A multi-site evaluation of the Person, Interactions & Environment Programme (PIE) to improve person-centred care for people with dementia admitted to hospital wards

Final Report

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Abstract

A multi-site evaluation of the Person, Interactions & Environment Programme (PIE) to improve person-centred care for people with dementia admitted to hospital wards

Background: Improving care of people with dementia on acute hospital wards is a policy priority. Person-centred care is a marker of care quality; delivering such care is a goal for service improvement.

Objectives: PIE (Person: Interaction; Environment) comprises an observation tool and systematic approach to implement and embed a person-centred approach in routine care for hospitalised patients with dementia. The study aims were to: evaluate PIE as a method to improve the care of older people with dementia on acute hospital wards; and develop insight into what person-centred care might look like in practice in this setting.

Methods: We performed a longitudinal comparative case study design in ten purposively selected wards in five Trusts in three English regions; alongside an embedded process evaluation. Data was collected from multiple sources: staff, patients, relatives, organisational aggregate information and documents. Mixed methods were employed: ethnographic observation; interviews and questionnaires; patient case studies (patient observation and conversations 'in the moment', interviews with relatives and case records), patient and ward aggregate data. Data was synthesised to create individual case studies of PIE implementation and outcomes in context of ward structure, organisation, patient profile and process of care delivery. Cross case comparison facilitated a descriptive and explanatory account of PIE implementation in context, the pattern of variation, what shaped it and the consequences flowing from it. Quantitative data was analysed using simple descriptive statistics. Qualitative data analysis employed grounded theory methods.

Results: The study furthered understanding of dimensions of care quality for older people with dementia on acute hospital wards and the environmental, organisational and cultural factors that shaped delivery. Only two wards fully implemented PIE, sustaining and embedding change over 18 months. The remaining wards either did not install PIE ('non-implementers'); or were 'partial implementers'. The interaction between micro-level contextual factors (aspects of leadership (drivers, facilitators, team, networks), fit with strategic initiatives and salience with valued goals) and miso and macro level organisational factors, were the main barriers to PIE adoption. Where implemented, evidence suggests that the programme directly affected improvement in ward practice with positive impact on the experience of patients and caregivers, although the

heterogeneity of need and severity of impairment meant that some of the more visible changes did not affect everyone equally.

Limitations: Although PIE has potential to improve the care of people with dementia when implemented, findings are indicative only: data on clinical outcomes was not systematically collected; and PIE was not adopted on most study wards.

Research implications: Further research is required to identify more precisely the skill-mix and resources necessary to provide person-focused care to hospitalised people with dementia, across the spectrum of need, including those with moderate and severe impairment. Implementing innovations to change practices in complex organisations requires more in-depth understanding of contextual factors that impact the capacity of organisations to absorb and embed new practices.

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List of abbreviations

A&E   Accident and Emergency

AP   Associate Practitioner

CCG   Care Commissioning Groups

CHC   Continuing Health Care

CQC   Care Quality Commission

DCM   Dementia Care Mapping

ED   Emergency Department

HCA   Health Care Assistant

NICE   National Institute for Health and Care Excellence

NAD   National Audit of Dementia

NSFOP   National Service Framework for Older People

NPT   Normalisation Process Theory

OT   Occupational Therapist

PIE   Person, Interaction, Environment Programme

PMG   Programme Management Group

PT   Physiotherapist

RCN   Royal College of Nursing

PLAIN ENGLISH SUMMARY

Improving care of people with dementia in general hospitals is a UK policy priority. Older people are the main users of in-patient care; and around half have dementia and/or acute confusion.

PIE (Person; Interaction; Environment) is a programme for staff to improve care of people with dementia on acute wards. Observation enables staff to 'see' from the patient perspective how care is delivered, and how this is affected by the ward physical and organisational environment. Reflection on observations informs goals and action plans to improve practice; and reviews of progress stimulate further action.

We aimed to find out:

- How PIE works in real life on hospital wards?
- Whether PIE improves ward practices, patient and caregiver experience and clinical outcomes?

Ten wards in five NHS Trusts in England took part. We collected information on each ward, including staffing; observed practice prior to installing PIE and subsequent on implementation; interviewed staff and relatives; and spent time in conversations with patients while observing their care. An important part of the study was the insight offered on what 'person-centred' care might look like in acute wards.

Only two wards fully implemented PIE. Here, staff found it useful as a means of improving practice, changes introduced became part of how the ward worked, and for some patients, their care experience was enhanced. In the remaining wards, PIE was only partially implemented or not at all. The main reasons were absence of 'drivers' to pursue change, staffing difficulties, ward pressures and organisational instability (ward closures and re-organisation) making planning for change impossible.

Although PIE has potential to improve ward practice and patient experience we cannot say for definite that it works. This is partly because of poor take-up, and partly because information on clinical outcomes was not collected on all wards, including the 'successful' implementers.

299 words

SCIENTIFIC SUMMARY

Background

Improving care of people with dementia in hospital is a policy priority in the UK and internationally. Older people are the main users of acute hospital care and theprevalence of dementia is high among older patients. Evidence suggests that their specific needs are often unrecognised and inadequately addressed.

PIE (Person; Interactions; Environment) is a programme aimed at improving care practice for people on acute wards with dementia. Implementation is a cyclical process starting with observation of current practice. Structured reflection on observations is the basis for identifying goals and action plans to improve practice. Review of progress against planned action, including appraisal of barriers and facilitators of change, enables adjustment of action and review of goals. Each step is supported by tools, guidance and flow charts, encapsulated in a manual; implementation strategies include an interactive training workshop and method for leading change. The process is systematic but the content (how observations are conducted (number, for how long, by whom, when), goals identified and action plans pursued) is flexible and tailored to local need. We used Normalisation Process Theory as a sensitising framework to inform implementation.

Objectives

The overall objective of the research was to evaluate the process and outcomes of PIE as a method to improve care of people with dementia on hospital wards. The study aimed to:

- Provide a descriptive and explanatory account of how staff engaged with PIE in the real life context of acute ward delivery;
- Test out the causal assumptions underpinning PIE (the theory of change);
- Explore the impact of PIE on ward practice, patient and caregiver experience and seek preliminary evidence of effectiveness of PIE in improving selected clinical outcomes (delirium and falls).

We also sought to develop insight into what person-centred care might look like in a hospital setting. Although 'person-centred' care is regarded as a marker of care quality, there is no consensus on what it looks like in practice. There is also a paucity of research on what it might look like for people with dementia in hospital.

Design and Methods

We adopted a longitudinal, comparative case study design to examine the process and outcomes of PIE over time and in context of the organisational setting into which it was introduced. Case studies are holistic and may be used to examine formal and informal processes as they occur in real time within organisations that are also dynamic. The comparative method permits examination of how things happen, and provides insight into why interventions work in some settings and not others.

Case studies were purposively selected: wards in which older people dominated among the patient profile, in NHS Trusts which varied in size and type of catchment locality, in different English regions. 'Readiness' criteria were employed to ensure wards selected met minimum criteria to engage in the programme (investment of resources of ward and practice development staff in initiating and facilitating PIE and taking part in the research).

We employed mixed methods: qualitative interviews and questionnaires with staff; ethnographic observation of ward routines and practice; patient/caregiver case studies (observation and conversations 'in the moment' with patients, interviews with relatives/carers and examination of patient case records); and collection of anonymised data relating to the structure and organisation of care delivery, patient and staff profiles. An embedded process evaluation examined how PIE was enacted by staff in real time through observation, informant interviews with PIE team members and qualitative interviews at the conclusion of the study with purposively selected staff. Outcomes relating to practice change and patient and caregiver experience, delirium and falls, was also collected. Data sets were combined to create individual case studies of PIE implementation and outcomes in context. Cross-case comparison facilitated an explanatory account of the pattern of variation, what shaped it and the consequences flowing from it. Qualitative data analysis employed grounded theory methods. Quantitative data was analysed using simple descriptive statistics. Emerging analysis at each stage involved discussion within the research team, programme management group, which included carers from the Alzheimer's Society Research Network, and a reference group of older people. Findings were also discussed within an established group of older people with dementia; and with people with dementia and their carers at a Dementia Cafe forum.

Cases were over-sampled. Ten wards in five acute NHS trusts in three regions in England were recruited. Wards were a mix of care of older people, acute trauma, dementia and rehabilitation.

Results

Patient profile, structure and organisational context

People with a cognitive impairment, including delirium, comprised at least half the patient profile: many had moderate to severe impairment; they lacked capacity to communicate verbally; required assistance with personal care; and active support with eating and drinking. On every ward there were people who called out repeatedly, seemingly in deep distress. Most were in advanced older age, with multiple health problems, in addition to the event that precipitated acute admission. Their care networks were often fragile and vulnerable to disruption as a result of deteriorating health and acute health crises.

There existed considerable variation between sites in their organisation and care culture pre-dating PIE. Three of ten wards did not attain the Royal College of Nursing staff/patient ratio for safe working on older people's wards (1:3.5); and most did not meet the recommended ratio of registered nurse to health care assistant of 65:35 or above, notwithstanding the level of medical acuity, complexity of patient need and prevalence and severity of cognitive impairment. The picture was bleaker than this suggests: on several wards, staff complement was only maintained through use of Bank and agency staff with consequences for staff morale, sustainability of a coherent care culture and availability of 'headroom' to engage in service improvement.

Most study wards had been subject of environmental improvement to make them more 'dementia friendly'. Apart from two dementia wards, including those recently refurbished, there was a dearth of spaces for patients to engage with each other or with staff.

Dimensions of quality care

The study provides insight into the content and dimensions of practice that comprise a person-focused approach and address the specific needs of people with dementia in an acute hospital setting. Comparing and contrasting how care was actually accomplished by staff across wards, we discerned a continuum of practices supportive of, or barriers to sustaining personhood and the organisational, spatial and care environment factors that shaped them. Although the literature contrasts person centred with task focused communication and care, we identified more differentiated styles of practice. Indeed, this binary conception of care delivery was unhelpful. The multiple and interacting needs of this patient group spanning medical, therapy and support meant that care delivery needed to encompass tasks suffused with understanding of the person. Specifically, providing appropriate support to facilitate acute recovery of people living with dementia and respond to the complexity of their needs required biographical knowledge to communicate with

and interpret embodied communication, including distress; knowledge, whether learned or experiential of how dementia affected the person; inter-personal skills to engage at a sensory, emotional and cognitive level with them; empathic connection with the person in 'their world' based on understanding that their actions and interactions were meaningful although the meaning might not be evident; and a problem solving approach to practice building on these multiple sources of knowledge, experience and expertise.   Further, recognition that there was an element of uncertainty and unpredictability about how the person would respond in a given situation meant that strategies to engage him/her were emergent, built up through trial and error and requird creative, tailor made solutions. This combination of knowledge and skills occurred in pockets apart from the dementia wards; and reported by staff as what they lacked. It also necessitated time with patients. Constraints on time included the legitimacy attached to such work by middle managers, staffing difficulties and the pressure of demand.

Although these dimensions of practice are not necessarily exhaustive, they were sufficiently sensitive to differentiate between wards in our sample, suggesting a continuum of supportive practices and the factors that contributed to them. On wards where practice was generally poor for people with dementia in the terms considered above, a vicious circle operated. Inadequate staffing including widespread use of temporary staff without the necessary skill and knowledge to work with patients with moderate to severe cognitive impairment meant that getting through daily routine tasks was a challenge; this contributed to a care environment in which there was neither time nor space to reflect on practice; which in turn affected the levels of distress of patients on the ward, taxing the skill level of staff to respond appropriately; resulting in staff stress and low morale and seeing the patient as the problem. The pattern of work reflected in this vicious cycle could be temporary, resulting from a particular confluence of organisational factors; or it could evolve as routinised practice, with little energy or headroom to change. Even within such wards, there were staff who sought to provide an empathic and supportive response to patients with dementia but were under considerable stress. Overall, such environments were not conducive to engagement in service improvement initiatives either.

PIE Implementation

PIE was fully adopted in only two of ten study wards; and had proceeded to innovation and sustainability in those. Evidence from observation and staff interviews on both suggests that the programme had a significant impact on practice. There was evidence that practice change impacted positively on the experience of patients and caregivers; although the heterogeneity of need and severity of impairment meant that some of the more visible changes did not affect everyone equally.

We are unable to draw any conclusions about the effect of PIE on clinical outcomes since data on delirium and falls was not collected on these wards.

Successful engagement in PIE from installation to adoption and sustainability required a 'driver' outwith the day to day demands of managing a ward whose professional authority and vertical networks legitimated the work of improvement in face of competing priorities; a 'facilitator' to provide support and encouragement, typically the ward manager, to legitimate staff time and investment in PIE and extend its reach to the wider staff team; and team members to pursue action on the ward and generate interest from colleagues, an additional factor in extending reach of the intervention. The PIE 'driver' was critical in getting the change process started and keeping it going, particularly in light of the day-to-day pressures on ward staff. These included: staff sickness and movement, crises events with major impact such as temporary ward closures resulting from norovirus outbreaks, and periods of high demand on beds during 'winter pressures,' a misnomer insofar as 'winter' pressures extended over most of the year. This confluence of aspects of leadership at ward level was enabled by features of the organisational context at Trust and executive level: clear and consistent focus on care quality, and 'fit' between practice change and strategic priorities on dementia.

In exploring why some wards proceeded to full adoption of PIE and others only partially or not at all, we examined the relationship between what was intended to happen, what actually happened and the interface with the organisational context over time. Factors contributing to failure to proceed with PIE installation were multiple and interactive. They included absence of one or more aspects of 'leadership' (drivers, facilitators, teams or networks), lack of congruence between PIE and strategic initiatives on dementia; and lack of resources to provide the headroom for staff to pursue service improvement.

While these factors are local expressions of forces operating at miso and macro levels, surprising was the degree of organisational instability and turbulence encountered: four of the ten wards closed during the study, either suddenly or over a protracted period affecting staff investment in a collective shared future, critical to a culture of service improvement.

Conclusions and Limitations

When implemented, PIE has potential to improve the care of older people on acute wards living with dementia.. However, findings are indicative for two reasons. First, since data on delirium and falls was not systematically collected on wards where PIE was implemented, there is no evidence as to whether the programme is effective in improving clinical outcomes. Second, although PIE worked as intended on two wards to effect change in practice, it was not adopted in most study wards. Partial

or non-adoption was affected by: a change in ward 'readiness' to pursue service improvement between site recruitment and programme installation; the absence of 'drivers' and 'facilitators' to harness the energy and creativity of front-line staff to make change happen; and sufficient staffing to provide the 'headroom' to reflect on practice, try out possible solutions and review progress. At a general level, these reinforce the conception of organisational context not as a background to action but as an interacting element in the change process. In the specific context of PIE implementation on these NHS wards, the degree of system turbulence expressed in staffing shortages, ward closures and re-modelling created an environment in which high work pressures and future uncertainty meant that the investment required for improvement was not forthcoming.

Research Implications

The combined and interactive effect of advanced older age, dementia exacerbated by delirium; chronic health problems; and acute events presents enormous challenges for staff in providing quality care. There is pressing need for further research to identify more precisely the skill-mix and resources necessary to provide person-focused care to this frail patient group across the spectrum of need. Specifically, what skill mix, training and resources are necessary to provide the appropriate 'balance of care' to respond to this complexity?

Implementing innovations to change practises in complex organisations, like acute wards requires more in-depth understanding of contextual factors that impact the capacity of organisations to absorb and embed new practices. Longitudinal research which examines the dynamic between interventions and the environments in which they are inserted, is needed . In particular, we require understanding of what are 'receptive change' contexts to secure quality improvement. This suggests a parallel line of investigation to that focusing on application of theories to the development and implementation of interventions to improve quality. More specifically, in the NHS context, there is need for research on the impact of different organisational cultures on innovation and service improvement.

Funding

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CHAPTER 1

INTRODUCTION

In this chapter, we set out the background and rationale to the study. We review evidence on the meaning of person-centred care, considered a benchmark of care quality, with reference to the care of people with dementia on acute hospital wards. We then describe the development of an intervention to improve care of hospitalised older people with dementia, the theory of change underpinning it and the objectives of the research to evaluate it.

Improving Care for People with Dementia in Hospital: A Policy Priority

Improving the care of people with dementia has been identified as a policy priority in the UK and internationally over the last decade. This has resulted in the development of national dementia strategies in England[1], Wales[2] and Scotland.[3,4] Similar initiatives have been introduced in other European countries,[5] in Australia[6,7] and New Zealand.[8] In the UK, policy and strategic objectives include improving care quality for people with dementia in acute hospitals (Objective 8 of the English strategy[1] and Target 2 of the 1000 Lives Plus campaign for Wales[2]); and making hospitals more 'dementia friendly'.[3] Both objectives are prioritised in the Prime Minister's Dementia Challenge.[9,10]

Older people are the main users of acute hospital beds and around half of patients who are aged 70 years or older have a cognitive impairment, including dementia, delirium and delirium on dementia.[11-13]

The needs of people with dementia in hospital are multiple and complex. They include care needs relating to functional impairments, a consequence of physical co-morbidities common among those in advanced older age; expressive, emotional and communication needs which vary depending on the nature, severity and impact of their cognitive impairment; and medical needs resulting from the type of acute event precipitating hospital admission, which may also exacerbate the dementia (for example, pain and infection).

People on hospital wards living with dementia are at heightened risk of unintended adverse events. These include delirium and falls that contribute to increased mortality, longer length of hospital stay and poor health outcomes such as loss of independence and new care home admissions,[11,12,16] with the attendant resource implications.[14,17] Being in hospital may be experienced as frightening and engender feelings of anxiety, distress and agitation[18--22] as a consequence of the busy and unfamiliar

environment. Features of physical design, organisational structure, care climate and care processes that do not take account of individuals' vulnerability and reduced resilience may exacerbate distress and contribute to poor outcomes.[21,22]

The dominance of older people on acute wards and the prevalence of dementia among those hospitalised, means that care delivery to people with a cognitive impairment is a litmus test of the quality of hospital care. Yet, despite the frequency with which people with dementia utilise acute care, evidence from systematic reviews,[21,22] recent in-depth studies[18,23,24] and national audits[25,26] suggests that their needs are often under-recognised and inadequately addressed.

Care of Hospitalised Older People with Dementia

Studies have identified organisational and cultural features of acute care delivery that negatively impact the care of patients with dementia. These include inflexible care routines that privilege the performance of medical and physical care tasks over time spent with patients,[27,28] and physical environments that are difficult to navigate.[21,22,25] The nature and quality of staff interactions with patients have been regarded as problematic: staff encounters that are primarily task focused and involve limited engagement of the person at a personal level;[17-19,21,22,24,25,29-33] communication practices that are poorly responsive to the emotional needs of patients[17,21-25,27,30-32] and/or fail to 'see' and act on behavioural cues that might indicate distress or pain.[34,35] Studies have reported stigmatising and negative attitudes toward people with dementia among some staff and that such patients should not be admitted to acute wards.[27, 29-32] Often conveyed as ensuring their safety and that of other patients, the consequence is to see people with dementia as 'other'. Conversely, staff with knowledge of dementia express lower perceived strain in caring for a person with dementia and less negative attitudes.[32] Research with caregivers has reported inadequate support for their relative with nutrition and hydration,[17] both risk factors for delirium;[36] the person with dementia not being treated with dignity and respect;[17,22,24,27,37,38] and limited engagement in decision-making, both for the person with dementia and the caregiver.[17,22,37] A key factor, contributing to poor care delivery from UK studies is lack of knowledge and skill in dementia care.[20,22,25,38]

Person-Centred Care: A Marker of Care Quality

What is Person-Centred Care?

'Person-centred' care has become ubiquitous in UK health and social care policy discourse as synonymous with care quality. Prioritised in the National Service Framework for Older People (OPNSF),[39] it is viewed as key to upholding dignity in care[40] and forms one of the key Principles of Nursing Practice developed by the Royal College of Nursing (RCN).[41] Its meaning in policy however, is

either implicit or there is varying emphasis on different domains. It is commonly conveyed as individualised care, holistic care, choice, autonomy and dignity; and use of the term and the particular emphasis attached to it, has varied over time and in relation to wider policy interests (see Appendix 6 for a document review).

From research, there is a similar lack of clarity on what is person-centred care. Two systematic reviews examined its meaning in health,[42,43] although they adopted different perspectives. Kogan[42] explored research relating to older people; and Sharma's[43] review of reviews addressed understanding of person-centeredness in nursing and medicine. Both concluded that there was no consensus on meaning, posing difficulties in operationalising the concept. Neither included studies in acute care; and only three of 132 papers in Kogan's review related to people with dementia, all conducted in long term care. To explore this further, we consider theoretical conceptions of personhood and person- centred care in dementia and draw on research evidence to explore what quality care might look like for people with dementia on acute wards.

Theoretical Conceptions of Person-Centred Care in Dementia

Personhood in dementia

Kitwood's[44] theoretical model of 'personhood' has been enormously influential as the basis for 'person-centred' care in dementia. He drew attention to the way in which people's experience, behaviours and actions do not simply arise as a consequence of neurological deficits. They are also shaped by interactional processes which result in the erosion of personhood and the consequent invisibility and diminishing of the person; in essence loss of cognition is equated with being a non-person with deleterious impact on the individual. Similarly, Sabat[45] has explored how the social positioning of people with dementia affects how they are related to, considered and conceptualized, and which in turn affects their personhood and their behaviour and interactions with others. This theory projects the malign impact of 'others' (whether at institutional, organisational, social, or interpersonal levels) on the person's sense of self.

Based on humanistic values and person-centred psychotherapy,[46] Kitwood suggests that a person with dementia can sustain relative well-being if personhood is maintained. Drawing on empirical research in long term care, he defines five psychological needs (not unique to people with dementia) to establish the main foci of interventions for sustaining personhood: *comfort, attachment, inclusion, occupation* and *identity*. Although the concept of 'person-centred' has been criticised on its 'individual' emphasis,[47] 'personhood' as articulated by Kitwood and Sabat is relational, the underpinning assumption being that the person is embedded in relationships in a social world. Person-centred care, therefore, is care that meets the person's psychological and social needs,

informed by values of respect and concern for others, and which has been summarised in the VIPS model.[48] Here, person-centred care comprises four elements: valuing people with dementia and those who care for them (V); treating people as individuals (I); looking at the world from the perspective of the person with dementia (P); and positive social environment such that the person can experience well-being (S). The significance of the quality of the relationship with persons with dementia is uncontested. Less evident is how to operationalise an appropriate response to the psychological and social needs identified by Kitwood into settings that are temporary, geared to specific purposes and where relationships are short-lived and transient, as are acute wards. Indeed, it is argued that operationalising person-centred care will vary with the nature of the setting in which it is delivered.[49]

Embodiment and dementia

Recent developments in understanding dementia have drawn on theories of embodiment.[50-53] Kontos[50] directs attention at the way in which people with dementia express selfhood through their embodied way of 'being in the world' i.e. through activity and engagement rather than reflection or contemplation. She contends that selfhood which resides in the pre-reflective body has two origins. The first is primordial whereby "*selfhood emanates from the body's power of natural expression, and manifests in the body's inherent ability to apprehend and convey meaning"[50]* (p837)*. This is seen, for instance, in how people, including those with severe dementia, communicate with gestures, body movements and facial expressions which carry meaning in inter-personal communication; they are reflective of agency or intentionality. The second origin of selfhood is the sociocultural dimension of the pre-reflective body: people's actions and interactions convey deeply internalised social-culturally specific ways of being in the world. For example, people with severe dementia may converse with each other following normative rules of engagement (for example, turn-taking), although the content may seem unintelligible to the listener. She argues that the notion of embodied selfhood refers to the complex inter-relationship between primordial and social characteristics of the body, which reside below the threshold of cognition, are grounded in the pre-reflective level of experience, and are manifest primarily in corporeal ways. Understanding the ways in which people are embodied is to challenge the assumption that there is loss of agency with cognitive impairment. The conception of embodied communication as meaningful has implications for engaging with people with dementia in acute care. Hughes[53] considers that if one is to share, if not fully understand the world of a person with dementia, one must draw on myriad non-verbal and expressive cues; and to make sense of them requires knowledge of the person.

Practice of Person-Centred Care on Acute Wards

Research relating to older people with dementia on acute wards primarily highlights difficulties in care practice; and evidence reviews conclude that a chasm exists between the rhetoric of 'person-centred care' and actual delivery.[21,22] Apart from a recent study,[24] this research does not draw on a theoretical conception of 'person-centred' care in dementia, although several studies offer insight into what person-focused practice might look like.

Studies on the quality of care delivery on acute wards have been mainly small scale, employing ethnographic[18-20,30,33] or mixed methods, including interviews with caregivers.[23,24,29,31,32,54] Two[20,54] drew out components of good practice from observation, interviews and conversations with patients. Tolson[54] employing critical incident interviewing with patients (possible only with a small number) and caregivers, identified four themes within a temporal frame around which components of quality practice could be delineated. 'Settling in' referred to the process of adjustment involving responsiveness to emotional signifiers and acknowledgement of the person as valued and part of a family/social network. Its significance stemmed from the person's need for reassurance, given the disorientation and distress resulting from being in an unfamiliar environment. 'Visible love' by engaging with the affective dimension of caring, including the connections between the patient and family, generated a sense of the person's worth. 'Reaching me, reaching you', related to the interactional quality of encounters in which sharing and knowing assumed central importance. 'My condition' embraced both the acute illness, existing health problems and the cognitive impairment. Quality practice meant achieving a 'balance of care' based on understanding the inter-relationship between these three. 'Best' practice in acute care required attention to the particular needs of people consequent on the cognitive impairment; strategies which promoted 'settling in' thereby enabling people to feel valued; and proactive communication that facilitated connections with the person's biography and significant relationships in providing care.

Norman[20] identified two further components pertinent to 'good' practice. First, patients were viewed not just as passive 'recipients' of care but as active agents, conveying a sense of 'self' in their actions and interactions. When staff viewed what patients' did as meaningless or problematic, it resulted in a construction of them as reduced and dependent. Conversely, seeing patients' actions and interactions as meaningful, drew forth a staff response which reinforced the person's individuality and sense of self. Second, a distinction was drawn between two types of nursing work: 'practical' and 'emotional', similar to that in recent literature between 'task-centred' and 'person-centred'. 'Practical' work was defined by minimal collaboration in which a provider/recipient relationship prevailed; 'emotional' work involved higher levels of collaboration, including prioritising patients' needs. However, this binary conception of forms of work in context of people with

dementia on acute wards appears limited. Instead, employing Tolson's conception of the 'balance of care', it would seem more useful to consider 'practical' and 'emotional' work not as polar opposites, but as infused one with the other.

Nilsson's[32] ethnographic study on a cardiology unit offers negative evidence in support of Tolson's 'balance of care' conception. The overarching category, 'falling behind' refers to the way in which patients' needs associated with dementia went largely unnoticed until they escalated and emerged as problems that disrupted the usual flow or threatened safety issues in the unit. The response generated was reactive and not proactive, with negative consequences for patients, relatives and staff. Clissett et al.[24] employed Kitwood's conception of the basic needs necessary to sustain personhood as an a priori framework to determine what was person-centred care, namely care that offered comfort, attachment, inclusion, occupation and identity. They concluded that although staff promoted attachment and inclusion, there was little evidence that they supported patients' sense of identity, occupation and comfort; and that practice was poor in these areas. Their conclusions and interpretations do not flow unambiguously from the empirical data presented. First, the content of what was contained within these domains appeared somewhat arbitrary. Second, the way findings were presented (conveying accounts of how these needs were met followed by missed opportunities) meant that the weight given to positive aspects of practice in relation to lost opportunities, is unclear from the illustrative data. Third, what shaped these positive and negative features of practice were not elucidated, as focus was on the inter-personal level of staff/patient engagement. Fourth, there is an assumption that needs conceived of as necessary to secure well-being developed in a care homes context are equally relevant to acute care. Another recent qualitative comparative study of care delivery to people with a cognitive impairment on a specialist medical and mental health unit and standard care wards within a randomised controlled trial,[33] provides further clarity on what person-centred practice might look like on acute wards. This involved a sub-sample of 60 (30 in each group) of 90 trial participants observed using Dementia Care Mapping and unstructured observation captured in fieldnotes. Many aspects of practice were similar across specialist and standard care wards: crowded, noisy physical environments; delivery of care in a routine and task-oriented fashion; communication that was usually brief or absent when meeting physical care needs; and prioritisation of physical over emotional needs. Some features of person-centred care were observed, described as care that included personal communication during routine care tasks, validating patient concerns, facilitating independence and delivering care at a relaxed pace. The main difference between standard care and the specialist unit related to the work carried out within the activities room with designated, activities coordinators in the specialist dementia unit. The authors concluded that the profile of patients on both ward types was similar (high dependency resulting from acute illness, functional dependency, behavioural and psychological

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problems with increased cognitive impairment).   Although the activities programme was very successful for some people, severity of illness and impairment meant others could not participate. The trial,[55] of which this qualitative study was a component, is the only published research to date which has examined outcomes of care practice on specialist medical and mental health units compared with standard care. Findings reported increased satisfaction among caregivers on the specialist unit but no significant differences in organisational or clinical outcomes.

In summary, although person-centred care is presented as a marker of care quality in health research, there is no consensus on its meaning.   Although the humanistic values underpinning person-centeredness offer a guide for practice, further work is needed to concretise what this person-centred practice might look like in an acute ward environment; and what methods and tools might be effective in improving practice.

Developing PIE (Person; Interaction; Environment) Observation Tool

The PIE observation tool was developed for use in the first national audit of dementia on NHS hospital wards[25] over a three year research study (2008-2010).   The aim was to develop and feasibility test an easy to use tool to:

a) Enable local observers (staff or volunteers) view care from the perspective of the person with dementia;

b) Provide observers with a means (and vocabulary) to report on care quality based on the findings;

c) Enable the care provided to be compared with that of other hospitals nationally;

d) Produce data for use by ward staff to develop action plans to improve practice.

The study was overseen by a steering group for the National Dementia Audit (NAD), comprising professional and 'experiential' dementia experts (including individuals with dementia and caregivers).

Process of PIE Tool Development

The first phase involved iterative scoping reviews to examine the concept of person-centeredness, and the observation tools used to measure it in an acute setting which could potentially be adapted for the audit. The literature review identified several potential candidate tools. However, these were either based on nursing models and not dementia specific,[56,57] dementia specific but not tailored for use in an acute setting,[58-60] or the complexity, level of expertise required and cost involved in using the tool made it impractical.[59,60] It was agreed to develop a new observation tool for the audit.

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A subsequent systematic search of the literature was undertaken to explore the dimensions of care valued by hospitalised older people generally and by those with dementia specifically. Findings from this review were discussed through a process of stakeholder consultation via focus groups with staff and patient representatives from different specialties in four hospitals, and a Public and Patient Involvement (PPI) group. The purpose was to inform the content and structure of the proposed tool and how it might be used in hospital.

The content of the tool comprises three dimensions: Person; Interaction; and Environment (PIE). These represent the elements of knowing and using information about the patient as a person in care delivery, the quality of staff-patient interaction, and the effect of the immediate organisational and physical environment. They reflect inter-alia the personhood of the individual, including their subjective experience (incorporating biography, values, life preferences and significant relationships); the interactional or relational character of the social world in which the person is embedded and which shapes sense of self and identity; and the nature of the surrounding physical, social and care environment which provides the context in which care is delivered. Drawing on interactionist[44] and social positioning[45] theories of dementia, it was understood that the type and severity of the cognitive impairment both impacts the individual's experience of the inter-personal, social and physical world and which in turn affects the person with the condition. This dynamic has implications for care delivery of people living with dementia on acute wards.

The draft tool and guidance were tested for feasibility in seven hospitals (18 wards) and through further consultation with the advisory group. A key criterion was that it should be acceptable to, and feasible for use by staff with minimal resources.

Following modifications and refinements, the PIE tool and guidance was presented in the form of a work-book manual and one-day workshop to train hospital staff in its use. For audit purposes, PIE involved gaining informed consent to observe the care of up to six patients with dementia or problems in a ward area in real time. Observations were conducted by two staff (one external to the ward), who paired up to observe different patients for at least two periods of two hours (one in the morning; one over lunch time). Following reflection and feedback with the ward team, each ward identified one aspect of good practice and one requiring improvement with achievable short-term and longer-term actions to undertake at ward, directorate and Trust/Health Board levels.

Use of PIE in the National Audit of Dementia (NAD)

An enhanced audit component of the NAD was conducted in a sub-sample of 55 hospitals (145 wards), and included PIE. Findings from PIE observations, conveyed in the published report[25] were that care and communication was generally reactive and based on an organisationally set, task-driven routine rather than being person-focused, flexible and proactive. Whereas there were "pockets" of positive, individualised care in the practice of individual staff, or as elements of ward practice, only a handful of wards (5/105) reported practices which were consistently focused on the person. There were periods of care-based activity interspersed with inactivity, leading to lack of attention and stimulation. The environment was often impersonal and dementia unfriendly, with a lack of orienting cues, dementia aids or areas for socialising.

Although the findings were not novel, the breadth of coverage underscored the nature and extent of the problem of care delivery to patients with dementia. Further, comparison between wards offered preliminary evidence of 'propellers' or features of staff/patient interaction that supported person-focused communication, suggesting scope to enhance care.

As the primary purpose of the audit was to document current practice, the process of translating action planning at ward level to effect organisational change, and the systems and mechanisms required to support and sustain it, were not developed. There was no attempt either to examine whether action plans derived from observation affected staff practice, patients' care experience or health outcomes. These conclusions prompted the current study: the development of PIE as a generalisable practice development process in conjunction with the PIE observation tool (PIE Programme); and evaluation of its effectiveness in improving care for people with dementia on acute wards.

From PIE Observation Tool to PIE Programme

The PIE Programme (referred to henceforth as PIE), tools, guidance, implementation process, manual and 'theory of change' was elaborated on as part of this current study.

This further development involved an iterative review of the literature on implementing change, a workshop with staff across the Yorkshire and Humber region who had used PIE in the NAD, and participation in workshops with NHS hospital staff (RW, JC&MG). These workshops were conducted as part of a Quality Mark for Elder-Friendly Hospital Wards, launched by the Royal College of Psychiatrists in partnership with the Royal College of Physicians, the British Geriatric Society, the Royal College of Nursing and Age UK. Within these fora, we tested out further acceptability and use

of PIE as a strategy and process to support cultural and practice change on acute wards to meet the needs of patients with dementia.

PIE Intervention and Implementation Process

PIE adopts a systematic approach and set of steps to implement and embed change in routine care on hospital wards; each step being supported by tools and guidance. Implementation is a cyclical process comprising observation of current practice (Observation tool and guidance). Observation is a means to, firstly document care as delivered and, secondly, consider the impact of the care on patients with dementia to promote fresh insights and potentially challenge existing practice. Reflection on observations is the basis for identifying goals and action plans to improve practice (Action planning tool and guidance). Goals for change are prioritised and action plans formulated. Action plans specify steps to move from current practice toward achieving goals; how these will be taken forward and by whom; and how they will be communicated to the wider staff group to extend the programmes' reach and engage them in action. Review of progress against planned action, including appraisal of barriers and facilitators of change (Review tool and guidance) enables adjustment of action and/or review of goals. The process is illustrated in Figure 1.
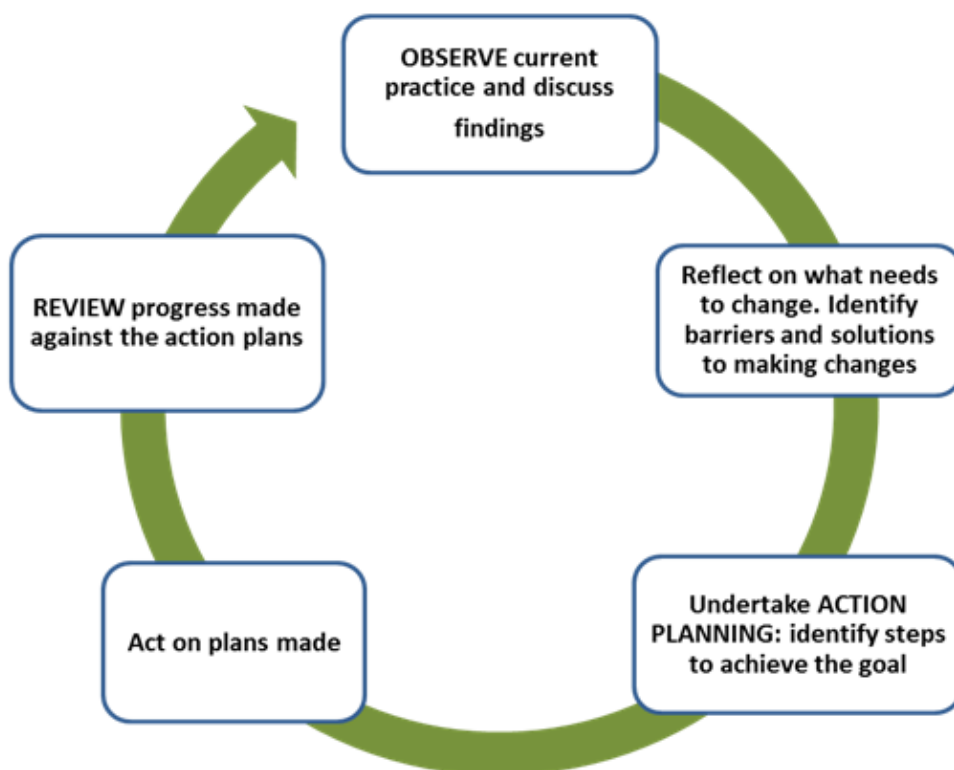
Figure 1: PIE Service Improvement Process

Implementation team

An additional mechanism to effect change is the establishment of an implementation team to lead it. Its core membership comprises: ward manager or senior nurse with the authority and legitimacy to drive the programme; matron or practice development lead outwith the ward to provide organisational and facilitative support, and act as a conduit between ward-based initiatives and dementia strategies at departmental and hospital level; and ward staff involved in directly providing care to patients, such as nurses, therapists and health care assistants. Within these parameters, the size and make-up of the team is flexible.

This conception synthesises a top down and bottom up approach to change:[61] active involvement of senior staff to secure organisational commitment to introducing and embedding the programme; and engagement of those directly in delivering it, to ensure that their views and experiences inform the pace and direction of change.[62-64] Responsibilities of the team include:

- Raising awareness of PIE among the whole staff group;

- Organising observations, action planning and review of progress;

- Engaging ward staff in change through discussion of priorities and action plans;

- Reviewing what systems and mechanisms need to be put in place to support sustainability.

Strategies to support implementation

Several strategies are in place to support implementation: a PIE manual; and an interactive training workshop to introduce participants to PIE.

PIE manual

The manual is organised as a workbook. It comprises three sections. Section one describes the PIE purpose and rationale, specifically why people with acute illness living with dementia require a tailored and dementia sensitive approach to meet their care needs <u>and</u> facilitate recovery. Section two provides an overview of the cyclical process of change involving observation, reflection, action planning, action and review. Section three details each step in the implementation process (observation, action planning and review); the tools for each step, guidance on using the tools and a flow chart to indicate what should happen and when. Worked out exemplars of observations, action plans and reviews are provided.

PIE introductory workshop

A one-day workshop to familiarise participants with PIE introduces the programme. The first part conveys through various media (role play, drama, video clips) how the social and spatial environment of an acute ward may be perceived by persons with a cognitive impairment. This is aimed at sensitising staff to how people with dementia may experience the world around them. Observation of encounters between professionals and people with dementia via drama and video clips are presented, for example 'Come feel with me' DVD.[65] The purpose is to elicit critical refection on how people with dementia may express agency through embodied action, thereby directing attention on 'knowing the person' to interpret behaviour and action. The second part takes people through each step in the observation, action planning, action and review cycle, preparatory to introducing PIE on their ward.

Theory of Change

In designing the PIE implementation process, we drew on Normalization Process Theory (NPT)[66] as a sensitising framework. From the range of theories available on implementation,[67,68] our use of NPT stems from its sociological focus and the utility of the broad constructs that comprise it. In contrast to psychological theories of change that address individual behaviour, NPT focuses on micro-social processes that affect implementation of a practice (or technique) in an organisation or clinical setting to account for how individuals and organisations understand and make sense of the new practice, engage with it, participate in the work relating to it, and reflect or appraise its effects in relation to valued goals. NPT appeared most apt in respect of PIE implementation. PIE is a whole ward intervention and does not simply involve change in individual behaviour. It also requires organisational, cultural and team level change. Further, PIE intervention uses and alters roles and patterns of communication between staff and between staff and patients. Changed meanings, practices, roles and relationships are intended to become part of 'the way we do things here' (ward culture).

Within NPT, normalization refers to the work of individuals as they engage in activities which become routinely embedded in knowledge and practice. NPT postulates four generative mechanisms that operate individually and collectively to explicate how practices become 'normalised' within routine care: coherence, cognitive participation, collective action and reflexive monitoring. New practices, the theory contends, become routinised when:

- The work that defines and organises a practice/intervention is understood as meaningful and invested in, in respect of the knowledge, skills, behaviours and actions required to implement it at an individual and collective level (coherence);

- The work is perceived as something worthwhile and appropriate to commit individual time and effort so as to bring about the intended outcome (cognitive participation);

- Work practices and the division of labour through which these are carried out are modified or adapted to incorporate the change/intervention into the social system of the host organisation (collective action);

- Those engaged appraise the effects as attributable to the intervention and congruent with valued goals (reflexive monitoring).

In PIE, the work of generating coherence begins with the introductory workshop, its content and participatory nature focused on a range of ways for participants to 'see the world' from the perspective of the person with dementia. This continues with the first step in the improvement cycle, observation of patients with dementia by staff in real time. Taking a 'step back' from work roles to observe 'persons, practice and context' for a short period of time, as an 'outsider' looking in will, it is assumed help staff to 'see' things in a different way (coherence). This is the pre-requisite to reflect on, and examine what may have been taken for granted assumptions, activities and practices. In contrast to use of the PIE observation tool in the NAD, how many observations, by whom and when, are flexible, to facilitate local buy-in. Collective discussion of observations within the PIE team further reinforces coherence, and by establishing the need for, and possibility of change, toward securing cognitive participation. These reflections form the starting point for identifying goals for change and the necessary steps or action plans to achieve the goals. Action planning, including who does what and how it will be communicated and discussed within the wider team is intended to pursue the work of collective action. Review of progress and re-appraisal of goals and actions in light of what works will, it is assumed, act as leverage to continue the process (reflexive monitoring).

The PIE implementation process is systematic and tools are provided for each step (observation, action plans and reviews). However the content - how observations are conducted (number, for how long, by whom and when), the goals identified and action plans pursued - is flexible and tailored to individual wards. Implementation is conceived of as a process and not a once off event.[69] A significant dimension of PIE implementation is temporality. Change through successive observation, action planning, action and review cycles mean that the process is likely to be non-linear and multi-directional;[70,71] the success (or failure) of action plans creating the conditions for subsequent review and new/re-worked action plans. The commitment and skill of those leading the change and in working through each phase of the improvement cycle will affect implementation and outcomes, so that there is a degree of unpredictability of the process (and outcomes).

PIE is an exemplar of a complex intervention.[72] It contains multiple interacting components; the levels at which change is directed are several (individual, collective and organisational); and there is

flexibility in delivering it. The change process is emergent and non-standardised.[73] The ward setting within which the intervention is being introduced and with which it interacts, is also dynamic, adding another level of complexity.[74]

The Research Study

The overall research purpose was to examine whether PIE enhanced the care of older people on acute wards living with dementia, how this was achieved, and whether and in what ways this impacted on ward practice, patient and caregiver experiences and selected clinical outcomes.

Objectives of the process and outcomes evaluation of PIE were to:

- Provide a descriptive and explanatory account of how staff engaged with PIE in the real life context of acute ward delivery;
- Test out and refine the causal assumptions underpinning PIE (the theory of change);
- Explore the impact of PIE on practice, patient and caregiver experience and clinical outcomes.

The research questions posed address the PIE process and outcomes at several levels. Specifically:

Process of Change

1) How is delivery of PIE achieved; and what is actually delivered?
2) How does PIE produce change or conversely, if the intended changes do not occur, is this because of poor/inadequate theory or poor implementation?
3) How and in what ways is PIE implementation (and outcomes) affected by the organisational and resource context of acute care delivery?

Outcomes

4) Does PIE change ward staff practice in ways that are consistent with person focused care?
5) Is PIE effective in improving care for people with a coincidental dementia on acute wards, as experienced by those patients and/or observed by their relatives/caregivers?
6) Is there preliminary evidence of effectiveness of PIE in improving selected clinical outcomes (days in delirium and falls rate)?

CHAPTER 2

EVALUATING PIE: METHODOLOGY AND METHODS

Introduction

This chapter elucidates the methodology and methods employed in performing a process and outcomes evaluation of PIE. It includes the rationale for the design, sampling strategy, data collection methods and analysis; the ethical issues posed; and how public and patient participation was pursued.

Methodology

We performed a comparative, longitudinal, mixed method, case study design. Case-based research[75-79] is characterised by the depth and detail of information collected within naturally occurring, bounded settings, where the boundary between the setting and focus of interest is permeable.[78] In this study, the analytic lens was care delivery to hospitalised older people with dementia on NHS acute wards. This is one facet of ward work; which is also affected by contextual factors outwith the ward.

The distinctiveness of the approach is its systemic and holistic perspective. Ragin and Becker[75] argue that:

> *"The …case oriented approach places cases, not variables centre stage. But what is a case? Comparative social science [answers this question]…Boundaries around places and time periods define cases"* [p5].

Embedded in this conception is that cases are complex systems in which "*trajectories and transformations depend on all of the whole, the parts, the interactions among parts and whole, and the interactions of any system with other complex systems among which it is nested and with which it intersects*" [75][p2].

The rationale for adopting a case study design flowed from the nature of PIE and the setting in which change was introduced. PIE exhibits several features of complex interventions;[72] the number and difficulty of behaviours and practices required to implement and deliver it; the levels at which change is required (individual, collective and organisational); the degree of flexibility permitted in delivering it; and the dynamic environment in which it is being implemented. The setting for initiating and implementing PIE is the acute ward; evaluation of effectiveness requires

understanding 'how' and 'why' change occurs within this organisational context. The comparative focus enables exploration of commonalities and differences between cases to develop an explanatory account that extends beyond the specificity of each case.

We sought to provide a rich description of care delivery to patients with dementia in the spatial, temporal and organisational setting of the hospital ward; to understand how, and the conditions in which PIE effects change over 18 months; and conversely why change occurs in some circumstances and not others. An embedded process evaluation examined how PIE was understood and enacted by staff in real time.

Methods

Sampling Strategy

Our intention was to recruit eight wards in four acute NHS Trusts. Cases were sampled purposively. Wards with a substantial proportion of older people with dementia among their patient intake were identified (care of older people, dementia and trauma orthopaedic) in trusts, varying in size and type of catchment locality in three English regions. We employed criteria of 'readiness' to implement PIE,[80] informed by previous research on delirium prevention:[81]

- Expressed interest among senior acute hospital staff in taking part in research to improve person-centred care for people with dementia;
- Agreement of senior ward staff to engage in a practice improvement programme over 18 months;
- Commitment from a clinical lead at directorate level or an individual with responsibility for practice development to assume a leadership role in initiating and facilitating PIE.

Site recruitment

Using networks developed through NAD, letters of invitation were sent to named individuals (directorate leads, practice development leads and ward managers) in 13 NHS hospital Trusts in different English regions, and followed up with telephone conversations. Those indicating interest in taking part were sent an 'expression of interest' pro-forma, which encapsulated the 'readiness' criteria. This was a signed commitment by a ward manager, directorate matron, and practice development lead to take part and assume responsibility for initiating and facilitating PIE.

Meetings with staff at ward and directorate level were organised in each of five acute Trusts that expressed interest. These offered diversity in their size (small, medium, large); type of catchment locality (small towns with rural hinterland, large city, metropolitan area, and a geographically

dispersed locality of large towns and villages); and geographical location (North, Central and South English regions). They spanned eleven wards: three medical, care of older people; two dementia wards; four acute trauma; one acute stroke and one older people's rehabilitation ward. All Trusts and wards agreed to participate in the research, returning their signed forms. Based on initial meetings with directorate and ward staff during recruitment, wards varied in their degree of 'dementia awareness' (reinforced in data collection).

We agreed to over-sample and include these Trusts and linked wards; prior experience of research in acute hospitals suggested organisational turbulence was common (for example, changes to ward models, ward re-organisation and bed closures). This proved prescient. Before fieldwork began, one of the sites (an orthopaedic trauma ward) dropped out because of staffing difficulties. Appendix 1 provides a summary of the structure of participating sites.

Data Collection Methods

A common set of data was collected for each ward over a seven/eight week period at baseline; and at nine and 18 months following PIE implementation for those wards that pursued PIE.

We collected qualitative data via interviews with staff to examine their views on care delivery and the meaning of person-centred care; explored how routine care was accomplished in time and space using ethnographic observations and informant interviews with staff; conducted in-depth case studies with patients and their relatives or caregivers to understand how people with dementia experienced care through observation of patients over their acute episode and conversations 'in the moment' with them; and interviews and conversations with relatives/caregivers; built up a picture of how their journey into and through the ward unfolded in time, via case notes and observation of handover and multi-disciplinary team meetings.

Quantitative data relating to ward structure (Trust policy, resources and priorities) and physical environment; organisation (staff and patient profiles) and care culture (staff questionnaire) which shape care delivery and patient experience, was collected. Outcome data to examine the impact of PIE was collected at baseline, nine and 18 months: selected clinical outcomes (days in delirium and falls), although systematic collection of this data across all implementation sites proved problematic (see below).

Ward structure and organisation

Physical environment

A description of the physical environment of each ward was constructed from observation.

Patient profile

A patient profile was created using a common pro-forma for all wards on an Excel spreadsheet. All patients on the ward and all new admissions during each data collection period were included. For each patient, we collected: demographic (age, gender, residence prior to admission), clinical (reason for admission, dementia diagnosis, probable dementia/memory problems, delirium) and service variables (date of admission and discharge, length of in-patient stay, discharge destination and re-admission within 30-days). We adopted a pragmatic approach to the problem of poorly diagnosed dementia[25] by classifying patients with a formal diagnosis and those assessed during their admission with probable dementia. In the report, we use 'dementia' to include both.

Collection of patient profile data required negotiation with Trusts and wards to facilitate completion, since it had to be provided in anonymised format and input by Trust staff. Researchers made strenuous efforts to ensure that the pro-forma was completed as fully and accurately as possible – a not in-considerable task, and some funding was provided to wards to support this. The resulting dataset provides a picture of variation in the patient journey between different ward types and across trusts from admission to discharge.

Staffing profile

As well as collecting information on staff mix and staffing complement, researchers noted actual staff numbers during observed shifts and whether these were permanent, temporary, Bank or agency. This provided a more accurate picture of the meaning of staff shortages and difficulties than simple reference to the designated staffing levels that should occur.

Care culture, staff knowledge and understanding of person-centred care

Care culture

The *Climate for Care Questionnaire*[28] comprised 38 items relating to staff views on: shared philosophy of ward care; adequacy of resources; mutual support; feeling safe; improving practice; involvement; developing skills; time pressures and team working. It was slightly modified to include core multi-disciplinary team members such as therapists and medical staff (Appendix 3).

All staff were asked to complete the questionnaire anonymously, responses were voluntary and returned (placed in a sealed envelope in a box file kept in a shared area where the researcher could collect them). Most returns were from nurses and healthcare assistants. Completion rates varied between wards with an overall response rate of just under 50% among nursing and care staff. It is difficult to be precise in that the calculation was based on staff complement; but the level of

vacancies carried by wards varied between wards and over time. We sought to maximise response using different methods (ward managers were asked to remind staff during handovers; ward clerks were approached to maintain the box for completed questionnaires in a prominent place (staff room or nurses station); and researchers gave out questionnaires to individual staff present during observation. It was notable that wards where fieldwork revealed poor staff morale had a low response rate. **[Total: 104 respondents]**

Interviews with ward staff

We conducted qualitative interviews, using a topic guide with a purposive sample of ward staff at different levels of seniority and discipline (e.g. medical, nursing, therapy and care staff) and different roles (ward clerk, housekeeping and domestic staff). The topic guide was employed as an aide memoire and interviewees were invited to discuss issues of importance to them. Conducted prior to PIE implementation, the purpose was to explore how staff understood the meaning of person-centred care for people with dementia and the factors from their perspective which affected care delivery. Interview times varied between 30 minutes and an hour; were subject to interruptions; often re-scheduled and resumed opportunistically in gaps between frenetic activity Interviews were audio recorded (with a few exceptions where staff declined) and fully transcribed. **[Total: 56 interviews].**

Collection of documents

These included trust strategies and performance; ward based assessment and care protocols for patients with cognitive impairment (dementia and delirium); treatment and care planning documentation; care pathways for dementia and delirium; policies and procedures.

Organisation of care, ward routines and practices

Ethnographic observation was employed to develop understanding of the pattern of ward activity and routines and how care for people with dementia was accomplished. This incorporated informant conversations with staff to clarify issues raised in the observation and to seek their perspective (albeit sensitive to staff's work demands).[82] It provided a richer account of what was happening including what people took for granted or were unable to articulate.

Each ward was visited by a researcher prior to fieldwork to acquire familiarity with the spatial environment and to develop an initial observational strategy: where to observe, when and the key actors involved. This provided opportunity for the researchers to acquaint staff with the study and to respond to any questions about it.

Observation occurred over approximately eight weeks in each of ten wards at baseline. Researchers covered a variety of shifts: early morning, afternoon and night; week-days and weekends; observed the daily pattern of work, regular routines (ward rounds, multidisciplinary meetings and handovers) and special events (staff away-days). Field notes captured descriptions of settings, events, interactions and activities. Contemporaneous jottings in the field were written up as expanded accounts as soon as possible after observation (observation sessions usually occurred over a three hour period to facilitate this). [83-85] A field note journal was maintained in chronological order. It included initiatives introduced at hospital or ward level relating to care of people with dementia or pertinent to the ward case study (for example, discussion and proposals around ward moves, staffing and hospital/trust performance. The researchers' impressions and reactions to interactions, activities and episodes were recorded separately since adopting such methods of reflexivity is an important quality check when undertaking such research.[85]

For general observation focus was on routine practice. Observational notes did not record names of individuals, only professional role/patient/visitor. Neither did the researcher engage in observations of one to one clinical encounters between staff and patients; in cubicles where clinical examinations were being carried out; in spaces deemed private, such as behind curtains, in toilets or bathrooms; or other spaces considered inappropriate by senior staff.

During observation, researchers were often asked for assistance by patients. Our approach was to respond to such requests by explaining the researcher's role and by alerting a staff member; except where the request involved normal courtesies (e.g. opening a carton of juice left on a tray or moving a drink closer to the patient, providing directions) and did not require medical or functional knowledge (as in providing assistance with standing or walking). This generally worked well.

Approximately 30 hours general observation occurred on each of ten wards at baseline (this varied somewhat with the size of the ward). **[Total: 295 hours]**

Further observation for the same duration and over the same time periods occurred at interim (four wards) and at follow-up (two wards) reflecting the stage to which PIE implementation was pursued. **[Total: 175 hours].**

Patient case studies

We intended to recruit up to six patients with a cognitive impairment on each ward, at each data point for in-depth study. The purpose was to explore patient's experience of care and their relatives or caregivers views about the care and their involvement in decision-making. Through conversations 'in the moment' with the patient during observation, we sought to include people with moderate to

severe impairment in ways which were meaningful and ethical as the method does not require verbal facility or ability to recall. This would also enable us to locate individuals' care experiences in the context of staff communication practices with them and the organisational, social and spatial environment of their ward. Additionally, we intended to conduct qualitative interviews with the patients' relative or caregiver, review medical and care notes, and observe multi-disciplinary meetings at which the person's care and discharge plan was discussed.

Early on it was evident that triangulation of data for patient case studies was very time consuming. Because of the length of time these patients spent on the ward and the depth and quality of data as a result of following patients to discharge, the research team proposed (and supported by HS&DR) to reduce the number of patient case studies, so as not to sacrifice depth for breadth of coverage. Purposive sampling was pursued to identify two patients at each site at each data point, selected as critical exemplars of those with dementia in acute wards. They included people unable to communicate verbally or perceived as challenging for staff to manage. Observation of selected patients enabled us to expand understanding of care routines that were not easily accessible through general observation but could be explored through the prism of individual patient journeys, for example, the often convoluted process of discharge planning. Each patient/case study involved five/six hour's additional focused observation. Appendix 4 provides pen pictures of two of them. **[31 patient case studies were completed: 156 hours observation and conversations 'in the moment'; 28 interviews with relatives].**

A summary of qualitative data by ward for different phases of data collection is presented in Appendix 5.

PIE Process Evaluation Methods

An embedded process evaluation[86] addressed the following research questions derived from NPT concepts, using a similar approach as we employed in two recent studies.[87,88]

- Were the strategies employed to engage staff (interactive workshops and manual) sufficient to engender a sense of purpose around the beliefs and values that inform person focused care for people with dementia (coherence)?
- Was the process for leading and implementing PIE (team and service improvement cycle) perceived as worthwhile and feasible to invest in to effect change in ward culture and practice (cognitive participation)?
- Was the work involved in pursuing PIE implementation (observation, action planning and review) conceived of as necessary and effective in engaging staff in implementing and sustaining change (collective action)?

- Did staff individually and collectively appraise PIE as worthwhile for themselves and their patients in benefits or outcomes achieved (appraisal)?

We utilised mixed methods to examine how delivery was achieved, what was actually delivered, the mechanisms of change and the effect of contextual factors on delivery.[89,90]

a) Observation of PIE action planning and review meetings to provide a contemporaneous account of the intervention: how it was activated, who was involved, problems encountered and solutions developed. Given the locally determined nature of the content (flexibility) within a systematic process, the question relating to fidelity is couched in terms of how precisely each step in implementation was pursued and proceeded to the next phase.[91]

b) Conversations/informant interviews with implementation team members to explore how the programme was understood and communicated to the wider ward team; how different programme components were implemented (tools and guidance); and whether they were perceived as necessary, sufficient and of value in facilitating change. These took place around three weekly intervals within full and partial implementation wards;

c) Collection and analysis of PIE documentation: observation, action planning and review tools to examine the content of the programme as enacted.

d) Staff narrative accounts of the process: through interviews with a sample of PIE team members at the conclusion of implementation to provide retrospective reflection on the process and impact of change. Additionally, we conducted interviews with individuals in sites that had not implemented PIE to explore implementation barriers **[29 Interviews with 37 staff].**

e) Events 'log': a contemporaneous 'events' log was maintained by researchers to capture change in policies, systems and procedures out with PIE implementation that might affect the change process and outcomes. This included initiatives undertaken by the Trust aimed at improving the care of people with dementia.

We had intended to organise two cross site workshops at interim and conclusion of implementation to compare experiences and the contextual factors influencing these. Because of the unevenness of PIE implementation and the wide geographical location of sites, this did not prove feasible. One cross-site meeting of staff in wards in two geographically distant hospitals within Seaford Trust occurred (Chapter five).

Impact of PIE

Ward staff practices

Ethnographic observation and interviews with staff (as above) were conducted at nine and 18 months where PIE implementation occurred.

Patient and relative/caregiver experience of care

Sources of data were ethnographic observation and patient case studies.

Clinical outcomes

We sought to collect quantitative data on delirium incidence and days in delirium; and falls at baseline and at 9 and 18 months. Delirium and falls are the commonest unintended adverse events affecting older people admitted to hospital. We hypothesised that the rate of falls and days in delirium would be affected by improvements in care practice.

Delirium is a common, serious and an unrecognised condition on acute wards;[13,36,92,93] dementia is a risk factor for delirium[36,94,95] and delirium accelerates cognitive decline.[96] Delirium incidence is associated with environmental (e.g. setting, lighting, sensory overload) and care related factors (e.g. fluid and nutritional intake, mobilisation, cognitive stimulation) which interact with patient vulnerability,[36,97] and is regarded as a critical marker of care quality.[36,97] Delirium incidence and occurrence is not routinely collected in hospital, in part reflecting poor knowledge of the condition.[93,97,98] In this study, we employed the validated Delirium Observation Screening (DOS) scale,[99] a 13-item scale developed to facilitate early recognition of delirium and based on the *Diagnostic and Statistical Manual-IV* criteria. It comprises a single sheet completed at least once daily by nurses as they attend to patients, with a score of >3 indicating delirium.

We negotiated for DOS to be incorporated into ward practice so as to prospectively collect information to monitor delirium rates and days spent with incident delirium. Although completion of DOS was reported to take less than one minute and therefore not resource-intensive, staff found it took considerably longer. It was not consistently collected; wards citing staffing difficulties. Several wards where staff were already sensitive to observational cues of 'acute confusion' and valued the information to inform practice (including both dementia wards) completed DOS . High delirium incidence and days in delirium on these wards did not (from observation) reflect poor care quality.

Regarding falls, evidence suggests a modest reduction in the falls rate with a multifaceted intervention in hospital settings.[100,101] The National Patient Safety Agency,[102] concluded that the

most useful measure of falls is the number per 1000 occupied bed days. Reported falls for patients admitted during each phase of data collection were recorded as one of the patient profile variables on the Excel datasheet and a calculation made of the rate of falls per 1000 occupied bed days. Unfortunately, there was considerable missing patient profile data, including falls for the two wards that successfully implemented PIE. Where such data was available, we have reported it. However, interpretation of the data is not straightforward. Risk factors for falls not only relate to the actions of ward staff, but there are also patient specific factors that give rise to variability in rates. Thus, risk increases with advanced age, presence of dementia, delirium and frailty so that ward patient profile will affect the falls rate.[103] Similarly, since hospital-related falls occur as a consequence of mobilising and recovering from illness, practices regarding the balance of risk, promoting rehabilitation and respecting autonomy, will also affect the falls rate.[103] Overall, data obtained on falls was patchy across sites. On both clinical outcome measures then, we were unsuccessful in securing reliable and consistent data for all wards. The attempt to do so has raised useful questions regarding feasibility, considered in Chapter six.

Service outcomes (length of stay, re-admissions within 30 days and discharge destination) were collected as part of the patient profile dataset.

Analysis

Qualitative data (interview transcripts and ethnographic field notes) were analysed using grounded theory methods;[104] including simultaneous data collection and analysis, constant comparison, search for negative cases and memo-writing. Descriptive and analytic codes were developed into higher order categories through processes of data reduction and re-assembly. Analysis was pursued firstly for each dataset (interviews, observations, patient case studies) within individual wards (the case study). We then compared analytic themes across these datasets, drawing out for example, similarities and differences between staff interviews and observation on understanding and practice of person-centred care. Through regular research team meetings the emerging data from individual case studies and reflections on them, were discussed. Similarities and differences between wards were drawn out, topics for more focused observation and ideas of analytic interest to pursue, identified. Hypotheses were generated to explore and account for variation between cases; these were tested out through cross case comparison and search for alternative explanations.

Regarding ward practices in respect of patients with dementia, we proceeded as follows. From initial observations, we focused on aspects of practice relating to the work of communication; routine care tasks; responses to different types of distress; the strategies adopted; and the attitudes and knowledge that informed them. For each case study, all incidents and episodes relating to this

work were mapped, alongside the environmental, organisational and interactional contexts in which they occurred; and the physical and emotional responses of patients. Through comparison between incidents and episodes captured in memos, we identified patterns of action and interaction. These patterns and what shaped them were refined through cross-case comparison. For example, the open code 'distress' was explored through perusal of all incidents and episodes pertaining to it. Through constant comparison, different forms of distress were identified which varied by how the distress was manifested, the perceived need giving rise to it, and the persistence of its expression. Staff responses were similarly coded and categorised based on the type of response and the context in which it occurred. The relationship between the varied forms of distress and the responses to them were interrogated to identify patterns, which were further refined through comparison between cases.

A similar analytic process was pursued in relation to PIE implementation. Qualitative data from interviews, workshop notes, observation of action planning and review meetings, and examination of completed documentation, were drawn together for each ward in chronological order. This provided a within case descriptive account of implementation over time; the nature of the engagement of staff with each step in the cycle and the barriers encountered, using NPT as a sensitising framework. Emphasis was on delineating the sequence of implementation steps over time and in context of events within the hospital and Trust; the conditions that impacted the temporal flow of action, and their consequences, whether persisting with or abandoning PIE. We then examined implementation processes through cross-case comparison to discern generalisable features that might account for variation. Analysis of qualitative data was conducted manually moving iteratively between the empirical data, sense making in relation to it and review of the literature.

Quantitative data was analysed using descriptive statistics.

Research Team

Three investigators conducted the case studies with academic support of the lead author (an experienced qualitative researcher and teacher in qualitative methods). The three attended a five-day module on the theory and practice of qualitative research at the University of Leeds which included ethnographic methods and analytic strategies. The four met regularly (at least monthly) to consider emerging findings and problems encountered. In between, telephone conversations and email discussions facilitated dialogue and mutual support, since observation made heavy demands on researchers practically and emotionally.   The wider research team, including the chief

investigator met bi-monthly to discuss progress. This was in addition to support and advice from the Programme Management Group.

Ethics

Ethical approval for the study was obtained from National Research Ethics Committee Yorkshire & The Humber Bradford (reference 12/YH/0442). The main ethical issues were: securing consent of patients to take part in specific ward observations, conversations and interviews especially those who might have dementia or delirium; and not seeking formal consent for general observations of ward routines.

Patient Consent

The consent procedures adhered to the Mental Capacity Act (2005) and accompanying Code of Practice. First, where an individual was identified by staff as having a cognitive impairment, we considered how best to approach the person, with advice from ward staff (for example, times when the person might be more alert, or when their relative was present). Second, the researcher explained the study in clear terms and ascertained whether the person understood the information. Third, if the person was deemed unable to make a decision about participation in the research, we sought a suitable personal consultee either with the patient or with a staff member (close relative or friend). Every effort was made to secure a suitable personal consultee, or in their absence, a nominated consultee to give patients without next of kin the opportunity to participate. If the consultee advised that a patient who lacked capacity would be willing to take part in the study then that person was included, providing that they showed no signs of unwillingness (for example becoming distressed, upset, or anxious in the presence of the researcher or when discussing the study). Consent was ongoing. The researchers checked that people were willing to continue and were sensitive to signs of distress, including verbal or nonverbal cues.

General ward observations

The decision not to seek research consent for the general observations of ward routines was carefully considered. As observations were unobtrusive, carried out in public or semi-public spaces, and did not identify individual staff, patients or visitors by name, we considered it would be impractical and likely more intrusive to seek formal written consent from all those present. Instead, e we sought informal, verbal consent. Prior to each observation, the researcher reported to a senior staff member and introduced themselves to staff not previously met at an opportune moment so as not to interfere with the work flow. At the end of each observation period, the researchers 'signed out' with the senior staff. Emphasis throughout was that observations were conducted with the full

knowledge, support and cooperation of ward staff. If anyone appeared unhappy, distressed or uncomfortable by our presence on a particular occasion, we did not include them in the observation. This happened rarely. There were several instances where a patient became annoyed with the researcher when she indicated that she was unable to help the person leave the ward and return home (call a taxi, get their coat). More often, when a patient was distressed and no staff member was available, the researcher sat with the person and sought to provide reassurance.

In the report, we have used pseudonyms throughout – Trusts, wards, staff, patients and caregivers – and have altered some biographical details to protect anonymity, privacy and confidentiality.

Patient and Public Involvement

There were several strands to our patient and public involvement strategy.

We involved our well-informed local Older Person's Group (approximately 15 people) with whom we have a longstanding relationship. This is a sub-group of a Forum established by the Local Authority that comprised approximately 300 retired local people who have been consulted on health and social policy issues. The sub-group has been acting as an advisory body in all aspects of our delirium and dementia research since July 2007. Three meetings of the group took place: at the beginning to inform data collection methods and contribute to the ethics application; following the conclusion of baseline data collection in the first two sites to reflect on the emerging findings and their implications for further data collection; and the third, to discuss issues around PIE implementation.

Two meetings were held with people with dementia of which one involved caregivers as well. One meeting occurred with people with dementia and/or memory problems (N=5). This 'Memoires' group is a long standing group of people who meet weekly for social leisure and arts based activities, organised by one of the locality based neighbourhood networks for older people in inner city Leeds. We held another meeting with people with dementia and their caregivers, hosted by another neighbourhood network in an outer suburb (N=34). In both, we discussed our emerging findings in relation to people's experiences of acute care (people with dementia and their relatives). These meetings were organised to include the voices of people with dementia in the study, especially as the cross site workshops did not happen.

Two caregivers of relatives with dementia recruited through the Alzheimer's Society research network were engaged as co-applicants and played a key role at all stages of the research. Our Steering Group also included a person with dementia and his caregiver both of whom participated in discussions about direction and progress.

CHAPTER 3

CASE STUDY PROFILES

Introduction

This chapter describes the structural, organisational and cultural context of the study wards prior to PIE installation. It also situates the ward within the wider hospital and Trust environment with specific focus on the policies in place, the priority attached to, and investment in, services for older people with dementia. At the same time, direction and resource deployment at Trust (and hospital) level is also shaped by national policy priorities, regulatory requirements and resource constraints. Interactions between these different levels create a fluid and dynamic environment for service delivery in wards and to patients.

National Policy Context: Dementia

When the study began in early 2013, the timing seemed propitious. National policy on improving care of people with dementia had been given impetus with publication of the Prime Ministers Challenge on Dementia.[9] This coalesced with other policy drivers: the report on the Francis Enquiry published in March 2013[105] on the failings in Mid Staffordshire hospitals, particularly around the care of frail, older patients; and the findings of the first National Audit of Dementia Care on acute wards.[25]

Interest in improving hospital care for patients with dementia was reflected across the five Trusts. All had in place or were in process of developing dementia strategies, although their content varied.

City NHS Trust

Organisation

City Trust is a long established Foundation Trust, being among the first wave to achieve foundation status. It provides services to a core population of around 500,000 and employs over 5,000 staff. Acute services are mainly located within a 900-bed hospital, with an 80-bed facility providing rehabilitation and outpatient provision from a separate site. It is a large, busy Trust with over 120,000 Accident and Emergency attendances annually. Situated in a region with post-industrial heritage and diverse culture, its diversity has contributed to increased demand on health and social care provision at both ends of the age spectrum.

Since attaining Foundation status, City Trust had generated an annual surplus. However Annual reports noted the challenge of securing improvements in quality and performance, managing reduced income growth, identifying efficiency savings and responding to the demands of a multi-ethnic population within one of the most deprived English local authorities.

Up until 2011, the Trust was assessed as meeting the performance targets set by the national regulator, Monitor. During 2012 and 2013, performance targets on waiting times for treatment were breached, resulting in review by the NHS Support Team, launch of a comprehensive Turnaround Programme, and a return to compliance in April 2013. In January 2014, the Care Quality Commission (CQC) issued a report on an unannounced inspection the previous October on the main hospital site and assessed that action was needed in several areas including respecting and involving people who use services and assessing and monitoring the quality of provision. A warning notice was issued on staffing because of staff vacancies carried. Strategic action centred on making improvements in problem areas, including recruitment of staff, for implementation during 2014. A CQC inspection in October 2014 assessed the Trust as 'requiring improvement'; medical care was 'good' at both hospital sites. A change in leadership at Board and senior management at this time created some organisational instability. This was the context in which strategic priorities around care of people with dementia were established.

Care of People with Dementia

A strategic Trust priority from 2011/12 was improving the physical environment for patients with dementia. City Trust was successful in securing external funding for this purpose, augmented by investment through its capital improvement programme. The design and execution of the changes on several older people's wards were described as 'exemplary' in the CQC 2014 Inspection Report. The 2013/14 Annual Report announced the extension of the improvement programme to the second hospital.

Since 2012, a rolling programme of 'Dementia Awareness' training tailored to different staff groups had been delivered jointly by the dementia lead within the Elderly Services Directorate and the Trust's Practice Development Lead. Both subsequently launched an initiative to recruit 'Dementia Champions'. The appointment of a Lead Nurse for Dementia in 2014 instigated a dementia strategy through formation of a multi-disciplinary Dementia Steering Group.

City Trust PIE Wards

Two wards took part in the study: a rehabilitation ward for older people located in the 80-bed hospital a distance from the main hospital site (Rivermead); and a trauma orthopaedic ward in the main hospital (Cedar).

Rivermead: Structure and Organisation of Care Delivery

Rivermead is a 'step-down' ward for rehabilitation. The hospital wherein it is located previously had more inpatient wards but now mainly comprises outpatient services and rehabilitation beds; acute services being centralised in the main hospital. Bed numbers fluctuate according to bed management demands, usually 27 during 'winter pressures' and 23 at other times.

Physical environment

At baseline and interim data collection, Rivermead comprised 27 beds (three side rooms and four six-bedded bays). Three bays contained a round table, large enough for four chairs. The fourth bay was less spacious, with a coffee table and two chairs. Outside 'winter pressures', a bed was removed from each bay, allowing more space around the table. It was common to see staff seated here, note-writing; patients rarely.

The physical environment was cramped. There was one very small office and one similar sized staff room. There was no designated space for activities with patients; corridors and bays comprised the only communal spaces.

Each bay was painted a different colour. There were pictures dotted around (local images of the city). Patient toilets had clear visual signage and braille. The toilet door frames were painted red as a visual cue. Staff were heard directing patients by telling them to head for the door with the red frame.

Patient profile

There were 123 admissions over seven weeks at baseline, of which eight were re-admissions (approximately 18 admissions per week). All had come from the main hospital following an acute episode. The median length of stay was 14 days (range 1-48). Table 1 provides a summary of patients' socio-demographic characteristics.

Table 1: Rivermead Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
65-69	1	1
70-74	-	-
75-79	17	14
80-84	32	26
85-89	38	31
90-94	30	24
95+	5	4
Gender:		
Men	28	22
Women	95	77
Residence prior to acute admission		
Own home	108	88
Extra-care housing	2	2
Intermediate care	1	1
Residential Care Home	2	2
Nursing Home	2	2
No information	8	6

More than half of patients were in advanced older age (85 years and older) and women dominated. Most had lived in their own home prior to the event that precipitated acute admission.

Over a third (n=44) had an ongoing cognitive impairment: 36 with a diagnosed dementia and eight assessed with probable dementia. Almost a fifth had delirium (n=24), of whom twelve had both delirium and dementia. Thus, just under half of patients (n=56) on this ward had a cognitive impairment on admission. Just over half of patients had delirium during their stay (n=64), although for most of them, the mean number of days in delirium was three (range one to 27 days). Only a quarter (n=32) were identified as having no cognitive impairment either on or during admission.

Reasons for admission are shown in Figure 2 although for most patients multiple factors, medical, functional and cognitive, were implicated.
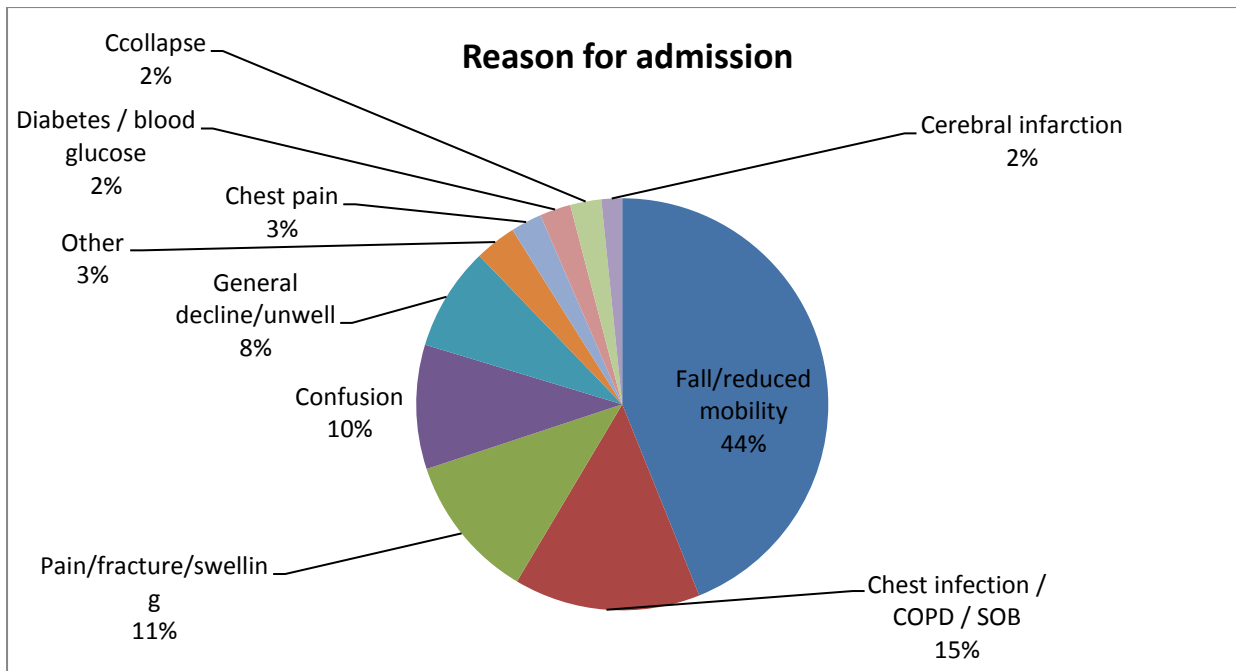
Figure 2: Rivermead: Reasons for admission

Further indication of patient's degree of frailty is discharge destination (Figure 3). 10% of patient discharges involved a new long term care admission; a further 10% were discharged to intermediate care for additional rehabilitation; 2% died in hospital.
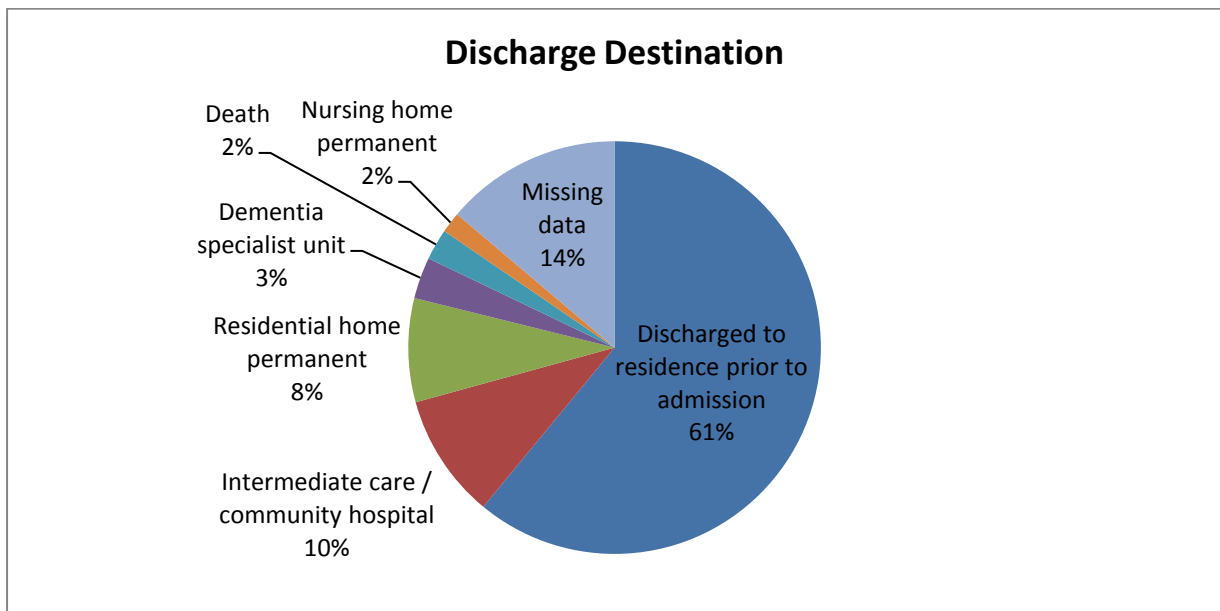
Figure 3: Rivermead: Discharge destination

Staff profile

The nursing/care staff complement was 30 FTE staff (25 in post). On the early shift (from 7am) there were three qualified nurses and four healthcare assistants (HCAs) [a ratio of registered staff to patients of 1:9]; late shift (from 1pm), three nurses and three HCAs; and night shift, two nurses and two HCAs. Staff numbers on each shift were achieved over the course of observation; when cover was short, it tended to involve the replacement of a nurse by a HCA. It was not uncommon for Bank or Agency staff to provide shift cover or to 'special' a patient on a one-to-one basis (typically a person who was agitated or distressed). The ward manager regularly provided direct patient care as and when needed.

Rivermead: Care Culture

At the start of fieldwork (February 2014), Rivermead had a stable ward leadership and purpose. The staff group had worked together for a long time (median four years and three months and up to 25 years among, those completing the Climate of Care questionnaire, n=15) reflecting the broader profile of a stable team.

Responses to the Climate of Care questionnaire indicated that staff shared an explicit philosophy of care and culture of caring, were respectful of each other's skills and knowledge and valued patient involvement in decision-making. The ward manager was viewed as someone who inspired confidence, consulted the team about daily problems, acted in a caring manner toward the team, was explicit about the care standards expected and set an example in hands-on care, actively coaching individuals. At ward level, staff felt supported and engaged, a picture reinforced from observation and interviews. The ward manager was a key driver in shaping the care culture: an experienced nurse and manager, she perceived her role in priority order as: "looking after my patients"; "looking after my staff" (emotionally, developing knowledge and skills, encouraging them to participate and further their career); and "as a manager" ensuring compliance with trust policies and procedures. She had undertaken advanced training in dementia and conveyed in values and practice a commitment to providing individualised care to patients.

There were mixed views regarding staff relationship vis-a-vis the Trust. The downside of being located at a distance from the main hospital site was poor communication and links with senior or specialist colleagues. There was a sense that colleagues in the main hospital lacked understanding of the ward's purpose (rehabilitation), had little appreciation of their particular skills and the complexity of the patients with whom they worked. Positively, they valued the sense of camaraderie engendered among staff in the smaller site and the greater autonomy and predictability of the work. External pressures on day-to-day-work were viewed as constraining their ability to deliver the

quality of care they aspired to provide. Among some staff, lack of time to reflect on ways to improve care delivery, was a source of stress. As the bridge between the hospital and ward, senior staff, particularly the manager, sought to contain the tension between the priorities and requirements of the Trust and their espoused values on providing individualised care and supporting staff. This, along with their physical separation from the main hospital meant that the 'troubles' of the Trust around meeting performance targets and the changes at Trust and senior management team level, were less salient for the ward team. Further, stability of the staff team meant that although there was recourse to Bank and agency staff to cover some shifts, hospital staff vacancy levels had less impact on Rivermead than on other wards with an unstable staff group.

Cedar: Structure and Organisation of Care Delivery

This orthopaedic trauma ward had moved to a temporary location at the end of 2013 and there was uncertainty surrounding its future purpose. Subsequently, following bed closures and ward re-modelling, a new ward was created involving half the beds on a former older people's ward and half for older trauma patients. This ward came into existence in August 2014 and agreed to participate in the study, with fieldwork commencing in September 2014. Given their late entry into the research, it was agreed that PIE implementation would occur over nine months rather than 18 months as originally envisaged.

Of the 28 beds on this ward, 14 were for patients aged 60+ years with fractured neck of femur, the remainder were for older, medical patients.

Physical environment

Physically, the ward was vast and modern in design, comprising one long corridor, 12 side rooms and four, four-bedded bays (three female, one male). Each bay had a TV, two large windows, and a notes trolley. All patients had a whiteboard above their bed, with their name. It was not possible to see into the bays without physically entering them. There was a room for relatives, two meeting rooms, and a Sisters office, but no day room.

The ward had been renovated using similar design principles as the 'healing environment' wards elsewhere in the hospital. The corridor was decorated in pleasant colours, including images of generic scenery, and with two, three-seater chairs opposite a television. It was usual to see staff and patients seated here (staff writing; patients watching TV or ward activity). Toilets had clear signage (male/female cartoon/silhouette) and surrounding walls were painted red as a visual cue. Information boards were placed around the ward, including boards about delirium and dementia.

Patient profile

During baseline there were 190 admissions to Cedar over seven weeks, of which four were re-admissions (approximately 27 per week). The median length of stay was seven days (range 1-47), facilitated by access to 'step-down' beds (Rivermead or similar). Table 2 provides a summary of patients' socio-demographic characteristics.

Table 2: Cedar Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
29-64	14	7
65-69	5	3
70-74	15	8
75-79	25	13
80-84	47	25
85-89	49	26
90-94	27	14
95+	8	4
Gender:		
Men	77	41
Women	113	59
Residence prior to acute admission		
Own home	58	31
Residential Care Home	4	2
Nursing Home	10	5
No information	118	62

Just under half of patients were in advanced older age (44% were 85 years and older). The majority for whom data was available had lived in their own home prior to hospital admission.

On admission, at least one third (n=62, missing data n=96) had an ongoing cognitive impairment: 41 with a diagnosed dementia and 21 assessed with probable dementia; eight patients were identified with delirium, of whom seven also had dementia) (missing data n=120). For those patients for whom data was available (approximately half, n=94), just over half (n=50) had a cognitive impairment on admission. Of the data collected on delirium during admission (missing data n=157) 18 patients had delirium (median days in delirium was three; range 1-12).

Reasons for admission to Cedar are shown in Figure 4. The pattern reveals a more acute profile compared to Rivermead; also suggested by the relatively high proportion of patients who died during their admission (15%).

Reason for admission

Diabetes / blood glucose 2%
Bowels/constipation /diahorrea 2%
Collapse 2%
Confusion 2%
Cellulitis 2%
Chest pain 2%
Wound 2%
UTI 3%
Acute renal failure 4%
General decline/unwell 4%
Missing data 6%
Chest infection / COPD / SOB 14%
Other 20%
Fall/Fracture / Reduced mobility 35%
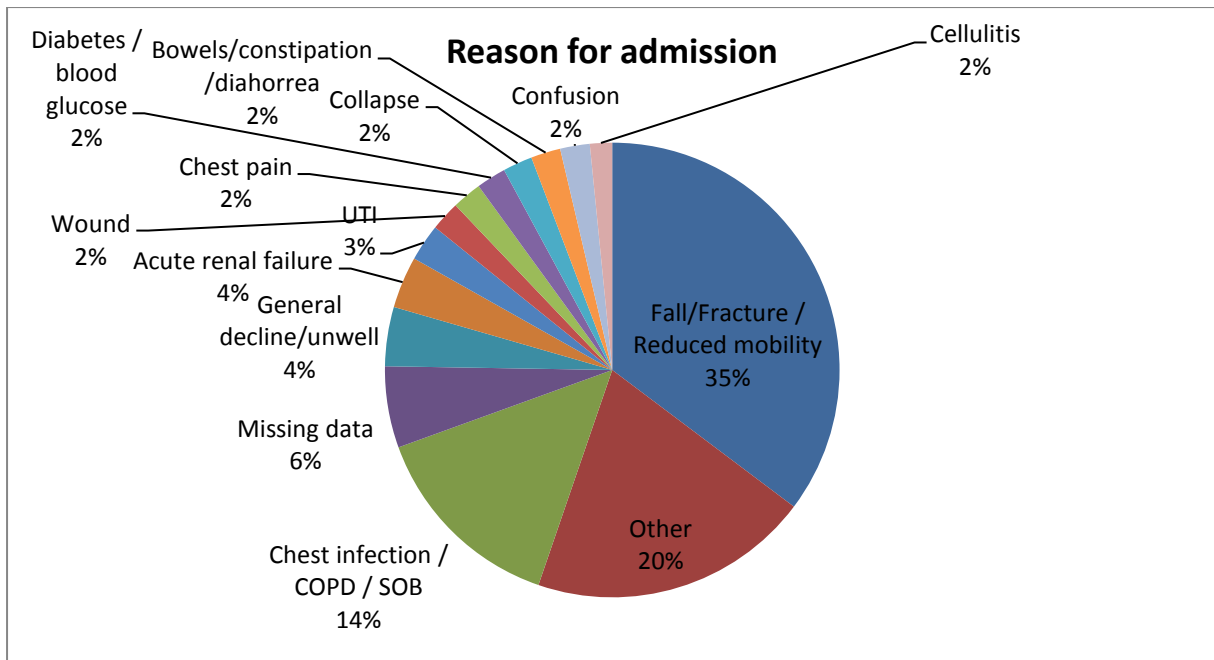
Figure 4: Cedar: Reasons for admission

Discharge destination (Figure 5) reflected the fact that a significant minority of patients from this ward were discharged to the 'step-down' ward when medically stable but still insufficiently recovered to return to their usual residence. The symbiotic relationship between the acute older peoples' wards and rehabilitation wards like Rivermead contributed to the very short length of stay on Cedar: the 'step-down' wards providing additional therapy for patients deemed not safe to be discharged.

Discharge destination

Temporary residence 0%
Other NHS 8%
Missing data 15%
To usual residence 62%
Death 15%
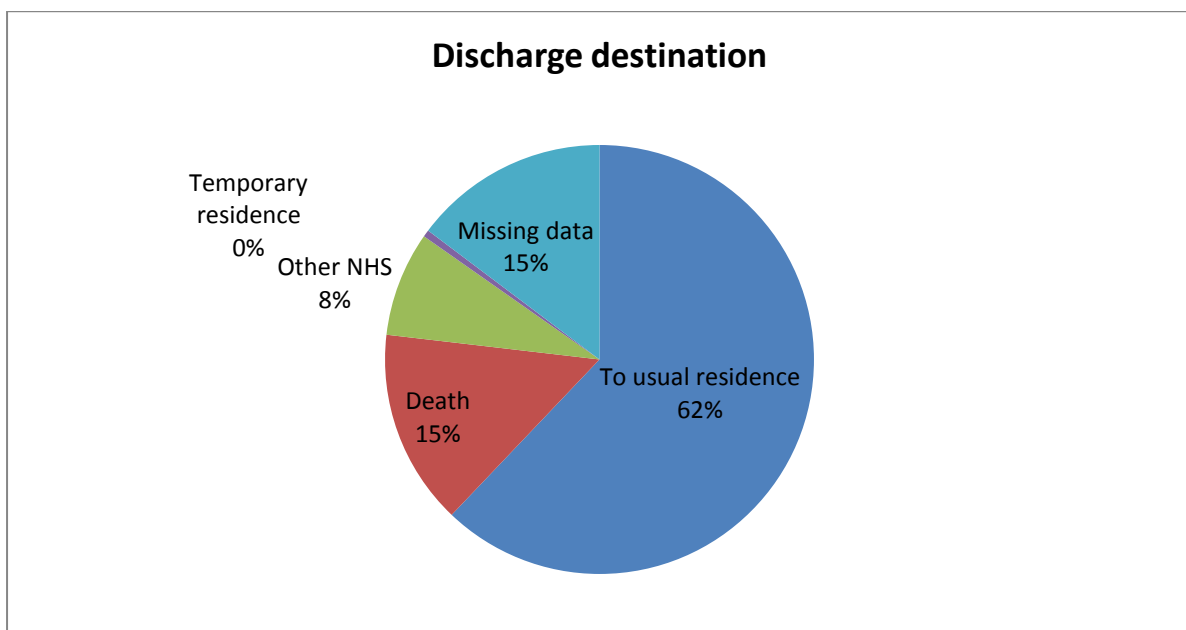
Figure 5: Cedar : Discharge destination

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Staff profile

The ward team comprised 35 FTE staff. Staff complement on the early shift (from 7am) was five qualified nurses and three healthcare assistants (HCAs) [ratio registered staff to patients 1:5.6]; on the late shift (from 1pm), four nurses and three HCAs; and at night, two nurses and three HCAs. In three-quarters of shifts observed the actual numbers of staff were consistent with intended staffing. This was achieved by having one fewer qualified and one additional HCA or by using Bank or agency staff; a quarter of observed shifts were down by one staff member.

Cedar: Care Culture

The ward manager had spent most of her working life nursing older people and like her colleague on Rivermead was an experienced ward manager. Although a number of team members had come with her from a care of older people's ward, melding a staff group into a team with a dual focus on complex medical conditions and orthopaedic trauma was still a work in progress when fieldwork commenced. The level of patient dependency was regarded as high, and the physical demands of providing care weighed heavily on staff as many patients required assistance of two people with personal care.

In interviews, the ward manager conveyed a strong ethos of individualised care, tempered with an acknowledgement of the reality of the multiple and simultaneous demands on staff. The work of a ward manager was presented as balancing different and competing interests: meeting hospital targets regarding flow and spending time with patients; reducing falls risk and undertaking rehabilitation work toward functional improvement.

From their responses to the Culture of Care questionnaire (N=14) staff echoed the priority their manager attached to individualised care, treating patients with dignity; putting effort into providing good quality care; meeting patients' care needs; and involving patients and caregivers in decision-making. They valued the skills, competence and support of colleagues; having trust and confidence in each other; communicating and working well within the multi-disciplinary team; and feeling able to bring up issues and challenge practice. The manager was perceived as inspiring confidence, consulting with the team about daily problems; acting in a caring manner toward staff; being explicit about the care standards expected; and setting an example in hands-on care.

Similar to colleagues on Rivermead, they perceived a gap between their aspiration to provide individualised care and inadequate support and resources to spend time with patients and develop new skills. In comparison with Rivermead staff, they were less critical of the resources available to them at hospital level, particularly valuing access to expertise on aspects of care. This likely

reflected their physical proximity on the main hospital site, being closer to decision-making structures. For senior ward staff, particularly the manager, hospital priorities on patient flow, reducing length of stay and cutting beds imposed a heavy burden, being closer to the everyday impact of these pressures.

Valley NHS Trust

Organisation

Valley NHS Foundation Trust provides acute, rehabilitation and community services in hospital and community settings for a geographically dispersed rural and urban population of over 200,000. It covers an area of over 700 square miles in North West England and acquired foundation status in 2010.

When the study began, the main hospital had 395 beds for acute, elective and specialist care and some 55,000 Accident and Emergency attendances annually. It had a strong local presence and community connection reflected in its large volunteer base; around 400 volunteers carrying out over 30 different roles across wards and departments. The Trust also managed three community hospitals in different locations across its wide area.

Annual Reports between 2010/2011 and 2013/14 revealed an organisation consistently meeting national targets on finance and governance, clinical safety and effectiveness and which had been operating with a relatively stable Trust leadership. Similar to City Trust, it had invested heavily in modernisation of its built environment, including improving the ward physical environment..

As with other study Trusts, NHS re-organisation posed considerable uncertainty for forward planning. Simultaneously with organisational upheaval, also noted were the challenges of delivering safe, quality care, managing a 3%-5% year on year increase in volume demand on services alongside the requirement on providers to find efficiencies of 4 to 5% per annum to absorb the growth within a fixed overall real-terms budget. The dual strategy pursued in meeting these competing demands was to cut costs and develop new services to grow income.

Care of People with Dementia

Local strategic priorities included reducing 'slips, trips and falls', viewed as a particular risk for people with dementia. Initiatives included: the development of a system to more accurately monitor falls; introducing screening, assessment and evaluation tools to improve risk management processes; purchase of monitoring equipment to reduce falls incidence; floor level beds for patients at high risk of falling out of bed; and including falls prevention and bed rail use in mandatory training.

For people with dementia, priorities were improving nutritional care, and implementing the 'Butterfly Scheme'. The former involved the expansion of an established 'feeding buddy' system with trained volunteers to assist vulnerable patients to eat and drink. The 'Butterfly Scheme', introduced in 2011, highlighted the needs of patients with a dementia diagnosis with a butterfly symbol; provided staff with practical guidance to meet their needs; alerted staff to the collection and use of information from relatives to better engage with these patients and to inform care planning. The scheme was supported through mandatory training for clinical and support staff directly providing care.

Increasing staff awareness of dementia was prioritised through a programme of 'Dementia Champions'; and the creation of more 'dementia friendly' environments was pursued through ward refurbishment in 2013/14 supported through external funding.

Valley Trust PIE Wards

Two hospital wards participated in the study: acute trauma (Oak) and care of older people (Ambridge). Both had benefited from funding to improve the ward environment, completed on Oak prior to fieldwork commencing. During most of baseline, Ambridge was in a temporary location because of refurbishment; moving into its permanent space in the final weeks. The moves created environmental disruption and upheaval for staff and patients.

Oak: Structure and Organisation of Care Delivery

This was a 28-bed, acute orthopaedic trauma ward. Around 30 months prior to the study, there was a change in medical leadership: ortho-geriatric consultants were introduced alongside orthopaedic surgeons to provide comprehensive geriatric assessment and care planning for older patients. This involved separate multi-disciplinary team meetings on a twice weekly basis.

Physical environment

Oak ward was organised as six four-bed bays (12 male, 12 female) and five single rooms (two male, two female). Male and female bays were located along corridors at right angles to each other, with a small work station in the space between. The waist high walls bordering the work station desk created a sense of an open space around this working area. There was a separate day room and relatives' room, staff room, and office for the Ward Manager and Senior Orthopaedic Nurse. The decor was bright with good natural light; feature walls in each bay were painted in different colours and there were clocks in each bay displaying time and date.

Patient profile

There were 174 admissions during baseline, of which one was a re-admission. This was a mixed aged profile (range 16 to 101 years). There were two distinct admission patterns: younger people with limb fractures typically from motoring accidents; and those in advanced older age with fractured neck of femur and co-morbid chronic health problems. The median length of stay was nine days (range 1-78). Table 3 provides a summary of patients' socio-demographic characteristics.

Table 3: Oak Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
Under 40 years	23	13
40-49	16	9
50-64	21	12
65-69	5	3
70-74	5	3
75-79	24	13
80-84	23	13
85-89	35	20
90-94	19	11
95+	3	2
Gender:		
Men	77	44
Women	97	56
Residence prior to acute admission		
Own home	148	85
Residential Care Home	4	2
Nursing Home	19	11
Dementia Unit	1	0.5
No information	2	1

Whereas around a quarter of patients overall had a diagnosis of dementia or were assessed having probable dementia on admission, this applied to 40% of those 80 years and over. Further, 9% had a delirium on admission, the majority of whom (11/15) had delirium on dementia. Most people were admitted from their own home; 13% were residents in a nursing or residential care home. Just over a third of older people (65 years and over) had delirium during their in-patient stay (36%); and median days in delirium was four (range 1-28).

Reasons for admission to Oak ward are shown in Figure 6. Given the nature of the ward, admissions were dominated by orthopaedic trauma; among older people, the largest single reason was a fractured hip.

Reason for admission

- Missing data 13%
- Pain (back, hip, leg) 8%
- Other-non orthopaedic 9%
- Other orthopaedic 9%
- Fall/Fracture/hip replacement 61%
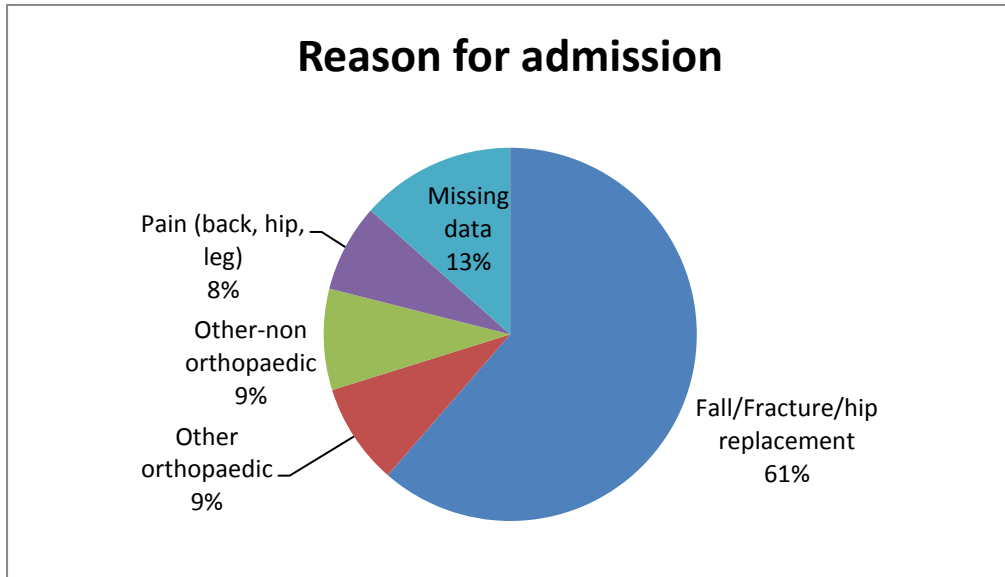
Figure 6: Oak: Reasons for Admission

Patient destination on discharge is shown in Figure 7. 5% died in hospital and of the rest, 9% went to a new permanent nursing or residential care home (although this applied to just under a fifth of older patients).

Discharge destination

- No information on discharge 6%
- Residential care home 2%
- Nursing home 7%
- Died 5%
- Own home to Intermediate Care 0%
- Returned to own home 80%
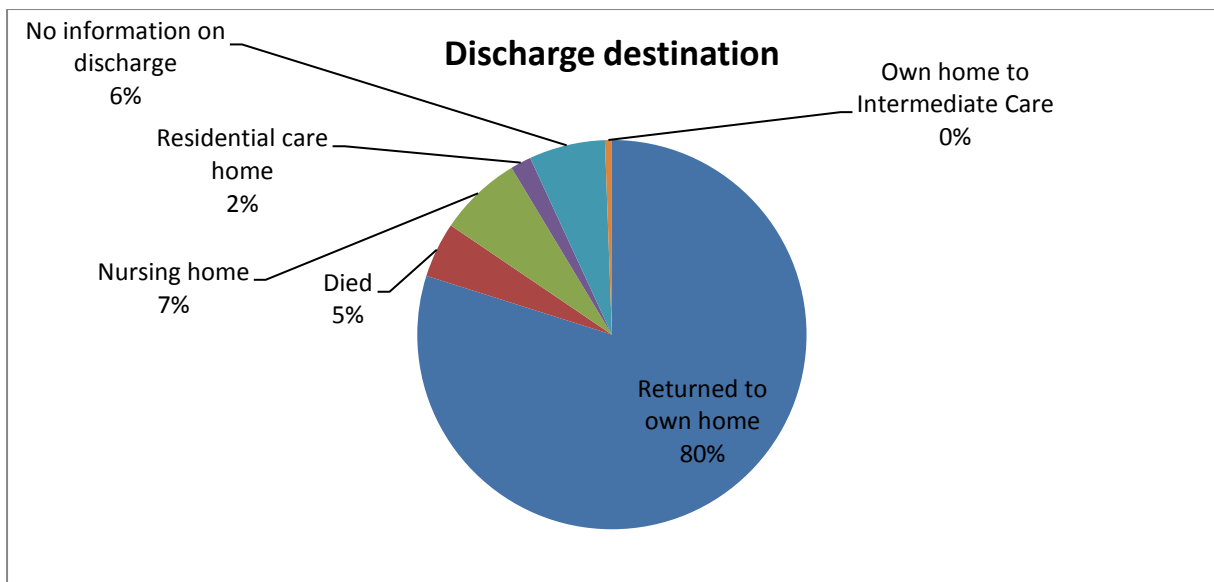
Figure 7: Oak: Discharge destination

Staff profile

The ward complement comprised 33 FTE staff. Typically, this was organised as: three qualified nurses and four HCAs on the early shift [ratio 1:9.3 registered staff to patients]; three qualified nurses and four HCAs on the late shift: and at night: two qualified nurses and three HCAs. Additionally, a specialist orthopaedic nurse practitioner working across A&E and the ward provided expertise and support during the day Monday to Friday; and the ward manager was a visible presence providing hands on care when required. Even so, during most of baseline fieldwork, the ward was considerably short-staffed as a consequence of sickness, vacancies and secondments. This resulted in considerable daily work for the manager/senior sister to secure cover either by cajoling existing staff to do additional shifts or using Bank staff (Bank staff comprised nearly a third of staff during most observed shifts).

Oak: Care Culture

During baseline (end November 2013 to early February 2014) the ward team was undergoing change. Until then, it had been relatively stable with a strong, supportive, team ethos. The manager had been in post for six years, first as a junior sister and then as manager; and many of the nursing and care staff had worked together for five years or more. However, several nurses had left or were in process of leaving when fieldwork commenced; difficulties and delays in recruiting new staff resulted in use of temporary staff, impacting on workload and ward morale.

The manager placed high value on supporting her staff considering that a 'stressed' staff member affected everyone, colleagues and patients. Observation revealed a leader who was a visible and cheerful presence on the ward and who conveyed to staff that their work was appreciated. Delivering 'quality care' was seen to require attention on patients emotional as well as their physical and care needs; further; spending time with patients was conveyed as a necessary and valued part of nursing and care work. Current staffing difficulties were regarded as compromising realisation of this vision. In her interview, she envisaged that an aspect of her role as manager was to absorb pressures from senior management so as to sustain a calm and 'happy' care environment. This conception of the ward leader as buffer between the demands of senior management and the day to day work of providing direct patient care was felt as isolating and stressful.

The change in the staff team was evident among those completing the Climate for Care questionnaire (n=14). Respondents were equally divided between those who had worked on the ward for between one and six months and those who had been there for five years and upwards. Staff reported that they shared an explicit philosophy of care; that there existed a culture of caring for patients; that the psychological aspects of care were highly valued, as was the involvement of

patients and their caregivers. They were generally negative about the adequacy of support services to enable them to spend time with patients and also considered that there was insufficient staff with the knowledge and skills to provide quality patient care. This was felt across the board: both among long-standing staff members and those who had been six months or less in post.

Respondents considered that the quality of care provided by the multi-disciplinary team met patients' individualised needs and was responsive to the needs of caregivers; staff were viewed as treating patients with dignity and respect; there was good communication between team members; people worked well together and were supportive of each other. The general view was that there was insufficient time to reflect on performance and ways of improving care delivery. This view was supported by observation: staff members were in continuous motion, a combination of the physical demands of patients who were immobile and staff shortages.   External pressures acted as a constraint on delivering the quality of care they aspired to deliver. The team viewed the ward manager as supportive, a visible presence and role model in delivering hands on care. In contrast, their perception of the hospital management was negative – considering that staff views were not listened or responded to, and that support for staff at ward level when needed was not forthcoming.

Ambridge: Structure and Organisation of Care Delivery

Ambridge was a 30-bed care of older people ward, although bed numbers were reduced to 29 during baseline, because of staffing shortages. It was designated for patients with 'acute and complex needs'.

Physical environment

The layout of Ambridge was similar to Oak ward with male and female bays located on corridors at right angles to each other. Along each corridor, there were three four-bedded bays and three single rooms with separate patient toilets and bathroom. One side room on each corridor was ensuite. There were some concessions to the creation of a 'dementia friendly' physical environment, for example toilet signage. However the flooring was shiny in places, there was little natural light, and the decor was worn and tired. There was a large nurses' station in a box shape between the corridors, such that the bays were not observable from this location.

There was a designated day room (labelled 'patient lounge' on a small notice on the door). The space had multi-functional uses: a place for multi-disciplinary team meetings; for staff to do paperwork; for visitors to wait while staff they had come to see was receiving medical or personal care; and occasionally where a patient might sit alone, watch TV or converse with a visitor. A monochrome, functional space with unforgiving florescent lighting, its size offered potential for patients to sit around one of three tables near the window or in the lounge area which had seating

for nine and where the TV was located. However, the room had the appearance of a storage area. It was generally full of stacked chairs; and Zimmer frames, two hoists and physiotherapy equipment blocked access to the small bookshelf and its stack of books. This was the environment in which care delivery as observed occurred; typical of old-style wards in hospitals dating from the 1960s.

Patient profile

There were 171 admissions to Ambridge over nine weeks (around 17 per week); of which two were re-admissions. (Baseline fieldwork extended a further two weeks here compared to other sites to take account of the disruption of the move to the new space). The median length of stay was eleven days (range 1-89). Table 4 describes the patient profile.

Table 4: Ambridge Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
65-69	1	1
70-74	6	3
75-79	18	10
80-84	51	30
85-89	50	29
90-94	37	22
95+	8	5
Gender:		
Men	80	47
Women	90	53
No information	1	-
Residence prior to acute admission		
Own home	144	84
Residential Care Home	19	11
Nursing Home	7	4
Intermediate Care	1	-

Over half the patients were in advanced older age (56% were 85 years and older). A quarter had a diagnosis of, or probable dementia. From fieldwork (handover, MDT meetings and observation), this appeared an under-estimate and inconsistent with findings from other care of older people study wards. Just under a fifth (30) had delirium on admission, of whom most (21/30) had a delirium on dementia. Data on delirium incidence was not collected.

Reasons for admission to Ambridge ward are shown on Figure 8.

Reason for admission

Cardiac/AF 6%
Stroke/TIA 4%
Sepsis 3%
Abnormal blood result 1%
Confusion 6%
Bowels/constipation/diahorrea 2%
Collapse 5%
UTI, urinary retention 13%
General decline/unwell 5%
Missing data 2%
Chest infection / COPD / SOB 19%
Other 12%
Fall/Fracture / Reduced mobility 20%
Acute kidney injury 2%
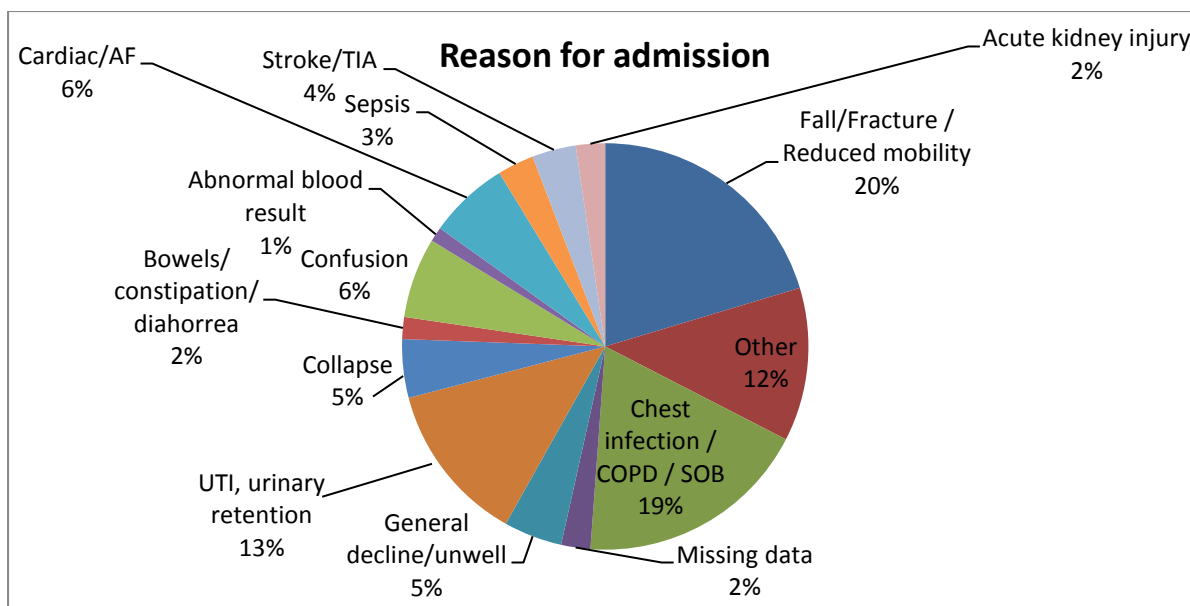
Figure 8: Ambridge: Reasons for admission

Discharge destination is shown in Figure 9. Two-thirds of patients returned to their own homes on discharge, a smaller proportion than Oak, reflecting a higher number who died during admission (9%) and a higher proportion of new admissions to long term care (13%) or to hospice/palliative care (2%).

Discharge destination

Hospice/palliative care 2%
Residential care 5%
Nursing home 8%
Intermediate care 3%
No information 5%
Died 9%
Own home 68%
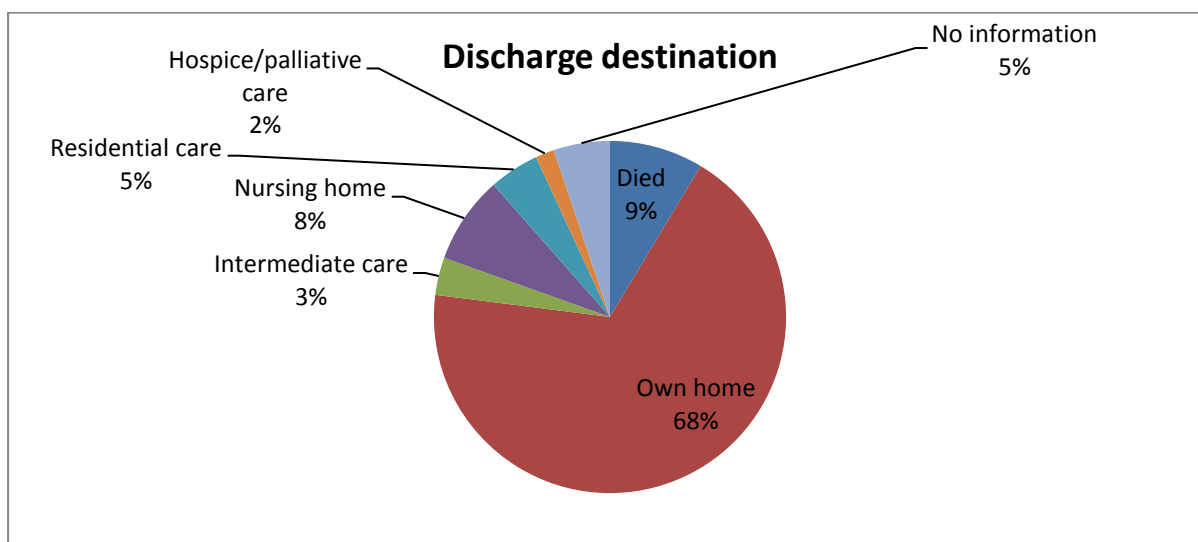
Figure 9: Ambridge: Discharge destination

Staff profile

Staffing complement was 33. On the early shift this was four qualified nurses and four HCAs [a ratio of registered staff to patients of 1: 7.2]; three nurses and four HCAs on the late shift; and two nurses and three HCAs at night. Thus, for a slightly larger bed base than Cedar ward in City Trust, there was a smaller staff complement numerically and in proportion of registered to care staff. Although most

shifts had the requisite numbers of staff, observed shifts indicated at least one and often two or more Bank or agency staff. Shortly, before fieldwork began, one of two senior sisters had left to manage the newly opened 'winter pressures' ward and a staff nurse had been promoted to junior sister. During a substantial period of fieldwork, both the remaining senior sister and the ward manager were on sick leave and the ward was managed by the junior sister, without additional senior staff support.

Ambridge: Care Culture

Similar to Oak, Ambridge was a ward in transition. This had a spatial dimension: being parked in a temporary location awaiting the move to its permanent, refurbished home; and a staff dimension: change in ward leadership and departure of experienced staff. Both contributed to disruption.

During most of baseline, the junior sister managed the ward. An experienced nurse, this was her first management post. She expressed strong commitment to providing care that treated 'people as individuals' and therefore placed store on finding out their concerns and wishes, including people unable to communicate through language. The combination of few experienced staff on the team, others in post only a short time, and reliance on temporary staff to cover shortages, exacerbated the difficulty in creating and sustaining a coherent ward culture. While some on the ward had chosen to work with older people and had knowledge and understanding of dementia, others had not.

There were only four respondents to the Culture of Care questionnaire, two had worked on the ward for 12 and 10 years; and the others for five and six months. Their responses echoed views of staff from informant conversations during observations and formal interviews. They conveyed common values: placing emphasis on caring for, and supporting patients, and seeing the involvement of patients and caregivers as important. Yet, they considered that there was an absence of resources and support to spend time with patients; insufficient staff to provide quality care; and as a team, did not review how to improve care delivery. Although supportive of each other, they reported inability to challenge poor practice or to raise difficult issues with colleagues. They were most negative about the hospital; perceiving that their concerns and opinions were neither listened nor responded to, and assistance was not available when needed.

Ironbridge NHS Trust

Organisation

Ironbridge Trust, similar to City, is a long established foundation trust. It provides acute, elective, specialist and some community services to a core population of around 650,000. Location of a major

trauma centre, it has over 150,000 Accident and Emergency attendances annually. With around 2000 in-patient beds and employing some 16,000 staff it is one of the largest trusts in the country and one of the biggest local employers.

Annual Trust Reports between 2010/11 and 2013/14 presented an organisation that in leadership, efficiency, safety and caring, was successful and consistently meeting national and local targets. Similar to other study Trusts, it presented as being challenged by the multiple and competing political, organisational, performance, financial and regulatory demands.

A major transformation in service delivery was initiated by the integration of adult community and acute services from spring 2011. A further integrative step from autumn 2014 involved combining the Directorate of Geriatric and Stroke Medicine (GSM) and the Primary and Community Services Care Group; a union with direct impact on our study ward.

Care of People with Dementia

From 2011/12, Trust strategic priorities included improving the care of people with dementia; and creating 'dementia friendly' physical environments on care of older people's wards.

In 2011, a new ward dedicated for older patients with dementia undergoing hip fracture surgery was established; and in 2012, an integrated multi professional care pathway for patients with both dementia and delirium was implemented, supported by training. A discreet symbol was developed (as in Valley wards) to enable staff recognise people with dementia; aligned with a personal information booklet, 'All about Me,' launched in spring 2014, for use by patients with confusion/ dementia and their caregivers.

Ironbridge PIE Wards

Two Ironbridge wards initially expressed interest in participating in PIE: a trauma orthopaedic ward and an acute, dementia ward; both meeting our 'readiness' criteria. Prior to fieldwork commencing in January 2014, the trauma ward withdrew, citing staffing difficulties. Efforts to engage another ward were unsuccessful.

Netherton: Structure and Organisation of Care Delivery

Netherton is an acute medical ward for those aged 70 years and over with co-morbid dementia or delirium/acute confusion. It was not a specialist dementia ward:[59] it did not employ specialist mental health staff; therapy input was similar to other care of older people wards; and it had no additional staff providing activities. During baseline, Netherton comprised 28 beds (including one bed for 'winter pressures', consistently in use during fieldwork).

Physical environment

Netherton was organised in four six-bedded bays and four single rooms; three female and one male bay. Bays were colour coded (purple, yellow, blue and green). Each had a small table near a window at which staff sometimes sat to write. Single rooms were relatively spacious and pleasant with natural daylight.

The ward presented as a bright, airy, clean and open environment. Each bay was separated by a low divider (work surface, no doors), opening on to a wide corridor with a large skylight, exuding a sense of spaciousness and allowing ample daylight. There was a very small work station down the entrance corridor with space for a single computer. There was a table with space for four to six people to sit in the corridor (which patients and staff did, interchangeably).

Off the bays (opposite the work station) was a large L-shaped day room with a separate door and half height windows overlooking the hospital grounds. Painted in neutral colours, it comprised of three tables with ample seating for dining and socialising. At the far end was a lounge space with chairs and TV (there were no TVs in bays). Various reminiscence/household objects were laid on side tables (an old-style radio, alarm clock and games); on the walls were old brand adverts and pictures of the locality. A small enclosed room off this served as a private space with settee, chair, lamp and bookshelf. It was slightly shabby, but homely in appearance.

Off the corridors to the left and right of the central ward space, and opposite the bays, were the patient toilets: with visible signage; toilet seats and rails which were dark blue, contrasting with the otherwise white suites. For patients who were mobile, their location afforded opportunity to walk between bed and toilet. Further along the corridor was a shower room and single rooms; leading to a designated staff space (toilet, with key access and a small room). There was an atmosphere of calmness and quiet efficiency, with staff and patients sharing communal spaces.

Patient profile

There were 75 admissions during baseline (average 8 per week); and no re-admissions. Most came directly from A&E or the Assessment Unit (70%; 52/75); just under a third were admitted from other hospital wards. The median length of stay was 41 days (range1-126 days); extended lengths of stay being attributed to changes in the system for financially assessing patients, resulting in delays to some discharges. Table 5 summarises patients' socio-demographic profile.

Table 5: Netherton Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
60-64	1	-
65-69	-	-
70-74	3	4
75-79	9	12
80-84	14	19
85-89	30	40
90-94	16	21
95+	2	2
Gender:		
Men	18	23
Women	57	76
Residence prior to acute admission		
Own home (including sheltered housing)	66	88
Residential Care Home	3	4
Nursing Home	5	6
Assisted Living	1	1

Just under two-thirds were in advanced older age, a slightly older profile than for other participating trusts, and women dominated. Most were admitted from their own home.

Most (70; 93%) had dementia (the remaining patients had delirium but not dementia). Nearly two thirds (60%; 31/52) of new acute admissions had delirium. Overall, 70% (54/75) had delirium during their stay, of whom 9 (13%) were in delirium for 30 days or more. Median days in delirium was 16 (range 1-57). Reasons for admission are shown in Figure 10.
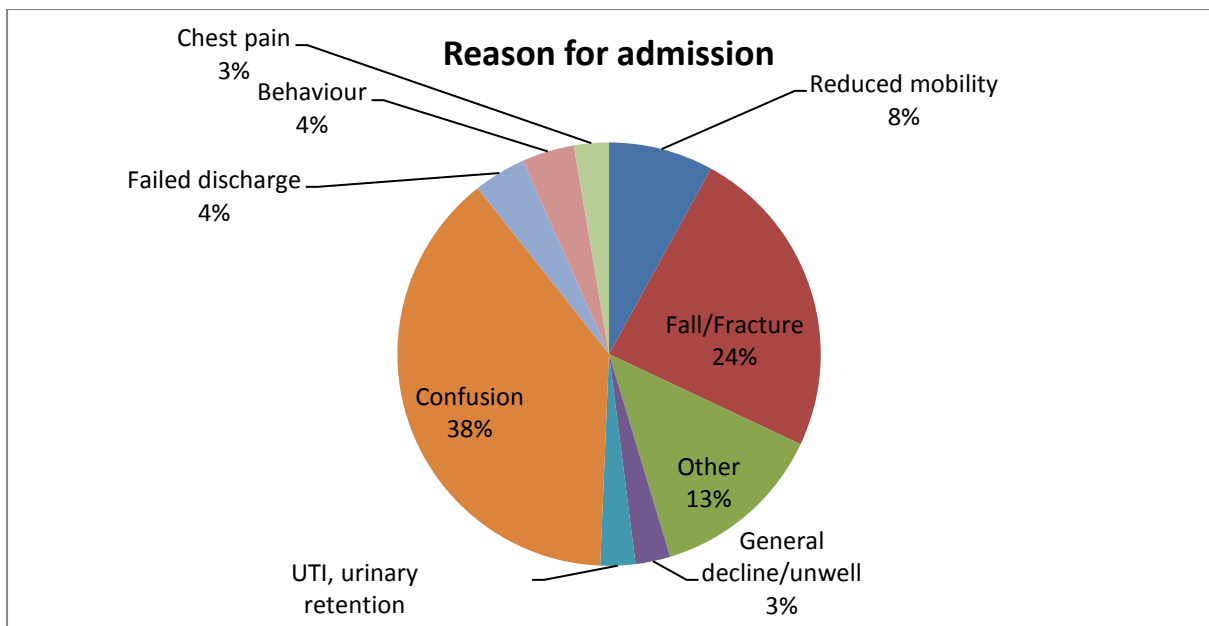
Figure 10: Netherton: Reasons for admission

Discharge destination data was available for 44 patients (the remaining 25 still being in the ward at data collection end). This is presented in Figure 11.
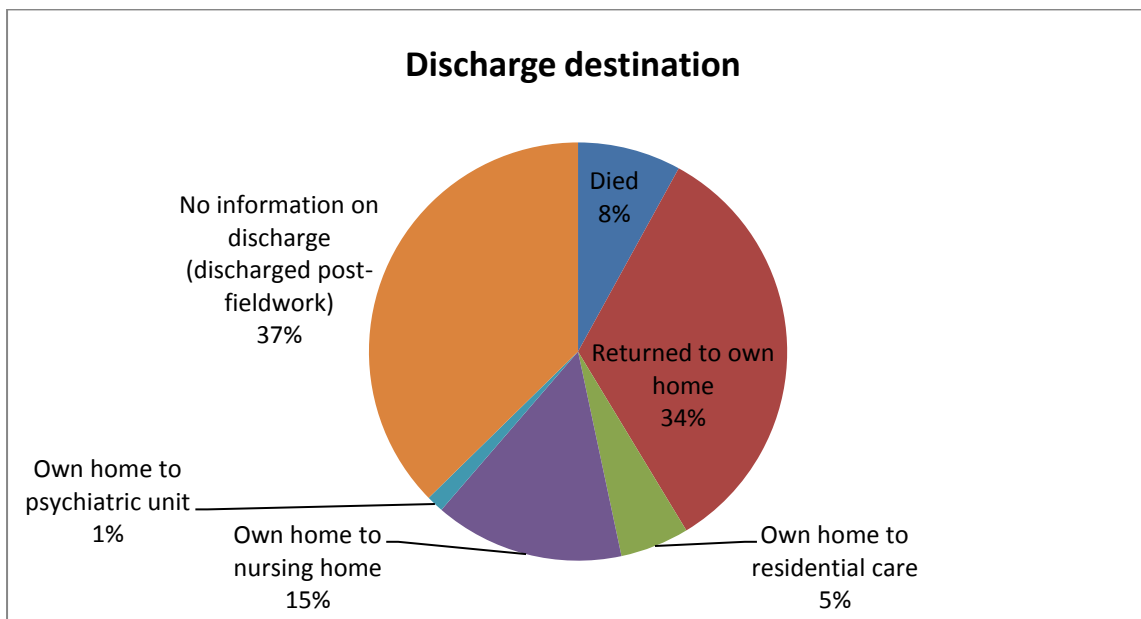
Figure 11: Netherton: Discharge destination

Of those for whom information was available, 25 (57%) were discharged to their own home; a fifth involved new admissions to long term, mainly nursing home care.

Staff profile

The ward team comprised 35 staff. Typical staffing complement was: five nurses and three HCAs (early shift); four nurses, three HCAs (late shift); and two nurses and two HCAs (night shift): a ratio of registered nurses to patients on the day shift of 1:5.6. Staffing complement was generally maintained during baseline; although as elsewhere, staff shortages on a shift involved substitution of a HCA for a nurse.

Netherton: Care Culture

An established, stable team, half had worked together for at least the eight years in which the current ward model had operated (acute, dementia care). This included senior staff (ward manager, senior sister and charge nurse) who had a wealth of knowledge and skill in caring for people with dementia, acquired through formal self-directed learning, personal and professional experience. They conveyed through formal and informal mechanisms a consistent and coherent team ethos and commitment to ongoing appraisal of work practices. Twice yearly away days were held for staff to examine practice and to identify problem areas to work on. Everyone was expected to attend (they were organised in two separate days to facilitate participation). Through these various mechanisms, new staff were enculturated into a style of team working that emphasised continuous improvement as 'how we do things on this ward'. The ethos of person focused care was reflected in the responses to the Culture of Care questionnaire, completed by just over half the team (n=18).

Consensus existed among respondents that the team shared an explicit philosophy of care; the psychological needs of patients were considered; involving patients and their carers was an important part of the work; and these values and expectations were communicated to new staff. There was agreement that patients were treated with dignity and respect; they experienced individualised care and patients' and families' care needs were met (reflected in research observations).

Most agreed that there were sufficient ward resources to deliver good care, including staff with the requisite knowledge and skills to provide it. Just under half regarded staffing levels insufficient to allow them to spend enough time with patients.

They felt supported as a team; could rely on each other; were relatively comfortable about bringing up problems with colleagues; and felt that they could influence ward decision-making. In concert with staff on other study wards, there was too much work to do in too little time, but they particularly valued learning and development opportunities available.

Strong, positive feedback was received about the ward's leadership and management style: especially the support provided and clarity of expectations around achieving care excellence. Perceptions of the wider hospital were mixed; although views were more neutral to positive about availability of training opportunities and access to resources.

Central NHS Trust

Organisation

This Foundation Trust is one of the largest in England, employing around 11,000 staff (one of the top five employers in the region). It treats more than 1.2 million people and has 250,000 A&E attendances, annually. Acute services are primarily located in one main hospital, with additional beds in two smaller hospitals. The study wards were located in one of these, comprising around 229 beds and providing a range of community, outpatient, inpatient and emergency care services. This hospital was situated around six miles from the main hospital, within a self-defined, organisational community (it has its own local authority) of 250,000 people.

Trust Board annual reports from 2011/12 reveal an organisation in which balancing finances was a persistent and significant challenge. In 2013, the Trusts contingency fund was under pressure; the research site hospital was in overspend by 15% and had not delivered on its cost improvement programme. A plan to reduce costs by closing flexi beds was set in train; and the financial position of the hospital was in focus, including weekly rectification update meetings. The Trust was also reviewing staffing models as a cost saving measure.

By November 2013, the A&E waiting time performance target had been missed for five consecutive quarters, creating concern that Monitor would intervene and prompting micro-management to regain control. All elective in-patient surgery was temporarily suspended, which resulted in failure to meet the 18 week referral to treatment target and the creation of a backlog in excess of 1,000. The research site hospital met A&E waiting time targets; but with significant pressure on the Trust affecting all sites, work was conducted to review capacity and demand.

A CQC inspection in autumn 2013 and published in January 2014, deemed the Trust as requiring improvement on all criteria apart from 'effective'. Trust Board and senior management were under considerable pressure to balance development and redesign against significant challenges including winter pressures, increased activity and securing financial recovery.

Care of People with Dementia

Local strategic priorities during 2011 to 2014, included a programme to deliver improvement in care of people with dementia and delirium, including policy, ward environment and drug treatment. The dementia strategy and steering group selected key areas to monitor, including education, improved pathways, metrics, and embedding personalised 'All about me' documentation into practice. A Supported Integrated Discharge Team was established to facilitate timely discharge of frail elders, and joint old age medical and old age psychiatry were to be available on every site. The Trust Dementia Steering group placed emphasis on improving dementia screening rates, which were well below target. Of the Trust hospitals, the research site had best compliance with screening: from 3% in September 2013 to 33% in December (target 90%).

A Trust-wide ongoing programme of 'Dementia Awareness' training had been delivered before the start of the research, tailored to different staff groups, with the intention of utilising a group of 'Dementia Champions.' In recognition of the increasing number of patients with dementia, 30 mental health nurses were recruited to Bank staff, and some volunteers received specialist training in dementia in the main hospital, with a roll-out plan to other sites.

Central Trust PIE Wards

Three wards took part in the study; collectively they formed the elderly care directorate in this hospital. Denton is a rehabilitation ward for people with dementia who were medically stable; similar to Netherton it is not a specialist dementia ward; Beech is a mixed trauma and care of older people ward; and Rose a stroke ward. On all three, baseline data collection began as planned in July 2013.

Denton: Structure and Organisation of Care Delivery

Denton comprised 13 beds. A designated 'enhanced recovery ward', it was intended to provided dedicated support to people with dementia who were medically fit, mobile and would benefit from the expertise and calmer environment offered there. It was also part of the Trust's Winter initiatives to manage patient flow. When fieldwork began, the ward was relatively new, having opened in January 2013. Early in the data collection phase, it emerged that long-term funding to the ward was insecure and that bed numbers were not included in the hospital total. The ward underwent waves of imminent closure threats. Impetus for keeping the ward open came from clinicians who were passionate about having access to a resource for people with dementia and positive feedback from patients and relatives.

Physical environment

The physical environment was spacious. It comprised of two, six-bedded bays (male and female) and one side room. The impression was of a less medicalised environment than other wards on the site. Décor was neutral and there was some signage for the bathroom. The staff office had clear visibility into the open, spacious day area, where patients and staff spent most time. In this area there were four round tables of four chairs, at which patients, visitors and staff sat. In addition there were some high chairs in a row, and more stacked chairs for visitors. There was access to a small garden with a bench.

Patient profile

During baseline there were 39 admissions over nine weeks, of which one was a re-admission (approximately four per week). Patients were admitted from other wards in this hospital, following an acute stay. Median length of stay was 25 days (range 4-79).

Table 6: Denton Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
65-69	2	5
70-74	1	3
75-79	5	13
80-84	6	15
85-89	12	31
90-94	9	23
95+	3	8
Gender:		
Men	15	38
Women	24	62
Residence prior to acute admission		
Own home	34	87
Residential Care Home	4	10
Nursing Home	1	3

More than half of patients were in advanced older age (median: 88 years) and the majority were women. Most had lived at home prior to their acute admission. All (n=39) had dementia; a quarter (n=10) had delirium (of whom seven had delirium and dementia). During their admission, most patients had delirium (n=33); median days in delirium was 11 (range 1-36 days). Reasons for admission are shown in Figure 12.

Reasons for admission

Other (diarrhoea, stroke, cardiac failure, panic attack) 10%

UTI 5%

Pneumonia / short of breath 8%

Reduced oral intake/dehydration 10%

Unresponsive / collapse 13%

Confusion / worsening dementia 15%

General decline/ unwell 21%

Fall / reduced mobility 18%
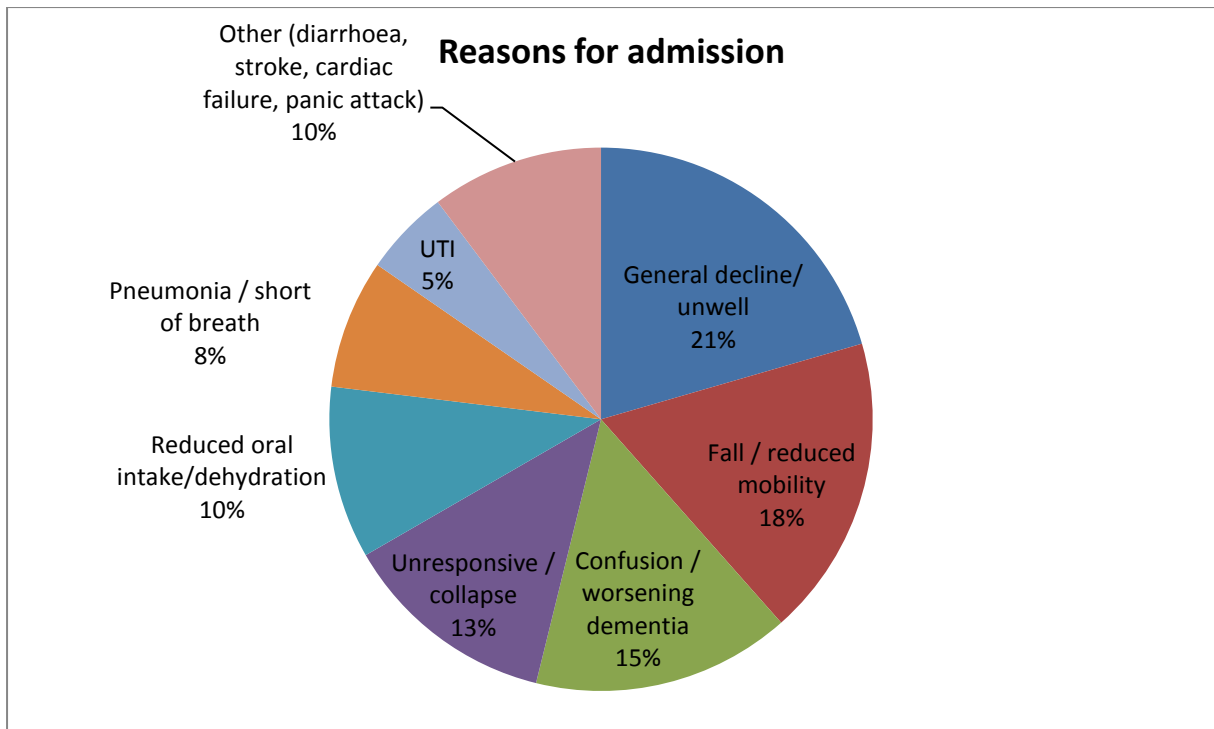
Figure 12: Denton: reason for admission

Further indicator of the frailty of the patient profile is the discharge destination pattern (Figure 13), showing that 15% of patients died, and 38% went to long term care.

Discharge destination

Residential home permanent 15%

Nursing Home permanent 23%

Death 16%

To usual residence 46%
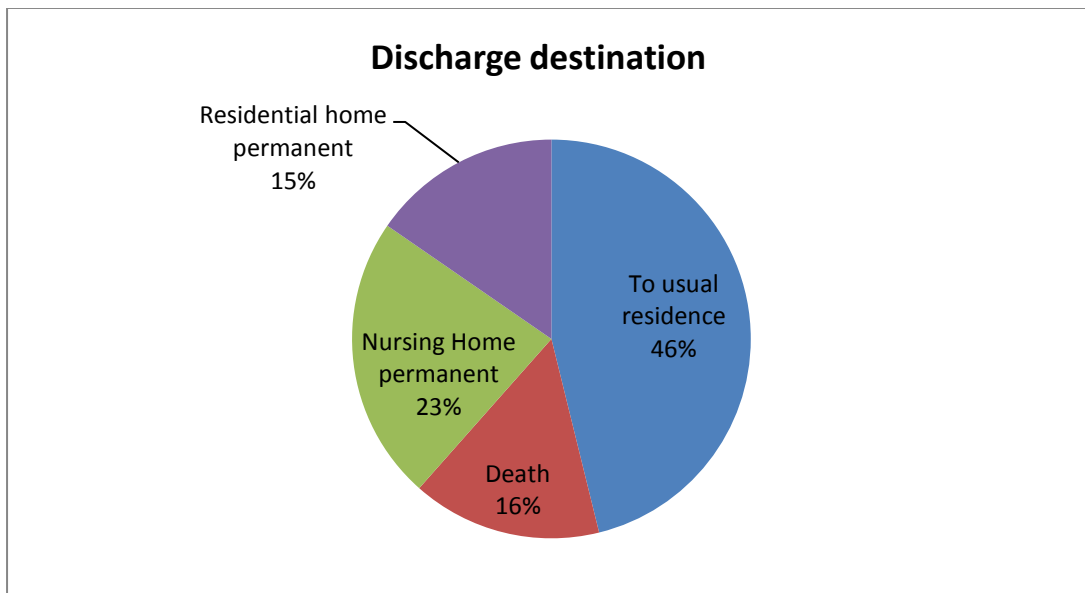
Figure 13: Denton: discharge destination

Staff profile

The ward team comprised 12 staff. Staffing complement was: two qualified nurses and two HCAs during the day and two qualified nurses and a HCA at night (patient to registered staff ratio, 1:6). A geriatrician provided a weekly patient review meeting, and a junior doctor was primarily based on

the ward; this post was not permanent. Therapy cover was provided by the senior occupational therapist with an interest in dementia, and by therapists who might follow patients from their previous ward.

Denton: Care Culture

Most staff had worked together since the ward opened, some seven months prior to baseline. All had chosen to work there because of an interest in dementia. Many of the resources on the ward – games, reminiscence materials – had been purchased through fund-raising initiatives by ward staff. There was heightened goodwill among staff, patients and relatives in joint working toward such initiatives.

Ten Culture of Care questionnaires were completed: eight by nursing and care staff; one each by a doctor and a housekeeper.

There was consensus that the team had a caring approach; shared an explicit philosophy of care; placed high value on psychological care of patients and provision of enabling support; and regarded involvement of patients and caregivers as very important. There was agreement that the team had access to adequate resources and that they routinely engaged in reflection and discussion aimed at improving care delivery.

Perceptions of the multidisciplinary team were almost unanimously positive, with good working relationships. There was consensus that patients were treated with dignity and respect; that they experienced good individualised care; and that patients' and families' care needs were usually met. Observation supported this picture, attesting to a style of collaborative work with families which embraced sensitivity and responsiveness to their anxieties and concerns. There was very positive feedback about the emotional and practical support offered within the team, being unanimous about the trust, competence and confidence they shared, and that they felt comfortable about discussing difficult issues together.

There was a slightly mixed response with regard to balancing resources and demands. Although some considered that there was too much work to do in too little time, most agreed that they could follow best practice within existing resources. They were generally very positive about ward learning and development opportunities.

Universal, strong, positive support about all aspects of ward leadership and management was conveyed: the ward manager was reported to consult daily with the team, was an on-going presence, and involved in hands-on patient care.

The most variable responses were provided to questions about the hospital – indicating mixed views about hospital resources, access to expert assistance and responsiveness of hospital management to staff concerns. It was largely agreed that the hospital provided adequate training opportunities, treated staff with dignity, and that staff had authority to make decisions.

Comparing all wards in the study, Denton respondents were most universally positive summed up in the comment of a HCA: "*I have worked on [Denton] since it opened …I have never been as happy since a started working for the trust. It is a lovely well run ward …patients get great care here".*

Beech: Structure and Organisation of Care Delivery

This ward provides care to a mix of older people with complex medical needs and those who suffered orthopaedic trauma, primarily fractured neck of femur. During baseline the ward usually had 24 beds, 12 trauma, and 12 medical. There was an additional bay, open as part of the hospitals capacity management strategy, making a total of 31 beds (over five bays and three side rooms). Historically, the ward had undergone many changes over the years (of purpose, size, patient group and physical location).

Physical environment

The ward appeared a 'busy', cluttered physical space, with people, artefacts and equipment. There were no meeting rooms or day room: team and MDT meetings were held in the ward manager's office or staff room. The environment was not 'dementia friendly'; bays all looked the same with no orienting features. Each bed had a pay-per-use television and radio screen.

Patient profile

During baseline, admission data was recorded for approximately five weeks, during which there were 60 admissions (12 per week). The median length of stay was 20 days (range 4-153). The physical and cognitive abilities of patients varied. For example, ability to mobilise spanned those who walked around the ward independently, to people who were mostly in bed. Many patients were physically frail, requiring assistance to transfer or to mobilise. Table 7 summarises patients' socio-demographic characteristics.

Table 7: Beech Patient Profile: Socio-Demographic Characteristics

	No	%
Age range		
65-69	1	2
70-74	6	10
75-79	7	12
80-84	11	18
85-89	10	17
90-94	17	28
95+	8	13
Gender:		
Men	13	22
Women	47	78
Residence prior to acute admission		
Private residence	50	83
Residential Care Home	4	7
Nursing Home	1	2
Respite Care	1	2

More than half of patients were in advanced older age (median age 87; range 67-99 years). The majority had lived at home (including many with caregivers) prior to the event that brought them into hospital. Just over a third had dementia (n=21). Given their age profile and based on observation, this likely under-estimated dementia prevalence (data was incomplete; data was missing for 27 patients. On admission, at least one fifth had delirium (n=12, missing data n=27). Of those who were assessed for delirium during their admission (n=18, missing data n=42), almost half were identified as having a delirium (n=8) for a median of three days, range 1-15 days. Reasons for admission are shown in Figure 14.

Reason for admission

Other (ulcer, pain, heart failure, anaemia, pulmonary embolism) 8%
Sepsis 3%
Rehabilitation 3%
Abnormal bloods 3%
Generally unwell 5%
Stroke / TIA/ AF 3%
Dehydration 5%
Confusion 9%
Pneumonia / respiratory infection 7%
UTI 9%
Fall / Fracture 45%

Figure 14: Beech: Reasons for admission

Discharge destination is presented in Figure 15. Just under three-quarters of patients returned to their usual residence on discharge; a further quarter were equally divided between those who died and those who were newly admitted to long term care.

Discharge destination

Intermediate care 3%
Death 12%
Nursing home permanent 13%
To usual residence 72%
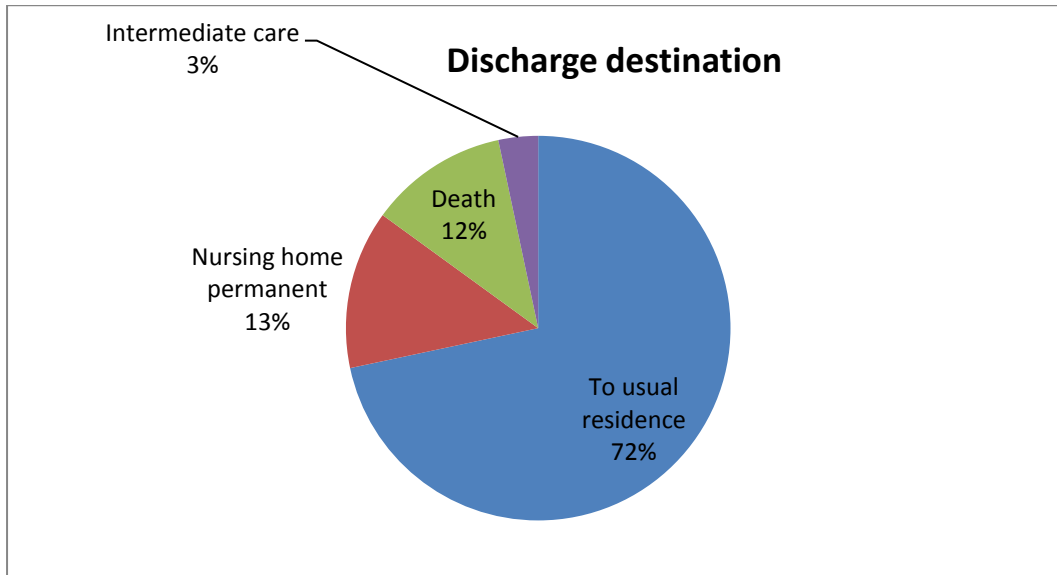
Figure 15: Beech: Discharge destination

Staff profile

Detailed information on staffing complement was unavailable (accounted in part from variability of available beds). Shifts were commonly staffed using Bank or agency, and it was not uncommon for such staff to 'special' a patient on a one-to-one basis (typically someone who was agitated or

distressed). The ward manager was primarily engaged in management tasks and was rarely involved in direct patient care.

Beech: Care Culture

The ward model was relatively new and there was considerable ongoing work necessary, from the ward manager's perspective, to construct a team and forge a common care ethos; made more difficult by shortage of permanent staff and reliance on temporary workers. This was reflected in the responses to the Culture of Care questionnaire, completed by five staff only (two nurses, one HCA and a geriatrician). Interpretations of the questionnaire data are limited, given the paucity of data; however, there are clear patterns in the responses which echo those derived from observation and interviews. Of all the wards, respondents here were most negative.

Generally, respondents conveyed low value among the team on involving patients and caregivers; insufficient basic ward equipment; inadequate support to allow time to spend with patients; and no routine mechanism for improving care delivery. Regarding multidisciplinary working, there were mixed views: while communication was perceived as good, it was felt that patients did not experience individualised care (a view shared by the ward manager in an informant interview). With regard to decision-making, respondents considered that they had little influence in how the work was managed; that there was too much pressure on resources and demands, such that there was insufficient time to deliver best care and pursue appropriate training.   While the manager was perceived as available and supportive, she was not visible in direct care provision. Respondents indicated that they did not feel well supported by the hospital, were not fairly rewarded for their work, not treated with respect, and that their concerns were not listened to by management.

Rose: Structure and Organisation of Care Delivery

Rose ward was for patients recovering from stroke who required medical care and rehabilitation. Non-stroke patients with medical needs were also admitted, including those with palliative care needs, particularly into the four single rooms, of which there was a shortage in this hospital. The ward had 23 beds (sometimes 24, with an additional bed in the male bay). It seemed from the patient profile that the ward was evolving from a specialist unit into a mixed medical ward.

Physical environment

Similar to Beech, the physical environment was 'busy', clinical and not 'dementia friendly'. There were three bays, two female bays (one eight-bedded, and one five-bedded), and one male, with six beds, as well as four single rooms. Some bays only were within view of the nursing station. A staff

member was based in one bay opposite the nursing station (stroke data coordinator who had been a HCA).

There was an office used by staff and for relatives meetings; and a small, cluttered staff room. Both were planned for refurbishment to better fit their purpose. There was no day room. A large therapy room at the end of the ward contained a small therapy office, lots of equipment and open space. The ward had a stroke-friendly garden, built with money raised by ward staff.

Patient profile

During baseline there were 167 admissions over eight weeks (approximately 21 per week). The median length of stay was five days (range 1-91). Table 8 provides a summary of patients' socio-demographic characteristics.

Table 8: Rose: Socio-Demographic Characteristics

	No	%
Age range		
18-64	48	29
65-69	12	7
70-74	19	11
75-79	14	8
80-84	36	22
85-89	21	13
90-94	11	7
95+	6	4
Gender:		
Men	81	49
Women	86	51
Residence prior to acute admission		
Own home	157	94
Residential care home	4	2
Nursing home	4	2
Care home other	1	1

Age, physical and cognitive abilities of patients varied considerably (median: 77 years, range 18-99). Given the age range and variability of recovery, there was potential for added complexity. Some patients had life changing newly acquired disabilities; some had the perspective of resuming paid work; and many required staff assistance to transfer or mobilise.

The majority had lived at home prior to acute admission. On admission, 13 patients (8%) had dementia; and three had delirium. Among those assessed for delirium during their admission (n=19, missing data n=148), over half were identified as having delirium (n=11), for a median four days

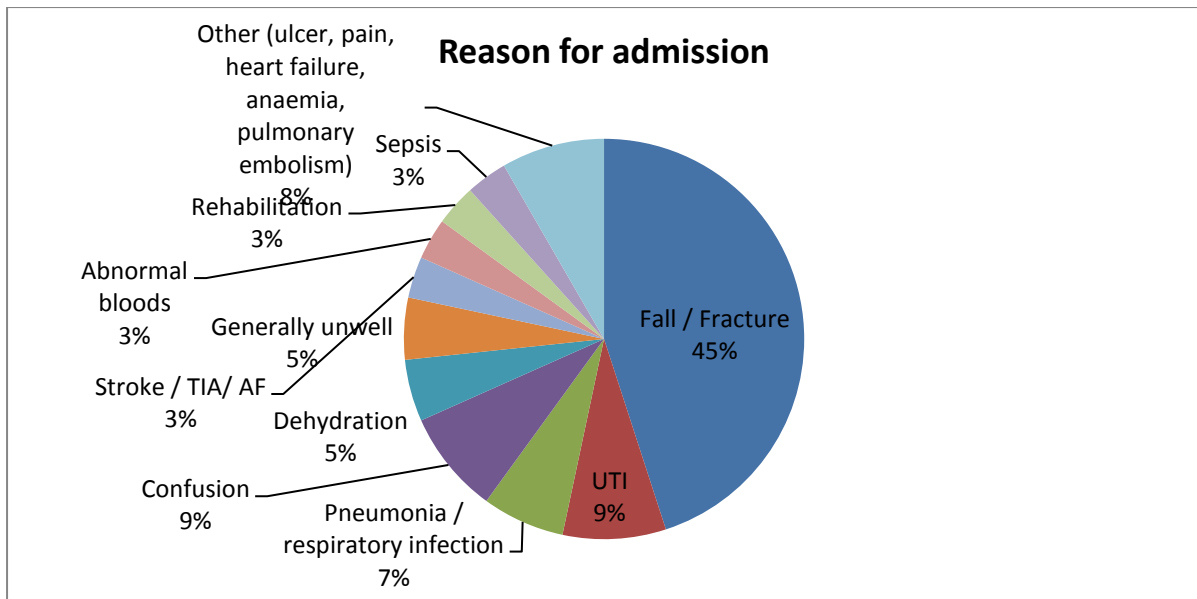(range 1-7) days. Reasons for admission are shown in Figure 16. Just under half had suffered a stroke; the remainder were admitted for various acute medical conditions.

Reason for admission

- Other 17%
- Sepsis 3%
- Collapse / unresponsive 3%
- Headache 3%
- UTI 4%
- Generally unwell / decline 4%
- SOB 4%
- CVA 5%
- ?Stroke / FAST positive 43%
- TIA 7%
- Fall / mobility 7%
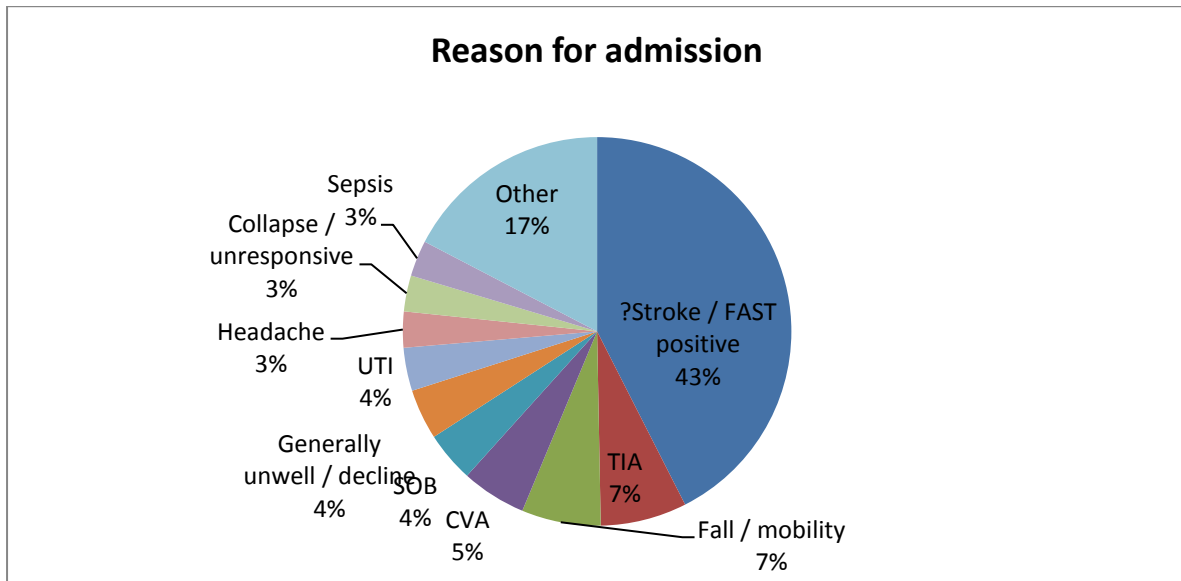
Figure 16: Rose: Reasons for admission

Discharge destination is shown in Figure 16.

Discharge destination

- Nursing home 3%
- Deceased 10%
- Unknown/other 5%
- Residential home 2%
- Intermediate Care 2%
- Hospice / palliative 1%
- Discharged to usual residence 77%
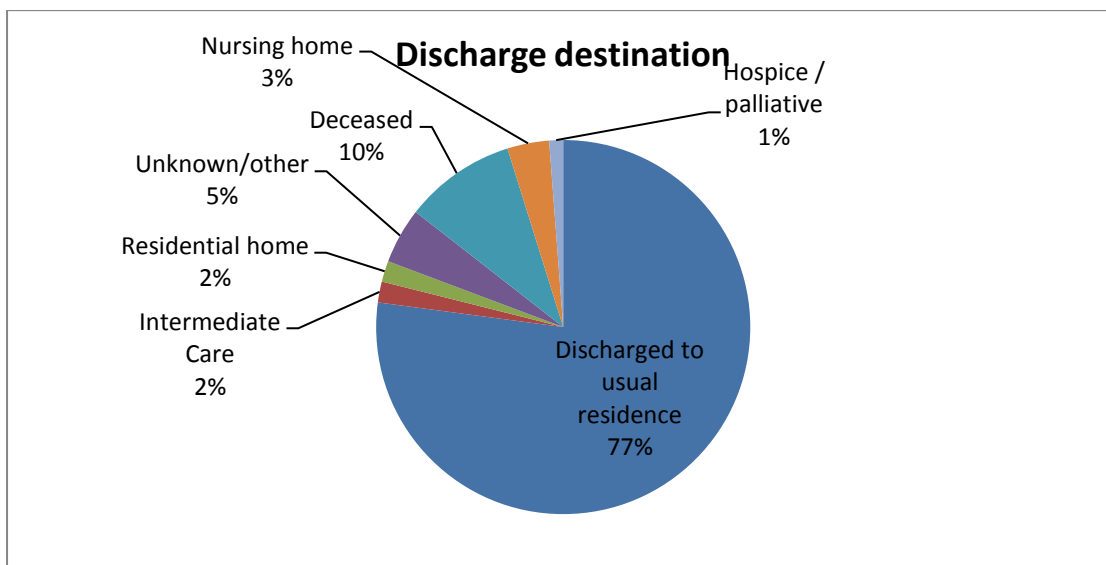
Figure 17: Rose: Discharge destination

The proportion of patients discharged to their usual residence was reflective of a population which prior to admission was slightly younger and healthier than other wards in this study. Additionally, patients here benefited from access to the Early Supported Discharge and Hospital at Home services, both of which facilitated continuation of monitoring, nursing support and rehabilitation on acute discharge.

Staff profile

The senior ward management team included: manager, a sister and charge nurse, and a senior stroke co-ordinator (the latter's role was to identify and coordinate stroke patients admitted to any part of the hospital). There was also a co-ordinator from the Stroke Association who performed the function of patient and family liaison and was a link to facilitate the patient's transition between the ward and their own home on discharge. Staffing complement was: early shift, four nurses and three HCAs; late shift, three nurses; two HCAs; and at night, three nurses; two HCAs (a registered staff/patient ratio of 1:6).

Rose: Care Culture

Based on observation and staff interviews, the manager had ward presence but limited patient contact. She was newly promoted and appeared stretched. She was supported by the sister and charge nurse, both of whom were visible and active in providing direct patient care and had long experience of working on the ward. Several HCAs had been based on the ward for many years. The existence of a stable group of staff at different levels over a period of time provided continuity and a strong sense of collegiate working. Morale was affected by staffing difficulties; as was working in a physical environment regarded as 'tired', cluttered, and dark. The manager considered that her staff team were over-burdened and was protective of them; for example being careful to ensure that feedback on performance and critical incidents was conveyed and reflected on in a constructive manner.

Responses to the Culture of Care questionnaire (12/30 questionnaires returned from nursing, medical and therapy staff), indicated mixed views about the care and ward working environment. Positively, it was reported that the team shared an explicit philosophy of care, and that the involvement of patients and caregivers was valued. However, staff considered that there was inadequate support to spend time with patients. They conveyed a positive sense of providing good care and working as a team, for example, indicating that staff worked well within the multidisciplinary team, provided individualised care, and treated patients with dignity and respect. Respondents were largely neutral about: team support; raising difficult issues; and being able to participate in ward decision-making. There was much disagreement about the extent to which resources and demands negatively affected work and care; although there was agreement on the availability of, and access to training. Ward leadership was perceived as positive, although in comparison with City, Ironbridge and Seaford wards, this was expressed in less enthusiastic terms. Perception of support from the hospital was mixed; respondents were generally positive about being able to obtain expert assistance when needed, and being treated with dignity and respect.

Seaford NHS Trust

Organisation

Seaford Trust is one of the largest in England, with five hospitals, spread over a wide geographical, socio-economically diverse area and serving a population of around 759,000. The three acute hospitals (two involved in PIE) employ over 7,500 staff, serving a bed base of 1,107. It was awarded Foundation Trust status in 2009.

Trust annual reports from 2010-11 to 2013-14 present a picture of high performance and future uncertainty which was similar to other participating Trusts. In the recent past, it had received the accolade of Trust of the Year, was the top performing hospital in the Healthcare, Excellence and Leadership Awards and met all Monitor's governance and financial targets. In the two years from 2012/13, the pattern of high performance was seen to persist; albeit foreshadowed difficulties included increasing demand on services, particularly through 'winter pressures

A major strategic initiative pursued was the development of a Shared Purpose Framework and set of values that would guide practice, launched in 2013, when the study began. This was intended as the starting point for a programme of cultural change, aimed at engaging staff at all levels around four key purposes: person-centred care; safe care; effective care; and creating an effective workplace culture to sustain and enable quality improvement.

Care of People with Dementia

Dementia per se was not identified as a key priority in Trust Annual Reports until the 2012/13 Report when two key initiatives were launched: a new Enhancing Quality Programme pathway for dementia; and the appointment of a dementia team, in early 2013. The dementia team comprised a matron, two experienced nurses and a consultant working closely with them to lead improvements and support implementation of the dementia strategy. The matron and specialist nurses were attached to each of three district general hospitals in the Trust, including the two study wards.

The dementia team was in post less than a year when the research began but had already instigated several initiatives which were quickly and widely acknowledged. In 2013 they won the Trust's Caring Award for their work which included a trust pathway for dementia care, staff dementia training, a 'confusion pathway' and a pocket guide to preventing falls and managing confusion in collaboration with the falls matron.

Seaford Trust PIE wards

These were the last wards recruited, partly due to the arm's length negotiations required for set-up. Even so, data collection and other research activity ran largely according to the planned timetable, due to a relatively (compared to the other sites) stable situation in that both wards retained their specialisms (one orthopaedic, one frailty/rehabilitation) over the research timeframe.

Poplar: Structure and Organisation of Care Delivery

The Easternmost site, location of Poplar ward, is an acute hospital with 388 beds providing a range of emergency and elective services and comprehensive trauma, orthopaedic, obstetrics, general surgery and paediatric services. The hospital dates back to the 1930s when the original building was constructed. Between 1996 and 1998 most services were relocated and expanded into a new hospital building linked to the original facilities.

The hospital has several specialist units and new staff accommodation. Co-located on the site are mental health facilities for working age adults and older people run by the local NHS and Social Care Partnership (mental health) Trust.

Poplar is a 22-bed orthopaedic ward for older people. Most patients are admitted as emergencies following a fall and sustaining a fractured neck of femur.

As baseline data collection started the ward clerk, who had agreed to assist with accessing ward profile data, sustained a fall and was hospitalised with bilateral ankle fractures. She was off sick for the whole of the period which made data collection a challenge, as the researcher did not have access to electronic patient data.

Physical environment

Poplar is comprised of three, six-bedded bays, two single rooms and one double and is situated in the new (1990s) building. There is usually one male and two female bays, all colour coded. The rooms are fairly spacious and there are small tables and chairs at the far end of each bay, near the windows. Other chairs, for visitors, are at entry to the bays. All bays and rooms have clocks and date calendars. The ward had relocated twice just before the study began, and its current 'home' meant the loss of a dayroom – a source of regret among staff.

Patient profile

At baseline there were some 90 admissions, all emergencies, having a median length of stay of 15 days (range 1-36). For the reasons above, there is much missing data. Table 9 presents the Poplar patient profile.

Table 9: Poplar Patient profile: Socio-Demographic Characteristics

	No	%
Age range:		
65-69	3	3
70-74	5	6
75-79	12	13
80-84	21	23
85-89	21	23
90-94	20	22
95+	6	7
No information	2	2
Gender:		
Men	27	30
Women	61	68
No information	2	2
Residence prior to acute admission		
Own home	46	
Extra-care housing	1	
Intermediate care		
Residential Care Home	10	
Nursing Home		
No information	33	

Patients were mostly aged 80+ years and women. The majority were admitted from home following a fall. According to documentation about 50% of patients had a degree of cognitive impairment at any one time. This is supported by staff interview data, although numbers appeared to fluctuate upwards. Delirium data were not collected. Figure 18 reports reasons for admission.

Reason for admission

Other includes
R. Hemi
Dislocated hip
acetabulum
nof & colles
#knee
THR
Hip pain
Displaced nof
Cellulitis
Removal of
metalwork to ankle

No information

Other

Fractured neck of femur
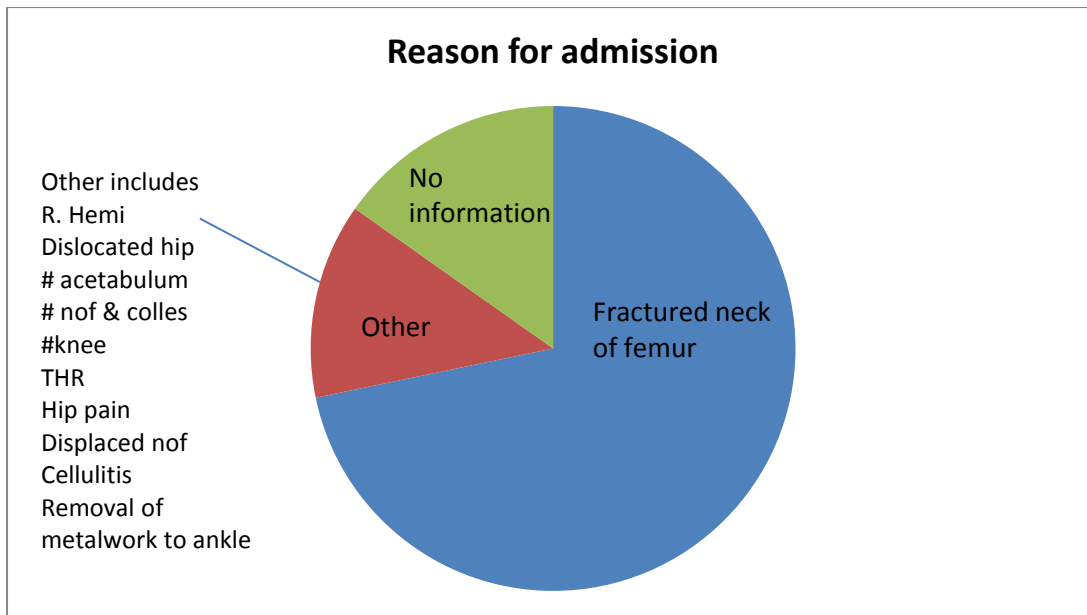
Figure 18: Poplar: Reasons for admission

Discharge destination is presented in Figure 19.

Discharge destination

Death
Nursing home
Residential care
Ward transfer
Transfer to different hospital
Intermediate care

Usual residence
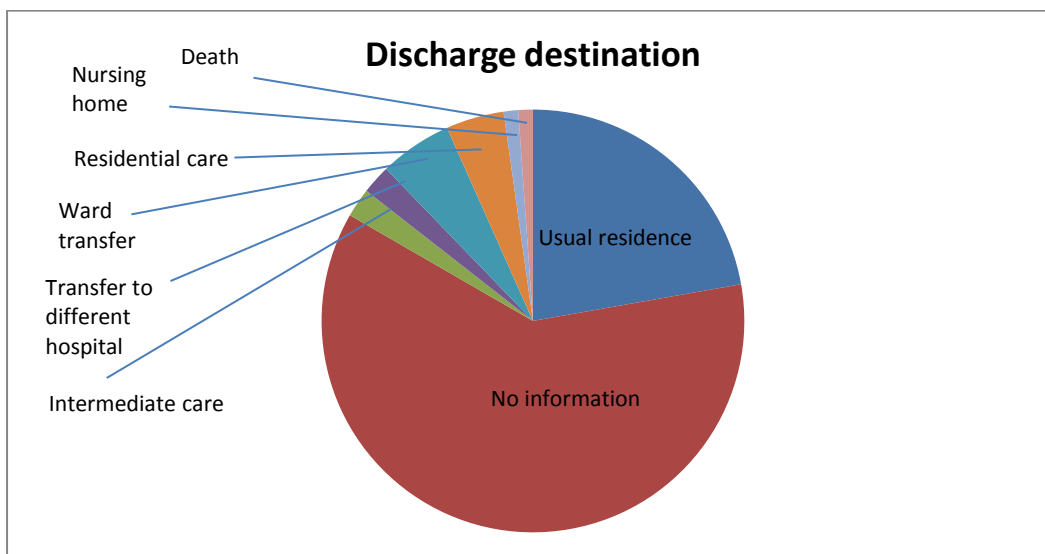
No information

Figure 19: Poplar: Discharge destination

For more than half of patients discharged at baseline, destination is not recorded reflecting difficulties with data collection. There is no information on discharge either for those patients remaining on the ward at baseline. Of those for whom information is available, some three-quarters were discharged to their usual residence and the rest were divided between Intermediate Care placements, transfers to another hospital or to long term care.

Staff Profile

The staff complement was 33: 15 nurses, two Assistant Practitioners (APs) and 16 HCAs meaning it was comparatively well resourced. This was mainly due to a determined ward manager who felt very protective towards her ward and staff. Cover was at least four registered and four HCAs per day shift; and two registered and two HCAs, per night shift (ratio of registered staff to patients of: 1:5.6. Some staff worked long shifts (7.30am – 8.30 pm); others worked conventional early or late shifts. There was much flexibility, including part-time and internal rotation or permanent nights. There were nine orthopaedic consultants attached to the ward.

Poplar: Care Culture

12 questionnaire responses were received from the 20 distributed (mainly nurses and HCAs, with one volunteer and student nurse respectively). Although most had not worked for long on the ward (seven for less than two years); most had worked in the hospital for between five and 21 years) and were experienced in care of older people.

Responses showed strong agreement on the existence of a shared philosophy of care which valued psychological support and involving patients and caregivers. It was considered that the ward had sufficient equipment and skills among the team. Interviews further suggested a strong team who could rely on each other and shared information and skills. Team members considered that they had influence on decision-making, and that there was time to share task-related information. There was strong support for the leadership and management style of the ward manager in all areas. In particular, she was seen as an ongoing ward 'presence', as supportive and protective of her staff and keen to ensure that everyone received appropriate training. She was also viewed as keen to appoint staff with particular interest in dementia care. The dementia nurse linked to the ward was highly respected and much appreciated. She had previously worked on Poplar prior to her role change and was well known.

Most staff agreed that there was too much work to do in too little time and without adequate resources. They generally felt that they were not listened to by senior managers, nor rewarded for their work. This is largely supported by comments from the 2014 CQC inspection regarding leadership (which included evidence of bullying and harassment). Moreover, there was some resentment at a recent ward move from an environment they perceived as more conducive to the well-being of patients and a sense that that other wards, not so skilled in dementia care, tended to send people with dementia to their ward.

Crane: Structure and Organisation of Care Delivery

Crane is a 26-bed ward based in the westernmost hospital. Opened in 1979, the hospital was part of a plan to expand the town and surrounding area in the late 1960's by relocating people from London. It employs about 2,500 people and has 476 beds. It offers a wide range of specialist facilities and services, including a shop run by Friends of the Hospital, a volunteer run society providing basic goods and services to patients and visitors, and which raised £2.5 million in donations.

Physical environment

The ward was comprised of three six-bed and one five-bed bays with a shower room located in each: two each for women and men. This smaller bay had previously been a dayroom. Each had a sink at the far end; there was no space for tables and chairs. They recently had clocks with the date put in each bay above the entrance.

Beyond the end door there was a linking corridor leading to another ward. This also housed three side rooms which appeared very separate from the main ward, although part of it. Further on and linking with the next ward was an annexe of half a dozen 'winter beds' (often open well into late spring/early summer and which, when open, usually took one or two staff from Crane). On the right side of the corridor were storerooms, the nurses' station, ward manager's office and a meeting room, which also housed the drug trolleys and patient toilets. The nurses' station was located opposite the first two bays, next to the ward manager's office. The medical notes were stored there and the space became very overcrowded when medical and nursing staff were reviewing patient notes. The ward clerk's desk was sited there.

Patient profile

There are a large number of days with no documentation towards the end of the baseline, as the acting ward manager, who had been maintaining records left around this time.

During baseline there were 121 admissions. The median length of stay was 8.5 days, (range 1-64). The socio-demographic patient profile is presented in Table 10.

Table 10: Crane Patient profile: Socio-Demographic Characteristics

	No	%
Age range:		
Under 65	1	<1
65-69	1	<1
70-74	4	3
75-79	23	19
80-84	27	22
85-89	37	30
90-94	20	16
95+	8	7
Gender:		
Men	69	57
Women	52	43
Residence prior to acute admission:		
Own home	92	75
Intermediate care	1	<1
Residential Care Home	15	12
Nursing Home	7	6
No information	6	5

The majority of patients were in their 80s and there were slightly more men than women. Three quarters were admitted from their own homes. From documentation and staff interviews at least half had dementia but this fluctuated upwards to over three quarters at times.

Reasons for admission are shown in Figure 20. Many included multiple pathologies and those categorised as 'other' included undifferentiated diagnoses, various cancers, heart and autoimmune diseases plus long term conditions or infections.
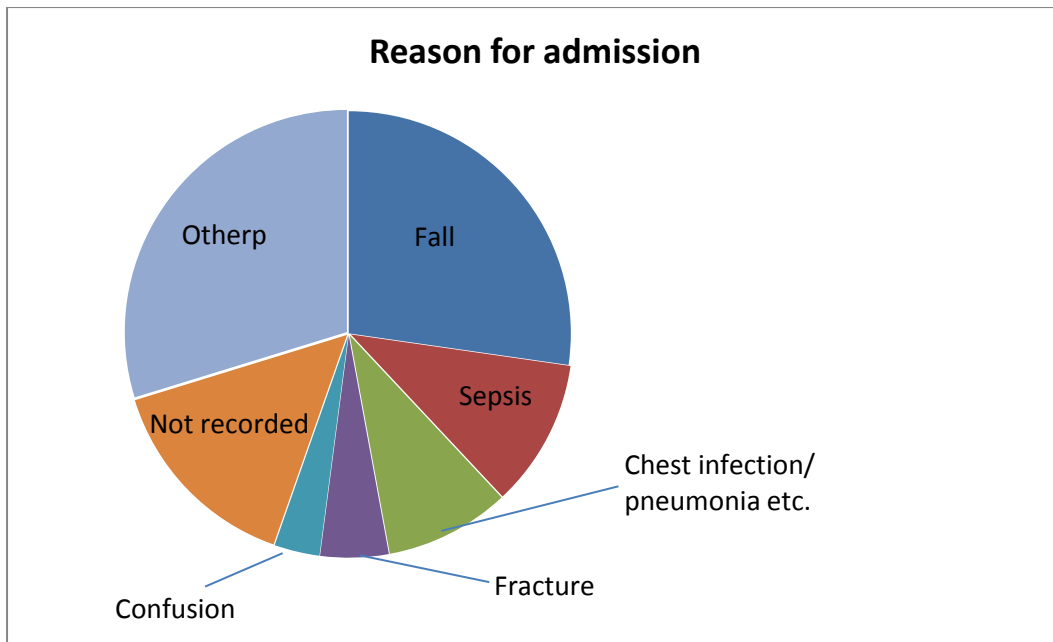
Figure 20: Crane: Reason for admission

Destination at discharge (Figure 21) indicates that most patients returned to their usual residence, although there is considerable missing information, including in respect of those who remained on the ward at the end of baseline data collection. There were also a number of deaths on the ward over this time.
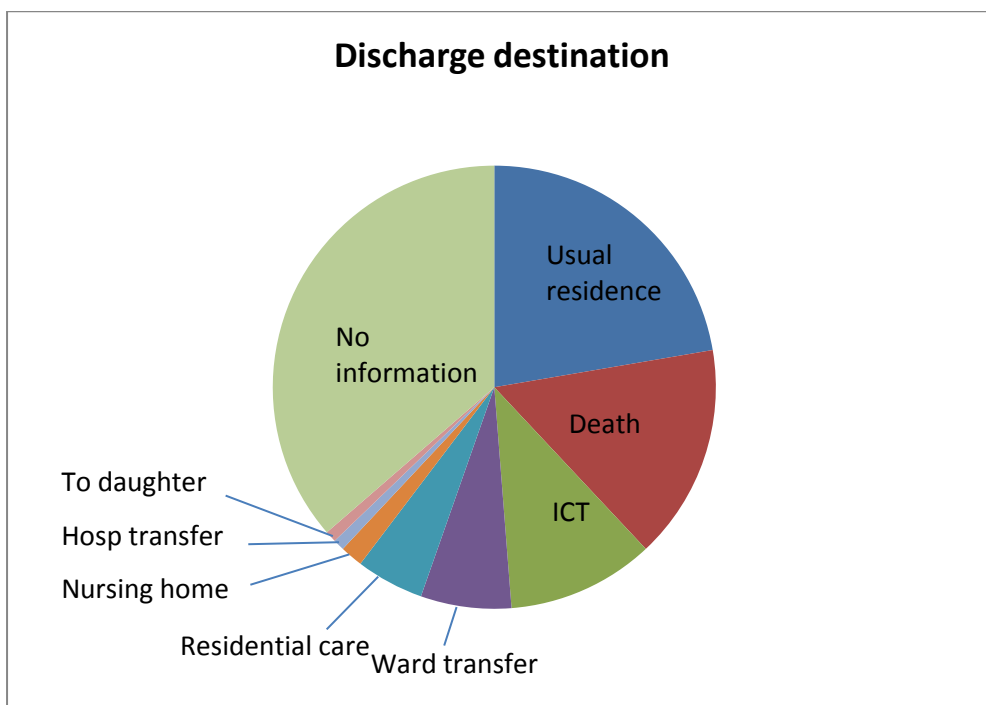
Figure 21: Crane: Discharge destination

Staff profile

There were 40 staff on the rota at baseline, but many were part-time. Staffing complement comprised of five nurses (including a sister) and four HCAs during the day; and two nurses and two HCAs at night. Most worked long shifts from 7.30am until 8.30pm, and many rotated to nights. Two staff were reallocated to 'winter pressure' beds when open, on a rotational basis. Ratio of registered staff to patients was: 1:4.4

Crane: Care Culture

Five responses were received from 13 Climate for Care questionnaires distributed. This is a small and unrepresentative sample, limiting interpretation of the findings. Two were experienced, one having spent 12 years on the ward; the others had been there for less than a year.

Questionnaire responses and interviews suggest support for a shared philosophy of care with psychological aspects highly valued, expectations communicated and knowledgeable staff. There was support for the effectiveness of the multidisciplinary team, with occupational therapists being particularly valued as a fount of information. Staff reported trying to shift from a task-orientated approach and toward supporting patients' families. Their approach to dementia care was shaped by the lead dementia specialist nurse based at the site and considered as an enormous support through provision of education and advice. She saw her role as offering a resource for practice based learning and modelling care. Her work was acknowledged at senior management level, including by the deputy nurse for quality and senior consultant. As with Poplar, there was support for the leadership style of the ward manager, which at baseline was an 'acting' one. Overall, the picture depicted was of an enthusiastic, motivated and optimistic workforce.

Less positively, respondents considered there was too much work for the time available, with inadequate resources and ambivalence about availability of wider trust support. In particular, there was insufficient time to sit with individual patients; it was difficult to take staff from the wards for training; and the physical environment was regarded as noisy and cramped. Similar to Poplar, ward staff complained of a lack of social space and the loss of a bathroom. They also expressed frustration at the paucity of step-down facilities so that patients remained on the ward longer than was ideal for their wellbeing.

Summary

Improving care of people living with dementia was becoming a priority in all participating Trusts. On most study wards, changes to their physical environments to make them more dementia friendly

had recently occurred or were underway during fieldwork. Although the changes had created more attractive and easier to navigate environments, communal or patient spaces were very limited except on Netherton and Denton.   All Trusts had introduced dementia awareness training programmes and had initiated or were in process of establishing a network of 'dementia champions.'

Wards varied in their organisation and care culture. On several , staff shortages contributed to low morale. A common theme from responses to the Culture of Care questionnaire was the problem of delivering high quality care, seen to embrace spending time with patients and 'having too much to do in too little time'.

People in advanced older age (85 years and over) dominated, being highest in the dementia wards, followed by rehabilitation, care of older people and ortho-geriatric wards. It was lowest on stroke and orthopaedic trauma reflecting their wider age profile. Prevalence of dementia followed this pattern. This inter-penetration of advanced older age, physical, cognitive, practical, emotional and medical needs poses major challenges for staff to deliver appropriate care.

CHAPTER 4

PERSON-CENTRED CARE: MEANING AND PRACTICE

Introduction

On all study wards, the daily work of care was largely delivered to patients with complex needs. In this chapter, we explore staff perceptions of the meaning of person-centred care; and how care was accomplished prior to PIE installation. Establishing staff understanding of person-centred care and the pattern of 'usual care' for people with dementia provided the baseline against which to explore what quality care might look like in practice and how it could be improved.

Person-Centred Care: Staff Perspective

'Individualised Care'

On all wards, staff typically conveyed person-centred *as 'individualised care', 'seeing the person and not the medical condition', 'tailoring care around the person'.* It was often presented as a short-hand descriptor of 'good practice' or 'quality care' which staff aspired to deliver.

> *All my patients are elderly and very, very vulnerable, and they might not have dementia as their diagnosis; a little bit forgetful… scared… muddled; they're out of their own environment…I firmly believe you give [person centred care] to everybody that you nurse.*

> Manager, Rivermead ward, City Trust

Multiple meanings were ascribed to the term 'person-centred' that have been variously referred to as according respect, acknowledging people's essential human dignity, treating people as individuals and finding out what is important to them relevant to their treatment and care. Staff who had been in practice or undertaken professional training prior to the policy use of the term 'person-centred' tended to refer instead to 'individualised patient care'. Yet, the meaning they attached to 'patient-centred' was no different to what others referred to as 'person-centred'.

'Person-centred' care on acute wards

Pressed upon to elaborate on the meaning of 'person-centred', interviewees offered examples varying from addressing patients by their preferred name, being flexible about such care routines as washing and serving breakfast, providing a choice of meals, respecting privacy, personalising bed space (family photographs) and involving patients in decision-making on treatment and care. Thus,

the content varied from the courteous and respectful to meaningful engagement based on knowledge of the person. Different professionals on different wards accorded more or less emphases on these varied dimensions of 'person-centeredness'.

Generally, health care assistants (HCA's) and less experienced staff appeared unfamiliar with the term.

> *Person centred care – do you mean looking after a certain person?*

> HCA, Ambridge ward, Valley Trust

And,

> *Is that where you…set out a care plan for that person…I think that's what it means, setting out a care plan for that person that has that condition.*

> HCA, Poplar ward, Seaford Trust

Unfamiliarity with the term or inability to articulate what it meant did not imply lack of attention on the person or denote depersonalising care practices. On all wards, individual care staff accorded value to spending time with patients, building trust, and engendering a sense of safety. Despite lack of formal dementia training, these workers explained how they drew on personal knowledge to make a connection with how the patient might be feeling. From being an inpatient, a HCA emphasised the emotional and practical work necessary to assuage patients' anxieties:

> *When I've been to patients here, and you said you'd be back in a minute and you weren't , I didn't understand how frustrating that was until I experienced that myself. For somebody to say to you: 'I'll be back in a minute' and then you never see them again and then all of a sudden this person's gone off shift. [And] not being told your diagnosis, what's going on …well they don't get angry. But I was angry that I was just left there…So now I say with their permission, 'do you want me to go and see what's going on for you'? I will then come and read the Kardex and if I can give them any information … because a lot of them think that they're being shoved into homes … Just to know that they're still in control because to lose control must be awful.*

> HCA, Rivermead ward, City Trust

Empathic connection with the patient's experience informed an approach to action aimed at reducing uncertainty and perceived loss of control.

'Seeing the Person not the Dementia'

Most participants did not distinguish between 'person-centeredness' for patients generally, and for people with dementia, for whom 'person-centred' translated into *'seeing the person, not the dementia'*.

…it's about… the individual as a human being before they are a condition or a set of circumstances, and before you attach the labels and treatments you acknowledge that they are a person… I'm not sure that I would particularly say that the person with dementia is different … although it might be more challenging to identify how you respond … you might have to … get information from a wider range of sources.

Practice development coordinator, Ironbridge Trust

The way staff translated the espoused values of 'individualised care' into practice for patients with dementia revealed important differences between those who were knowledgeable about the condition, whether derived from experience and/or training, and those with poor understanding of it. First, we describe staff views on what was necessary to provide individualised care and the conditions that shaped practice; second, we draw out the specific knowledge and skill required, and challenges posed in delivering individualised care to people with dementia.

'Knowing' the person

There was consensus that 'knowing the person' was crucial to delivering 'individualised care'. Relevant knowledge as a minimum, included aspects of the person's life history, significant relationships, likes and dislikes relevant to care delivery (for example, food preferences and preferred name).

Systems and processes to 'know the person'

Most wards had mechanisms in place (or were introducing them) to gather biographical knowledge, through such tools as "This is me" or "See who I am" booklets. These were frequently alluded to by staff as a resource to begin a conversation. As a means of engaging close relatives in dialogue about the person at admission, the tools performed a useful function. Collection of biographical information to inform practice required that staff placed value on eliciting such knowledge; that when information was sought from family members, staff efforts were reciprocated; and that the knowledge acquired was used in day-to-day staff/patient interactions.

This can be really helpful…because you have something to talk about to the patient …if you take time to read it…then when they're agitated or upset you can sit down and talk to them about things they used to do and just try and interest them and get them settled again.

Nurse, Crane ward, Seaford Trust

On all wards, completion of formal biographical tools was very patchy; and when recorded, use was inconsistent. Moreover, unless these tools were employed as 'living' documents' and built on through subsequent interactions with the patient and family, they were of limited value.

Several wards had a strong culture of eliciting and sharing personally meaningful information about patients, whether informally or via such routine mechanisms as daily handovers and MDT meetings. This was a 'live' process, whether additional to or in the absence of, formal recording of biographical knowledge.

Dialogue with patients' 'significant others' was an important source of personally meaningful knowledge. Its collection and use was predicated on the value attached to engaging with relatives/friends routinely, particularly during visiting times.

At one end of the spectrum, there were wards, particularly, but not exclusively, dementia wards, where senior staff placed high value on nursing and care staff 'knowing the person' through ongoing conversations with family members. It was also acknowledged that organisational factors could act as impediments:

> We like to build up close relationships with the family where we can…just talking to them and seeing that staff talk to them…We try to encourage staff to walk around at visiting time and ask relatives: 'is there anything you want to know'… And [charge nurse] is very good at that. .. But it can be hard … because visiting times tend to coincide with shift end times.

> Manager, Netherton ward, Ironbridge Trust.

On some of these wards, a division of labour existed such that senior staff assumed primary responsibility for engaging with families. Observation during visiting times showed that these staff spent much of the time in conversations with relatives, both pro-actively seeking out particular family members, and conveying openness to talk when approached.

At the other end of the spectrum, there were wards where staff appeared more ambivalent about collaborative work with relatives. While acknowledging their importance in the person's life, they emphasised in their talk how family members' interests did not necessarily coincide with those of the older person. Stories of patients and families they had dealt with were recounted to illustrate the problem of inter-familial conflicts and divergent preferences of patients and caregivers regarding future care, including discharge destination. 'Close others' were often perceived as having 'unreal' expectations of what was possible in terms of recovery or what was feasible for services to provide. Their stance could be termed 'hesitant' collaboration: acknowledging the need to work with families to facilitate the person's recovery and onward movement, but viewing this as a source of stress.

Staff on most wards adopted a negotiated collaborative stance: families were viewed as a resource and source of support; but their interests and those of the patient might diverge and family members might not agree with each other about what was best for the patient. Nevertheless,

emphasis was on negotiating between different interests and views. These varied stances and their consequences are conveyed in the following:

> *It's very rare to have a 'difficult family' on this ward and I think that's because of all the good work that the nurses do, especially when there's terminal issues and … it's quite difficult for the family… The approach that the nurses take here because they have this interest and it's seen as the thing to do to talk to the family* [means] *it's noticeable how it's very rare I'll have a family that have got to the point of distress and aggravation …It happens a lot on other wards: you know, 'what's happening to my dad, no-one's telling me anything?'...Rarely happens here. 'No one's listening to my dad, no-one's feeding him', never happens here…*

Senior consultant, Ironbridge Trust

Valuing time with patients

Most staff emphasised that 'knowing the person', a pre-condition for delivering 'individualised care', meant spending time with people. Expenditure of time required that value was placed on talking to patients, and having sufficient staff to do it. As noted elsewhere, it was dependent on the legitimacy accorded to such work by senior staff, conveyed through formal supervision, team meetings and mirroring 'good practice'.

Time: a scarce resource

The ward care environment was a key factor in the legitimacy attached to spending time with patients; also significant was the support proffered by middle managers in proximate seniority to the ward. At this level, and reflecting wider demand and supply pressures, mixed messages were conveyed. In Seaford Trust, both study wards had secured a generous staffing complement in recognition of the complexity of their patient profile in comparison with wards elsewhere. However, they risked having staff taken off shift to support a neighbouring ward. The message they 'heard' was if they had time to talk to patients, they had too little to do.

Ward pressures created conflict between the aspiration to spend time with patients and the limits imposed by organisational constraints. The espoused value among senior ward staff that nurses and HCAs should sit with and talk to patients was compromised by staff sickness, vacancies and recruitment difficulties. As a consequence, staff often spent most of their shift 'on the move.' Time spent with patients was short and limited to encounters relating to the 'bodywork of care'[106] (washing, dressing, toileting, assisting with mealtimes) or delivering clinical and therapeutic care (observations, dispensing medication, mobilising). Similarly, periods of heavy demand as for example, during 'winter pressures' constrained time spent with individual patients.

'Knowing the person' with dementia

'Knowing the person with dementia' posed challenges at several levels: in the time and skill required to communicate with the person, especially with loss of language; and in the nature and depth of knowledge required to understand the person 'in their world'.

As described later, there were staff on some wards whose contact with patients with dementia was primarily limited to carrying out routine tasks. There were others for whom engaging with these patients was highly valued: spending time with them was a means through which a relationship of trust could develop. Further, knowing something of the person could provide an opening to pursue a conversation which in turn reinforced their 'personhood'.

> *Personally, I'd get to know them…sit and just ask questions about the past, what they used to do…communication is everything because if you can get something back from them…you can work on that and …build up a friendship…earning their trust.*

> HCA, Rivermead ward, City Trust

A different level of knowledge: understanding the person 'in their world'

For staff with understanding of dementia, 'knowing the person' involved more than biographical knowledge. It encompassed a deeper knowledge of the person including what was personally meaningful and what evoked emotion (whether positive, like joy, or negative as anger, irritation and distress). A pre-requisite to acquiring such knowledge was 'imaginative connection with the person' whether professionally and/or experientially derived.

Many staff had experience of working with people with dementia and they understood that being in hospital could be disorienting and frightening. Some, connected in imagination with the emotional impact of being in a strange place where patients were metaphorically *"pushed and prodded".*

> *A lot of people don't sit down and think, 'oh what would it actually be like if I had dementia'. and you think what it must be like: all them strange faces; we're coming at them; we're moving them; we're hands on them… what must that actually feel like if you don't understand what are going on.*

> Occupational Therapist, Cedar ward, City Trust

The process whereby care staff drew on their imagination to make a connection with the person with dementia was underscored by recognition, even if implicit, of their common essential 'personhood'. Seeing the person as 'someone like us' appeared central to valuing and engaging with them.

Communicating with patients, particularly those unable to express themselves verbally, required considerable time and complex skill set. Being attuned to observational cues did not mean that one

could easily interpret people's needs. Spending time with the person to seek out and make sense of observable action and reactions was also necessary.

> *… sometimes they'll be trying to get up and you think they're just trying to get up but really they need to go to the toilet but they can't voice that. So you have to be able to judge… And it … does get quite difficult to understand what their needs are, what they're trying to communicate with you if you don't spend a lot of time with them…*

Staff nurse, Crane ward, Seaford Trust.

For staff on dementia wards, overlaying the salience and value attached to 'individualised' care was how to make it work in a meaningful way, taking account of the complexity of delivering such care in practice. This required a particular form of 'knowing;' seeking to understand and respond cognitively and emotionally to where the person was at 'in their world' i.e. how they experienced reality.

In the following, the nurse explains why it is necessary to understand the patient, 'Daniels', perspective. Daniel did not communicate verbally and often hit out at staff during personal care. In describing working with him, she highlights the significance of physical contact and of trying different things to find out what works with each person.   She notes how important it is to understand that Daniel's dignity has been compromised by his condition and that staff have a role in sustaining it, even if Daniel is not aware.

> *Daniel can't take instructions, he doesn't understand instructions.   So really you can understand why he gets so frustrated, because if we didn't understand something, if someone spoke to us in a different language and tried taking our clothes off or something like that we'd start hitting out.   So … we have to understand where he's coming from, we have to get in the mind set of him. Do you know where I'm coming from? How do you do that? Holding his hand, he likes to hold people's hands, he shakes people's hands, he smiles, laughing, if you say something. So you laugh with him and say, 'Oh come on then Daniel'. He does like that, that's the thing. But we've also got to remember if he knew what he was doing he'd be absolutely mortified. It's not that man, the man that we, that his family know … that's sitting down and likes to eat, and likes to laugh and joke about with you. It's not the man in the bathroom. The man in the bathroom is completely different and he's scared more than anything; you can see that he's scared… What we've found is … hold his hands and talk to him face to face, get eye contact and then someone changes him from behind. Then it works out better.*

Staff Nurse, Denton ward, Central Trust

This account exemplifies several distinct features of the work of 'knowing' and engaging with the person with dementia in a positive way. It demonstrates how personally meaningful knowledge derived from multiple sources can assist with interpreting embodied communication. It underscores the importance of interpersonal skills, including the sensitive use of touch and eye contact, to convey empathy. It illustrates the need for specific knowledge about dementia and how it affects the person. Alongside openness to embodied communication, it is understood that communication

is imbued with meaning, although this might not be immediately 'knowable'. It recognises that there is an element of uncertainty and unpredictability about how the person will respond in a given situation such that strategies to engage him/her are emergent, built up through trial and error and will likely involve creative, tailor made solutions. It was often this distinctive knowledge and skill that staff, particularly those providing direct care, reported that they lacked.

People with dementia as 'other'

There were wards where some staff expressed in their talk embedded assumptions that people with advanced dementia particularly, had lost their 'personhood'. The language they employed in informant interviews, conveyed the sense of the person with dementia as 'other'. People with dementia were a collective or group ('the dementia patients'), characterised by their 'problematic behaviours', typically 'aggressive' and 'wanderers'. The 'dementia patients' were viewed as posing difficulties for staff, who derived little personal or professional satisfaction from working with them: *'we duck and dive to avoid being hit',* and *'we spend our days trying to keep them in the ward safe and not fall'.*

This conception of 'the demented patients' as 'other' was associated with the view that such people had no place on general wards but should be in specialist units. Although this view was atypical among staff in this study, unlike other research,[27, 29-32] it was found among those without personal or work experience or knowledge of dementia. Referring to the challenges of working with colleagues who lacked such knowledge, one interviewee commented:

> *Some of them say 'we don't want to work in here because of the dementia people, how they behave'. I do feel for them to be honest because if they had the knowledge and the skill, I don't think anyone could say that…*

> Staff nurse, Ambridge ward, Valley Trust.

While poor dementia knowledge was commonly attributed to temporary staff, including Bank and agency workers, the picture was more complicated. Routine reliance on temporary staff tended to reflect organisational instability including staff shortages, poor team morale, and changes to the ward profile and model as a consequence of bed closures and re-organisation. Organisational instability in turn exacerbated the problem of creating and sustaining a care environment that supported 'personhood', thereby ensuring that the ward team mirrored respectful practice. Thus:

> *No I wouldn't say that was shared…*[conception of 'individualised care]. *We don't normally talk…We just come to work…and do what we're supposed to do, then we go home. It would be nice if one day we sat down as members of the team in this ward to talk about things; the challenges that we have and what it is that we can do with that.*

> Staff nurse, Ambridge ward, Valley Trust.

Now, drawing on ethnographic observation and patient case studies, we consider how care was accomplished in practice for people with dementia, how this varied between wards, and the implications for what 'quality' care might look like in this setting. We set the scene by conveying in broad outline the rhythm of ward life.

Accomplishing Care: Ward Routines and Practices

Routines

The daily routine and tasks that comprised it had a similar shape and content on all acute wards, although timing and degree of flexibility varied.

On some wards, the day for patients started early – around 6.30am, as night staff began washing and dressing the few patients awake. Activity in corridors and by the nurses' station began with the arrival of the early morning shift at 7am, albeit bays and rooms remained in semi-darkness. Nursing handover from the night shift signalled the start of the new day. Each patient was briefly discussed, whether settled during the night, adverse events that transpired, action to be taken during the day, and snippets of information gleaned from patients during the shift, shared (*'whenever we talk about home, she becomes teary and doesn't want a care home'*).

Staff were allocated a working area – often one HCA for each bay and one Nurse for two bays. After handover, dispersal of staff to their work locations signalled washing and dressing patients, and preparation of breakfast. Most wards allowed a degree of flexibility in the order of these activities; but for all wards this was a pressured, busy time, the aim being to get patients ready before the arrival of the rest of the multidisciplinary team. On some wards, the lights were turned on in the bays straightaway, on others, 'lighting up' of patient areas was pursued at a more leisurely pace. Staff moved from patient to patient seeing who was awake and who needed help with toileting and washing. Domestic or cleaning staff were often present from this time.

Breakfast was typically served from 8am onwards: the clatter of trolleys added to the chatter of staff as they greeted patients; moving quickly in and out of bays and rooms with trays. On all wards, there were those who required either direct help or coaxing and encouragement to eat, tasks that could occupy a HCA with a single individual for 30 minutes. With one or at most two staff in a bay of five or six patients, several of whom required assistance, patients who just needed encouragement might be overlooked or left waiting. Although personal care tasks were the primary domain of HCAs, a strict division of labour between nurses and HCAs was atypical. On most wards, once it seemed that sufficient progress had been made with getting patients up, and breakfast was underway, around 8.30 or 9am, nurses would begin medication rounds. This was another pressured task, as

different patients might need medication before or after eating, or pain relief in advance of seeing the therapist.

From 9am, the pace of work shifted up a gear with the arrival of other members of the MDT – therapists and doctors, phlebotomists, pharmacists, porters, the ward clerk – adding to the cacophony of sounds: telephone ringing; buzzers buzzing; trolleys squeaking; and patients calling out. To the external observer, the picture conveyed was of ordered chaos as each professional went about their specific tasks, working through with patients: doctors doctoring; therapists mobilising; nurses medicating; and care staff moving quickly in and out of bays assisting with care tasks. The multiple and competing demands on staff during this period meant that calls for assistance were not always responded to speedily, particularly when a patient required help of more than one staff member with personal care. Shouts of: *'too late; I've done it…the bed's a mess'* were not uncommon as assistance with toileting wasn't responded to quickly enough; adding to the pressure on staff and the distress of patients.

By late morning, patients were dozing or propped up with pillows, and those well enough to get up were dressed and sat on a chair by the bed; the ward round was underway and therapists occupied in one-to-one work with individuals. On several wards, the placement of tables and chairs in spaces in or between bays, facilitated conversation between people; however with the exception of Netherton and Denton (dementia wards), on most wards there was limited or no collective space for activities or interaction. Where communal rooms existed they were rarely used by patients; more often by staff. Wards varied in the extent to which patients used the ward space beyond their immediate location around the bed and in the bay. On some wards, it was unusual to see patients moving about the bays and in the corridors. Although partly due to lack of space and people being unable to move due to frailty, pain or hip replacement, it also reflected the care environment. On some wards unsupervised movement was discouraged as symptomatic of 'wandersome' behaviour, thereby placing patients at risk of falling. On others, staff tolerated the risks and patients could be seen walking about, albeit staff kept an eye out for, or were ready to provide supportive assistance to, individuals whose mobility was poor.

Mid-day and the round of mealtimes, toileting and dispensing of medication resumed. It was common for staff to have spent most of the morning into early afternoon from 7am to 2pm on their feet apart from a short break mid-morning.

On several wards, open visiting from late morning saw a trickle of visitors, often encouraged to assist their relative/friend with eating. On most, visiting times were scheduled for up to 2 hours from 2pm, and up to 2 hours from 6.30 pm. In practice, there was considerable flexibility: where patients

were very ill, when visitors had come a distance, or had simply arrived early. The steady stream of visitors in the afternoon altered the ward rhythm as movement and noise emanated from patients and visitors. Their departure heralded repetition of routine tasks: meal, clinical observations, toileting and then visiting again. The exiting of visitors in the evening was the signal for commencing night work. Formal handover from day to night staff reversed the sequence of the early morning: and another busy period of putting patients to bed, toileting, and medications began. For patients, dimming of the central lights in the bays signalled the days end, although movement within bays and between beds, bays and toilets continued into the night.

The apparent orderliness of the routine was deceptive. Moaning and shouting out of people in distress, a flurry of activity with the arrival of a new patient on a trolley, the pacing of a patient by the entrance to the ward anxious to leave and being remonstrated with by staff, a sudden crisis event such as a patient collapsing or falling, punctured the order. For several people with a cognitive impairment on each ward, the period late afternoon/early evening often presaged extreme agitation and distress manifested in shouting out, pacing up and down the bay and corridor, disruptive to other patients and difficult for staff to manage, many toward the end of a 12 hour shift. For staff too, the semblance of orderly transfer from the day to the night shift could be disrupted and protracted: crises or staff shortages during the day meaning that the 'day' jobs weren't completed to time. Although the 'burden' of organising and managing completion of the shift 'work' fell heavily on senior ward staff, the unfinished tasks were also assumed by nurses over-extending the day shift and adding to the 'night' work.

Practices

From comparative analysis of fieldnotes within and across sites, we could discern a continuum of practices supportive of, or barriers to sustaining personhood and the organisational, spatial and care environmental factors that shaped them. We report on three inter-related illustrative features of practice: communication, toileting and continence (exemplar of personal care) and responding to distress. How staff communicate with patients may contribute to patient distress or ameliorate it; and staff responsiveness to requests for assistance with toileting will be shaped by the ability of patients to convey their needs and by ward organisational and environmental factors. Our intention here is to draw out what might be the dimensions of 'person-centeredness' in practice in the specific context of the acute ward.

Communication

A common critique of nursing practice generally[107,108] and care of people with dementia specifically from research[17-19,21,22,24,25,29-33] is the dominance of task versus 'person-centred' communication.

Practice in our study, even at baseline, was considerably more differentiated and nuanced than this binary conception implies.

A continuum of communication practices was discerned. At one end of the spectrum were wards in which interactions between staff and patients were viewed as opportunities to communicate with the person with dementia at a social and emotional level. At the opposite end were wards where staff/patient communication concerned tasks relating to care, clinical or therapy work. These encounters could be suffused with warmth and concern; they could also entail lack of responsiveness to expressed emotion that was painful for researchers to observe. Among most wards at baseline, the communication style was mixed along a continuum between these extremes: varying levels of personally meaningful communication and/or inconsistency within teams.

Personally meaningful and engaging communication

On both dementia wards, there existed a consistent and coherent care ethos among senior staff that 'knowing the person with dementia' was fundamental to care that recognised the individual's 'personhood'. Spending time with patients and relatives was legitimised by senior staff and mirrored in how they went about their daily work. It was reinforced in individual supervision and mechanisms for team reflection and practice review (ward-based training and regular events, as bi-annual away days).

The field note below illustrates how these staff employed a personally engaging communication style with patients while carrying out routine tasks. This form of communication was an expectation on all staff, irrespective of role, as an essential feature of care delivery. The time of the encounter is pertinent in that the ward rhythm from early through late morning was observed as 'hectic' with staff continuously on the move.

> *Field note: 10.30am Friday*
>
> *In one of the male bays there are five men each sat next to their bed… Two care staff come into the bay and begin to make up the beds, changing the sheets. They chat with Max as they do his bed, initiating conversation with him about his travels in South Africa: 'why did you like to travel'? Although Max has only been on the ward a couple of days, they clearly have some knowledge of his personal history. A conversation ensues, moving on to his proficiency in different languages.*
>
> Netherton ward, Ironbridge Trust.

In their conversations, staff drew upon their knowledge of the person and built on it to communicate at a personally meaningful level. The process both reinforced the person's sense of self and offered reassurance and sense of security when the person was confused, disoriented or distressed.

In the following episode, a staff nurse sat at the patient, Annie's, bedside. With poor ability to communicate verbally, Annie had periodically conveyed observable signs of distress and agitation (moaning and pulling at her jumper). As well as reinforcing the significance of personally meaningful knowledge to facilitate engagement, there were features of this encounter that typified a style of communication that sought to connect with the person: use of touch; and of positive emotional memory to alleviate distress.

Field note: Saturday 14.45

Staff nurse Ellie comes into the bay and goes over to Annie. She sits down by the bedside and takes Annie's hand in hers, looking directly at her: 'Where's your lovely smile, Annie?' Annie responds with a wide smile looking at Ellie. 'Annie, would you like to sing with me, that song you've said you really like'? Ellie begins to sing: Lady in red. Annie joins in, hesitantly at first; then more confidently; she knows most of the words. Ellie remains with her singing and talking for about 15 minutes until called away.

Netherton ward, Ironbridge Trust

Over the afternoon, several staff came to sit with Annie, using touch and voice to connect with her, illustrating a collective team response (also highlighting how such encounters could be cut short as a result of the myriad, competing demands made on staff).

Although not every interaction on these wards was conducted utilising this personally engaging style and not every staff member had the level of inter-personal skill seen above, this was the dominant mode of communication with people with dementia and was regarded as an expectation about 'the way we do things around here'.

Task focused communication

Varied forms of task focused communication could be distinguished on all wards: respectful and warm; minimal verbal exchange; and communication unresponsive to patients' expressed emotion. These different forms could be construed as more or less problematic depending on context.

Respectful, warm and task focused

Here the content of the exchange was related to the task, although the form was warm and respectful. The episode below unfolded over 20 minutes after lunch, a lull following the 'busyness' of meal-time.

Field note: 13.10 – 13.30

From one of the bays, I hear Edie talking in an agitated fashion. I look in, she's sitting on the chair by the bed and is pulling at the blanket covering her legs…'You're c…', Edie says to no one in particular. Different staff members pop their heads into the bay briefly, acknowledge Edie but don't go in.

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Edie speaks out at intervals over the next ten minutes…Now she is slumped over a bit, her eyes closed…no one has been in the bay for the past half hour.

Two staff go into the bay: 'Edie, Edie'…they call her in a cheerful and friendly tone of voice. Drawing the curtains around her, they again say her name to waken her/get her attention. 'We'll just get you into bed'. She laughs…they chat together – how is she feeling, does she need anything – as they help her into bed. She responds as if she enjoys the company and attention.

Ambridge ward, Valley Trust

This form of interaction typified more episodic staff/patient exchanges, as for example, of doctors and pharmacists.

Minimal verbal exchange: total focus on task

These were interactions in which there was limited verbal communication with patients as staff concentrated on the task. In the account below, following a brief salutation, care tasks were performed in relative silence and without explanation with an un-well patient, who had severe dementia and limited verbal facility.

Field note: 12.40pm

I sit in the bay. The patient (Alice) is sitting in her chair; the food arrives. The nurse puts it on the table in front of her and says "that's yours"; without making eye contact, she walks away. Alice sits up and moves forward to the edge of the chair. She slowly picks up the napkin and unfolds it; ignoring the food, she plays with the napkin: folding and unfolding it. After 5 minutes another nurse arrives, gets a chair and sits beside Alice. She physically assists Alice to eat, cutting up her food and taking the spoon with food to her mouth for the next 10 minutes. There is no talk between them. With food still on the plate, the nurse writes in what appears to be a food chart and leaves. Alice seems aware of food on her plate but doesn't eat any more.

Beech ward, Central Trust

What elevated these encounters with people with dementia as diminishing of their 'personhood' was the dissonance between the personal nature of the task (physically assisting the person to eat) and the way it was done.

Communication unresponsive to patients' expressed emotion

This form of communication ignored or at least was unresponsive to the patient's embodied and emotional cues. In the first example below, the patient appears disoriented to place although she expresses this quietly, more as a question than as evident distress and addressing no-one in particular until a nurse enters the bay.

Field note: 16.55

The lady in bed 5 talks quietly but audibly; she is not addressing or looking at anyone in particular. I don't know if she is aware we are here. She says 'where am I' repeatedly and 'put my head up' and at one point when a nurse comes into the bay exclaims: 'please!'. The nurse says 'I wish I could, I wish I was an octopus' and asks down the corridor 'is Joan about? To sit somebody up'. A HCA comes in and she and the nurse then pull the curtain around bed 5. They adjust the patient's position and give her instructions: 'hold on to that…we need you to hold on to that so we can help you'; 'put your head up.' The lady makes a noise. One staff says to another: 'It's no wonder our backs are absolutely knackered'. The curtains are drawn back and the patient is sitting upright on the bed with her head on the pillow. The food on her tray has so far been untouched. The table is drawn up within the patient's reach and one staff member stays to assist her with eating, spooning food into her mouth and talking to her a little, 'you need to eat something'.

Oak ward, Valley Trust

Although staff respond to the request, 'put my head up', the question about where she is, is ignored. Over the next hour she continues periodically in a low voice: 'where am I,' until she falls asleep.

In the further example, the patient exhibited distress (moaning and crying out), repeatedly asked for her mother, and at one point reached out her hand as if seeking comfort. Although the two staff assisting her focused on making her physically comfortable, they did not respond to her at an emotional level.

Field note: 11.40

All the patients in the bay are in bed, in their nightclothes. A nurse and HCA have been with Peggy; the curtains are pulled around her bed. I hear both staff giving Peggy instructions, asking her to move. She calls out 'ah!' (sounding like in pain) repeatedly for most of the time they are with her; then she quietens down. She says she's cold, and 'I love me mother'. Neither staff makes a response to this. When the curtain is drawn back, Peggy now faces forward a little more, still lying down and largely facing upwards. She continues talking 'where's me mother? She's looking after me?' She moans as though in pain from being moved, 'my legs, my legs'; talks about her mother, and 'please, help'. The HCA and nurse don't engage with her talk. At one point, Peggy reaches her hand toward one of the staff whose hand is nearby; the staff member moves her hand away, intent on what she is doing [very sad to watch]. Having completed their task, they both leave the bay.

Cedar ward, City Trust

Engaging with people with dementia at an emotional level, particularly where the person seemed in a world unrelated to the reality of the here and now, was viewed as difficult for some staff. Even so, inability to 'see' and respond to embodied communication and empathically connect with the patient's distress, could exacerbate it.

There were several wards in which little personally meaningful communication was initiated by staff generally with people with dementia, although some individuals responded to patients' expressed

emotion, offering reassurance and empathy. On most wards and for most staff, task focused communication occurred in some contexts, most commonly in a warm and respectful manner. Even so, there was considerable variation in the extent to which the style of communication staff adopted was responsive to expressed or embodied emotion, particularly with patients who had little or no verbal facility or were perceived as being challenging to manage.

Mixed communication styles

Even within the same wards, staff neither adopted a consistently personally meaningful nor consistently task focused, communication style. Variability is vividly illustrated below.

> *Field note: 10.25 am -11.45 am*
>
> *10.25: In the bay, I see Pat fiddling with her cover as she murmurs: 'oh dear'…then : ' Joyce, Emma, I'll come over to you' … 'don't let me fall'. A nurse calls from behind another patient's curtain to ask 'what's the matter'. Getting no reply, she continues with what she's doing. Pat continues to murmur.*
>
> *10.45: Two doctors on ward round approach Pat. As the other patients in the bay watch with apparent curiosity, one doctor introduces himself: 'Good morning, how are you? Do you feel OK'? Pat responds: 'yes'. Each subsequent question from the doctor is responded to with 'yes': ('have you stood up and walked yet? Have the physios been? Can you show me your tongue? Are you drinking enough water'? He asks if she knows where she is and she responds 'in hospital'. The second doctor comments to the first that she was in retention, and they proceed to discuss symptoms and diagnosis as she's asked to breathe in and out. They agree to put her on antibiotics. They thank the patient; tell her to drink water and move on to the next patient.*
>
> *11.45: Pat starts murmuring again. Her neighbour in the next bed asks what is wrong but she doesn't respond. The associate practitioner (AP) who is in the bay goes over to Pat; crouches down to Pat's level and takes her hand: 'Are you comfortable?' Pat asks when she can go home. 'You can go home when you're eating and drinking better – that's why I'm nagging you'. Pat responds: says 'you're not nagging, you're very nice people'. She tells the AP she's not a big eater, who responds in a reassuring tone of voice: 'I know' and asks if she puts a small portion on a smaller plate could Pat manage to eat a bit. Pat responds with 'yes' but she cannot remember what she's ordered.*

Poplar ward, Seaford Trust

Although the patient appears disorientated to place (thinks she is falling) and person (calling for Joyce and Emma) and is distressed, she answers the doctor's questions appropriately. The doctors focus on physical problems (hydration, mobilisation, elimination, cardiac and breathing difficulties), and perform a cognitive test in conversational style, although they also talk over the patient about symptoms. The AP using body language (touch, bending down to Pat's eye level) tries to elicit what is wrong – comfort, hydration, nutrition – and suggests a solution to Pat's verbalisation of the problem (anxiety about going home) and immediate issue (smaller portions of food). With time and patience, Pat is enabled to express anxiety and her immediate need.

Communicating with patients with limited verbal facility was challenging for staff. It demanded time and work to interpret the meaning of their expressive gestures and emotion. It also required understanding that these had meaning as intelligible manifestations of a social, relational and embodied self.

Toileting and continence

Of considerable significance in ward routines was the 'bodywork of care'[106] relating to toileting and continence. Ordinarily a private act, on the hospital ward, it had the character of a 'public', medical event. Bowel and bladder functioning was an ongoing topic of talk of staff with patients during clinical observations and in medical encounters, as for example on ward rounds. In daily handovers, issues relating to urine output and bowel movements were a focus of discussion as observable indicators of infection and explanation for increased confusion. In MDT meetings, incontinence, particularly of faeces was regarded as a key risk factor in need for 24-hour care, particularly if the person lived alone or could be at risk of falling during the night. Thus, assistance with toileting was more than a care task; it assumed clinical significance.

For patients, toileting was an essentially private act. In context of dependence (immobility or loss/reduced control of bowel and bladder), the management of, and staff responsiveness to needs with toileting was a major source of anxiety. Among those who were incontinent and wearing pads, the physical sensation of passing urine or faeces and consequently feeling wet and dirty, contributed to their distress. There were many occasions during observation and conversations with her when Brenda, a 90-year old patient with dementia on Oak ward, indicated she needed the toilet and pressed the buzzer. Although Brenda had been provided with incontinence pads during her stay, these did not alleviate her fear of 'accidents'. The urgency of her need meant that the response was often not quick enough and she felt unclean and embarrassed that staff had to deal with the dirty pad and '*wipe my bottom'. S*he tried to get out of bed several times during the night. While this was interpreted as 'wandering' by some ward staff (her case notes indicated that she had delirium earlier in her admission and tried to climb out of bed), for Brenda's family, it replicated her practice of getting up during the night in her own home to go to the toilet. On the ward, it served to reinforce the professional assessment of her as a 'falls risk'.

With regard to illustrative tasks of care, we distinguished between types of staff response, namely: *anticipatory; enabling; sensitivity to the emotional significance of practical needs;* and *the task as object of the work.* These were shaped inter alia by the care environment and ward context, specifically place (physical environment) and time (what happened and when).

Anticipatory

This pattern is exemplified in practice on Netherton ward. The ward physical environment facilitated staff 'seeing' observational cues and anticipating needs. The four six-bed bays while separated from each other by ceiling height walls, opened directly on to the main corridor with a waist high wall between bay and corridor. The two main patient toilets (separate male and female with visible signage) were located in the corridor near the centre of the ward. This area was used as a shared patient and staff space: both groups were observed seated around the table and chairs placed here. The ward clerk was usually based in the nearby, small nurses station with space only for a computer and trolley on the desk and trolley with patients' notes alongside. From the corridor and shared space, patients in the bays were in sight of staff; staff were also allocated to work in a particular bay (or single rooms), although they helped each other when needed. With the exception of the three single rooms, staff and patients were visible to each other.

As noted above, there was an expectation on staff here that they should spend time with patients. They were also sensitive to observational cues to expressed need by people who had limited ability to use language. This is illustrated in the scenarios below which occurred at different times of the day and evening, indicating that the response was not time dependent.

> *Field note: 11.20am*
>
> *Gabbi moves out of the bay using her frame. She stops, looks around at the entrance with a puzzled look on her face. A HCA sees her: 'Do you want the toilet, Gabbi?' Her face lights up and she nods. The HCA suggests that they walk together and at the toilet door, she opens the door for Gabbi and waits outside. The HCA says to a staff member nearby: 'That's normal' (Gabbi frequently needs the toilet, but needs orienting to get there).*
>
> *Field note: 16.00*
>
> *Tom, who is very frail and wobbly on his feet, makes his way out of the bay toward the toilet. The discharge co-ordinator notices him: 'Is he alright?' A HCA goes over to help him as he's getting agitated – maybe he's disoriented. He walks with Tom to the toilet, waits for him, then he guides him back to his bed when he's finished.*
>
> *Field note: 20.55 pm*
>
> *Paul is walking again. A nurse chats to him, notices he is pulling his trousers a bit. She discreetly asks him: 'Are you wanting the toilet?' 'Pardon'? She repeats the question. 'Yes', he says. 'Come with me, we'll go together.*
>
> Netherton ward, Ironbridge Trust

For people with dementia, orientation to and from the toilet posed a difficulty and even if mobile they required assistance in finding their way.

Enabling

These scenarios illustrate another aspect of practice, namely the enabling approach adopted. Staff provided an unobtrusive steer while supporting patients' own initiative, guiding them to the toilet and back to their bed. They only provided support if necessary, checking this out with the person. This attention and effort of the team in assisting with toileting flowed from the value they attached to being responsive, and enabling of independent action. Encouraging and assisting patients to walk to the toilet contributed to the goal of optimising mobility. This work was transformed from a chore to an opportunity to support mobility, part of the broader objective of sustaining residual competence and skills.

The anticipatory, enabling approach to this task was observed across the team, including the ward clerk. All staff (in various roles and at different levels of seniority) were observed to be responsive to individuals needs for assistance. Although HCAs' most often followed through with help, others were vigilant in picking up on patient cues. Staff ability to anticipate need necessitated shared knowledge of the person; knowledge also communicated informally to team members who might be new and therefore not 'in the know'.

Sensitivity to the emotional significance of expressed need

'*Sensitivity to the emotional significance of expressed need*' is illustrated in the scenario below. Once the practical need was identified, it was responded to by the senior nurse immediately. She 'listened' to the patient's distress to ascertain the nature of the problem and to provide reassurance at an emotional and a practical level. This episode occurred during the morning rush.

> *Field note: 07 50 am*
>
> *A lady in side room 3 comes into the corridor. I talk to her a little. She looks upset, and tells me that she needs the toilet. I see the manager in the corridor helping another patient... I tell her about the patient in room 3 and she makes her way toward the room. A nearby HCA notices and says that she checked with this lady and that she didn't seem to have had a bowel movement. The patient clearly feels unwell. The ward manager asks her if she is constipated. She starts to cry. The manager gets her to sit down, kneels in front of her and talks to her...The patient weeps a little... she says she wants her husband. The ward manager reassures her that her husband will be coming later and she will give her medication to deal with the constipation.*
>
> Rivermead ward, City Trust

Constraints on responsiveness

Awareness of need was shaped by the physical environment and staff availability during periods of intense activity. The physical layout of some wards and the siting of single rooms did not allow for easy visibility of patients such that staff could anticipate their needs unless the staff member was in their vicinity. This included, for example, single rooms at a distance from the nursing station and/or separate bays organised as rooms with full height walls and doors that when closed did not permit visibility of patients. In order to 'see' what was happening in the bays (and single rooms), staff had to physically enter them. Although a HCA was usually allocated to each bay, during 'busy' periods there were times when there were no staff in a bay, having been called away to provide assistance elsewhere.

There were also specific times during which constraints operated to affect responsiveness: during handover from day to night staff; during busy periods and at night when staffing was much reduced. Although individual staff might have experiential and skill based knowledge of people with dementia and/or the capacity to make empathic connection with patients' experience, their ability to anticipate need and respond pro-actively was limited by the physical and organisational context.

The following scenario occurred during the busy morning period. Responsiveness to the patient's request was affected by the multiple, simultaneous tasks required of staff and the priority attached to some, such as medication administration. It was not permitted for dispensing nurses to leave the medication trolley unattended, so that their physical presence in the bay did not denote availability to respond.

> *Field note: 9.00 am*
>
> *A patient in the bay tells me she would like to go to the toilet. I go to the nurse who is giving out medication. The nurse presses the patient's buzzer; the HCA comes back into the bay, sees the buzzer and the nurse says that the patient wants the toilet. The HCA says to the nurse that the patient has just been and that she is behind with the breakfasts. She then goes over to the patient and asks her 'can you wait a minute or are you desperate for the toilet?' The patient replies she can wait. Five minutes later she buzzes again; this time a nurse comes and takes her.*
>
> Rivermead ward, City Trust

On most wards, as here, nurses and HCAs' helped each other out with requests for help with practical tasks; similarly, senior staff were actively involved in care, conveying in their practice the value attached to this work, and mirroring collaboration between staff having different roles and responsibilities.

The task as object of the work

This is where the task is pursued simply as a job to be done. The staff member responds to the request but there is no interpersonal exchange. So for example, the person may be supported to the toilet but it is done in silence.

Experience of distress and the response

Patients on acute wards are at high risk of experiencing distress: pain and discomfort as a consequence of being ill and the medical procedures carried out on them; anxiety about the potential for recovery; and fear about their ability to resume valued aspects of life and which give pleasure. There is additionally the sense of loss of control, particularly acute for people with dementia. For these patients as well, their distress is compounded by the effects of the condition that both impacts negatively on capacity to make sense of, and negotiate an 'alien' environment; the temporary absence of familiar artefacts and people that provide a 'handhold' to a concretely present reality or to past memories;[109] and the loss of 'competence' that ensues as a consequence of the unfamiliarity of faces, places and routines. These affect how people feel and act. Another source of distress is disorientation and heightened fear from hallucinations that accompany forms of delirium or acute confusion[118-120] from which patients with dementia are at particular risk.

Disorientation and feeling 'muddled' were common sources of distress among patients with dementia. Bridie, unlike many others with dementia on our study wards was able to articulate her disorientation. In a conversation 'in the moment', she described the myriad ways in which she felt muddled': being in a strange place where *"you don't know what to do or what's expected of you"*; where *"it was tiring"* trying to figure it out, to work out *"what the rules were"* and *"to be doing things you're not used to"*; where other patients too *"don't know if they're on their head or their hands"*; where it can *"be different every day"* and you're *"not used to chaos in your life, are you*?" It wasn't nice, she added, *"to be muddled up all the time"* not just yourself but others as well: *"you can't just put all these people muddled up together and expect them to be happy"*.

Many patients with dementia were unable to verbalise their needs and conveyed their distress through behaviour and action. We can delineate different forms of distress and staff response to them: episodic distress, in respect of an immediate unmet need; persistent distress, the source of which was unclear and which appeared impervious to action by staff or at least only temporarily; and distress manifested as agitation, verbal aggression or hitting out. Whereas some forms of distress called forth an empathic response; others elicited fear, anger and restraining action that addressed the behaviour and not the person.

Episodic distress

This is distress in context of an unmet need, the nature of which might not be immediately evident, and /or required interpretation on the part of those responding. In the example below, knowledge of the person was initially drawn upon to engage with Peter. When this did not alleviate his distress, a discussion between the two HCAs who observed that he was fiddling with his hearing aid, suggested an alternative source and approach.

> *Field note 11.30*
>
> *Peter appears very agitated. He is fiddling with hearing equipment, calling for his wife, then 'help me. I want to go home'. The HCA in the bay knows him from a previous admission, know he likes singing and tries to encourage him to sing, without success. She speaks to her colleague and they consider that his hearing aid might need new batteries. They agree to ask his wife about it when she visits. Later, Peter is observed as more settled; his hearing aid is working and he's singing: 'Singing in the rain'.*
>
> Poplar ward, Seaford trust

Recognising that distress was an appropriate response and didn't necessarily need to be 'fixed' required particular sensitivity on the part of staff whose role emphasised 'doing':

> *Field note:*
>
> *A HCA stands at the table writing, the lady in bed 4 starts to cry. The HCA notices and goes straight to her, asking; 'what's the matter? Are you in pain'? The patient shakes her head and says 'remembering' (a new song just started playing); the HCA appears to realise that this is what might be triggering the emotion. She asks if she would like another song on. The patient says 'no' and shakes her head. The HCA offers a sympathetic tone, strokes her head, holds her hand, and says 'are they good memories?' The patient nods. 'Are you remembering all those dances you went to?' The patient says something I can't hear. The HCA stays with her a little. The HCA leaves her; the patient continues crying gently, looking straight ahead.*
>
> Rivermead ward, City Trust

The HCA simply and calmly asked the patient why she was crying, and understood that it was all right for her to cry, to re-live her memories, stimulated by the music. She offered her physical (stroking her head, touching her hand) and verbal comfort and left her alone, and seemed aware of her (checking back) after the song finished.

Persistent distress

There were always a number of patients on all wards who expressed persistent and observable distress – moaning, crying out, shouting – that was not easily assuaged. At most, an empathic staff response secured temporary respite, as for example, with Annie on Netherton, described earlier. Practical solutions, such as continually checking on the patient, asking if s/he wished to go to the toilet, or offering food, had no effect. Inability to identify from their repertoire of solutions to

practical problems how to temper distress gave rise to staff frustration and helplessness. Additionally, staff awareness of the impact on other patients added to the difficulties in responding. The following account summarises an incident from Rivermead, but such episodes were observed on all wards, evoking a similar response in most of them.

> *For several days, the researcher had heard Rosa crying from out in the bay. She called out for help and cried; appearing in deep distress. Staff went over to her periodically, asked her if she wanted to go to the toilet, if she was in pain, if she needed anything. Rosa didn't respond but continued to cry out. One particular staff member would sit for a little while with Rosa, holding her hand; when she left, Rosa resumed crying. Other patients on the ward were affected by Rosa's cries: 'It's hell here', the researcher overheard one patient saying to another.*
>
> *When the researcher returned to the ward several days later, she noted that Rosa had been moved from the bay to a side room which was some distance from the bays and the nurses' station. She continued to call out as before. The researcher noticed that as a staff member passed by the door to her room, she would pop her head in: 'are you all right Rosa'. Apart from engaging in routine tasks, staff didn't tend to stay with her. They told the researcher that Rosa also cried out when her relatives visited.*
>
> Rivermead ward, City Trust

One solution to the constancy of the expression of distress was to establish physical distance by moving the patient from a bay into a single room (Cecil's experience, Appendix 4). Although ameliorating the distress on other patients, it created dissonance among staff who aspired to being responsive to patient need.

Distress manifested as agitation

Where the person's expression of persistent distress included forms of action and interaction regarded as 'difficult' or 'unacceptable' such as shouting, swearing or hitting out, the response of staff was more mixed, evoking both empathic connection and 'telling off'.

> *Field note 11.00 – am; 12.30pm; 19.30-21.00*
>
> *Of the four beds in this bay, three of them (Beds 1, 3 &4) have a flower above the bed, indicating that the patient in each of these beds has dementia. All of the patients in the bay are in bed and wearing their night clothes. During this observation, there are multiple streams of activity. The woman in bed 3 is distressed or unsettled to some degree almost constantly: pulling her bedsheets off, fiddling with the sheets or her nightie, talking to herself, seemingly random and very loud shouts (often swearing, occasionally for help). Her distress sometimes fleetingly disappears and she smiles at staff. The woman opposite her in bed 1 is rattled by the noise and occasionally shouts over to her to be quiet; that she shouldn't be allowed to make that noise, it's not fair on others 'it's time she left'.*
>
> *Over the next hour, different members of staff approach the woman in Bed 3 and attempt various tasks with her: taking bloods and doing clinical observations. She refuses verbally and physically, pushing them away and appears unable to understand what they want. At*

different times, several staff come into the bay, talk to her politely, addressing her by name and make eye contact, but the patient's gestures and language are aggressive. No one stays with her.

At one point, the patient in bed 1 adopts a more sympathetic tone toward the person in bed 3: "what are you saying love? Are you alright? You don't look alright but then I suppose that's not up to me..." On each occasion, a staff member comes into the bay, they brightly say 'hello' to the patient in bed 1 – she generally presents as pleasant and chatty and appears easy to engage with.

The patient in bed 3 continues to talk to herself, fiddles with her blanket, swears frequently when shouting/talking. No one responds; she is isolated in her own world with these conversations. Then she looks up and says 'hello' and talks to me. For a few minutes she looks happy and relaxed. When she relaxes, her whole demeanour softens and she talks more calmly, and laughs often. She talks about where she lives and about her mother.

Observation mid-to-late evening reveals a similar pattern: the patient in bed 3 periodically talks to herself, lists names, counts them on her fingers and cries a little. During one of these episodes a HCA goes to her, takes her arm and rubs it gently, speaking softly, offering comfort. When she leaves, the patient resumes talking to herself and cries again.

Cedar ward, City Trust

Critical in supporting people with dementia on acute wards was understanding that there was an underlying meaning to their actions and interactions and that making a connection with the person in 'their world' was necessary in appropriately responding to them. The following example is illustrative.

Field note: 21.45pm – 23.40

Daniel, has been walking continuously up and down the corridor and in the bay since about 10pm. Now and again he stops, picks something up, puts it down, moves things about, straightens things or pushes them away (chair, bin). Other patients are either in bed or getting ready for bed; the lights are dimmed in one of the bays where everyone is in bed.

22.40: The nurse and HCA talk about how best to get Daniel to settle. They conclude that as long as he doesn't disturb other patients, they will leave him for a while.

23.15: Daniel is still walking in the corridor. I notice that he sometimes places his hand on his tummy/groin area or undoes or redoes his trouser fly. The student nurse, Maeve, notices this. She puts her arm around Daniel's shoulders, speaks to him using his name, holds his hand, asks if he wants the toilet and suggests they walk there together. He refuses; becomes more agitated. Maeve tries again five minutes later with assistance from the HCA– saying she can't leave him wet. This time he goes with her.

23.20: I can hear Maeve talking to Daniel in the toilet. He comes out, changed nightclothes on and pad changed. Maeve and the HCA help him to bed.

I hear Maeve and the HCA talking to each other about how Maeve managed to get him to the toilet and to bed. Maeve indicated it wasn't a problem in that once in the toilet, Daniel

just wanted to hold her hand and with this he was okay. They continued to share different ideas and solutions about what worked for different patients.

Denton ward, Central Trust

This episode occurred during the night shift with four staff on duty. Even so, staff responded with patience and effort, attempting to engage with Daniel and work collaboratively with him.

For staff without knowledge of dementia or skill in responding to it, focus on the behaviour as lacking purpose or meaning could elicit 'controlling' action.

Field note: 12.00-1.0pm

12.00: The male patient… walks around, sometimes standing still by the nursing station, he appears to be waiting to leave and occasionally voices that he wants to go or that he wants his money. Staff acknowledge him as they walk past, asking him to go to his chair and eat otherwise his food will get cold. He says he doesn't want food… But they don't stop; they are in continuous motion as they move into and through the bays.

12.15: The man is now waiting by the Nurses station and appears agitated. A member of staff walks past him asking 'do you want some pudding Mr X?' He doesn't respond and is clearly preoccupied with something else. He sees someone walk toward the ward entrance/exit and begins to follow. I hear him say 'bloody hell' (it sounds like the door has closed). A member of staff down the corridor calls to him 'come back down here for us, I can't run'. He mutters 'stuck here all day'. He walks with a stick, wearing jeans, a nursing gown, and a jacket. He says; 'I need my money, I keep telling her, I should be home now'. He starts to walk slowly toward the female end of the bay, the ward clerk is near and asks him: 'what's the matter', using his name, and saying he doesn't want to go down that side, suggesting he go back to his bed. He replies 'oh I'm not stopping'. He becomes more agitated, saying he's been waiting two hours and wants his money. Someone suggests he sit down (meaning in the bay; he goes to the nurses' station and sits down… He mentions money again …Staff nearby discuss this patient, I hear 'he's suddenly just gone hasn't he…he was alright this morning.

Ambridge ward, Valley Trust

Despite awareness among several staff involved in the episode that the patient had become more confused, his agitation was attributed to the confusion and not perceived as having meaning. Staff were also focussed on it being lunchtime – mealtimes being one of the prioritised events of the day which for a short period consume most ward resources. However, repeated instruction to 'sit down', to go back to his 'bed' increased his agitation. Episodes, which similarly elicited an 'instructional' response included women patients standing near the ward entrance in the early afternoon who from their demeanour and talk were waiting for their children: *'where are the babies'.*

This form of 'controlling' action was also an organisational strategy on some wards, reflective of how patients deemed 'difficult' and requiring one-to-one support were 'managed'. This involved one to one assistance provided by 'specials' or 'sitters'. These included Bank or agency HCAs in Valley;

mental health trained nurses in Central; and security staff in Seaford. Typically, these 'specials' engaged in surveillance and control: sitting or walking with the patient either in silence or with short, sharp injunctions to 'sit down,' 'don't do that'. The determining factor in the response was how the work was defined, namely as control and management, and not the experience or profession of the staff member. On other wards, 'specials' were employed as an extra pair of hands to aid a group of patients or a bay, which could be a positive experience for patients.

Summary

The conception of 'person-centred' care held by staff mirrors that in policy and practice. Meanings were multiple and varied, although most commonly understood as 'individualised care'. Drawing out what this might mean for patients with dementia, provided a nuanced and particular account.

Comparing and contrasting actual care delivery, we discerned a continuum of practices from those which were supportive of 'personhood' to those that undermined it, and features of the organisational, environmental and cultural factors that shaped them. Our findings reinforce and extend what good practice might look like on acute wards from previous research,[20,54] and concretise the significance of embodied communication in engaging meaningfully with patients living with dementia.

CHAPTER 5

PROCESS OF PIE IMPLEMENTATION

Introduction

This chapter examines PIE implementation over 18 months. This focus on process over time conceptualises improvement interventions not as single, discrete changes but 'facilitated evolution'.[110]

Not all wards proceeded to PIE adoption. We distinguished between: 'full implementers'; 'partial implementers' and 'non-implementers'. 'Full implementer' wards pursued change over 18 month broadly as intended (two wards within a single Trust). 'Partial implementers' were located on a continuum between those which made some progress but did not persist to full adoption (two wards in two different Trusts) and those that were lost early on during installation (two wards in the same Trust). 'Non-implementers' did not even begin PIE installation (four wards in three Trusts) (Table 11).

Table 11: Pattern of variation in PIE implementation

Full Implementers		Partial Implementers				Non Implementers			
Seaford Trust		City Trust	Ironbridge Trust	Central Trust		City Trust	Valley Trust		Central Trust
Poplar Ward	Crane Ward	Rivermead	Netherton	Beech	Rose	Cedar	Ambridge	Oak	Denton

Stages in Implementation

Initially, we examined these implementation patterns as they unfolded in time. First, we compared the constellation of factors that shaped PIE implementation on wards that varied in the extent to which the process was pursued. Second, we compared implementation processes between wards to discern generalisable features that might account for variation.

We found it useful to draw upon a stages-of-implementation framework from a review[69] of implementation research to explore in more depth the factors that contributed to progress (or were barriers to it) at each stage. The framework comprises four stages (Box 1).

Box 1: Stages of Implementation[69]

> **Exploration and adoption:** making a decision whether to proceed based on the match between the needs of the organisation, assessment of the intervention as relevant and the resources required to carry it through.
>
> **Programme installation:** active preparation to begin implementation, for example introducing the programme to staff, recruiting people to lead the work, and organising training.
>
> **Initial implementation:** first steps in making change happen. Typically a challenging period when confidence in the decision to adopt is being tested and the implications of the resource investment are becoming evident.
>
> **Full adoption:** programme becomes fully operational.
>
> **Innovation:** period during which the programme is being refined and expanded; desirable changes are being considered for inclusion as part of routine practices.
>
> **Sustainability:** the goal at this stage is long term survival of the practices introduced.

In this study, *exploration and adoption* occurred through informal discussion and meetings with senior ward staff and middle managers at directorate level about participation in the research, what it would involve, and securing their signed agreement to invest the necessary support and resources, thereby meeting our 'readiness' criteria. *Programme installation* took planning for change a step further through the preparatory work of implementation: facilitating PIE workshops and identifying staff to take part with a view to comprising the PIE team. The phase of *initial implementation* started with observation, the first step in the improvement cycle. *Full adoption* involved completing a full action planning and review cycle. Stages of *innovation* and *sustainability* entailed embedding change in routine practice.

All wards had gone through *exploration and adoption,* nevertheless further preparatory work by the research team was necessary to support first steps in PIE installation. Less than six months after agreement to implement PIE, organisational changes impacting on wards (for example, temporary and permanent moves to new locations) and personnel moves involving key staff at ward and middle manager level, meant that relationships had to be developed anew with incumbent staff in leadership roles. Additionally, negotiation on the organisation of the preparatory workshops and securing attendance of staff who would comprise the PIE team, was pursued ward by ward, drawing on our evolving knowledge through fieldwork, of staff with interest in dementia care and respect of their peers.. The fluid and dynamic nature of large organisations means that this first stage is unlikely to occur as a once-and-for-all agreement.

Full Implementers

Engagement with PIE to Programme Installation

Both Seaford wards implemented PIE to timescale over 20 months (February 2014 – October 2015, Poplar); and 19 months (May 2014 – December 2015, Crane). Each was located around the middle of the continuum in their responsiveness to patients with dementia and being person-focused in their practice (Chapter four). The first step in programme installation occurred with the introductory workshops. The recent establishment of a specialist dementia team in the Trust opened up the possibility of developing reciprocal linkages of mutual benefit to improve practice. Over several meetings with the PIE researcher, the dementia team lead expressed interest in the team becoming actively involved in PIE.

Workshops

Separate workshops were organised for each ward because of the geographical distance between the two hospitals. These occurred shortly after baseline and were intended for staff who expressed interest in assuming leadership of the programme. They comprised informally emergent dementia 'champions': nurses, HCAs and therapists involved in direct patient care; and senior staff both from the ward and those with a remit for service improvement (practice development lead, specialist dementia nurses). Participants expressed enthusiasm at taking part, and at the conclusion of the workshop made plans to get together and organise observations.

PIE teams

The wards differed in the composition of their PIE teams. The Poplar team comprised nursing and care staff at different levels of seniority (practice development facilitator, dementia nurse specialist, ward sister, staff nurses, HCAs and therapy assistant). Joint leadership was assumed by the practice development facilitator and dementia nurse. Both were external to routine ward work and had a developmental role in relation to staff on it. The dementia nurse had previously worked on Poplar and attracted considerable respect from staff. The ward manager was not a formal team member, but provided active support, facilitation and encouragement.

On Crane, the PIE team included the lead dementia nurse specialist, senior occupational therapist (Senior OT), occupational therapist (OT), two therapy assistants and ward sister. At the outset, direct involvement of front-line nursing and care staff was absent.

From Installation to Initial Implementation: A Critical Stage

The first PIE cycle on Poplar began after the introductory workshop. Five team members, working in pairs conducted five hours observation over different times of the day, including a week-end, in time spans of around an hour. For observers and observed, it was perceived as 'out of their comfort zone' at the beginning. 'Observers' found it difficult to look without acting; and the objects of observation, the 'observed' were wary:

> *'Why are you doing that?' … Now no-one takes any notice of us [observing] do they? …they see it as supporting them…and it's made everyone aware of dementia.*

> Senior nurse, Poplar

In this cycle, there was a gap of around six weeks between observations and development of action plans during which very little PIE work occurred. Local contextual and situational factors were implicated. The ward was temporarily re-sited because of refurbishment creating disruption for staff; this was the second move coming not long after the ward had moved to what was intended to be its permanent home. An immanent CQC site visit also absorbed energies of senior staff. Both contributed to difficulties for the team in identifying a mutually convenient time to meet, reflect on their observations and develop action plans..

Informal discussions between individual team members helped to sustain momentum; as the practice development facilitator supported by the dementia nurse acted as PIE 'drivers'. Together they reviewed the observations, agreed a process for communicating findings, and for extending discussion to the wider staff group. All observations were organised as *claims* (positive or favourable), *concerns* (negative or unfavourable) *and issues* (areas of potential disagreement). This method, from Fourth Generation Evaluation,[111] was being employed with staff across the Trust to engage different stakeholders on a common vision to improve care culture. Observations under each heading were captured on paper and displayed in the staff room, inviting comment.

The journey to initial implementation on Crane was considerably slower, compared to Poplar. Only one set of observations had taken place by the end of May and no work on action planning had occurred. Partly this reflected situational factors at ward level: the acting ward manager who had been supportive of the research, retired as implementation started. Ward leadership, for a period, was held by two acting-up sisters, one of whom was on leave as initial implementation began.

A new ward manager with a practice development background was appointed in June 2014. The research team proposed a second workshop to focus on action planning and to re-energise the PIE process. This was well attended including by the incoming manager. It generated renewed

enthusiasm and resulted in a planned meeting to organise further observations. Implementation resumed in August 2014, some five months after the first workshop, and the lead specialist dementia nurse assumed responsibility for steering PIE. Team members included a ward sister, senior OT who attended the workshop, and several of her staff (OT and therapy assistant).

Although both wards experienced some disruption (physical re-location and transition to a new ward manager) which extended the timeline from installation to initial implementation, such changes were temporary. Critical at this juncture in moving PIE forward was the pro-active role assumed by external 'drivers', and the role enacted first, by the Poplar ward manager and then by the new ward manager on Crane, as a facilitator, supporting and encouraging staff to get involved.

From Initial Implementation to Full Adoption

The first action plan developed on Poplar established several broad areas to work on, with short and medium to longer term action around communication, nutrition and activities. An important feature of action planning was how observations generated creative solutions to address multiple issues simultaneously. Box 2 presents an action plan around meal-times as a social event, starting in a single bay. Addressing several goals, it was initially directed at communication. It set in train a stream of work beginning with small steps, subsequently expanded to all bays through the process of appraisal and review (including new observations). An additional goal to which the initiative contributed was patient mobilisation; getting people up and moving between bed and tables.

Box 2: Poplar Action Plan: Mealtime as a Social Event

This action plan was developed through reflection and discussion of observation of a joint activity (creating a mural for the ward) involving patients on the ward and young people, part of a time-limited, intergenerational project. Patients, including those with dementia and limited language demonstrated enthusiasm and enjoyment and talked about aspects of their lives which had been unknown to staff as they took part in the activity. Reflecting on their observation, staff were surprised at what could be gleaned about people's lives through patients talking to each other in a convivial setting.

This prompted the plan to get patients to eat lunch communally (tablecloths, flowers) with music after, making it a social event. As noted in Chapter three, this ward had space for tables and chairs in the bays but these were primarily used by staff to do paperwork. It was agreed that this would start in one bay and extend to others depending on progress. It required negotiation with staff beyond the ward to pursue (infection control and catering) as well as agreement of the ward manager and wider team. With catering, for example, one of the issues raised was the size of meal portions: patients found that the standard portions were too large and therefore unappetising, and with support from the housekeeper, the contracted agency which supplied the meals, agreed. Sitting with patients at the meal allowed staff to observe patients dietary intake but unobtrusively. It was seen to work as a social event and as a means to encourage eating (the dietician who worked on the ward also became interested and involved in the work).

On Crane, implementation began in earnest following the second workshop and continued thereafter. For the first cycle there were four sets of observations, typically conducted in pairs, each an hour long, undertaken at different times and in different spaces. Plans arising from these included immediate action on nutrition: eliciting patients' food preferences and ensuring consistent use of food charts; initiating work to increase activities with patients, including engagement of dementia visitors in the work (a recent initiative via the Dementia matrons, these were volunteers who came to the ward once weekly) (Box 3).

Box 3: Crane Action Plan: Music as Stimulating Activity

One of the first sets of observations concerned the level of noise on the ward, in particular the constant music from the radios, which was felt to be mainly for the benefit of staff. Reflection on its potential adverse impact on patients with dementia (over-stimulation and increasing stress) and discussion within the implementation team about the therapeutic effect of music resulted in an initial short term action plan including: monitoring use of music for a week; discussing with patients about the music they enjoyed; eliciting ideas from staff about the appropriate use of music, including how to manage varied preferences (head-phones etc.); and using observations within the wider staff group to engage them in reflection about how they might feel if hospitalised.

Review of the action plans led to the introduction of music during lunchtime. It was noted that as several patients enjoyed singing along to the CDs, a further action plan was identified: to establish interest in having a regular singing session a couple of days a week; and to organise a trial with Christmas carols (meeting in December).

This example is illustrative of the emergent nature of implementation and change. Action plans evolved through the dynamic of action and appraisal of progress; this in turn opened up further possibilities which were not anticipated at the outset. Observation about noise from the radio resulted in a plan to elicit patient preferences about the music played on the ward; moved onto establishing music as a collective and purposeful activity at lunchtime; and then extended to plans for a regular monthly singing session as patients appeared to derive pleasure from joining in. Similar to Poplar, a small step at one level, could lead to a significant change in how things were usually done, with space and momentum created through the action planning and review process.

Full Adoption toward Sustainability

On Poplar, 'mealtime as a social event' had by the conclusion of the study not only been extended to all bays but was incorporated as part of ward routine. There were aspects of the initiative that required ongoing work based on experience: men appeared more reluctant to engage than women; and staff needed to consider which patients would get on with each other.

PIE observations continued periodically throughout the research. New issues identified and which resulted in immediate action plans to pursue included: ensuring that patients did not feel isolated, ignored or disconnected (e.g. leaving curtains closed around patients post-care delivery, being mindful not to exclude patients from discussions when within earshot, and regular checking that the clocks in the bays were accurate to time and date).

A persistent focus of action planning was provision of stimulating activities for patients who were well enough to take part but insufficiently recovered to be discharged, including puzzles,

newspapers, games and reminiscence resources (REM Pods). Plans required identifying staff time and sources of funding to purchase materials. By the end of the third improvement cycle, reviews indicated some positive change: staff sitting with, and encouraging patients to read and using pictures as prompts for conversation. Overall, these action plans were evaluated as 'partially met'. Engagement was constrained by staff availability which waxed and waned depending on demand, patient flow and level of patient acuity, which was unpredictable.

Over time, the composition of the PIE team changed as some members moved on and were replaced by new staff. Although never a formal member of the team, the ward manager continued to play a crucial enabling role; in supporting and encouraging staff to get involved in PIE and in facilitating communication of action plans to the wider staff group. Her commitment to PIE, the authority and legitimacy this gave to implementation work and the support provided to enable staff to take time out to do observations, were critical to the process. Her inclusive management style was a factor in involving HCAs directly in the PIE team. One HCA, when asked by the researcher why she felt able to take the initiative with PIE, commented: *"the ward manager treats all her staff as equals"* and *"there is no hierarchy here."* Another HCA, who took special interest in nutrition (which dovetailed with PIE action plans) also reported that her enthusiasm was due to the ward manager's encouragement. Apart from a period of absence (as a result of injury), she was present throughout the research but retired just as it came to a close.

On Crane, alongside 'music as stimulating activity' which expanded in form and content over time, new action plans identified and pursued included: encouraging patients who were well enough and near to discharge to dress in their own clothes during the day, not usual on this ward. This was viewed as supporting normalisation of the transition from hospital to home and encouraging independence. It was also aimed at nursing, care and therapy staff to increase person-focused interaction while they helped the person choose their clothes and assisting them to get dressed. Making this happen involved negotiating with relatives to bring in clothing and ensuring staff went about the work with individual patients.

Four PIE cycles were completed on Crane by the end of the study. Subsequent observations were shorter – around 30 minutes duration – to make the process manageable given the demands on staff time. Ward staff, not part of the PIE team, conducted some observations, extending its reach. An explicit objective of the manager, integrated into action plans, was to engage the wider staff team in discussion about change and provide opportunities for them to put forward ideas through team meetings and handovers. Inclusivity was valued as a principle of team working and a strategy to ensure staff 'buy-in' to change. For example, use of food charts was systematised through flagging up on handover sheets which patients needed them.

Trying out different ideas around activities to increase stimulation for patients was an ongoing topic of action plans, including encouraging use of reminiscence materials secured for the ward via the dementia team and creating themed 'memory boxes' to add to them. This work tended to proceed in fits and starts. Initially, it was very successful with support of the dementia visitor, a volunteer who came to the ward once weekly, and two nurses who were keen to take part. As on Poplar, success depended on demands, investment of time and staff was an ongoing issue particularly during winter pressures when the team helped to cover an additional six beds. The cramped nature of the environment and lack of separate space for patients outside of the bays, was an additional constraint. On this ward also, engagement in activities was assessed as being 'partially' implemented. The long term plan, advocated by the specialist dementia team, through the Dementia Strategy, was recruitment of an activities organiser to work with a number of wards, including Crane, to enhance activities for patients.

The composition of the PIE team for a long time did not extend beyond senior nurses, occupational therapists and therapy assistant. As therapists rotated between wards, this meant that individuals changed, although ongoing therapy involvement was maintained. More than 12 months into implementation, a staff nurse was 'recruited' to the PIE team. Even so, success in accomplishing specific action plans required active engagement of frontline staff, including nurses and HCAs (for example, music at lunchtimes, observational monitoring of nutrition intake and encouraging patients to dress in their own clothes). Strategies to enable 'buy-in' of the changes were both essential and contributed to translating plans into action on the ward.

Joint action between PIE teams

A cross site workshop and a significant event for members of both PIE teams, was held in spring 2015, just under a year following PIE introduction. This was instigated by the Poplar team. Ten staff from both wards took part, including the dementia specialist nurse from a third Trust hospital; the researcher was also invited. Networking between wards initiated through the meeting was important in facilitating a shift from PIE adoption to programme innovation.

The meeting provided opportunity for reflection on what needed to be done, using the claims, concerns and issues framework. There was considerable enthusiasm about being part of a process that actively involved staff on the front line in collaborative action to effect change, which in turn encouraged them to use their initiative to try out new ideas. They perceived a change in practice: increased use of the patient biographical tool, 'This is me' booklet; greater involvement with patients' families; and heightened awareness of patient experience as being at the centre of what they did. Concerns centred on time constraints; how to sustain PIE after the research ended; and

how to embed changes in routine practice. Ideas on joint action to pursue included: incorporating information on PIE into a general induction pack for staff; and involving all new staff in undertaking a short PIE observation with a link PIE team member.

Throughout the day, there were explicit linkages made between the PIE objective of enhancing person centred care and the Trust's Shared Purpose Framework; the criticality of the role played by the Dementia specialist team in championing PIE, which was also perceived as a vehicle through which aspects of the dementia strategy could be pursued. Both were viewed as operating in synergy one with the other.

Did Implementation Work as Intended?

Drivers, facilitators, teams and networks

We had conceptualised the process of PIE implementation as requiring simultaneous top down and bottom up leadership. This was encapsulated in a team involving senior ward staff, those at the 'sharp end' of care delivery, and practice development expertise to provide external support and a voice for PIE between the ward and middle managers. Even so, we considered that senior ward staff would assume a leadership role for PIE.

On both Seaford wards, the 'external facilitators' were the key 'drivers' of change. They were committed and motivated to improve care delivery, either as part of their broader role in enabling cultural and practice change in the Trust or because of their interest and remit to improve care of people with dementia. Ward managers also acted as 'drivers' of change, although not as we had envisaged. Instead, they were change 'facilitators'; on the one hand legitimating staff time and investment in PIE and on the other, extending its reach to the whole staff group. it was neither feasible nor practicable for managers to lead PIE; their day was dominated by work to ensure the ward operated in a smooth, safe and effective fashion. But the teams were essential too. Team members pursued action on the ward and also contributed to generating interest and enthusiasm among their colleagues. On both wards, although in different ways, the interface between members of the PIE team and wider staff group was an additional factor extending reach of PIE across the ward.

The role played by the specialist dementia team, extended beyond driving PIE at ward level. The establishment of the team was consequent on a Trust Board initiative; it had strong high level support and both formal and informal links with senior managers and Board. For the dementia lead nurse, PIE was conceived of as a vehicle through which the dementia strategy was pursued, and one method for achieving practice change for hospitalised patients living with dementia. This

encapsulated her vision of improvement through simultaneous high level strategic initiatives and ground level practice change. Nevertheless, maintaining this duality was perceived as an ongoing challenge for the team within a large, geographically dispersed organisation and several large hospitals serving very different catchment populations. Such a vision was not evident in any of the other study Trusts. Although high level support for PIE occurred through the dementia team's vertical and horizontal networks, staff on Crane and Poplar were actively involved in supporting the work of the dementia specialists in their respective hospitals, as for example, the Dementia cafes. Patients from both were observed being taken along to events by staff.

On Poplar, the practice development facilitator also played an important role in making PIE visible in the hospital and Trust through presentations to middle and senior managers, as an exemplar of a process of cultural change. The existence of a clearly articulated, unifying vision by the Trust with explicit goals for quality improvement, was aligned with the change model pursued in PIE. PIE was conceived of as synergistic with key strategic Trust priorities and therefore as a legitimate target for investment of time and resources.

PIE Change Process

Full adoption and routinisation of PIE in Poplar and Crane enables us to draw out how and in what ways the change process as envisaged was carried through in practice; and conversely what was different here compared to partial and non-implementer wards.

Implementation spiral

We envisaged implementation proceeding in cyclical and sequential fashion: through observation, reflection, action planning, action and review. Interest was in whether the functions reflected in each step were necessary. In practice, the process took the form of a spiral with simultaneous reviewing, amending action plans and actions in pursuit of them, alongside identifying new action plans, all at the same meeting. As actions were reviewed some were abandoned as unworkable or an unnecessary addition; others became fully embedded in ward routines, becoming part of ward culture ; yet others were extended beyond the areas in which they were tried out. This was most pronounced on Crane ward (see Figures 22 and 23). Thus, although each step was a necessary component of implementation, change occurred as an interactive spiral movement.

Conduct of observation

The manual and guidance regarding observation suggested that observations could be conducted in pairs over about an hour, each observer focusing on several patients (focus on individual patients was the approach adopted in the NAD, influenced by DCM). While initial observations on both wards proceeded in this way, subsequent observations were much shorter. In part, the involvement of several pairs of staff at different times and in different locations built up a composite picture of patterns of action and interaction that fewer observations over a longer time span could not achieve. In part, it made the conduct of observation feasible in context of a busy ward; and distributed the experience of doing observations among a larger number of people. Similarly, focus of observation broadened to include not only patients but ward routines and how these impacted on patients. These changes were incorporated into the manual.

A feature of the conduct of observation, emphasised in guidance and reinforced in the workshop, was that in their recording and feedback to staff, observers should convey what was positive about practice as well as what needed to change. Thus observations were aimed at simultaneously establishing objectives for change and ensuring that staff continued to feel valued, motivated and engaged in the improvement process.

On both Seaford wards, in presenting feedback, the PIE teams refrained from direct criticism of individual colleagues' communication practices. Nevertheless, it was evident from action plans that staff communicative practices featured in one way or another in most of them: in the emphasis placed on expanding opportunities for socialisation and interaction between patients and staff and between patients themselves; and in making the quality of the encounter with patients central to routine work (for instance, action on encouraging patients to dress in their own clothes had the dual of objective of staff spending time with patients while they helped them to dress).

Documentation

Completing PIE documentation on both wards often took place following on from the action planning meetings, since it required both time and access to writing space. This had implications for the timing and flow of action. Since it was team members with designated office space, namely the practice development lead on Poplar and lead dementia nurse on Crane who undertook this task, it was completed post-hoc when time permitted. It was often reliant on the researcher's contemporaneous record of the discussion (the researcher, attended upon invitation, nearly all of PIE meetings).

Although the content of PIE documentation was seen as useful, providing a broad framework to consider goals and steps to achieve them, it was felt to involve unnecessary duplication. The need for simplification was discussed with the research team and revised documentation was developed, tried out and shared with other sites. Over time as the action planning and review process became embedded, meeting notes that conveyed the rationale for action and review provided a steer for framing and appraising goals and progress; and the action and review forms simply summarised action points. In this respect, the systematic format for structuring action plans and reviews appeared necessary at the outset to implement a different way of working. As the process became embedded, there was less reliance on the format to make change happen i.e. local adaptation occurred without compromising the function.

PIE and NPT

On both wards, although implementation was neither smooth nor linear, each of the change steps was necessary and facilitated movement forward. Observation and reflection sensitised staff to aspects of routines and practices they had previously taken for granted; once observers resolved their initial wariness as to whether they were doing it 'right', observation was viewed as feasible, enjoyable <u>and</u> offered new insight. Thus, the process generated coherence among PIE team members and increased interest and motivation to move to the next step, action planning (cognitive participation). Collective reflection and discussion on observations gave rise to creative action to effect change which was perceived as meaningful and worthwhile (collection action). The work of negotiating step changes with different team members taking responsibility, reinforced coherence, participation and action. Actions involved different PIE members in ways which provided opportunity to reach beyond their existing roles (for example, HCAs on Poplar). Simultaneous review of progress (appraisal), modifying goals and action plans and extending existing work into new areas generated by experience of plans in action, further enhanced coherence and cognitive participation. PIE was seen as a useful and effective means of making change happen.

Several aspects of PIE implementation on both wards add further insight into the mechanisms of change, and therefore how the NPT framework could be further elaborated on in particularly complex and dynamic environments, as acute wards.

First, to achieve 'normalisation' of new ways of doing things, strategies to generate mechanisms of change (coherence, cognitive participation, collective action and appraisal) needed to occur at multiple levels. It was not sufficient for the PIE team to make sense of the intervention, to distinguish it from their current ways of working, and to buy into the work as a worthwhile investment; front line staff also had to be engaged. Without their active participation, the depth

and reach of action plans to achieve coverage across the ward, would not happen. In this, the ward manager as 'facilitator' assumed a key role in in enabling this to occur. On both wards, strategies to secure engagement in the change process beyond PIE teams were actively pursued through established routine fora, for example handovers and board rounds as well as staff meetings and supervision.

Second, there was the dynamic environment of acute wards. Staff turnover was one aspect of this; another was the unpredictability of the pattern of ward work. Staff turnover affected both PIE teams: a HCA on the Poplar team moved on from the ward within a couple of months of the first cycle; and the rotation of therapists on Crane meant that individual team members changed regularly. There were no difficulties in recruiting new people to replace those who left; itself indication that PIE was valued and worthwhile.

Unpredictability in the work pattern derived from the particular conjunction of patient need and profile at any one point in time; and the variable weight of demand on routines and practices. 'Winter pressures' were often cited as contributing to high demand but in actuality duration was elongated as the additional beds extended from November to June. Sustaining understanding and 'buy-in' to PIE (coherence and cognitive participation) required processes for renewal. For example, involving an interested individual to do observation, paired with a more experienced team member, proved useful. Time and situational factors pertaining to work patterns and flow meant that coherence and cognitive participation might require re-invigorating prior to securing collective action. Maintaining morale and belief in the possibility of change during periods when demand on staff surged, required flexibility in devising and implementing action plans.

Evaluating progress through appraising action, and delegating aspects of the work to different team members with appropriate support, had potential to reinforce coherence, participation and collective action; and to extend and deepen reach of the action. Critical appraisal and reflection on why actions were not pursued as intended, whether alternative strategies to reach the same goal needed to be considered, or whether the goal should be changed, also improved action planning. The generative mechanisms then operated interactively, between levels and over time, and not in linear fashion. Sustaining momentum in a dynamic environment meant that the generative mechanisms theorised as necessary to 'normalise' new innovations in practice were not once off achievements but had to be re-worked until they were no longer recognised as new but simply part of 'the way we do things'.

Organisational Context

At Trust level, PIE implementation was bookended by a negative CQC inspection report and outcome which resulted in the Trust being placed in 'special measures'; although care on medical wards, including older peoples' wards was judged to be good. Implementation took place between the first visit by the regulator in March 2014 and ended (for research purposes) with results of the second visit in November 2015.

While work relating to the CQC inspection, subsequent outcome and responsive action dominated the business of the Trust Board and senior managers, it did not appear to impact directly on PIE progress or the day-to-day work of the wards. Related issues, including changes in personnel at Board and senior management were similarly not seen as directly affecting ward organisation and practices. What appeared decisive was that despite these events, Trust strategic priorities remained unchanged. Action taken by the Board in response to the findings of the inspection included intensifying the drive to engage staff at all levels in joint work to translate shared values into improving services. For ward staff, the factors which had most resonance for organisation and care delivery were demand on beds and availability of resources to facilitate the timely flow of patients in, through the ward and transitioning beyond it. The systemic pressures staff on Poplar and Crane experienced in relation to these were a constant. They occurred before and after the Trust was placed in special measures and were not exacerbated by the remedial action taken by the Board. We return to this in comparing the experience here with City Trust, which also received a poor CQC rating about the same time as Seaford, with very different consequences for PIE.

In addition to the general problem of demand and flow, there were specific contextual features of Crane which influenced PIE implementation in practice: ward design and layout, and the cramped nature of the space. The latter in particular made PIE observations by staff difficult, since there was no obvious place from which to discreetly observe patients and staff. The lack of a dayroom, much wanted by staff, meant that, as with Poplar, finding a meeting venue was problematic. Latterly, the OTs offered one of their rooms off-ward, when not in use. On the creation of hubs at each site (resource rooms where events were held and CPD material was freely available), meetings were held at the site hub. Ward factors also included recurrence of norovirus which twice meant ward closure and a halt to PIE activity (and delayed fieldwork).

Partial Implementers

There were two 'true' partial implementer wards and two others that took faltering steps to PIE installation. Located betwixt and between partial and non-implementation, we discuss them under non-implementers; although intending to proceed, in actuality, movement was cut short very early.

Over a period of 12 to 18 months, Netherton and Rivermead moved through the phase of initial implementation, but did not proceed to full PIE adoption. Interest and enthusiasm carried senior staff on Beech and Rose wards (Central Trust) to PIE installation; but both just crossed the threshold into initial implementation and did not go further. They are discussed with Denton ward, the third ward in this Trust, which although characterised as a non-implementer is not qualitatively different in the implementation stage reached compared with Beech and Rose, having stalled at the boundary of initial implementation.

Engagement with PIE

Rivermead and Netherton were initially 'slow' to get going (not dissimilar to Seaford wards); then moved forward with initial implementation, albeit in fits and starts. Neither, for varied reasons, proceeded to full PIE adoption.

In terms of practice with patients living with dementia (Chapter four), staff on Netherton were observed as being at the high end of the quality continuum; those on Rivermead were in the middle, similar to Seaford wards.

More than other PIE wards, Netherton in Ironbridge Trust had in place multiple facilitating factors that augured positive engagement with PIE. The introductory meeting with staff revealed a passionate commitment to continuous improvement in care delivery for their patients, directorate level support to facilitate the research, and interest among the training and practice development team to assist with PIE. Senior ward staff had worked together over a long period and had created a cohesive team.

The ward team in Rivermead, was similarly long established and cohesive. The manager was very supportive of improving care of people with dementia and had worked closely with the practice development lead (who was identified as the external 'driver'); both had particular interest in dementia care.

Senior staff on both wards had interest in delirium; understood the value of delirium screening and worked to facilitate collection of DOS data as part of routine nursing observations.

Workshops and PIE teams

The Netherton introductory workshop in early November 2013 was attended by a nucleus of seven staff, at different levels of seniority and roles (manager and charge nurse, staff nurses, HCAs and an occupational therapist attached to the ward) who would form the PIE team. Training and practice development staff also took part, the intention being that they would support Netherton in

implementing PIE. Feedback on the workshop was very positive and ward staff indicated willingness and enthusiasm to get going.

From Rivermead, nine staff attended the PIE workshop in February 2014 (two Sisters, two Staff Nurses, three HCAs, housekeeper and therapy assistant). Their composition reflected engagement and interest among the staff group in a diversity of roles. Although they did not formally constitute themselves as a PIE team, there was tacit understanding that they would take responsibility for leading on PIE with support of the Trust's practice development lead, who would steer implementation on the ward.

At the conclusion of the workshops, both wards had plans underway for PIE installation: actual and virtual PIE teams and identified support outwith the wards. Some aspects were tentative: how a loosely organised team would work (Rivermead); and how practice development support would contribute to PIE (Netherton).

Initial Implementation: A Sticking Point?

Following the workshop, at the instigation of the Netherton PIE team, the site researcher met with them to discuss the process and tasks. The ward manager suggested she would lead PIE and that they would carry out practice observations to build their confidence during December. The first PIE cycle began in earnest with observations from mid–January 2014. These were conducted over a two hour period in pairs on two occasions, at different times of the day (mid-morning and afternoon). Staff initially felt inhibited and anxious, concerned that colleagues might act differently knowing that they were being observed, similar to Seaford. Afterwards, they met to share reflections.

Observations indicated positive features of practice (staff responsive and reassuring with anxious patients; encouraging interaction between patients; offering choice of food and drink and going to it straight away; ward clean; patients in bed appearing content; others up and about in the day room and corridor). Feedback was provided to staff on shift and welcomed as acknowledging the strength of team working. Immediate action was initiated from these observations. The introduction of short, staggered staff breaks in the morning to ensure responsiveness during a period when staff were relatively invisible in the bays (observed as buzzers going unanswered, and patients being left longer than usual for assistance); and attention to the temperature of the ward for patients who were inactive by offering blankets (staff constantly in motion did not notice).

Over the following two months (February/March 2014), further observations occurred involving all seven PIE team members and practice development co-ordinator. Additional support anticipated from staff at directorate level did not materialise. Apart from individual examples of a particular

patient being ignored or a dozing patient not being offered a drink, observation elicited a picture of responsive practice; an image with which the ward 'outsider' – practice development co-ordinator – concurred. A facilitation meeting between members of the research team, PIE team lead and senior charge nurse, was held in early April 2014 to support translation of observations into action plans. It was reported that plans were being developed from the second set of observations, on reducing noise in the morning and increasing activities.

By summer 2014, six months after initial implementation began, progress had stalled. Examination of action plans from previous observations by the research team revealed difficulties in moving beyond a general 'wish' list to identify specific steps and devolution of responsibilities to achiever them. For example, although use of volunteers to support activities such as reminiscence, exercise groups, games etc. was identified as an action, as was increasing activities provided by staff to patients, concrete steps to take these forward were vague ('manager to pursue'). Indeed, from informant conversations with PIE team members, although they concurred with the objective of doing more stimulating activities with patients, they felt that this could not be done within their existing staff complement. Similarly, engaging volunteers was viewed as a good idea, but the steps to make it happen had not been worked through.

The research team offered a further half-day workshop to consider action planning and review , held in August 2014, when interim data collection was to start. Five PIE team members attended, including two senior staff. Anonymous ethnographic observations were used to explore practice in its organisational context. These were intended to provoke discussion of factors shaping practice that might be focus for change without 'blaming' individuals; and to work through action planning around concrete examples. Evident from discussion was the openness of the team to debate aspects of practice that were regarded as contentious (use of language and terms of endearment with patients). The workshop appeared to generate renewed enthusiasm as had previously occurred with Crane. It was agreed that they would develop an action plan for discussion with ward staff at the forthcoming six-monthly staff away-day in November (to which the researcher was invited). Thus, as the PIE implementation phase approached nine-month interim data collection, there was prospect of resumption.

In Rivermead, similar to Seaford wards, nearly three months elapsed between the introductory workshop and the first set of observations. In May 2014, three pairs of staff (three HCAs, a housekeeper, nurse and ward manager) conducted observations at different times of the day: early afternoon, teatime, and late evening, over two hours on each occasion. Reflections on observations occurred informally afterwards. Despite the number, range and length of observations, documentation revealed a relatively superficial portrayal of practice and goals for improvement,

largely related to professional 'visitors' to the ward (pharmacists, phlebotomists, porters and medical staff). For example, positive features of practice were greeting every patient when entering the bay; contrasted with poor practice such that 'visiting' professionals did not do likewise. Observers here were mainly care staff; posing the question as to whether their social location made it more difficult to raise issues of practice; in other sites observations were undertaken by a more hierarchically diverse group. Yet, feedback with the researcher revealed that observers had 'seen' and noted little interaction between staff and patients for long periods in the evening, but since it was interpreted as requiring additional staff to resolve, did not feature as a goal for change. 'Knowledge' of the problem was uncontested; their judgement that they were powerless to act on it impacted its utility as a focus of action planning.

Informal conversations between virtual PIE members occurred to discuss observations but no formal meeting to pursue action planning took place. The practice development co-ordinator who was to provide a steer for PIE implementation had taken up the post of matron shortly after the PIE workshop. Although she had negotiated time for PIE, her working life was absorbed by organisational demands: staffing shortages and a wide-ranging re-organisation of ward models and bed closures, following a poor CQC inspection (inadequate staffing being a particular focus of concern). The ward manager was also on sickness leave in the month following observations. Similar to Netherton, the PIE implementation record had stuck on observation.

Starting Again

In Netherton, the away day in November 2014 was attended by half the ward team (a second day was to involve remaining staff). Discussion on PIE was facilitated by the site researcher and PIE team. Ward observations were considered in groups charged with identifying priorities and action plans arising from them. Deliberations (recorded for the PIE team to work on afterwards) were wide ranging, generating lots of ideas, varying from staff training in working with patients deemed 'challenging' to reducing bed numbers to allow for more time with individuals. From subsequent discussions on the day, senior staff appeared preoccupied with changes occurring at ward level: what they perceived as increased medical acuity and dependency of their patient profile, a push from managers to speed patient flow (a recent managerial directive to all wards required reduction in length of in-patient stay), and concerns around staffing, particularly loss of a qualified member of staff 'taken away' to cover neighbouring wards as the hospital entered 'winter pressures'.

Following the away-day, action planning stalled again; the length of time since observations had taken place and the changes in the ward patient profile since then were arguments proffered by

senior staff to carry out a further set of observations. These were organised with external support from practice development/clinical education colleagues. This would be a new start.

A second PIE cycle was begun in February 2015 with 'external' ward observers. Observations were conducted over a week at different times and locations. As before, feedback was very positive, reinforcing the picture of person-focused practice. As a means of reinforcing and celebrating the quality of care delivered on the ward within, and to their professional peers beyond, PIE observation was successful. The OT who had conducted some observations with colleagues took the initiative in writing up action plans from them but was reluctant to assume a leadership role in PIE, viewing her position as a 'part-time' member of the ward team (nurses and HCAs' perceived as the 'core').

In the months that followed, prompts by the site researcher revealed little further progress; the PIE team had not met. This remained the position at the end of December 2015. Their difficulty in developing action plans (recognised by senior ward staff) suggested that a contributory factor was a ceiling effect around identifying areas for improvement at least in context of existing resources. The staff group (and senior staff) had many ideas for desired changes but they were seen to require additional staffing.

Final data collection was delayed as timing coincided with a CQC inspection; interim had also been delayed because of infection and ward closure. Timescale for study completion meant that a further round of data collection was not feasible.

In Rivermead, informant conversations between the researcher and PIE team members between July and September 2014 reported that ward staff were working day to day; there was neither time nor 'headroom' to do more than get through the daily routine. 'Winter pressures' beds (an additional five) were still open on the ward: they closed and re-opened the same week in September. The matron (external PIE lead) continued to be enmeshed in work around staffing, bed closures, and ward re-modelling . The research team offered a workshop to help with moving PIE on; it was not taken up.

With autumn behind and winter approaching, anticipation of increased demand made the prospect of resuming PIE remote. Senior staff indicated that while the team had made positive changes over the years 'in the small things' (respectful of patients dignity and privacy), moving to the next step required a more fundamental examination of their practice and review of resources. Yet the daily pressures on staff made this 'out of time'.

Late December 2014, the matron held an action planning meeting with the PIE team. Action plans were discussed and the team was to develop and consider them with the wider staff group. The

confluence of elapsed time since the observations, demand pressures on the ward and long term sickness among established staff, resulted in no further work on PIE.

Interim data collection began in January 2015, a heightened period of 'winter pressures'. Observation indicated no discernible improvement in practice that might be attributable to PIE, unsurprising given that implementation had not been pursued.

Partial Implementers: Barriers and Facilitators

Drivers and teams

On both 'partial implementer' wards, leadership (or rather its absence) was a barrier to pursuing PIE. Nevertheless, the form it took and its relative weight in interaction with organisational and ward level contextual factors differed between them.

On Netherton, the ward manager assumed the PIE leadership role but only partially enacted it, and participation of the 'external' facilitator, who had helped with observations, was not called upon to assist in driving PIE. The OT took on some of these tasks, going through observations and completing documentation on action plans. In light of her perceived peripheral position in the team viewed her role as supportive only. This suggests that external facilitation is critical to successful implementation, albeit aligned with the active support and encouragement of the manager, as on Seaford wards. The work of ward management, being the bridge between patients and staff on the one hand, and the organisation on the other in an ever changing, dynamic context, made it difficult, if not impossible to assume leadership of PIE as well. The strength and cohesiveness of the senior management team suggested that it might be different on Netherton. It was not.

Yet, the ward had invested considerable resources in observation, including involvement in additional workshops and meetings aimed at energising the PIE process. Staff were enthusiastic; and senior staff actively facilitated time to conduct them. This included people who were not members of the PIE team, as for example the ward clerk who played a pivotal role in the smooth running of the ward. Their principal difficulty was in translating observations into meaningful action to take practice forward.

We hypothesise that two linked features of the care environment are implicated, providing a plausible, explanatory account of the inability of Netherton to proceed to full adoption: the high quality of practice on the ward; and the existence of well-established mechanisms and processes to pursue continuous practice improvement. The positive picture of practice conveyed through use of the tool was consistent with baseline and interim data collection (observation and interviews with stakeholders external to the ward). Analysis revealed a strong, shared ethos of person focused care

and high value placed on all staff in spending direct time with patients (and relatives) as an essential component of their day to day routine. From data presented in Chapter four, Netherton was one of two wards in which understanding and practice of person-centred care for people living with dementia was most highly developed (Denton being the other). This was enabled and reinforced through team reflection, discussion and review via away days; and built on routinely through handovers, supervision, mirroring and applauding good practice. Although the problem was not 'solved', and would always be a work in progress as evidenced in the new challenges posed with a potentially altered patient profile; the mechanisms they had developed to effect change were not obviously wanting. In this context, the PIE observation tool offered a systematic and novel approach to enhance their systems, but the rest did not offer benefits over and above what already existed. Ward staff had not abandoned goals for change: often expressed were organisational goals to which they aspired: a reduction in the size of the ward to allow them to provide more one to one support; and staffing levels that would enable them to deliver therapeutic care and stimulating activities.

The PIE team in Rivermead was more of an informal group of staff who had worked together with the ward manager over a long period and who had particular interest in improving the care of people with dementia on their ward. Apart from the manager, they comprised mainly unqualified and support staff (HCAs, housekeeper and therapy assistant). Similar to Netherton, although they conducted multiple observations, they experienced barriers in translating their observations into meaningful action plans that could take practice forward. Their difficulties could be viewed as reinforcing the necessity for, and form of the PIE 'driver/team' model; the inclusion of a staff mix to ensure authority and legitimacy of the change process, vertically beyond the ward and horizontally among their peers. The ward manager while supportive and encouraging assumed a mainly facilitative role, necessary, as observed in Seaford, but insufficient to provide effective leadership of PIE on account of ward demands. If the matron had been able to 'drive' PIE as intended, this would have enhanced the legitimacy of the action planning process and provided staff with the confidence to challenge practice. Her inability to do this was an expression of the wider, organisational context. Even so, there were also indications that one of the difficulties in pursuing action plans that would make a difference was staff belief that they were impossible to pursue with their existing staffing. Evident then were multiple and interacting contextual features that elucidate the interaction between an innovation and its context and expressed in such comments as: *'we're as good as we could be with the resources we've got'.* In both partial implementer wards, although for different reasons coherence and cognitive participation of PIE as aa vehicle for change initially secured, was lost.

Vertical and horizontal networks

Absent on both Netherton and Rivermead were what we termed vertical and horizontal networks linking the action on PIE beyond the immediate environment of the ward to wider networks of support on dementia, as in Seaford. In part, this reflected the absence of an external driver who could provide such a link; it was also affected by the perceived lack of congruence between the direction pursued within the Trusts on the immediate priorities for action on dementia and focus of PIE on ward level practice change.

There were other dementia improvement initiatives being carried out in City and Ironbridge Trusts. Unlike in Seaford, these operated in parallel with PIE and there was no interchange between them. In both Trusts, recruitment of 'dementia champions' was a key element of the dementia strategy; and the champion model broadly operated in similar fashion in both.

In Ironbridge, focus was on developing a dementia champions network with two champions in each area (clinical and non-clinical). The requirement on them was to attend a minimum number of meetings a year and to raise awareness of dementia within their work spheres. The aim was to generate interest among staff at all levels, thereby building awareness of dementia in small steps from what was considered to be a low base of understanding. Staff on Netherton expressed impatience at the evolutionary nature of the approach: improving ward practice needed to be addressed and focus on enhancing general awareness would not achieve this. As the Seaford Trust experience indicated, there is no necessary conflict between adopting parallel approaches (practice change alongside enhancing general awareness). For Netherton staff, the lines of difference were an expression of what they viewed as the low priority attached to patients with dementia with high level needs. In City, the vision conveyed by the matron who played an important enabling role in the dementia champions initiative was that once the 'champions' were in place on each ward, they could use PIE to improve practice. This initiative too was affected by organisational upheaval and there was little indication over the course of fieldwork of diffusion of the dementia champion's network and its reach into wards to improve practice.

Organisational context

In comparison with the other 'partial implementers', the organisational context in Netherton and within which PIE was being introduced, was relatively stable and benign. A process of integration of the Elderly Care Directorate and Community Services was underway during interim data collection, and although it involved senior ward staff in additional work, it was perceived as a welcome development.

Micro-system change at ward level, was a perceived shift in the patient profile from baseline. During interim data collection a persistent topic of staff informant conversations and interviews was that the patient profile had become more medically acute and physically dependent. As an ongoing presence on the ward, the researcher was conscious of the level of emotional and physical work undertaken by staff to maintain a pro-active and responsive approach, to relieve and manage distress and agitation among people with delirium and dementia, and to sustain a relatively calm environment.

Patient data collected at interim supported staff perception of a change in the patient profile. The age and gender profile was similar for the two time periods, as was the prevalence of dementia (93% and 98% respectively) and delirium on admission (80%). At interim, however, a fifth of patients were admitted from long term care, double that at baseline. The mean length of stay had also reduced from 42 to 31 days. These indicators would tend to suggest a more dependent patient profile; a picture that was supported by research observation. Thus, few patients were seen routinely walking about on the ward compared to previously. Staff perceived that more of their patients were presenting challenging behaviour (acting out in anger at staff, shouting, and unpredictable in their actions and interactions). Such a change was not discernible from fieldwork: at baseline also, staff were working with many patients with delirium and dementia whose agitation and distress escalated during late afternoon and at night. Further, although the staffing complement was unchanged between baseline and interim, fieldwork indicated that during the morning and afternoon shifts, actual staffing was frequently down by a nurse; typically moved to support a neighbouring ward. Qualitatively, many staff projected weariness in their body stance; unnoticed during baseline. This might have reflected timing of data collection phases: baseline occurred between mid-August and early November; interim fieldwork began end of November to the beginning of February, a period of heightened demand on beds.

As indicated above, the problem of leadership as it impacted PIE implementation in Rivermead was shaped by turbulence in the Trust. By summer 2014, organisational changes resulted in high work pressure on the ward as the effects of ward closures (30 beds across care of older people wards) percolated to ward level. Across the Trust, the level of admissions was regarded as unprecedented. For ward staff and middle managers it meant an absence of 'headroom' for reflection and planning as 'firefighting' consumed the working day: "*we're so focused on the basics today that we have no time to look at tomorrow".* Work pressures contributed to reduced morale. It was also observed that sickness and staff vacancies had resulted in more extended use of Bank staff. In informant interviews, staff expressed hope that PIE would be picked up again when timing was more

favourable. Work pressures persisted on Rivermead through interim data collection between January and March 2015; and several staff left, exacerbating staffing difficulties.

A further full CQC inspection in October 2014, reporting in April 2015 resulted in an overall assessment of 'requiring improvement'. Governance and staffing levels were identified as issues to address. A re-organisation of middle and senior manager tiers was aimed at addressing the former; the persistence of recruitment difficulties contributed to further bed closures and ward re-organisation. In summer 2015, a decision was taken by senior managers to close Rivermead with immediate effect; the manager being informed the week before it was to take place. Over several weeks, concerted opposition from clinicians resulted in revision of the plans: the merger of two wards. As a strategy to retain staff with perceived expertise in care of older people and a resource built up over several years, it was unsuccessful. Many staff had already moved to other posts and what had been a stable ward team, dispersed. The end of Rivermead ward brought the research here to a conclusion.

Non-implementers

Creating Local Engagement with PIE

Based on their response to PIE, we characterised non-implementers as: 'tentative'': wards that expressed continued interest in PIE but timing for change was wrong; and 'disengaged', wards which did not engage with PIE after re-assessment of the decision to proceed, 'true' non-implementers..

Tentative implementers

The three wards in Central Trust were 'tentative' implementers Although two of them – Rose and Beech – took faltering steps to PIE installation; and the third – Denton – made no progress beyond the exploration and adoption stage, the factors which shaped their varied responses were the same.

Denton, a dementia ward, was established in early 2013 to provide support to people with dementia who were 'medically fit' but would benefit from 'enhanced recovery' (Chapter three). From a performance perspective, an additional objective was to facilitate timely flow of patients from the acute wards of those deemed 'challenging' and either 'unsafe' to return home or likely to need long term care placement. The staff team had been recruited for their knowledge and interest in working with people living with dementia; and care delivery, similar to that on Netherton, was person-centred. From the outset, staff were enthused by the potential of PIE to enhance care of people admitted to the ward. Shortly, after fieldwork began, it became evident to the research

team that its continued existence was uncertain. From one week to another, the site researcher was apprised of varied accounts of the future of the ward oscillating between closure, expansion and permanence. By Autumn 2013, the dominant narrative was closure, ostensibly because of the lengthy stay of patients admitted. Although work practices were directed at supporting individual patients, and staff in their own time pursued fund-raising initiatives to enhance what they could offer, a consequence of the lack of a clear strategic vision for the ward at hospital and trust level was that goals for improvement were immediate to short term. Even so, the ward manager assumed the role of PIE 'champion', advocating with peers on Beech and Rose wards to engage with PIE and took the lead in organising and facilitating PIE workshops.

Both Beech and Rose ward managers were open that knowledge of dementia among staff and care of people with dementia on their respective wards, required improvement. Additionally, both wards were in transition. The Rose manager was new in post and building relationships with the team; her Beech ward colleague, although very experienced, had assumed leadership of a new ward model and staff group. For her, forging a team ethos and ward culture was regarded as a work in progress. Both expressed interest in being actively involved in PIE.

These three, along with three staff from Rose, Beech and Denton wards respectively took part in a joint PIE workshop in early November 2013. The event sparked interest in using PIE. At its conclusion, all three ward managers arranged to meet and discuss how to work jointly to take PIE forward. They anticipated working collaboratively to support each other. There were potential difficulties: Beech had moved physical location and the manager had been informed that the ward purpose was changing from an acute medical facility to a step-down assessment unit. The perception of managers on these wards, and conveyed in informant accounts was of decisions being discussed and pursued at Trust and senior management levels, and involvement of them at the point when decisions had been arrived at. Further that changes could not be communicated to their staff until the decision was actioned. Although the research remit did not extend to decision-making beyond the ward, staff on all three, conveyed in interviews and informant conversations, their sense of being continuously 'acted upon' with regard to changes in their work roles and environments in which they had little input to shape. For the Beech ward manager, the proposed change in ward model was the third in as many years.

In some respects, Beech and Rose wards were unlikely implementers in that the scale of change required to improve practice was considerable. Even so, PIE was regarded as a lever to effect improvement. Following the workshop, Denton, Beech and Rose managers working in pairs undertook several practice observations on Beech and Rose respectively. The research team offered a further workshop on action planning which was difficult to organise: Beech was in transition

between an acute ward and step-down unit, maintaining both functions with a lower staff complement, and Denton's future was uncertain. In Spring 2014, the Denton ward manager confirmed that the decision to close the unit had been definitively made, Rose ward was also planned for future closure, and further changes to the Beech ward model were being planned. Staff on all three wards were reported to be demoralised and looking to move on: they were unable to continue with PIE..

Non-implementers: Re-visiting the *exploration and adoption* stage

In Valley Trust, the senior nurse for older people and intended 'driver' of PIE on both Ambridge and Oak wards moved to a new post during baseline fieldwork. Although the research team sought to involve a staff member at a similar level, no-one was identified to provide it. Facilitation support at ward level was not forthcoming either, in part reflecting staffing shortages on both Ambridge and Oak wards. Two of three introductory workshops organised for staff on both wards during January and February 2014 were poorly attended; a third was offered but cancelled on the day as staff could not be released. No senior ward staff were able to attend any of the workshops.

Feedback from the workshops posed the question as to how those attending perceived PIE: as an approach to engaging them in a process of change; or as training in dementia care. The first part on the dementia experience was perceived as valuable; the second, on implementing PIE was not viewed as salient to their current concerns, namely getting through daily tasks with patients. For some participants the gap between current practice and 'person-centred' care was so wide that improving care required basic knowledge and skills in dementia care to move forward; for others, the care they provided was as person-centred as it could be with the resources at their disposal.

Further attempts to organise workshops were unsuccessful, including pursuing negotiation at directorate level for support. Both ward managers indicated that PIE implementation was not possible; it was 'out of time'. The current constellation of factors, staffing difficulties on both and senior staff moves on one of them, indicated that if circumstances changed, pursuing PIE might be possible. The research team agreed to contact ward managers later in the year. Over the following six months, the research team made several attempts to re-engage senior ward staff on both Oak and Ambridge: some had moved on; staffing difficulties persisted; and Trust priority was on dementia training with staff.

Similar to all recruited wards, 'buy-in' to PIE had been negotiated and 'readiness' criteria met. The departure of the senior nurse who was to drive PIE curtailed further engagement. Attempts to pursue PIE occurred, first, through discussion at directorate level on how to identify a replacement 'driver'; and then by returning to the stage of *'exploration and adoption'* with ward managers.

Neither were successful. Although the senior nurse had acted as a 'change champion' through the initial *exploration and adoption* stage, there was no-one willing to assume this role on her departure. Whereas change 'champions' can play a pivotal role in facilitating innovation, their effectiveness also depends on whether they can harness networks of support to carry it through.[80,112] Regarding PIE, those networks did not survive the 'champion's departure, although here too there appeared a lack of resources at ward level to pursue a service improvement process requiring 'headroom' to action.

Cedar ward in City Trust, the companion ward to Rivermead, was the outcome of ward re-organisation, an amalgamation of medical and orthopaedic beds resulting from reduction in beds within the hospital. A late entrant to the study within weeks of its creation, the task for senior ward staff was to construct a team and develop systems and mechanisms to deliver care to a new patient group.

Although a number of staff from the original older people's ward had attended the PIE workshop, there was no further engagement at any level in PIE. As with Rivermead, the PIE driver had no capacity to lead the work and the same demand pressures and organisational change at City Trust which impacted on Rivermead also affected Cedar ward directly. Reflecting back, the ward manager considered that the decision to take part in the research had underestimated the level of work involved in forging a new team, which coupled with demand pressures meant that 'timing' was not right. Although, the 'timeliness' of an intervention is a feature of context receptivity in adoption, it has not been an explicit focus of research interest.[80] We suggest that although 'timing' is a relevant 'readiness' criterion in site selection, it does not determine successful implementation in absence of a facilitative organisational context.

Summary

Only the Seaford trust wards had all the conditions in place to effect PIE implementation.   In essence, interaction between micro-level features at ward level and a facilitative organisational environment created the conditions for a receptive context for change on these wards. Elsewhere, organisational turbulence impacting in multiple ways at ward level, resulted in an organisational environment which was unreceptive to change.
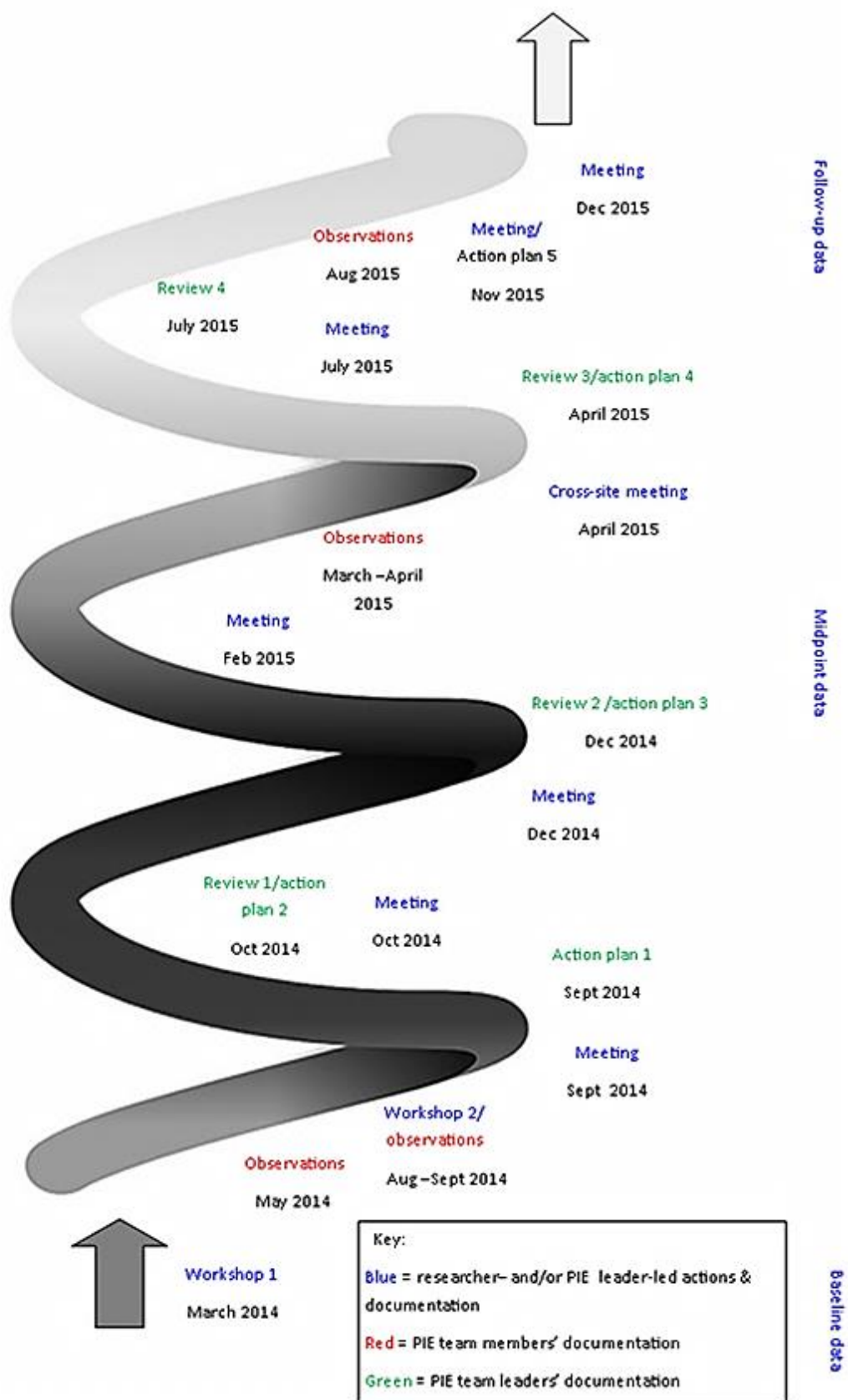
Figure 22: PIE implementation on Crane, Seaford Trust
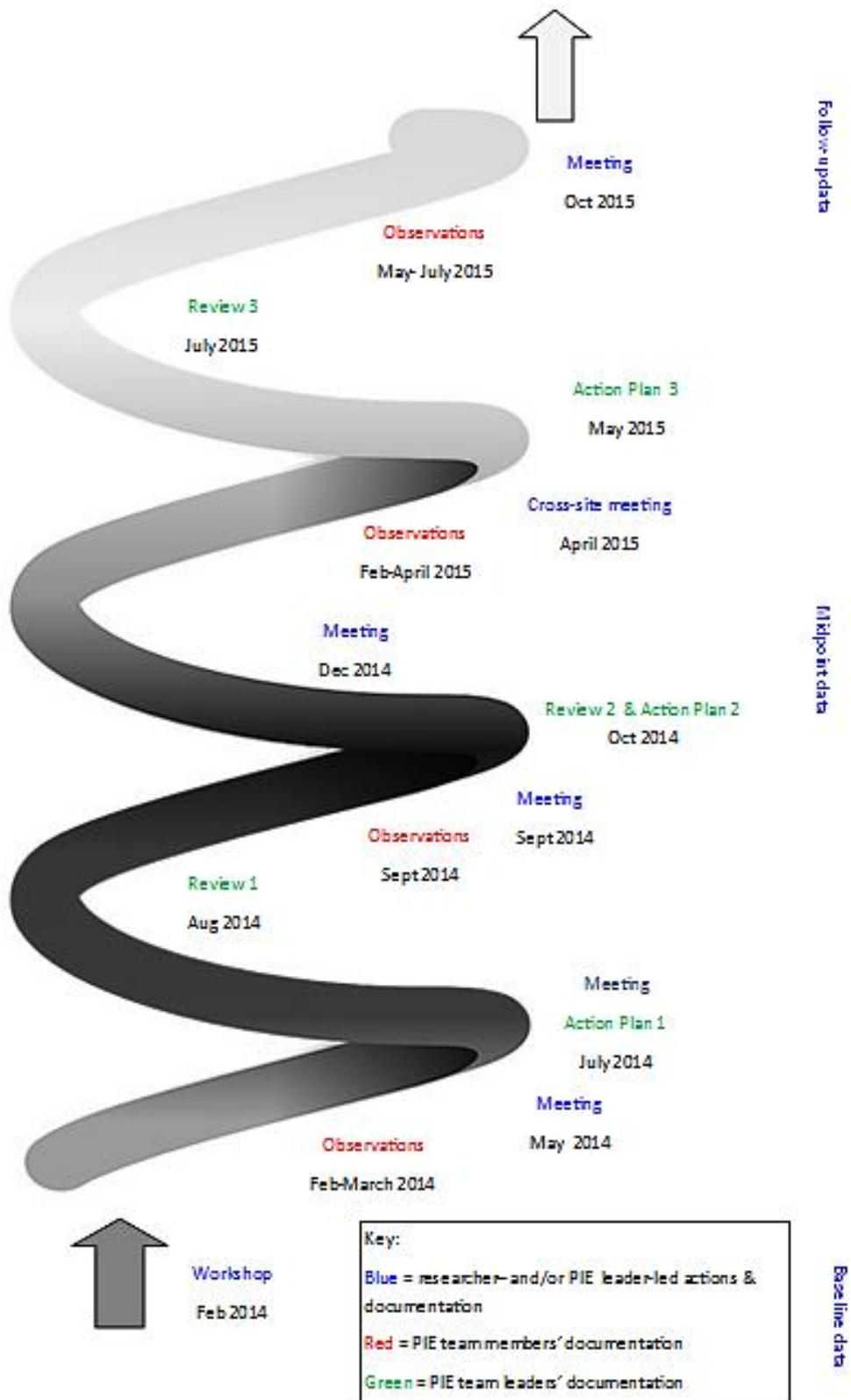
Figure 23: PIE implementation on Poplar, Seaford Trust

CHAPTER 6

OUTCOMES OF PIE

Introduction

This chapter examines outcomes of PIE: in improving ward practice; in enabling a positive experience of care for people with dementia and their relatives/caregivers; and in providing preliminary evidence of effectiveness with regard to clinical outcomes (delirium and falls).

PIE Implementation and Practice Change

On both Poplar and Crane wards where full PIE adoption occurred, there were discernible changes to ward practice, directly attributable to the intervention. The experience of doing observation reinforced its value as a means to 'see' action and interaction in a different way:

> It's allowed us to step back and look at what we're doing. 'Cos when we're right in the middle of it it's all quite difficult, seeing what's going on and what you should be doing.

> Staff nurse, Poplar

Senior staff also saw new ways of 'seeing', as indicated in the discussion with the dementia specialist team:

> **DN**: And it's the good stuff that you don't pick up unless you're doing the observations and you realize – because you don't have the time to see it.

> **LDN:** Because you're in the middle of it.

> **DN:** And you do see much more when you just step back and watch.

> Dementia specialist nurses, PIE meeting December 2015

Observations heightened perceptions of what it was like to be a patient: "I *didn't realise the levels of noise and stuff around patients … or what an effect that has …"* At the heart of work initiated through PIE was increasing awareness of patient experience as being at the centre of how staff worked. It reinforced the necessity for additional work by staff to facilitate a 'connection' with the person so as to pursue the work of 'recovery'. Creating opportunities for communication between staff and patients in a 'normal' setting contributed to the collection of meaningful knowledge about the person. For example, on Poplar the practice of patients sitting around tables for lunch was a significant change resulting from PIE action plans. Observation and staff reports indicated that the broader objectives of the activity – to improve nutrition and enhance social interaction and

communication were achieved. Staff reported that patients had better appetites and were socialising with others at the table, as well as benefiting from being mobilised more often as they walked to the table. Social interchange in an informal environment enabled staff to discover new things about the person and pick up more information about individuals' dietary likes and dislikes.

On Crane similarly, the focus on nutrition, led to regular 'lunch-club' style events in the middle of bays, against the odds, given the restricted space. This resulted in improved communication between staff and patients and between patients themselves, albeit often largely incomprehensible to outsiders. Events like the Dementia Cafes, held off ward provided opportunities for patients who were well enough to socialise in a convivial environment. Although not initiated through PIE, provision of support to attend was integrated into PIE action plans.

The PIE process, observation and space to reflect collectively on practice, along with the observable changes which were set in train, gave staff confidence that they could make a difference, including those who were not directly involved in PIE teams.

> I think it's just made us more aware of what we can achieve…. as the word has spread, there's been more of an understanding.

> HCA, follow-up, Poplar ward

On both wards, staff felt able to challenge aspects of established practice including where other services were involved, for example, negotiating with external caterers to serve smaller portions and a wider selection of finger food to support nutritional intake among frail patients.

These practice changes represented steps forward, contributing to an enhanced patient experience. They positively impacted on ward care culture in myriad ways even if not fully transformative of it. Respectful, warm task focused communication practices still dominated in routine staff/patient encounters particularly during busy periods, although staff responsiveness to patients' emotional needs during tasks were also observed:

> HCA returns to patient in bed 1 and pulls the curtains round. 'Can you wash your face?' she asks. Then 'you're a bit down in the dumps today, Ron. What are you thinking about?' He says his wife. The HCA provides reassurance, reminds him his wife phoned yesterday and said she is coming in today …that she wanted a rest yesterday so couldn't come. She asks the patient to stand up as she continues to help him wash. She encourages him to walk a few steps – 'it will do you good'.

> Fieldnote Crane ward, Interim, February 2015

Staff perceptions of PIE

Interviews with staff at the conclusion of the study showed that PIE had harnessed enthusiasm and engendered confidence, collaboration, sense of empowerment and agency, including among unqualified staff, in trying out new ways of working. They also talked about the time pressures on them from increased throughput and higher patient dependency, both affecting the time they were able to spend with individual patients; and reinforcing the criticality of staff outwith the ward in driving change. Given the timing (winter 2015) this likely reflected seasonal variation in demand, although the lengthening period during which 'winter pressure' beds remained open on most sites suggested ongoing high demand.

> *Because we've been really busy, we've had a lot more patients with higher needs and I think we've struggled …to achieve what we had been achieving….We come up with the ideas, but it needs someone [to say] 'yes that's OK let's do that'… Whereas if you've not got that support I think some of it might flounder.*

> HCA, Poplar ward

Some staff were impatient at what they regarded as the slow speed of change. Lack of involvement of front-line staff in the Crane PIE team was a disappointment to some senior staff. Yet without the engagement of nurses and HCAs in pursuing action plans, PIE adoption would not have occurred or its reach gone beyond the PIE team. The Crane manager considered that PIE had stimulated reflection and action across the team as a whole; but that sustaining the process would necessitate renewal through involving new staff in PIE. One proposal being considered at the conclusion of the study was to initiate new staff through use of the observation tool alongside an experienced 'observer'.

On both wards, plans were in train to continue PIE beyond the study conclusion. A further year on, it had been sustained in Crane, with increased participation of front line staff. The merger of Poplar with another ward, encompassed plans to extend PIE to the joint ward.

Impact on Patient and Caregiver Experience

From observation at baseline, we characterised care delivery on both wards as competent, caring and broadly responsive to people's expressed needs; although time to respond was slower during busy periods (early to mid-morning and during meal-times). There were staff who were particularly sensitive to the emotional needs of people with dementia, and used their knowledge of the person to anticipate and respond to those who were unable to communicate verbally. Openness to, and engagement with families was distributed among all staff, from HCAs to ward managers; a collaborative, negotiated response to relatives and caregivers being an expectation on everyone.

These features of care delivery contributed to a positive experience of care from patient case studies on both wards (six at baseline; and five over the course of PIE implementation).

Experience of Care

Without exception – patients and relatives at baseline – described their experience of care in positive terms: staff were kind and responsive when they needed assistance; and relatives indicated that staff made themselves available to discuss their concerns, kept them informed about what was happening, and involved them in decisions about the future. In the detail, we get a more nuanced picture both of experience in context of what was viewed as 'good'; and variability in responding to preferences and needs.

Warmth and responsiveness

The characterisation of care delivery on both Seaford wards as 'warm, sensitive and task-focused' was mirrored in the case studies. For patients, what was conveyed was not simply being acted upon, but actively engaging with the ward environment. Staff responded quickly when asked for assistance; but people also described 'seizing the right moment':

> *Well, I wait 'till I think they're not busy. If they're rushing, rushing backward and forward, I keep quiet. But if they're just wandering, I'll say: 'nurse', like that and they come over. But if I see them running then I wouldn't because I think, well they're off to do something important.*
>
> Rose, Poplar ward

Lily, moved from a bay to one of the single rooms similarly, expressed the same sense of being patient and seeking acknowledgement that she only looked for help when it was 'important':

> *I press my buzzer and if they don't come there and then, I wait a bit longer and I have another press. Because I must realise they've got work elsewhere. So you just sit and wait until they can get to you. But it's really… important you keep your finger on the buzzer; but I wouldn't do that if it wasn't important.*
>
> Lily, Poplar ward

Iris had also moved from a bay to a single room – not of her choosing – she had developed an MRSA type infection. Her daughter described her as very upset and agitated with the move but had settled after a while. Now she considered her mother as contented on the ward:

> *She was very frightened about coming in to hospital. It's her one dread – being in hospital. I know it's a terrible thing to say but this has actually done her good because it's taken away her fear of hospitals now.*
>
> Iris's daughter, Poplar ward

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John's daughter-in-law voiced the absence of more staff time spent directly sitting with patients. As a HCA in a residential care home, she acknowledged the importance of spending time with people; but viewed this as requiring more staff on the ward as the nurses were so busy: *"they're always darting about quite a bit",* although *"always they do go out of their way to make sure that the patients' are comfortable"* and *"they come and make sure that we're okay"* [relatives].

Other patients: source of disturbance, friendliness and reciprocal help

Being on a ward, meant that close proximity to other patients was a source of conviviality <u>and</u> disturbance. Women interviewed considered that 'friendliness' was important. They distinguished between liking to sit and talk with people, 'being sociable' and being 'best friends': *"you get friendly…it's not a good thing to try to make friends because it doesn't last".* Daisy described her relationship with other patients as "*vaguely to talk to*", but she had become good friends with Bessie. Conveyed in her account is a level of understanding and acceptance of others' disorientation:

> *Bessie and I are quite good friends now…but I still haven't found her husband though (Daisy laughs)…She does get in a muddle sometimes looking for Fred. She says: "where's Fred"?*

> Daisy, Crane ward

The conversation with Daisy was punctuated with interjections to Bessie: *"are you all right, Bessie"; "Careful Bessie"…she doesn't look safe* [to the researcher].

Rose liked to sit with people and talk, *'getting on'* but not *'close friends'*. She was sanguine about other patients calling out:

> *You can look around at everything and think, 'oh I wish they wouldn't do that'. I don't like the way they do that…but that's only your personal opinion. I can't judge what all these people think…There's a lady, she does a lot of shouting…I think she's a very disturbed person…but if you pull the clothes over your head and don't listen, it's okay…when they moan and groan there's a reason for it…they're unhappy…with myself I'm perfectly happy as things are* [Rose laughs good humouredly].

> Rose, Poplar ward

Lily had been moved to a single room from a bay because of disturbance from other patients, who she described as "rowdy and grumbly". She felt better on her own, "*it's a rest*" (being in bed).

Men interviewed appeared less interested in the potential for conviviality and social interchange. John was moved to a single room: he was unable to sleep because another patient was shouting out during the night. His daughter-in-law would have preferred that he stayed in the bay for the company but understood that he preferred to be on his own. He found enjoyment in at the bird

through the window; enjoyment in nature replicated how he spent time at home. Robert was happy to sit with people in the bay and found comfort in the routine: *"I was in the medical corps in the war…it's got to be run as a routine".*

Going home

Everyone wanted to resume life as before. Apart from Rose, who was to return to her care home, their destination was uncertain. It was not always clear from patients how much involvement they had with the decision about planning for discharge. In part this reflected memory difficulties. Rose hoped to return to her care home but indicated that she didn't know when this would happen; her daughter reminded her she was being discharged within a couple of days. There was a sense from patients' talk that there had been discussion but that ultimately the decision was not in their hands; it rested elsewhere – not only with professionals but with close relatives. Thus Robert hoped to go back home, but his relatives had talked to him of going into care:

> *I know they've been thinking of me going into another place where I could talk to other people and that…but…in some ways I would and others I wouldn't.*

Robert, Crane ward

Lily wasn't sure how much longer she would be in hospital except that the doctor had said she would be ready when she could walk a little way, adding: *"they know better than me".*

Relatives on the other hand, described how they were very much involved in the decision about discharge; a process perceived as emotional and conflicting in reconciling their relative's wish to resume life as before with their deteriorating health.

Did PIE make a Difference to Patient Experience?

The five patient case studies following PIE implementation were purposively selected to include those who were frailer, as critical exemplars of patients perceived to be more challenging and therefore particularly testing of progress made. All had limited ability to communicate verbally, although this varied depending on time of day, and they deteriorated over time.

Experience of care

Similar to baseline, relatives assessed care as very good: staff were described as kind and responsive, and available to discuss the carer's problems and concerns. Emily's daughter visited her mother daily: *"If I only mention something to the nurses, its dealt with".* Acknowledged too was the significance of staff caring for her mother: *"she doesn't take much in. I don't think they could do much more for her".*

Observation and conversation with patients revealed a deteriorating trajectory of inter-related physical and cognitive impairment. Frail when first encountered, these people alternately conveyed frustration at others not responding to them in relation to their conception of reality; and derived pleasure in the moment from encounters with others, including the researcher.

It was in respect of these patients, that understanding of, and emotional engagement with them 'in their world' was not consistent across staff on either ward, even though they generally acted with warmth and kindness in carrying out day to day tasks.

Dorette, who was French in origin had lived in England for decades; she was often distressed, wanting to get to the train station and had reverted to her first language. She called out frequently to be taken to '*Gare St. Lazare',* expressing anger and frustration in absence of a response. Whereas some staff would talk with her about her life; others would ignore her. She evinced pleasure when staff spoke to her in French, smiling, apparently at their faltering efforts (including the site researcher's) with the language. Other times, she became angry when asked to do a task (for example, changing her clothes when wet) as it would make her late for the train. Annie often shouted out in protest during routine observations or personal care work; but responded to being comforted by touch – holding her hand and stroking her hair – when distressed. Connie often expressed her desire to go home, getting off the ward and catching a bus back home. When a staff member sat with her, she talked animatedly about the place where she grew up and had spent all her life and to where she talked of returning; she never spoke of the care home she had lived in for some time.

From observation, staff at follow-up appeared more responsive to patients embodied action as meaningful and sought to address care needs. Thus, Emily, exemplifying the 'uncooperative' patient, repeatedly tried to pull out the IV line (for hydration); scratched staff when angry; and was reluctant to eat and drink when assisted. Staff would sit with her, trying her out with fortified drinks and dessert being the only things they discovered she would touch. As she transitioned to being unresponsive and sleeping most of the time, the work of 'care' including care relating to nutrition, hydration and elimination became increasingly challenging to carry out; comfort through touch seemed all important. For these patients, responding cognitively and emotionally to them 'in their world' also enabled completion of care tasks.

These patients, with the exception of Connie, did not take part in mealtimes as 'social events' – they were either too ill and in bed (Emily) or did not wish it. Connie was the exception; also enjoying being taken to the Dementia Café. She was joyous at the music; joined in the singing; and conveyed how much she loved being around children who had come along from the local primary school.

Returning to the ward, she became preoccupied again with getting the bus home and being taken to the bus stop.

These illustrative accounts attest to the challenge of working with patients whose hold on a 'shared reality' diminished;[109] even while moments of pleasure and joy were experienced, facilitated through sensory and emotional engagement with others.

Declining trajectory: physical and cognitive

Cognitive deterioration among these patients was inter-linked with physical decline. Within a week of her operation, Dorette was being assisted to walk with a Zimmer frame and described as 'medically fit' for discharge on the ward round. Ten days subsequently, she was 'poorly', receiving blood transfusions, indicated she was very tired and wanting to sleep all the time. In conversation with the researcher she expressed a wish that she "had wings" to take her home. Unable to stand, even with assistance, she lay in bed or was helped to sit on the chair by the bed. Repeated attempts by therapists to get her up and moving failed, further contributing to physical deterioration. This pattern in different forms applied to other patient case studies. Activities initiated through PIE: communal meal-times; and opportunities for patient to patient and staff/patient interaction, occurred around them and they were too ill to take part. Emily and Annie died in hospital; Dorette and Beatrice were newly admitted to long term care following 50 and 73 days hospital stay respectively. Connie and Beatrice were still on the ward at the conclusion of fieldwork. It was planned that Beatrice would go to a nursing home when a suitable place was found; a different care home placement was being sought for Connie; she was perceived as too dependent to return to her previous care home.

In summary, at each time point, patients (and close relatives) perceived staff as warm, caring and responsive. Patients were 'forgiving' of staff not always being available when needed, and spoke of choosing an opportune moment to ask for assistance. Ethnographic observation suggested that apart from busy periods, patients were responded to quickly on both wards when they expressed a need unlike on some other study wards. For relatives, that staff made themselves available, heard their concerns and addressed them, inculcated trust in the care provided to their relative.

Observation indicated two aspects of practice which changed as a result of PIE with positive impact on patient experience: enhanced sociability and sense of well-being from communal mealtimes; and pleasure and shared memories evoked by listening together at music sessions. For staff, these activities provided opportunities to acquire personally meaningful knowledge of the person to make sense of their behaviour and action and provide appropriate emotional support; realising the meaning of a 'person-centred' approach in their practice. For people with severe dementia, this

'person-focused' practice was more inconsistent within staff teams. Although all staff engaged with such patients with warmth and care, responding to the emotional needs of those whose sense of a shared reality had diminished required a level of knowledge and skill not shared by everyone – as well as time.

Clinical Outcomes

Days in Delirium

Prior to the research, none of the wards had routinely used a screening tool for delirium; although City Trust was considering introducing the SQUID, a single question asked of relatives to assess onset of increased confusion. Collection of DOS data was inconsistent. Unfortunately, although there is some data on days in delirium for both Seaford wards at baseline, none was collected at subsequent time points. Thus, on both Seaford wards at baseline, a fifth of patients for whom DOS data was collected screened positive for delirium although for most of them, the number of days in delirium was low (median=4 days). Midway during baseline both wards stopped collecting DOS, deeming it too onerous to pursue. On Crane (care of older people) most patients who screened positive for delirium at baseline had dementia (75%); the proportion was lower (30%) on Poplar (orthopaedic trauma).

Both partial implementer wards – Netherton and Rivermead – collected consistent DOS data at baseline and interim data collection points. Although neither proceeded far with PIE implementation, it is of interest to examine delirium rates on both wards, to highlight some challenges in collecting and interpreting results. Table 12 reports delirium rates at both time points.

Table 12: Delirium outcomes: Netherton and Rivermead

	Netherton Ward		Rivermead Ward	
	Baseline	Interim	Baseline	Interim
% Patients with delirium on admission to ward	31/52 (60%)	66/87 (76%)	24/123 (20%)	33/110 (30%)
% Patients with delirium during their stay on the ward	54/75 (70%)	75/87 (86%)	64/110 (59%)	72/110 (66%)
Days in delirium	16 (median; range 1-57)	20 (median; range 1-44)	10 (median; range 1-27)	9 (median; 1-27)
N of Patients 30+ days in delirium	7	6	-	-

Delirium occurrence (on admission and during in-patient stay) was considerably higher on Netherton than on Rivermead, unsurprising as most patients admitted had dementia (the few that did not were assessed as having delirium). The co-occurrence of delirium and dementia was evident from patient profiles for all participating wards (Chapter three). Further people with dementia are at particular risk of developing delirium.[36,94,95]However, from multiple sources of data (observation, patient case studies), we found that care quality for people with dementia on Netherton was consistently high. Most people during their admission experienced delirium at some point, including the small number who were not admitted with it. The number of patients experiencing extended delirium (30+ days) was very small and similar across time points.

Although the overall number of patients with incident delirium across time points is too small to draw inferences about the relationship with care quality, results highlight the scale of the problem of delirium among this 'at risk' group, given the level of distress caused to patients[113-115]and the challenges in providing appropriate care as a consequence. To make meaningful inferences about the relationship between delirium and care delivery would require the collection of delirium data over a longer period of time pre- and post- intervention with a sufficient sample size to make the necessary adjustments to reflect varying levels of risk.

Falls

Similar to delirium, falls data was not collected consistently in Seaford wards. Table 13 provides the number and rate of reported falls per 1000 occupied bed days for Netherton and Rivermead wards at baseline and interim.

Table 13: Falls per 1000 occupied bed days: Netherton and Rivermead

	Netherton Ward		Rivermead Ward	
	Baseline	Interim	Baseline	Interim
Falls per 1000 occupied bed days	9	27	25	18

As discussed (Chapter two), risk factors for falls not only relate to the actions of staff, patient specific factors are also implicated, including advanced older age, dementia, delirium and frailty as well as practices regarding rehabilitation.[100] Further, the pattern of falls fluctuates and it is argued that pre and post-intervention data needs to be collected over at least nine months to deal with potential

confounders resulting from changes in staffing, case-mix, activity or recording practices.[100] The three-fold increase in the falls rate in Netherton, for example, between baseline and interim is likely to reflect the more dependent patient profile, compared to baseline. Field notes during interim did not indicate that the quality of care delivered had deteriorated. Similarly, the reported reduction in the rate of falls on Rivermead at interim, does not from observational data imply that the quality of care had improved; rather staffing difficulties which placed increased pressures on ward staff suggested that staff were able to spend less time with patients with dementia at interim. The multiple and interacting risk factors for falls (as for delirium) present considerable challenges in drawing inferences about the impact of an intervention to improve care delivery on falls rate. Here also, larger samples to deal with confounders, and a longer timespan for data collection to take account of seasonal and case-mix variation would be necessary to detect meaningful change.

Summary

On both wards in which PIE was fully adopted real, observable practice changes occurred; and these were sustained over time. There was evidence that the care experience of some patients who benefited from the practice changes improved, although the most visible changes did not impact on those who were too ill to take part. We cannot draw any conclusions about the impact on clinical outcomes since neither of the full implementer wards collected consistent data on delirium or falls. From the literature and examination of falls and delirium in the partial implementer wards, we can conclude that although these outcomes are relevant to explore as indicators of care quality, meaningful interpretation of their impact would require considerably larger patient samples, collected over a more extended before and after period to take account of confounders.

CHAPTER 7

DISCUSSION AND CONCLUSIONS

Introduction

The research aim was to evaluate PIE as an intervention to improve the care of people living with dementia on acute hospital wards, effecting care which was more person-centred. The objectives were to understand how PIE worked in acute care (process of change) and what contributed to success (or not); to examine its effectiveness in changing staff practices, thereby improving patient and caregiver experience; and to seek preliminary evidence of impact on selected clinical outcomes (delirium and falls). An additional objective was to develop insight into what person-centred care might look like in practice in an acute hospital setting.

When our research began in 2013, the timing seemed propitious. There was renewed UK policy impetus on improving care quality for people with dementia, including on acute hospital wards, resulting in national performance targets on identifying people with dementia and improving staff knowledge and skills of staff through training.[1-4,9] Findings of the first national audit of dementia in general hospitals provided a spur to Trusts to make improving care of people with dementia a strategic priority. At the same time, there was uncertainty about the impact of major structural and organisational change in the NHS alongside ongoing challenges: achieving continuous improvements in performance, quality of care and the hospital environment; identifying efficiency savings; managing the impact of reductions in social care provision on patient flow; and responding to year on year increased demand with reduced income growth. Both sets of challenges found expression within participating Trusts and wards in context of local history, health and social care economy and relationships, and economic situation.

Discussion

Patients with Dementia on Acute Wards: The Challenge for Care Providers

The patient profile on wards dominated by older people (dementia, care of older people and ortho-geriatric wards) revealed the scale of the challenge in acute hospitals to improve care of people with dementia. People with a cognitive impairment, including delirium comprised at least half of the patient profile: many had moderate to severe impairment: they lacked ability to communicate verbally; required assistance with personal care; and active support with eating and drinking. On

every ward there were patients who called out repeatedly, seemingly in deep distress. Acute care for people living with dementia therefore cannot be conceived of as peripheral to, or disruptive of the routine work of ward staff but is a central feature of it.[23,24,29,30] As well as the health event that precipitated acute admission, these patients were in advanced older age, with multiple health problems, physically frail and with care networks which were often fragile. Achieving a 'balance of care'[54] in an acute setting required delivery of clinical, therapeutic and personal care based on an understanding of the interaction between these multiple and complex needs, including cognitive impairment, and how they mediated the process of recovery. Although all participating wards had introduced training in caring for people with dementia, the level of skill required to respond to the complexity of need of their patient profile was not generally addressed on these programmes.

On all wards, medical, nursing and care work was generally perceived by staff as rewarding, physically hard, emotionally taxing and demanding of specific skills, expertise and knowledge of dementia and delirium. Some staff on most general wards (i.e. not the dementia wards) felt ill-equipped through training and resources to provide appropriate support. They conveyed a gap between a broadly supportive and engaging staff culture at ward level and ambiguity and tensions between competing priorities at the level of the hospital which affected their day to day working practices. The width of the gap varied considerably between trusts.

Three of ten wards did not attain the Royal College of Nursing staff/patient ratio for safe working on older people's wards,[116] namely eight staff for 28 beds, a ratio of 1/3.5. Most did not meet the recommended ratio of registered nurse to health care assistant of 65:35. The picture was bleaker than this suggests in that on several wards, the staff complement was only maintained through extensive use of Bank and agency staff with consequences for staff morale, sustainability of a coherent care culture and availability of 'headroom' to engage in service improvement. Of the two wards that successfully implemented PIE, both had a relatively generous staff complement, a ratio of registered staff to patients of 1:5.6 (Poplar) and 1:4.4 (Crane) although here too, staff were often moved to support other wards when numbers were depleted.

Across most wards, environmental changes to create more 'dementia friendly' spaces had occurred, making for more attractive environments that were easier to navigate. However, communal or patient space was extremely limited, and the layout of some wards meant that the scope for movement of patients to recover/sustain mobility was restricted.

'Person-Centred' Care: Meaning, Content and Practice

Meaning and content

'Person-centred' care in UK health policy has, over nearly two decades, set the standard for care quality. In health policy discourse the concept has become a portmanteau term with multiple meanings: 'individualised care', 'seeing the person and not the medical condition', 'tailoring care around the person', care that accords dignity and respect (Appendix 6). Further, there has been varied policy emphasis at different times on particular aspects or dimensions of 'person-centred' care, currently 'compassionate care'.[117-119]

There is a similar lack of consensus on the meaning of person-centred care from research. Although theoretical conceptions of personhood and person-centred care in dementia provide a powerful value base to inform practice,[44-48] there is a dearth of research on what practice might actually look like for people living with dementia in acute care,[49, 120] as most such has been undertaken in long-term care. Yet, care delivery in acute hospital has specific purposes (treatment and recovery); the physical environment is intended as a temporary and ordered space geared to these purposes; and relationships within the setting, although of major significance, are short-term and transient. An important aspect of this study is the insight provided on the dimensions of care practice on acute wards that has the person with dementia at its centre, the knowledge and skills that underpin them, and the organisational and cultural factors that are necessary to support them.

Practice

Staff understanding of person-centred care was consistent with the multiple descriptions and explanations of 'person-centeredness' in the policy and research literature. It was variously referred to as 'individualised care', 'seeing the person and not the medical condition', 'tailoring care around the person'. For most staff, it denoted 'good practice' or 'quality care' which staff aspired to deliver to all patients, and not only to those with a cognitive impairment. The extent to which the aspiration could be translated into ward work was viewed as constrained by the pressures of demand, resources of time and staffing and operational priorities – mostly external to the ward and outside of their immediate control. Organisational constraints on spending time with patients were real and included the legitimacy attached to such work by middle managers negotiating between competing national, local and organisational priorities.

Comparing how care was actually accomplished we discerned a continuum of practices supportive of, or barriers to sustaining personhood and the organisational, spatial and care environment factors that shaped them.

Although the literature adopts a binary conception of person-centred versus task focused communication, we delineated between more differentiated styles of communication that we termed: *personally meaningful and engaging with the person*; *respectful, warm, task focused*; *minimal verbal exchange*; and *communication unresponsive to patients' expressed emotion*. These reflected more of a continuum than fixed points. On most wards, the style was mixed albeit dominated by warm, respectful and task focused communication.

A personally meaningful' communication style required the ability to make an imaginative connection cognitively and emotionally with how the person might be experiencing the 'social world'. This has been variously referred to as 'caring imagination'[121] and 'embodied selfhood'.[50,51] For some staff, it was developed through personal knowledge of dementia; for others through advanced learning and professional experience. 'Imaginative connection' with the person was seen to involve time and effort to 'see' and make sense of non-verbal communication and emotion[122] and to understand such embodied communication as meaningful, a source of agency[20,54] and reflective of personhood even where linguistic ability was lost. At the other end of the spectrum, minimal engagement and communication that was unresponsive to expressed emotion typified an approach that viewed the person with dementia as 'other', without agency. A critical point was that these observed methods of communication were pre-formed and were not influenced or shaped by PIE .

The multiple needs of this patient profile on hospital wards, required nursing, therapy and care work that embraced such tasks as administering medication, assisting with toileting, nutrition and hydration and supporting mobilisation. In the conduct of such tasks, we delineated approaches to practice that were responsive and supportive of recovery in respect of people with dementia. These are termed: *anticipatory; enabling;* and *sensitivity to the emotional significance of practical needs.* Knowledge of the person, including routines, preferences, anxieties and ways of communicating need, facilitated an anticipatory response to a practical need, particularly where the person was unable to communicate verbally. Providing assistance in a way that built on the person's level of competence increased their confidence and was supportive of independent action. A further feature of a responsive approach was sensitivity to the emotional significance of expressed need. For example, need for assistance with personal care tasks such as toileting is not comparable to help with picking up a paper from the floor: it has symbolic and emotional meaning in terms of control over basic personal care tasks, as well as 'being' and feeling 'clean'. In contrast to anticipatory, enabling and emotionally responsive approaches to tasks were those where completion of the task was to sole object of the work, in a manner that treated the person as 'object'.

Responsiveness to the needs of people with dementia also required particular knowledge and skills embracing knowledge of dementia and how it affected the person. This recognised that there was an element of uncertainty and unpredictability about how the person would respond in a given situation such that strategies to engage him/her were emergent, built up through trial and error and likely involve creative, tailor made solutions. This practice knowledge and skill was often what ward staff, particularly those providing direct care, reported that they lacked. Application of general values to sustaining personhood, we would argue, does not provide a sufficient guide to practice in acute care settings in absence of a 'caring imagination' and dementia specific knowledge and skills. Although these dimensions of practice are not necessarily exhaustive, they were sufficiently sensitive to differentiate between study wards, suggesting a continuum of supportive practices and the factors that contributed to them.

Implementing PIE: Interaction of Micro, Miso and Macro Level Factors

Despite the gap between the quality of healthcare that patients should receive and what actually happens, programmes to secure improvements in care quality have demonstrated inconsistent, variable and patchy results.[110, 123,124] This in part reflects the fact that such interventions are more appropriately construed as events in multi-layered and interacting systems meaning that the organisational, political and social contexts in which the intervention is located are not simply background noise; they are part of the programme of change[74,89, 90, 110,125-127] and interact with it. Other features of complexity include: the multiplicity of programme components and their dynamic and emergent nature such that different groups interact with programmes in different ways.

PIE was fully adopted in only two of ten study wards; and had proceeded to innovation and sustainability in those. To explore why some wards adopted PIE and others only partially or not at all, we examined the relationship between what was intended to happen, what actually happened and the interface with the organisational context over time using a stages-of-implementation framework.[69]

Micro-level facilitators/barriers to change

Factors contributing to failure to proceed with PIE adoption were multiple and interactive. At a micro-level ward level they included leadership and stakeholder engagement, 'fit' with strategic priorities and the perceived salience of PIE to achieve valued goals

Drivers, facilitators, teams and networks

Engagement in PIE from initial implementation, through innovation to sustainability required active leadership out with the day to day demands of managing a ward; facilitative support and

encouragement from senior ward staff; and collective team involvement to make change happen. These dimensions of PIE leadership and stakeholder engagement provided the necessary levers of change: key individuals beyond the ward whose professional authority and vertical networks legitimated the priority attached to the work of improvement in face of competing priorities; senior ward staff facilitating and encouraging direct involvement in the change process and in ensuring planned changes were communicated to the wider staff team; and implementation team members with respect of their peers to extend reach of the intervention to the ward. Only in Poplar and Crane were all of these elements in place; absence of one or more of them were contributory to failure to proceed to full adoption.

The conception of 'facilitation' in our study differs from that projected in some frameworks for implementing change, for example PARiHS[128-130] and practice development[131-133] both of which place emphasis on skilled facilitation in effecting change. Here, the ward manager as facilitator did not drive' implementation but played a critical role in extending its reach to the whole ward, necessary to effect practice change.

'Fit' with strategic priorities

PIE was not the only initiative aimed at improving the care of people with dementia underway in participating Trusts. In Seaford, there was heavy investment at strategic trust level with the establishment of a team of three specialist dementia matrons in early 2013, attached to each of three district general hospitals in the Trust, including the two wards in our study. They worked directly with ward staff to mirror good practice in dementia care, provided support and in-depth training around communication and in anticipating and responding to challenging behaviour; and engaged in high level organisational changes at Trust level (for example, developing dementia pathways). From the outset, the dementia specialists embraced PIE, as one vehicle through which to pursue practice change, the team lead acted as 'driver' of PIE in one ward and one of the dementia nurses actively supported PIE, in the other. The lead specialist matron had both seniority and a direct line to the senior management team, and provided a conduit between senior managers and the ward in both directions: securing high level commitment and resource for local PIE initiatives; these in turn were celebrated as exemplars of the wider strategy in action. In this respect PIE and the Trust dementia strategy were synergistic one on the other.

In other Trusts (City and Ironbridge), a high level priority and centrally driven was the creation of Dementia Champions and initiating awareness training for staff at all levels around dementia. The role appears to have been variously interpreted: from increasing awareness of dementia within a work arena; as a mirror of good practice vis a vis colleagues; and as a change mechanism within a

workplace. How the recruitment of 'champions' would translate into a means of changing practice at ward level wasn't clear however; the conception underpinning the approach was that the creation of a wide network of 'champions' who would meet together at intervals would lead to change at workplace level. In City, the matron who had championed PIE envisioned that the initiative would feed into use of PIE at ward level; a vision that was not necessarily shared among those involved in developing the dementia strategy. For staff on Netherton, the Champions initiative appeared diffuse and lacking depth and impact. Further, as the initial focus of the initiative was in raising general awareness of dementia, this was not seen to address staff perception of the problem, namely how ward staff were to be provided with the skills necessary to work with challenging patients.

Salience of PIE to achieve valued goals

Focus of PIE in addressing practice change generated interest and enthusiasm among staff on wards that varied in the quality of care, and therefore scope for practice change. In both wards in Seaford, the process of PIE implementation engendered confidence, collaboration, sense of empowerment and agency among the staff group, including among HCAs in trying out new ways of working. Positive change was visible and in turn acted as a spur to keep going.

Among 'partial' implementers PIE was embraced enthusiastically at the outset. In Netherton, observation reinforced pride among the staff team of the general quality of care provided. Herein lay the difficulty. Translating observations into action plans that addressed valued goals proved more difficult. Although not articulated in the beginning, observations reinforced and solidified the primary goal of senior staff to improve patient care: reduction in the size of the ward and staff time to provide stimulating activities, neither seen as actions which could be pursued through PIE. This poses the question as to whether there exists a quality 'ceiling' effect in terms of a 'person-focused' approach within the constraints of acute care delivery. Additionally, within this ward, there existed a team culture and routine systems and mechanisms to engage in deliberative practice reflection to secure quality improvement; apart from observation, the additional work of PIE seemed superfluous.

Enthusiasm and interest in improving practice also required supportive environments to sustain belief in staff agency to affect change so that investment of time and resources was seen as worthwhile. Demand pressures and organisational uncertainty dampened both, evident not only in Rivermead but in all three Central Trust wards.

Miso and macro level facilitators/barriers to change

Organisational turbulence

Features of leadership and fit with strategic priorities were local expressions of forces operating at miso and macro levels. Whilst our starting point was understanding that organisations in which interventions are inserted are dynamic, what was surprising was the degree of organisational instability and turbulence encountered in the study and the impact of decision-making and action at senior and middle management on the capacity of staff at ward level to engage in change.

Although all participating wards experienced staff shortages and demand pressures, two wards experienced a level of staff shortages and service delivery pressures which affected the resources available to provide the headroom to pursue service improvement. For example, on the non-implementer Valley Trust wards there was an absence of all aspects of leadership when the research commenced. Although 'buy-in' at ward and directorate levels to engage with PIE had been negotiated at the outset, the departure of the senior nurse during fieldwork who had championed PIE participation during baseline fieldwork, stalled and then curtailed further engagement, resulting in the withdrawal of both wards prior to PIE installation. This was one facet of a deeper organisational problem. Although change 'champions' who are in a position to harness support within an organisation can play a pivotal role in leading change,[80,112] personal influence may not outlast individuals in absence of organisational support. PIE found no resonance at either ward or middle management levels: ward staff neither had the headroom to pursue service improvement; nor was there support from middle managers whose priority was on managing performance, demand and patient flow. [134,135]

Four of the ten wards closed during the research, either suddenly or over a protracted period. In Rivermead, closure was sudden, within a week of being announced, part of a major re-organisation of ward models and bed reductions in response to a staffing shortage and financial re-structuring. The same factors had contributed to absence of a PIE 'driver' on this ward to support implementation. With Denton, Beech and Rose wards, re-modelling and closure occurred over a protracted period during which proposals shifted and changed, demonstrating a lack of clarity and transparency in decision-making at executive and senior management level and sapping morale and motivation of staff to future plan, critical to pursuance of a care improvement initiative.

Cedar in City Trust differed from these others in one respect. It was formed as result of ward re-modelling, an amalgamation of medical and orthopaedic beds resulting from reduction in the hospital bed base. A late entrant to the study within weeks of its creation, the ward manager considered in retrospect that their priority had been to construct a team and develop systems and

mechanisms to deliver care to a new patient group and PIE implementation was 'out-of-time.' Although, the 'timeliness' of an intervention is a feature of context receptivity in adoption, it has not been an explicit focus of research interest.[80] We suggest that although 'timing' is a relevant 'readiness' criterion in site selection, it does not determine successful implementation in absence of a facilitative organisational context as the experience of Rivermead, the second ward in this Trust, attests.

In a programme of research on quality and safety in the NHS,[135] the authors concluded that success in implementing quality improvement initiatives required that the process was adequately resourced. This included time for staff involvement in changing practices and acknowledgement of the effort, expertise and investment necessary to make such approaches work. We would further argue that time and investment of energy, enthusiasm and commitment requires cognitive and emotional space to plan and work toward an aspired future – difficult if not impossible to mobilise in context of organisational uncertainty and staff disengagement and disempowerment.   These findings also reinforce the conception of interventions as *"events in systems that either leave a lasting footprint or wash out depending on how well the dynamic properties of the system are harnessed"*[50] (p270) or equally as here where organisational factors at organisational level act as barriers to engagement in a change process at the front-line. The corollary is that 'readiness' to engage in service improvement initiatives requires better understanding of 'receptive contexts'.[136]

NPT

NPT offered a useful framework to consider what might comprise the components of the PIE change process. However, even on successful implementer wards, strategies to generate mechanisms of change (coherence, cognitive participation, collective action and isal) needed to occur at multiple levels. Here, ward managers as change facilitators played a crucial role in engaging staff beyond the implementation teams in PIE, using routine communication mechanisms (handover and team meetings) to ensure their 'buy-in'. Further, 'buy-in' at all levels was not achieved once and for all. The dynamic nature of ward environments meant that for PIE adoption to proceed, PIE teams were confronted with the task of developing systems for renewal of staff engagement in sustaining the programme.   The experience of 'partial' implementers also attests to the fact that the generative mechanisms hypothosised in NPT require 'receptive' organisational contexts to effect routinisation i.e. they do not work in isolation.

Impact and Outcomes of PIE

Evidence from observation and staff interviews on both full adoption wards suggests that the PIE programme had a significant impact on practice. Specific changes, as for example, communal meals,

increased staff knowledge of patients, staff/patient interaction, patient/patient interaction and nutrition intake. Observation and interviews indicated that providing opportunities for patients to socialise facilitated patients conversing with each other as well as with staff. Although the content of patient to patient conversation was not always meaningful to the observer, it conveyed a sense of warmth; conviviality and sociability that was absent on other wards, and similar to what occurred on the dementia wards through communal dining. It reinforced the 'friendliness' and 'looking out' for each other expressed by some patients with their fellows, and of demonstrable benefit.[137,138]

There was also evidence that practice change impacted positively on the experience of patients and caregivers; although the heterogeneity of need and severity of impairment meant that some of the more visible changes did not affect everyone equally. Indeed, findings throw into relief the varied needs of patients on acute wards living with dementia: opportunities for social interaction and activities may be valued by some but not all; for others' use of touch and emotional connection with the person in 'their world' involving time spent in one-to-one contact may be more appropriate.

We are unable to draw any conclusions about the effect of PIE on clinical outcomes since data on delirium and falls was not collected on these wards.

Learning from PIE Implementation

Within the full adoption wards, PIE was effective in identifying a need for change and providing a systematic method to pursue action planning and appraisal, where organisational supports were in place. It offered an approach that *"tapped into the wisdom, skills and enthusiasm of front line staff* [and] *helped to generate not just innovation but energy and commitment"[134]* (p105).

There are aspects of learning from the research and experience of PIE implementation to incorporate into refinements of the guidance and tools. First, the dimensions of person-focused practice from the research relating to communication, tasks and managing distress may provide an explicit focus for service improvement; albeit without constraining the flexibility and creativity of implementers. Second, the content of some of the PIE documentation may be simplified without undermining its function in the process. Thus, the distinction made in the action planning documentation between short, medium and long term action plans appeared unnecessarily complicated and unhelpful. A key factor in teams getting going and keeping going was identifying goals and priorities around which staff could be mobilised to act. Indeed the difference between short, medium and long term action plans is likely to be in the number of steps required to achieve longer term goals. At the same time progress in working through the steps to achieve a longer term goal may involve a re-assessment/review of the goal and/or how to pursue it. Third, while some simplification of the documentation is suggested, we consider that completion of observation, action

planning and review tools through initial and full implementation is helpful in systematising engagement with the process as others have argued.[74]   Fifth, it became evident early on that additional support and guidance to translate observations and reflections into action plans was required and provided, requiring expansion of this part of the manual.

Generalisability of PIE

Is the PIE method too difficult for widespread use on acute wards? Would an alternative approach to service improvement be more effective? It is difficult to draw clear conclusions here. On the one hand, there is little research on what strategies for implementing innovations work in health settings or which work better for which kind of intervention. A compilation of implementation strategies[139] identified nearly 70, of which most complex interventions involve several in combination (as in PIE).

One strategy for improving care delivery and a key element of the national dementia strategy is provision of staff training. There has been considerable investment in training for staff in care of people with dementia in hospital. Between the first and second national audits of dementia in general hospitals in England and Wales,[25,26] there had been a three-fold improvement in the proportion of hospitals with a training and knowledge framework in place to identify the skills required of staff to work with and care for people with dementia (from a quarter to just over three-quarters of hospitals).   However, a recently published review[140] of training for hospital staff concluded that of the 14 studies identified relating to ten training programmes (four were a repeat of the original interventions with amendments), all except four evaluated learning, staff attitudes and confidence. The four that examined changes in practice relied only on staff self-reported data. Similarly, there were no studies that assessed patient and family members' experience of care following training. Most studies employed pre- and post- research designs and the methodological quality was rated as mixed. The authors concluded that evidence of effectiveness of training on changing care practice and influencing patient outcomes was very limited. Another strategy, also highlighted in the national audits[25,26] is the introduction of dementia champions. The second audit[26] concluded that although the vast majority of hospitals (82%) had a champion for dementia at directorate level and around three-quarters of hospital had a champion at ward level, there ws a dearth of evidence as to the impact of such roles on day-to- day practice. The report concluded that focus of attention in future audits should be on practice and not only systems and strategies.

Conclusions and Limitations

PIE has potential to improve the care of older people on acute wards living with dementia when implemented. However, findings are indicative for two reasons. First, since data on delirium and falls was not systematically collected on wards where PIE was implemented, there is no evidence as

to whether the programme is effective in improving clinical outcomes. Second, although PIE worked as intended on two wards to effect change in practice, it was not adopted in most study wards.

Research Implications

Several broad areas for further research are indicated:

The combined and interactive effect of advanced older age, dementia exacerbated by delirium; chronic health problems; and acute events presents enormous challenges for staff in providing quality care. There is pressing need for further research to identify more precisely the skill-mix and resources necessary to provide person-focused care to this frail patient group across the spectrum of need to provide the appropriate 'balance of care' to respond to this complexity. At the same time, more insight is required about the recovery trajectories of patients with such complex and multi-dimensional needs and the contingencies that impact on and shape them, in order to provide the most appropriate place and type of care to facilitate recovery.

Implementing innovations to change practices in complex organisations, like acute wards, requires more in-depth understanding of contextual factors that impact the capacity of organisations to absorb and embed new practices. Longitudinal research which examines the dynamic between interventions and the environments in which they are inserted, is needed . In particular, we require understanding of what are 'receptive change' contexts, suggesting a parallel line of investigation to that focusing on application of theories to the development and implementation of interventions to secure service improvement.

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Contributions of authors

Mary Godfrey has expertise in qualitative research and experience in mixed method studies involving the development and evaluation of complex interventions. She was involved in all aspects of the study from inception through to completion, including drafting and editing all sections of the final report.

Professor John Young is an academic geriatrician with expertise in multi-method research designs including randomised control trials, systematic reviews, qualitative and health economic studies relating to older people. He is on the steering group for the National Dementia Audits. Professor Young was chief investigator and involved in all aspects of the study from inception to completion, including editing all sections of the report.

Ms Rosemary Shannon is a health services researcher with experience of conducting mixed method studies and expertise in qualitative research methods. She was involved in data collection and analysis in three Trusts, drafting sections of the report and editing all sections.

Dr Ann Skingley is a health services researcher with expertise in qualitative research and a disciplinary nursing background. She was involved in data collection and analysis in one Trust, drafting sections of the report and editing all sections.

Ms Rosemary Woolley was a senior research fellow in the Academic Unit of Elderly Care and Rehabilitation and project manager of the research until November 2015. She had been involved in the development of the PIE observation tool for use in the National Dementia Audit. She was involved in the conception of the study and in data collection and analysis in two hospitals until leaving on account of illness.

Professor Dawn Brooker has an international reputation in the field of person-centred care service development for people with dementia. She was involved in protocol development and contributed to Programme Management Group meetings and to the final report.

Professor Claire Surr is an expert in Dementia Care Mapping having been instrumental in the development of DCM 8. She was involved in protocol development, contributed to Programme Management Group meetings and to edits of the final report.

Professor Kim Manley has an international reputation for the development of effective workplace cultures in healthcare linked to the provision of quality services that are person-centred. She has extensive experience in participatory action research and the use of observation tools to change practice. She has been a Steering Group Member for the National Audit of Dementia. She contributed to all aspects of the research including edits of the final report.

Frank Arrojo is a Research Network Volunteers for the Alzheimer's Society with experience of a close relative living with dementia. He contributed to the study conception, to Project Management Group meetings and commented on the final report.

Data Sharing

This is a qualitative study and therefore the data generated is not suitable for sharing beyond that contained within the report. Further information can be obtained from the corresponding author.

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APPENDIX 1: Summary Trust and Ward Profiles

Seaford Trust		City Trust		Ironbridge Trust	Central Trust			Valley Trust	
Population: 759,000 Wide geographical spread (small city, towns and rural hinterland) Large Teaching Hospital Staff: 7,500 Beds 1100 (over a number of hospitals)		Population: 500,000 City with diverse cultural and ethnic mix Large Teaching Hospital Staff: 5,200 Beds: 900 (large hospital and small hospital on separate site)		Population: 650,000 City-diverse ethnic and cultural mix Large Teaching Hospital Staff: 16,000 Beds: 2000 (across a number of hospitals)	Population: 1,200,000 Wide geographical spread: ethnically diverse city and suburban town Large Teaching Hospital Staff: 11,000 Beds (across several hospitals) Wards within suburban hospital (229 beds)			Population: 200,000 Geographically dispersed rural area Small District Hospital Staff: 2400 Beds: 395	
Poplar Ward	Crane Ward	Rivermead	Cedar	Netherton	Beech	Rose	Denton	Ambridge	Oak
Trauma orthopaedic (older people)	Medical : Care of Older People	Rehab: older People	Older People Medical/ acute trauma	Dementia	Older people medical/ Trauma orthopaedic	Stroke/ Medical/ Palliative	Dementia Rehab	Older People Medical	Mixed age: trauma Orthopaedic
22 beds Staffing: Ratio registered/non registered Early [E] 4:4 Late [L] 4:4 Night [N] 2:2	26 beds Staffing E 5:4 L 5:4 N 2:2	27 beds Staffing E 3:4 L 3:3 N 2:2	28 beds Staffing E 5:3 L 4:3 N 2:3	27/28 beds Staffing E 5:3 L: 4:3 N 2:2	24 beds Staffing NA	23 beds Staffing E 4:3 L 3:2 N 3:2	13 beds Staffing E 2:2 L 2:2 N 2:1	30 beds Staffing E 4:4 L 3:4 N 2:1	28 beds Staffing E 3:4 L 3:4 N 2:3

APPENDIX 2: Delirium Observation Screening Tool (DOS)

Patient Name:

The DOS Delirium Observation Screening Scale
PLEASE COMPLETE TWICE DAILY

Hospital number: ....

Never = The described behaviour was not observed

Sometimes = The described behaviour always was observed once, or a few times, or all the time

Unknown = The patient was asleep or did not give necessary responses OR the rater does not

		Date:						Date:					
		Timepoint 1, e.g. am Time:...................				Timepoint 2, e.g. pm Time:...................		Timepoint 1, e.g. am Time:				Timepoint 2, e.g. pm Time:...................	
		Never	sometimes-always	unknown/unable		never	sometimes-always	unknown/unable	Never	sometimes-always	unknown/unable		never	sometimes-always	unknown/unable
1	Dozes during conversation or activities	0	1	-		0	1	-	0	1	-		0	1	-
2	Is easily distracted by stimuli from the environment	0	1	-		0	1	-	0	1	-		0	1	-
3	Maintains attention to conversation or action	1	0	-		1	0	-	1	0	-		1	0	-
4	Does not finish question or answer	0	1	-		0	1	-	0	1	-		0	1	-
5	Gives answers that do not fit the question	0	1	-		0	1	-	0	1	-		0	1	-
6	Reacts slowly to instructions	0	1	-		0	1	-	0	1	-		0	1	-
7	Thinks to be somewhere else	0	1	-		0	1	-	0	1	-		0	1	-
8	Knows which part of the day it is	1	0	-		1	0	-	1	0	-		1	0	-
9	Remembers recent event	1	0	-		1	0	-	1	0	-		1	0	-
10	Is picking, disorderly, restless	0	1	-		0	1	-	0	1	-		0	1	-
11	Pulls IV tubes, feeding tubes, catheters etc.	0	1	-		0	1	-	0	1	-		0	1	-
12	Is easily or suddenly emotional	0	1	-		0	1	-	0	1	-		0	1	-
13	Sees/hears things which are not there	0	1	-		0	1	-	0	1	-		0	1	-

Researcher to complete this section. A score of 3 or more = a delirious episode

Total Score	
Is a delirium indicated?	YES/ NO YES/ NO

APPENDIX 3: Questionnaire for Ward Staff

The Climate for Care Questionnaire for staff

How to complete the questionnaire
For the purposes of this questionnaire we are interested in the ward on which you work. In order to respond to the questions, please circle the number which best represents your view. For example, this question below is about the levels of training on the ward.

		Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
	These questions are about the ward					
a.	We receive enough training on this ward to provide good quality care for patients	1	2	3	(4)	5

Now you have read the instructions, please begin the survey below. Please read every question carefully before responding and answer every question. Thank you.

Section 1: Your ward

1. The following questions refer to the <u>MDT (including therapists and medical staff on the ward where you work)</u>.

How much do you agree with each of the following about your ward?		Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
a.	The team share an explicit philosophy of care	1	2	3	4	5
b.	The psychological aspects of care are highly valued on this ward	1	2	3	4	5
c.	Values and expectations for care are communicated to new members of the team	1	2	3	4	5
d.	We have a culture on this ward about caring for patients and supporting them rather than being about 'doing tasks'	1	2	3	4	5
e.	Involving patients and their carers is considered very important on this ward	1	2	3	4	5
f.	We have sufficient basic equipment and supplies to deliver good levels of care	1	2	3	4	5
g.	There are adequate support services to allow us to spend time with our patients	1	2	3	4	5
h.	There are sufficient staff with the knowledge and skills to provide quality patient care	1	2	3	4	5
i.	We regularly take time to figure out ways to improve our care delivery	1	2	3	4	5

2. These questions are about how the <u>MDT</u> is able to do its job.	A little of the time		Some of the time		All of the time
a. Our team treat patients with dignity and respect on this ward	1	2	3	4	5
b. Our team put in extra effort to improve the quality of care that patients receive	1	2	3	4	5
c. Our team does a good job in meeting family member's needs	1	2	3	4	5
d. Our team meets its patients' care needs	1	2	3	4	5
e. Although there are a variety of patients, our team's outcomes are very good	1	2	3	4	5
f. Our patients experience very good individualised care	1	2	3	4	5
g. We work well with other members of the MDT	1	2	3	4	5
h. There is good communication among people on the MDT	1	2	3	4	5

Section 2: Nursing team, including auxiliary staff

3. These questions are about <u>support</u> within your nursing team.	Strongly Disagree	Neither agree not disagree		Strongly Agree	
a. Colleagues show concern and support to help each other deal with stresses at work	1	2	3	4	5
b. Colleagues provide each other with emotional support	1	2	3	4	5
c. The emotional demands of care-giving are acknowledged in this nursing team	1	2	3	4	5
d. Members of this ward team feel confident about the competence and abilities of other nursing team members	1	2	3	4	5
e. There is a great deal of trust among members of the nursing team	1	2	3	4	5
f. The nursing team can really count on each other to help out with any difficult tasks at work	1	2	3	4	5
g. People feel safe to be themselves in this nursing team without fear of criticism, censure or feeling foolish	1	2	3	4	5
h. This is a ward where it is safe to bring up problems and tough issues	1	2	3	4	5
i. This is a nursing team where anyone can challenge poor practice without fear of being rejected	1	2	3	4	5

4. These questions are about <u>roles and decision making</u> within your nursing team.			Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
a.	Our team discusses performance objectives		1	2	3	4	5
b.	We discuss ways to make our team vision a reality		1	2	3	4	5
c.	Our team makes the time to share task-related information		1	2	3	4	5
d.	When mistakes or errors happen we discuss how we could have prevented them		1	2	3	4	5
e.	The team takes the time to reflect on its performance		1	2	3	4	5
f.	We can influence what goes on in the ward		1	2	3	4	5
g.	We have a say in how work is managed within the ward		1	2	3	4	5
h.	The team participate in decisions that affect them on this ward		1	2	3	4	5
i.	Team members have the freedom to make important work decisions		1	2	3	4	5
j.	We can determine how we do our work		1	2	3	4	5
k.	We can carry out our work in the way we think best		1	2	3	4	5
5. This question is about <u>relationships and confidence</u> within your nursing team			Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
a.	We handle differences of opinion between staff well here		1	2	3	4	5
6. These questions are about <u>resources and demands</u> within your nursing team.			Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
a.	There is too much work to do in too little time		1	2	3	4	5
b.	We are asked to do work without adequate resources to complete it		1	2	3	4	5
c.	We cannot follow best practice in the time available		1	2	3	4	5
d.	We have to make trade-offs between the quality of work and cost savings		1	2	3	4	5
e.	We are given time and opportunity to develop new work skills		1	2	3	4	5
f.	Training and professional development is readily available for everyone		1	2	3	4	5
g.	Staff development is supported by an active programme of mentoring and clinical supervision where appropriate		1	2	3	4	5

7. The following questions are concerned with the <u>leadership and management</u> on your ward.		Strongly Disagree		Neither Agree nor Disagree		Strongly Agree	
The ward manager…							
a.	Instils a sense of pride in our ward by focusing on what we do well	1	2	3	4	5	
b.	Inspires confidence by saying positive things about the ward	1	2	3	4	5	
c.	Ensures the interests of team members are considered when making decisions	1	2	3	4	5	
d.	Consults with the team about daily problems and procedures	1	2	3	4	5	
e.	Acts in a caring and supportive manner towards members of the team	1	2	3	4	5	
f.	Is clear and explicit about the standards of care expected	1	2	3	4	5	
g.	Takes initiatives to establish strong standards of excellence in care	1	2	3	4	5	
h.	Sets clear care goals and objectives for this team	1	2	3	4	5	
i.	Is an on-going "presence" on the ward – someone who is readily available	1	2	3	4	5	
j.	Actively coaches individuals to help them improve their care delivery	1	2	3	4	5	
k.	Sets an example by involving herself/himself in hands-on patient care	1	2	3	4	5	

Section 3: About you and how you feel at work

8. The following words describe different <u>feelings and emotions</u>. Thinking of the <u>past week</u>, how much of the time has your job made you feel each of the following: I have felt…[†]		Never	Occasionally	Some of the time	Most of the time	All of time
a.	Tense	1	2	3	4	5
b.	Miserable	1	2	3	4	5
c.	Depressed	1	2	3	4	5
d.	Optimistic	1	2	3	4	5
e.	Calm	1	2	3	4	5
f.	Relaxed	1	2	3	4	5
g.	Worried	1	2	3	4	5
h.	Enthusiastic	1	2	3	4	5
i.	Anxious	1	2	3	4	5
j.	Comfortable	1	2	3	4	5
k.	Gloomy	1	2	3	4	5
l.	Motivated	1	2	3	4	5

Section 4: About the hospital

9. These questions are concerned with your views of your <u>hospital</u>	Strongly Disagree		Neither Agree nor Disagree		Strongly Agree
a. This hospital has access to the resources it needs to get its work done	1	2	3	4	5
b. This hospital provides good training opportunities	1	2	3	4	5
c. It is easy for our ward to obtain expert assistance when called for	1	2	3	4	5
d. Staff's concerns and opinions are listened and responded to by management in this hospital	1	2	3	4	5
e. Staff in this hospital are treated with dignity and respect	1	2	3	4	5
f. Employees are given authority to act and make decisions about their work	1	2	3	4	5
g. People in the hospital are rewarded fairly for the work they do	1	2	3	4	5
h. There are good career opportunities in this organisation	1	2	3	4	5

Section 5: Background details

About your Job:

10. **What is your current job title?**

_____

11. **What is your current grade?**

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

12. **How long have you worked on this ward?** _____ years ____months

13. **How long have you worked In this hospital?** ____ years ____months

Many thanks for completing this questionnaire. If you have any further thoughts or comments for the research team, please use this space.

APPENDIX 4: Patient Case Studies

The case studies presented below (Cecil and Brenda) are illustrative of the diversity of need, impact of impairment and the ways in which the patient's sense of self is conveyed through conversation and observation. We also draw on organisational accounts presented in medical and nursing notes and the views of 'close others' conveyed in interviews. On admission, neither Cecil or Brenda had a formal diagnosis of dementia. Both were assessed as having a delirium, although there was uncertainty in the medical notes as to whether this was a consequence of the trauma that resulted in the acute admission or contributed to the event that began the journey into hospital.

Cecil

Cecil, 82 years old was admitted to Ambridge ward via A&E on 4 December following a fall. His wife heard the clatter, then moaning about 9.30 pm and found him lying at the bottom of the stairs. She called the ambulance, and her daughter, Janet. Janet came straight away with her son. When the ambulance arrived Janet went with her father and her son followed. Living at the furthermost boundary of the catchment area, it was nearly midnight when they got to A&E. Causes of concern were fractures and internal bleeding as Cecil was on Warfarin. Following an assessment and various tests, he was admitted and transferred to the ward around 5am; Janet and her son stayed with Cecil until the transfer.

The Clinical Story (nursing notes)

Reason for admission: fall and head injury… was delirious and had a chest infection. No known dementia (normally oriented to time and place); some confusion; no hearing, speech or language deficit; GCS 14/15. Full trauma scan carried out in A&E and results NAD.

<u>On ward admission</u>

Will need full assistance at present due to confusion; awaiting medical RV, MRI, MRF, Waterlow, MRSA; no EOL (end of life) considerations, no mental capacity concerns and no problems with sleeping recorded on the relevant paper work. He has dentures and spectacles.

Washing and dressing x2 required; independently eating and drinking though needs assistance with red tray. He is dependent in terms of mobility (restricted) and at risk of falls; continent, pain (usually not); no anxiety/ breathing/ other problems. Health (underlying): TIA, DNT – Jan 2013, Bowel Cancer 2004, bilateral knee replacement.

Cecil observed

Cecil was first seen by the researcher on the 6th December (two days following admission) during general observation. Within a day of admission he had been moved from a bay to a side room in a high/low bed: his agitation and calling out had disturbed other patients, and he was seen as at risk of falling. At this point, he looked very withdrawn. Cecil had some personal effects in his room, including a picture of him and his dog. Over his bed was a Butterfly symbol to indicate dementia. In his notes was a chart with pictorial symbols in the first column and a description alongside providing personal information. For example: *Cecil is a picky eater; likes cereal and hates porridge; has always been a sociable person.*

Cecil was next observed on 12th December when shadowing the doctor. He is awake, bright and responds with 'hello'; answers the doctor's questions: 'not had a bad night'. Asked his date of birth and where he is, he is unable to answer and becomes upset. He's reassured; it's okay; the doctor will come back later. Later on, the doctor tries again: he does well counting backwards from 20, but is unable to answer questions about the Royal Family. He holds the doctor's hand who asks: 'are you in pain'? 'No'. 'Do you want to ask me anything'? He replies: 'Can I go home'? Later the doctor describes Cecil as 'very confused'; and that it is unclear how much is new or recent. The doctor notes that Cecil has had a hyperactive delirium since admission, a factor in his agitation.

A week later, during general observation late afternoon, the researcher sees Cecil walking with a Zimmer frame, being 'special-ed' by a staff member. He walks alongside the staff member from the day room down the corridor and back to the day room. One of the nurses' remarks: *'Cecil needs 1:1 care as he becomes very agitated'*.

On several occasions over the next week, Cecil was observed being coaxed to eat, usually expressing his disinclination by waving his arm and not opening his mouth. Interaction with staff during general observation mostly involved staff coaxing/instructing him to do things: taking medication, eating meals and him refusing/becoming angry.

Cecil's ability to communicate verbally was very impaired; he struggled to find the words, yet his eyes and face lit up when he was spoken to. He was regarded as 'difficult' and 'challenging' and interactions with staff over time became dominated by an 'instructional' mode of communication which in turn drew forth his resistance. This pattern of interaction was common in respect of patients with dementia deemed 'challenging on this ward. Several individual members of staff did, however, spend time with him, although mostly he was on his own.

After the Christmas break, Cecil was still on the ward and in the side room. He appeared very withdrawn, although he called out periodically. The researcher approached Cecil's wife and daughter about participating in the research and both agreed; they also agreed that Cecil would have been pleased to take part. Signed caregivers' consent and advice from the personal consultee, enabled more focused observation and case note review. When the researcher went in to see Cecil with a member of staff to introduce herself, he smiled and responded; he struggled to say something but the researcher could not tell what: he seemed to enjoy having people with him.

The Clinical Story continued: Excerpts from nursing case notes

Lives with wife, unable to cope; no previous help from home care; request for referral/ contact assessment. Needs 24 hour care/ new care package for personal needs.

High risk of pressure sores; handling assessment x 2 required & side room; verbal encouragement; falls risk high during stay so far because of confusion at all times; needs assistance to toilet; hearing and communication deficits; urinary tract infection; high risk of pressure sores.

05/12: Patient nursed on high low bed; appears confused trying to climb out looking for his wife at beginning of shift; calling out, reassurance provided, eventually settled after taking meds; infection prevention plan; no falls to report, safety maintained, remains unsteady on feet.

06/12, 03.40: Slept on and off, asking staff to help him get out of bed. Eventually settled and slept; nursed on high low bed; taken meds and obs. stable at bed-time.

06/12, 18.00: Wanting to go to his wife this evening, delirious, remains confused throughout the day; remains high risk of falls, nursed on high/ low bed, no falls up to time of report. Bruising to left shoulder; appears to have discomfort and pain; x-ray performed this afternoon; bladder scan performed – nil residual; please observe. Standing transfers poor today, but has managed to stand unaided this evening – needed 1:1 at present, now back in bed.

08/12, 04.20: Incontinent of urine, assisted with hygiene needs, full bed change given several times.

08/12, 11.30: Rolled out from low bed and found on floor, no injuries sustained; hoisted back to bed, bleeped doctor for falls review, patient confused. Continue with antibiotics; await MSU results.

13/12, 06.00: Confused, urinating on the floor, redirected back to bedroom!

15/12: Urine infection treated, muddled.

16/12: Very muddled when trying to express his needs. Daughter raised concerns that patient will need support on discharge. Ward request for social work assessment.

18/12: In night very unsettled & agitated & aggressive (first time latter noted), needing up to 3 staff.

Pattern of agitation persists over the next weeks particularly at night. Ongoing urinary infection and delirium; becomes incontinent of urine from beginning of January; given Lorazepam when agitated.

Multi-Disciplinary Team Perspective

The MDT meeting on 16th December agreed that Cecil should be given more time prior to organising discharge to see if the delirium resolved; then the work with the physio would start. It was noted that Cecil's family wanted him home but that they were scared to leave him as they feared he would fall. The doctor and senior nurse expressed the view that Cecil needed 24-hour care; it was agreed that this would be discussed with his family.

Following discussion with the family, the MDT meeting on 23rd December agreed that as there was no resolution to the delirium, a long term care placement would be pursued. Whether this was to be a nursing home or specialist dementia unit (EMI home) would be confirmed when all assessments were completed and a funding decision made.

After the MDT, a Section 2 (assessment for social care) and request for a continuing health care (CHC) assessment, was sent to Adult Social Care. The care manager responded on 27th December with a request for a behaviour chart, details of the plan in place to resolve/ treat his behaviour, and for a psychiatric assessment; that without these, an assessment for care could not be completed.

On the 30th December, the social worker completed the CHC Checklist and met with Cecil's family.

On the 6th January, Cecil was assessed by the social worker. In the afternoon after his wife and daughter had left, Cecil was observed up and about at his own initiative, supported by staff. He went in to see the lady in the next door room to his.

On the 7th January, a nursing needs assessment was completed. The MDT meeting on the 10th January, confirmed that an EMI placement was required, based on the assessments.

Observation over the next weeks revealed that Cecil had become more and more withdrawn and always looked tired; he was often sitting in his room, head slumped on his chest; when anyone passed the door he looked up. He was often mentioned by staff as being 'very confused', very agitated at times. Cecil was viewed as a patient who was 'difficult to care for' on account of his agitation and 'refusal to co-operate'.

On 10th January, late afternoon, the researcher went in to see Cecil. He was on his mattress on the floor in the darkened room. He asks: 'what time it is please'. The researcher replies: 20 to 5. He repeats 25 about ten times; points to the end of his bed. She asks if he'd like his dressing gown (which is there), he indicates yes. However he did not want it when she gave it to him. He repeats 20 5, then: 'Night love' he says and she leaves, saying she will be sat outside if he needs anything. He turns over and reaches for a pillow on the mattress next to him, then he turns onto his back

again, eyes closed. After a few minutes he repeats the action. He tries to reach for his pillow then stops, his eyes closed, facing the door.

Over the next week, observations reveal a recurring pattern: Cecil is mostly in his room; he appears to have lost a lot of weight and is resistant to eating and taking medication. The following is illustrative: A HCA goes in to Cecil: 'Have you had something to eat?' 'No!' 'Here's your tea'. She kneels on the mattress next to him and starts to unwind the cord and adjust his bed.

'Sit up, sit up' the HCA encourages Cecil. 'Cecil, sit up. Right, I'm going to try you with this… don't go to sleep, Cecil; its tea-time, are you going to have something to eat Cecil; open up, a bit more Cecil'.

Often when the researcher goes in to see Cecil; he is asleep, lying on his side on the mattress, facing into the wall, his arms out and eyes closed.

The family story (pieced together from the interview with Janet and her mother, Ivy with Cecil present).

Presentation of confusion

Janet: *We'd thought he had a little bit [of confusion] because he would forget certain things …or else he'd come into my mum and say, oh have they all gone and she's, well nobody's been here and things, so we've put it down, but nobody had ever classed him…* [Interrupts her flow to look at her Dad]

I don't know, I think is he trying to pick something up, I don't know? 'Right, you sit back now'. So yeah, so it was fine …you could cope. Oh what's he doing now? You could cope quite all right, but then it's just his fall and they've diagnosed his vascular dementia and they said they've waited long enough to see if he is going to get better, he says 50% do, 50% don't and unfortunately he's in the category…

Ivy: *Take that out of your mouth [to Cecil].*

Janet*: What's he doing?*

Ivy: *Picking something up off the floor.*

Janet: *But there's nothing there, he's just pretending. But yeah, so unfortunately he's in the category that does, that won't get better…Yes, he was all right before, because when we …first came in and we were downstairs in the A&E and they're saying, well 'can you count from 1 to 20', and then they asked me if he could count backwards, where me and my son brought him in. And I looked and I said, 'there's no chance'. But he did. And I thought, well that even surprised me …And then when we came to see him he was confused wasn't he, when he had a water infection you see. So we put it down to the water infection that was…making him. Because when he'd been in previously in January, he'd got a water infection then and that had sent him…funny as well. And so, but he'd never been right since he'd been in, in January, has he, he's always been a bit more confused than what he was before and he never came back the same. But then he's just… gone now and they've just said the fall has brought on a rapid, this rapid dementia and things, so yeah.*

Ivy: *Yes, but you see he's hardly eating. I look at his chart, but he's hardly eating and the portions that they give him, I know he wouldn't eat a lot anyway, but they're only tiny. So when it says he's eaten whole lot, it's only a little tiny…*

Janet: *A little bit… he has lost a lot of weight.*

Ivy: *Yeah, he didn't do a lot anyway; he didn't walk as much as…*

Janet: *…he had been doing, no, but they still managed fine at home and things together, didn't you? You helped each other, didn't you?*

Ivy: *You stay there in your chair[to Cecil]*

Janet: *Sit back in your chair.*

Ivy: *You'll fall.*

Janet: *Well have a rest then. Yeah, these tablets totally zonk him out, look he's thinking he's got it…. Yeah, well he's got the Zimmer there, but he also needs people with him as well, yeah, which before you see, he didn't have a Zimmer at home and things, he used to have a stick, didn't he, what?*

Ivy: *Yeah, but not in the house. No, he could, he could walk about no problem in the house.*

Janet: *But if he went out he needed a stick*

Ivy: *Eh, I don't know, he just wanted to stand up. I don't know why he wanted to stand up. That's it, you sit back down again, yeah, so.*

Janet: *What he's like all day, bless him….*

Later in the interview, the picture conveyed above of Cecil's dementia being of recent origin shifts: episodes suggestive of a more insidious onset over a longer period of time are recounted. Additionally a previous acute admission a year earlier documented in Cecil's medical notes records that Cecil's wife and daughter had expressed concern about his ongoing confusion.

Ivy: *And he used to get up in the morning when I told him to and get himself dressed.*

Janet: *Sometimes he used to get a bit confused with that, didn't he?*

Ivy: *Aye.*

Janet: *Because they couldn't understand why he's like that … they've done all their, he's had loads of scans and things to try and see, and I honestly think that they still don't know why he is like that. I don't think they've got an answer, all they've said is, he's got vascular dementia and it's just been a rapid onset of it…*

Ivy: *At home he just, basically he just used to sit in his chair, didn't he and he used to have telly on, not that he took a lot of notice of it, but it was just something there. But he couldn't really do a lot, could he anyway. And since he stopped driving at the start of this year and I think he really missed that didn't he as well. But he just wasn't safe to do the driving, and especially with the roads being as busy as what they are. He just used to potter about…*

Janet: *Yes, yeah, but then you were frightened that he'd park the car and forget where it was, so.*

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Ivy: *It was his last bit of independence really where he could go and do things for himself, so I think that really upset him when he had to give up the car. Because sometimes in here he still thinks he's got it, doesn't he, he's thinking back and he still thinks he's got it… They are kind to him here aren't they and things?*

Janet: *Well I don't know, he gets aggressive with them sometimes, doesn't he?*

Ivy: *Well sometimes he does, if he's in one of them moods, doesn't he, if they're trying to tell him something and he doesn't want to do it, isn't he? But we say, he's not really like this, he's not…he's not been an aggressive person.*

Janet: *No, it's not in his nature.*

Ivy: *No, but he's just, he doesn't know; he just doesn't know what he's doing… which in one sense is good that he doesn't know he's like this…*

Janet: *No, I don't think he knows, my dad, I don't think he realises what is happening.*

Ivy: *He doesn't even realise he's in hospital.*

Janet: *Because sometimes he'll say, I think I'll go upstairs and you say, no, you're in hospital*

Ivy: *He says, I'll go and have a bath and go out for a pint.*

Janet: *He thought he was driving, didn't he? What did he say, dear?*

Ivy: *Can't find bloody accelerator or something he was saying.*

Janet: *And he was trying to get down and trying to do some of the other things wasn't he?*

Ivy: *But then one of the nurses said that she'd sat in with him one day and she says 'I didn't know he used to work in a printer's office'. She says we had a right good chat and that was when he was…*

Janet: *No, but how old was he when he worked in the printers?*

Ivy: *Well, from leaving school…that was good, yeah.*

Janet: *Exactly, yeah, well I brought a picture of my dog up with him, so, and he'd been telling everybody, this is Casper, well actually it's Tilly. We did have a dog called Casper who died, but, so he could remember Casper, he can't remember Tilly obviously, so he was just reminiscing or telling everybody.*

A nurse comes in to administer medication – it takes some time: the nurse repeatedly asking Cecil to open his mouth and take the tablet; he, resisting. *'Hello, do you want to open your eyes please, so I'm just going to give you a tablet… Hello, open your mouth love, open your mouth, yeah…Do you want some more drink, that's it, have another, is that nice'?*

[The nurse leaves]

Cecil: *Aye…. broke*

Ivy: *What do you want?*

Cecil: *I … forget*

Janet: *Don't get up out of your seat.*

Ivy: You stay there, OK? He just thinks I'm getting on at him all the time.

Janet: *Then he'll tell you to shut up won't he?*

Ivy: *He will tell me to shut up, yes.*

Janet: *It's like, God she doesn't…half get on at me.*

Ivy: *You can't blame him*

Cecil: *I … when do we go out?*

Janet: *What, when are we going out, you're in hospital aren't you at the moment?*

Ivy: *Yeah, you see, he keeps saying no, but I keep giving it him and things, but whether they do here, if he says no then they might just leave it, but he doesn't know he's saying no, he doesn't understand that he's saying no. So he, because it's like when they try to do blood pressure things, isn't it… a lot* of [notes] *says refused, but I don't think he understands.*

In a conversation with the researcher 13ᵗʰ January, Janet and Ivy describe their difficulties in identifying a suitable home. They had been advised by the social worker to look for a dual registered home. Janet had searched on the internet but found identifying dual registered homes not straightforward and they were unclear as to whether he would need to be in a specialist dementia unit: *"I found a nice one if he isn't EMI, it's nice, but if he is then I just don't know… we just don't want to bung him anywhere do we"?* They explained that as they wanted a home near to where they lived which was in a different local authority area, hospital staff did not have the local knowledge to help: "*so you just feel like you're on your own really".*

Cecil was discharged to an EMI home on 28ᵗʰ January. He had spent 55 days in hospital. He died shortly after his admission.

Brenda

Brenda is 90 years old and had prior to her acute admission been living in extra-care housing with carers coming in three times daily. Her family described her as very sociable, and although she had become more forgetful over the previous year, she was 'managing' at home and very involved with family activities.

On the 6th December, Brenda came to A&E with a urinary tract infection and was transferred overnight to the medical assessment unit for further investigations. The next day she fell on the unit and sustained a hip fracture. Following surgery, Brenda was moved to Oak ward on the 8th December; she had also developed post-operative delirium.

In the course of the next two weeks, Brenda was very ill and acutely confused. Her case notes indicate that she was very poorly, 'un-cooperative' (pulling out her IV cannula; trying to climb out of bed) and incontinent. During a ward round in mid-December, the geriatrician notes that Brenda has dementia; that there is uncertainty about the degree of impairment until the delirium resolves; and that staff need to observe closely for changes in behaviour and attention.

Toward the end of December, Brenda picked up. She was moved from a single room to a bay and referred to Adult Social Care before Christmas for an assessment to plan discharge.

The Clinical Story (nursing notes and MDT)

09/12: Comfortable post-op night

10-28/12: Noted that patient is very confused; incontinent at night; very ill, and placed in one of the side rooms.

27/12: Possible infection; stool sample sent for analysis; very sleepy.

6/01: MDT: The consultant comments that Brenda has/had delirium on top of dementia so they need to work out what is reversible. They query sepsis, UTI: 'she's got hyperactive delirium'.

10/01: Brenda appears to have had a settled night…'chatting away…'

12/01: Spitting tablets out despite multiple encouragements and explaining importance of taking medication.

13/01: Nurse spoke to Mental Health worker –will assess Brenda's mental health.

13/01: Settled in the afternoon, but 'found wandering at times without Zimmer frame'. Assisted with toileting by HCAs

14/01:Wandering around bed area at times overnight. Incontinence cares given, used toilet with supervision.

15/01: Has been mobilising well with her Zimmer.

Similar to Cecil, Brenda was regarded by staff as 'challenging' particularly during these early weeks on the ward. At the same time, she enjoyed conversation, conveyed interest in the people around her and expressed gratitude to staff for the help provided, and staff responded positively to her.

The researcher's first direct contact with Brenda was on the 6th January. In her field notes, she describes the Butterfly symbol over Brenda's bed, indicating that she has dementia. The Butterfly folder at the foot of her bed, provides information about her preferences:

Makes me anxious: being in pain

Makes me happy: friends, family and socialising

Food and drink dislikes: currants, raisons, coconut, green beans.

Food and drink likes tea with no milk or sugar, cranberry juice

You know I'm in pain; I tell you.

I can walk normally to the toilet.

Brenda is described by staff as looking much better. In conversation with the researcher, she says she is waiting to go to the hairdresser today; that she's looking forward to it because she'll feel better afterwards, but is anxious that she doesn't know when she's going or where.

Brenda presents herself as someone who doesn't want to offend anyone. She tells the researcher: 'I always say thank you; I'm very grateful; I've got a lovely family; I'm very lucky'. She says she always gets on with people; doesn't make enemies; and that since she left school has not fallen out with anyone.

Brenda enjoys chatting to people; she always has a few words with staff and with the caterers bringing drinks and meals and they joke with her. She keeps a solicitous eye out for other patients in the bay. In a conversation with the researcher she remarks on the swollen legs of the patient in the bed opposite, and says the lady might need her legs covering up (the researcher notes that the patient's legs and catheter tube are visible as her nightie has bunched above her knees). Brenda often expresses anxiety about reaching her buzzer at night; she mentions it to the researcher every time she sees her. Staff comment that Brenda gets up at night and 'wanders'; her daughter says that she was used to getting up at home during the night to use the toilet. Is she looking for the toilet during the night?

> **Who is planning for Brenda's discharge?**
>
> 10/01: The ward manager in conversation says that Brenda hasn't been assessed yet by the social worker. Initial discussion with the social worker had indicated that social services were looking to getting her back home with a support package. The ward manager comments that Brenda isn't safe to go home: she gets up at night, wanders, and is at risk of falls. She considers that Brenda needs an assessment bed (step-down bed without rehabilitation) with a view to a long term care placement. The social worker had asked for a mental health assessment prior to carrying out a social care assessment.
>
> 13/01: At MDT, ward staff report that the social worker has requested a mental health assessment before proceeding: no further information about progress. Some cynicism expressed by staff: is this a delaying tactic on the part of Adult Social Care?
>
> 15/01: Brenda has been walking with a Zimmer frame; and has made her way to the day room. At visiting time, the researcher talks to Brenda and her family (son, daughter-in-law and grandson). The family say they haven't a clue about what is happening about discharge, and suggest that the nurse they spoke to didn't appear to know anything either. Brenda's daughter-in- law says that she didn't feel she could ask more of the nurse and leans to one side to demonstrate how the Nurse's body language conveyed that she was busy. She wanted to ask about how Brenda was eating, but felt the Nurse was too busy. The family know that there is mental health assessment planned but have heard nothing further. They say they always have to initiate discussion with staff about what is happening.
>
> The family report that Brenda's medical care has been good and that her health has definitely improved.

Although Brenda can communicate her needs, often in conversations she will say to the researcher that she needs to go to the toilet and presses the buzzer. When the staff member comes, she will ask about her pain medication; or talk about the pain in her back. It is unclear whether she's forgotten about wanting assistance with toileting or that this is her way of expressing a general need. Brenda has arthritis and experiences pain and discomfort, unconnected with the fracture.

In conversation on 10th January, Brenda tells the researcher that she'll be going home in 2 or 3 days; she wants it to be today. In responding to the researcher as to how she feels about going home, Brenda replies that she is looking forward to it. 'They'll be able to come every day (her family) only half mile away…do my cleaning and everything'.

From conversations with ward staff, Brenda herself and family members, different perspectives emerge about when Brenda will be discharged and to where. It is unclear who holds the whole picture and who is leading on discharge planning.

The ward manager expresses concern as to whether Brenda is safe to go home; the social worker wants a mental health assessment done before any options are considered as Brenda was managing on her own before; and Brenda just wants to go home.

Brenda's family are unsure about the extent of her confusion. She did forget things before but she was very confused and not herself following admission and surgery until around Christmas. They wonder how much of the confusion might be due to the environment and under-stimulation on the ward. They all consider that they have to initiate conversations with staff; staff will never come to them to convey what is happening.

What should happen to Brenda? Different perspectives

The social worker

Brenda is incontinent with care needs at night – so how will she manage returning to where she was before? She acknowledges that Brenda may have fewer needs in her own environment. In conversation with a junior physio, the social worker advocates putting Brenda in a temporary rehab bed: she has two places available now.

The physiotherapist

The senior physio has documented that Brenda has 'no rehab potential'. She will do as instructed under supervision but has 'no carry over'. Her view is that Brenda needs 24-hour care.

Social worker and physios

The social worker asks for informal feedback from two physios on the ward. One explains that in the opinion of her senior colleague, there was nothing more that therapists could do for Brenda. The three debate the merits of referring her for rehab and whether she would do better in her own familiar environment. For the social worker the options are a step down bed with no rehab at a distance from where she was living to assess need for long term care; or a rehab bed to give her a chance to get back home. Getting back home is what Brenda and her family want. The social worker's preference is for the rehab bed: Brenda *'will be pushed to be independent and will be in a more normal and sociable environment, for example eating with others'*. The physios consider making the referral; get out a form but decide that they cannot do it, given their senior colleague's assessment. For the social worker, there remains the problem of how Brenda will manage night time needs.

The occupational therapist (OT)

The researcher is approached by the OT. She has made the referral for a rehab/assessment bed for Brenda having discussed it with the social worker. They both agreed that Brenda would be better out of the hospital environment. Although it was uncertain whether she would be able to go back to

her own flat: *'I'd like to give her the chance'.* Their decision, she explained had been a joint one: between herself, the social worker, Brenda and her family.

20th January: Brenda is discharged to the rehab bed today. Ward staff had tried her with the commode by the side of her bed the previous night and she had used it without asking for help. She had spent 43 days on Oak ward.

The family assessment of the ward

The researcher talks with the family as they get Brenda ready to leave. Their experience of the ward is mixed. *"it's just getting hold of staff to talk to…"* And Brenda often had to wait a long time after ringing the buzzer for someone to come. Her daughter-in-law, Anne comments that Brenda had got into *'hospital mode'* in that she was in the habit of pressing the buzzer for assistance. Anne says that she's been telling her to just go to toilet herself if she needs to go, to get better. Anne shakes her head to indicate that Brenda wasn't doing this. The researcher asks how Anne thinks Brenda will manage in the assessment unit. Anne replies that she doesn't know… Brenda has been getting up at night herself and asking for help during the day, so she is incontinent (from waiting for the buzzer to be answered).

APPENDIX 5: Summary data collection

	TRUST WARD):	Central Rose	Central Denton	Central Beech	Ironbridge Netherton	Valley Oak	Valley Ambridge	City Rivermead	City Cedar	Seaford Poplar	Seaford Crane
	Type of ward:	Stroke	Older People (dementia)	Older People + #NOF	Older People (dementia)	Trauma orthopaedic	Older People	Older People	Older People + #NOF	Trauma and ortho-geriatrics	Older People
BASELINE	Dates data collection	July-Nov 2013	July-Nov 2013	July-Nov 2013	Aug-Nov 2013	Nov 2013-Jan 2014	Nov 2013 – Mar 2014	Feb-Apr 2014	Sept-Nov 2014	Dec 2013-Feb 2014	Feb-Mar2014
	General ward observation (n of hours)	22hrs	26hrs	19hrs	39hrs	33hrs	38hrs	34hrs	33hrs	24hrs	27hrs
	Patient case studies (n of patients) / Patient observation (n of hours)	0	3 / 5	3 / 4	2 / 5	2 / 6	2 / 6	2 / 5.5	2 / 6	3 / 5	3 / 5
	Number of staff interviews Conception of person-centred care	2	5	2	10	6	8	6	7	5	5
INTERIM	Dates data collection				Nov 2014 -May 2015			Jan- Mar 2015		Nov 2014-Feb 2015	Jan-Mar 2015
	General ward observation (n of hours)				31			34		29	26
	Patient case studies (n of patients) / Patient observation (n of hours)				2 / 6			2 / 6		1 / 3	2 / 4.5
	Number of staff interviews Process of implementation of PIE				7			4		4 (5 staff)	3 (4 staff)
OUTCOME	Dates data collection									Aug-Oct 2015	Oct-Dec 2015
	General ward observation (n of hours)									29	26
	Patient case studies (n of patients) / Patient observation (n of hours)									1 / 4	1 / 4
	Number of staff interviews PIE: Barriers and experience		1		1		1	3		3 (5 staff)	3 (7 staff)

APPENDIX 6: Person-Centred Care in Policy

What is 'Person-Centred' Care in Policy?

'Person-centred' care has become ubiquitous in UK health and social care policy discourse as synonymous with care quality. Its meaning in policy however, is either implicit or there is varying emphasis on different domains. It is commonly conveyed as individualised care, holistic care, choice, autonomy and dignity. Moreover, use of the term and the particular emphasis attached to it, has varied over time and in relation to wider policy interests..

One of the first UK policy documents to use the term 'person-centred' care was the National Service Framework for Older People (NSFOP).[1] In Standard 2, it refers to the requirement on health and social care services to *'treat older people as individuals'* and ensure that they receive appropriate and timely packages of care which meet their individual needs, regardless of health and social services boundaries. Treating people as individuals was conceived of as: listening to older people, involving them in all decisions about their care and needs, enabling them to make choices about their care and providing a co-ordinated and integrated service response. These were to be achieved through the single assessment process, integrated commissioning and provision of services across health and social care. It was incumbent on staff that services should be delivered in a manner that accorded respect and dignity. For older people with mental health problems, including dementia, the hallmark of a quality system of care was that it be *'comprehensive, multidisciplinary, accessible, responsive, individualised, accountable and systematic'*. 'Person-centred' care then was a multi-dimensional construct comprising interactional, relational and systemic components.

There was no explicit reference to 'person-centred' or 'person-centeredness' in respect of care in general hospitals; emphasis was on promoting dignity and privacy. It was asserted that care in hospital should be underpinned by *"fundamental principles for the promotion of dignity"* (p52). This was translated into the creation of physical and care environments which were: *"clean, allow for privacy and assist in promoting independence"*; provided for such personal needs as help with nutrition, dressing and bathing; and facilitated access to specialist care and advice with staff appropriately trained in caring for older people.

Subsequently, the term dignity became the standard bearer to carry care quality in policy, being the focus of a campaign with particular emphasis on older people and care on hospital wards. The aim was *'to put dignity at the heart of care'* and to create *'dignity'* champions in every health care

organisation to promote it.[2] The primary emphasis in this campaign on the behaviour and attitudes of individual staff was criticised on the grounds that these exist within a complex set of organisational cultures and competing priorities which impact on individual and team approaches to the care and treatment of older people.[3,4]

In its vision for modernising the NHS, High Quality Care for All,[5] values of respect, dignity and compassion were emphasised. It was noted in the preface that the NHS…*"touches our lives at times of most basic human need, when care and compassion are what matters most".* In this paper, the term 'person-centred' was not used. It was stated that the NHS was committed to providing *'safe, personalised, clinically effective* care' and *'locally led patient-centred and clinically driven change'.* Whereas 'person-centred' had been applied in a generic sense across sectors and services within the NSFOP, the term 'patient-centred' was more commonly utilised in a health context. Nevertheless, both terms were used interchangeably to encompass similar content. The policy shift toward dignity, respect and compassionate care did however direct attention on the relational aspects of care delivery and therefore how care was experienced by those receiving it.

Person-Centred Care: People with Dementia

Regarding the care of people with dementia, NICE Guidelines[6] made specific reference to Kitwood's theoretical model of 'personhood',[7] the only policy document up to this point to locate person-centeredness in a theoretical framework. Many of the recommendations reflected values deemed supportive of 'personhood':

1) The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them;

2) The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia;

3) The importance of the perspective of the person with dementia;

4) The significance of relationships and interactions with others to the person with dementia, and their potential for promoting wellbeing.

The fourth principle places explicit emphasis on 'relationship centred care' as a component of 'person-centeredness' in the emphasis placed on social networks and social interaction. Recommendations on hospital care included provision of services that addressed personal and social care needs and the mental and physical health of people with dementia, through specialist assessment involving medical and liaison teams and a co-ordinated and integrated approach to delivery.

The first national dementia strategy[8] did not use the term 'person-centred', although it's focus on social inclusion of people with dementia by reducing stigma and empowering people to make choices, have also been subsumed under the term. The vision underpinning the strategy was that everyone with dementia would have access to needed care and support wherever they lived, and that:

> "… …public and professionals… are well informed … fear and stigma associated with dementia have been allayed … false beliefs that dementia is a normal part of ageing… have been corrected…. families affected by dementia know where to go for help, what services to expect… quality of care is high…."(p. 15)

This emphasis on equitable, anti-discriminatory, accessible and quality services reflected the chasm between the vision and the contemporary reality of provision. The priority was the creation of a service infrastructure to establish the conditions in which relational dimensions of quality care could flourish. Although improving general hospital care for people with dementia was a policy objective, primary emphasis was on strategic initiatives (identifying leadership for dementia, establishing a care pathway and commissioning specialist liaison older people's mental health teams).

Experience of Care: Patient or Person-Centred?

Although the term 'person-centred' was introduced into policy around 2000, by the end of the decade, it was still not embedded in the policy lexicon. Neither had it supplanted 'patient-centred' as both terms co-existed in different policy contexts.

The concept of 'patient centred' care is rooted in a shift from the traditional bio-medical model in favour of embracing personal choice and autonomy for people receiving health services. 'Patient centred 'care was defined by Balint[9] as understanding the patient as a unique human being and a patient centred approach was one in which *"the physician tries to enter the patient's world to see the illness through the patient's eyes".*[10] It was viewed as representing a style of consulting in which the doctor used the patient's knowledge and experience to guide the interaction,[11] forging a therapeutic alliance in which power and responsibility was shared[12] to deliver care which was *"closely congruent with, and responsive to patients' wants, needs and preferences*.[13] Even so, debate has continued as to its precise meaning although Mead and Bower[14] argue that the term *"has been used to refer to so many different concepts that its scientific utility may have been compromised".*

An internationally recognised and widely used definition of patient centred care which has been influential in North American health policy is that of the US Institute of Medicine (IoM).[15]

> "Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."

Informed by the work of Gerteis et al,[16] seven dimensions of patient centred care were identified: respect for patients; co-ordination and integration of care; information, communication and education; physical comfort, emotional comfort/alleviation of fear and anxiety; involvement of family/friends; transition; and continuity. Further layers of responsibility on health systems at service, sector and programme level were added to ensure that organisational processes and regulatory and governance frameworks were underpinned by these principles.

Until the mid-2000s, this conception of patient-centred care was also reflected in influential UK based policy organisations. The Kings Fund Point of Care Programme[17] was intended to work alongside frontline staff and their managers and focus attention on patients' experience of care in the NHS. The authors argued that the quality of a patient's experience was '"*seeing the person in the patient*" (p9) and *"being cared for with kindness and compassion by everyone they come into contact with"*(p1). They emphasised that the paradigm shift toward 'patient experience' was not simply about the relational dimension of care. Rather, different aspects of the experience – the process of care and treatment, the environment in which it occurs, the physical sense of the place – come together with the manner in which it is delivered to inform the subjective experience.

In projecting a definition of quality to capture the experience of 'the person in the patient', Goodrich and Cornwell[17] drew on the IOM[15] definition of patient centred care and the dimensions that comprise it. These were similar to those adumbrated in the NSFOP under the term 'person-centred'.

A consultative exercise commissioned by the Picker Institute around the same time concluded that the factors contributing to patient centred care based on the IOM definition were:[18] leadership; strategic vision clearly and constantly communicated to every member of the organization; involvement of patients and families at multiple levels; care for the caregivers through a supportive work environment; systematic measurement and feedback; quality of the built or physical environment; and supportive technology. Delivery of patient-centred care was seen to require action at multiple and interacting levels: organisational, cultural, environmental, individual and relational as well as the qualitative dimensions of the work environment of those delivering care.

Although describing similar ideas, the term 'patient centred' has been the subject of critique on the basis that it still addresses the person as 'patient' i.e. in context of their illness or condition. Person-centred, is seen to cover a wider range of settings other than health. It also implies a person as both a social and relational being, and part of a wider social network which shapes the pattern of daily life and sense of well-being.

Ascendancy of Person-Centred Care in UK Health and Social Care Policy

Over the last decade, the concept of person-centred care has become the term most widely used in UK policy discourse; yet its meaning and how it should be enacted in practice is ambiguous and fluid. In different areas of health policy, there are varied nuances of meaning. Considerable work has been undertaken by organisations aiming to influence policy, to achieve consensus on meaning and content.

The Health Foundation[19] identified a framework of four basic principles to guide the 'new' relationship between providers and users of health services to secure care tailored to individual needs:

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

This summarises person-centred care as individualised, caring and enabling; involving collaboration between professionals and those using services; providing people with the knowledge, skills and confidence to manage and make informed decisions about their health and healthcare; and co-ordinated and delivered in a manner that accords dignity, compassion and respect to the person.

This embraces principles relating to care systems to enable people live a 'good life' and those geared to the care delivery process and the relational encounter. It is similar to the IoM definition of patient centred with the important exception that understanding of personalised care and the focus of co-ordination goes beyond health.

The similarities and differences between the concepts of 'patient-centred' and 'person-centred' are noted in a policy briefing by the Picker Institute.[20] Recognising that both terms described similar ideas, 'person-centred' was preferred: it embraced a wider range of care settings; recognised people as individuals rather than as 'patients'; and was better able to reflect the important role of people's families, friends, and caregivers in their health and wellbeing. Further, it opened up a more inclusive model for building a quality health system by encompassing people who lacked health literacy or capacity. Whereas in dementia, the concept of 'personhood'[7] and the persistence of self[21] had countered the dominant bio-medical model, an inclusive conception of 'person-centred' care also posed a challenge in actualising principles of enablement and collaboration for and with people with dementia, particularly those with moderate/severe impairment.

Translating Person–Centred Care into Service Development and Delivery for People with Dementia

The major challenges in the NHS, which include increased demand, fundamental structural and cultural change and the context of economic austerity, have prioritised achievement of health efficiencies. As a result, 'person-centeredness' in policy discourse has assumed a double-edged meaning. For example, involvement in decision making and effecting choice, both regarded as dimensions of person centred care, have found expression in such initiatives as personalised budgets aimed simultaneously at meeting productivity and 'patient as person' objectives; and pose considerable challenges in respect of people with dementia. The Health and Social Care Act 2012 places a legal duty on NHS England and Clinical Commissioning Groups (CCGs) to involve patients in their care. However, increasingly decision-making on local health priorities are driven by budgetary constraints, posing the question as to what level of involvement and by whom, defines a service as 'person-centred'. The Scottish Government's 2020 Vision[22] states that *"care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions"*. Less evident is what 'being at the centre of decisions' look like, especially for people with dementia.

Some aspects of the direction of travel may be seen in more recent policy documents. There is emphasis on singular dimensions of person-centred care, particularly the inter-personal level of the professional/person interaction.

The first Prime Minister's Challenge on Dementia[23] set out three broad objectives: driving improvements in health and care; creating dementia friendly communities; and committing to increased research, which also includes engagement of people with dementia. Under the rubric of these objectives were infrastructural and service development initiatives: increasing diagnostic rates through improvements in awareness, including in acute hospitals, education and training of the health workforce, geared to role and purpose; an NHS guarantee of a written integrated personalised care plan; and better assessment and support for caregivers. Although 'person' centred' care was not explicitly used in the document, components of it featured heavily, namely a 'personalised care plan', relationship focused care, and 'seeing the person' not the dementia through strategies to enhance social inclusion.

The Foreword in the recent Prime Minister's Challenge[24] refers to compassionate care, and *'that kindness, care and dignity take precedence over structures and systems".* While the broad objectives as set out in the first Challenge remained the same, they were now couched in terms of outcomes articulated through engagement of people with dementia, including: staff/professional encounters, based on compassion, dignity and caring; a partnership approach involving listening, offering and supporting people to make choices about their health and care; and ensuring more consistency of

access, care and standards of provision. The notion of 'compassionate care' delivered through encounters that accord dignity and respect for the person, however dominate.

Focus on the relational dimensions of health care in professional and policy discourse is not surprising, following on from the mid-Staffordshire hospital scandal. Interpersonal aspects of the nursing role, namely care, dignity and respect were conveyed by the Royal College of Nursing as critical in transforming acute hospital care for people with dementia.[25,26] Moreover, the language of 'compassion' and 'compassionate care' has increasingly dominated policy. The nursing vision for care as explicated in the '6 Cs of care, compassion, competence, communication, courage and commitment[27] presents the nursing role primarily in interpersonal and social terms; and applies the same model in care of people with dementia.[28] This is not to suggest that the relational dimension of 'person-centeredness' is unimportant; it is the extent to which it directs attention from the organisational, environmental and systemic dimensions that facilitate person-centred care at the relational level, that is problematic. As elucidated in a Kings Fund paper,[29] enabling compassion which involves staff openness to distress and suffering also requires the existence of teams which are supportive of staff and organisational cultures that create and sustain healing environments.

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