
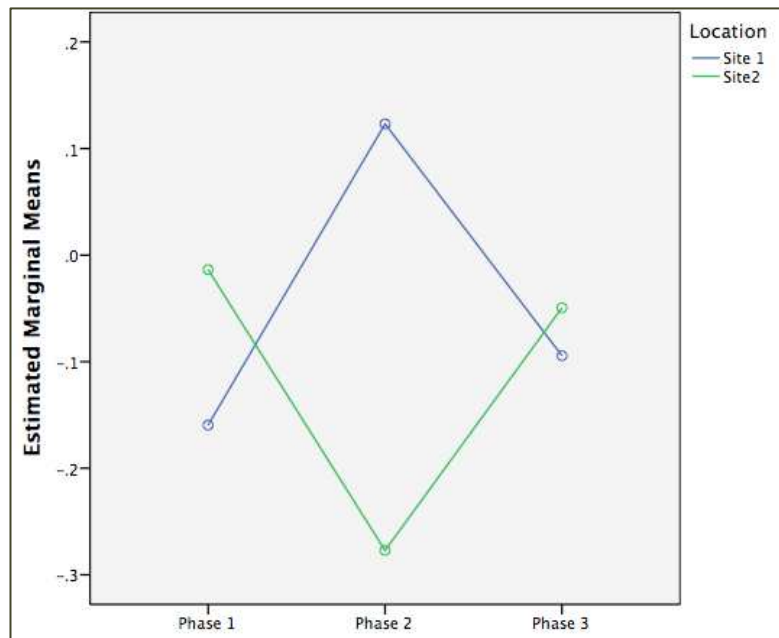
As can be seen in Figure 56, at Phase 1 the mood was slightly higher on Site 2 than Site 1. During the intervention phase, however, the average mood on Site 2 dropped, but increased on Site 1. At Phase 3, however, the moods on each Site came back to near-baseline levels, improving on Site 2 and worsening on Site 1 between Phases 2 and 3. This was similar to the findings in Section 6.4.2.4 showing that amount of food eaten increased and then dropped back to baseline levels on Site 1, but decreased and rose back to baseline levels on Site 2. Overall, this suggested that the process of change (i.e. Phase 2) was disruptive to patient outcomes on Site 2, but beneficial on Site 1 on several outcome measures. As argued in Section 6.4.2.4 this difference in pattern might stem from a different baseline, where mealtimes on Site 1 saw more baseline issues and were therefore easier to improve beyond baseline, while more effective mealtimes on Site 2 at baseline meant that change was disruptive to the already well-thought-out processes.

6.4.3. Individual Outcomes

While group-based outcomes provide effective summaries of mealtime change between the research sites, the process of summarising findings for all participants within a setting obscures patterns of individual change. As could be expected, patients/residents within a research site experienced mealtime change (or lack thereof) differently from one another. In addition to this, some of the interventions were particularly tailored towards a specific individual, further affecting their experiences and outcomes. To illustrate individual change, the current section offers 6 vignettes (3 per research site).

Site 1: _Maureen - eating independently, walks a lot, medical comorbidity_

Maureen was admitted to the ward in March 2014 due to her experiences of dementia (she was reported to act aggressively sometimes) together with Type 1 diabetes, which required nursing input. She was considerably undernourished with a BMI of 15.7 at admission. She was able to eat independently and would often ask for food or say she is hungry. She did, however, remain very active, and would rarely settle at a table or any one place for an extended period of time. Due to this she often ate while walking. Ethnographic observations soon demonstrated that staff (especially HCAs who did not have a nursing background) often opted to not give Maureen any food outside of mealtimes and not serve her extras due to apprehension that it would adversely affect her diabetes. On numerous occasions when diabetic desserts were not available, she would not be served a dessert, while difficulties in maintaining attention and frequent walking meant that she would sometimes leave food behind. Staff often interpreted this behaviour as 'choice' not to eat and rarely encouraged Maureen to continue eating or hand her the plate back. When this did occur, however, Maureen would eagerly continue eating, suggesting that leaving food was more about attention deficit, than an active choice to stop eating.

Maureen would often get frustrated, shout, and/or throw crockery on the floor when her requests for more food were refused. She would, on occasion, take food from other patients, but usually when offered or after telling them she was hungry (she also shared her food with others). If staff spotted Maureen helping herself to food either from the kitchen area or other patients' plates, they would at times take it away from her. On one occasion, when Jackie gave Maureen her yogurt, staff assumed Maureen had "snatched" the food from Jackie and forcibly separated them. The Activity-Engagement-Mood observations that took place during this

mealtime, however, demonstrated that both women experienced a more positive mood than usual, while Jackie ate more than she did on most other teatimes.

During the 'intervention' stage of the research Maureen's situation was often brought up in staff meetings and the researcher attempted to question the medical basis behind the decision to not give Maureen larger portions and food outside of mealtimes. Some disagreement about what foods were or were not appropriate was present among the nurses, but overall they did agree that eating more food in general did not pose significant health risks. Health Care Assistants, however, remained doubtful about what food they could give Maureen; while nurses were rarely directly involved in the mealtime. Refusing extra food decreased in frequency, but remained present, while extra food and food outside of mealtimes was still rarely offered (the staff approach was not unified). Maureen's weight did slightly increase during the intervention phase, although this was not enough to reach healthy BMI levels. However, her BMI dropped slightly in the post-intervention state. This could not be explained by illness, change in ability to eat, which remained largely the same, or a change in Maureen's activity, engagement or mood during the mealtimes, which also did not show much variance across phases. However, the weight loss seemed to coincide with a decrease of foods available outside of mealtimes in the post-intervention phase (i.e. lack of snacks).

Site 1: _Hazel – some eating dependence, does not accept assistance, good mobility_

Hazel was admitted to the ward 5 months after the start of the project. She experienced advanced dementia, but was physically able-bodied and could mobilise unaided. Her cognitive capacity to maintain attention was significantly affected and Hazel would rarely be able to focus on an activity or stay in one place for more than a few minutes. Her restlessness affected mealtimes because she was not able to stay at a table and would frequently walk off to unsupervised areas. Given the complex and multiple demands at mealtimes, along with a high number of patients who were wholly dependent on mealtime assistance, assisting Hazel at mealtimes proved difficult. In addition to that, Hazel at times reacted negatively to close supervision (i.e. being followed around by a member of staff). At the initial stages of the research, Hazel would often seek out food when hungry (although she could not always communicate this verbally, she would take any food left around - such as biscuits - and eat it, which sometimes resulted in an offer of further snacks). While her attention difficulties

prevented Hazel from eating an entire meal in one sitting, providing that staff gave her the plate or cup back, she would often finish all or nearly all of the food provided; her absence from the dining room, however, meant that even when extra food was available and offered, she rarely received a second helping.

As the study progressed, Hazel's ability to eat independently got further affected by dementia processes. Procedural aspects of eating (such as using cutlery and recognising that the vessel she was holding contained edible substances) became more difficult and attention deficits worsened. Some of the staff have recognised the deterioration in Hazel's mealtime abilities and would at times attempt to feed Hazel. This was also the personalised suggestion that arose from research feedback and group discussions; although it is impossible to say how much the research itself has contributed to the way Hazel's mealtime needs were approached. Nonetheless, Hazel was rarely receptive to feeding and multiple attempts to engage and establish rapport prior to feeding were necessary although very rarely implemented by staff. She also appeared to require - and respond better to - more physical prompting (e.g. putting food in her hand), rather than feeding. Hazel's wakefulness and sleep cycles also changed somewhat and she would sometimes be napping on a sofa at lunch or teatime. Overall, this resulted in a steady deterioration in Hazel's nutritional intake and weight. This seemed to result from a collision of moderate need for mealtime assistance (i.e. not being fully independent, but also not in need/accepting of feeding) and unwillingness to accept full mealtime help / feeding. As a result, Hazel's weight declined dramatically, and she was nearly at the point of being categorised as malnourished at the end of the research.

Interestingly, Hazel's engagement and mood did not seem to follow a similar pattern of deterioration. She engaged better with other patients, where negative reactions were rarer, with interactions remaining very similar in incidence and type, while mood showed a slight increase. Both her engagement and her mood seemed to peak when she was in the foyer and able to move around without much restriction or verbal encouragement to stay put.

Site 1: _Flynn_ – *mostly independent eating, visual impairment, mobility difficulties*

Flynn has lived in Site 1 for the past 9 years before the project started, diagnosed first with a schizoaffective disorder and very limited eyesight / near-blindness, he was both thought of and treated by staff as having dementia. He was tall and visibly emaciated at the start of the project.

Flynn was able to make choices about preferred foods and ate independently. Any difficulties in eating ability were directly related to his lack of sight. For example, he was sometimes unaware there was still food on the other side of the plate and scooping some foods, such as peas, was particularly hard and would often result in frustration. Flynn was rarely offered assistance beyond verbal prompting, while prompting itself (including drawing Flynn's attention to spillages) would often result in him becoming embarrassed and refusing to eat. Help to scoop or cut up foods meals were also soon refused. However, Flynn rarely struggled with custard or cream-based puddings eaten from a bowl and would frequently accept seconds if offered. He also enjoyed a strawberry milkshake that staff would make using milkshake powder from a well-known brand.

During the intervention stage it was suggested that Flynn should be offered a second pudding whenever possible (especially given that he was very rarely able to finish the first course), but this was applied sporadically. Some staff also attempted to mix nutritional supplements into Flynn's drink, but only after successful modelling from the researcher (see Section 6.3.1 for more information). Attempts to provide more food and more calorific options to Flynn showed considerable success, potentially because they were relatively 'easy fixes'. Corroborating the notion of 'easy solution' while Flynn was given more food, the incidences of him speaking to the staff and not being responded to remained high throughout the research stages; low interaction rates in general demonstrated that Flynn was not receiving more prompting or assistance in general than before. While his ability to eat also remained the same, his weight increased substantially and nearly reached healthy weight. In September 2014 Flynn contracted sepsis (which resulted in abrupt drop in weight) and passed away several weeks later.

Site 2: _Sarah – complete mealtime assistance, walks a lot, often sleeps during the day_

Sarah was admitted to Site 2 approximately 18 months prior to the commencement of the research project and was in her early 50s. Due to relatively young age, Sarah was physically capable and walked a lot, although cognitive deterioration meant that she could not orient well in physical spaces and would often get stuck in corners or behind furniture, not being able to assess the situation and turn around. Sarah also experienced irregular sleep and wakefulness patterns, often sleeping in a chair for several hours at a time during the day.

Sarah was no longer able to eat independently and was fed all her meals. Due to advanced aphasia Sarah spoke very little and usually in utterances of a single word. While she did show reactions to being spoken to via facial expressions and body language, during most of the mealtimes she was rarely spoken to by the person feeding her.

Sarah was able to chew and swallow well, meaning that her meals were of ordinary consistency. She also liked her food and would rarely refuse meals or snacks when offered. Throughout the research period her BMI was at the top level of Healthy, nearly researching Overweight in Phase 3. However, before developing dementia Sarah was slim and athletic, swimming daily and taking part in various sports. Due to this, the ward staff were particularly concerned with her weight. As mentioned already, Sarah was not classed as overweight and did not have the highest BMI on the ward, however, in Phase 2 of the research the staff spontaneously put Sarah on a diet and closely monitored her intake via a 'Food & Fluid' chart (interestingly, the underweight residents were not monitored with the same scrutiny). Conversations with staff revealed that this was taking place as staff wished to protect Sarah's identity before dementia, as expressed by her physical appearance (a number of staff said "she would not want to be this *way*"). A tension therefore arose between respecting the person who *was* and the person who *is.* Sarah's lack of capacity to make many informed decisions about her life was therefore used to interpret her keen acceptance of food as a reflex rather than a choice. The researcher discussed Sarah's case with the ward staff on several occasions, pointing out that mealtime observations showed that Sarah drew sensory pleasure from food. Rather than reducing her food intake overall, it was therefore decided to offer her reduced-calorie options, especially for puddings. However, Sarah's weight continued to increase slightly but steadily throughout the research period, potentially due to gradual decline in her mobility and time spent walking.

Site 2: <u>*Jeremy*</u> *– attention difficulties, resists mealtime assistance, deteriorating mobility*

Jeremy was admitted to the ward less than a year before the start of the research project. He was at times aggressive (both verbally and physically) and physically strong. While able to walk and eat fairly independently at the beginning of the project, Jeremy suffered a succession of small strokes, gradually reducing his mobility (he was able to walk, but only when aided by two members of staff) and eating. Most of Jeremy's eating difficulties stemmed from attention deficits common in stroke-related dementias. Jeremy increasingly could not

identify food and would frequently become distracted during mealtimes. He was often seen 'portioning' his food into smaller chunks and licking his fingers (potentially indicating some desire to eat), but could not initiate the eating process itself. His difficulties also became worse as the day progressed, with total amount of food consumed dropping dramatically at teatime. Importantly, Jeremy was also resistive to mealtime assistance / feeding on most occasions. As expected from his physical and cognitive deterioration, Jeremy's BMI declined throughout the study. However, given his difficulties, the decline in weight was not as pronounced as expected (and not as abrupt as Hazel's in Site 1, who experienced a lesser deterioration in abilities).

This was mostly achieved through individualistic and tailored staff approaches. While Jeremy was reluctant to accept most mealtime assistance, he related best to older female staff. Paula [HCA] who was in her 70s had a particularly strong relationship with Jeremy and was often chosen to assist Jeremy with personal care, which he also resisted. An outstanding example of mealtime assistance, however, was recorded during a lunchtime in Phase 2, while Jeremy was assisted by Veronica [HCA]. Veronica started the mealtime by holding and later stroking Jeremy's arm, making eye contact, smiling and talking to him. She spoon-fed Jeremy all his food, but instead of focussing on the food itself, she emphasised the social side of the interaction. Prone to slightly negative mood at mealtimes in general and moderately-to-strongly negative mood when assisted, on these occasions Jeremy exhibited strongly positive mood, laughing and smiling throughout an entire mealtime interaction.

Observational data from this mealtime was subsequently communicated to the ward staff, and became a best practice example for the ward. While none of the other mealtimes demonstrated such degree of positivity from Jeremy, enhancing his social experiences has likely contributed to slowing the decline in Jeremy's weight. Also, in Jeremy's case the benefit of social experiences at mealtimes was not only appreciated in staff-resident interactions. As illustrated in Section 6.3.1, even when in an angry mood initially, Jeremy was not discouraged from eating socially with other residents, which in turn often improved his mood and increased his food/fluid intake.

Site 2: _Jean – mostly dependent at mealtimes, limited mobility, often sleeps during the day_

Jean has resided on Site 2 for over two years at the start of the project and was the most underweight participant on the ward. She was mostly dependent on mealtime assistance,

being fed all her meals and appeared to highly enjoy food and eating. However, she would rarely manage an entire portion of food, falling asleep mid-way meal, at which point her food would be taken away and disposed of.

Helping Jean to gain weight and continue to enjoy food and drink started by researcher-staff discussion on providing high-calorie options in small portions but at frequent intervals (i.e. little and often). The researcher also engaged in some modelling of these interventions, by demonstrating that Jean had a substantial appetite. For example, due to one of the night and morning observation periods the researcher was able to assist Jean with 3 rounds of breakfast, starting at 5am when Jean first woke up and finishing at 10am. While Jean continued to fall asleep after eating, she keenly ate after each waking up.

However, the little and often approach could only be applied sporadically, due to staff availability and lack of food outside of mealtimes (as mentioned before, hot food had to be disposed of 40 minutes after serving). Need for assistance, however, was addressed by observations that demonstrated Jean's ability to eat independently if no cutlery was required. Once this was emphasized in feedback meetings, the ward staff and Jean's son started purchasing finger-food options such as sausage rolls or strawberries for her (and other residents on the ward). Once served finger food, Jean still required physical prompting, but did not need full assistance and appeared to show a more positive mood once eating independently.

Due to this, Jean's weight rose slowly yet steadily throughout the research process, nonetheless remaining in the underweight BMI category. It is important to note, however, that while Jeremy (see story above) lost and Jean gained weight, Jeremy's story demonstrates more success. It involved more time-consuming interventions to delay Jeremy's weight loss due to his refusal to be assisted. Jean, on the other hand, ate keenly, even if little and often, and a greater improvement could have been expected with less effort needed.

This section therefore demonstrates that both general and individually-tailored mealtime interventions on the wards affected participants in different ways. Crucially, weight increase alone, was not always an indication of intervention success, while in cases such as Jeremy's, who did lose weight, a slower BMI decline was considered particularly successful.

6.4.4. Catalysts and Barriers

The choice, implementation, and overall success of interventions were site-dependent. Micro cultures heavily dictated how action would be decided and implemented. As already mentioned, many of the 'mealtime issues' or problems referred to by the stakeholders differed across the sites. However, even when these were the same or very similar, the solutions each site came up with were often considerably different. Both the perceived issues and their solutions were constructed within the micro cultures of each ward. As discussed in section 6.4.2.1, constraints of each setting (such as the availability of staff or access to funds) did play a considerable role in shaping interventions, but the influencers went beyond the practical and reflected the (micro) culture itself. While some helped create change, others served as barriers. This section, therefore, offers researcher reflections on catalysts and barriers of mealtime change.

Figure 57. Micro-cultural Aspects Impacting on Mealtime Change
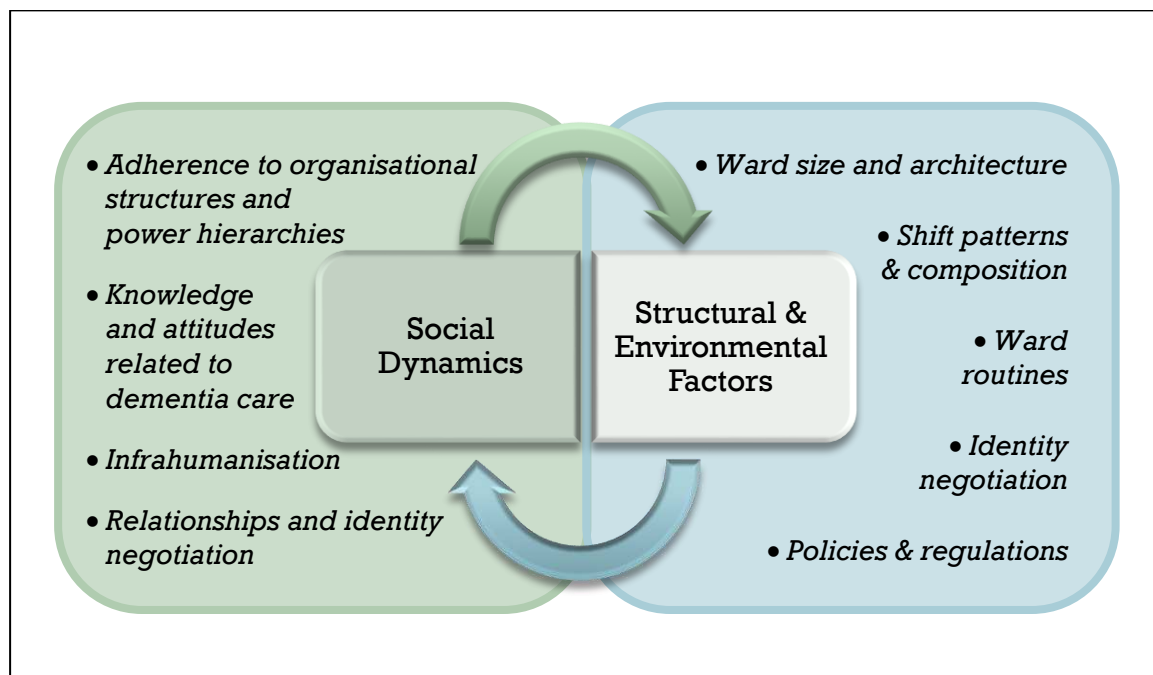
Importantly, the influence of micro cultures on the intervention process transcended the static function of an 'ideas platform', and instead served as a dynamic process affecting all aspects of intervention creation, implementation and retention. The processes that distinguished the micro cultures and the way they impacted on mealtimes between research sites included both social dynamics between and within stakeholder groups, and structural and environmental factors on the ward (see Figure 57). It is also noteworthy that many of the social dynamics that facilitated or hindered implementing mealtime interventions closely resemble mealtime influences that have been discussed in the Ethnography section of the

results (Section 6.3.1). While some illustrations are repetitive, it was deemed necessary to discuss them in the current section, as the focus here is specifically on interventions and their success.

A number of factors within the ward micro cultures helped create change. Notably, being consulted (i.e. asked for opinions about mealtimes and ideas for change) was appreciated by all stakeholders and generated a lot of suggestions and opinions. While no direct comparisons are available between top-down and bottom-up processes of change, several interviewees (especially staff) have expressed surprise and appreciation at being consulted and listened to. Researcher spending long periods of time on the wards, socialising with patients, relatives and staff, and actively assisting during mealtimes (when structured observations were not taking place), helped to gain trust. This encouraged honest contributions from the stakeholders (e.g. staff on Site 2 were open about their worries that mealtime change may negatively affect mealtime aspects that were working well) and because the stakeholders were better able to regard (often critical in nature) research findings and reflections as credible.

During implementation of mealtime changes, dividing responsibilities and capitalising on people keen to implement their own suggestions was particularly useful. For example, staff on Site 2 who advocated benefits of having more fruit and fibre in diets became leads on fruit purchasing and ran 'Fruit Thursdays', keenly trying different ingredient combinations for smoothies and excitedly offering drinks to the residents.

Due to units' hierarchical structure, support from managers and effective management of the ward were crucial in implementing change. While it is hard to measure/capture *per se*, differential implementation of mealtime change on the wards could at least in part be attributable to management styles and manager involvement. On Site 1, the manager was often absent from day-to-day operations and rarely participated in mealtimes. Although she was the person to request a formalised Mealtime Action Plan and lead on its implementation, her lack of presence and a strong relationship with nursing staff and healthcare assistants meant that the change advocated by the manager was often resisted. This was also because while the manager on Site 1 instructed change and took part in some negotiations around it, she did provide other staff with a rationale for implementation. On two occasions she explicitly observed the mealtimes to ensure that agreed upon change was implemented, but this ceased as soon as her active involvement stopped.

In contrast to this, the manager on Site 2 had a close and open relationship with her staff, often inviting critique and discussion. She was noted saying on several occasions and to different audiences that "[her] staff often tell [her] off" if they are displeased with her actions and decisions. The manager on Site 2 not only negotiated (instead of instructing) change, thus discussing the rationale behind it, but also took an active part in mealtimes, assisting residents or serving food, if the ward was short-staffed or busy/chaotic. She also expressed support for the researcher's observations, took an active part in change implementation, and showed excitement about the changes and their impact. When a nurse on Site 2 became anxious about the potential disruptions of the interventions, the manager also immediately and spontaneously reassured her.

Other micro-cultural factors hindered change. Hierarchical and authority structures within the wards were particularly influential. Who could 'authorise' change mattered both in terms of actual approval (e.g. a manager had to sign off equipment and serveware purchases) an in terms of staff perceptions. The former aspect – needing management approval to enact many of the agreed changes – often resulted in long delays, and, crucially, diminished collaboration. Even when autonomy was afforded to them, some staff (especially Health Care Assistants) sometimes felt too junior to make an impact and hesitated to put forward ideas if they felt the same views were not held by professionals in more senior positions. For example, Anna (one of the HCAs on Site 1) talked about the benefits of background music during mealtimes, but when asked why she would not switch the music player on herself, she talked about observing one of the nurses once switching off the music when it was left on. Anna did not feel she had the authority to put her ideas on the benefits of music forward and no discussion ever took place; it was not clear whether the aforementioned nurse objected to background music at mealtimes. Instead, the perception of disproval from someone in a more senior position was enough to remove agency and hinder trialling a small-scale change.

Nonetheless, not all impact of hierarchies was purely perceptual. In casual conversations numerous HCAs have talked about a regular staff meeting which – among other aspects of care – considered ways to improve nutrition and hydration. The staff reported that the group was initially attended only by HCAs/Therapy Technicians. The staff told the researcher that once a nurse was asked to join the meetings, the HCAs found most of their ideas 'trumped' by opinions of the aforementioned nurse. The meeting attendance soon diminished and eventually the meetings ceased altogether (approximately six months prior to the commencement of the research project). Conversations with nurses, however, revealed that

due to their higher position and higher pay they often felt under pressure to contribute more and to overtly demonstrate knowledge on any care subjects on the ward. Hierarchies within the ward were therefore self-reinforcing, and affected mealtime change and its implementation in complex ways.

However, as already mentioned, while institutionally imposed, staff hierarchies were less visible on Site 2, with all staff, including nurses and the ward manager, engaged in many of the care activities such as feeding or assisting with personal care. This increased the perception of agency, and HCAs as well as agency staff felt comfortable trying new things without seeking permission. For example, Beatrice (agency staff) keenly and spontaneously volunteered to make pancakes once a relative purchased a device for the ward that enabled making small cakes, doughnuts and pancakes.

Staff roles and priorities, although considerably overlapping with hierarchies, also affected mealtime change in a specific and discernible way. Site 1 experienced more role differentiation in terms of both staff roles, and the perceived priority activities. Due to the clinical setting (i.e. an NHS ward), clinical activities and medically trained staff (i.e. nurses) were seen as more important. Crucially, because mealtimes on Site 1 were (rightly) perceived as non-clinical activities, they were also assigned less importance and not seen as a priority. As the emphasis was placed on safety and meeting patients' basic needs, bolstering happiness and quality of life were not seen as a direct responsibility of the ward.

Conversely, Site 2 was less differentiated. Staff of all roles spoke about the importance of a homely feel within the ward (in fact many considered the setting to be one of a care *home*) and the whole setting functioning more as a family. Within this perception of what the staff role and the role of the setting was, mealtimes were afforded more importance. This may at least in part explain why mealtimes were already experienced in a more positive way on Site 2 and why mealtime changes (especially environmental ones that made mealtimes more home-like) were implemented and retained more successfully.

An emphasis on clinical roles and clinical work on the wards also had an impact on which aspect of mealtimes was prioritised. As pointed out above, social change was rarely enacted and clinical outcomes (e.g. weight increase or higher energy intake) were prioritised on both wards. A clinical view of food and eating also meant that staff prioritised healthy foods (on Site 1 staff spoke about feeling uncomfortable with offering patients food that they saw as unhealthy, even if it was the only type of food undernourished patients would eat, while on

Site 2 'Fruit Thursdays' received more support than 'Cake Wednesdays'). This was further impacted by the widespread belief that weight loss was *normal* (and therefore unavoidable) in advanced stages of dementia and infrahumanisation of people with dementia on the wards (for more details, see section 6.3.1). Altogether, these processes made it easier for the ward staff to implement a predominantly clinical view of mealtimes, at least in part ignoring (or finding a way to deal with) lack of positive mealtime experiences.

Importantly, micro-cultures did not have a 'random' influence on mealtime change. Instead, the micro-cultures were self-reinforcing. Even minimal change with high consensus from all the stakeholders was hard to implement. Because these were structured settings guided by procedure that the *actors* within it have learnt, defaulting back to the 'usual' way of carrying out mealtimes was easy and frequent. The self-reinforcement of micro cultures was particularly visible within relationship patterns on the wards.

Relationship patterns between stakeholders on the ward also affected success of interventions. The asymmetrical relationship between staff and patients, where staff exclusively saw themselves as *providers* of care and patients/residents as *receivers* of care, meant that interventions which enabled or encouraged contributions from the patients were usually met with scepticism. This was more pronounced on Site 1; Angela, who did not have a diagnosis of dementia and was a caterer prior to retirement was never allowed to take an active role in serving food, although she routinely expressed an interest in doing so. Although residents on Site 2 were also not encouraged or allowed to be part of the food service, despite experiencing advanced dementia Shannon was sometimes allowed to wash up after meals when she wished to do so, with some staff actively encouraging and assisting her in doing so. While some aspects of mealtime participations were in part constrained by policy (e.g. food hygiene and health and safety considerations), other activities, such as involving PWD in laying up tables before the meals demonstrated that lack of involvement stemmed from the maintenance of the relationship asymmetries.

Tensions between staff and relatives also impacted on intervention success. As discussed in Section 6.3.2 mealtime focus was different between staff and relatives' groups. In general, while the former group saw mealtimes from a more physiological perspective, the latter group prioritised sensory aspects of mealtimes. This meant that at times the proposed interventions between relatives and staff were at odds and a tension arose around who knew how to care for the patient better. These tensions were more pronounced in Site 1, with relatives already excluded from participation in mealtimes and most of mealtime decisions,

yet still being perceived as 'intruders' by some of the staff. On Site 2, the relatives were seen as an asset and included in mealtimes. But when disagreements arose, staff perceived their clinical knowledge as superior to that of the relatives. Some degree of tension and separation between staff and relatives, therefore, was always present on both sites.

The separateness between stakeholder groups also meant that meeting representatives from all stakeholder groups together was unexpectedly difficult. In turn, reaching a consensus regarding the less-agreed-on interventions (e.g. provision of high-fat foods) was also hard to achieve and involved more facilitation from the researcher.

The liminal 'outsider-insider' status of the researcher also hindered implementation of change. The staff simultaneously perceived the researcher as part of a team (e.g. asking her to assist with providing personal care for the patients), but also as a potentially threatening outsider, who could potentially complain about practices on the ward to higher management. This liminal status meant that staff on both wards were willing and satisfied with allowing the researcher to observe mealtimes, but were less receptive to suggestions of change that stemmed from these observations. This also resulted in an ethical dilemma for the researcher. To successfully negotiate change, the researcher had to compromise the level of truthfulness about the severity of current shortcomings; an outsider suggesting staff failures was likely to result in distrust, weariness or animosity. In fact, Phase 3 on Site 1 was discontinued early after the researcher had to follow official whistleblowing procedure and inform her clinical supervisor about some of the patients receiving insufficient amounts of food (i.e. starving). Once the ward staff knew about the complaint, they have expressed to the researcher that she has broken the trust they afforded to her; the ward manager has also referred to the researcher as 'a troublemaker'. Relationship dynamics, therefore, not only impacted on mealtime change *per se,* but also served as a form of change resistance, thus maintaining and re-enforcing ward micro cultures.

Micro cultures, however, are a sum total of all aspects of the wards, including not only social dynamics, but also structural and environmental factors. These factors, too, served either as catalysts or barriers to mealtime change. For example, NHS Trust-level policies on mealtimes helped encourage staff on Site 1 to regularly weigh patients, but also prevented them from purchasing an electric grill to cook food on the ward due to fire safety concerns. Change was accepted and implemented more readily, if it was part of a policy requirement. External mealtime provision also hindered mealtime success, as staff had a limited impact on what type of food what available to the patients and at what time of the day.

Staffing levels, too, had an impact on ability to enact change. For example, when the number of people requiring extensive mealtime assistance (i.e. feeding) increased, staff found it more difficult to meet mealtime demands, and going beyond addressing the most basic needs became difficult; psychosocial needs were particularly ignored. On these occasions staff were likely to be stressed and react negatively to patients being restless or not eating (which usually exacerbated patient distress). Unit size and architecture further interacted with staffing. While the number of HCAs was proportionate to ward occupancy, the minimum number of nurses on shift was constant. Therefore, the ratio of nurses (and thus staff overall) per patient/resident was substantially higher on Site 2, which, until Phase 3 of the research, was half the size of Site 1 (for more detail, see Chapter 5). Furthermore, the two wings on the L-shaped Site 1 further reduced staff ability to sufficiently assist every patient at mealtimes; as both wings had a dining room, staff were split in half, some fulfilling the exact same task on each wing. In addition to this, due to door width on Site 1, bed-bound patients could not leave their rooms at mealtimes and were assisted individually, while on Site 2 Rupert and (in Phase 3) Norman's bed were wheeled out to the dining room. This meant that while staff fed Rupert and Norman, they could provide verbal prompts to more independent residents and oversee the mealtime in general (i.e. be available in case of any complications).

Finally, as discussed in Section 6.4.1., the nature of mealtime interventions themselves, once interacting with other aspects influencing mealtimes, was either a barrier or a catalyst for change. The interventions were least successful if they required more input/work from staff (e.g. encouraging patients to the table before the meal), co-ordination of multiple staff members (e.g. changing shift patterns on Site 1 to have two sets of staff working at lunchtime) or long-term input rather than offering a 'quick fix' (e.g. providing mealtime cues prior to each mealtime). Challenging impermeability of the setting (e.g. opening mealtimes to the relatives on Site 1) and giving more autonomy to the patients by encouraging independent eating and including patients in mealtime preparation was also less successful.

The complex and interacting catalysts and barriers to mealtime change should be taken into account in future Action Research within institutional settings. For example, it is important to select a site with adequate staffing so change can be enacting. Securing research meetings with members from all stakeholder groups is also important to ensure collaboration and majority consensus on interventions. A manager who has a positive relationship with the staff and one who is supportive of research that aims to facilitate change is also crucial, while initial commitment to change (especially by the staff) should be investigated beyond face

value before the research starts. For example, although change is desired, it should be established whether the staff have the capacity and willingness to implement change. The researcher and the research framework also need possess characteristics that minimise barriers and enhance catalysts for change. Transparency and effective sharing of information by the researcher is paramount, as are conflict resolution skills and ability to manage different modes of engagement (e.g. ability to carry out conversations with people with advanced dementia in relation to the research questions). Flexible timelines should also be available so the research can continue within complex and unpredictable environment where delays are likely.

6.5. Summary and Reflections

As has been discussed throughout the Results' chapter, there were a number of incidences when different measures have corroborated similar research findings. However, it is crucial to point out that overall, there was more disagreement than agreement in findings in both exploring mealtime experiences and measuring mealtime change. While methodological issues and limitations were present – and discussed above – the diversity of findings also suggests that each of the measures had a unique ability to tap into mealtimes, thus justifying the need for researching mealtimes in a holistic way, employing mixed methodologies, instead of single measures that are common throughout mealtime literature (see Chapter 3).

Chapter 7
DISCUSSION

This chapter aims to bring together the diverse findings of the study, situating them within mealtime literature and highlighting their distinct contributions to the knowledge base. The chapter also discusses limitations within the study (both in methodological and practical terms) and reviews implications for research, care practices and policy.

7.1. Bringing it all together

Due to the complexity of intersecting research dimensions and the multiplicity of methodologies within the current project, the purpose of the Discussion chapter is to bring together all dimensions and cross-sections of the research findings into a coherent narrative, along with relating the findings to initial hypotheses, as well as situating them in existing literature on mealtimes and beyond.

As the overall aim of the research was to facilitate small-scale collaborative improvements of mealtimes, the discussion predominantly focusses on what influenced mealtime change. Findings about mealtime experiences (which occupied a large part of the research) are also discussed, specifically as a platform for change creation and an explanation of the patterns of change. Overall, the findings have demonstrated that a number of powerful influences have guided change creation, implementation and retention (or lack thereof); these influences also served as a way of organising Section 7.1. In relation to this, the power of micro-cultures, the power of divisions and the power of mealtimes will be discussed, as they shaped attempts to enhance mealtimes on NHS Continuing Care wards for people with dementia, their relatives and staff.

7.1.1. The Power of Micro-cultures: A Tale of Two Wards

Despite belonging to the same NHS Trust, performing the same function, accommodating a highly similar profile of patients and being governed by similar policies, the two research sites were highly different. While mealtime experiences for stakeholder groups were broadly guided by the same processes (e.g. infrahumanisation and proceduralism), how these processes manifested was often starkly different. As explained in the Results chapter, despite some expected similarities, the wards were substantially different from one another. Site 1 was characterised by formalised procedures and adherence to hierarchies both during and outside of mealtimes. Paradoxically, despite a much higher importance placed upon

procedure, the Site 1 also failed to comply with some of the basic organisational policies, such as regular weighing of the patients. Site 2, however, was much more home-like. While procedure was present and adhered to, and Site 2 possessed overtly institutional features (e.g. the presence of a medication trolley), more attention was paid to relationships; the staff knew more about resident's histories, positive physical contact among staff and patients (e.g. hugs) was common and most relatives had a positive and friendly relationship with staff, especially if they visited routinely. There were also differences in the way mealtimes were run, with Site 2 having already implemented many of the 'more basic' and easier to achieve interventions compared to Site 1, before the research on Site 2 commenced.

Overall, the differences between the sites confirmed the existence of distinct micro-cultures within the wards. The definition by Fine (1987, p. 125), stating that micro-cultures are "…. a system of knowledge, beliefs, values and behaviours shared by the members of an interacting group to which the members can refer and which serves as the foundations for new interactions" was also supported. Many of the processes guiding mealtimes on the wards were not overtly communicated or articulated among the stakeholders; for example, the perception held by relatives and staff that social mealtime needs became less signigicant as dementia progressed. These processes were nonetheless shared by members of the interacting groups (apart from people with dementia themselves). Expressed as behaviours, the unspoken knowledge, beliefs and values of the micro-cultures also served as a platform for new interactions – any new members coming to the ward either as staff, patients or relatives were tacitly expected to adapt to the existing culture, instead of creating a slight shift in a micro-culture due to their own values and beliefs.

This is of particular importance, as research to date has not explored micro-cultures in LTDC. A scoping review by Mikelytė & Milne (2016) identifies that research on long-term care in general and specifically LTC for people with dementia 'skirts around' the concept of micro-cultures. The authors argue that while concepts related to, or sub sets of, micro-cultures are both important and relevant, they fail to capture the complexity or multi-dimensionality of all that a 'micro-culture' encompasses nor do they capture its dynamism.

For example, a considerable proportion of reviewed research explores 'care cultures' or (care) 'culture change'. These studies tend to focus on caring relationships, or on the impact of specific care practices (e.g. person-centeredness) on the wellbeing of the residents (ibid). This reflects a wider tendency in research to equate 'LTC' to 'care provision' rather than appreciating its more complex systemic nature; living in a care home is much more than just

receiving care (Lee, *et al.*, 2002). While caring relationships (Walsh & Schutes, 2012) are a very important aspect of micro-cultures, researching their role in isolation from the other dimensions of LTC such as resources, and relatives' involvement, runs the risk of amplifying their importance. It is also taking the line of least resistance: it is easier to quantify what care staff do (or do not do) and/or focus on the 'practice' of care than to take account of the many issues that impact on, and affect, the delivery of care and the role it plays in the overall culture (see Buse & Twigg, 2014; Mold *et al.*, 2005; Thorrington, 2006).

Another issue relates to how older people are positioned in research on 'care cultures'. Residents tend to be constructed as passive receivers of care as opposed to providers of care or in a reciprocal relationship with a staff member. This is not only inaccurate - Pruchno & Rose (2002) found that a LTC care environment can facilitate residents showing support to one another - but can also contribute to sub-standard care provision. Research identifies a lack of perceived reciprocity in the staff-resident relationship as related to staff burnout and linked to poor quality care (Duffy *et al*, 2009). It suggests that perceived position of older people is an issue, which needs exploring in a way that recognises 'care' as a relational and embedded part of a culture, not as a dismembered part of the whole (Thomas and Rose, 2010).

Research on another concept related to micro-cultures – namely, 'social climate' - tends to disproportionately focus on staff perceptions and/or relies on staff views of resident wellbeing rather than gathering the views of residents' themselves (Milne, 2011). This is problematic for a number of reasons. Staff already have a profound influence on resident wellbeing as most residents rely on staff for their survival (Edvardsson *et al*, 2011); staff also have a disproportionate influence on psychosocial factors (e.g. depression, hopelessness or helplessness), and often act as catalysts for positive and negative resident experiences (Cassie and Cassie, 2010). Therefore, focusing on staff views, or even considering staff's views to be of equal value to residents' own, amplifies the pre-existing asymmetry of power between staff and residents. In other words, while research with LTC populations could be used to empower residents (Shura et al., 2010), the approach most often taken has the opposite effect.

Figure 58. Conceptual Overlap (Mikelyte & Milne, 2016, p. 200)

Micro-Culture
A distinctive culture shared by a small group that is often based on location or within an organization
Macro-Culture
The dominant culture in a society
Care Culture
Subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that enable another individual or group to maintain or improve their well-being
Social Climate
The perceptions of a social environment that tend to be shared by a group of people
Organisational/Institutional Culture
A system of shared assumptions, values, and beliefs, which governs how people behave in organizations
Care/Social/Environmental Context
The immediate physical and social setting in which people live or in which something happens or develops

Other studies explore 'organisational culture' (see Figure 3). Although this term may be regarded as an overarching cultural construct, research in LTC tends to focus narrowly on procedures, policies and compliance. This approach fails to unpick the distinction between an individual care home's micro-culture and the culture of a provider organisation (e.g. BUPA, or NHS Trust). Whilst an 'organisational culture' may - in theory - be shared across a number of homes, a focus on procedures and policies neither identifies what this broader culture is nor exposes the nuanced features of micro organisational cultures that distinguish

one care home from another. There is evidence that homes do develop their own micro-culture even if they are run by the same provider. For example, Shin's (2015) ethnography of 4 LTC facilities, all of which belonged to the same organisation, found that "… residents gradually projected their identities into their primary territories of home by actively manipulating and maintaining the spaces" (p. 121). Differences were not only present between facilities, but even within facilities; sub-units or 'wings' inside the same facility had different micro-cultures which influenced residents' sense of security, routine, and permanence.

Focusing on the social and/or environmental contexts is also problematic. Contexts are likely to be seen as a backdrop or a mediator for interpersonal dynamics or care processes (Marventano, 2015). Micro-cultures, on the other hand, represent/construct social environments as dynamic representations or negotiations of the culture itself (Lalueza, *et al*., 2008). In other words, the former view suggests that care contexts exert influence on care processes and resident outcomes (a uni-directional process), whereas the latter suggests that social and environmental contexts themselves are dynamically created and maintained by the micro-culture (a complex interaction). In support of the latter perspective, Pruchno & Rose (2002) demonstrate that living in a nursing home, assisted living facility, or at home are not differentially associated with older people's satisfaction with the way their day is spent (i.e. the context itself is not the defining factor). Instead, residents adjust their identities and behaviours based on their interpretation of the context (Anderson et al, 2003). Focusing on social and environmental care contexts alone, therefore, obscures the dynamic aspects of co-creating and adapting to the micro-cultural context.

However impotant research on one or more elements of a micro-culture may it does not constitute exploration of the more complex dynamic umbrella construct of which they are a part. A more holistic perspective on micro-cultures is necessary to capture this 'living' construct.

In contrast to research to date, the current study has explored micro-cultures and the way they operate. Crucially, the dynamic and multi-dimensional nature of the way micro-cultures operate in relation to mealtime change was evaluated. As expected in the research aims, due to the distinct micro-cultures on the research sites, the ideas for enhancing the mealtime experience were substantially different in nature. Even when the stakeholders across the wards identified similar issues, the solution (i.e. proposed intervention) differed. This supported the original research expectation, that copying practical suggestions for improving

mealtimes from practitioner literature (e.g. The Caroline Walker Trust) or empirically evaluated interventions (e.g. Tanaka & Hoshiyama, 2014) may not be relevant for the specific wards or not be a priority.

Nonetheless, the impact of micro-cultures transcended that of an ideas-platform for the creation and selection of mealtime interventions. Instead, microcultures dynamically affected change implementation, retention and overall impact. This went against the initial hypothesis, which stated that if the interventions are collaboratively designed by the stakeholders and relevant to the mealtimes within the specific wards, they would be keenly and successfully implemented. Instead, even those small-scale changes that were universally agreed-upon (i.e. welcomed by all stakeholder groups) were hard to implement and even harder to retain. As discussed in Section 6.4., practical aspects, such as management approval and securing of funds, as well as additional pressures placed on staff impacted both implementation and retention. However, the micro-cultures and the process of self-reinforcement (or Status Quo maintenance) were also influential.

Because staff were the primary implementers of change, their knowledge and beliefs about the patients and their needs had an impact. For example, staff beliefs that patients' social needs are of lesser prominence during institutional mealtimes (especially on Site 1) appeared to relate to psychosocial mealtime interventions being the least likely implemented and the least likely retained. This went in line with existing research that emphasise the importance of staff approaches (e.g. Amella 1999, 2002). Equally, as staff on Site 2 appeared to value relationships (both with patients and in general) more than on Site 1, this was reflected in a retained improvement in interactions from staff; especially with residents who could not respond. Similarly, the self-reinforcing nature of micro-cultures meant that even simple, easy to implement and not resource-demanding changes were hard to put in place and to retain (e.g. swapping over which dining room is served first on Site 1). As can be seen from the Result's chapter, despite initial change in the intervention phase many of the mealtime outcome indicators (e.g. proportion of food eaten during mealtimes and patient mood on both sites, as well as staff-initiated interactions with patients on Site 1 and frequency of having no opportunities to socialise on Site 2) went back to baseline levels in the post-intervention phase.

The pattern of change was also site- (and therefore micro-culture-) dependent. For example, patient mood and total amount of food eaten increased on Site 1 and decreased on Site 2 during the intervention, before going back to baseline levels. Other change was maintained

or even continued to change in the same direction post-intervention, but also showed radically patterns across sites. While initially higher on Site 1 than on Site 2, the incidence of verbal prompting continued to decrease throughout the research process on Site 1, while Site 2 showed a continued increase in verbal prompting. Physical prompting (e.g. handing a patient their fork) decreased on both sites during the intervention phase, but increased on Site 2, while continuing to decrease on Site 1.

There were also site-based differences on the effect of the intervention phase. Total amount of food eaten and patient mood showed an opposite pattern of effect on each research site; while these outcomes improved during the intervention phase on Site 1, they worsened on Site 2. This suggested that despite the way staff felt about implementing the interventions (interviews demonstrated that Staff on Site 2 were more positive about the process of enacting change), mealtime change was disruptive to some aspects of mealtimes / mealtime outcomes on Site 2, while improving them on Site 1. As argued in the previous chapter, this was potentially because mealtimes were performed and experienced more positively on Site 2 at baseline. Improving them further was harder compared to some simpler changes on Site 1 (e.g. room-serving patterns), and thus detrimental/disruptive to an already positive process. Conversely, as mealtime shortcoming were more prevalent on Site 1 and some of the changes were required little effort, mealtime change was facilitative instead of disruptive.

Overall, the findings went in line with research demonstrating that even geographically close facilities belonging to the same organisation can be starkly different in terms of resident experiences (Shin's, 2015). However, the findings from this project were also novel in showing that these differences were a result of micro-cultures. The power of micro-cultures to shape all aspects of mealtime change (not only the selection of what change is both needed and meaningful) should therefore be taken into consideration when conducting Action Research. Also, as change is harder to achieve when the micro-cultural processes maintain the Status Quo, the magnitude of change should also be understood within this context.

While it is true, that many of the co-created interventions were not implemented or not retained, and mealtime outcomes did not overwhelmingly improve, any change is noteworthy. With literature suggesting that people with dementia in long-term care are likely to gradually lose weight and experience malnutrition (e.g. Chang & Roberts, 2011; Magri et al 2003), and ward staff holding the belief that weight loss is directly caused by dementia, ability maintaining patient weight or increasing it (even if insufficiently to reach healthy body mass) is particularly noteworthy. As 61% of patients on Site 1 and 66% on Site 2 gained

weight during the research period, the current research project not only demonstrated that weight loss is preventable for most individuals with dementia, but that weight increase is also feasible (this went in line with other intervention-based studies; e.g. Charras & Frémontier, 2010; Nijs et al, 2006; Young et al, 2005). Nonetheless, as will be discussed in section 7.1.3., what constitutes an improvement of mealtime experiences for people with dementia should not be constrained to weight or body mass (Mahmidir, et al., 2007). An increase and retention of more interactions with PWD who cannot or are unlikely to respond on Site 2 is particularly encouraging and suggests a potential for mealtime interventions to impact on mealtime *experiences* and meet social, as well as nutritional needs (e.g. Beattie et al, 2004).

7.1.2. Power of Divisions

Another factor influencing mealtimes and mealtime change was divisions; divisions among the stakeholders, within some of the stakeholder groups and across organisations. While this was somewhat less pronounced on Site 2, stakeholder groups – i.e. patients, relatives and staff – were seen as highly separate entities on the wards. Although staff on Site 1 were more negative towards relatives and their involvement in care decisions, with one Healthcare Assistant even describing the relatives as "intruders", both wards struggled to incorporate relatives' knowledge of patient histories within care planning, including that of mealtime care. While both wards wanted to find out more about the patients' pre-morbid mealtime and food preferences, this was not achieved via direct communications, but instead by sending relatives (even those who visited the ward frequently) a Mealtime Preference form to fill in. Both wards also resisted joint stakeholder meetings. While it should be acknowledged that involving many of the patients in such large meetings may have been overwhelming, confusing and overall detrimental to them, accommodating communication needs of the relatives (i.e. not using clinical jargon) was feasible and did not require a lot of effort. Instead, relatives on the ward were usually informed of changes in care approaches (e.g. introduction of a pureed diet) only after the decision was made and the change has already been implemented clinical team.

Stakeholder divisions also meant a lack of true collaboration in the co-creation of mealtime, leaving the researcher in a position of a mediator or messenger, whose role was to ensure that relevant information about mealtime changes was communicated to all stakeholders

whenever possible. While involving patients/residents in group decision-making was problematic (see above), it remains noteworthy that ward staff did not *ask* PWD how mealtimes could be improved. When deciding on change/improvements, staff would instead base their decisions either on clinical guidelines or observations of PWD. Even when patients/residents asked for particular changes (e.g. salt and pepper), these wishes were often over-ridden by concerns around risk and safety.

As can be seen from the interview findings, actively consulting PWD and enabling them to generate their own suggestions was achievable in many cases if the person could communicate verbally. Although some interpretation was necessary, it should be stressed that dementia care staff are used to interpreting patient/resident needs from what PWD say and do (e.g. Berg et al, 1998; Hubbard et al, 2002). The power of divisions, therefore, impacted strongly on whose experiences and opinions were taken into account when instituting change on the wards.

This further impacted on the co-ownership of the change. Due to institutionally-afforded roles and authority, as well as the imposed divisions, ward staff were the principle implementers of change. While Site 2 welcomed and celebrated changes introduced by the relatives, this was usually in terms providing equipment or additional food. For example, although staff spontaneously (i.e. independently of the researcher's observations) agreed that Jerry was more successful in encouraging his wife Shannon to eat, this was attributed solely to Shannon recognising him as her husband. No attempts were made to learn from Jerry's skilful turn-taking and focus on social interactions. Research, however, suggests that focussing on the relationship, rather than the care task is particularly beneficial when providing care (Bailey et al, 2015). Nonetheless, due to the maintenance of separation and divisions between the *perceived* roles of relatives versus staff, this information was never collected. Equally, even despite the repeated emphasis within trust-level policy that both allows and encourages relatives to assist at mealtimes, mealtimes on Site 1 remained impermeable to the relatives. As described in the ethnography section, while exclusion of relatives was justified as beneficial to the other patients, instead it served a function of disguising mealtime shortcoming from the relatives and maintaining staff-dominance during mealtimes (Amella, 2002).

The division between staff and patients also went beyond objective differences in capacity. The staff (an already dominant/powerful group at mealtimes with ability to decide how to deliver mealtime care) saw themselves exclusively as *givers*, while simultaneously

constructing patients as *takers* or *receivers* of care. This meant that in cases where the patients could and wished to take a more active role (e.g. Angela, who did not have dementia, asking to help with serving), this was discouraged. While more mealtime participation was *allowed* on Site 2 (e.g. Shannon washing up), neither of the sites *encouraged* residents to take an active part in the mealtimes. Interventions that suggested involving residents in laying the tables or serving food for themselves (as shown beneficial in previous research studies; e.g. Shatenstein & Ferland, 2000) was rarely taken up and not maintained on either of the sites. Reinforcing the distinction between care *providers* and care *receivers* therefore deprived some of the patients from exercising/maintaining the skills they already had, and performing a *giving* role many have stressed as central to their past mealtime experiences and current needs. Social Exchange Theory (Emerson, 1976) suggests that in all interactions there is a reciprocation, a giving and taking, that perpetuates the relationship, while research on LTDC stresses that staff experience lower levels of burnout, if they perceive the relationship with residents as reciprocal (Duffy et al, 2009). Therefore, supressing reciprocity in order to maintain divisions paradoxically disadvantages the staff themselves.

The general ignoring of psychosocial mealtime needs the patients among staff and relatives also came from decision to maintain divisions. As is evident from different mealtime foci, while staff and relatives identified social dimensions as central to their own positive mealtime experiences, they no longer identified them as important for the patients/relatives (albeit to a lesser degree on Site 2). Literature, however, stresses that eating in dementia care is seem as the most social of all Activities of Daily Living (Amella, 2002; Manthorpe & Watson, 2003). Ignoring social needs within mealtimes, therefore, was a lost - yet outstanding - opportunity.

Particularly in the case of staff, these imposed divisions may have also served as a defence mechanism (Lyth, 1990a). Low staffing levels meant that meeting all mealtime needs was difficult (social needs in particular involved more time and more effort; see Section 6.4.). The distress that may come from knowing that negative patient mealtime experiences or lack of positive ones can be prevented with sufficient (human as well as infrastructural) resources, was difficult for the staff to deal with. This explanation, although speculative, was corroborated by the difficulty staff had in adopting the patients' perspective during interviews. Divisions, therefore, actively protected the already most powerful stakeholder group within mealtimes (i.e. the staff; Lyth, 1990b), while simultaneously further disadvantaging patients and relatives.

Impermeability of the setting (i.e. a division between the setting and the rest of the world) also impacted on staff's ability to use defence mechanisms and ignore distress and suffering from the patients (e.g. Maureen (Site 1) crying while saying that she is starving, while staff refused to give her food due to – generally unfounded – worries about her diabetes, or Marie (Site 1) loudly questioning why she was "separated" to eat on her own and calling for her mother in distress, while staff provided no answers and continued to talk among themselves). As already pointed out, some of the impermeability and dominance was enacted by the staff themselves (e.g. Site 1 excluding relatives from taking part in the mealtimes and preventing patients from entering such spaces as a staff room during meetings, although neither of these measures were in place on Site 2). Nonetheless, organisation structures meant that the ward could not be entered by unauthorised individuals; not only members of the public wishing to visit the ward, but also other health or social care professionals. For example, although the researcher had an 'Honorary Researcher' contract with the NHS Trust within the, which the wards were situated, she needed senior management permission to approach the wards.

Some staff practices that were abusive or neglectful in nature remained unseen (e.g. forcibly separating residents who were sharing food or not giving some of the underweight patients food even after the patient had reported hunger; see the ethnography and patient interview findings). It is important to acknowledge that very few staff intend to abuse, and instead saw their role as helpers or protectors. However, the impermeability of the setting made it what Goffman (1969) titled a "total institution", which normalised distress and allowed an abusive/neglectful set of institutional practices to develop that remained unchallenged. Once the researcher followed official procedure and 'whistle-blew' about the aforementioned practices on Site 1, she was overtly labelled as a 'trouble marker', staff refused to engage with her (e.g. take part in interviews in Phase 3) and the research had to be discontinued before all Phase 3 data could be collected. The closed nature of the ward and its separation from the rest of the organisation (i.e. the NHS trust) and the society in general was therefore detrimental to both meantime / mealtime change and experiences of PWD in general.

While staff possessed the most power within the ward, they did not, however, have complete decision-making power on mealtimes and mealtime change. Organisation-level policy and decision of the managers had to be adhered to, with little-to-no space to question rationale or suggest alternatives. Despite all stakeholders on Site 1 and particularly staff wishing to purchase an electric grill so they could cook breakfast on site, a Health and Safety assessment prevented them from doing so (despite Site 2 already having and using an electric grill). No

opportunities to challenge the assessor's decision were present. Similarly, a number of interventions were delayed or altogether abandoned due to the difficulty in securing funds from the service manager's budget. It is therefore possible that staff attempted to maintain power via enforcing divisions on the ward, because it was the only power they had being low within the overall organisational hierarchies of autonomy (Magee & Galinsky, 2008).

Overall, the power of divisions on the wards was detrimental to co-developing, enacting and maintaining change, and should be taken into account within other research into mealtimes in institutional care for people with dementia.

7.1.3. The Power of Mealtimes

While micro-cultures and divisions were powerful factors influencing mealtime change, mealtimes *per se* were also a powerful event impacting the progression of action research.

Firstly, mealtimes were both particularly atypical and particularly complex as a ward-based activity (Liu et al, 2014). In part, their complexity stemmed from it being a group event. No other event on the ward (apart from therapeutic activities which involved only a subset of patients) simultaneously involved all patients. Personal care, for example, was performed on a sequential basis, with at least one member of staff attending to one individual at a time. The simultaneous nature was challenging not purely because of the staff-to-patient ratio; as described in Chapter 2 as well as individual vignettes in Section 6.3 the way dementia affects individuals is both extremely diverse and largely unpredictable in the precise ways it progresses (Aselage & Amella, 2010).

This produced a complex, high in number and changing set of mealtimes within the entire ward population, all of which had to be attended to in order to provide adequate mealtime assistance and care. Compared to ordinary, community-based mealtimes (whether at home or, say, in a restaurant), mealtimes on the ward required a wider and more flexible set of approaches. In contrast to this, institutional procedures provided less flexibility that available across other settings (Ott et al, 1991). Patients could not choose when they ate and the mealtime was restricted to less than an hour, after which uneaten food had to be disposed of in compliance with organisational policies. Choice of meals was rarely afforded, and even in those exceptional cases it took place 2 weeks before the actual meal. There was no space for patients to choose a different meal on the day or eat at a different time. Food itself was

constrained by provider budgets, and options to meet cultural needs (e.g. rice for Angela) as well as needs arising from dementia (e.g. soft-textured food or finger foods) could not be obtained. As can be seen from Figure 59, this produced a process of tension, where increased heterogeneity of patient mealtime needs was met by an increasing homogeneity of mealtime routines as a result of institutional/organisational restrictions. The collision of these process meant that positive mealtime experiences were particularly difficult to achieve within institutional settings.

Figure 59. *Mealtime Tensions within Institutional Settings*
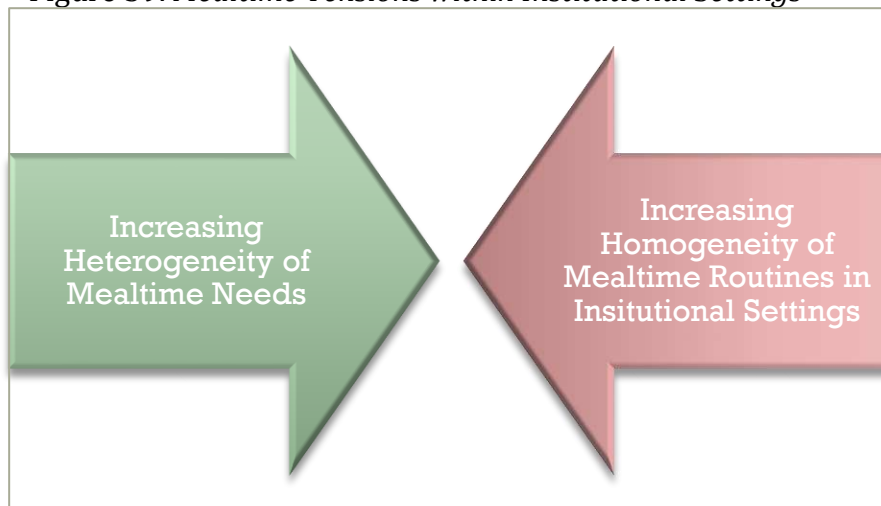
The nature of the diverse mealtime needs also posed a challenge for enhancing mealtime experiences. Mealtime needs and difficulties observed within this research matched the conceptual framework outlined in Chapter 3, which suggests that mealtimes posses not only physiological, but also physical/environmental and psychosocial dimensions (Manthorpe & Watson, 2003). Patient needs, too, were not simply physiological in nature; they were not only about having enough calories and nutrients, as well as suitable texture to account for difficulties with chewing and swallowing, and receiving sufficient assistance to eat (i.e. feeding). Sensory pleasure was also important (e.g. tasty, visually appealing food), as were environmental cues indicating to the resident that the mealtime is taking place / will take place soon, and providing a recognisable, home-like atmosphere. Psychosocial needs were also prominent. Patients/residents spoke about mealtimes and food as a way of affirming their relational identity (e.g. that of a husband or a mother), a way of *giving,* and an opportunity for social interactions.

However, while all these dimensions of mealtimes and mealtime needs were present, they were not all recognised equally by those providing assistance. As discussed throughout the Results' chapter, both staff and relatives downplayed the social aspects of mealtimes and did

not recognise mealtimes as a social activity (see Harner & Orrell, 2008, for stakeholder disagreement on meaningful activities in dementia). This meant that not only the social needs of the residents/patients, but also of relatives were often not met in many of the cases. While relatives did not believe social aspects of mealtimes to remain important for people with dementia, relatives who were allowed to take part in mealtimes (i.e. Site 2) identified mealtimes as (often) the only event where they felt connected to their family member, even if they no longer recognised their relatives. Social needs of relatives, therefore, should also be considered (Herkusens et al, 2014).

The lack of acknowledgement for social needs, as well as the importance of mealtimes and the distinct opportunities afforded within mealtime events likely stemmed from a difficulty of fitting mealtimes within other ward activities. While unusually complex, mealtimes – arguably – were too 'normal' for the ward staff to emphasize them (Amella, 2002). As was evident from interviews with some of the staff, meals were seen as a challenge, but also just 'something you have to get though'. Where mealtimes did matter, it was thought their clinical or health aspects, as these neatly matched the self-perceived health-based role of both the nurses and *health*care assistants. For example, staff on Site 1 were not comfortable providing patients with foods such as pork pies to even the most undernourished patients, because these foods were not healthy while staff on Site 2 were more preoccupied with nearly-overweight residents, rather than those who were severely underweight. Overall, the fact that the wards were situated within hospitals, meant that staff were more preoccupied with health and survival, than a pleasant experience. Enhancing mealtime experiences there fore did not within the institutional processes and frameworks.

Despite clear hierarchies and power structures, it was equally not clear who 'owned' mealtimes and was responsible for ensuring positive outcomes (even if not positive experiences). The role of nurses was to meet the medical comorbidities due to which many of the patient were admitted to a Continuing Care wards instead of residing in Care *Homes*, while health care assistants provided personal care and dealt with symptoms of dementia (e.g. behaviour that was perceived as challenging). Only feeding and specific mealtime difficulties such as dysphagia (i.e. difficulty swallowing) were therefore 'owned' by the staff.

This section therefore demonstrates that mealtimes in NHS Continuing Care for people with dementia are simultaneously the most complex and also the most downplayed or overlooked activity. Neither the unique challenges nor, importantly, the unique – and powerful - potential of the mealtimes were sufficiently acknowledged.

7.1.4. Summary

While the current research faced considerable pressures and powerful influences affecting the success of small-scale interventions in enhancing mealtime experiences, the key findings provide notable contributions to research literature on mealtimes. The contributions are summarised below.

The research project:

- Supported the existence of micro-cultures and influence of micro-cultures within dementia care settings.
  - While previous research covered other settings (MacLean, 2003; Sandhu, 1964; Soeters, et al., 2006; Wing, 1962; Zurcher, 1965), micro-cultures within dementia care and, in fact, any institutional care for older adults have not been discussed in research to date, despite older adults being the single largest group residing within institutions (Office for National Statistics, 2014).
- Demonstrated that as while NHS Continuing Care wards are uncommon dementia care settings (Miller et al, 2013), they are distinct from other LTDC settings due to being organisationally (and often physically) situated within hospitals. The wards should therefore receive separate research attention.
- Demonstrated that all stakeholder groups within the wards are both willing and able to design interventions which are particularly relevant to the setting. This shows that more Participatory Action Research is both feasible and beneficial within the topic area.
- Demonstrated that people with advanced dementia can be active participants in research, if enough time and care are taken to accommodate the needs for PWD (i.e. careful, mindful research inclusion). PWD were able to both provide compelling accounts on their mealtime experiences and needs, and generate suggestions on how mealtimes could be improved. Importantly, specialist communication skills (see section 6.3.2.1) with PWD during the conversations and an interpretative approach to analysis were needed to maximise participation of individuals with dementia.
- Suggested that for mealtimes to be understood and improved as a rounded experience, mixed multi-method research is needed. A multi-method approach is able to capture distinct aspects of mealtimes, mealtime change and mealtime outcomes,

not all of which go in line with one another. For example, nutritional status, eating ability and body mass did not show a clear relationship.

- Confirmed the multi-dimensional nature of mealtimes, and – crucially – ability to study multiple aspects at once. The majority of studies to date show a narrow focus both in terms of how mealtime explored and how mealtime change is chosen and enacted.

- Demonstrated the importance of psychosocial aspects of mealtimes and commented on reasons why psycho-social needs are often ignored within mealtimes.

- Demonstrated that preventing weight loss and facilitating weight gain is achievable for most patients/residents, also suggesting that high incidence of malnutrition (Abbasi & Rudman, 2004) is largely preventable.

- Demonstrated that while most interventionist studies employ a pre-post design, measuring the change in mealtime outcomes during the intervention period is equally important.

7.2. Strengths, Limitations and Research Reflections

The findings of the current research project are encouraging and suggest that despite the complexity of both mealtimes in dementia care, and facilitating as well as maintaining change within self-reinforcing micro-cultures, enhancing mealtime experiences can be achieved. Nonetheless, notable limitations remain.

In terms of research measures, it is crucial to acknowledge that staff-initiated assessments demonstrated a low response rates. The Quality of Life measure was removed from the set of measures at the time of consultation with research sites as the staff found it too long and time consuming. While initially approved by the staff due to their brevity, eating ability (EdFED) and nutritional status (MNA-SF) assessments were found neither useful nor informative by the ward staff. Less than half of the patients were assessed using these measures in the re-intervention phase, with staff declining to repeat the measures in the intervention and post-intervention phases. Where ratings on these were available, rater agreement was low, with extreme differences in opinion present in some cases. This was in direct contrast to qualitative information collected along with nutritional status and eating ability assessments, which showed very high similarity on content per individual patient. While this posed a clear limitation on the amount of data that could be collected, low reported usefulness and low inter-rater agreement of the aforementioned measures suggest that despite their wide application (e.g. Amella et al, 2008; Chang, 2012; Charlton et al, 2010; Persson et al, 2007, Vischer et al, 2010; Watson & Deary, 1997), these measures should not be used as sole indicators of mealtime outcomes or replaced with more ecologically valid and of higher inter-rater reliability.

Consistent data on Body Mass Indexes was also hard to obtain on Site 1, where staff did not weight staff routinely. This made it hard to track and compare weight changes for the entire patient population. Rather than being a purely methodological limitation, however, it was also a practical one, suggesting that prior to the commencement of the research, more effort should be placed on finding out if data that the researcher cannot obtain themselves can certainly be obtained.

The statistically-low numbers of patients on the research sites also made it impossible to perform certain inferential statistical analises (e.g. inter-rater agreement could not be measured using the intra-class correlation coefficient, and a repeat measures ANOVA could not be performed to assess if weight change was significant). The changing population of

participating patients on Site 1, with some exiting the research and other joining at different stages also made measuring change difficult. Other methods, such as tracing patient BMI trajectories, however, have been employed instead of inferential statistics. While it was a limitation in terms of quantifying change, it is, however, equally important not to fall into the trap of ascribing more value to quantitative methodologies. As can be seen from the current research, in contrast to the commonplace approach where qualitative data only serves to illustrate or explain quantitative findings, the opposite was true. Qualitative data provided the majority of findings and captured mealtimes from a holistic perspective, while quantitative results served to illustrate and track changes (or lack there of) in some of the individual factors that are part of the larger whole. Longitudinal research within changing and complex environments with a large number of factors is hard to control, which in itself would be detrimental to the research process.

Qualitative methodologies also exposed shortcomings. Firstly, despite the intensity of qualitative research (i.e. over 3000 hours of ethnographic observations and a relatively large number of interviews; at least with staff), it cannot be guaranteed that saturation has been achieved. Instead, the researcher is confident that sampling more data would indeed lead to more information related to their research question. While it was not feasible to take the current research beyond the employed timeframe, more research on the topic is needed.

While impartiality is neither feasible nor desirable in qualitative research, it is acknowledged that long periods of time may have resulted in the researcher 'going native', becoming part of the ward-microculture and failing to notice mealtime access due to these processes. The processes of witnessing instances of neglect and abuse also had a psychological impact on the researcher, and may have impacted data analysis. However, the researcher employed strategies to deal with the emotional implications of the research, thus minimising potential influences.

While qualitative and quantitative measures and data analysis possessed some limitations, the same was true for the Action Research part of the current project. Practically, the assumption that if change was desired by the stakeholders and funds were available to enact those changes it would be implemented proved to be incorrect. Instead, as described in the sections above, enacting change was difficult even when it was generated by the stakeholders themselves. The originally selected Site 2 (labelled as 'Discontinued' for clarity) signed up the research, but showed a particular lack of initiative in implementation, coupled with general shortcomings of care that resulted in 'poor practice' ratings from the Care Quality

Commission. As Action researched showed an extreme lack of progress, it was decided to discontinue the research on this site, which resulted in a considerable loss of time.

Methodologically, lack of action and collaboration from stakeholder groups, along with institutional pressures led to questioning how suitable collaborative / participatory methodologies are in institutional settings. Stakeholder collaboration and 'empowerment' does not fit in with institutional micro-cultures, where higher management decisions can trump any bottom-up action. Even if collaboration can be achieved despite the power of divisions among the stakeholder groups, it may create a false sense of agency and power. For example, once Site 1 were told by Health and Safety officials that they could not operate an electric grill on the ward, motivation for other forms of improvement was also lost. The issues with applying participative methodologies therefore transcend feasibility and raise ethical concerns of facilitating 'false hope'. Nonetheless, instead of being seen as a push to avoid participative methodologies altogether, this limitation merely raises the need for future research to explore the full extent of the impact that collaborative projects have on the stakeholders.

The use of a muti-method approach is a particularly noteworthy and unique aspect of this research and a significant strength. Using a set of measures that allowed to tap into physiological, physical *and* psycho-social aspects of mealtimes within the same study allowed a holistic understanding of mealtimes and mealtime change (see Figure 60). Moreover, as described in the Methods chapter, conceptual mealtime dimensions were followed by operationalisation of aspects within these dimenstions that could be measured; physiological aspects of mealtimes were measured by looking at eating ability and assistance, as well as nutrition and hydration, physical aspects were measured by investigating food and the wider mealtime environment, and psycho-social aspects were tapped into by measuring engagement, activity and mood. Crucially, as can be seen in Figure 60, each of the operationalised constructs was measured using a combination of qualitative and quantitative methods. For example, as well as employing structured observations to measure mood, ethnographic observations and interviews/conversations also provided insigts into emotions/mood during (and about) mealtimes.

Using multiple measures to explore the same construct also allowed to note any cases where the findings did not corroborate one another. For example, in terms of nutrition, BMI did not necessarily conside with staff-assessed nutritional status; an individual could be simultaneously overweight and undernourished if they recently lost weight at a rapid rate.

Unlike mixed-method studies, which often use qualitative findings to back up or contextualise quantitative ones, or those studies which attempt to give qualitative and quantitative findings equal weight, the current study drew mostly on wide-scope ethnographic findings and insights from interviews. Quantitative data often served as confirmation, or added depth regarding explanation, of qualitative findings. For example, qualitative stakeholder reports of variable food quality during interviews and conversations were corroborated by structured mealtime observations of eating, where patients were noted to complain about food quality during some of the mealtimes and were recorded as eating less.

Figure 60. Multi-Method Approach Mapped on Mealtime Cosntructs
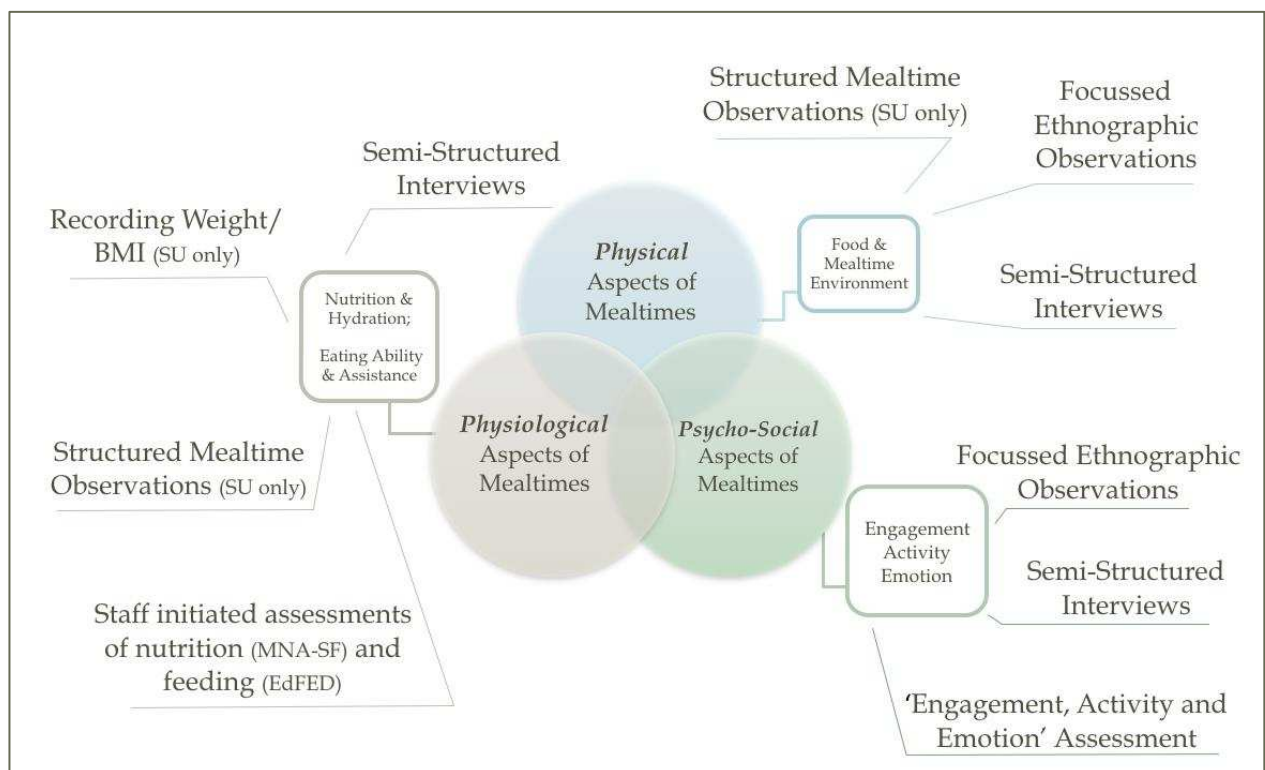
The multi-method approach, particularly the qualitative measures, proved especially suitable in measuring the *process* of implementation. Both due to the chosen methods and due to the pre-during-post procedure (instead of a more commonplace pre-post intervention approach), the project was able to capture the complexities of implementing mealtime change. Specifically, it allowed the researcher to comment on why, despite the multiplicity of ideas regarding mealtime improvements and intial keeneess to implement changes, the agreed changes were hard to put in place or were not retained. While micro-cultural processes which proved to be barriers for change (see Section 6.4.4) were largely explored within a focused ethnography, quantitative findings at times elicited processes or reactions

that impacted on change and could then be captured ethnographically. For example, in Site 1 staff rationalised a high proportion of underweight and undernourished individuals by suggesting that weightloss was a natural part of dementia. If nutritional status was not measured as part of tihis project, staff may not have had the chance to openly discuss the aftementioned belief – which then would not have been captured as part of the enthography.

It is also important to mention that data gathering within the project at times served both as an outcome measure and an intervention. For example, as Site 1 failed to weigh patients at a policy-required frequency, encouraging the collection of BMI data to became an intervention in itself.

Finally, a multi-method approach also allowed the inclusion of PWD who often cannot take part (or are not enabled to take part) in research. For example, where conversational / interview approach was unsuitable due to poor verbal ability in some patients, their experiences were recorded ethnographically and via quantitative activity, engagement and mood observations. For example, even when a patient could not *tell* the researcher they were frustrated or distressed about aspects of the mealtime such as noise levels, their reaction of distress was recorded. A multi-method approach integrating qualitative and quantitatve elements provided a number of benefits that should be considered in future research on the topic on care home micro-cultures.

Overall, the limitations discussed above are important to acknowledge, but they should be considered within the research context and inform, instead of discouraging future research. Equally, the strengths and benefits of using a multi-method approach in a complex and changing context should recognised.

7.3 Implications

7.3.1. Implications for Future Research

The current research demonstrates that in the arena dominated by medical/clinical approaches (e.g. Watson & Green, 2006), social science approaches offer a valuable perspective and can bring new understandings of mealtimes. The holistic approach and focus on overall experiences instead of clinical indicators of undernutrition allows to capture the complexity of mealtimes in long-term dementia care.

Social science approaches also bring more focus on the lived experience of people with dementia (Harris, 2008), focussing especially on the social aspects. A direct focus on user perspective (i.e. hearing the voice of) individuals with advanced dementia is particularly missing from research to date.

The invisibility and impermeability of long-term care settings for people with dementia and particularly NHS Continuing Care wards also means that these settings have not been sufficiently looked at by research. A lot of current knowledge on mealtimes in dementia comes from community-based settings and most of the practice-based literature is aimed at informal carers (e.g. Nutrition & Diet Resources UK, 2014). Considering the potential that mealtimes in the community hold (e.g. Atta-Konadu et al, 2011), it is crucial to explore how to capitalise on this potential within institutional mealtimes.

Action Research on mealtimes also holds particular benefit within LTDC settings. As these are complex locales and mealtimes are often fraught with difficulty, purely exploratory research that occupies time and effort becomes ethically problematic. Action Research, however, provides opportunities to give something back to the research sites in return for their contributions. Exploration of mealtimes and consultation of the stakeholders, however, should remain an integral part of Action Research, as many of the interventionist studies to date test predetermined interventions, that are not necessarily the best fit or most needed within the specific settings.

Also, despite some ethical concerns, participative aspects of research methodologies should also be strengthened. As the scope of mealtime improvements is wide and diverse (from lighting, McDaniel et al, 2001, to seating plans, Cleary et al, 2008, to use of aquariums, Edwards & Beck, 2013), stakeholder participation is crucial when choosing research priorities. As demonstrated within the current research, lay individuals (i.e. relatives), care

professionals (i.e. staff), and – crucially – people with dementia themselves were able to generate ideas specifically relevant to the settings. Research incorporating participative methodologies is therefore of particular benefit.

Overall, while the current project adds some new knowledge about mealtimes, more research on mealtimes is needed. To fill existing knowledge gaps, however, particular effort should be placed on generating research that explores the lived experience of people with dementia in long-term care settings and places an emphasis on the relatively overlooked social/psychological needs, while also exploring the complex and dynamic micro-cultural processes that impact on mealtimes.

7.3.2. Implications for Care/Practice

The research findings demonstrate that mealtimes on Continuing Care wards are currently overlooked, as they do not neatly fit clinical frameworks. Instead, care providers should place importance on mealtimes and utilise their potential to meet social and psychological needs of people with dementia. The value of mealtimes and relational care during mealtimes (including mealtime care provided by relatives) should be embedded in care planning and practices, while mealtimes should be seen as an important part of dementia care.

Decentralised meal provision is also important. Currently, hospital meals are tailored to general hospital patients who spend a short amount of time on the ward. As has been demonstrated within this research, hospital mealtimes do not take into account the specific mealtime needs for people with dementia and do not offer nutritious finger foods, an array of textures, flavour alterations (e.g. more flavourful meals, Pouyet et al, 2015) or enhanced nutritional content (e.g. added protein meals), while the routines and rules around centralised provision mean that PWD often lose out on opportunities to eat (e.g. if they are asleep during the short period within which the meals are served). More autonomy around meatime provision as is common in care homes (Herne, 1994) and at least some capacity to make own food on the wards, may also allow for involving PWD in mealtime preparation (e.g. making sandwiches).

Bottom-up approaches on improving mealtimes should also be encouraged instead of applying prescriptive and often uniform (i.e. the same across all similar settings within an organisation despite distinct micro-cultures) policies and procedures. Giving the ward and the staff permission and autonomy to be creative and engage with mealtime change in a

legitimate way, instead of the often tokenistic regard for staff opinions while designing management-driven approaches, is also crucial. Instead, the management structures within the organisation should ensure sufficient funding to meet mealtime needs of people with dementia (e.g. purchase of patient's favourite snacks and drinks).

7.3.3. Implications for Policy

National-level policy should also take into account mealtimes in dementia care. While dementia has gained increasing policy attention (DOH, 2012), it is important to note that the predominant concerns within policy documents is around research on curing dementia and a timely diagnosis. Relatively little attention is placed on quality care for people who already experience dementia and (as discussed in Chapter 3), the already sporadic mention of mealtime and nutritional needs are being erased from national level policy and guidance documents (DOH, 2009). Moreover, the already clinical focus on nutrition (instead of positive mealtime experience overall) is being replaced by standards that simply require LTC settings to provide enough food and drink to be made available, not referring to skilled assistance to consume the food/drink (CQC, 2011, 2016).

The policy and guidance principle that meals should be nutritious is – of course – a positive one. However, it should not be the only focus. National standards should be looking at the overall *experience* of mealtimes, stressing not only nutrition, but also Quality of Life and psychosocial outcomes.

It is also noteworthy, that the current research revealed a need for more (flexible) funding for ward mealtimes. Shrinking public resources (House of Commons Health Committee, 2016) have a direct impact on supporting people with dementia with long-term needs living in publicly funded institutions. Not being able to provide finger foods on Site 2 due to increased costs provided a direct example of low public recourses affecting patient mealtime experiences.

Importantly, while the author invites policy specific to mealtime experiences in long-term care, such policy should not be prescriptive. For example the current Hospital Food Standards (Department of Health, 2014) includes calorie and salt reduction pledges. people with dementia, however, are likely to need more rather than less calories in the food that they consume, because the volume consumed is often below the entire portion. Equally, while

salt-reduction is important for long-term health outcomes, considering the age of most PWD (Alzheimer's Society, 2014), the average time spent in long-term care before death, and some support that enhanced flavours are consumed at a greater rate (Pouyet et al, 2015), salt reduction is likely to be detrimental rather than helpful. Instead of being prescriptive and equalising care approaches despite very diverse mealtime needs, policy should set desirable outcomes or standards, along with providing sufficient funding and agency to the ward staff to employ their creativity in researching these standards.

Finally it is important for policy and research to share the same value base on the importance of positive mealtime experiences for people with dementia. The premise for this research rests on the belief people with dementia have a right to – and deserve - positive mealtime experiences (and more broadly good Quality of Life) are a right. While this is a reasonable and humane position, it is important to acknowledge that it may not be universally shared, as physiological outcomes have been prioritised so far (Department of Health, 2014).

Overall, therefore, policy on dementia care should consult PWD themselves – at various stages of the illness and prioritise outcomes that are important to the population who are most affected by policy trends.

Chapter 8:
CONCLUSION

This study focussed on mealtimes in two NHS Continuing Care facilities for people with dementia in Kent. The overall aim of the study was to develop small-scale interventions to enhance the experience of meals in the long term care facilities for People with Dementia, their relatives and staff. In order to achieve this the study employed multiple and mixed methodologies to both explore the role of mealtimes within the settings and evaluate change. Action Research approaches with participative elements were also employed to enable stakeholders on the wards (i.e. patients, relatives and staff) to collaboratively develop small-scale mealtimes relevant to the specific sites, and later implement these. The impact of the interventions on body mass, eating ability and assistance, patients' interactions and emotional experiences of mealtimes, and reported experiences of all stakeholder groups was measured, before, during and after the intervention period.

The key findings demonstrated that mealtimes were multi-faceted and complex events on the wards, presenting with a unique set of challenges, but also providing distinct opportunities for meeting a diverse set of needs, trending that of having enough to eat and drink. All stakeholder groups were willing and able to generate suggestions for interventions, that differed substantially across the research sites. This confirmed the prediction that the micro-cultures of each ward would dictate what change is needed and which of these should be prioritised. However, micro-cultures on the wards did not serve purely as a static platform for idea generation and instead actively affected the implementation and retention of mealtime changes. Due to the micro-cultural processes (and resulting divisions between stakeholders) meant that even co-created and mutually-desired change was not implemented in some cases and often not retained. Some lasting change, such as increase in communication with non-verbal patients on one of the research sites, was, however, noticed, along with the demonstration that despite high incidence of malnutrition in Long-Term Dementia Care (Abbasi & Rudman, 1994) weight loss can be prevented and weight gain is achievable for most individuals.

Dementia is experienced by a large and growing number of the population (850,000 people in the UK; Alzheimer's Society, 2014), many of whom reside – and experience mealtimes in - Long Term care faculties (ibid.). Both due to the high importance of mealtimes in dementia

care and because the topic sits on the intersection of research, care policy, and practice, the findings served to inform all of these domains.

Although a distinctive contributions to the knowledge base have been made as a result of this project, more research on mealtimes in Long-Term Dementia care (especially research that explores psycho-social mealtime needs and actively involves people with dementia) remains needed.

While mealtime related research in LTDC is complex to start (in terms of research ethics permissions), complex to carry out (due to its intensity and processes that resist change) and difficult to communicate to wider audiences due to the nuaned and complexity of interacting factors, it is both highly rewarding and much needed.

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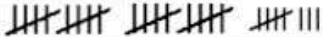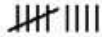
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APPENDIX A Example Observation Form for Eating & Eating Ability

Location:_____   Time of Day:_____   Date:_____   Name of Participant:_____

		Additional comments:
Number of Self-Feeding Cycles	Main: Dessert: Drink: ~~JHT JHT~~ ~~JHT JHT~~ ~~JHT~~ III	
Number of Spoon Feeding Cycles	~~JHT~~ IIII	
Eating Assistance	Verbal prompts: Physical prompts: 3 0	
RIE = number of self-feeding cycles / total of feeding cycles x100	28 / 37 x100 = **75.7%**	
Dysphagia (*choking, hoarseness in throat*)	*None observed*	
Difficulty initiating a meal (>5mins)	*None*	
Difficulty using utensils	*None*	
Difficulty scooping food	*Slight*	*Due to hands shaking*
Difficulty recognising total (*spatial neglect*)	*None*	
Difficulty maintaining attention	*Frequent*	
Difficulty maintaining alertness	*None*	

General observations:

Ate very quickly. Not offered seconds.

APPENDIX B   Example Observation Form for Activity, Engagement & Mood

Location:_____   Time of Day:_____   Date:_____

Part.	Activity	Engagement	Mood	Additional Comments
W	Asleep	-	-	
A	Being fed. Alert. Touching cardigan buttons.	NST (not spoken to)	+1 (smiles)	Looking at RC
J	Eating independently a the table; no other act	Spoken to by staff, does not respond	0	

Participant Information Sheet

Research project: Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

About the study

My name is Rasa Mikelyte and I am PhD student at the University of Kent (School of Social Policy, Sociology and Social Research). I would like to invite you to participate in a study, which explores people's experiences of mealtimes on NHS Continuing Care facilities (wards) for people with dementia in Kent. The overall aim of the study is to develop small-scale interventions to improve the tone, nature and experience of meals in the facilities. The goal of these interventions is to enhance residents' enjoyment of meals and mealtimes, and improve nutrition and hydration levels. It is hoped that relatives' and staff enjoyment of mealtimes will also be enhanced. Limited work has been done in this important area. I think it is a very important issue to understand more about and also to improve.

The first phase of the research will focus on collecting observational data on mealtimes and conducting interviews with staff, family members / friends and, where possible, service users. Small-scale interventions will be developed collaboratively with residents, relatives and staff and implemented over 12 months. Examples include the introduction of a colourful tablecloth, different cutlery or crockery, the use of teapots, and/or relatives and residents enjoying a cup of post mealtime coffee or tea in a relaxed setting. The impact of the interventions on service users' interactions, mood, Quality of Life, and the quantity and benefit of food consumed, will be evaluated using a number of research measures. Interviews will also be conducted to explore the experiences and views of staff and family members in relation to the interventions.

Why have I been invited to take part?

I would like to explore the experiences mealtimes on the ward from the perspectives of all groups of people who reside in, visit or work on the ward. Hearing from you about your experience of food and mealtimes on the ward and your ideas on the improvements that could be made.

Do I have to take part?

It is entirely up to you whether you wish to take part in the study or not. If you decide to take part and then change your mind later, you can withdraw at any time and do not have to give a reason. I will respect this and your involvement in any research procedures (i.e. interviews or observations) will cease immediately.

If I decide to take part, what will it involve?

I would like to interview you about your experiences of mealtimes on the ward. I am likely to wish to interview you 3 times during the study period – before the changes to the mealtimes, when the changes are in the process of being made, and after they have become part of the usual mealtime routine. The interviews will always take place in a part of the ward you feel comfortable in and free to

11/04/2013 **RESGOV232 V1.2**   Page 1 of 2
Contact: Ms Rasa Mikelyte Tel: 07842 257607   Email: rm457@kent.ac.uk
Address: SSPSSR, University of Kent (Medway), Gillingham Building, Chatham Maritime, ME4 4AG

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talk, they will only last as long as you can manage, and will be conducted in a respectful and careful way. You will be free to ask the interview to stop at any time if you become tired or simply wish to end it. I would also like to observe ward routines during, and around, mealtimes. The observations should last several consecutive hours within a day and take place at least once a week. These observations might take place when you are in the communal areas of the ward and would thus include you. My research is likely to last between 9 months and a year.

What will happen to the information from the interviews/observations?

With your permission, I will make notes during the interview and while observing ward routines. To ensure confidentiality and protect your identity, you will be given a pseudonym ie a false name. Only one copy of a list linking people's names to their pseudonyms will be kept and this list will be securely stored on the ward; it will never leave the ward, and will be securely destroyed as soon as the study is completed. Only the PhD student conducting the study will have access to this list; staff never will. All study notes will be made using your pseudonym; these will also be stored securely at the University of Kent and kept no longer than 7 years after the study is complete. If you decide to withdraw from the study I will retain the data that has already been collected about you, unless you inform me that you would like it to be withdrawn. I may use excerpts from the interview in project reports, presentations or articles, but your name will not be included and any information, which may reveal your identity, will be removed.

Will my taking part in the study be kept confidential?

Everything you say is confidential unless you tell me something that indicates that you or someone else is at risk of harm. If this was the case I would discuss my concerns with you before telling anyone else.

Who has reviewed the study?

This study has been approved by the Social Care Research Ethics Committee.

Who can I contact to find out more?

If you are interested in taking part, would like to know more, or have any questions about this study, please do not hesitate to contact me: Rasa Mikelyte, School of Social Policy, Sociology and Social Research, University of Kent, Gillingham Building, Chatham Maritime, ME4 4AG; tel. (mobile): 07842 257607; email: rm457@kent.ac.uk. I would be delighted to hear from you.

I look forward to hearing from you.

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Telephone: 01227 82 3229, Email: directorofresearchservices@kent.ac.uk, Address: University of Kent, Canterbury, CT2 7NF

This is a PhD research project supervised by Dr Alisoun Milne at the University of Kent and Alison Culverwell at Kent and Medway NHS & Social Care Partnership Trust.

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Address: SSPSSR, University of Kent (Medway), Gillingham Building, Chatham Maritime, ME4 4AG

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Participant Consent Form

**Research project: Improving mealtime Experiences
for People with Dementia in Continuing Care NHS Faciities (Wards)**

Please tick the following as appropriate:

I confirm that I have read and understand the participant information sheet.
Yes ☐   No ☐

I have had the opportunity to ask questions about the study and have received satisfactory answers.
Yes ☐   No ☐

I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving a reason and without detriment to me in any way.
Yes ☐   No ☐

I agree that notes will be taken during the interviews / discussions for the use of data analysis. The notes will not contain any names and will be stored securely.
Yes ☐   No ☐

I agree that anything I may say during the interviews can be used in any presentation or papers written about the research and that I will not be identified.
Yes ☐   No ☐

I understand that should I withdraw from the study the researcher will retain the data already collected about me unless I request that all data relating to me is withdrawn from the study.
Yes ☐   No ☐

I agree to take part in the above study.
Yes ☐   No ☐

_____   _____   _____
Name (participant)   Signature   Date

_____   _____   _____
Name (researcher)   Signature   Date

This is a PhD research project supervised by Dr Alisoun Milne at the University of Kent and Alison Culverwell at Kent and Medway NHS & Social Care Partnership Trust.

ENHANCING THE MEALTIME EXPERIENCE

For People with Dementia in NHS Continuing Care* Facilities, their Relatives and Staff

We are looking for 2 Continuing Care wards to take part in the research project.

The aim of the research is to develop small-scale interventions to improve the tone, nature and experience of meals in the facilities. The goal of these interventions is to enhance residents' enjoyment of meals and mealtimes, and improve nutrition and hydration levels, as well as improving the mealtime experiences of staff and visiting relatives/friends.

Limited work has been done in this area and we think it is a very important issue to understand more about and also to improve.

This research project is a collaborative process. Following initial observations and interviews on the ward, as well as sharing of collected information, staff, visiting relatives, and (where possible) patients themselves would decide what changes should be put in place an how. Staff would carry out short assessments measures of patients' nutrition/hydration and eating ability. The researchers' role is mainly advisory, as well as observing and evaluating the process and measuring the impact of the changes.

The project is likely to take place over 9 months and be divided into 3 stages.

We would be delighted if you wished to take up the opportunity to be part of this exciting project!

RESEARCH DETAILS

Researcher: Rasa Mikelyte
Tel: 07842 257607
Email: rm457@kentforlife.net
Address: SSPSSR, University of Kent
         Gillingham Building
         Chatham Maritime
         ME4 4AG

If you are interested in the study, would like to know more, or have any questions about the study, please do not hesitate to contact me!

Supervisors:
Alison Culverwell
Head of Older Adult Psychological Services for Eastern & Coastal Kent KMPT

Prof. Alisoun Milne
School of Social Policy, Sociology & Social Research, University of Kent

This research project is hosted by:

Kent and Medway **NHS**
NHS and Social Care Partnership Trust

University of **Kent** | School of Social Policy, Sociology and Social Research

and sponsored by:

KentHealth

The study has been approved by the Social Care Research Ethics Committee.
REC reference: 13/IEC08/0018

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Telephone: 01227 823229, Email: directorofresearchservices@kent.ac.uk, Address: University of Kent, Canterbury, CT2 7NF

Participant Information Sheet

Research project: Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

About the study

My name is Rasa Mikelyte and I am PhD student at the University of Kent (School of Social Policy, Sociology and Social Research). I would like to invite you to participate in a study, which explores people's experiences of mealtimes on NHS Continuing Care facilities (wards) for people with dementia in Kent. The overall aim of the study is to develop small-scale interventions to improve the tone, nature and experience of meals in the facilities. The goal of these interventions is to enhance residents' enjoyment of meals and mealtimes, and improve nutrition and hydration levels. It is hoped that relatives' and staff enjoyment of mealtimes will also be enhanced. Limited work has been done in this important area. I think it is a very important issue to understand more about and also to improve.

The first phase of the research will focus on collecting observational data on mealtimes and conducting interviews with staff, family members / friends and, where possible, service users. Small-scale interventions will be developed collaboratively with residents, relatives and staff and implemented over 12 months. Examples include the introduction of a colourful tablecloth, different cutlery or crockery, the use of teapots, and/or relatives and residents enjoying a cup of post mealtime coffee or tea in a relaxed setting. The impact of the interventions on service users' interactions, mood, Quality of Life, and the quantity and benefit of food consumed, will be evaluated using a number of research measures. Interviews will also be conducted to explore the experiences and views of staff and family members in relation to the interventions.

Why have I been invited to take part?

I would like to explore the experiences mealtimes on the ward from the perspectives of all groups of people who reside in, visit or work on the ward. Your ideas on how their and your experience of mealtimes on the ward could be improved would be greatly appreciated.

Do I have to take part?

It is entirely up to you whether you wish to take part in the study or not. If you decide to take part and then change your mind later, you can withdraw at any time and do not have to give a reason. I will respect this and your involvement in any research procedures (i.e. interviews or observations) will cease immediately.

If I decide to take part, what will it involve?

I would like to interview you about your experiences of mealtimes on the ward. I am likely to wish to interview you 3 times during the study period – before the changes to the mealtimes, when the changes are in the process of being made, and after they have become part of the usual mealtime routine. The interviews will always take place in a part of the ward you feel comfortable in and free to talk, they will only last as long as you can manage, and will be conducted in a respectful and careful

way. You will be free to ask the interview to stop at any time if you become tired or simply wish to end it. I would also like to observe ward routines during, and around, mealtimes. The observations should last several consecutive hours within a day and take place at least once a week. These observations might take place when you are present on the ward and would thus include you.

In addition to this, you might be offered to answer some very brief questionnaires about patient's eating, assistance with eating and Quality of Life. These should then help to think about small changes the ward staff would like to implement in order to improve mealtime experiences.

My research is likely to last between 9 months and a year.

What will happen to the information from the interviews/observations?

With your permission, I will make notes during the interview and while observing ward routines. To ensure confidentiality and protect your identity, you will be given a pseudonym ie a false name. Only one copy of a list linking people's names to their pseudonyms will be kept and this list will be securely stored on the ward; it will never leave the ward, and will be securely destroyed as soon as the study is completed. Only the PhD student conducting the study will have access to this list; staff never will. All study notes will be made using your pseudonym; these will also be stored securely at the University of Kent and kept no longer than 7 years after the study is complete. If you decide to withdraw from the study I will retain the data that has already been collected about you, unless you inform me that you would like it to be withdrawn. I may use excerpts from the interview in project reports, presentations or articles, but your name will not be included and any information, which may reveal your identity, will be removed.

Will my taking part in the study be kept confidential?

Everything you say is confidential unless you tell me something that indicates that you or someone else is at risk of harm. If this was the case I would discuss my concerns with you before telling anyone else.

Who has reviewed the study?

This study has been approved by the Social Care Research Ethics Committee.

Who can I contact to find out more?

If you are interested in taking part, would like to know more, or have any questions about this study, please do not hesitate to contact me: Rasa Mikelyte, School of Social Policy, Sociology and Social Research, University of Kent, Gillingham Building, Chatham Maritime, ME4 4AG; tel. (mobile): 07842 257607; email: rm457@kent.ac.uk. I would be delighted to hear from you.

I look forward to hearing from you.

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Telephone: 01227 82 3229, Email: directorofresearchservices@kent.ac.uk, Address: University of Kent, Canterbury, CT2 7NF

This is a PhD research project supervised by Dr Alisoun Milne at the University of Kent and Alison Culverwell at Kent and Medway NHS & Social Care Partnership Trust.

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Contact: Ms Rasa Mikelyte Tel: 07842 257607   Email: rm457@kent.ac.uk
Address: SSPSSR, University of Kent (Medway), Gillingham Building, Chatham Maritime, ME4 4AG

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Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

Interview Recording Consent Form

As part of the research project, I would like to record an interview with you. Everything you say will be kept confidential at all times. The audio recording will only be used to transcribe the interview and will be securely destroyed immediately afterwards. During the transcription, I shall take out all the names or other identifiable information you mention in the interview. Exerts from our interview might be used in reports or research publications, but will never identify you or anyone else.

This is completely voluntary and up to you. You may request to stop the recording at any time or to erase any portion of the recording.

I have read the information above and agree to have my interview recorded.

_____   _____   _____

Name   *Signature*   *Date*

Grey areas disguise identifiable information
to ensure patient confidentiality

RE: Research project on 'Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)'

I am writing to let you know about a research study that is taking place ⬛⬛⬛⬛⬛⬛⬛⬛. The study is being conducted by the Kent and Medway NHS Trust in partnership with the University of Kent.

The research project will explore people's experiences of mealtimes on NHS Continuing Care Wards, including people with dementia, their relatives and ward staff. The overall aim of the project is to collaboratively develop small-scale interventions to improve the nature and experience of meals on the wards. Enclosed is a leaflet describing the study in more detail.

You have been contacted for two reasons. Firstly, some of our patients will not be able to make a decision whether they would like to take part in the research. As someone who knows the participant well, you might be able to advise us as to what that person's wishes would have been if they had capacity to consent. Secondly, you are invited to take part in the study yourself.

At this stage we only need to know whether you might be interested in taking part and/or if you are able to offer an opinion regarding your relative's participation. If you are, please return the reply slip and the researcher will get in touch with you soon and to discuss things in more detail. You are also very welcome to contact the researcher, Rasa Mikelyte, yourself on the phone (07842 257607) or via email (rm457@kentforlife.net).

Yours sincerely,

⬛⬛⬛⬛ Team

University of **Kent** | School of Social Policy, Sociology and Social Research   **KentHealth**   Kent and Medway **NHS** NHS and Social Care Partnership Trust

Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)
Consultee Reply Slip

Please choose one option below:

I am able and willing to offer an opinion as to the wishes of my relative (who currently resides on a Continuing Care Ward) in relation to their participation in the study.   ☐

I do not wish to offer an opinion about their participation, but I am happy for the researcher to consult the clinical staff instead   ☐

I *do not* wish my relative to take part in this project.   ☐

Name: _____

Telephone Number: _____

University of **Kent** | School of Social Policy, Sociology and Social Research   **KentHealth**   Kent and Medway **NHS** NHS and Social Care Partnership Trust

Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)
Study Reply Slip

Please choose one option below:

I may be interested in participation in this Project; please contact me about it   ☐

Please *do not* contact me about this project   ☐

Name: _____

Telephone Number: _____

CONTACT DETAILS

Researcher: *Rasa Mikelyte*
Tel: 07842 257607
Email: rm457@kentforlife.net
Address: SSPSSR, University of Kent
            Gillingham Building
            Chatham Maritime
            ME4 4AG

If you are interested in the study, would like to know more, or have any questions, please do not hesitate to contact me!

Supervisors:
Alison Culverwell
Head of Older Adult Psychological Services for Eastern & Coastal Kent
KMPT

Prof. Alisoun Milne
School of Social Policy, Sociology & Social Research, University of Kent

RESEARCH DETAILS

This research project is hosted by:

Kent and Medway **NHS**
NHS and Social Care Partnership Trust

University of **Kent** | School of Social Policy, Sociology and Social Research

and sponsored by:

KentHealth

The study has been approved by the Social Care Research Ethics Committee.
REC reference: 13/IEC08/0018

ENHANCING THE MEALTIME EXPERIENCE

For People with Dementia in NHS Continuing Care Wards, their Relatives and Staff

ABOUT THE RESEARCH

The aim of the research is to develop small-scale interventions to improve the tone, nature and experience of meals in the Continuing Care wards.

The goal of these interventions is to enhance residents' enjoyment of meals and mealtimes, and improve nutrition and hydration levels. It is hoped that relatives' and staff enjoyment of mealtimes on the ward will also be enhanced.

Limited work has been done in this area and we think it is a very important issue to understand more about and also to improve.

The project is likely to take place over 9 months and be divided into 3 stages: initial observations, implementation of changes, and evaluation of the impact of these.

COLLABORATION

This research project is a collaborative process between the participants and the researcher. Following initial observations and sharing of collected information, staff, visiting relatives, and (where possible) patients themselves would decide what changes to mealtimes should be put in place and how.

The small-scale changes can involve anything that is considered necessary, from changing the food or altering the table set up to encouraging more conversations between people with dementia around a dining table.

It is important that the agreed changes are relevant to the ward life. Therefore, we need as many people as possible to make a contribution!!

MEASURES

The project will involve the researcher conducting:

- general observations on the ward;
- structured mealtime observations (e.g. how much patients eat, eating independence, mealtime interactions)
- monitoring patients' weight/BMI;
- measuring patients' Quality of Life, mood and engagement;
- interviewing staff, relatives and (where possible) patients about their mealtime experiences,
  and
- staff conducting short assessments of nutrition and eating ability.

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Email: directorofresearchservices@kent.ac.uk, Tel: 01227 823229, Address: University of Kent, Canterbury, CT2 7NF

Participant Information Sheet

Research project: Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

About the study

My name is Rasa Mikelyte and I am PhD student at the University of Kent (School of Social Policy, Sociology and Social Research). I would like to invite you to participate in a study, which explores people's experiences of mealtimes on NHS Continuing Care facilities (wards) for people with dementia in Kent. The overall aim of the study is to develop small-scale interventions to improve the tone, nature and experience of meals in the facilities. The goal of these interventions is to enhance residents' enjoyment of meals and mealtimes, and improve nutrition and hydration levels. It is hoped that relatives' and staff enjoyment of mealtimes will also be enhanced. Limited work has been done in this important area. I think it is a very important issue to understand more about and also to improve.

The first phase of the research will focus on collecting observational data on mealtimes and conducting interviews with staff, family members / friends and, where possible, service users. Small-scale interventions will be developed collaboratively with residents, relatives and staff and implemented over 12 months. Examples include the introduction of a colourful tablecloth, different cutlery or crockery, the use of teapots, and/or relatives and residents enjoying a cup of post mealtime coffee or tea in a relaxed setting. The impact of the interventions on service users' interactions, mood, Quality of Life, and the quantity and benefit of food consumed, will be evaluated using a number of research measures. Interviews will also be conducted to explore the experiences and views of staff and family members in relation to the interventions.

Why have I been invited to take part?

I would like to explore the experiences mealtimes on the ward from the perspectives of all groups of people who reside in, visit or work on the ward. As a relative or friend of a person with dementia, you can contribute to this research by telling us how mealtimes on the ward differ from mealtimes throughout your and your loved ones' life. Your opinion on how their and your experience of mealtimes on the ward could be improved would be greatly appreciated.

Do I have to take part?

It is entirely up to you whether you wish to take part in the study or not. If you decide to take part and then change your mind later, you can withdraw at any time and do not have to give a reason. I will respect this and your involvement in any research procedures (i.e. interviews or observations) will cease immediately.

If I decide to take part, what will it involve?

I would like to interview you about your experiences of mealtimes on the ward. I am likely to wish to interview you 3 times during the study period – before the changes to the mealtimes, when the changes are in the process of being made, and after they have become part of the

usual mealtime routine. The interviews will always take place in a part of the ward you feel comfortable in and free to talk, they will only last as long as you can manage, and will be conducted in a respectful and careful way. You will be free to ask the interview to stop at any time if you become tired or simply wish to end it. I would also like to observe ward routines during, and around, mealtimes. The observations should last several consecutive hours within a day and take place at least once a week. These observations might take place when you are present on the ward and would thus include you. My research is likely to last between 9 months and a year.

What will happen to the information from the interviews/observations?

With your permission, I will make notes during the interview and while observing ward routines. To ensure confidentiality and protect your identity, you will be given a pseudonym ie a false name. Only one copy of a list linking people's names to their pseudonyms will be kept and this list will be securely stored on the ward; it will never leave the ward, and will be securely destroyed as soon as the study is completed. Only the PhD student conducting the study will have access to this list; staff never will. All study notes will be made using your pseudonym; these will also be stored securely at the University of Kent and kept no longer than 7 years after the study is complete. If you decide to withdraw from the study I will retain the data that has already been collected about you, unless you inform me that you would like it to be withdrawn. I may use excerpts from the interview in project reports, presentations or articles, but your name will not be included and any information, which may reveal your identity, will be removed.

Will my taking part in the study be kept confidential?

Everything you say is confidential unless you tell me something that indicates that you or someone else is at risk of harm. If this was the case I would discuss my concerns with you before telling anyone else.

Who has reviewed the study?

This study has been approved by the Social Care Research Ethics Committee.

Who can I contact to find out more?

If you are interested in taking part, would like to know more, or have any questions about this study, please do not hesitate to contact me: Rasa Mikelyte, School of Social Policy, Sociology and Social Research, University of Kent, Gillingham Building, Chatham Maritime, ME4 4AG; tel. (mobile): 07842 257607; email: rm457@kentforlife.net. I would be delighted to hear from you.

I look forward to hearing from you.

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Telephone: 01227 82 3229, Email: directorofresearchservices@kent.ac.uk, Address: University of Kent, Canterbury, CT2 7NF

This is a PhD research project supervised by Dr Alisoun Milne at the University of Kent and Alison Culverwell at Kent and Medway NHS & Social Care Partnership Trust.

ENHANCING THE MEALTIME EXPERIENCE
For People with Dementia in NHS Continuing Care Facilities, their Relatives and Staff

RELATIVES' MEETING
Saturday, 12th of October
2pm - 4pm

Please come see me if you would like to discuss the research project, have any questions about the consent forms, or would like to share your ideas on how to improve mealtimes on the ward.

I look forward to meeting you!!

Side A

CONTACT DETAILS

Researcher:
Rasa Mikelyte

If you would like to contact me, please do not hesitate to do so:

Tel: 07842 257607
Email: rm457@kentforlife.net
Address: SSPSSR
            University of Kent
            Gillingham Building
            Chatham Maritime
            ME4 4AG

If you cannot make the Relatives' Meeting, but would like to see me in person, I will be on   most **Mondays**, **Tuesdays** and **Wednesdays**.

Side B

Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

Consent Form

Thank you for coming to the Relatives' Meeting. The meeting is part of a research project, which aims to develop small-scale interventions to improve the tone, nature and experience of mealtimes in Continuing Care Wards. During the meeting, I am interested in learning about any ideas you may have for further improving mealtimes on the ward. There are no 'right' or 'wrong' answers. I am also talking to patients and wards staff.

If it is okay with you, I will be recording our conversation. The purpose of this is so that I can get all the details of what you are saying, but at the same time be able to have an attentive conversation with you rather than writing what you say down at the same time as talking to you. Any recorded material will remain entirely confidential. The transcribed conversation will not contain your name (or any names you might mention during our conversation), and the recording will be destroyed as soon as I have transcribed the interview. I might use small exerts from the meeting in documents such as my PhD thesis and/or a paper for a journal, but these will be **anonymised** at all times. In other words, nothing you say can be attributed to you. I want you to feel comfortable and to be hones. If you agree that the conversation can be recorded, please sign below.

_____   _____   _____
Name   *Signature*   *Date*

University of Kent | School of Social Policy, Sociology and Social Research   **KentHealth**   **Kent and Medway NHS** and Social Care Partnership Trust

Consultee Information Sheet

Research project: Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

I am conducting research on mealtimes on two Continuing Care wards for people with dementia. Some patients will not be unable to make a decision whether they would like to take part in the research. You are being invited to act as a 'consultee' for a person unable to provide consent. This means letting me know whether you think they themselves would have wished to take part in this study. Please take time to read this information carefully and talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to be a consultee.

Why have I been approached?

You may have been chosen because you know the patient personally, either as a friend, partner, or relative, and they would trust you to help with this decision. Or, you may be a member of the care team who looks after the patient (such as member of care home staff, GP, or healthcare professional), and you have the patient's best interests in mind.

What does it mean to be a consultee?

A consultee is someone who knows the participant well and is willing and able to offer an opinion as to what that person's wishes would have been if they had capacity to consent. You do not have to act as a consultee if you do not want to. If you decide to act as consultee, you will be asked to sign a Consultee Form. If you think that this person would not have wanted to take part, then the researchers will respect this. *Please remember that you are not being asked for your personal views on the research but consider only what the person's wishes would have been were they being asked to take part in this research.*

What is the purpose of this study?

The study explores people's experiences of mealtimes on NHS Continuing Care facilities (wards) for people with dementia in Kent. The overall aim of the study is to develop small-scale interventions to improve the tone, nature and experience of meals in the facilities with the goal of enhancing residents' enjoyment of meals and mealtimes, and improving nutrition and hydration levels. Examples include the introduction of a colourful tablecloth, different cutlery or crockery, the use of teapots, and/or relatives and residents enjoying a cup of post mealtime coffee or tea in a relaxed setting. It is also hoped that relatives' and staff enjoyment of meals will also be enhanced. Limited work has been done in this area. We think it is a very important issue to understand more about and also to improve.

Why has this person been chosen?

We are inviting all patients on the two identified hospital wards for people with dementia in Kent to participate. The ward this patient is on is part of our study.

Do patients have to take part?

No.

What will happen to patients taking part in the study?

They will be observed in a non-intrusive manner during and around mealtimes. I might want to talk to them about their experiences of mealtimes and staff might perform an observational assessment to see if the patient has any difficulties during the mealtimes. Quality of Life, e.g. happiness and crying, will also be noted. Information about their weight and height would be collected from the ward records. As a result of the observations, small-scale changes around mealtimes are likely to take place, including changes to food content and availability. However, this will at all times comply with special dietary requirements (e.g. not eating meat) should the patient have any. All personal identifying information will be kept confidential.

What are possible benefits of taking part?

The study involves small-scale interventions aimed at improving ward patients' mealtime experiences, with likely benefits during the mealtime and potentially beyond (e.g. improved mood and quality of life). There are no known risks to taking part in the research. However, if during the study the patient shows any signs of distress or indicates that they do not wish to take part (e.g. by walking away during a conversation), I will respect this, stop collecting information about this patient immediately.

What will happen to the information from the interviews/observations?

To ensure confidentiality, all observations and interviews will be anonymised and any identifiable information will be kept securely on the ward. If the patient decides to withdraw from the study I will retain the data that has already been collected about them, unless they or their consultee inform me that they would like it to be withdrawn. I may use excerpts from conversations with the patients in project reports, presentations or articles, but their name will not be included and any information, which may reveal their identity, will be removed.

Will the patient's taking part in the study be kept confidential?

Everything the patient says is confidential unless they tell me something that indicates that they or someone else is at risk of harm. If this was the case I would discuss my concerns with them before telling anyone else. The patient's GP will be informed that they are taking part in the study.

Who has reviewed the study?

This study has been approved by the Social Care Research Ethics Committee and has received Research & Development approval from the NHS hospital trust.

Who can I contact to find out more?

If you would like to know more, or have any questions about this study, please do not hesitate to contact me: Rasa Mikelyte, School of Social Policy, Sociology and Social Research, University of Kent, Gillingham Building, Chatham Maritime, ME4 4AG; tel. (mobile): 07842 257607; email: rm457@kenforlife.net. I would be delighted to hear from you.

I will keep you and the ward staff periodically informed about the progress of the study.

If you wish to make a complaint about the study, you may contact: Simon Kerridge, Director of Research Services, University of Kent, Canterbury, CT2 7NF, Telephone: 01227 82 3229, Email: directorofresearchservices@kent.ac.uk

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University of Kent | School of Social Policy, Sociology and Social Research   **KentHealth**   Kent and Medway **NHS** — NHS and Social Care Partnership Trust

Personal Consultee Declaration Form

Research project: Improving mealtime Experiences for People with Dementia in Continuing Care NHS Faciities (Wards)

Name of Consultee:_____   Name of Participant (patient):_____

Please tick the following as appropriate:

I have been consulted about the above named individual's participation in this research project. I confirm that I have read and understood the Personal Consultee Information Sheet for the above study. I have had the opportunity to ask questions about the study and understand what is involved.
Yes ☐   No ☐

In my opinion the individual named above would have no objection to taking part in the above study.
Yes ☐   No ☐

I understand that their participation is voluntary and that I am free to withdraw them at any time, without giving any reason, without their medical care or legal rights being affected.
Yes ☐   No ☐

I understand that relevant sections of their medical notes may be looked at by the researcher
Yes ☐   No ☐

I understand that all information will be anonymised and that information will remain confidential and only be used for research.
Yes ☐   No ☐

I understand that their GP will be/has been informed of their participation in this study.
Yes ☐   No ☐

_____   _____   _____
Name (consultee/relative)   Signature   Date

_____   _____   _07/10/2013_
Name (researcher)   Signature   Date

This is a PhD research project supervised by Prof Alisoun Milne at the University of Kent and Alison Culverwell at Kent and Medway NHS & Social Care Partnership Trust.

Joan

Is finding nutrition and hydration increasingly more problematic.

Keep a constant supply of biscuits and tea

(This should supplement rather than replace meals). Also:

- **Sweeten most foods**
- **Try more finger foods**

Sarah

Sarah often falls asleep mid-meal due to lack of sensory stimulation

- **Talk a lot and try 'deep touch' techniques when assisting with food**

Shannon

- **Trial sweetening most foods**
- **Offer small amounts at frequent intervals**
- **Always offer a second pudding**
- **Provide Shannon & Jerry with two sets of cutlery**
  (Jerry feeding often encourages Shannon to eat independently for a while, but she does not always have a second set of cutlery)

Jean

- **Talk a lot and try 'deep touch' techniques when assisting with food**
- **Offer food at frequent intervals**
- **More finger foods needed**

Hugh

- **Monitor swallowing and choking**
- **Invite to eat socially whenever possible**

On those occasions he is more likely to eat what everyone else is having.

Rupert

- **Ensure John eats and drinks something at snack times**
- Until weight becomes healthy, **offer high-calorie options**

Jeremy

- **Offer finger foods whenever possible**
- **Jeremy does much better when he can see someone else eat**
- **Try to maintain the same mode of eating throughout the courses**

Alistair

- **Prioritise hydration**
- **Keep food behind to offer Alistair when he feels like eating;** sticking to meal*times* might not work anymore
- **A pleasant conversation might help Alan stay alert long enough to eat**

Norman

- **Focus on hydration / foods high in water**
- **Norman is starting to struggle with chewing and swallowing; offer softer foods**

More finger foods
More mealtime cues
More social opportunities
More celebration of food and mealtimes

There are 4 underweight residents on OU:

- **Keep offering seconds if the resident is eating;** do not stop if they have finished their portion
  - Don't take plates away when offering seconds; bring food to the residents plates instead

- **Offer smaller portions on bigger plates**

- **If a part of the meal is not eaten, offer calorific replacements** (e.g. biscuits or chocolate)

- **Dehydrated people eat much less**
  - Prioritise adequate hydration

- **Some people eat little and often and cannot manage large portions**
  - Offer small snacks periodically

Patient Mealtime Preferences

We fully acknowledge that a person's likes and dislikes around food and mealtimes may change throughout their life and will always respect the choices our patients make. However, learning about patients' past preferences and habits would provide us with ideas when encouraging patients to eat and ensuring that their mealtime experiences are as positive as they can be.

Please answer the questions below:

1.   What, in your opinion, would constitute an enjoyable mealtime for your relative?
       (think about their mealtimes before coming to the unit)
_____
_____
_____

2.   What are your relative's favourite meals/food? (*both now and in the past*)
_____
_____

3.   What are their favourite drinks? (*both now and in the past*)
_____
_____

4.   Do they have any dislikes regarding food or drink?
_____
_____

5.   In the past, did they prefer to eat on their own or with people?
_____
_____

6.   In the past, did they usually eat at a table or somewhere else (e.g. while watching TV)?
_____
_____

7.   In the past, did they eat their main meal at lunchtime or in the evening?
_____
_____

8.   Can you think of any other mealtime habits or preferences?
_____
_____

9.   Do you have any suggestions on how the staff could encourage your relative to eat and drink
       more (if this is/becomes an issue)?
_____
_____
_____

10.   Do you have any suggestions or comments about the 'Mealtime Preferences' sheet?
_____
_____
_____

MEALTIME MATTERS

Resources on Improving Mealtimes for People with Dementia in Long-Term Care

Side A

Contents

- **EATING WELL:** Supporting Older People and Older People With Dementia
- **MEALS MAKE SENSE:** An audit checklist to consider how far a Care Home is implementing quality re mealtime experience
- **EAT WELL:** a practical guide for supporting people with dementia
- **COMMUNICATION AND MEALTIMES TOOLKIT:** helping people with dementia to eat, drink & communicate
- **NUTRITION AND DEMENTIA:** a review of available research EATING WELL: your guide to enjoying food and drink when you have memory problems
- **DEMENTIA AND FOOD:** dietary advice from NHS Norfolk
- **DEMENTIA CARE - SUPPORT WITH EATING AND DRINKING:** a practical guide for carers
- **EATING WELL FOR OLDER PEOPLE:** practical and nutritional guidelines for food in residential and nursing homes and for community meals
- **FOOD FIRST:** a guide to detecting, preventing and managing malnutrition for Care Homes for the Elderly
- **HELPING A PERSON WITH DEMENTIA TO EAT WELL:** informational leaflet from Stockport NHS
- **NUTRITION AND HYDRATION IN DEMENTIA AT END OF LIFE**
- **WEIGHT LOSS IN ADVANCED DEMENTIA:** Information for family members
- **MALNUTRITION UNIVERSAL SCREENING KIT**
- **DEMENTIA GATEWAY - EATING WELL:** key messages
- **EATING WELL FOR PEOPLE WITH DEMENTIA:** promoting independence a mealtimes
- **IMPROVING NUTRITION IN DEMENTIA THROUGH MENU PICTURE CARED AND COOKING ACTIVITIES**
- **THE DINING EXPERIENCE OF RESIDENTS WITH DEMENTIA IN LONG-TERM CARE FACILITIES**
- **DIFFICULTY SWALLOWING:** a practical guide to food, fluid and medication in advanced dementia
- **PRACTICAL TIPS TO HELP RESIDENTS WITH DEMENTIA WHEN EATING AND DRINKING:** a guide from Leicestershire NHS
- **GUIDELINES FOR THE MANAGEMENT OF DEEDING AND SWALLOWING PROBLEMS IN DEMENTIA:** Mid Cheshire NHS
- **DEMENTIA CARE - A PRACTICAL GUIDE TO EATING AND DRINKING**
- **DEMENTIA CARE CENTRAL - EATING**
- **EATING AND DRINKING:** Alzheimer's Society
- **FEEDING ISSUES AND DEMENTIA:** NHS leaflet
- **DINING AND DEMENTIA:** Alzheimer's Alaska
- **FIGER FOODS:** leaflet from South Essex NHS
- **ENCOURAGING EATING:** advice for care givers
- **FINGER FOODS:** leaflet
- **THE EATING ENVIRONMENT:** leaflet
- **EATING NON-FOOD ITEMS:** leaflet
- **EATING OUT:** leaflet
- **EAT WELL WITH DEMENTIA:** a carer's guide
- **MEAL TIMES:** a guide from Alzheimer's Society

Side B

Phase 1:

1. Have you ever been on the ward during a mealtime?
   a.   Were you in the dining room?
   b.   Where you in your relative's room?

_____
_____
_____
_____

2. What are your impressions (what do you think of) mealtimes on the ward?
   • Food
   • Atmosphere and Environment
   • Mealtime Assistance (Feeding)
   • The social side of mealtimes
   • Staff involvement
   • Mealtime routine (time of mealtimes, flexibility)

_____
_____
_____
_____
_____
_____

3. In your opinion, how does you relative experience mealtimes on the ward?

_____
_____
_____
_____
_____

4. What do good, or enjoyable mealtimes mean to you?

_____
_____
_____
_____
_____

5. Can you tell me about your relative's mealtimes before they came to ████████?

_____
_____
_____
_____
_____

6. Can you tell me about your relative's mealtimes before they came to ██████████?
- Did they enjoy food?
- What did they like & dislike about the food?
- Where did they enjoy eating: at a table, while watching TV, etc.?
- Did they socialise during mealtimes?
- Would they have preferred a quiet environment?

_____
_____
_____
_____
_____

7. Do you have any ideas on how mealtimes could be improved on ██████████? Should anything definitely stay the same?

_____
_____
_____
_____
_____
_____

8. Do you have any concerns or compliments about mealtimes on the ward?

_____
_____
_____
_____
_____
_____

_____

Phase 2:

1. Have you ever been on the ward during a mealtime?
- c. Were you in the dining room?
- d. Where you in your relative's room?

_____
_____
_____
_____

2. What are your impressions (what do you think of) mealtimes on the ward?
- Food
- Atmosphere and Environment
- Mealtime Assistance (Feeding)
- The social side of mealtimes

- Staff involvement
- Mealtime routine (time of mealtimes, flexibility)

_____
_____
_____
_____
_____
_____

3. In your opinion, how does you relative experience mealtimes on the ward? Has this changed in any way recently?

_____
_____
_____
_____
_____

4. Have you noticed any changes to mealtimes? If so, how? *What are your* impressions of these changes (where they for the better or for worse)?

_____
_____
_____

5. Do you have any concerns or compliments about mealtimes on the ward?

_____
_____
_____
_____
_____
_____

_____

Phase 3:

1. Have you ever been on the ward during a mealtime?
   e. Were you in the dining room?
   f. Where you in your relative's room?

_____
_____
_____
_____

2. What are your impressions (what do you think of) mealtimes on the ward?
- Food
- Atmosphere and Environment
- Mealtime Assistance (Feeding)
- The social side of mealtimes
- Staff involvement
- Mealtime routine (time of mealtimes, flexibility)

_____
_____

_____
_____
_____
_____

3. In your opinion, how does you relative experience mealtimes on the ward? Has this changed in any way recently?

_____
_____
_____
_____
_____

4. Have mealtimes on the ward change in any way during the past year? If so, how? *What are your* impressions of these changes (where they for the better or for worse)?

_____
_____
_____

5. Were there any changes you hoped would take place, but didn't?
   (If answered positively, ask "Why didn't these changes take place?")

_____
_____
_____

6. Do you have any concerns or compliments about mealtimes on the ward?

_____
_____
_____
_____
_____
_____

7: Do you have any comments on the Mealtime Research project that took place on ██████████ ward? *(If not mentioned spontaneously, ask for comments on research aims, timeline, the researcher, resources/funding, etc.)*
   - Did the research have any impact on mealtimes on the ward?
      ~ *If so:* Was this impact positive or negative and in what way?
   - What was done well or poorly? What could have been done differently?

_____
_____
_____

Improving Mealtimes for People with Dementia in NHS Continuing Care Facilities, their Relatives, and Staff

Interview Protocol: Ward Staff

INSRTRUCTIONS:

Good morning/afternoon. My name is Rasa Mikelyte. Thank-you for agreeing to take part in the interview. This interview is part of a research project which aims to develop small-scale interventions to improve the tone, nature and experience of meals in the Continuing Care Wards. During this interview I am interested in learning about your experiences of mealtimes on the ward. The aim of the interview is to explore your ideas and experiences and thus there are no 'right' or 'wrong' answers.

RECORDING:

If it is okay with you, I will be recording our conversation. The purpose of this is so that I can get all the details but at the same time be able to have an attentive conversation with you. I assure you that all your comments will remain confidential. The transcribed interview will not contain your name (or any names you might mention during our conversation), and the recording will be destroyed as soon as I transcribe our interview. I might use small exerts from your comments in documents others within and outside the ward can see, but these will be anonymised at all times. If you agree to be recorded, please read and sigh the consent slip.

Before we start, have you any questions?

_____

Q1: What are your impressions (what do you think) of mealtimes on the ward?

> If not mentioned spontaneously, ask what they think about:
> * Food
> * Atmosphere and Environment
> * Mealtime Assistance (feeding)
> * The social side of mealtimes
>   (conversations, togetherness, sharing)
> * Relatives' involvement
> * Mealtime routines
>   (is it a part of day they look forward to? most liked/disliked

Space for general observations (e.g. body language):

_____
_____
_____
_____
_____

Q2: In your opinion, how do the patients experience mealtimes on the ward?
(if the interviewee asks for more information or is unsure how Q2 differs from Q1, ask them to "Try to imagine what mealtimes would be like for you if you were a patient here")

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_____

_____

Q3: Now, think about your personal experience of mealtimes (at home, with family and friends, now and throughout your life). What do nice mealtimes mean to you?
(if further prompting need, ask: "What are the most important aspects of mealtimes for you"; can also use items from Q1 if a second prompt is needed)

_____

_____

_____

Q4: Coming back to mealtimes on the ward, is there anything you would like to change? Perhaps you had an idea about doing something differently for a while or thought of one as we were talking...

Q5: What are the challenges of making changes to mealtimes on the ward?

_____

_____

_____

Q6: Is there anything about mealtimes on the ward you think should definitely stay the same?

_____

_____

_____

_____

DEBRIEF:
Thank-you very much for your time. Your opinions and ideas are very important for our research and will contribute to designing small-scale interventions to improve mealtimes on the ward.

If you have any questions now or at a later date, please do not hesitate to get in touch.

Improving Mealtimes for People with Dementia in NHS Continuing Care Facilities, their Relatives, and Staff
Interview Protocol: Stage 3

INSRTRUCTIONS:

Good morning/afternoon. Thank-you for agreeing to take part in the interview. This interview aims to evaluate a recent research project, which explored mealtimes in continuing care wards. During this interview I am interested in learning about your experiences of the research project and of mealtimes on the ward at the present time. There are no 'right' or 'wrong' answers.

RECORDING:

If it is okay with you, I will be recording our conversation. The purpose of this is so that I can get all the details of what you are saying but at the same time be able to have an attentive conversation with you rather than writing what you say down at the same time as talking to you. Any recorded material will remain entirely confidential. The transcribed interview will not contain your name (or any names you might mention during our conversation), and the recording will be destroyed as soon as I have transcribed the interview. In other words nothing you say can be attributed to you. I want you to feel comfortable and to be honest. If you agree that the interview can be recorded, please read and sign the consent slip.

Before we start, have you got any questions?

_____

Q1: What are your impressions (what do you think) of mealtimes on the ward?

> If not mentioned spontaneously, ask what they think about:
> * Food
> * Atmosphere and Environment
> * Mealtime Assistance (feeding)
> * The social side of mealtimes (conversations, togetherness, sharing)
> * Enjoyment of mealtimes (patients and staff)
> * Relatives' involvement
> * Mealtime routines
>   (is it a part of day they look forward to?, most liked/disliked aspects)

Space for general observations (e.g. body language, distractions/detractors, etc):

_____
_____
_____
_____
_____
_____

Q2: In your opinion, how do the patients experience mealtimes on the ward?
(if the interviewee asks for more information or is unsure how Q2 differs from Q1, ask them to "Try to imagine what mealtimes would be like for you if you were a patient here")

_____
_____
_____

Q3: Have mealtimes on the ward change in any way during the past year? If so, how? *What are your* impressions of these changes (where they for the better or for worse)?

_____
_____
_____

Q4: Were there any changes you hoped would take place, but didn't?
    (If answered positively, ask "Why didn't these changes take place?")

_____
_____
_____

Q5: Do you have any comments on the Mealtime Research project that took place on ▬▬▬▬▬▬▬ ward? *(If not mentioned spontaneously, ask for comments on research aims, timeline, the researcher, resources/funding, etc.)*
    - Did the research have any impact on mealtimes on the ward?
        ~ *If so:* Was this impact positive or negative and in what way?
    - What was done well or poorly? What could have been done differently?

_____
_____
_____

DEBRIEF:
Thank-you very much for your time. Your views, reflections and ideas are very important and will inform both on the success of the Mealtime Research Project and on future research taking place within KMPT. I wish to reiterate that nothing you have said will be attributable to you and the interview will remain confidential.

If you have any questions now or at a later date, please do not hesitate to get in touch.

University of **Kent** | School of Social Policy, Sociology and Social Research   **KentHealth**   Kent and Medway **NHS** — NHS and Social Care Partnership Trust

Enhancing Mealtimes for People with Dementia in NHS Continuing Care Wards, their Relatives and Ward Staff

Below are the suggestions from patients, staff and relatives on changes that could improve mealtimes on Heart's Delight ward, as well as some based on my observations of mealtimes. Please read them carefully and **tick up to 10 ideas that you think would be most beneficial** or add ideas of your own:

Suggestions:	Tick up to 10:
A functional kitchen on the Frank Lloyd Unit	
A separate kitchen/serving area in the dining room (sectioned off from the rest of the room; with a serving hatch and more cupboard space and new worktops)	
Making pureed food more attractive (e.g. using moulds)	
Smaller portions of food served on larger plates (with a second helping offered routinely)	
Learning more from relatives about the dietary and mealtime likes/dislikes	
A café area next to the FLU kitchen	
Ability for relatives to purchase cakes, hot drinks and snacks from the café	
Encouraging (but not forcing) patients to sit at the table during meals.	
Making sure that drinks are always available at mealtimes, as well as between mealtimes	
Relatives being able to go to the 'parlour' and eat with the patient / help them eat rather than staying in the patient's room.	
Better quality food.	
Less noise while dishing up.	
Having a separate dining area from the lounge.	
Organising seating areas before the mealtimes, so this does not have to be done at the same time as serving food.	
Very occasionally having a take-away from the patients (and staff if they pay)	
Staff being able to eat their own food together with patients at mealtimes (without loosing break time)	
A wider choice of drinks routinely available for the patients (e.g. lemonade)	
Occasionally serving non-alcoholic beer, cider and wine (especially during holidays)	
Encouraging independent eating whenever possible	
A greater variety of specialized meals (diabetic, pureed, soft-texture, finger food). More options in general and making sure that the same meal is not offered twice a day or the next day.	
Better presentation of meals.	
Not having to wait for food for a long time once it is dished up.	
Having fresh-cooked food	
Having the TV for patients who like watching TV during meals (possibly in the foyer area)	
Having appealing cutlery and crockery, as well as more cutlery and crockery in general.	
Having and routinely using table cloths, placemats and serviettes.	
Better balance of food within meals (i.e. more meat and less vegetables)	

Asking patients what they would like to eat during mealtimes (even when choice is limited)	
Informing the patients what their meal is once it is served.	
Better, more nutritious meals for teatime (not just sandwiches)	
More diabetic puddings.	
A larger (possibly) modular dining table.	
More space in dining room(s).	
Having smaller cups and saucers, instead of large mugs, and nice plastic glasswear.	
Having a cooker.	
Involving patients in food preparation (e.g. buttering bread, making sandwiches or mixing batter for cakes and cupcakes)	
A jug of water on the table during mealtimes.	
Frequent tea parties in the garden for the patients (weather permitting). *Similar format to breakfast club.*	
Having a leaflet of 'dos and dont's' for families who visit during the meals.	
Spreading out across more rooms during mealtimes (e.g. using the foyer and parlour) for a less stressful and crowded atmosphere.	
Creating two different eating atmosphere in the two rooms: eating at a large table in one room, and sitting in chairs in small groups in another depending on how patients prefer to have their meals	
Routinely assessing chewing and swallowing and adjusting food accordingly.	
Frozen meals available for patients who skipped meals and/or feel hungry at night	
More and greater variety of food available in the evening and at night.	
More verbal and physical prompts given to people who are not eating.	
Bringing back picture menus.	
Patients encouraged to choose their own meals whenever possible and as close to the meal as possible.	
Encouraging communication between patients and between staff and patients during mealtimes.	
Holding tea parties for the patients, relatives and staff at least quarterly.	
Having relaxing musing playing during mealtimes (at least in one of the rooms).	
A freezer or a larger fridge space so relatives can bring and store some food for the patient (especially if hospital catering cannot provide patient's favourate foods)	
Having better quality food.	
Bread and rolls available with every meal.	
More variety in food that is available.	
Having salt, pepper and sauces available with each meal.	
Having salt and pepper pots on every table, including individual table-trays.	
High-calorie and/or high-protein food available for people who are underweight or rapidly loosing weight	
Having a range of specialized cutlery so patients can eat independently for as long as possible.	
Putting cream in hot drinks, as well as making coffee with milk and no water for people who need to gain wait	
Having routine contact with a dietitian.	
Low-calorie options for people who are significantly overweight, as well as low-calorie snacks available between meals if the person is feeling hungry.	
Your own suggestions:	

Enhancing Mealtimes for People with Dementia in NHS Continuing Care Wards, their Relatives and Ward Staff

PATIENT REQUESTS

A number of patients on ████████████ ward were spoken to in relation to their experiences of mealtimes on the ward. The responses were restricted to those patients who took part in the study and were able to verbally communicate with the researcher. As the majority of participating patients have dementia, asking them to fill in the survey was deemed inappropriate. Instead, all suggestions made by the patients should be prioritized in developing interventions to enhance mealtimes on the ward.

The suggestions/comments were:

- **4 people** *(3 of them over multiple occasions)* **complained about choice/availability of food**
- **2 patients complained of not being able to chew their food and suggested softer meals**
- **2 patients complained about the quality/taste of food** *(one person mentioned this multiple times and on different occasions)*
- **3 people asked for a particular type of food / their favourate meals**
- **1 person said they feel left out by having to eat on their own. They said: *"I don't want to eat alone… why don't they like me?"*** (this person is often sat at a table on their own during mealtimes)
- **2 people said they would like salt and pepper on their tables (or table trays) and 1 person complained of not having any sauces to accompany food.**

It should be acknowledged, that while some participating patients were unable to verbally express their opinion about mealtimes, they were observed during the mealtime (for at least 10 mealtimes each). Suggestions from these observations (both general and individual to each patient) will be outlined in associated documents.

SURVEY RESULTS

The results below are based on the survey responses by ████████████ ward staff and relatives of patients on the ward. The survey included 62 suggestions from patients, staff and relatives chose up to 10 suggestions to prioritise. A total of 19 staff and relatives completed the survey and the areas of higher agreement are displayed in the table below. **Only suggestions that were prioritized by at least 20% of respondents were included** and presented in rank order**.** To maintain representativeness, staff and relatives' responses were weighed equally.

	Suggestion:	Percentage of respondents who would like to implement it:
1	**A functional kitchen on** ████████████	**69%**
2	**Better quality food**	**69%**
3	**A separate kitchen/serving area in the dining room** (sectioned off from the rest of the room; with a serving hatch and more cupboard space and new worktops)	**60%**
4	**A greater variety of specialized meals (diabetic, pureed, soft-texture, finger food). More options in general and making sure that the same meal is not offered twice a day or the next day**	**49%**
5	**Having fresh-cooked food**	**43%**
6	**Encouraging (but not forcing) patients to sit at the table during meals**	**39%**
7	**Better, more nutritious meals for teatime (not just sandwiches)**	**39%**
8	**Routinely assessing chewing and swallowing and adjusting food accordingly**	**36%**
9	**Having a leaflet of 'dos and don'ts' for families who visit during the meals**	**35%**
10	**Frozen meals available for patients who skipped meals and/or feel hungry at night**	**35%**
11	**Having a separate dining area from the lounge**	**32%**
12	**A freezer or a larger fridge space so relatives can bring and store some food for the patient** (especially if hospital catering cannot provide patient's favourite foods)	**32%**
13	**Making pureed food more attractive (e.g. using moulds)**	**26%**
14	**Encouraging independent eating whenever possible**	**26%**
15	**Having and routinely using table cloths, placemats and serviettes**	**26%**
16	**More and greater variety of food available in the evening and at night**	**26%**
17	**Having a range of specialized cutlery so patients can eat independently for as long as possible**	**26%**
18	**Relatives being able to go to the 'parlour' and eat with the patient / help them eat rather than staying in the patient's room**	**23%**
19	**More verbal and physical prompts given to people who are not eating**	**23%**
20	**Better balance of food within meals (i.e. more meat and less vegetables)**	**20%**
21	**Having salt and pepper pots on every table, including individual table-trays**	**20%**

A small number of new suggestions was also made. These stated:
- Employing mealtime staff (from housekeeping or HCA)
- Better diabetic snacks
- Never leaving anyone alone to eat or drink

The remaining 41 suggestions that were not prioritised by 20% or more of the respondents should be considered at a later date; once the prioritised suggestions are implemented.

Audit name: **Improving mealtime Experiences for People with Dementia in Continuing Care NHS Facilities (Wards)**	Audit date: April 2014	Directorate + Team/Ward: ██████████████████ ██████████
Key Contact: ███████	**Version number and date:** N/A	**Persons responsible for monitoring/ review:** ████████████████████████████

No	Findings	Recommendation	Action Agreed	Priority	Owner	by	Progress of action (including dates)	Evidence
1	Staff and researcher assessments show that the majority of patients are undernourished. Especially for patients experiencing under-nutrition (but also for everyone on the ward) current food provision is inadequate; food availability, quantity and variability, as well as food composition are not optimal for patients needs	A number of recommendations are made to improve patients' nutrition. These involve both nutritional monitoring and food availability. Please see sections: **1a-h**	TBC	TBC	TBC	TBC		
2	There are little or no changes made in the dining rooms before the mealtime is served. In other words, there are no indications of cues to the patients that the mealtime is about to start. However, research shows that environmental cues and prompts have a positive physiological and psychological effects, result in greater food consumption and greater enjoyment of meals.	A list of recommendations is made for enhancing the mealtime environment. The proposed changes involve changes of the mealtime routine, as well as the physical environment. Please see sections: **2a-h**	TBC	TBC	TBC	TBC		
3	Observations show that while most of the time patients do not experience distress or become unhappy in direct relation to the mealtimes, enjoyment and positive emotions are also lacking. Communication and engagement during mealtimes, however, have been found to be the key elements in enhancing enjoyment and overall QoL.	Recommendations are made to enhance communication between patients, between patients and staff, and between clinical staff and catering staff. Please see sections: **3a-h**	TBC	TBC	TBC	TBC		
1a	According to assessment of nutritional status carried out by the ward staff, 75% (6 out of 8) of the participating patients are malnourished, one patient is at risk of malnutrition and one patient's nutritional status is healthy.	Due to this, there is a clear **need to maximise nutritional intake and dietician consultations are desirable in these cases**.	TBC	TBC	TBC	TBC		

			TBC	TBC	TBC	TBC		
1b	Staff initiated assessments show that staff largely agree when evaluating patient's nutrition status and eating ability. Staff agreement appears to depend on how long the patient has been on the ward. More discrepancy in ratings is present when the assessed patient has been admitted more recently. However, unlike other ratings, assessment of weight loss in the last 3 months shows a lot of variation in rating and many staff report to be unsure of the rate of weight loss (even for patients who have been on the ward for over a year). This indicates that the weight change is either not monitored at a sufficient frequency, or while monitored, this information is not sufficiently shared with ward staff.	**A chart of patients' monthly weight changes is recommended to be displayed in staff rooms.** Being able to see the rate of changes is likely to encourage staff to develop short-term strategies of improving/increasing food intake.	TBC	TBC	TBC	TBC		
1c	It is important to note that an ordinary diet is unlikely to be sufficient for people who are experiencing or are at risk of under-nutrition. They should be consuming more food (and nutrients) until their weight and other nutritional indicators become 'normal'.	**Greater food availability and high-nutrient, as well as high-calorie food options are recommended.**	TBC	TBC	TBC	TBC		
1d	Where the person is unable to consume more food or such food is not available, oral supplements (e.g. Ensure drinks) should be used.	Ideally, **the ward should have oral supplements available for all patients upon request/necessity**, rather than being available only to specific people.	TBC	TBC	TBC	TBC		
1e	Due to food hygiene, hot food cannot be kept on the ward for longer than 40 minutes. This means that if a person is unable or unwilling to eat during the allocated meal times, they are likely to miss out on a meal altogether.	To avoid associated risks of malnutrition, it is **recommended that the unit is equipped with an industrial freezer and stocked with microwavable frozen meals in addition to meals provided by on-site catering.** This would allow for patients who did not eat (sufficiently) at mealtimes to eat a balanced meal at any point of the day or night. If extra food cannot be provided by site-based catering, frozen meals would also allow greater food consumption for people who are experiencing (or are at risk of) under-nutrition.	TBC	TBC	TBC	TBC		
`1f	At least half of the participating patients often talk about their favourite food and drink, which are rarely available on the ward. This is an important issue for all patients (given extended periods of time spent on the ward) and relates to person-centered care and enhancement of personhood. There is an additional benefit for people at risk of or experiencing under-nutrition, as availability of favourite foods/meals is likely to increase dietary intake.	It is therefore **recommended that the weekly budget for purchasing of breakfast food and drinks is extended to accommodate purchase of patient's favourite food and drink.** If housekeeping / site-managing staff are responsible for procurement, a system of communication needs to be established, which would allow to add and subtract order items upon requirement and ideally on weekly basis. This could be trialed for a period of at least 6 weeks.	TBC	TBC	TBC	TBC		
1h	Daily dietary monitoring is in place for some of the patients	However, **a review of monitoring processes and sheets, as well as deciding who should be monitored should take place routinely**	TBC	TBC	TBC	TBC		

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			TBC	TBC	TBC	TBC		
2a	Availability of snacks in between mealtimes would also increase patients' food intake, while a 'little and often' approach is likely to be particularly beneficial for patients who usually eat small amounts of food at a time and rarely finish their meals. This should also be taken into account when extending the budget for purchasing food & drink items.		It is therefore **recommended that snacks are made available between mealtimes**, potentially coinciding with the periods when drinks are offered (at 3.30pm and 8pm), but also upon request. Given that some patients have breakfast later in the morning and fairly close to lunch time, it should be left at staff's discretion whether to offer snacks at 11am. Drinks, however, should be offered regardless. Available snacks should include sweet and savoury foods, as well as low-calorie snacks for those people who are experiencing over-nutrition	TBC	TBC	TBC	TBC	
2b	The staff role division during mealtimes is somewhat unclear, apart from having a dedicated person to serve the food. This often results in the primary focus on serving food and often no staff is available to set up the dining areas and encourage patients to come to the dining room from other areas of the ward. It is rarely announced to the patients that the mealtime is soon to start and what meals are available.		It is therefore **recommended that as well as having a dedicated 'server', a designated person in charge of each dining room is also identified for each mealtime**. The mealtime leads' task would be to encourage (but not coerce) patients to come to the dining room and sit at the table, encourage patients (who are able to do so) to help with laying the table, informing patients of the menu and any available choices. The mealtime leads would also assist in the dining rooms, oversee the mealtime routines and coordinate other staff.	TBC	TBC	TBC	TBC	
2c	Patients and their relatives often remark that meals are too large. This might be discouraging to some. Importantly, people who often leave the table, might find the meal they have partially eaten unappealing upon their return.		In relation to this, it is **recommended that smaller portions are served to most patients, with second helpings available and *encouraged***	TBC	TBC	TBC	TBC	
2d	Patients are rarely told what the meal is, even at the point when the meal is served to the patients. This information is available on the whiteboard and should remain displayed in this way. However, in addition to the information on the board, which not all patients can see or read.		**Staff should ensure that they inform patients on the available food both when encouraging patients to come to the table and once the food is served**	TBC	TBC	TBC	TBC	
2e	There are little or no changes made in the dining rooms before the mealtime is served. In other words, there are no indications of cues to the patients that the mealtime is about to start. Even when placemats are used and cutlery laid before serving food, patients are rarely involved in this process and do not have an	**The following environmental changes are recommended**: - the **setup of furniture and the laying of tables** becomes a routine part of the mealtime, providing cues to patients that the meal is coming soon - the use of a larger (potentially modular) table to **accommodate more people at the table in the dining room** - the use of **tablecloths, table mats and serviettes** is advised. *This is currently in place during the Breakfast Club and is proving a success; patients comment positively about the table set up and show an increase in overall enjoyment.* - both patients and staff have mentioned their dislike of the current cutlery and crockery and the ward often runs out of cutlery. The use of more **visually appealing and possibly smaller crockery** is advised, as well as **a greater number and a wider ranger of cutlery**, including specially shaped cutlery which enable independent eating for people with motor problems		TBC	TBC	TBC	TBC	

	opportunity to take an active part in the mealtimes. Previous research shows that if the patients are made aware that the food will be served soon, and if the mealtime environment is changed accordingly, **making the mealtime an _event_**, rather than an instance of eating, food intake is likely to increase.	• during interviews/conversations patients have said that they would like **more condiments on the table** and those whose food is served on tray tables said they are rarely given salt and pepper or any sauces. Every table, including tray tables, should have salt and pepper pots during mealtimes (excluding cases when specific risks are identified). If a range of sauces cannot be placed on every table, they should be routinely offered to patients eating in arm chairs – at the moment this happens mainly if the patient overtly requests a particular condiment during the mealtime. • not everyone likes eating at a table or with large group of people. If one dining room accommodates a large (potentially modular) dining table, the other one could be further adapted to **allow patients to eat while sitting in armchairs (providing a set-up that still allows patients to socialise with one another)**. _Who sits in which room should depend on their preferences, rather than the location of their bedrooms._ • **opportunities to share food and serve oneself** should be provided whenever possible. Provision of bread and butter or bread rolls is advised. • research shows that background music during mealtimes can reduce distress and thus increase dietary intake. **Playing background music in the dining rooms is recommended.** • on a number of occasions, certain patients have been observed to ask for the TV to be on at mealtimes. This should be made available providing that the other patients in the room agree. Alternatively, the foyer could be used as a space where **patients who wish to watch TV while eating could do so**. • **the 'parlour' should be used as an additional dining space if needed**, especially if someone is distressed during the mealtime and could use one-to-one support in a pleasant environment while encouraging eating at the same time. • relatives have indicated that they do not object to leaving the dining rooms with their relatives if they visit during mealtimes. However, they also remarked that patients' bedrooms are not the most suitable place to encourage a relative to eat. The **'parlour' was identified as an ideal space regarding both the atmosphere and set-up where relatives can encourage their family member to eat and even eat with them**. • on the majority of occasions patients are served a drink after their meal. _This can be justified in some cases_, but for most patients **a drink served with the food** would allow better chances of adequate hydration and ensure that should food be too dry or too thick, providing a drink would aid chewing and swallowing						
2f	A general lack of staff was observed during mealtimes, which prevented person-centered mealtime care. As some staff need to provide one-to-one support for some patients and feed patients in their own rooms, there are often not enough staff left to encourage patients into the dining room, set up tables and assist eating in a person-centered manner. At lunchtime (which is the biggest meal of the day), it would be ideal if the mealtime started when staff from both morning and afternoon shifts are on the ward.	Therefore, **shifting meal provision to 1.15 pm is highly recommended**	TBC	TBC	TBC	TBC		
2g	Serving food is often very noisy and this is hard to avoid given	**A walled serving area with a serving hatch in one**	TBC	TBC	TBC	TBC		

	metal food trays and other aspects of dishing food	**of the dining rooms is recommended to minimise noise and distraction during mealtimes. Alternatively, food could be dished out elsewhere on the ward and delivered to both dining rooms on trolleys** (however, this would negatively affect ability to choose food whenever such option is present).					
2h	Some people prefer to walk during mealtimes and are unlikely to sit at a table.	While some encouragement to join others is advisable, **food and cutlery/crockery should be specially chosen/adapted to enable food and fluid intake even while walking**	TBC	TBC	TBC	TBC	
3a	It was found during interviews that ward staff have a lot of ideas about improving mealtimes, but are often unsure if they can put it in place.	**It is suggested that mealtime aspects are discussed on a monthly bases either within a separate meeting or dedicating a sufficient amount of time during one of the hand-over meetings**					
3b	Patients, staff and relatives have all complained about quality, quantity and range of food provided by the on-site catering; these issues were also observed by the researcher. It has to be acknowledged, that due to a number of issues communication with catering staff is strained. However, it is highly recommended that these issues are relayed to catering staff in a polite manner and resolutions sought. Current issues involve: • not enough food, especially at supper time • not enough variability in available dished (patients have complained about this) • poor quality of some of the dishes (patients have complained about this) • sub-optimal ratio of meal components (patients have complained about this) • not enough options for and insufficient availability of 'special diet' meals, including diabetic meals, soft versus pureed options (and lack of different consistencies of pureed food), high-protein and high-calorie options, low-calorie options, finger food, etc.	**Inviting representatives from the catering staff to monthly meetings about meal provision and discussing potential solutions to existing issues would be ideal.**	TBC	TBC	TBC	TBC	
3c	Observations have demonstrated that mealtimes on the ward often involve minimal opportunities for socialising. Even when present, communication between patients is not celebrated and sometimes discouraged. While on some occasions, conversations between patients can result in one or both of the patients becoming distressed, there were many more observations where	**Conversations between patients should, therefore, be encouraged as much as possible during mealtimes.**	TBC	TBC	TBC	TBC	

	communication encouraged patients to eat more (either by improving general alertness or by maintaining interest and attention due to which the person did not leave the table) and improved mood. In relation to this, it was often observed that in the dining room without a dining table patients are often sat (or left to sit) far from one another, often facing in a direction where they cannot see any other patients. Seating arrangements should be reviewed to maximise potential for communication.						
3d	Staff-initiated conversations with patients are also infrequent during mealtimes and the predominant form of communication is encouragement to eat. In some instances, even while being fed patients are rarely spoken to. This is likely to result from the perception that conversations (or any noise in general) are distracting. However, a distinction should be made between detrimental noises, like shouting or clattering of food trays when dishing up, and positive sounds like music or pleasant conversations. The latter has been shown to increase alertness, 'normalise' mealtimes on wards and make them more home-like, and increase food and fluid intake.	**Staff should therefore be encouraged to speak to patients during mealtimes beyond encouraging them to eat.**	TBC	TBC	TBC	TBC	
3f	Patients are rarely given an opportunity to choose their meals. Choosing in advance is, of course, not ideal, but on-site catering can provide food given a 24h notice.	**Re-introduction of picture menus is, therefore, recommended. Alternatively, each patient could have a 'preference diary' outlining their preferred dished on the ward**; this could be developed based both on communicated preferences and staff observations. **Using 'preference diaries' staff could make a number of suggestions to the patients regarding their meals for the week and amend according to given responses**	TBC	TBC	TBC	TBC	
3g	Active participation in food preparation is shown to increase dietary intake	Due to this, **it is recommended that therapeutic activities incorporate food preparation activities such as making jam sandwiches or buttering bread**. Should the unit be equipped with an oven at a later date, baking activities could also take place (e.g. preparing batter for cupcakes later to be baked by therapy technicians)	TBC	TBC	TBC	TBC	
3h	Both relatives and staff have identified a lack of clear guidance on whether relatives can visit their family at mealtimes, whether they can stay in the dining rooms and whether they can help their family member to eat (including feeding).	Relatives and staff have indicated that a **leaflet** of 'Dos & Don'ts During the Mealtimes' would be very beneficial to avoid misunderstandings or uncertainty.	TBC	TBC	TBC	TBC	

01/12/14

Research project: Improving Mealtime Experiences for People with Dementia, their Relatives and Staff in Continuing Care NHS Facilities (Wards)

Interventions *(based on suggestions from patients, staff and relatives)*

Successfully Implemented:

- o Monthly weights
- o Chart of patients' weight
- o Increased availability of high-calorie oral supplements
- o Purchase and use of more serving utensils, bowls and pots
- o Larger table brought to the Sitting Room
- o Table cloths introduced
- o Fruit routinely purchased (although not always readily available)
- o More cakes and puddings available on the ward

Implemented but not retained:

- o Mid-morning and mid-afternoon drinks
- o Snacks on the ward
- o Purchasing a few of patient's favourate food and drink items
- o Relative's survey regarding patient mealtime preferences (for each patient upon admission)
- o More condiments (purchased, but rarely made available)
- o Using the parlour during the mealtimes (either for patients with visitors, or patients who need quieter environments)
- o Tasting food and reporting on quality to caterers
- o Amending monitoring sheets to record not only if food is served, but also how much was eaten
- o Even when there are leftovers, 'seconds' are offered sporadically rather than routinely

Not implemented to date:

- o Microwaveable meals for patients who did not eat sufficiently at mealtimes
- o 'Patient Mealtime Profiles' for care plans and personal boards
- o Moving lunch forward so that shifts overlap and more staff are available
- o *Routinely* setting up the dining area and helping patients to the table
- o Further differentiation of staff roles at mealtimes
- o Improving table set-up at mealtimes
- o Visually appealing crockery and a wider range of cutlery
- o Changing seating arrangements, so patients eating in armchairs / specialist chairs have opportunities to socialise
- o Serving drinks with (instead of after) food for most patients
- o Separate monthly meetings to discuss mealtimes, nutrition and hydration + inviting catering representatives for
- o Encouraging more positive interactions during mealtimes
- o Encouraging eating independently whenever possible (including use of adapted crockery and cutlery) and feeding slower
- o Introducing a pictorial 'Menu' board or reintroducing picture menus
- o Involving patients in some form of food preparation (e.g. buttering bread or making jam sandwiches)

The most important items are highlighted in _____

	Item	Supplier	Price	Quantity	Total	Link
5	Adult Neckerchief	Able2Wear	£8.00	10	£80.00	http://www.able2wear.co.uk/product/200/254/adult-neckerchief-to-help-protect-clothes-from-dribbling
6	Large tabard-type bibs	Complete Care Shop	£6.95	10	£69.59	http://www.completecareshop.co.uk/eating-aids/adult-bibs/adult-bib-with-crumb-catcher-green
7	Tabbard Clothes Protector	Healthandcare.co.uk	£20.99	3	£62.97	http://www.healthandcare.co.uk/bibs/BTBL-19-Blue.html?gclid=CjwKEAjwzuisBRClgJnI4_a96zwSJACAEZKeoDTXsu3FoG2XE_Wfn8v9-oMGQocTPrDLcaIiDpfr5RoC96Hw_wcB
8	Non-slip Matting	Complete Care Shop	£20.95	1	£20.95	http://www.completecareshop.co.uk/household-aids/non-slip-matting/dycem-yellow-non-slip-matting
9	Scoop Dish	Complete Care Shop	£13.95	2 (triple packs)	£27.90	http://www.completecareshop.co.uk/eating-aids/dishes/scoop-dish-red-triple-pack
10	Egg suction cup	Complete Care Shop	£3.45	10	£34.50	http://www.completecareshop.co.uk/eating-aids/bowls/egg-suction-cup-red
11	Red bendable forks	Complete Care Shop	£7.95	2 (triple packs)	£15.90	http://www.completecareshop.co.uk/eating-aids/red-handled-cutlery/bendable-fork-red-triple-pack
12	Red bendable spoons	Complete Care Shop	£7.95	2 (triple packs)	£15.90	http://www.completecareshop.co.uk/eating-aids/red-handled-cutlery/bendable-spoon-red-triple-pack
13	Red bendable knives	Complete Care Shop	£7.95	2 (triple packs)	£15.90	http://www.completecareshop.co.uk/eating-aids/red-handled-cutlery/rocker-knife-red-triple-pack
14	Care Spoons	Complete Care Shop	£12.95	1 pack	£12.95	http://www.completecareshop.co.uk/eating-aids/adapted-cutlery/care-spoons-pack-of-10-large
15	Cake fork	Nisbets	£1.69	2 packs	£3.38	http://www.nisbets.co.uk/Olympia-Kelso-Cake-Fork/DP229/ProductDetail.raction
16	Cutlery	-	£14.99	5	£74.95	*Not yet confirmed*
17	Egg boiler	Lakeland	£17.99	1	£17.99	http://www.lakeland.co.uk/18921/Lakeland-Egg-Cooker

18	Red portion plate	Complete Care Shop	£16.95	2 packs	£33.90	http://www.completecareshop.co.uk/eating-aids/portion-plates/red-portion-plate-triple-pack
19	Cotton aprons	Tesco	£8	12	£96.00	http://www.tesco.com/direct/bia-classic-camembert-design-cotton-apron/290-6323.prd?pageLevel=&skuId=290-6323 **Please see note below**
20	One Direction Straws	Find	£9.90	(1 set of 10)	£9.90	http://findsignage.co.uk/index.php/checkout/cart/
21	Unbreakable glasses (tumbler)	Find	£10.95	2 packs	£21.90	http://findsignage.co.uk/index.php/shop/dining/unbreakable-glass.html
22	Unbreakable glasses	Find	£15.60	2 packs	£31.20	http://findsignage.co.uk/index.php/shop/dining/6-pack-wine-glass.html
23	Tablecloth	Dunelm Mill	£9.99	8	79.92	http://www.dunelm.com/product/lime-spectrum-round-tablecloth-1000033666?searchTerm=tablecloth

1. If cheaper alternatives are found, they:
- must have wheels and a shape that prevents easy tipping
- tilting function would be a bonus
If there is money left, CompleteCareShop does foldaway tray table, which fold flat for easy storage (to replace the cheaper options)
http://www.completecareshop.co.uk/beds-and-bedding/overbed-tables/foldaway-bed-table
3. Colour not yet determined. Please consult Sue Wrintmore before ordering
19. Varying sizes and styles to make mealtimes less clinical.

Optional, but very much appreciated: Tea set for parties and events:

	Item	Supplier	Price	Quantity	Total
1	Teacups & Saucers		£2.99	24	£71.76
2	Dessert Plates		£1.99	24	£47.76
3	Teapot		£6.99	1	£6.99
4	Cake Stand	Dunelm Mill	£9.99	1	£9.99
5	Tea Tin		£5.99	1	£5.99
6	Coffee Tin		£5.99	1	£5.99
7	Sugar Tin		£5.99	1	£5.99
8	Dinner Plates (for serving)		£2.49	6	£14.94
					£169.41

ENHANCING THE MEALTIME EXPERIENCE

Research Newsletter ~ March 2014

Thank you very much for all your help so far! *Stage 1* of the research, the aim of which was to collect baseline information and ideas for improvement, has now ended.

During *Stage 1* of the research I have:

* conducted over 100 hours of ethnographic observations

* carried out 40 structured mealtime observations of food and drink intake, and eating assistance

* and a further 40 observations of patient activity, engagement and mood during mealtimes

* asked staff to answer some short questions about patients' nutrition and eating ability (resulting in at least 2 repeat assessments for each participating patient)

* assessed participating patients' Quality of Life

* talked to participating patients about their experience of food and mealtimes on the ward, as well as changes they would like to see take place

* held 2 group meetings for relatives and collected their opinions on mealtimes on the ward and ideas for improvement

* conducted 12 in-depth interviews with ward staff, management and catering providers

* provided 'Suggestion Boxes' for staff and relatives to propose strategies to improve mealtimes and collected 12 responses

A **detailed report of findings and recommendations** is currently in preparation and will soon be available upon request (along with an Executive Summary and a summary of recommendations).

If you would like to know more about the findings, please do not hesitate to ask!

What's next?

I have compiled all suggestions made by patients, relatives and staff as well as my own recommendations. In the upcoming weeks, I would like to ask staff and relatives (and, where possible, patients) to identify which changes are most important and should be prioritised. I will distribute a questionnaire to collect and compile this information.

Afterwards, I would like to hold a joint meeting to discuss the most popular strategies and ways of implementation.

Thank you once again for your contributions!

If you would like to contact me, please do not hesitate to do so:

Tel: 07842 257607
Email: rm457@kentforlife.net

ENHANCING THE MEALTIME EXPERIENCE

Research Newsletter ~ March 2015

Thank you very much for all your help so far!

Since the start of the research I have:

* conducted general mealtime observations
* carried out structured mealtime observations of food and drink intake, and eating assistance
* asked staff to answer some short questions about residents' nutrition and eating ability
* talked to some of residents about their experience of food and mealtimes
* talked to some of the relatives about mealtimes
* conducted interviews with staff

The observations have shown a high proportion of positive mealtimes, where residents' individual needs are met, and one-to-one support is available. Relatives being able (and encouraged) to visit during mealtimes also has a positive impact on residents' experiences and food intake.

However, there are aslo some areas with potential for further improvement. For example, teatimes are sometimes hectic and/or stressful for all involved.

If you would like to know more about my observations, please do not hesitate to ask!

I have also conducted a number interviews with ward-based staff. Among other things, I have asked ward staff about potential changes they thought would improve mealtimes.

Below are the changes that were mentioned most often:
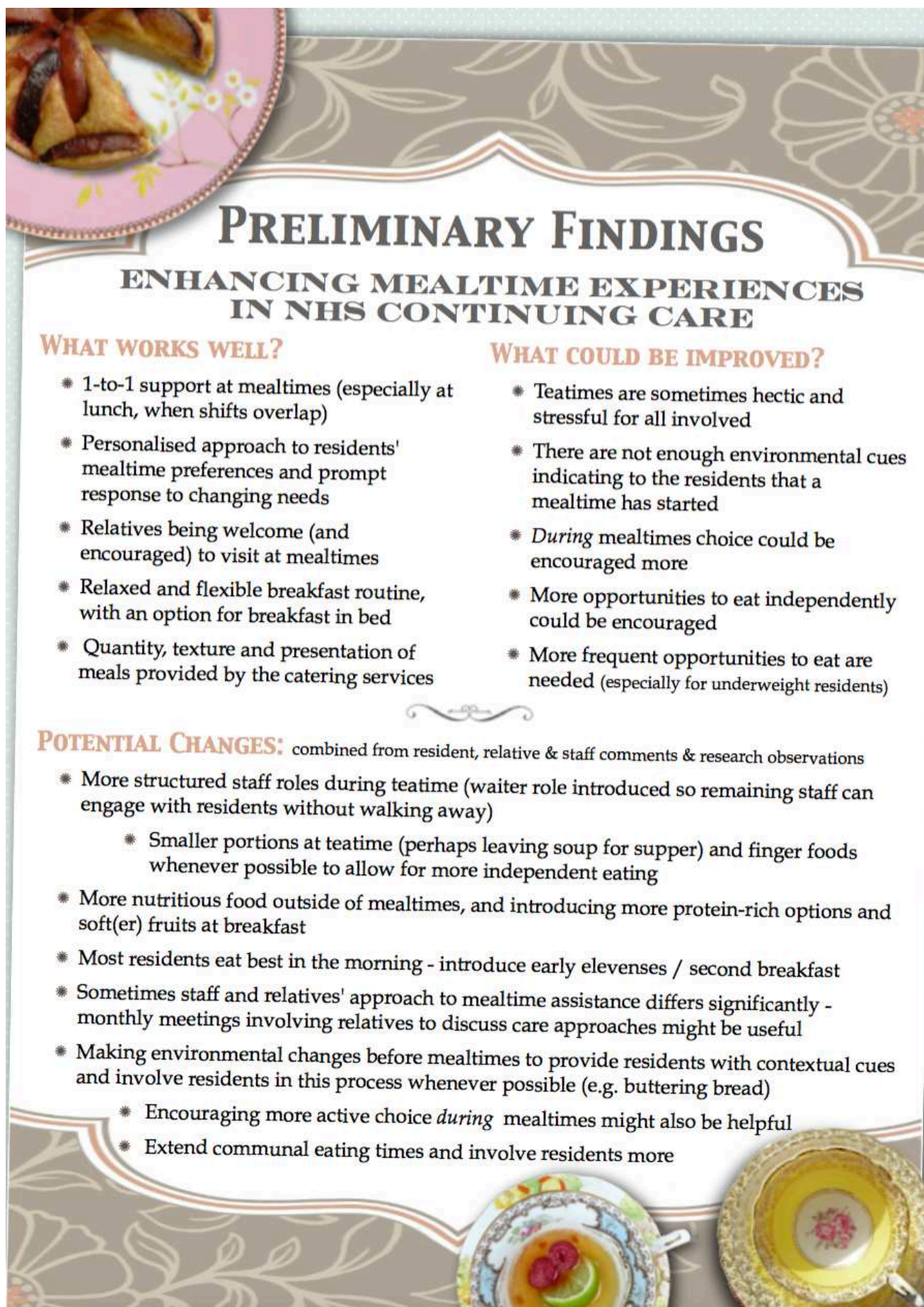
* A greater choice of foods at breakfast and outside of mealtimes, especially protein-rich options, as well as soft(er) fruit
* Further adapting communal spaces for mealtimes; providing more opportunities to socialise at mealtimes
* Enhancing flavours of meals provided by catering services

I also spoke to some residents on the ward, and asked if they enjoyed their meals and if they would like anything done differently. While not everyone was able to contribute, a couple of residents told me about food they would like to eat more often and spoke to me about how they prefer eating their meals.

However, I would also like to speak to relatives and find out if they have suggestions on how mealtimes on the ward could be further enhanced. Relatives' contributions are especially important for those residents, who are less able to communicate their wishes.

If you would like to contact me, please do not hesitate to do so:

Tel: 07842 257607
Email: R.Mikelyte@kent.ac.uk

PRELIMINARY FINDINGS

ENHANCING MEALTIME EXPERIENCES IN NHS CONTINUING CARE

WHAT WORKS WELL?

* 1-to-1 support at mealtimes (especially at lunch, when shifts overlap)

* Personalised approach to residents' mealtime preferences and prompt response to changing needs

* Relatives being welcome (and encouraged) to visit at mealtimes

* Relaxed and flexible breakfast routine, with an option for breakfast in bed

* Quantity, texture and presentation of meals provided by the catering services

WHAT COULD BE IMPROVED?

* Teatimes are sometimes hectic and stressful for all involved

* There are not enough environmental cues indicating to the residents that a mealtime has started

* *During* mealtimes choice could be encouraged more

* More opportunities to eat independently could be encouraged

* More frequent opportunities to eat are needed (especially for underweight residents)

POTENTIAL CHANGES: combined from resident, relative & staff comments & research observations

* More structured staff roles during teatime (waiter role introduced so remaining staff can engage with residents without walking away)
    * Smaller portions at teatime (perhaps leaving soup for supper) and finger foods whenever possible to allow for more independent eating

* More nutritious food outside of mealtimes, and introducing more protein-rich options and soft(er) fruits at breakfast

* Most residents eat best in the morning - introduce early elevenses / second breakfast

* Sometimes staff and relatives' approach to mealtime assistance differs significantly - monthly meetings involving relatives to discuss care approaches might be useful

* Making environmental changes before mealtimes to provide residents with contextual cues and involve residents in this process whenever possible (e.g. buttering bread)
    * Encouraging more active choice *during* mealtimes might also be helpful
    * Extend communal eating times and involve residents more

Ogden Unit
Celebrating Food
Weekly Schedule

Treat Tuesdays
a small buffet and drinks

◉◉◉

Cake Wednesdays
tea and cakes or other sweet treats

◉◉◉

Fruit Thursdays
soft fruit & yogurt ~ fruit smoothies

Families & friends welcome to join!

Also... **pancakes or wafles for Sunday Breakfast**

Sausages and eggs for breakfast – available daily

APPENDIX EE   Meal / Food Rating Scale (Site 1)

Date	Name of Meal / Food	Rating		
		Taste	**Visual Appeal**	**Portion Size**
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent
		Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent	Very Bad 1 2 3 4 5 Excellent

Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q)*

Score answers to questions 1-10: never (0), sometimes (1), often (2)

1. Does the patient require close supervision while feeding? _____
2. Does the patient require physical help with feeding? _____
3. Is there spillage while feeding? _____
4. Does the patient tend to leave food on the plate at the end of the meal? _____
5. Does the patient ever refuse to eat? _____
6. Does the patient turn his head away while being fed? _____
7. Does the patient refuse to open his mouth? _____
8. Does the patient spit out his food? _____
9. Does the patient leave his mouth open allowing food to drop out? _____
10. Does the patient refuse to swallow? _____

Total Score = _____

(Total scores range from 0 to 20, with 20 being the most serious. Scores can be used to track change.)

11. Indicate appropriate level of assistance required by patient: supportive-educative; partly compensatory; wholly compensatory

* Used with permission of author, R. Watson.

Mini Nutritional Assessment
MNA®

Nestlé NutritionInstitute

Last name:			First name:	
Sex:	Age:	Weight, kg:	Height, cm:	Date:

Complete the screen by filling in the boxes with the appropriate numbers. Total the numbers for the final screening score.

Screening

A Has food intake declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties?
0 = severe decrease in food intake
1 = moderate decrease in food intake
2 = no decrease in food intake ☐

B Weight loss during the last 3 months
0 = weight loss greater than 3 kg (6.6 lbs)
1 = does not know
2 = weight loss between 1 and 3 kg (2.2 and 6.6 lbs)
3 = no weight loss ☐

C Mobility
0 = bed or chair bound
1 = able to get out of bed / chair but does not go out
2 = goes out ☐

D Has suffered psychological stress or acute disease in the past 3 months?
0 = yes   2 = no ☐

E Neuropsychological problems
0 = severe dementia or depression
1 = mild dementia
2 = no psychological problems ☐

F1 Body Mass Index (BMI) (weight in kg) / (height in m^2)
0 = BMI less than 19
1 = BMI 19 to less than 21
2 = BMI 21 to less than 23
3 = BMI 23 or greater ☐

IF BMI IS NOT AVAILABLE, REPLACE QUESTION F1 WITH QUESTION F2.
DO NOT ANSWER QUESTION F2 IF QUESTION F1 IS ALREADY COMPLETED.

F2 Calf circumference (CC) in cm
0 = CC less than 31
3 = CC 31 or greater ☐

Screening score (max. 14 points) ☐☐

Save Print Reset

12-14 points: ○ Normal nutritional status
8-11 points: ○ At risk of malnutrition
0-7 points: ○ Malnourished

Ref. Vellas B, Villars H, Abellan G, et al. Overview of the MNA® - Its History and Challenges. J Nutr Health Aging 2006;10:456-465.
Rubenstein LZ, Harker JO, Salva A, Guigoz Y, Vellas B. Screening for Undernutrition in Geriatric Practice: Developing the Short-Form Mini Nutritional Assessment (MNA-SF). J. Geront 2001;56A: M366-377.
Guigoz Y. The Mini-Nutritional Assessment (MNA®) Review of the Literature - What does it tell us? J Nutr Health Aging 2006; 10:466-487.
Kaiser MJ, Bauer JM, Ramsch C, et al. Validation of the Mini Nutritional Assessment Short-Form (MNA®-SF): A practical tool for identification of nutritional status. J Nutr Health Aging 2009; 13:782-788.
® Société des Produits Nestlé, S.A., Vevey, Switzerland, Trademark Owners
© Nestlé, 1994, Revision 2009. N67200 12/99 10M
For more information: www.mna-elderly.com

Mealtime Research Quote of the Week:

"It is better for a patient to eat 500 junk calories, than leave 500 healthy calories on the plate"

Diane Jeffrey
Head of the Malnutrition Task Force
Chair of Age UK
Co-chair of the Commission on
Improving Dignity in Care

Drinks

- Lemonade (diet, cloudy, full-sugar)
- Cream Soda
- Ginger Beer/Ale
- Sprite (diet for Maureen)
- Dandelion & Burdock
- Vimto
- 0% Shandy
- 0% Beer
- 0% Wine
- Horlicks
- Ovaltine
- Crackers

Snacks
non-perishable

- Toast topping
- Pickle
- Tinned soup
  - Chicken
  - Beef
  - Vegetable
- Quavers
- Crisps
- Cheese puffs
- Cheese straws
- Skips
- Chocolate biscuits
- Sauces
  - Mayonnaise
  - Salad cream
  - BBQ sauce
  - Brown sauce
  - Hot pepper sauce (for Angela)
  - Tartar sauce
- Custard
- Baked beans
- Spicy noodles (for Angela)
- Corned beef
- Tinned macaroni & cheese
- Sardines
- Evaporated milk

Snacks
perishable

- *Sandwich spread*
- Strawberries
- Trifle pots
- Cakes (various)
- Mini doughnuts
- Chocolate pots
- Individual jelly pots
- Sugar-fee jelly (for Angela and Maureen)
- Protein yogurt
- Drinking yogurt
- Tinned fruit
- Scones
- Bread rolls
- Diabetic sweets
- Tinned puddings
- Lemon curd
- Ice-cream
- Sausage rolls
- Chocolate
- Swiss roll
- Apple pie
- Rhubarb crumble
- Carrots
- Stewed apples

- The 3pm snack trolley idea has been revisited. Not operational as of yet, but the trolley has been assembled and teapots purchased for it.

- Most stock for the snack trial has been used (but that is 2-week supply over 4 months) and according to Pat (head of housekeeping) some items went off or she had to encourage ward staff to use these.

- There are now table mats and more cutlery, although mats (and laying-up in general) were only used at lunch time. Paper bibs were also offered around and used as napkins. However, the mats and cutlery were put on the table just before the meal, defeating the purpose of providing cues. Two ladies at the table were previously remarking on the absence of cutlery.

- More plates and cups purchased for the ward. The residents all got the same red plastic ones as they had before. The staff, on the other hand, have lovely colourful mugs with animals that some of the patients keep talking about - just don't get to use.

- Staff have changed the furniture in one of the rooms to make the table more accessible

- I have noticed more drinks being given out in between meal times and staff have brought in a chocolate roll to share (not a wide range of snacks, but it is extra food). Some organisation in giving drinks at 2pm, but this was done by a nurse who knew I was pressing on the issue - so I am not sure how regular this occurrence is.

- [Maureen] now on 1-to-1 supervision now. As you can see from the weight chart (attached) she continues to loose weight. But she is keen to eat and often hungry, although in small-ish portions at a time. So with 1-to-1 support, if staff give her food, her weight would soon increase.

- Some encouragement to come to the table, but this remains fairly minimal.

- Drinks are offered before food at lunch. At teatime they are pre-poured, but offered after the food is eaten.

- Table cloths are no longer in use

- Second helpings still not encouraged

- Nutritional replacements still not given out

- Some positives about new menu, but still not enough food at teatime, food often bland and dry, and specialist diets (pureed, soft-textured, vegetarian, etc) are either not catered sufficiently or the quality poor (e.g. pureed soup has lumps)

- Rice is still not provided. Apart from [Angela] for whom rice is culturally more appropriate, another (new) patient refused to eat lunch because it is "the same thing again", and asked for a curry and rice which could not be offered.

- The ward has nominated 2 nutrition champions to join the scheme.

- Encouraging calm and quiet has been taken to new extremes. In one of the dining rooms lights are dimmed and staff avoid talking - I almost fell asleep myself, and a few patients did. I wonder if this was a recommendation taken too far.

- One of the patients is now strapped in a chair at each mealtime so she eats. Use of restraints in chairs (or leaving people in bed) is becoming more frequent. They had some falls recently, which triggered this.

- Weighing is done more frequently, but since September the number of weighed patients is dropping a bit. December weights are missing altogether (no one could explain to me if the sheet was missing, or if no one was weighed).

Successfully Implemented:

- Structured staff roles (e.g. waiters)
- Protein-rich foods routinely available
- Fruit routinely available
- A more homely environment
- Providing more mealtime cues
- Equipment to cook some foods on the site
- More social opportunities at mealtimes
- Colour-contrast crockery

Implemented, but application remains sporadic

- Cooking extra food on site
- Offering seconds
- 3 afternoon activities around food per week

Implemented but not retained

- Smaller portions
- 'Second' Breakfast
- Communal eating at teatime
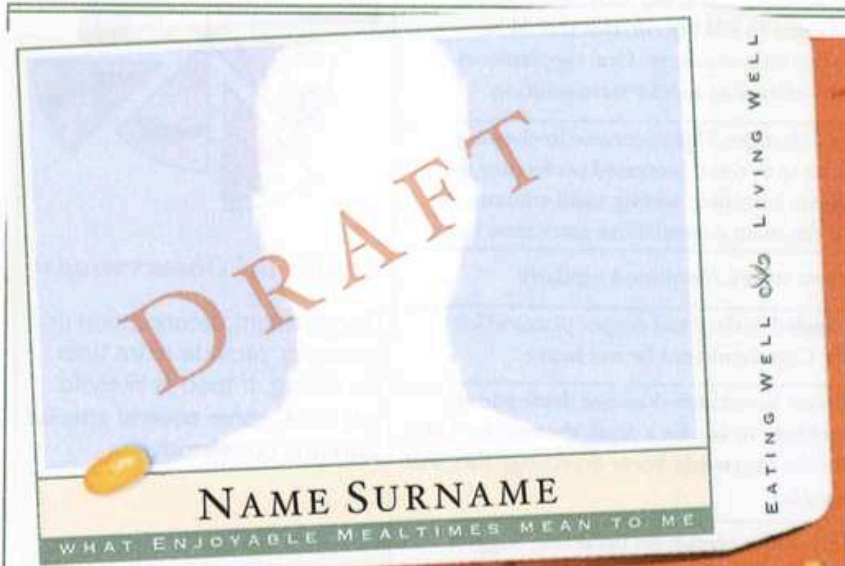- Frequent snacks
- Extended times for eating

Not implemented

- Finger foods for tea
- Monthly care-planning meetings with relatives

N.B.: The list does not include individual interventions (see Appendix P)

MEALTIME PREFERENCES

15/07/14

DRAFT

NAME SURNAME

WHAT ENJOYABLE MEALTIMES MEAN TO ME

EATING WELL AND LIVING WELL

This document should give you an idea of what I like to eat and drink, as well as where and how I prefer to eat my meals. But please remember that we all change over time. If my eating preferences, habits or abilities change over time, please respect that and amend this document accordingly.

TO BE UPDATED EVERY 6 MONTHS OR MORE FREQUENTLY IF NEEDED

Eating & Drinking

Preferred way to eat

Throughout the majority of my adult life, I used to come back home late due to my job. My wife and children would have already eaten, so I would have my meal on a lap tray in an armchair. Due to this, I might not always come to the table at mealtimes and will be happy to eat in a comfy chair.

I do not like noise when I eat. If it is noisy, I might walk away and leave my food.

Assistance

I am still able to eat on my own, but due to arthritis in my hands I need adapted cutlery.

Sometimes when the food is brought to me I might say that I am not hungry. Please do not take the food away yet - I need a moment to inspect it to arouse my appetite.

Please pour me a drink when I am having my food, not after. This will help me chew.

Avoid hard-to-chew foods. When possible, serve soft-textured meals.

Cutting up food sometimes proves difficult, but if you cut my food in front of me I often get embarrassed. If the food needs cutting, please do so before you serve it to me.

LIKES

I like most foods, but my favourites are:
- Cottage Pie
- Fish & Chips
- Crumble & Custard
- Apples
- Pears

When possible, offer some Brown Sauce with my meal

My favourite drinks are:
- Ale
- Lemonade

Cultural and religious beliefs concerning food:

DISLIKES

I don't like:
- Raw onions in salad
- Mash
  (*I would rather have chips*)
- Turnips
- Parsnips
- Marmite
- Dry food
  (*I find it hard to chew*)
- Milk

Allergies: NUTS

Ward Assessments:

Chewing and Swallowing	The patient finds it difficult to chew some textures, like roast beef. Soft-textured food should be offered instead. No problems swallowing.
Monitoring of weight / BMI	Current BMI = _____. If any substantial and/or rapid changes in BMI occur, this should be followed by an assessment. Oral supplements should be offered as a short-term solution.
Changes to eating & drinking habits	No major changes. Slight increase in chewing difficulties over time. Increased preference for sweet foods (consider adding small amounts of sugar to the main course). Give extra time to eat.
Oral & Dental health	No current issues. Monitored regularly.
Crockery & Cutlery	Use of angled cutlery and deeper plates when possible. Cup should not be too heavy.
Fluids	The patient sometimes does not drink enough and is unlikely to ask for a drink themselves. Offer small drinks frequently. Serve drinks together with food, *not after*.
Fibre intake	Adequate. Offer cereals for breakfast. Suggest wholemeal bread, but respect choice
Pain assessment	No pain during meals recorded.

Additional Observations:

Due to slight deterioration in chewing, provide extra time for eating. If food is likely to get cold, serve several smaller portions consecutively.

EATING WELL ❀ **LIVING WELL**

"In older age being underweight poses a far greater risk to health than being overweight"

(The Caroline Walker Trust, 2004)

Snacks

If I skipped a meal or am feeling peckish, offer me easy-to-make snacks and treats.

I particularly enjoy:

- Banana & Custard
- Sponge & Custard
- Cheese scone with butter
- Apple slices (no peel)
- Milk Chocolate Buttons

Please do not offer me Ensure milkshakes. I do not like milky drinks. Instead, mix 1 part FortiJuice and 1 part lemonade.

Side B

Patient Order Sheet	**W2 D3**															
Diet Reference Guide E=Energy Dense, H=Healthy Eating, S=Soft Choice, V=Vegetarian Choice																
Luncheon																
Fruit Juice																
Roast Beef in Gravy																
Tuna Cheesy Bake																
Vegetable Hotpot																
Sausage Roll Salad																
Brussel Sprouts																
Parsnips																
Roast Potatoes																
Creamed Potatoes																
Semolina Pudding																
Rhubarb & Strawberry Crumble																
Custard																
Yoghurt – Thick and Creamy																
Yoghurt – Diet																
Ice Cream																
Fresh Fruit																
Cheese and Biscuits																
Supper																
Red Pepper & Tomato Soup																
Bread Roll/Slice of Bread																
Ham Sandwich																
Egg Mayonnaise Sandwich																
Corned Beef Hash																
Dairy Cream Slices																
Yoghurt – Thick and Creamy																
Yoghurt – Diet																
Ice Cream																
Fresh Fruit																
Cheese and Biscuits																

Sandwiches available in white, brown and granary bread

APPENDIX OO   Example Meal Order Form (Site 2)

Please order from the menu below other options not available unless a dietary requirement

MONDAY

Back by 5 pm Saturday please

LUNCH		WEEK 1

Date   23 | 2 | 15   Larger
Unit   Low Fat
                              Gluten Free
Number of residents   10   Puree
                              Soft
                                    L
                                    L/ F
              1 puree   G/F
                                    p
                                    S

		Count	L/F/G/F/p/S
Salad	Ham		
	Cheese		
Main	Cottage Pie	7	
	Salmon & Dill Pasta	3	
	Vegetable Cottage Pie		
	Gravy		
	~~New~~ Potatoes Mashed	7	
	Saute Potatoes	3	
	Green Beans	10	
	Sweetcorn	10	

DESSERT

	Count	
Semolina	5	
Strawberry Mousse	5	

SUPPER

		Count	
Soup	Vegetable	10	
Main	Cheese & Onion Pasty & Tomatoes	7	
	or		
	Assorted Sandwiches	3	
	Lemon muffins	10	
	Ice Cream		

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Social Care REC
An NRES Research Ethics Committee

06 August 2013

Miss Rasa Mikelyte
PhD Student
University of Kent / Kent Health
SSPSSR
University of Kent
Gillingham Building
Chatham Maritime
Kent
ME4 4AG

Dear Miss Mikelyte

Study title:	**Improving Care for People with Dementia in NHS Continuing Care facilities: Enhancing the Mealtime Experience for Older Patients and their Relatives**
REC reference:	**13/IEC08/0018**
Protocol number:	**RESGOV232**
IRAS project ID:	**124573**

Thank you for your letter of 07 July 2013 and email of 22 July 2013. I can confirm the Social Care REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 14 May 2013

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		07 July 2013
Covering Letter		22 July 2013
Other: Participant Invitation Letter	1.2	25 May 2013
Participant Information Sheet: Service Users	1.3	25 May 2013
Participant Information Sheet: Relatives	1.3	25 May 2013
Participant Information Sheet: Staff	1.3	25 May 2013
Participant Information Sheet: Consultee	1.3	21 May 2013
Participant Information Sheet: General Practitioner	1.4	25 May 2013
Protocol	1.3	
REC application	Amended - 12457/47979 4/27/653	24 April 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Covering Letter		23 April 2013
Covering Letter		07 July 2013
Evidence of insurance or indemnity		25 July 2012
Investigator CV	Miss Rasa Mikelyte - PhD Student	17 April 2013
Investigator CV	Dr Alisoun Milne - Academic Supervisor	
Investigator CV	Ms Alison Culverwell - Supervisor	
Letter from Sponsor		23 April 2013
Other: Research Diagram	1.1	17 April 2013
Other: Interview Topic Guide	1.2	21 April 2013
Other: Consultee Declaration Form	1.1	11 April 2013
Other: Participant Invitation Letter	1.2	25 May 2013
Participant Consent Form	1.1	11 April 2013
Participant Information Sheet: Service Users	1.3	25 May 2013
Participant Information Sheet: Relatives	1.3	25 May 2013
Participant Information Sheet: Staff	1.3	25 May 2013
Participant Information Sheet: Consultee	1.3	21 May 2013
Participant Information Sheet: General Practitioner	1.4	25 May 2013
Protocol	1.3	
Questionnaire: Measures		
REC application	124573/4417 35/27/925	23 April 2013
REC application	Amended - 12457/47979 4/27/653	24 April 2013

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You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/IEC08/0018	Please quote this number on all correspondence

Yours sincerely

Barbara Cuddon

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