University of Essex

East Suffolk and North Essex
NHS Foundation Trust

# Dementia: Fundamentals of Care in Acute Settings (DemFoCAS)

## Final Project Report

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## Stakeholders

Dementia Cafés

- Age Well East, Veranda Club - North Hill, Colchester
- Age Well East Dementia Café - Church Hill, Colchester
- Ansell Memories Café, Hadleigh
- Clacton Community Voluntary Services
- Home Instead (Trimley and Felixstowe)
- Ipswich Memory Lane Dementia Café
- Ipswich, Unity Café
- Community 360 Dementia Café
- Wivenhoe Friendly Club and Café

Professor Giles Thorpe, outgoing Director of Nursing, ESNEFT

Assistant Directors of Nursing, ESNEFT

Essex County Council

Healthwatch Essex

Healthwatch Suffolk

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Deb Bunt, co-author of Slow Puncture, Living Well with Dementia

**Special thanks**

We would like to extend a thank you to all the dementia café organisers and helpers who have been so supportive of the project, as well as all carers, families, and individuals living with dementia who have been involved in the project.

*Figure 1 Dementia healthcare (Stock photo)*

*Figure 2 DemFoCAS project team. From left to right Victor Ashby, Camille Cronin, Rachel Marrow, Thomas Currin, Rebecca Impson, Marie Alexander*

> **"While no one can change the outcome of dementia or Alzheimer's, with the right support you can change the journey."** Tara Reed

# Executive Summary

People living with dementia represent a significant proportion of acute hospital admissions, yet research consistently shows that hospitalisation can be distressing for patients, families and staff. Acute environments are often not designed for people with cognitive impairment, and staff frequently work under considerable pressures while attempting to deliver compassionate, person-centred care.

The Dementia: Fundamentals of Care in Acute Settings (DemFoCAS) project was a partnership between the University of Essex and East Suffolk and North Essex NHS Foundation Trust (ESNEFT). The project aimed to understand how dementia care is currently delivered and experienced within ESNEFT acute hospital settings and to identify opportunities to strengthen care quality, staff support and organisational practice.

A mixed-methods case study design was used, guided by the Donabedian framework for evaluating healthcare quality. The project combined several complementary approaches, including analysis of patient admissions data, patient pathway mapping, staff interviews, carer interviews and extensive patient and public involvement and engagement (PPIE). This multi-method case study design enabled the project to explore dementia care from organisational, clinical and experiential perspectives.

Across the study, staff consistently demonstrated strong commitment to providing compassionate dementia care. However, they also described the significant challenges associated with delivering this care within busy acute environments, including staffing pressures, communication barriers and the emotional labour involved in supporting patients with complex cognitive needs.

Carers provided detailed accounts of hospital admissions, often describing anxiety, uncertainty and difficulties navigating hospital systems. At the same time, they highlighted the importance of small but meaningful acts of kindness, clear communication and staff who took time to understand the person behind the diagnosis. These experiences reinforced the importance of person-centred care and meaningful partnership with families.

Patient and public involvement activities, including focus groups at dementia cafés and stakeholder engagement events, identified a series of interconnected themes shaping dementia care experiences, including carer involvement, individualised care, basic care, communication and staff issues. Importantly, the findings demonstrate that dementia care quality is influenced not only by individual staff practice but also by wider organisational systems and resource pressures.

A scoping review and systematic review conducted as part of the project showed that many of the issues identified locally reflect wider national and international evidence. While recognition of dementia-friendly care is increasing, the literature also highlights a limited number of robust intervention studies evaluating how best to deliver individualised care in acute hospital settings.

Overall, the project demonstrates that improving dementia care requires a whole-system approach that supports staff, values carers as partners in care and embeds dementia-friendly principles across policy, education and clinical practice. The DemFoCAS project provides ESNEFT with an important evidence base to inform service development, workforce training and quality improvement initiatives.

Beyond immediate organisational learning, the project has strengthened partnerships between the Trust, the University of Essex and wider stakeholders, and has created a strong platform for future dementia and delirium research, and innovation for service development, and clinical academic leadership and development for research in the trust.

# Summary for patients, families and carers

People living with dementia are frequently admitted to hospital, yet many experience distress, confusion and care that does not always meet their individual needs. This project was developed to understand how dementia care is currently experienced in acute hospital settings within East Suffolk and North Essex NHS Foundation Trust (ESNEFT), and to identify ways care could be improved for patients, families and staff.

The project brought together clinical staff, researchers and people with lived experience of dementia through patient and public involvement and engagement (PPIE). We listened to staff working across different hospital roles and spoke directly with spouses caring for people with dementia who had been admitted to hospital. Their experiences helped us understand what works well, what is challenging, and where changes are needed.

Findings showed that staff are highly committed to providing compassionate care but often work under significant pressure. Families described feeling excluded, anxious and unsure who to turn to for information, particularly during hospital stays. The hospital environment, communication processes and staffing pressures were all identified as influencing the quality of care and experience.

This work highlights the importance of listening to both staff and carers, supporting staff wellbeing, and embedding person-centred dementia care across hospital services. The findings will inform improvements in practice locally and contribute to national learning about dementia care in acute hospitals.

# Key points

- **People living with dementia represent a significant proportion of hospital admissions**, yet acute environments are often not designed to meet their complex cognitive and emotional needs.

- **Staff across ESNEFT demonstrate strong commitment to delivering compassionate dementia care**, but face increasing pressures related to workload, staffing and the emotional demands of caring for patients with cognitive impairment.

- **Carers play a critical role in supporting patients**, but frequently experience anxiety, lack of information and limited involvement in care decisions during hospital admissions.

- **Person-centred care and effective communication were consistently identified as key factors shaping positive experiences** for both patients and families.

- **Dementia care quality is shaped by both relational and organisational factors,** including staff wellbeing, hospital environments, systems of communication and the integration of carers into care processes.

- **Findings from the DemFoCAS project mirror wider national and international evidence**, highlighting ongoing gaps in robust research evaluating interventions to improve dementia care in acute hospitals.

- **Improving dementia care requires a whole-system approach,** combining staff support, dementia-friendly environments, effective communication processes and stronger partnerships with carers.

- **The project has strengthened collaboration between ESNEFT, the University of Essex and community stakeholders,** creating a foundation for future dementia and delirium research, clinical academic development and service innovation.

# Key Recommendations for ESNEFT

## 1. Increase dementia specialism across the Trust

The Trust should expand the dementia specialist team by enhancing its skill mix and exploring support from allied health professionals and trained generic staff, such as Assistant Practitioners or HCAs on apprenticeship programmes, to strengthen expertise, resilience, and succession planning. It should also identify other nursing and allied health professionals who can deputise in the absence of any dementia specialist team member. In addition, we recommend cognitive champions are trained and identified across the Trust.

## 2. Develop an integrated dementia-focused training strategy

Develop an overarching framework to strengthen ESNEFT's in-house dementia training, pool resources in partnership, and coordinate Trust-wide delivery. The framework should draw on multiple training sources, centrally managed by an ESNEFT training lead in collaboration with the dementia specialist team and key stakeholders. CPD-delivered training should be regularly evaluated, and the framework should align Virtual Dementia Training with the ESNEFT Dementia and Delirium Policy, NICE standards, and CQC domains.

## 3. Develop a comprehensive dementia-friendly environment strategy

Develop a comprehensive dementia friendly environment strategy to co-ordinate efforts to make the hospital environment dementia friendly. This could include converting unused spaces to dementia friendly resting areas, installing 'bus stops' or similar, and producing guidelines for placement of patients with dementia.

## 4. Develop a ‘care partners’ framework to broaden volunteer and family carer support

Develop a supportive care partners strategy which provides a framework to increase additional care support from carers, families, volunteers and external partners. This includes increasing volunteer numbers, broadening their involvement to different supportive activities and encouraging carers to become volunteers.

## 5. Assign a dementia care partnership and engagement lead

Assign a lead for ESNEFT who would be responsible for co-ordinating and integrating partnership projects which involve external parties, such as charities and local government, to provide on-ward support to patients and families. In addition, this role should include oversight of all dementia related projects across the Trust to ensure alignment, reduce duplication, and maintain a coherent strategic direction.

## 6. Embed carers and persons living with dementia in strategic involvement

Adopt a collaborative approach to dementia care that embeds people living with dementia and their carers across training, care processes, feedback, and service improvement to ensure services remain relevant and experience led. This includes training, documentation, care processes, ongoing service improvements, patient feedback and volunteering roles.

## 7. Enhance family and carer support through a dementia engagement framework

Develop a dementia communication and family engagement framework in partnership with experienced carers, providing clear information to help families navigate the hospital and access support.

Standardise dementia-friendly discharge planning with early initiation, consistent family communication, and stronger community integration to ensure safe, timely discharges and reduce avoidable readmissions.

## 8. Monitor optimal dementia care pathways according to dementia care policy

Utilise the dementia care policy to monitor the care of patients with dementia, assess adherence to the policy, and identify areas for ongoing improvement. We recommend that EPIC reporting features enable the ESNEFT dementia nurse specialist team and a senior clinician to monitor and audit features of the dementia care policy, so they can effectively shape, plan, and contribute to strategies for dementia care across the Trust.

## 9. Enhance workforce capacity and wellbeing through improved staff levels and a wellbeing strategy

Review and enhance staffing-level reporting to provide accurate, meaningful data. Support the emotional and practical demands of dementia care through staff wellbeing initiatives, workforce development, interdisciplinary collaboration, and strengthened roles for dementia clinical nurse specialists, including links with community services and voluntary partners. In addition, staff should be routinely consulted about the effectiveness of these support measures, rather than relying solely on annual surveys, to ensure that interventions remain responsive to their needs.

## 10. Embed clinically led dementia research and innovation within Trust strategy

Prioritise future research and establish dedicated, protected time for ESNEFT clinicians to work in partnership with University of Essex researchers, ensuring projects have embedded clinical expertise and the organisational support required for high quality delivery underpinned by people with lived experience.

# Preface

This final report presents the outcomes of the **Dementia: Fundamentals of Care in Acute Settings (DemFoCAS)** project, a three-year partnership between the University of Essex and East Suffolk and North Essex NHS Foundation Trust (ESNEFT). The project was undertaken across two acute hospital sites, Ipswich and Colchester, with the aim of evaluating and strengthening the fundamentals of care for people living with dementia in hospital settings.

The importance of this work lies in the recognition that people with dementia are among the most vulnerable patients in acute care. Their experience of hospital is shaped not only by medical treatment but by the quality of everyday care, communication, and support provided. For this reason, it is essential that definitions of "fundamentals of care" are clearly established and consistently applied. Clarity in definitions ensures shared understanding across disciplines, supports effective training and service development, and ultimately improves patient outcomes.

The project has been shaped by extensive engagement with a wide range of stakeholders, including healthcare professionals, expert clinicians, dementia specialist teams, and representatives from voluntary and statutory organisations. Central to the work has been patient and public involvement and engagement (PPIE), which ensured that the voices of people living with dementia, carers, families and stakeholders have informed every stage of this project, focusing the lens on priorities and guiding the project throughout (Cronin et al., 2023).

Alongside this participatory approach, the project employed a systematic review of relevant evidence-based literature and policies; and made use of the Donabedian model to evaluate structures, processes, and outcomes within the acute hospital context. A steering group, including expert clinicians and dementia leads, provided vital oversight and guidance throughout, helping to refine methods, validate findings, and build shared understanding across a complex healthcare organisation.

This report details the outcomes of these activities and highlights touchpoints for service improvement identified in the interim report (Cronin et al., 2024) and subsequent work. It reflects a collective effort to understand how care can best be delivered in the challenging environment of acute hospitals and provides recommendations designed to be practical, achievable, and sustainable.

# Definitions

The **World Health Organization (2025)** defines dementia as “a syndrome usually of a chronic or progressive nature that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.”

The **Alzheimer’s Society (2024)** describes dementia as a group of symptoms that may include memory loss, difficulties with thinking, problem-solving or language, and changes in mood, perception, or behaviour. These symptoms occur when the brain is damaged by diseases such as Alzheimer’s disease or a series of strokes.

**Alzheimer’s disease** is the most common cause of dementia, accounting for an estimated 60-70% of cases worldwide (World Health Organization, 2025). Other causes include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

In the United Kingdom, an **acute hospital setting** refers to a large, bedded hospital that provides short-term, immediate care for people who are acutely unwell. Acute care focuses on patients experiencing sudden illness, injury, or a significant deterioration of a long-term condition that requires urgent medical or surgical attention. Acute hospitals deliver services that include emergency admissions, unplanned treatment, inpatient and outpatient care, and specialist investigations. They are distinct from community or long-stay facilities, as their role is to stabilise patients, treat urgent health needs, and support recovery or discharge to appropriate ongoing care.

In relation to dementia, **Alzheimer’s Society (2020)** highlights that people with dementia are frequently admitted to acute hospitals, with an estimated one in four hospital beds in the UK occupied by a person living with dementia. While admission may sometimes be necessary, the unfamiliar and busy environment of an acute hospital can be particularly distressing for people with dementia, and is associated with increased risks of delirium, longer lengths of stay, and greater likelihood of discharge to residential care.

Thus, in this project, the term **acute setting** is used to describe the two main hospital sites within East Suffolk and North Essex NHS Foundation Trust (Ipswich and Colchester), both of which provide acute medical and surgical care for people who are acutely ill, including a significant proportion of patients living with dementia.

## Fundamentals of Care

Historically, the phrase ‘fundamentals of care’ in nursing was often used interchangeably with terms such as ‘basic’ or ‘essential’ care. These terms were not consistently defined and tended to emphasize physical tasks over psychosocial elements of care and nurse-patient relationships. The Fundamentals of Care Framework (Kitson, 2018) sought to formalize the concept through a point of care nursing theory that gives equal weight to physical, psychosocial, and relational needs. Within the framework ‘fundamentals of care’ are seen as the essential everyday aspects of nursing practice, delivered by patient and caregiver working collaboratively. People-centred care is achieved by addressing three core dimensions: caregiver/patient relationship, integration of fundamental of care needs into patient care plans, and a wider care context which provides supportive policies and systems to facilitate quality care.

# Explanatory notes

The following notes are appended to assist readers understand the thinking behind the choice of specific wording within the definitions. They are presented in the order of appearance in the definitions.

**Person-centred:** The scholarship underpinning ‘person-centred’ care is acknowledged and used within this project. The term ‘people-centred’ is a term used by WHO rather than ‘person-centred’ as it is more inclusive of the familial, cultural, and community contexts that shape health care practices and designs.

**PPIE:** Public and Patient Involvement and Engagement (PPIE) is used in this document to refer to how the project involved members of the public effected by dementia in the project from the start. This approach ensures projects are carried out “with” or “by” patients, families and carers rather than “to”, “for or “about” them.

**Safe environments:** This term encompasses the importance of creating environments that are not only safe for patients, carers and staff but also the communities who visit. It acknowledges the importance of the environment and emphasizes the complex nature of the environment with personal, and public health.

**Profession/Professional:** By definition, a profession has three main elements: disciplinary knowledge and skills, a form of regulation specifying standards of practice and codes of behaviour expected by the public, and the application of these elements in a practice which is in the interests of others.

**Patient/system safety:** Patient and system safety is included as healthcare workers play a crucial role in ensuring the safety of individuals, therapies, and health care organizations. This encompasses various forms of safety, including cultural, physical, and psychological safety.

**Continuity of care:** The smooth transfer of information and care between health care providers and settings, whether this is shift-to-shift or provider to provider, nurses perform this integrative safety and quality function such that health care is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences.

**Skills:** The term 'skills' is used to encompass the multitude of skills used in nursing practice from the technical capability and dexterity to the interpersonal engagements of mental health nursing, to the advocacy and negotiation skill of shaping policy.

**Skill mix:** A variety of roles exist within the hospital setting and cross over different disciplines. We spoke mainly to nursing staff, health care support staff, allied health professionals and volunteers.

**Across settings:** The term 'across settings' captures the expansive nature of nursing work, acknowledging that nurses operate in diverse environments such as hospitals, communities, schools, and government settings, adapting their expertise to various contexts.

**Evidence-informed decision-making**: The term 'evidence-based' is commonly used in relation to decision-making, but 'evidence-informed' offers an added dimension. Evidence-informed decision-making allows for the inclusion of other factors that might influence a choice of action, for example: patient's choices, matters of belief or personal preference, and critical factors such as resource availability.

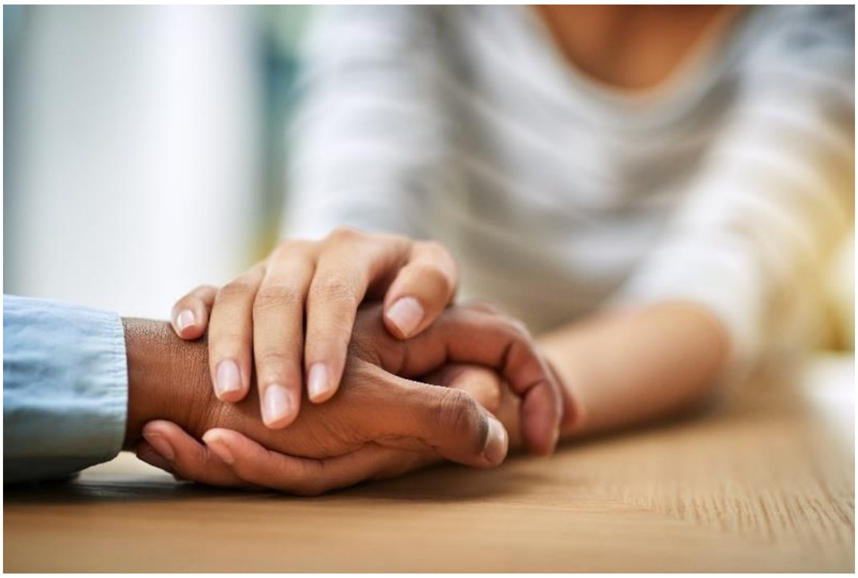


*Figure 3 Individualised care (Stock photo)*

# Section 1 - Introduction

## Background and context

**Dementia: Fundamentals of Care in Acute Settings (DemFoCAS)** is a three-year partnership project between the University of Essex (UoE) and East Suffolk and North Essex NHS Foundation Trust (ESNEFT). The project seeks to evaluate the quality of dementia care across ESNEFT's two acute hospital sites, Ipswich and Colchester, with a particular focus on the *fundamentals of care*—the essential aspects of everyday care that directly shape patient safety, dignity, and wellbeing.

The purpose of the Project is threefold:

- To assess current care provision for people living with dementia in acute hospital settings.
- To identify areas for improvement through a systematic, evidence-based service improvement design.
- To develop recommendations that are practical, achievable, and aligned with ESNEFT's priorities to improve patient outcomes, support staff wellbeing, and enhance organisational efficiency.

*Figure 4 DemFoCAS project banner*

## Project origin, design and rationale

The rationale for this project came from the desire to promote homegrown clinical research led by nurses and allied health professionals from within ESNEFT. By building a programme of research it would provide the foundations of practice to inspire staff to innovate practice within ESNEFT for the benefit of patient care. The Director of Nursing at the time, Dr Giles Thorpe and Dean of the School, Professor Victoria Joffe worked together with their respective teams to collaborate and build the premise of this partnership providing finance and institutional support from the university to invest and support two 3-year projects: DemFoCAS and CoastGem (which focuses on stroke provision in the community). Each project supports a research team - senior researcher, researcher and doctoral student. For DemFoCAS, Rebecca Impson a physiotherapist specialising in older person care is looking at the "*Use of interactive technology for activity, engagement and connection in dementia care in acute hospita*l"

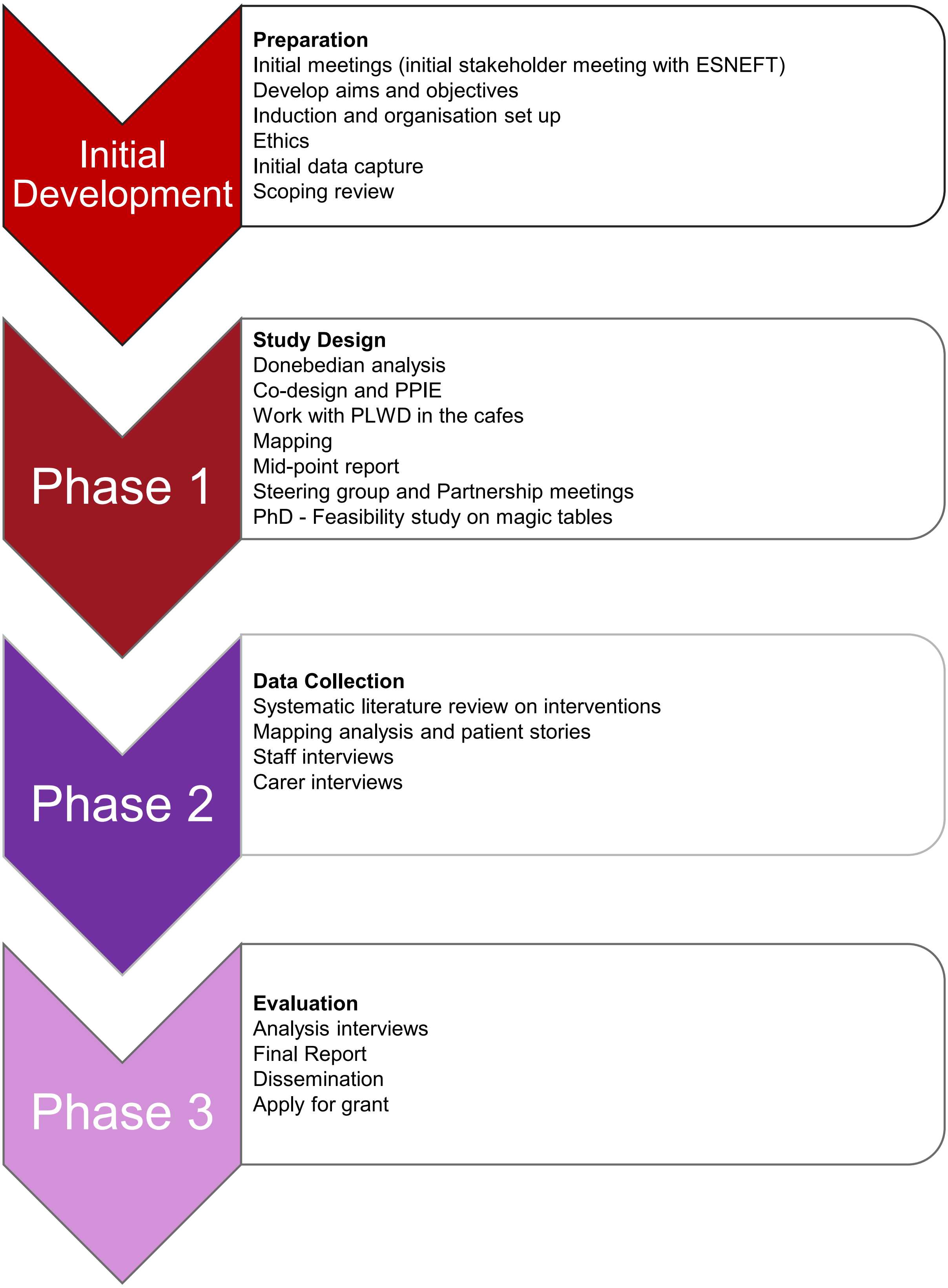
Before the commencement of the project, there was consultation with ESNEFT clinical staff in late 2022, to determine the broad framework and of the project was agreed: a concentrated focus on the fundamentals of dementia care within ESNEFT's acute settings. Between February and September 2023, a primary focus for the DemFoCAS team was the initial participatory element of the project, through Public and Patient Engagement using focus groups at dementia cafés, and through stakeholder involvement. This established themes and practical focus areas which underpin the project. A report of this initial stage of the project was distributed in December 2023 (Cronin et al., 2023). From June 2023 to July 2024, the project team undertook a detailed evaluation of existing care provision, drawing on hospital records, policies, and national guidance.

The Project is designed using a case study approach, the case or unit of analysis ESNEFT. As it has two sites, it is therefore viewed a multi-case design with a structured evaluation process using the **Donabedian model (2005)**, which examines *structures*, *processes*, and *outcomes* as interconnected dimensions of healthcare quality. This enabled a number of methods to be used to view the organisation, this case. This approach enabled the team to highlight specific "touchpoints" in care where improvements could be made. Findings from this first phase of the Project were shared at the halfway point with ESNEFT in July 2024 (Cronin et al.), providing an initial framework for discussion and refinement.

Building on this foundation, subsequent phases of the project focused on deepening understanding through:

- **Patient and carer stories** that captured lived experiences of inpatient dementia care.
- **Interviews with staff** across all levels of the organisation, from senior clinicians and managers to ward-based staff and support workers.
- **Interviews with spousal carers**, to reflect the perspectives of families and unpaid carers.
- **Process mapping**, to chart how dementia care is delivered across the acute pathway and identify gaps or barriers to good practice.

Together, using this combined approach, these methods provide a comprehensive evaluation of dementia processes and care provision within ESNEFT, balancing organisational data with lived experience and professional expertise. An outline of the project process is presented in the flowchart below (fig 5).



**Preparation**
Initial meetings (initial stakeholder meeting with ESNEFT)
Develop aims and objectives
Induction and organisation set up
Ethics
Initial data capture
Scoping review

**Study Design**
Donebedian analysis
Co-design and PPIE
Work with PLWD in the cafes
Mapping
Mid-point report
Steering group and Partnership meetings
PhD - Feasibility study on magic tables

**Data Collection**
Systematic literature review on interventions
Mapping analysis and patient stories
Staff interviews
Carer interviews

**Evaluation**
Analysis interviews
Final Report
Dissemination
Apply for grant

*Figure 5 DemFoCAS project study phases and workstreams*

## Wider context

This work has taken place in the aftermath of the COVID-19 pandemic, which had profound impacts on hospital wide services, staff wellbeing, and dementia care. Many services were disrupted or lost, particularly those supporting people living with dementia. Even though the pandemic accelerated the adoption of digital health processes across the health service some services have been taken time to re-establish. The pressures of recovery post-COVID affected hospitals nationwide, including ESNEFT.

At the same time, rising healthcare expenditure and the drive for sustainability are pushing trusts to consider new models of care. Within this landscape, ESNEFT is well-placed to show leadership in older people's care, keep dementia high on the organisational agenda and lead research and innovation through service improvement. By building on the insights of this project, and the continued efforts of service design ESNEFT has the opportunity to shape the dementia care pathway in a way that is person-centred, consistent and sustainable.

## Local context

Dementia is an umbrella term describing a range of symptoms that affect memory, reasoning, perception, communication, and the ability to carry out everyday activities such as personal care, cooking, or dressing (Department of Health and Social Care, 2022). It is caused by a number of brain-related conditions, the most common of which is Alzheimer's disease, responsible for between 50% and 75% of cases (Alzheimer's Disease International, 2024).

In the United Kingdom, dementia affects an estimated 1.33% of the population. Within the ESNEFT region, prevalence is higher than the national average across nearly all constituencies. Notably, Clacton (2.43%) and Suffolk Coastal (2.23%) have among the highest rates in the country, ranking fourth and eighth nationally (Alzheimer's Research UK, 2023).

National policy guidance emphasises that hospitalisation for people with dementia should occur only when clinically necessary, as remaining in familiar surroundings usually supports better outcomes (NICE, 2018). The Prime Minister's Challenge on Dementia 2020 similarly prioritised community-based support to reduce avoidable hospital admissions (Department of Health and Social Care, 2015b). Despite these aims, admissions of people living with dementia continue to rise, with estimates suggesting that around one in four UK hospital beds is occupied by a person with dementia (Royal College of Psychiatrists, 2019).

Hospital stays can be particularly challenging for this population. People with dementia may find the environment distressing, and admission is associated with an increased risk of delirium (George et al., 2013; NICE, 2018), longer lengths of stay, higher mortality, greater likelihood of discharge to care homes, and functional decline that reduces independence in daily living (Alzheimer's Society, 2009; Fox et al., 2021; Mukadam & Sampson, 2011; Palese et al., 2016). These pressures extend to staff: caring for people with complex dementia needs without adequate resources has been linked to increased stress, burnout, and reduced capacity to deliver person-centred care (Kang & Hur, 2021).

Against this backdrop, the concept of the **fundamentals of care** is central. As set out in the *Fundamentals of Care Framework* (Kitson, 2018), these include the integration of physical, psychosocial, and relational needs, underpinned by three core principles: the development of meaningful caregiver–recipient relationships, embedding fundamentals of care within individual care plans, and ensuring organisational systems and policies support delivery of high-quality, person-centred care.

The DemFoCAS project is positioned within this context. Its purpose is to review and evaluate dementia care provision at ESNEFT's acute hospital sites, identifying strengths and gaps, and producing recommendations that are both relevant and achievable. By focusing on fundamentals of care, the project seeks to understand the lived reality of dementia care in acute settings and inform improvements that can be implemented and sustained across the Trust.

# Project scope

The scope of the Project included:

- An examination of data
- Creating formal definitions to aid and provide universal understanding for the structure, design and duration of the Project
- Engaging diverse stakeholders, people with dementia, carers and clinical experts to ensure the Project reflects a true understanding of services provided by the organisation.
- Employing the Donabedian method, a service improvement methodology that looks at the structure, processes and outcomes of the organisation enabling the team to work iteratively through the project.

- Drafting and redrafting reports, circulating them for feedback, and validating them through expert consultation, meetings and workshops.
- Securing University of Ethics approval [ETH2223-1808], and Trust approvals for the project as a service improvement. Additional permissions obtained through Honorary contracts for project team and data sharing agreement.
- Implementing a dissemination plan to ensure communication of the Project across relevant platforms and stakeholders.

Engagement was online and/or via electronic means as well as in-person or face-to-face engagement for meetings, appointments, team meetings, fieldwork, interviews, workshops, stakeholder and partnership events and conference presentations.

## Understanding the “scope” of conducting research in a clinical setting

Conducting the DemFoCAS research project within a busy clinical environment has presented the team with a unique set of challenges from the beginning and throughout and stalled momentum before it even began. High patient volumes, urgent clinical priorities, and limited staff availability often meant that research became a lesser concern. Access to clinicians, specialists, stakeholders, or even basic resources became difficult, as calendars filled quickly and time is allocated primarily to hospital ne eds and direct patient care. As a result, coordinating meetings, interviews, or data collection became a complex logistical task rather than a straightforward step in the research process.

Communication barriers compound these difficulties. In fast-paced clinical settings, information tends to move through informal, fragmented channels rather than structured, organisation-wide systems. While we were an external team, with a clinical senior member of staff assigned to the project and passport access to ESNEFT. Emails were missed, messages often delayed, and updates often shared verbally via Teams online via scheduled meetings that were postponed. This makes it hard to maintain continuity and can often left the research team unclear about who is involved, what permissions are needed, or how decisions are being made. Even when individuals expressed interest, staying connected amidst clinical pressures was a continual struggle due to staff changes, movement in roles, attrition and sickness.

Another layer of difficulty rose from variable levels of engagement. Many clinicians may value research but often do not have the bandwidth to participate, yet alone capacity and others may feel disconnected from its relevance to their daily work. When enthusiasm did exist, it often becomes apparent that people across the organisation do not know one another or lack established pathways to collaborate. Teams often work in silos, unaware of parallel efforts or key contacts who could support the project. This fragmentation slowed progress, and the team often finding out other teams or key people missing thus creating additional challenges and barriers to accessing sites, data, staff, teams or participants.

Taken together, these factors can make the research effort feel like a “wicked problem”, a stubborn, system-level challenge that resists straightforward solutions. Gaining traction requires more than generating interest; it requires navigating organisational boundaries, building relationships, and creating shared understanding in an environment where time is scarce and pressures are high. The result is a process that demands persistence, adaptability, and a recognition that progress may be slow even when everyone has the best intentions. The team work diligently and with sensitivity with staff who had high workloads, sickness, pressure of doctors strikes, winter sickness workloads and organisational structural changes. Despite all this, the team has continued to work in partnership with the clinical senior project lead and keep the project on track.

Working across ESNEFT and its geographically separate sites added yet another layer of complexity. Although they sit under the same organisational umbrella, the two locations often function like distinct entities, each with its own culture, workflows, priorities, and systems. What works smoothly in one site can be completely impractical in the other. Processes for approvals, communication, or even accessing clinical areas differed, requiring the research team to adapt and re-navigate structures at each location. This divergence made it difficult to create consistent pathways for engagement and often slowed progress as the team attempted to learn and work with different styles and expectations. In practice, it sometimes meant running what feels like two parallel projects rather than one unified effort, stretching capacity further in an already demanding clinical landscape.

To this end we have been lucky to have the continued support of key nursing staff - Marie Alexander, Rebecca Impson, Vanessa McClean, Georgia Baggot and later in the project, Holly Fudge. The team documented weekly project meetings, attended the ESNEFT delirium and dementias committee meetings and organised partnership meetings and events throughout the project (discussed elsewhere in the report) and were supported by key stakeholders and a steering group.

*Figure 6 Clinical Environment (stock photo)*

# Section 2 – Project Methodology

## A Case Study Design

The project is a mixed methods case study design using a range of methods to systematically explore the case (Yin, 2009). These were designed and conducted across ESNEFT (unit of analysis) which included two acute hospital sites: Ipswich (case) and Colchester (case). Stakeholders and service users were engaged through phases 1 to 3 of the project to help co-design, co-produce, and co-evaluate the project. The Donabedian (2005) model, which focuses on structure, processes, and outcomes guided the evaluation framework and the project was underpinned by Kitson's fundamentals of care framework (2018).

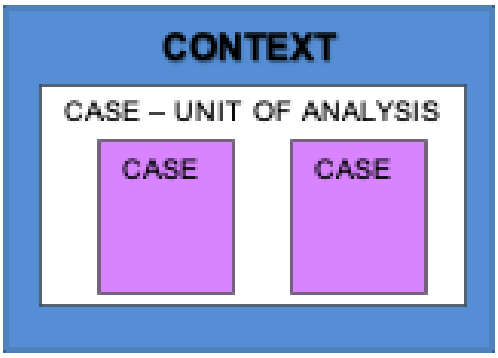


*Figure 7 Multiple case study design*

This project aimed to explore dementia care within the acute hospital settings by engaging directly with individuals affected by dementia. Using a participatory approach, it evaluated the quality of care and sought to explore wellbeing and support systems for patients with dementia at ESNEFT.

Project objectives are:

- To work with persons directly affected by dementia care
- To evaluate the quality of acute care for people with dementia
- To explore dementia care and wellbeing in the hospital

# Methodology Overview

This study adopted a phased, participatory design underpinned by principles of co-design, case study research and realist evaluation. The methodology was structured across three sequential but interconnected phases, progressing from collaborative project design, through participatory and informed evaluation, to the co-production of outputs. The approach enabled iterative learning, stakeholder engagement and reflexive analysis across the project lifecycle, ensuring that patient, carer and staff perspectives informed both process and outcomes. Figure 5 illustrates the overall study design, timeline and key methodological components across each phase.

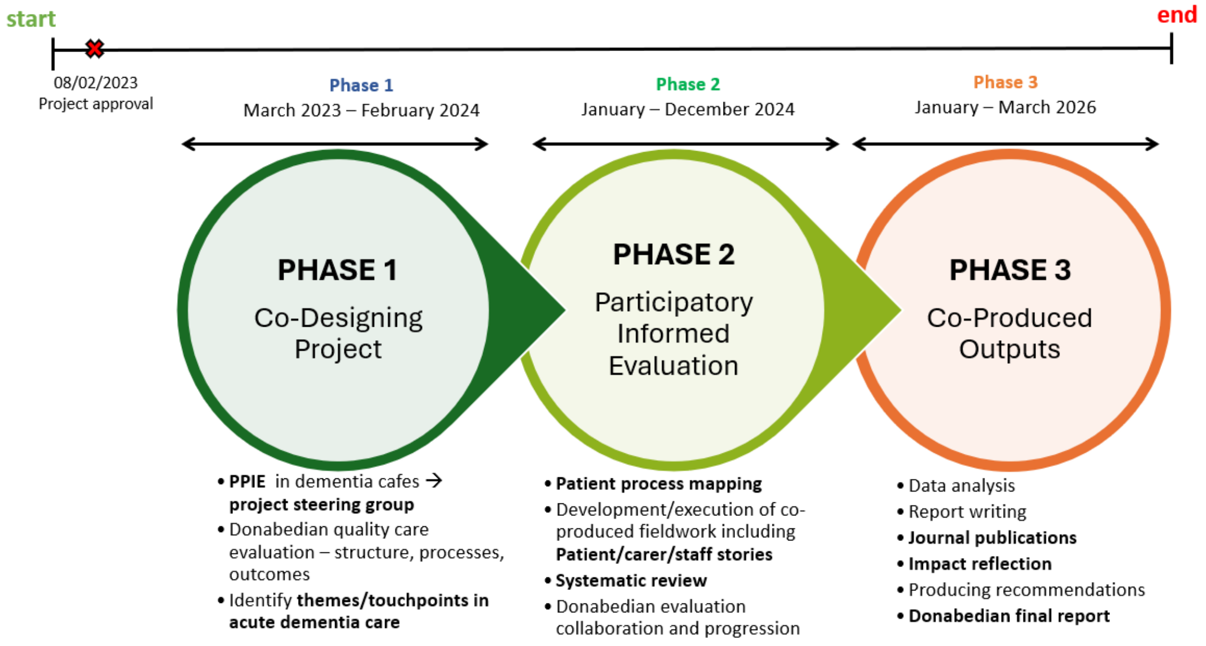


*Figure 8 DemFoCAS 3-year project plan*

### Summary of Phase-specific Methods

**Phase 1: Co-designing the project (March 2023 – February 2024)** Methods included patient and public involvement and engagement (PPIE) activities within dementia cafés, establishment of a project steering group, and application of Donabedian's quality framework to identify key themes and touchpoints in acute dementia care.

**Phase 2: Participatory informed evaluation (January – December 2024)** Methods comprised patient process mapping, co-produced fieldwork incorporating patient, carer and staff narratives, a systematic review, and clarification and update of Donabedian analysis findings though consultation.

**Phase 3: Co-produced outputs (January 2025 – March 2026)** Methods focused on field work, data collection, data analysis, report writing, preparation of journal publications, structured impact reflection, development of recommendations, and production of the final Donabedian-informed report.

# Consultation

The DemFoCAS project adopted a network of regular meetings and attendance at external meetings to facilitate the project.

**Weekly team meetings** were the primary method of steering the project activities, led by PI Professor Cronin and attended by attended by University of Essex team members plus additional invitees Marie Alexander as ESNEFT main project contact, and other invitations were extended for specific discussions.

**University of Essex Dementia research network** was formed in 2023 to facilitate inter-faculty collaboration for anyone involved in research or other activities based at UoE relating to dementia. Meetings are quarterly.

**Stakeholder events** have been held annually with community stakeholders, ESNEFT, EPUT, Essex County Council, Healthwatch Essex and others. The purpose of these events was to discuss project findings, call on expertise from around the ESNEFT catchment area and facilitate collaborative relationships amongst stakeholders.

**ESNEFT key dementia specialist nurse's meetings** occurred regularly to discuss project workstreams and call on ESNEFT expertise and ensure DemFoCAS activities remained focused, realistic and aligned to the work of the Trust.

**Finance meetings** between PI Professor Cronin and ESNEFT lead Marie Alexander were held monthly throughout the project duration.

**Dementia and Delirium steering group:** From October 2023, DemFoCAS research team was invited to attend the ESNEFT Dementia and Delirium steering group meetings, held bi-monthly. The group includes mainly key clinical staff involved in the care of patients with dementia, plus other non-clinical staff such as from pharmacy and volunteer lead. The meetings cover main workstreams and issues related to the governance of care for patients with dementia, including policy documents, changes in procedures and audits. The meetings also provide a forum to present relevant matters relating to the project but also as a way of feeding in the work of DemFoCAS.

**Establishing key contacts** has been both a challenge and a necessary part of the DemFoCAS project. The project team required regular clinical support to ensure the project continue to be situated within ESNEFT. This was extremely challenging due to the nature of the clinical setting, but also fundamentally in the way the project was contracted. The project was support with input from the PhD student, a senior clinician physio based at ESNEFT but also input has been provided by the Clinical Nurse Specialists in Dementia Care for each site, who form the core of the dementia specialist team at ESNEFT.

**Ad hoc meetings with ESNEFT stakeholders** were used intermittently for discussions and presentation of DemFoCAS progress, for example presenting at the monthly Assistant Directors of Nurses meeting.

**Collaborations with patients and carers** throughout the project has most often focused on dementia cafes in Essex and Suffolk area. This was initially as part of the Patient and Public Involvement and Engagement at the start of the study, involving the research officer and senior research officer attending cafes and conducting focus groups. This has formed a significant collaboration and continued throughout the project with regular revisits for disseminating information, recruiting for the DemFoCAS steering group and carer interviews, and stakeholder and partnership events.

# Phase 1 Outputs

Phase 1 of the project involved two main elements: co-design through public and patient involvement and engagement (PPIE), stakeholder engagement and establishing our steering group, and secondly, the initial evaluation of the ESNEFT acute care provision for patients with dementia.

## Public and Patient Involvement and Engagement

Cross-sector collaboration underpinned the methodological approach to this research, bringing together clinical, academic and community expertise to support inclusive and innovative project design. This collaborative framework created the conditions for meaningful involvement for those who care for people living with dementia and their support networks, ensuring that their lived experience shaped both the focus and conduct of the project.

The PPIE produced a set of themes and subthemes which captured the issues carers and persons with dementia felt were most important in relation to hospitalisation. These themes and subthemes became the backbone of the project, ensuring that all subsequent work remained grounded in these priorities (table 1). Section 9 of the project outlines how PPIE was embedded throughout the study to shape its development and delivery.

*Table 1 Themes and subthemes*

| Theme | Subthemes |
|---|---|
| **Role of carers** | • Prioritise carer concerns<br>• Carer challenges<br>• Carers involvement<br>• Extended visiting |
| **Individualised care** | • Respect<br>• Individual care<br>• Respect diversity<br>• Patient wellbeing |
| **Basic care** | • Dignity<br>• Cleanliness<br>• Nutrition and hydration<br>• Patient safety<br>• Mobility |
| **Communication** | • Carers / families communication<br>• Staff / patient communication<br>• Understanding patient behaviour<br>• Sharing information is crucial (previously a separate theme) |
| **Staff issues and wellbeing** | • Insufficient time<br>• More training is needed<br>• Not enough staff<br>• Staff culture and attitudes |

## Donabedian Evaluation

The evaluation in Phase 1 aimed to develop a comprehensive understanding of the structural and procedural context of dementia care within East Suffolk and North Essex NHS Foundation Trust (ESNEFT). This part of the project was reported on and published in the DemFoCAS Progress Report (2024). Guided by the Donabedian model of healthcare quality, the work focused on identifying and synthesising information relating to structures (organisational context, resources, governance) and processes (care delivery, pathways, systems and practices) that underpin care for people living with dementia in acute hospital settings. This phase drew on a wide range of documentary, empirical and experiential sources in order to capture both formal organisational arrangements and how care is operationalised in practice.

### Information Sources (including documentary and digital sources)

Sources included information from the ESNEFT public website and intranet, national datasets, and a range of clinical guidelines and strategies, including NICE guidance, national dementia pathways and statutory frameworks such as the Care Act 2014. These documents provided insight into the policy context, formal care pathways and expected standards of care against which local practice could be understood.

Nationally conducted surveys, including the National Audit of Dementia (NAD), the Care Quality Commission (CQC) inpatient survey, and the NHS Staff Survey, were also reviewed. These sources offered comparative and contextual data relating to patient experience, staff wellbeing and organisational performance relevant to dementia care.

### Engagement with ESNEFT Staff and Environments

The scoping phase involved direct engagement with ESNEFT staff across clinical, managerial and analytical roles, including dementia specialist nurses, quality improvement staff, data analysts and senior nursing leadership. Attendance at Dementia and Delirium Steering Group meetings supported understanding of governance arrangements, current priorities and ongoing service developments.

Orientation tours of both hospital sites provided contextual insight into the physical environments, ward layouts and practical processes involved in admission, assessment and ongoing care for people living with dementia.

### Organisational Structure and Population Context of Dementia

ESNEFT is a large, complex NHS Trust serving a population with a higher-than-average prevalence of dementia, particularly in coastal areas. Dementia diagnosis rates in the region remain below national targets, complicating accurate identification of patients living with dementia within acute settings.

Patients with dementia are cared for across multiple wards and specialties, rather than within a single dedicated service, highlighting the importance of trust-wide systems, training and environments to support consistent care delivery.

### Governance, Policies and Care Pathways

The evaluation identified a comprehensive set of national and local policies relevant to dementia care, including NICE guidance, quality standards and ESNEFT specific dementia care policies. However, alignment between national guidance and local operational pathways was variable, and some policies were identified as being due for review or requiring clearer implementation plans. Governance arrangements for dementia care involve specialist dementia teams and steering groups, though these teams were noted to be small relative to the scale of need and breadth of responsibilities.

### Physical Environments and Staffing

Dementia-friendly environments were recognised as a strategic priority, with guidance and assessment frameworks identified; however, local audit activity had been paused due to workload pressures. Staffing challenges, including sickness, turnover and vacancies, were identified as ongoing structural constraints influencing care delivery and staff capacity for training and service development.

### Processes of Care Delivery including Volunteering and Family Carer Involvement

Processes supporting volunteering and family carer involvement were reviewed, including policies around visiting, mealtime support and communication with carers. While these processes were recognised as valuable, scoping identified variability in implementation and opportunities for greater clarity and consistency, particularly in how carers are supported and informed during hospital admissions.

### Discharge Planning and Patient Safety

Discharge planning processes were examined in relation to legislation, NICE guidance and ESNEFT practice. The scoping highlighted the complexity of discharge for people living with dementia, particularly where diagnosis is incomplete or community support is limited. Staffing levels and patient safety management processes, including the use of Datix reporting, were reviewed to understand how risks and incidents are identified and managed within the organisation.

### Diagnostics, Tools and Information Systems

The Donabedian analysis included identification of multiple systems used to record and manage patient information, including Evolve and Careflow. Fragmentation across systems, inconsistencies in documentation and challenges in accessing complete patient records were identified as key process issues affecting the ability to understand patient journeys and evaluate care quality.

While diagnostic tools and documentation such as This is Me are in use, the evaluation highlighted variability in uptake and recording practices, limiting their effectiveness as mechanisms for person-centred care.

## Donabedian Analysis Outcomes: Implications for Subsequent Project Phases

Overall, phase 1 demonstrated that dementia care within ESNEFT operates within a complex organisational and system context, characterised by multiple interacting structures and processes. While substantial policy, guidance and professional expertise are in place, variability in implementation, data quality and system integration present challenges to understanding and improving care at scale.

The findings formed part of our interim report but also informed the identification of emerging touchpoints across structures and processes, which subsequently shaped the design of further project phases. These phases focus on stakeholder engagement, validation of findings, and the co-development of targeted improvement actions grounded in both organisational priorities and lived experience.

### Summary

Phase 1 of the DemFoCAS project established the context of the project and understanding of its core subjects of dementia, acute care for people with dementia, and the project cases of Ipswich and Colchester hospitals.

The scoping literature search provided a wealth of literature on the core subjects of dementia, acute care, and fundamentals of care. This established that hospital stays for patients with dementia are well documented as being detrimental for patient outcomes. These included length of stay, number of ward moves, primary presentation, type of dementia. These outcomes formed the basis of the admissions data requested from ESNEFT in order to establish a picture of core outcomes for patients with dementia at the two sites.

# Phase 2 – Sections 4 to 8

## Systematic Literature Review

The systematic literature review aimed to synthesise published evidence on interventions designed to improve individualised care and care experiences for people with dementia in acute hospital settings. Specifically, it sought to identify which interventions have demonstrated effectiveness in enhancing personalised care, and to explore how such interventions are experienced by patients, staff, families and carers within acute care contexts. The methodology and findings are presented in section 4.

## Mapping the case

To gain a comprehensive understanding of dementia care across both sites within ESNEFT (the case), the project employed a multi-method approach combining quantitative data analysis, process mapping and storytelling in order to understand the case (this is discussed in detail in Section 6).

Anonymised admission records of patients aged 75 and over from Colchester and Ipswich hospitals between October 2022 and September 2023 was used to establish dementia prevalence and examine patient presentations and outcomes.

Complementing this, process mapping based on the NHS QSIR framework provided visual insights into inpatient journeys, revealing variations in care between those with and without dementia. To deepen this understanding, personal narratives from patients and carers were collected, offering rich perspectives that illuminated the realities of dementia care and informed the interpretation of clinical case notes.

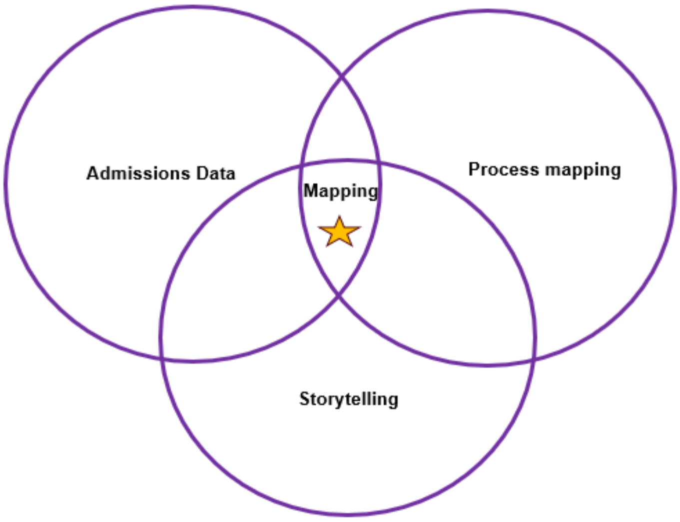


*Figure 9 Venn diagram showing mapping elements of DemFoCAS project*

## Staff perspective

While the Donabedian evaluation incorporated organisational-level data from the annual staff survey, including indicators such as sickness absence and staff wellbeing, the DemFoCAS team identified the need to capture more detailed insights from staff directly involved in the day-to-day care of patients with dementia. Consequently, as part of this case study design, qualitative interviews were conducted with a range of staff across the two ESNEFT acute settings. This component of the project aimed to develop an in-depth understanding of current dementia care provision from the perspectives of staff working closest to patient experience and is presented in Section 7.

## Carers perspective

Findings from the Donabedian analysis identified a notable absence of patient and carer feedback relating to the inpatient experiences of people with dementia at ESNEFT. Evidence from the DemFoCAS PPIE activities further highlighted the significant challenges faced by patients and carers during hospitalisation. In response to this, as part of the case study design, in-depth qualitative interviews with spousal carers from the ESNEFT community were conductive to provide their experiences of acute hospital care, which are reported in Section 8.

# Phase 3 – Sections 10 - 12

The final phase of the project involved completion of analysis of fieldwork, triangulation of findings across the project (section 10), followed by the development of the recommendations, which are shown in detail in section 11. Future steps are discussed in section 12.

# Section 3 – Stakeholder Engagement

## Stakeholder meetings

Effective dementia care requires a collaborative approach that brings together diverse stakeholders, including clinicians, researchers, community organizations, people living with dementia (PLWD), and their carers. The DemFoCAS project prioritized stakeholder engagement as a cornerstone of its inclusive approach. It ensured that all activities were firmly rooted in the lived experiences of those affected. By cultivating shared ownership of solutions, these collaborative meetings not only amplified the relevance of interventions but also significantly enhanced the project's sustainability and impact

Cross sector collaboration served as a catalyst for innovation by weaving together clinical expertise, academic research and community insights. This enabled project activities to be co-designed with people living with dementia (PLWD) and their support networks. Moreover, stakeholder collaboration strengthened advocacy efforts, particularly for underrepresented groups such as carers, whose voices are often marginalized in policy and service design.

Ultimately, DemFoCAS believed that stakeholder engagement was not just a procedural necessity, it was a transformative practice that has proven benefits to elevate the effectiveness and equity in building fundamental care strategies for people living with dementia (World Health Organization, 2017).

## Initial meetings - November 2022

This workshop marked a critical first step in identifying the current challenges within dementia care. Its primary aim was to shape the direction of the DemFoCAS project by gathering insights from a diverse group of stakeholders representing the East Suffolk and North Essex Foundation Trust, Essex County Council, Community 360, and the University of Essex.

Through collaborative dialogue, key systemic issues surfaced, including workforce constraints and fragmented service delivery which highlighted the urgent need for better integration across care pathways. The discussion emphasized upon the importance of continuity of care, stronger community support and the reimagining of service models to meet the complex needs of individuals living with dementia.

Major takeaways from this initial scoping exercise included a deeper understanding of what constitutes fundamental dementia care, the operational challenges faced by healthcare professionals in dementia care, and the pivotal role of community services in shaping dementia care outcomes.

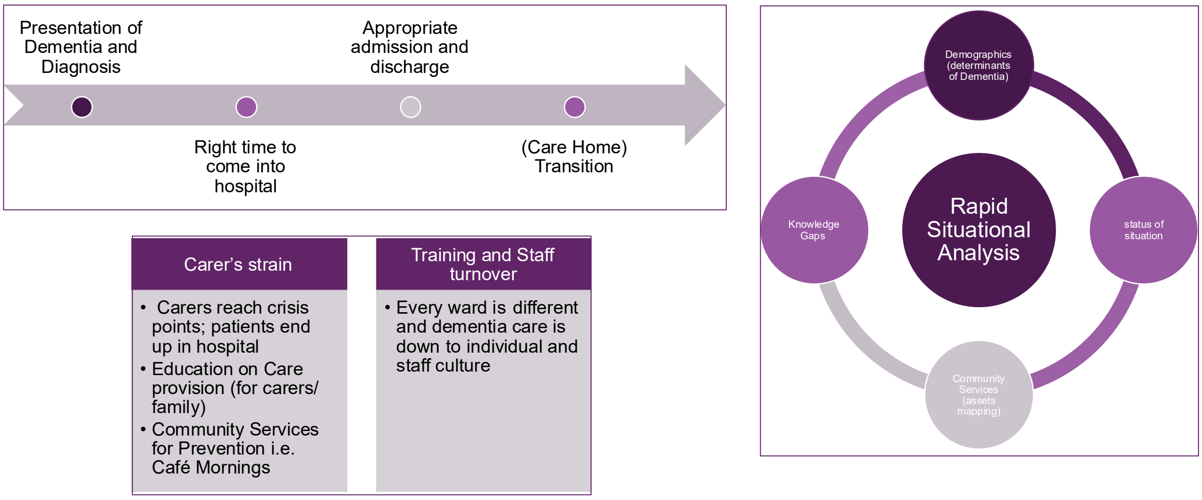


*Figure 10 Addressing the current challenges in dementia care with stakeholders*

The event aimed to showcase ongoing dementia care research across the region, with objectives to map current activities, understand how partners and stakeholders collaborate, and explore opportunities to expand the dementia research network. It offered a snapshot of the broader work being done and encouraged future collaboration.

Structured into three main sections, the event featured ten presentations followed by roundtable discussions. These discussions explored key themes in dementia research, including the role of intervention technologies, assistive tools, artificial intelligence and the importance of community-based activities. Participants highlighted the need to support informal carers, address health inequalities, and improve acute care environments, which are often chaotic and disorienting for people with dementia. Cultural considerations, such as stigma and language barriers in minority communities, were also discussed, alongside national initiatives like the Memory Services National Accreditation Programme (MSNAP) and the National Dementia Audit.

Major takeaways of the events were its success in bringing together a wide range of stakeholders passionate about improving dementia care. It underscored the importance of understanding local needs, fostering collaboration, and continuing to build the Dementia Research Network within the Institute of Public Health and Wellbeing.

*Figure 11 Attendees of the stakeholder event during group activity*

## Stakeholder Event - 21st July 2023

This event stakeholder event included a range of clinicians from ESNEFT and EPUT, community dementia care leaders, representatives from local charities, Healthwatch, local government and the local Integrated Care System, and University of Essex researchers and post-graduate students. The main focus of the event was presenting findings from the PPIE workshops and using these to discuss how themes arising from these can be acted upon in a practical, solution focus way. For many attendees, this was their first introduction to the DemFoCAS project.

Following presentations from the DemFoCAS project team, a workshop approach was used to discuss PPIE findings alongside ideas for approaching issues raised in the themes and subthemes. Ideas and challenges were discussed in relation to each theme, asking how the themes can be addressed from practical perspective. This led to our DemFoCAS practical focus areas, explained in more detail in section 9 of this report.

The event also included a talk from author Peter Berry, who was diagnosed with early onset Alzheimer’s at the age of 50. Peter was accompanied by his friend and co-author, Deb Hunt. The talk provided an invaluable first-person account of his everyday personal experiences, encounters with healthcare, development, diagnosis and living with Alzheimer’s Disease.

## Stakeholder Event - 14th May 2024

The aim of this stakeholder event was to bring together professionals, carers, volunteers, and researchers to collaboratively explore and improve dementia care in acute hospital settings. Specifically, it sought to:

- Examine current practices and identify challenges in delivering person centred care (PCC) to people living with dementia.
- Promote better communication and carer involvement in hospital care.
- Share practical insights and research to enhance care quality.
- Foster collaboration across sectors to build a stronger Dementia Research Network.
- Generate actionable ideas for training, systemic review, and staff wellbeing to support sustainable improvements.

**Collaborative discussions on person centred care.** PCC was widely acknowledged as best practice but inconsistently applied. Tools like “This is Me” were praised for helping staff understand the individual needs of people living with dementia (PLWD). Stakeholders emphasized the importance of involving carers in care planning and decision making and highlighted the valuable role trained volunteers can play in supporting PCC and easing clinical workloads. The hospital environment, staff attitudes, available activities for patients, cultural sensitivity and comprehensive training for all staff were viewed as effective ways to improve PCC. Staff wellbeing surfaced as a recurring concern, with time pressures and heavy workloads often impeding the delivery of personalized care.

**Collaborative discussions on communication**. Communication was closely tied to PCC, and carers were viewed as key intermediaries that help staff interpret patient behaviours and preferences. Volunteers were also viewed as contributors to building rapport and emotional support for PLWD. Cultural factors were discussed as having an influence on communication styles, underscoring the need for tailored approaches by staff. Suggestions to improve hospital culture and reduce stigma included using written instructions to mitigate noise and anxiety, expanding dementia friendly environments, and extending training to all staff. Effective information sharing across services was deemed essential, with calls for streamlined protocols, carer handbooks, and improved documentation to prevent mislabelling patient behaviours.

**Collaborative discussions on basic care**. Basic care discussions focused on enhancing patient experience through fewer ward transfers, open visiting policies, and increased support from carers and volunteers. Training and education were seen as vital to raising awareness and improving care quality. Staffing constraints were acknowledged as a major barrier, prompting suggestions to reskill staff, deepen carer involvement, and utilize volunteers to fill gaps. Carers were recognized as essential partners in hospital care, with proposals to develop carer groups, assign hospital link persons, and provide training to help carers support patients effectively. For patients without carers, volunteers and community groups were suggested as alternative sources of support.

**Collaborative discussion on literature review.** A systemic review was recommended to assess current practices and identify areas for improvement, including alignment with dementia policies and the Donabedian model of care quality. Understanding hospital culture through observations and staff interviews was seen as necessary to challenge stigma and enhance care delivery. Staff training was viewed as foundational to effective dementia care, with proposals to establish an awareness hub and involve carers and volunteers in training. Staff wellbeing remained a consistent theme, with high workloads and emotional pressures seen as obstacles to quality care. Stakeholders stressed the importance of monitoring and supporting staff wellbeing to maintain standards and prevent burnout.

**Conclusion.** Several issues were acknowledged but considered outside the scope of the project, including financial concerns, GP communication, care home admissions, travel logistics, and hospital parking. While these factors affect the broader experience of living with dementia, they were excluded due to their limited relevance to acute care settings. The event concluded with enthusiasm for further collaboration and a commitment to involving carers and PLWD in shaping care.

*Figure 12 Attendees at stakeholder event May 2024*

## Stakeholder Event - 15th May 2025

This stakeholder event aimed to provide an update on the DemFoCAS project and share related research and activities around dementia care in the region. The event showcased dementia care related research, encouraged collaborative dialogue, and invited participants to co-design, co-produce, and co-evaluate dementia care initiatives.

Key findings from presentations and workshops revealed critical areas for improvement, including the need for more dementia-friendly hospital environments and websites, clearer navigation for service users, updated visiting hours, and accessible multi-format patient information. Emergency departments were identified as high priority zones for dementia-specific training and environmental adjustments. Ward transfers were flagged as distressing for PLWD, underscoring the importance of minimising unnecessary moves. Standardising the use of “This is Me” documentation and integrating it into electronic patient records was recommended to support personalised care. Case mapping also exposed gaps in communication, discharge planning, and continuity of care.

### Action Points

To address these challenges, several action points were proposed, each offering tangible benefits:

**Improve Accessibility of Information**. Redesigning hospital websites and physical spaces to be dementia-friendly and offering clear, multi-format resources (written, visual, verbal) can reduce confusion and anxiety for PLWD and their carers. This fosters independence, improves patient experience, and ensures critical information is understood and retained.

**Strengthen Communication**. Enhancing staff identification and providing proactive updates during care transitions builds trust, reduces stress, and improves coordination. Clear communication helps carers feel informed and involved, which can lead to better outcomes and smoother transitions.

**Standardise Use of "This is Me"**. Embedding personalised care tools into patient records ensures that staff understand each patient's preferences, routines, and needs. This promotes dignity, reduces distress, and enhances the quality of care by making services more person-centred.

**Enhance Staff Training**. Providing dementia-specific education, especially in emergency and triage settings, equips staff to respond with empathy and skill. This reduces the risk of miscommunication, improves patient safety, and creates a more supportive environment for PLWD.

**Foster Collaborative Practice**. Continuing to co-design services with stakeholders, carers, and PLWD ensures that care models reflect the needs and experiences of PLWD. This leads to more effective, inclusive, and sustainable solutions.

**Support Carers**. Actively involving carers in decision-making and offering tailored support acknowledges their vital role and reduces caregiver burden. Empowered carers are better equipped to advocate for and support PLWD, improving overall wellbeing.

**Leverage Technology**. Using QR codes, virtual tours, and digital passports enhances engagement and accessibility. These tools can simplify navigation, personalise experiences, and provide instant access to important information, making hospital visits less daunting.

## Next Steps

Attendees of this stakeholder event agreed that the produced materials of the event should be shared with feedback. They endorsed the establishment a follow-up forum via email, Zoom, or LinkedIn to maintain momentum and foster ongoing collaboration. In addition, participants backed the formation of a "Task and Finish" group to pilot key initiatives. Although a future Dementia Network conference was viewed as an ideal next step, budgetary constraints were acknowledged as a potential barrier. As a more feasible alternative, attendees proposed organising a carers' focused meeting at the hospital, recognising its potential to offer meaningful support and strengthen connections.

*Figure 13 Group activity*

## Focused analysis of evidence base

Bringing the pieces of work together.

## Focused methods to explore organisation

The four stakeholder events significantly shaped the project's methods by embedding lived experience, cross sector collaboration, and systemic insights into its foundation. Co-production emerged as a core principle, with carers, people living with dementia, and frontline professionals actively involved in planning and decision making for the project. This ensured that project activities reflected in the current needs for service improvement at ESNEFT.

# Developing Research Capacity Through Student Placements

An important additional benefit of the DemFoCAS project has been the opportunity to support learning and research development among clinicians undertaking postgraduate study. Projects of this nature provide a valuable environment in which clinicians can gain first-hand experience of applied health research while remaining closely connected to clinical practice.

Student placements embedded within active research projects allow clinicians to develop key research skills such as qualitative analysis, critical appraisal and evidence interpretation. These experiences help bridge the gap between academic research and clinical practice, strengthening the ability of clinicians to engage with and apply research findings within their own services.

For organisations such as ESNEFT, integrating postgraduate student placements into research projects can contribute to the development of a sustainable clinical academic workforce. Supporting clinicians to engage with research early in their careers helps build confidence, research literacy and the capacity to contribute to future innovation in care delivery.

In October 2025, the DemFoCAS project was pleased to welcome student Sarah Watson on to the project for a 60-hour placement. Sarah is currently studying for a master's in health research at the School of Health and Social Care and is also a full-time occupational therapist at Essex Partnership University NHS Foundation Trust (EPUT).

Sarah’s placement hours were mainly spent with DemFoCAS team for a day a week, during the time the team were coding the carer stories from the mapping workstream (section 3), and the carer interviews (section 7). As such, the team were pleased to provide placement experience of qualitative methods in action. As an occupational therapist who regularly supports residents living with dementia in their private homes as well as a University of Essex student, Sarah was able to bring a valuable clinical viewpoint to the DemFoCAS team and its work.

### Reflexive statement

> *“As a student studying for a master's degree in health research, I completed a 60-hour placement that offered a vital bridge between my clinical specialism in Dementia and the rigours of academic inquiry. Although I joined the project in its final stages, the clarity of its objectives allowed me to engage deeply with the thematic analysis of anonymised transcripts.*
>
> *This experience highlighted a fascinating tension: the transition from clinician to novice researcher. I often found my clinical impulse to 'solve' problems competing with the researcher’s need to remain objective and grounded strictly in the data. This dual perspective was challenging but ultimately enriched my understanding of how research translates to clinical practice. I am deeply grateful to the authors for their mentorship, and I look forward to seeing these findings improve acute care pathways for individuals living with Dementia.” Sarah*

## Supporting Future Clinical Academic Development

Experiences such as this highlight the potential role of research projects in supporting the development of early-career clinical researchers within ESNEFT. Clinicians undertaking postgraduate study often bring significant professional expertise but may have limited opportunities to engage directly with research processes. Structured placements within active projects provide a practical pathway for developing these skills.

Looking forward, future research programmes within the Trust could further strengthen this approach by working with local universities to create opportunities for nurses and allied health professionals to participate in research through initiatives such as the NIHR MSc Insight programme and other postgraduate training routes. These initiatives provide important stepping stones for clinicians considering clinical academic careers and can help build capacity for nurse and AHP-led research within the organisation.

Embedding early research exposure within Trust-based projects, alongside mentorship from experienced researchers and clinical academics, can support the development of a new generation of clinicians who are able to combine clinical expertise with research leadership. In turn, this strengthens the ability of the organisation to generate evidence, improve services and contribute to regional and national research priorities in areas such as dementia care.

# Section 4 – Systematic Literature Review

## Introduction

The purpose of the review was to synthesize evidence from published manuscripts reporting interventions that improved individualised care and experiences of patients with dementia in acute care settings. The research questions were:
What interventions have been shown to improve individualised care for patients with dementia in the acute hospital setting and how do patients/staff/families and carers experience such interventions designed to improve care?

## Method

The review used the JBI methodology for convergent segregated mixed methods systematic reviews and produced a narrative synthesis of studies. Peer reviewed publications since 2015 were located through six databases. Papers were restricted to interventions in acute hospital settings. Studies using any interventions designed to enhance individualised care for patients with dementia were included. Studies were screened by two or more independent reviewers and presented in the Prisma diagram below (Figure 14).

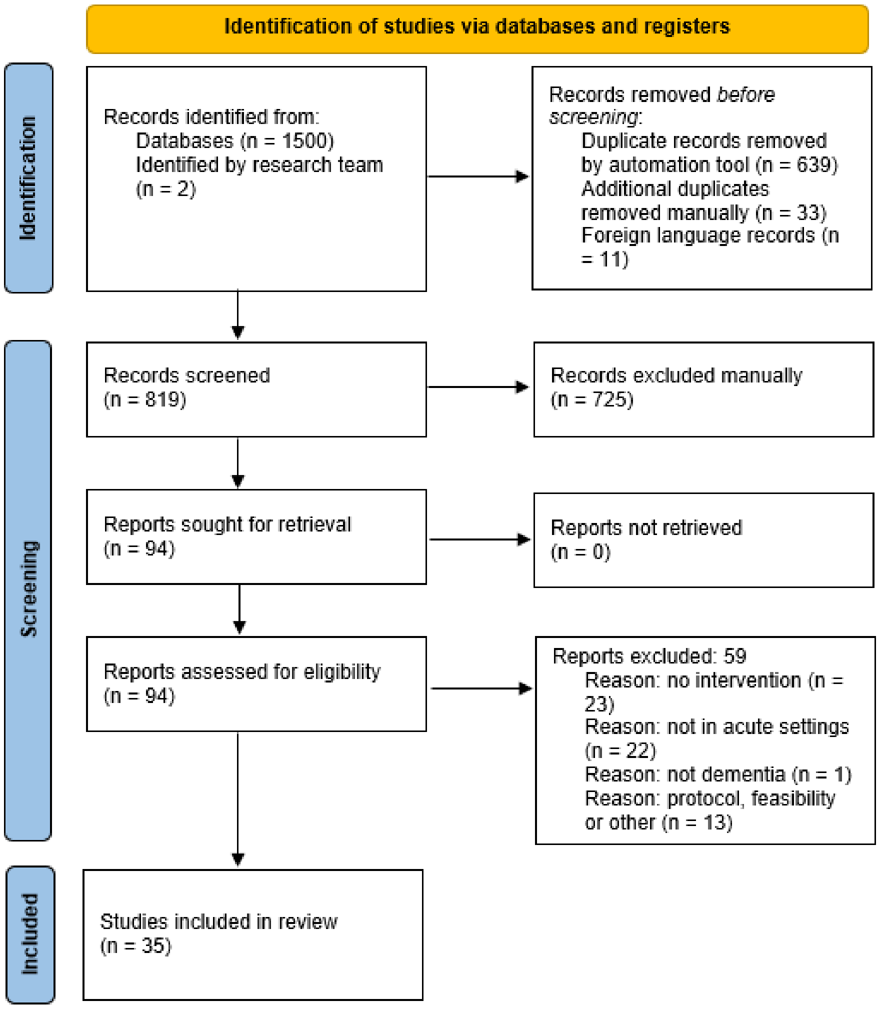


*Figure 14 Prisma flow diagram*

# Findings

The review identified 35 studies conducted across 12 countries, comprising 21 quantitative, five qualitative, and nine mixed-method designs. In several cases, the study settings and participant details were not clearly specified. Critical appraisal revealed a range of methodological quality, with qualitative data from mixed methods studies being of particularly low standard. Interventions were varied and diverse. They were grouped into five main categories of similar intervention types. These were ‘therapies’, ‘environment’, ‘technology’, ‘volunteers’, ‘carers’ and ‘care management’ (table 2). The full list of studies included in the review is shown in appendix A.

*Table 2 Summary of intervention types and research designs*

| Intervention type | Mixed | Qualitative | Quantitative | Total |
|---|---|---|---|---|
| Care management - behaviour | 1 | | 2 | 3 |
| Care management – person centred care | | 1 | 3 | 4 |
| Care management - practice changes | | 1 | 3 | 4 |
| Care management - specialist setting | | | 4 | 4 |
| Environment | 1 | 1 | 3 | 5 |
| Technology | 2 | 1 | 1 | 4 |
| Therapies | 2 | 1 | 5 | 8 |
| Volunteers | 1 | | 1 | 2 |
| Carers | 1 | | 1 | 2 |
| **Total number of studies** | **9** | **5** | **21** | **35** |

The quantitative analysis provided some support for interventions that positively influenced patient outcomes, including reductions in responsive behaviours, use of antipsychotic medications, length of hospital stay, and improved mood.

Person centred care studies showed improvements in BPSD and ADLs, specialist settings showed improvements in medication use and length of stay, carer involvement suggested a reduction in the number of patient falls and need for 1-2-1 care. Two studies showed environment improvements when involving single bedrooms, may lengthen length of stay rather.

The qualitative synthesis grouped types of findings into three categories: those relating to patient responses to the interventions, those related to care, and other (findings relating to staff and families) Overall, the synthesis emphasized enjoyment experienced by patients and calming effects on BPSD behaviours. Barriers and facilitators revolved around staff, and the level of their acceptance of the interventions, dependant on adequate resources, sufficient time, and strong leadership being present. The findings were spread across all categories of interventions, with no clear intervention types providing evidence for the different types of responses.

*Table 3 Facilitators and Barriers*

| **Facilitators** | **Barriers** |
|---|---|
| • Supportive management<br>• Multi-disciplinary involvement<br>• Staff time | • Work pressures<br>• Resistance to change<br>• Resources |

# Discussion

## Key Points from Systematic Literature Review

- Interventions made synthesis challenging and research questions difficult to answer
- Evidence for ‘Care management’ interventions targeting person centred care and specialist settings can improve BPSD, ADLs, QoL, medication use, falls and LoS
- Evidence for therapies and technology-based interventions reveal benefits through qualitative patient mood/engagement, calming effects, social connection
- Single-bed rooms may increase length of stay
- Healthcare staff are supportive but have significant pressures
- Supportive leadership and organisational facilitation are key
- Publications often poor research quality.
- Acute settings are challenging environments for research

This review examined a wide range of interventions designed to improve individualised care for people with dementia in acute hospitals. Overall, the evidence shows that many approaches have potential, but the benefits are inconsistent, and the quality of research varies considerably. This limits our ability to determine which interventions work best and in which circumstances.

Interventions with the clearest, most consistent benefits were rooted in person-centred care, especially when implemented through staff training, specialist dementia teams/units, or dementia-friendly wards. Across these models, studies reported reductions in BPSD (Allegri et al., 2022; Chenoweth et al., 2022; Graham et al., 2024), decreased agitation (Tay et al., 2018), and lower antipsychotic use (Graham et al., 2024; Sinvani et al., 2018). Specialist teams and dementia-specific settings were also linked to reduced use of benzodiazepines and PRN medications compared with standard care (Gilmore-Bykovskyi et al., 2021; Shimomura et al., 2024; Travers et al., 2018), indicating that integrated multidisciplinary support in dementia-aware environments can cut back on potentially inappropriate pharmacological management while enhancing safety.

By contrast, volunteer programmes (Bateman et al., 2016; Blair et al., 2018), carer initiatives (Isaac et al., 2018; Luxford et al., 2015), and environmental modifications (Brooke & Semlyen, 2019; Innes et al., 2016; Motzek et al., 2016), including single room occupancy, showed mixed or, at times, adverse effects, such as increased length of stay (Knight & Singh, 2016; Young et al., 2017). Although several therapies and technology enabled activities showed improvements in mood and engagement (Appel et al., 2021; Cheong et al., 2016; Daykin et al., 2018; McAulay & Streater, 2020; Tsuchiya et al., 2022), these signals were inconsistent and often supported by lower quality evidence.

Qualitative components of publications in the review were often methodologically weak and frequently anecdotal observations and under-analysed, especially in mixed-methods studies where the qualitative component was comparatively thin (Appel et al., 2024; Appel et al., 2021; Bateman et al., 2016; Daykin et al., 2018; Gilmore-Bykovskyi et al., 2021; Innes et al., 2016; Luxford et al., 2015; McAulay & Streater, 2020). Even so, qualitative findings pointed to positive engagement and calming effects for patients (Appel et al., 2024; Appel et al., 2021; Bateman et al., 2016; Brooke & Semlyen, 2019; Couzner et al., 2022; Daykin et al., 2018; Hung, 2020; Mandzuk et al., 2018; McAulay & Streater, 2020), especially in music and cognitive stimulation therapies (Daykin et al., 2018; Mandzuk et al., 2018; McAulay & Streater, 2020). This was accompanied by perceived benefits for staff workload and communication when carers and volunteer were involved (Bateman et al., 2016; Luxford et al., 2015).

A pervasive issue across the literature is the ethical and operational difficulties of conducting high-quality research in acute hospital settings with people with cognitive impairment, especially around consent and follow-up (Chandra et al., 2021). Many interventions lacked standardised outcomes, short follow-up periods, seldom addressing sustainability, scalability or cost-effectiveness. Addressing these limitations is essential for strengthening the evidence base and enabling the effective implementation of care interventions within acute hospital settings for people living with dementia.

## Conclusion

In summary, dementia-specific interventions grounded in person-centred care show the clearest benefits to outcomes for patients with dementia in acute general hospital settings, but the overall evidence remains fragmented. High-quality, well-designed research is needed to determine which approaches deliver the greatest improvement in outcomes, staff experience, and organisational efficiency. Future work should focus on using stronger research designs such as RCTs and rigorously conducted qualitative approaches and ensure that mixed-methods studies give balanced attention to both their qualitative and quantitative elements.

### Future Focus of Research

- Increase clinically led research to optimise patient experience and individualised dementia care in acute hospitals.
- Identify and remove barriers that currently hinder research in complex hospital environments.
- Invest in specialist dementia teams, dementia-friendly environments, and scalable person-centred training.
- Expand integrated therapeutic interventions that support meaningful engagement.
- Ensure carers, families, and people with dementia are actively involved in care design and delivery.
- Strengthen the future evidence base through sustained policy backing, funding, and organisational commitment

# Section 5 – Embedded PhD Feasibility study on Magic Tables

## Introduction

This section introduces a PhD research study which forms part of the DemFoCAS project. Starting in October 2023, the study will conclude in 2026. Using case study research to explore the utility, practicality & experience of the “magic table” with older people living with dementia on acute inpatient wards. The study is an example of a clinically-led embedded research project which designs, implements and evaluates an intervention for patients with dementia in acute settings at ESNEFT.

As shown in the Section 4, in the systematic literature review, there is a dearth of quality research in this area, and this research study serves as an example of how such work can be carried out, while also shedding light on the challenges inherent in this type of research and the approaches used to overcome them.

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- PhD student at University of Essex with the ESNEFT commissioned Dementia - Fundamentals of Care in Acute Settings project (DemFoCAS) in the School of Health and social care 2023 – 2026 - Full Time.

## Background

Up to 25% of acute general hospital beds are occupied by people living with dementia (PLWD; Royal College of Psychiatrists, 2019) who find hospitals particularly distressing and often experience poor outcomes including reduced function (deconditioning), leading to challenges in returning home and longer than average hospital stays.

### Intervention

The “Magic Table” is a portable, interactive light projector designed to promote stimulation, physical activity, and social engagement. It offers enjoyable and meaningful activities that support emotional wellbeing.

Research in care home settings has demonstrated improvements in behaviour, self-image, discomfort, and apathy. However, there is currently no robust published evidence supporting its use in acute hospital settings.

### Study Aim

This study seeks to address this evidence gap by exploring the utility, practicality, and lived experience of using Magic Tables with PLWD on acute general hospital wards.

## Design

An observational case study design will be employed to investigate the real-world use of Magic Tables in older people's hospital wards on the 2 acute hospital sites of an NHS Foundation Trust. The study will use mixed methods to generate both qualitative and quantitative data through:

- Document review
- Staff questionnaires
- Patient observation and interviews
- Staff and volunteer focus groups

### Ethical Approval

Health Research Authority and NHS REC approval has been granted.
REC: Camden & Kings Cross, Reference: 25/LO/0070, IRAS ID: 345641

## Study Progress to Date

### Staff Questionnaires

A total of 122 staff responses have been collected from acute older people’s wards—62 from Hospital A and 60 from Hospital B. Questionnaires were collected from across all 8 care of the elderly wards (figure 15).

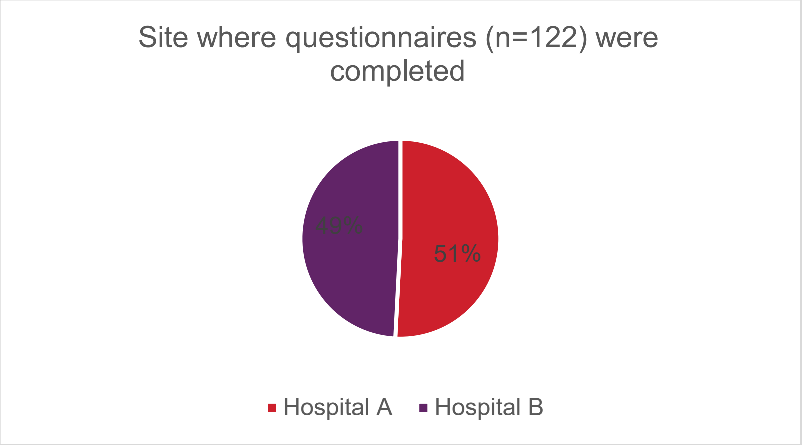


*Figure 15 Staff questionnaire fig. A*

66% were nurses, HCAs, therapy staff, or specialist dementia support staff who directly use /could use Magic Tables as part of their role. Others included doctors, ward clerk & housekeeping staff and specialist visiting teams who may facilitate or promote Magic Table use (figure 16).

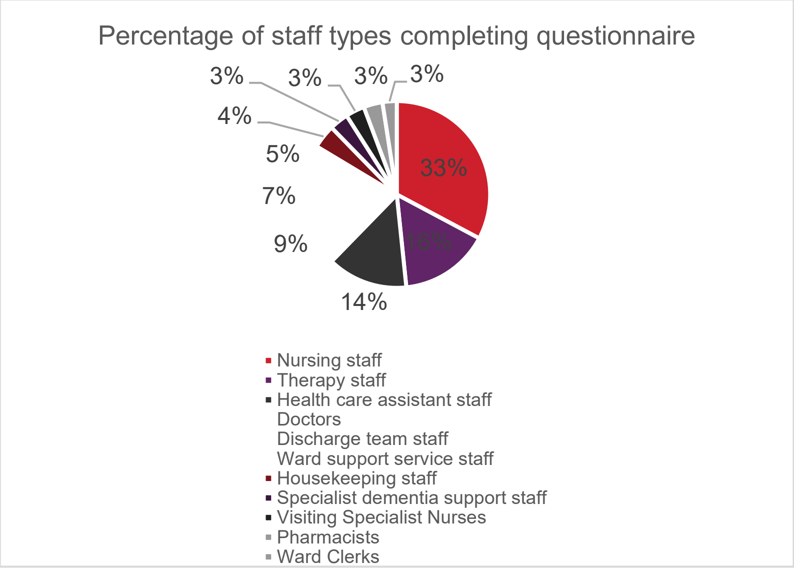


*Figure 16 Staff questionnaire fig. B*

Just under 30% of staff completing the questionnaire at both hospital sites said that they had used the magic table before with patients (figure 17).

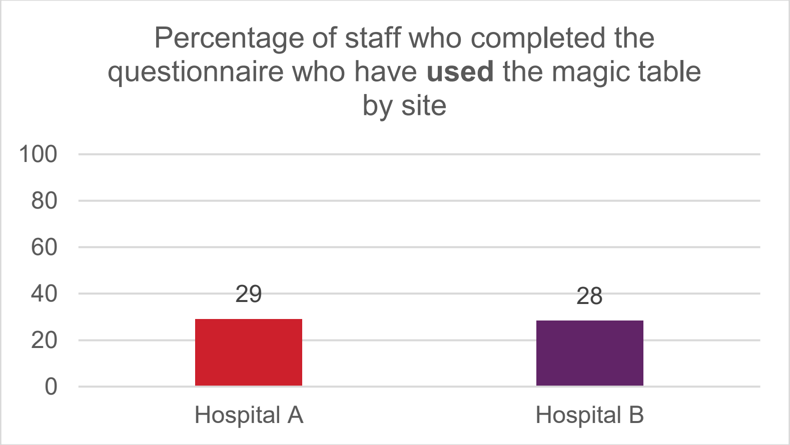


*Figure 17 Staff questionnaire fig. C*

# Findings

## Usefulness

On average staff completing the questionnaire scored the magic table **4.5** on a scale of 1 – 5 (where 1 is not at all useful and 5 is very useful).It was thought to be useful for patients with **dementia & cognitive impairment** but also those with **psychosocial & emotional vulnerability** – those bored, lonely or those with other mental health issues. At Hospital A in particular it was also thought it could be useful with any inpatients if they wanted to engage (figure 18)

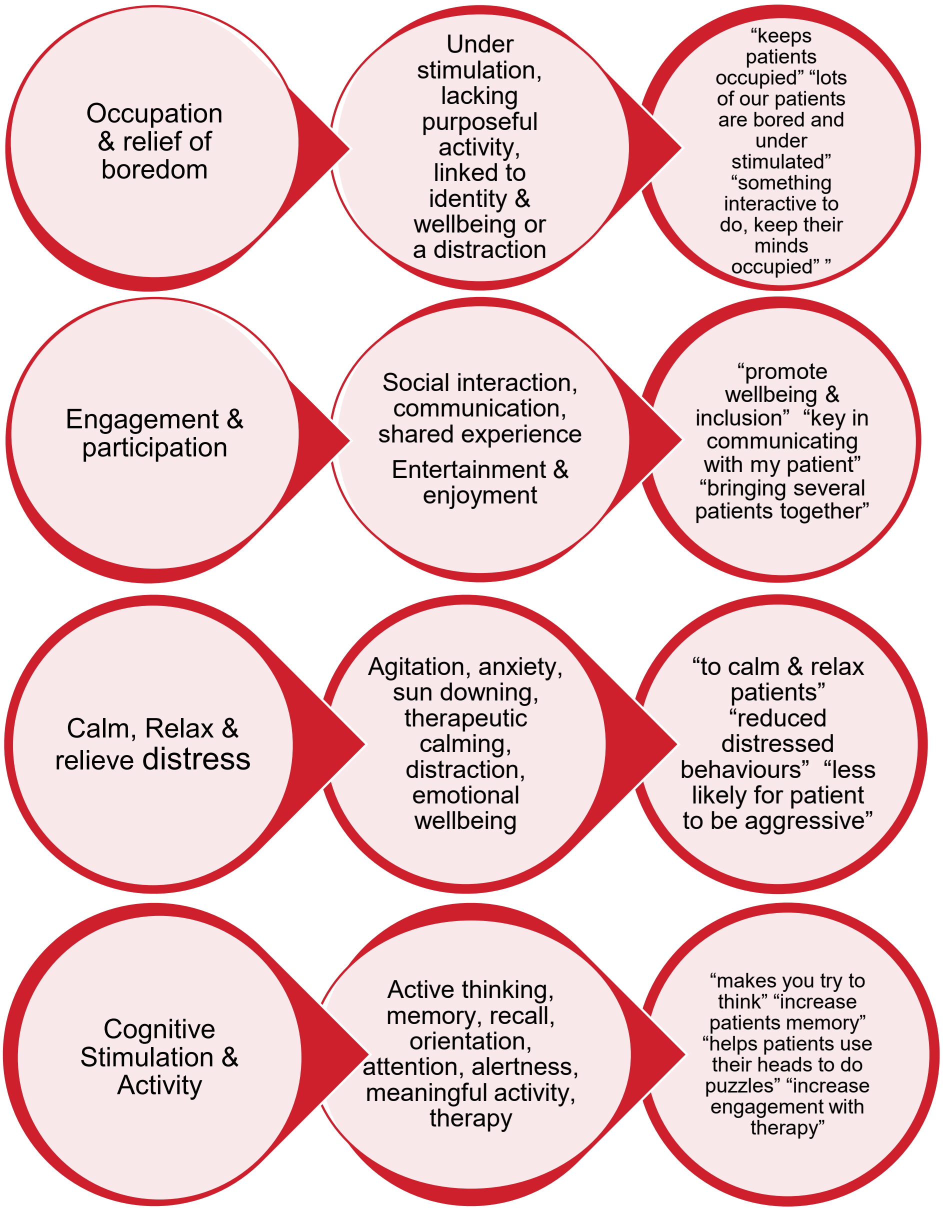


*Figure 18 Uses of the magic tables*

Occupation and relief of boredom was commonly cited as an important use but just as common was engagement and participation i.e. promoting social interaction, shared experience and enjoyment.

It was also felt to provide cognitive stimulation and promote activity – an active input from the patient to counter the cognitive, physical, social and psychological deconditioning often seen.

Calming, relaxation and relief of distress was another use.

## Practicality

On average staff completing the questionnaire scored the magic table 4.4 on a scale of 1 – 5 (where 1 is not at all easy to use and 5 is very easy to use).

Most staff perceived the magic tables as easy to use with an intuitive design. There were a few comments that its use was conditional on time and staffing, the environment wasn't always ideal (including a lack of plug sockets & space) and some issues with the technology such as difficulty with focus at times.

Suggestions included

- use of volunteers
- more training and time to familiarise themselves with the activities available
- improved menu navigation

## Experience

*Figure 19 Experience*

Staff thought that the patient experience was generally enjoyable, entertaining and fun. It could be calming and relaxing – but also perhaps for some patients overstimulating or frustrating (depending on the activities selected).

## Patient Observations and Interviews

Thirteen PLWD have been recruited. Three became too anxious during the initial data collection phase and were withdrawn at their request. Ten participants have been observed using the Magic Table during their inpatient stay, followed by a semi-structured interview exploring their thoughts, experiences, and perceptions of the intervention.

The average age of the 10 participants is 85 and they represent a range of dementia diagnoses with 40% diagnosed with Alzheimer's disease, 20% vascular dementia and then Lewy body, Parkinson's and unspecified dementia. There are 5 male and 5 female participants, with 5 recruited from each hospital site (figure 20).

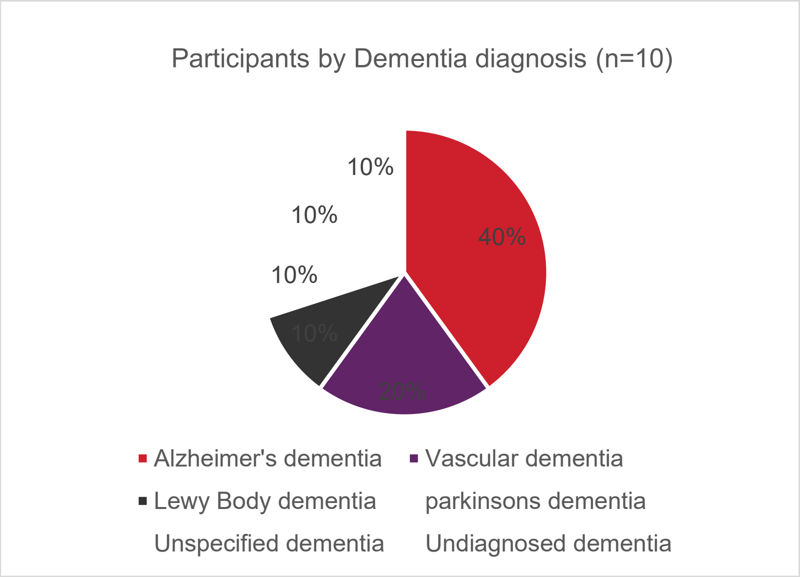


*Figure 20 Dementia diagnoses*

## Staff and Volunteer Focus Groups

Eight staff and volunteers who have used the magic table with patients on these wards (five from Hospital A, three from Hospital B) have participated in Focus groups to gain further understanding of the utility, practicality and experiences of using the magic tables in this setting.

Analysis of the observations and interviews with PLWD and the staff focus group discussions will next involve transcription, coding and thematic analysis following Braun & Clarkes framework.

## Ongoing Work

It is anticipated that there may be multiple possible uses for the magic tables - helping patients be more cognitively & physically active, improving their experience & outcomes as well as the experience for staff & relatives.

New promising technologies in health care though often face challenges of non-adoption, abandonment, scaling up, spread & sustainability. The findings of this study will help to inform a co-produced and sustainable implementation plan that is useful and realistic for ESNEFT.

The magic tables companies are keen for any feedback too - so there is potential to contribute to future adaptation and improvements to the magic tables and possible further interventional research work around improving activity in hospitals.

## Challenges and Limitations

The study was conducted within a single NHS trust but across two hospital sites 20 miles apart. It involved both NHS staff and patients and so required NHS ethical approval. The trust then acted as the study sponsor and was responsible for coordinating and monitoring the research, with academic supervision and methodological oversight being provided by the University of Essex.

The study therefore required approval through multiple governance processes. In addition to review by a Research Ethics Committee, including meeting attendance due to the potential involvement of adults who may lack capacity to consent, the project also underwent the University of Essex ethical review process and the trust’s internal quality assurance procedures.

It took some considerable time to complete these processes; that often feels contrary to the pace of acute clinical healthcare, but it ultimately ensured compliance with both clinical governance requirements and academic research standards.

The researcher’s position as a clinical academic embedded researcher within the trust facilitated navigation of the governance procedures, through familiarity with the research department and established professional relationships. This positionality also enabled access to clinical settings that can be more difficult for external researchers.

However, conducting research in an acute healthcare environment was still very challenging, with many practical constraints, including competing clinical priorities, staffing pressures, sickness absence, and periods of industrial action, which influenced the timing and feasibility of data collection.

Questionnaire data for example, was collected while undertaking the dual task of increasing awareness and delivering training to staff on the wards about the magic tables. Focus group discussions were delayed during periods of particularly high pressure within the wards and ultimately could have benefitted from more participants. Interviews with people living with dementia were conducted primarily at one site in September and at the second site during November, periods characterised by differing operational pressures.

These contextual factors, together with the researcher's embedded role, need to be considered reflexively during analysis and interpretation of the data.

## Opportunities and Benefits

Other opportunities and benefits from this Scholarship within the ESNEFT commissioned Dementia - Fundamentals of Care in Acute Settings project (DemFoCAS) in the School of Health and social care at the University of Essex include:

- Working as part of the DemFoCAS research team has enabled me to establish links with many departments and individuals, including with the Dementia research network, across the University of Essex. This builds on ESNEFTs academic collaboration with the University of Essex

- Working as a senior clinician in the Trust allows for staff to see me working as an embedded clinical researcher across the wards & see the benefits of having clinical academic roles and the real impact they can have on patient care.

- This, alongside development of a new clinical research facility on the Colchester site, opens up opportunities for further collaborative research with our patients and the university, especially for people living with dementia.

# Acknowledgment and Thanks

- UoE & ESNEFT – PhD Scholarship – as part of the partnership project DemFoCAS evaluating the fundamentals of care in acute settings with patients with dementia

- ESNEFT R&D department – Sponsorship & support for the research project

- EEPRU, ESNEFT Education Fund & ESNEFT RFG – Funding contributions

- My research mentors at ESNEFT – Dr Richard Smith, Marie Alexander

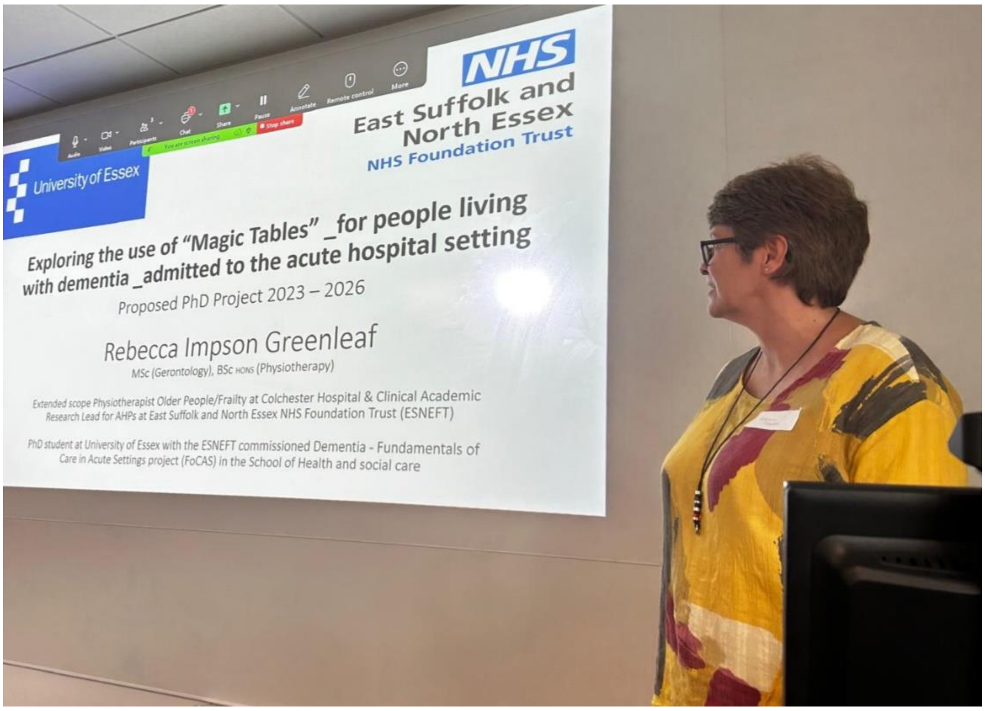
- My clinical colleagues & collaborators at ESNEFT

- My PhD supervisors for all their advice and support – Professor Camille Cronin, Professor Jo Jackson & Dr Nestor Asiamah

## Presentations

10th May 2025 - Presentation of research at Council of Allied Health Professionals in Research regional conference

15th May 2025 -Presentation at the University of Essex Dementia Network Partnership Event (figure 12).



East Suffolk and North Essex NHS Foundation Trust

Exploring the use of "Magic Tables" _for people living with dementia _admitted to the acute hospital setting

Proposed PhD Project 2023 – 2026

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*Figure 21 Rebecca Impson presenting*

# Section 6 - Mapping Process

## Introduction

The mapping process used three types of data with increasing depth: Admissions data enabled the calculation of high level trends over a 12 month period for patients 75 and over; conventional process mapping following 18 patients with and without dementia produced detailed insight into patient pathways from hospital records; and patient/carer stories from three carers provided an in depth record of recent experiences from carer and patient perspective. This section brings together these three elements to form a comprehensive picture of acute care at ESNEFT.

## Admissions data

Using anonymised data compiled by ESNEFT's Business Informatics team, the team analysed records of patients aged 75+ admitted to Colchester and Ipswich hospital between October 2022 and September 2023.

Of the 55,959 admission records received, the research team removed day patients and patients who had attended A & E for less than 12 hours, leaving 25,295 inpatient admission records for analysis. The team then calculated new variables from the original data for length of stay and patients with dementia were identified through dementia related diagnostic codes assigned by ESNEFT's coding team. Records were separated by acute site (Colchester and Ipswich hospital) and every patient received a unique identifier code.

Data was analysed and explored associative, comparative, and predictive relationships observed within the data with particular focus on patient presentations, processes and outcomes across the two sites. All analyses were done using SPSS version 29, an alpha level of .05 was utilized, and have previously been reported in detail in the DemFoCAS progress report (Cronin et al., 2024).

### Major findings

- Prevalence of dementia amongst inpatients was 18.8% (1 in 5 beds).
- The proportions of inpatients with a dementia diagnosis did not differ between hospital sites.
- Female inpatients displayed longer lengths of stay than male inpatients.

- Length of stay for inpatients with a dementia diagnosis was significantly higher than that of all other clinically diagnosed inpatients (10 days vs 8½ days).
- There was a statistically significant main effect of dementia classification on length of stay and age presentations at varying times, days, and seasons.
- Inpatients with dementia admitted over the weekend from Friday had the highest mean length of stay (11 days). Inpatient with dementia admitted on a Monday had the lowest mean length of stay (9 days).
- For every unit increase in length of stay for inpatients aged 75 years and older the probability of that inpatient having a dementia diagnosis increases by 1%.
- For every annual increase in age for inpatients aged 75 and over the probability of the inpatient having a dementia diagnosis increases by 6%. (This means that inpatients aged 85 and over have increased odds of being 60% more likely to have dementia diagnosis).
- The most common primary presentations were lobar pneumonia (5% of inpatients), urinary tract infections (4% of inpatients) tendency to fall (3% of inpatients) and delirium (1% of inpatients).

# Conventional Process Mapping

## Background and context

Conventional process mapping is an established Quality Improvement (QI) tool that enables healthcare teams to visualise and analyse the flow of patient care, identify inefficiencies and highlight critical touchpoints that influence patient experience and outcomes (NHS Institute for Innovation and Improvement, 2008). When applied to dementia care, process mapping offers a valuable lens through which service providers can appreciate the complexities of hospital systems, including communication gaps, and variations in practice. It can also support the development of more person-centred care models that align with national policy and suit the experiences of people living with dementia.

## Method

A conventional process mapping approach was employed to examine the care pathways of inpatients aged 75 and older within ESNEFT. This piece of work used retrospective case note analysis to identify patterns in care delivery and emergent touchpoints, with a focus on comparing experiences of patients with and without a dementia diagnosis. This approached was co-designed by the project’s steering group which consisted of local carers for patients living with dementia and with recent hospital experience at the acute hospital trust.

## Participants

Eighteen inpatient admissions were selected from a dataset of all patients aged 75 and older admitted between 1st October 2022 and 30th September 2023. Twelve patients had dementia and six patients had no dementia diagnosis. Sixteen cases were selected randomly from patients who had presented with one of four most prevalent primary clinical presentations identified through descriptive statistical analysis (lobar pneumonia, tendency to fall, delirium, UTI). An additional two cases with a primary diagnosis of vascular dementia were included to provide insights on dementia-specific care. Cases were matched by age and length of stay and evenly distributed between the two acute hospital sites. (See table 4)

## Data Sources and Extraction

Three electronic patient management systems, EVOLVE, Careflow, and Lorenzo, were used to access and review clinical documentation, including ward moves and care notes. Handwritten notes were manually reviewed. Where patients were admitted more than once in the period, one admission was explored in detail. Data extraction was guided by the local dementia care policy (ESNEFT, 2022; ESNEFT, 2025) and observed information between the dataset and the case notes included the categories: admission, diagnosis and screening, ward entry and transfers, activities of daily living (ADL), communication, quality of care, length of stay and discharge planning. The data was summarised and analysed to identify any patterns and touchpoints in the patient journey examining differences in care processes between patients with and without dementia.

*Table 4 Patient details*

| ID | Hospital | Admissions in period[1] | Age | Gender | Evaluated Admission date[2] | Length of stay (days) | Primary Presentation |
|---|---|---|---|---|---|---|---|
| **Patients with dementia** | | | | | | | |
| 2272 | B | 6 | 77 | M | Jul 23 | 24 | Vascular dementia unspecified |
| 1063 | A | 4 | 77 | F | Mar 23 | 23 | Vascular dementia, unspecified |
| 20878 | B | 2 | 82 | F | Mar 23 | 5 | Urinary tract infection |
| 18642 | A | 4 | 79 | F | Apr 23 | 9 | Lobar pneumonia, unspecified |
| 5246 | A | 6 | 83 | M | Nov 22 | 25 | Urinary tract infection, site not specified |
| 2351 | B | 4 | 80 | M | Apr 23 | 9 | Lobar pneumonia, unspecified |
| 1656 | A | 3 | 80 | F | Sep 23 | 33 | Senility/Tendency to fall |
| 1048 | A | 5 | 83 | F | May 23 | 21 | Delirium superimposed on dementia |
| 12289 | B | 4 | 80 | M | May 23 | 17 | Tendency to fall/ sepsis x2/ pain in shoulder |
| 24034 | B | 3 | 79 | M | Oct 22 | 12 | Tendency to fall |
| 1138 | A | 4 | 81 | M | Aug 23 | 8 | Tendency to fall |
| 25490 | B | 4 | 78 | M | Dec 22 | 10 | Delirium superimposed on dementia |
| **Patients with no dementia** | | | | | | | |
| 28100 | A | 3 | 79 | F | Dec 22 | 10 | Lobar pneumonia, unspecified |
| 8376 | B | 5 | 80 | F | Aug 23 | 13 | Lobar pneumonia, unspecified |
| 25195 | A | 2 | 82 | F | Jan 23 | 5 | Delirium, unspecified |
| 15895 | B | 6 | 82 | M | Dec 22 | 14 | Delirium not superimposed on dementia |
| 4312 | B | 10 | 82 | F | Feb 23 | 19 | Urinary tract infection |
| 12930 | A | 8 | 82 | F | Dec 22 | 26 | Urinary tract infection |

*Notes*

1. Period = 12 months between 01/10/2022 and 30/09/2023
2. Evaluated admission = Month of admission assessed in detail

## Results

The mean length of stay (LOS) for admissions was 15.72 (SD = 8.12). The mean LOS was slightly longer for PLWD (16.33; SD = 9.90) than for patients with no dementia (14.50; SD = 7.29). Most patients lived in private homes before admission, with four PLWD living in care homes (table 5).

*Table 5 Showing where patients resided prior to admission*

| Residence before admission | No. patients with dementia | No. patients without dementia |
|---|---|---|
| Living with spouse/family in private home | 3 | 4 |
| Living on own in private home | 3 | 1 |
| Living in care home | 4 | 0 |
| Unclear | 2 | 1 |

### Patients Pathways

Both groups of inpatients followed broadly similar pathways through the hospital. All 18 patients entered either the Emergency Department (ED, n=16) or the Emergency Assessment Unit (EAU, n=2), with 14 of the ED admissions subsequently transferred to EAU. From there, every patient was moved on to a specialised ward, either directly from A&E (n=2) or via EAU (n=16) and most inpatients (n=10) experienced at least one further transfer to another specialist ward during their stay. These wards included care of the elderly (4), escalation (2), general medicine, cancer services (1), and surgical (1). Examples of individual process maps for patients are shown in Appendix B.

Table 4 shows touchpoints for several aspects of care in the sample cases. It highlights differences in documentation, clinical alerts, screening practices and ward movements, as well as the frequency of incidents and discharge placement discrepancies.

*Table 6 Process mapping touchpoints*

| **Touchpoint** | **Patients with dementia (n=12)** | **Patients without dementia (n=6)** |
|---|---|---|
| No record of "This is me" | 10 patients | N/A |
| Dementia alerts | 6 patients | 1 patient [1] |
| Unobserved screening for dementia or delirium | 3 patients | 0 patients |
| Safeguarding issues recorded | 2 | 0 |
| Datix submitted | 3 | 0 |
| Discharge placement discrepancies | 4 patients | 1 patient |
| No. patients with one or more night-time ward moves | 8 patients (66.67%) | 4 patients (66.67%) |
| No. patients with two night-time ward moves | 2 patients | 0 patients |

*Notes*

1. One patient with no diagnostic code for dementia in admissions records had a dementia alert on their electronic record

A number of inconsistent patterns were identified against the dementia policy and these were found in the following areas: *discharge destination* (discharge destination being coded differently from what was written on patient discharge summaries), *unobserved dementia alerts* (dementia alerts are used to help staff identify patients with dementia in hospital being absent on review of patient notes), *unobserved screening for dementia and/or delirium*, *ward moves*, *no record of 'This is me'*, and *Datix incidents*.

## Patients without dementia

Patients in the 'without dementia' group had no dementia diagnostic codes allocated to them in the period covered by the hospital admissions data. However, three of the six patients had some reference to dementia in their records. One patient's record included a note stating there was a 'suspicion of dementia' (28100), a second had ‘delirium on a b/g (background) of dementia’ stated as a possible diagnosis (4312). A third patient had a dementia alert on electronic records (12930), which may have been placed on the system after 30/09/2023.

## Ward Moves

Results focused on ward moves, however patient records indicated there were notable additional moves to different bays within A&E and for investigations such as endoscopy and x ray for some patients. Ward moves for each patient ranged from one to four, although only one patient, without dementia, was moved four times. There was little difference between ward moves in patients with and without dementia.

All but five of the patients were moved at least once between 2000 and 0600, in contrast to best practise. Two patients with dementia were moved twice during the night, and the remainder were moved once, except for one patient where details were unclear.

Ward moves were discussed with senior nurses at stakeholder meetings who were involved in bed management; and while the policy was not to move patients unnecessarily, ward moves mainly occurred to ensure patient safety.

## Discharge

There were four instances of hospital admissions data stating patient was discharged to a destination that did not reflect the detailed data in patient notes. Three had dementia (18642, 1656, 24034) and one did not (4312). One patient’s records (1063) noted discharge to patient’s usual place of residence. However, other notes and hospital admissions data show patient was discharged to a temporary place of residence in a care home.

Three patients died during their admission, one of whom had dementia. The four PLWD living in care homes were all discharged back to their residences. Four of the six PLWD previously living in private homes were discharged to a new care setting (table 7).

*Table 7 Discharge destination*

| Discharge destination | No. patients with dementia | No. patients without dementia |
|---|---|---|
| Patient died in hospital | 1 | 2 |
| Discharged to new care home | 1 | 1 |
| Discharged to temporary placement/community setting | 3 | 0 |
| Discharged back to care home | 4 | 0 |
| Discharged back to private home | 2 | 3 |
| Discharged to usual residence (no further details) | 1 | 0 |

## Behavioural and Psychological Symptoms of Dementia (BPSD)

Behavioural and psychological symptoms of dementia (BPSD) together with safeguarding needs often present in acute settings for those requiring dementia care. Records for three PLWD suggested had Datix incidents reported. One was for grade 3 ulcer, one for an unwitnessed fall, and the third for safeguarding. Another four PLWD showed complex care needs due to mental health, two of whom were reported as having safeguarding issues. Records showed security guards had been present during the care of two PLWD due to responsive behaviours; and two PLWD had diagnoses of bipolar disorder.

# Patient stories

## Rationale

To deepen the understanding of patient pathways and dementia services, a patient and carer story exercise was conducted. This exercise sought to provide the case study with real time patient and/or carer experiences and provide some supportive information around the patient pathways collected in the process mapping exercise. The personal storied from patients and carers, real perspectives that illuminate the realities of dementia care in hospital and provide context to the clinical case notes.

## Method

### Visits

Between May and October 2025, 25 hospital visits were conducted to recruit patients and their carers for storytelling interviews. These visits were split between the two hospital sites: Site A received 14 visits from May to the end of July, while Site B had 11 visits between July and October.

Across both sites, 79 patients aged 60 and older and their carers were approached and invited to share their story. Together, these potential participants were approached and invited to join video or telephone interviews by dementia nurse specialists, band 3 Health Care Assistants (HCAs) of ESNEFT or a member of the DemFoCAS team. Approached inpatients had a formal diagnosis of dementia and illustrated having sufficient capacity to partake in storytelling. Inpatients were not approached if they are living with complex illnesses or treatments, as this may have been an emotionally tense period where care should be prioritized. Inclusion criteria included: Patients age 60 years or older with a formal dementia diagnosis.

Carers were approached and given one day to review Information sheets and to ask questions before signing on their follow up visit. Consenting carers that agreed to partake in interviews were contacted via telephone or email to arrange an appropriate interview date 1 month post discharge.

**Site A Visits.** Patients and their carers (n=55) were approached at the hospital. The first three visits were used to meet with the Integrated Rapid Assessment Service (IRAS) team to identify suitable patients to approach. Recruitment was then extended across all care of the elderly wards and select specialty wards where patients had dementia alerts on EVOLVE and Careflow. Over the remaining weeks of recruitment, the researcher periodically visited the IRAS team, and hospital systems like Careflow and EVOLVE to identify patients for recruitment.

**Site B visits**. At this hospital, the researcher was provided with a list of patients (n =24) to guide their recruitment efforts. This list was provided by the Dementia Specialist Nurse and Health Care Assistant. The patients enlisted were located across several care of the elderly wards at the hospital. Across hospital sites, staff rotations occurred on a weekly basis, but the researcher's presence ensured that hospital staff became familiar the team and project objectives. During ward visits, the researcher with every patient using the list provided. Staff members often identified additional patients on the ward who had a formal dementia diagnosis, facilitating broader access. This hospital site operated a "buzzing system," requiring staff to be contacted for entry and exit, which added a layer of logistical coordination to each ward visit.

**Negotiating Access.** Building trust and negotiating access required multiple visits and ongoing communication with staff, patients, and carers. Staff frequently rotated weekly but due to the constant presence at hospitals over 3 months, most staff recognised the DemFoCAS team and their project objective. Over time, conversations with ward staff at hospitals expanded, and the DemFoCAS team negotiated access to every selected patient with a formal dementia diagnosis. Site A's open ward layout and "open door" policy facilitated ease of movement. Team members could readily enter wards and identify carers and patients present. Additionally, the wards were consistently well staffed, ensuring that any queries could be addressed promptly and efficiently. Site B's staff helped to identify additional patients to the research team on visits.

## Screening and Recruitment

The patients visited across both hospitals failed the initial capacity screening assessment. Engagement was challenging for many patients due to reduced communication abilities. Patients who were able to converse expressed appreciation for being included in discussions about their care experience. Carers became the primary focus for obtaining consent for the storytelling exercise. However, predicting carer presence at hospitals proved challenging, making it difficult to coordinate screening. To address this, various hospital departments supported the recruitment process by distributing consent forms to carers or notifying the DemFoCAS team when carers were available on site.

From both hospital sites, 20 patients and their carers agreed to participate in the story telling exercise with five being excluded after initial telephone contact due to readmission, withdrawal or deceased patient. Of the 15 remaining carers and patients, eight were from Site A and seven from Site B. A great deal of time was spent attempting to follow up and collect the story data. Over 60 telephone calls collectively were made for this part of the recruitment between July 2025 to November 2025 to the 15 carers who consented to be part of the story telling exercise (figure 22).

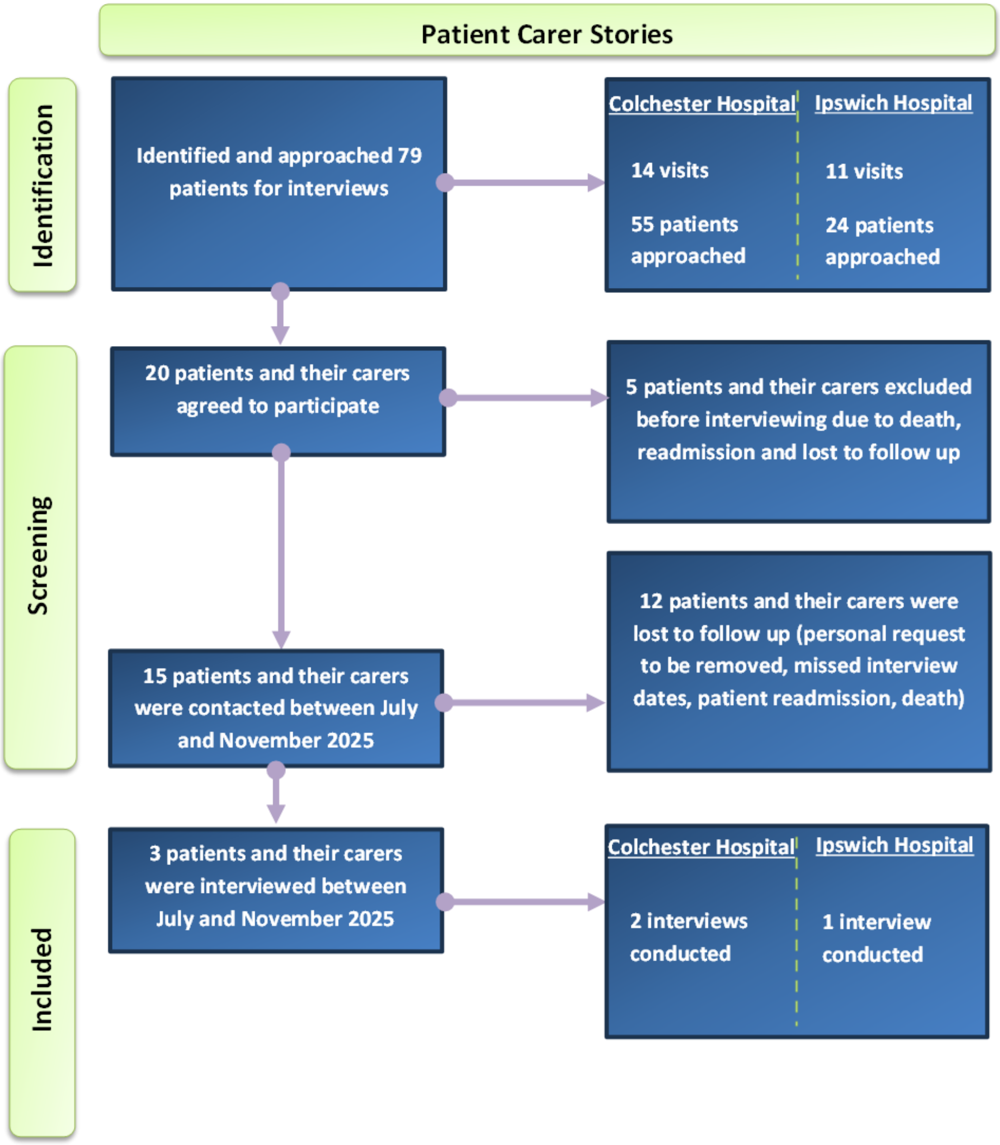


*Figure 22 Patient/Carer stories flowchart*

### Recruitment Challenges

Several challenges emerged during recruitment, including fatigued patients and those with hearing impairments, which made communication difficult. Carers often visited at unpredictable times, limiting opportunities for coordinated conversations about recruitment and consent, and some declined participation due to emotional exhaustion, loss of hope, or uncertainty about the value of the interviews. Others took consent forms but did not return them, while post-discharge transitions or time pressures further prevented participation, alongside cases where no carers were available or the patient had died.

Despite these obstacles, the researcher extended the timeframe for this phase and made sustained efforts to engage with carers and patients, including additional visits during evenings and weekends. This stage of the project highlighted the complexities of hospital-based recruitment over an extended period, particularly when reliant on post-discharge follow-up.

## Results

There were 3 successful conversions from recruitment to story post charge where the researcher was able to interview the carers and listen to their story (table 8).

*Table 8 carer descriptions*

| | | | |
|---|---|---|---|
| Carer 1 | Wife of the patient living with dementia | She visited the hospital regularly with her sons. | Online interview |
| Carer 2 | Wife of the person living with dementia | She was admitted along with her husband to hospital due to covid infection. They shared a side room in hospital. | Telephone interview |
| Carer 3 | Daughter of a patient living with dementia | Her mother was the patient. She visited the hospital regularly with her father. | Telephone interview |

Their stories covered several themes including patient wellbeing, role of carers and families; basic care: cleanliness, dignity, mobility, nutrition, hydration and safety; and information sharing and communication; staff attitude and culture; Dementia Awareness and environment including discharge. These themes are summarised below with supported quotes from the stories.

### 1. Role of Carers and Families

Carers and families play a crucial role in patient support, however their supporting responsibilities often come with significant challenges. Feelings of helplessness can arise when they have little control over medical decisions. Also, their need for constant vigilance and on-going responsibility can lead to emotional and physical exhaustion, highlighting the need to recognise carers' wellbeing.

**Carer 1**: *"You're just helpless, aren't you really? Because you just had to put up with whatever came."*

**Carer 2**: *"I can't leave Patient 2 on his own indoors, so he's got to come with me."*

**Carer 3**: *"I didn't feel that I could leave my mum and that my mum would be safe. And for me that was the only reason why dad and I spent the time there."*

### 2. Individualised Care

***Patient wellbeing:*** Patient wellbeing is an important consideration during hospital admission and shaped by the emotional, psychological and physical changes that accompany a hospital stay. In addition to clinical care, carers may provide support related to emotional reassurance and cognitive needs.

**Carer 3**: *"Basically, all I would do with her is sit and just constantly answer her questions about where am I? What am I doing here? What's wrong with me? Where's your dad? What's that lady doing over there? Who is that person who's just come? I would be answering that question hundreds of times in the day and just trying to keep her calm because she'd get anxious quite quickly."*

### 3. Basic Care

***Cleanliness:*** Carer 3 provided an example of how lapses in cleanliness and environmental safety compromise patient safety and wellbeing. Her story suggests that when patients with dementia are overlooked, there can also be consequences and exposure to unnecessary risks.

**Carer 3**: *"Mum, who's just had a hip replacement, was wiping the floor with a towel because the floor was wet."*

***Dignity:*** Carer 1 felt her husband's dementia diagnosis took precedence over his head injury taking away his individuality and respect. Carer 3 shared how procedures were untaken with her mother without explanation leaving her confused and distressed.

**Carer 3**: *"People would just walk up to her and start taking blood pressure and she wouldn't know*

**Carer 1**: *"Well, he had sustained a tremendous head injury and had a bleed on the brain, which was probably the priority, but because of the diagnosis of dementia I felt that he was judged as a demented patient rather than his head injury.*

***Mobility***: Carer 1 described her husband's increased level dependency following a head injury, relying on daily carers upon discharge. Carer 3 described a level of misunderstanding around her mother's mobility and staff, while she might agree to walk to the toilet, she was not safe to do it on her own.

**Carer 1**: *"Before he went into hospital, he was mowing the lawn, cooking for himself, now he needs carers four times a day."*

**Carer 3**: *"If somebody came up to my mum and said, can you make your own way to the toilet? She'd say yes, but she can't."*

***Nutrition and Hydration*:** Nutrition and hydration are important for patient recovery. Carer 3 described how her mum was placed on a fluid monitoring chart, but no one paid attention to what she was drinking or when she was going to the toilet. She was concerned that her mum will forget what she drinks and is unable to communicate her needs.

> **Carer 3**: *"She was on a fluid monitoring chart, but nobody ever took any notice of what she was drinking or what she was outputting."*

***Safety***: Patients admitted to hospital do tend to be quite ill, and a person's condition can fluctuate depending on their condition on admission. Carer 1 described being called late at night by staff due to her husband's rapid deterioration after a fall and DNR discussion.

> **Carer 1**: *"So, it was quite late when he got assessed in A&E. My sons left him and he seemed to be OK-ish. And then they rung me at 2:00 in the morning to ask me to agree to a DNR because they didn't think he was going to make the night and that the surgical team had discharged him because they felt that he was in such a bad state that he wasn't, he wasn't able to have any surgery."*

Carer 2 felt she could not leave her husband alone at any time, even in the hospital because of his dementia. She felt his safety depended entirely on her presence.

> **Carer 2**: *"Oh yes, I can't leave him indoors at all. I have to take him*

Carer 3 felt there were potential safety issues due to the nature of her mum's dementia which included walking her to the toilet and leaving the buzzer when she could not use it.

> **Carer 3**: *"There's no point in putting a buzzer in someone's hand who's got dementia, they don't know what it's for."*

## 4. Communication

***Staff – patient communication:*** Staff-patient communication is vital for building trust in care – patient and carers reported gaps in communication often leaving them confused. For example, lack of explanation about medical changes, unclear information about treatments and the limited introductions by staff causing disorientation. Other times it was just difficult to speak to the right nurse who was providing the care.

**Carer 1**: *"No rationale for why they changed all his meds. No communication as to why."*

**Carer 2**: *"I used to ask them what the tablets were for, I don't understand the tablets."*

**Carer 3**: *"If somebody could come up to mum and say hello to XXXX, my name is, she would then have a picture of what was happening, but they weren't doing that."*

**Carer 1**: *"Communication on the ward is a nightmare because there was never the nurse that was the right one, because every time you asked a nurse a question, it would be on, it's not my patient. Sorry, you'll have to speak to somebody who… couldn't be found. And when you rung, to get through eventually to the ward, it would ring and the answer machine will come on and say everyone on the ward is busy at the moment. Sorry we can't take your call, goodbye."*

## 5. Staff issues and wellbeing:

Carers recognised that staff were genuinely caring but limited by shortages and systemic pressures, which affected the consistency of care. This helps to illustrate that culture is often shaped by the wider environment.

**Carer 1**: *"Ward A, communication was a nightmare. Ward B seemed to be much more on the ball."*

**Carer 2**: *"Some of the nurses were nice, but someone who was in charge of me, she was a bit strict… I thought, well, she's doing it for my benefit, you know."*

***Dementia Awareness & Environment:*** Carers reported they felt that the initial hospital admission e.g. fall or head injury was overshadowed by the dementia diagnosis, leaving them feeling they care was not always well targeted. Other times carers reported the lack of dementia awareness around communication and assessment of needs.

**Carer 1**: *"You would have to be quite clued up to look at him and say, oh, he's got Parkinson's. It wouldn't be obvious, nor would the dementia have been obvious."*

**Carer 3**: *"There was no understanding from the staff about short-term memory and how it would impact her."*

***Discharge***: Carers described discharge planning and resulting readmissions within 24 hours because the person with dementia was just not ready.

**Carer 1**: *"Within 24 hours I put him back in as a failed discharge because he was in such an appalling state, he was still infected."*

**Carer 3**: *"She was discharged on the 25th of July from the ward, and she ended up going back in again on the 27th and was discharged on the 28th."*

## Summary of Mapped Findings

The mapping exercise brought together analysis from ESNEFT admissions data, a detailed conventional process mapping of 18 inpatients and carer stories of recent experiences.

**Admissions data.** This provided a starting point for exploring high level trends in patients aged 75 and over, such as the most common primary presentations, and prevalence of dementia, which, at 18.8% was slightly lower than expected, compared to an estimate of 25% occupation of acute NHS beds (Royal College of Psychiatrists, 2019). Patients with dementia were shown to have longer lengths of stay than patients with no dementia, in line with current findings (Alzheimer's Society, 2025b).

**Process mapping exercise**. This allowed us to look at the detail of a selection of patients from the admissions data with and without dementia who had one of the most common conditions. It revealed additional data such as care complexities of the patients, bed moves, discharge and safeguarding issues. In addition, drawing from the ESNEFT dementia care policy (ESNEFT, 2022; ESNEFT, 2025), adherence to local guidelines could be explored. Key points arising from process mapping included a substantial number of patients with no documentation for ‘This is Me’ in their records, highlighting challenges in implementing person-centred care tools, which need to be available and embedded in care practices to be effective. The importance of personal histories and preferences and their pivotal role in providing responsive, person-centred care have been highlighted by the Care Quality Commission (2024).

Alerts for dementia were absent for 50% of the dementia cases, as identified through admissions records, suggesting dementia can often be missed or under-recognised during admissions as found in existing literature (Penfold et al., 2026). Interestingly, of the six patients selected with no dementia codes in admissions records, three had either dementia suggested as a diagnosis in their files, or in one case there was a system alert present for dementia. This could explain the lower than expected prevalence of dementia in admissions records, and again reflect the complexities in obtaining accurate identification of patients with dementia.

Ward move patterns were similar for those with and without dementia, with the majority of patients being moved between 2000 and 0600 at least once, in contrast to best practice. Research suggests, however, that patients with dementia can be more detrimentally affected by such moves, especially overnight, which can increase risk of falls and patient distress (Arun & Lewis, 2026), which could in turn increase length of stay should additional complications arise. Therefore, additional measures to reduce night-time ward moves would especially benefit patients with dementia.

**Carer stories** Finally, feedback from carers and family of persons living with dementia who had been recent inpatients provided further insight into care from the patient and family carers’ perspective. This was used to reflect on information from the other sources and applied to the DemFoCAS project themes. The interviews showed some communication challenges, a concern about lack of dementia knowledge, and discharge issues such as readmission within 24 hours and delays due to awaiting care packages.

# Section 7 – Staff Perspectives

## Introduction

The Donabedian evaluation was able to include general information from the annual staff survey such as sickness absence and wellbeing. However, the DemFoCAS team felt it was important to include the views of staff who are regularly involved in the patient experience when inpatients at ESNEFT. To this end, as part of this service evaluation project, staff views were collated through interviewing a range of staff from the two ESNEFT settings.

## Aims and objectives

The aim of this part of the DemFoCAS project was to understand the current care provision for patients with dementia at ESNEFT acute settings from the perspective of a broad range of staff. Objectives are:

- To understand the challenges experienced by staff relating to providing quality individualised care to patients with dementia
- To explore staff views of elements of care and collect ideas for optimising care
- To understand how the COVID-19 pandemic continues to influence the care provision and the environment
- To understand a range of views from different staff groups and levels

# Method

## Participants

Participants were staff and volunteers involved in the care of patients with dementia in acute settings at ESNEFT. In line with expectations, the final number of staff and volunteers interviewed was 21, ten from Colchester and eleven from Ipswich hospital. Roles were from a broad range, including a senior matron, health care assistants, dementia specialist nurses, porters and ward hosts.

*Table 9 Staff roles interviewed*

| Role |
|---|
| Physiotherapist |
| Dementia specialist nurse lead |
| Senior Matron/Deputy ADON |
| HCA, Dementia |
| Alzheimer's Society Dementia support worker |
| Consultant (geriatrician) |
| Advanced nurse practitioner, DIST |
| Transfer of Care Hub nurse |
| Porter |
| Ward clerk |
| Falls practitioner |
| Assistant associate practitioner |
| Porter |
| Cleaner |
| Discharge team lead |
| Ward host |

## Recruitment

Recruitment was carried out with assistance from Dementia specialist nurses at Ipswich and Colchester hospitals and Marie Alexander, ESNEFT Associate Chief Nurse (Education and Research). The study was introduced to the dementia and delirium steering group by the senior research officer on the DemFoCAS project and interested parties were sent participant information sheet and consent form via email. In addition, the Senior research officer visited both Ipswich and Colchester hospitals to recruit and interview several staff on site.

## Interviews

Interviews were conducted online using Microsoft TEAMS or equivalent or on site at Colchester and Ipswich hospitals. Interviews lasted between 15 and 90 minutes, with most around 50 minutes. Shorter interviews were with staff such as porters and cleaners who had less complex involvement with patients and longer interviews tended to be with those who had complex and in-depth involvement with patients.

The interviews were semi-structured, covering a range of topics including and questions were developed through consultation with the project steering group. The carers were asked what they thought was important to ask the staff. Questions asked are shown in appendix C.

## Ethics

University ethical approval was received through application reference: ETH2324-1890.

## Analysis

For the purposes of this report, interview transcripts were collated thematically, using the questions from the steering group as themes. Transcripts were analysed using NVIVO. Relevant quotes were extracted for each theme.

# Findings

The findings are organised into 9 themes relating to the questions asked and will each be discussed and supported with narrative data.

| **Themes** |
|---|
| Theme 1: Ideas for improving the patient experience |
| Theme 2: Feeling valued within the organisation |
| Theme 3: Working with patients with dementia |
| Theme 4: COVID |
| Theme 5: Challenges |
| Theme 6: Security |
| Theme 7: Carer wellbeing |
| Theme 8: Carer involvement |
| Theme 9: Staff issues and wellbeing |
| Theme 10: Dementia awareness and training |

## Theme 1: Ideas for Improving the Patient Experience

All interviewed staff were asked what they thought would improve the care and experiences of patients with dementia. In addition, due to the interviews being semi-structured, suggestions were made in answer to other questions.

### Cognitive Stimulation

A significant theme was for patients to be more occupied, which was expressed in several ways. Some staff felt there could be more activities on the wards to help keep patients cognitively stimulated. In some cases, staff reported that previous activities were no longer happening, for example therapy dogs, and organised activities such as exercise and music. Magic

Tables and activity trolleys were mentioned several times. However, the need for additional people on the wards to run the activities was a prominent issue, and several people mentioned that having **volunteers and activity co-ordinators** in the past had been a useful resource. Some staff made a link between lack of stimulation and responsive behaviours, such as distress (SI14) and 'aimless wandering' (SI7), indicating that patients being more occupied was valuable to patients and staff.

> *"I think boredom, boredom and fear are two massively underrated reasons why our patients become distressed." S14*

> *"Then actually we need to adapt… with activities like that going on, otherwise we do end up with a lot of aimless wanderers" S7*

## Social Stimulation

In addition to cognitive stimulation, several interviewees noted that social stimulation could be beneficial. It was noted a few times that social dining no longer occurred on the wards and had previously showed to be a valuable way of encouraging socialising between patients.

> *"I can't understand why, certainly for the lunchtime meals, those that are able can't sit around a table and have their meal." S5*

Having more one to one social interaction was another common idea. This was at times seen as relating to staff not having enough time to spend with patients. Speaking about activity trolleys, one member of staff said

> *"They didn't even know it was in there. And I think and I know, again, it's time. That they haven't got the time." S4*

## Additional Staff and Volunteers

Additional dementia-focused volunteers or non-clinical staff such as activity co-ordinators on the wards were seen as solutions to patients being more occupied because staff already had high workloads. Ideas for what they could do included helping patients to make use of magic tables, playing games, using activity trolleys and providing patients with company for improve wellbeing.

> *"Maybe volunteers, (not to) get involved in medical care, you know, and so actually, something like that, or a group of staff that you know, help us to deliver a better experience." S1*

### Training

Some staff suggested more staff training in dementia awareness would improve care of patients with dementia. Staff were also asked about their training and confidence in dementia knowledge and this is covered in more detail under theme 10, Dementia awareness and training.

### More Specialised Staff

Linked to training was the suggestion that a bigger team who specialised in dementia would be beneficial.

> *“I think we just have more expertise of specialist nurses…Throughout the hospital.“ S9*

### ‘This is Me’

‘This is me’ was mentioned several times as a valuable tool for enabling individualised care, which could, for example, be useful to de-escalate responsive behaviours. Volunteers helping to get ‘This is Me’s filled out and the promotion of using ‘This is Me’ was acknowledged a positive move, however, there were various issues reported of the use of the document not being well enough embedded into care. Concerns included not being fully filled out and not being read by staff:

> “*The patient’s really agitated. And ‘oh, have you read the This is me?’ and they say ‘no’, you know.” S4*

Having additional help to ensure the documents were fully filled out was seen as valuable:

> *“She has the time to sit with the patient of really going to depth about what they like, what they don't like, what triggers them, you know, so we learn what triggers that particular patient or, you know, what we can do to help make that patient's experience better.” S16*

### Improved Environment

There was a sense from some staff that the hospital environment could be improved to assist with enhancing patient experience. Examples included dimming the lights to encourage rest, providing sensory and calm areas, and reducing noise on the wards. One interviewee felt is was about trying to approach available resources differently, saying

> *"I don't think this is about money. If you look at the spaces, it's just about reconfiguring what is there. And that just comes down to people being able to give their time to organise it. It's not. I don't think it requires money as such. I just think it requires re rethinking a little bit." S5*

### Other Suggestions

There were some new approaches to addressing included nicotine patches, scrubs that

Amongst other suggestions were to provide better family support and fewer bed moves for patients with dementia, especially during the night.

## Theme 2: Feeling valued within the organisation

Staff were asked how valued they felt in their job. Responses reflected different aspects of 'feeling valued'.

### By Colleagues

On the whole, staff expressed feeling valued by their team. One nurse explained that through challenging times, this became especially important, saying:

*"I think that's what's kept me here so long, is the sense of feeling valued, and appreciated. It's a lovely ward. Yeah. Yeah. I do feel valued. A lot of us do feel valued. We just get frustrated." S16*

However, some staff in roles who were not always on the wards were not as sure their roles were valued, or perhaps understood:

> *"I suppose they get frustrated that we're not able to support every patient as well. So, they probably think well, what are you doing? Because they might not see me from one week to the next because I've been on different wards, so I've been needed elsewhere" S4*

### By Patients and Families

Staff in all roles said they felt valued by the patients and families, although there were exceptions:

> *"Patients and relatives. Very, very good. I feel very valued. Not always. Most of the time it's very rare that I don't feel values by families and relatives, families and patients." S2*

Although sometimes challenging, staff tended to be appreciative that the families were under significant pressure in what was often an emotional situation from them. One said,

> *"You only get the odd relative who is unhappy with the service, unhappy with the care. I try not to take that personally, you know, it's their mum, they're full of feelings, you know they're going to feel a certain way." S16*

However, there were several comments about difficult situations with families. One said they did not feel appreciated, saying

> *"Sometimes it always feels like it's never enough, from their point of view, you know. You just feel sometimes, you know, you can only do so much and sometimes you feel like it's never good enough" S15*

### By Management

Some staff felt dementia was not prioritised enough.

> *"I think dementia should be higher on the agenda for the hospital than it is." S2*

One staff member expressed concern that pressures to support the Emergency Department meant that patients with dementia had less quality care, saying

*"ED is very much prioritised...It does sometimes feel like well actually if you've got to send nurses from every ward to support ED because they've got additional patients there above and beyond and you have to send nurses from an older adult ward to support those corridor care, actually that takes away from our patients." S3*

Others did feel the organisation generally valued the roles that staff undertook. One said,

> *"The trust, they value what we do…They do, yeah." S8*

In terms of management style, some staff commented they were valued.

> *"Like my management, yeah, I am. I feel like I am. They are always checking on me and always say thank you, but I'm not micromanaged." S11*

However, the same person felt there was a conflict when senior management did not have a health background, saying

> *“They're great at what they do, but a lot of management aren't health, they don't have a health background…I think people in the hospital will find that barrier between health and management because you're either one or the other, aren't you?” S11*

There was some acknowledgement of the pressures the Trust was under and how that made things challenging for the organisation. For example, it was accepted that staff were valued ‘as a whole’ SC1 but due to the large size of the Trust, feeling individually valued was “too much of an ask” S1

Money constraints were recognised, with one staff member saying they understood there was insufficient funds to ‘fund another four of me’ S14 and another acknowledged staff issues meant that when additional support was required, saying

> *“I think you have to be fair to the higher up at certain points, like they're not going to magic staff out of thin air.” S17*

### General Comments

Some staff responded generally about how valued they felt. Some felt that it very much depended on the day, what was happening and who was working. One staff member who has since left the organisation, simply stated

> *“Yeah, I would say not a lot, I don't feel very valued, no.” S4*

## Theme 3: Working with patients with dementia

Staff were asked how they felt about working with patients with dementia. The responses were largely positive, with most staff saying they enjoyed this aspect of their jobs, found it rewarding, although sometimes challenging. These data to support this are displayed in the word cloud in Figure 23. The main negative reflection was that it was sometimes frustrating to not be able to spend more time with the patients or be able to help them more.

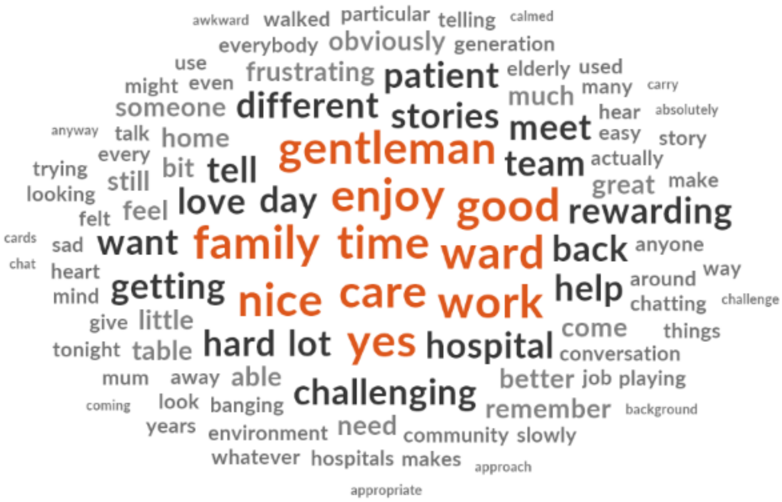


*Figure 23 Word cloud showing narrative data on how staff enjoyed their work*

## Theme 4: Lasting effects of COVID

Staff were asked how much they feel COVID is still an influential factor in hospital care at ESNEFT. Many staff believed the hospital and processes were back to normal, however there were some influences.

### Infection Control Awareness

Some of the staff reported that staff were generally more cautious of infection control issues, which could result in staff being more likely to take time off sick/work from home to protect colleagues and patients, and some staff still wearing masks and being cautious of infection the wards.

Another element of this was changes on the wards which had not been reinstated, and a more risk averse approach to activities, such as social dining.

### More Complex Health Issues in Patients

It was reported that during COVID, reduced access to healthcare, increased isolation and decreased activity has contributed to patients being sicker when admitted in the hospital, alongside continuing backlogs in healthcare services.

### More Reliance on Technology

Some interviewees pointed out that there was an increased use of technology for meetings, and for training, which could make training less effective.

### Staff Culture Changes

Several staff mentioned differences in staff, including higher turnover, lower morale, and differences in motivation for working in healthcare.

### Volunteers

Finally, one person mentioned that volunteers had depleted significantly due to COVID but that numbers had since increased.

## Theme 5: Competing Challenges

Each interviewee was asked about challenges they have experienced. These mainly fell under the following headings. Some challenges have separate sections. From the data you can see a range of complex challenges some of which overlap but characterise the complexities of the organisation which staff and volunteers experience.

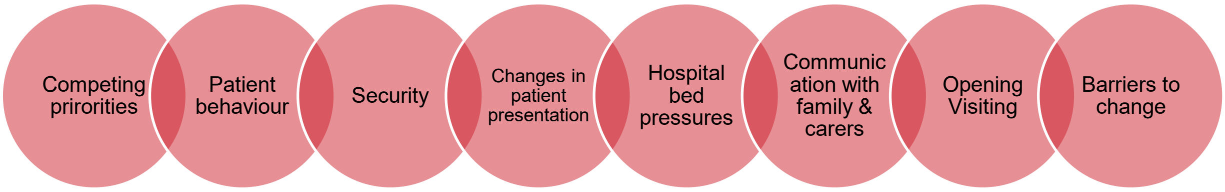


*Figure 24 Competing challenges*

### Competing Priorities

Some staff mentioned that not having sufficient time to do as much as they wanted, with completing priorities often a problem. These ranged from having insufficient time to read emails and do training, having less time with patients than was ideal, and difficulties with prioritising the most complex patients, so that those with fewer needs received less individualised care.

> *"Sometimes I can't spend as much time and that's quite difficult sometimes because I want to be able to spend the time, but obviously I've got competing priorities as to what's needed of the service. No one day is the same. It could be anything." S2*

### Patient Behaviour

A few staff mentioned that managing responsive behaviours and BPSD in patients was often challenging. Generally, there was an acceptance that this was part of caring for patients with dementia, but some felt there were improvements were possible. There was a sense that responsive behaviours were more prevalent than previously. Some staff reported an increase in abusive behaviour which was a was more frequent in patients with dementia.

> *"Challenges? Well, you know, you get pulled about, you get sworn at, you'll get cussed at, you know, all sort of things. You just don't take it to heart. It's just part and parcel... . You can be hit, you can be, you know. Yeah, they've happened and unfortunately, we just take it in our stride, don't we, because we kind of accept that that's just the way it is. And we just do what we can… You've got staff to help you if you need anything, you know, generally they're pretty good" S15*

## Security

The use of security personnel for patients exhibiting behaviour that puts themselves, other patients or staff at risk was a significant challenge and is covered in more detail in a separate section.

## Changes in Patient Presentation

For some of the staff, patients were seen to have more complex needs than in the past, presenting sicker and needing longer stays. Elements of this were seen as COVID related, with one interviewee finding that frailty, deconditioning and lack of vitamin D were more common, especially in older patients. Additionally, dementia was seen to be generally more prevalent in patients.

> *"I think the other thing is the volume of people who are living with dementia has massively increased. So, you know, maybe when I first started, you had a dementia ward, whereas now, if I'm honest with you, I would say probably if we've got 500 and what we've got 560 beds, I could well imagine that, you know, 3/4 of those have probably got someone with a dementia or delirium diagnosis." S14*

## Hospital Bed Pressures

Bed pressures were mentioned by several staff, acknowledging that boarding was on the increase, and detrimental to patients, staff and families.

> *"And the frustration of the patients and the relatives, you know that their relatives been boarded in the corridor in A&E for 15 hours. Then they moved to a ward, and they're boarded on that ward as well." S4*

## Communication with Families/Carers

Issues raised in relation to communication with families and carers included difficulty for families to understand diagnosis of dementia was not possible, for most, during their acute stay and negotiation of family tensions. One interviewee felt staff were scared to enforce rules such as number of visitors, for concern they may receive abuse. There was also a view that open visiting hours created issues with visitors being present and wanting information during the time patients were being washed and eating breakfast.

### Open Visiting

During the time that interviews were being conducted, visiting rules were changed to open visiting between 8am and 8pm. This presented challenges such as privacy issues, increased traffic during early morning routines and noisier wards that reduced the ability to create a calming environment for the patients, especially later in the day when sundowning is common.

> *"I get it in the acute medicine ward. I totally get that, that's fine. But predominantly, I think for care of the elderly wards I think they should have separate visiting times like they did years ago. I just don't think it's right, having. Because it upsets them, doesn't it? It upsets the patients. Then they said the noise levels, they're not eating their dinner because there's so much going on" S11*

### Barriers to Change

Barriers to making improvements included lack of funding, high workload, and a need to think differently

> *"I don't think this is about money. If you look at the spaces, it's just about reconfiguring what is there. And that just comes down to people being able to give their time to organise it. It's not. I don't think it requires money as such. I just think it requires rethinking a little bit." S5*

### Other Challenges

Other challenges included discharge delays, being short staffed, staff being moved to areas at risk of running at clinically unsafe staffing levels and needing more dementia specialist support.

## Theme 6: Security

Placing security personnel in patient bays because a patient has exhibited responsive behaviours such as aggression and violence and who may be a danger to themselves, other patients or staff was brought up as a challenge by some staff. Reported patient behaviour included biting, hitting, scratching, crying and shouting, with some staff stating that such behaviour was becoming increasingly common.

Unfortunately, it was not possible to interview any of the security team for the DemFoCAS project, so the topic is only discussed from the perspective of other staff.

## A Last Resort

It was acknowledged that security was used as a last resort and was something the organisation was actively trying to move away from. .

> .*"So, when we have someone with dementia and we really can't safely manage behaviours, we sometimes have to have one to one security and there's a number of reasons for that. And there's a lot of projects and a lot of work we've been doing to try and stop it and reduce it down a step away from that." S3*

There were concerns that even though security staff were used as a last resort, it was not always in the best interest of patient wellbeing and could sometimes have a detrimental effect. This was attributed to security uniforms and lack of interaction with the patients, seen as largely being due to lack of awareness or skills to de-escalate.

> *"Like I said about the security side of things. They'll sit outside the patient's room talking. And it's a bit like the police. You put yourself in that situation. The police are watching me and they're talking about me and they're writing things down. Yeah, that's enough to make anybody paranoid." S6*

## Operational Issues

Operational issues were thought in some cases to be responsible for behaviours escalating, or not being able to be de-escalated, so that security was required.

> *"Because their (patients') care needs aren't met soon enough. Yeah, I mean, someone needs the toilet, but six other people also need the toilet. There's two HCAs. So someone is going to have to wait. Then they'd become distressed because of that. Or maybe someone just needs that extra 1 to 1. They need that extra time, and the HCA wants to give that. But she's also got five other people to see. I think the environment being noisy, being busy, you know, sets people up to become more distressed…Yeah, it's tricky. And then once things escalate, it's very difficult to then de-escalate without involving, in my*

> *opinion, what I see, without involving security, which I don't think, very rarely actually adds." S9*

Additionally, due to changing personnel because of new shifts or staff being moved to cover shortages on other wards, continuity of care for patients being given security was sometimes challenging.

> *"But that's very hard, again because we have different people come in for different shifts. So you can't say, well I've got Mr so and so here I'm going to make sure he's got some training and he knows what to do with this patient because the next shift it could be somebody different and you might not see that person again." S3*

## Retraining

Solutions to issues around using security included a popular suggestion that security staff could do more to mitigate the detrimental effects of having security in place. It was acknowledged this would require a different approach from security personnel and additional training to promote de-escalation skills. Some staff told how they had encouraged security to interact more with patients.

> *"I try to include them and talk to people just to, you know…share some guidance around how they can support people while they're there doing their job. I think that's quite important. When I talked about the magic table, we had, this lady had security in a side room and we included the security chap in what we were doing, why we were doing it, how he could support her, why he's there. So, there's no reason why these people couldn't use the magic tables. We had a bit of a tech issue. He knew a little bit more, so that was quite helpful at the time. So, this is all about educating people, isn't it? On how they can approach these situations really, I think." S5*

## Understanding Behaviours

It was universally regarded that de-escalation was always preferable to providing security and that this was often related to understanding the origin of the responsive behaviour. Solutions included having additional staff, or volunteers or active co-ordinators who could de-escalate rather than needing to use security.

> *"But often the trigger is, there isn't perhaps just not the number of staff to de-escalate the situation. And so actually someone you know, like*

> *the Alzheimer's volunteer being another person to talk to an individual or sit with them with a cup of tea is the difference that you need" S7*

## Theme 7: Carer Wellbeing

There are two themes relating to carers. This theme, carer wellbeing, reflects the significant role for staff of supporting carers and families of patients with dementia.

### Crisis Point

Families are often at crisis point when a person living with dementia is hospitalized, and many have not been able to access community support. Social complexities become apparent, with staff identifying social and family issues such as self-neglect and safeguarding issues such as financial and other types of abuse.

> *"If a family member feel that the mum and dad have been struggling and not been able to care properly. They've got care needs. But they will say they haven't. Financial abuse, that can come up quite a lot. I think self-neglect is probably. And it's obviously just someone who is forgetting to, you know, go have a shower or to clean themselves or something like that. And not intentionally, I don't think it is, most of the time, but just someone who wants to stay in their own home but have hasn't got the capacity to be able to do that. So yeah, it's but financial abuse, unfortunately, and also I've been in a few cases of domestic abuse as well." S4*

### Carer Burnout

ESNEFT staff look for signs there may be issues at home from early on in their admission, where discharge planning commences. Sometimes family carers have reached a point where they are no longer coping and this can become clear during a patient's stay and even lead to carers leaving the patient in hospital.

> *"Perhaps a carer for an individual was already struggling. Whether that's often it's because of behaviour and psychological symptoms of dementia, and is this a point where we need to offer support at home, or have we already reached a threshold where the caregiver is burnt out, asking for help or reached a crisis point, and that's why they've come into hospital. So it's at those board rounds that we often coordinate and identify early on those that we perhaps might need to*

> *have more discussions or time with because the way out of hospital is not so clear.“ S7*

### A “Listening Ear”

Being a listening ear for carers is often key, with staff in various patient-facing roles finding themselves being the first person the carer has spoken to about their issues. Those in dementia specialist roles sometimes become involved in educating family carers who are not well educated in the complexities of dementia, and arranging for ongoing community support.

> *“A lot of the families that I support they are at crisis point. They're not sure what's going on with their loved one. But also you have all of these thoughts and feelings behind them as to what they're experiencing at home, to try and support their loved one. And there's just not enough resources to go round.“ S2*

## Theme 8: Carers - Involvement in Care

This second theme relating to carers shows the ways in which family carers feature in the care of patients with dementia, painting a complex picture.

### Family Carers are Helpful

Many staff were keen and supportive of carers helping with patient care, which could reduce staff workload. Ways in which family carers help with care included assistance with feeding patients who needed help with eating, settling patients who may be agitated, help with choosing meals. This was seen as a positive influence on the patient care for both patients and staff.

> *“Family carers, when they come in and they help feed the patient, I promote that. I promote that. If they can help them sit down and help with their dinner and tea, help with toileting or just to calm down, particularly with our patients who are really confused that are dementia patients. “S16*

### Reduced Staff Input

One person suggested that family carer presence reduced staff involvement which could be both positive and negative.

> *“I think it's always helpful to have carers there and I think sometimes when the carer is there, staff don't go up to the patient, they almost leave them more because the carers are there looking after them. So, they get less attention from the staff because they think Oh, well, their daughter's there and then they avoid going over there…In some ways it's helping, because they can go to see other patients instead. But also, it's not necessarily always helpful, because they're not, you know, they avoid talking to the relatives” S1*

## Care and Discharge Planning

Some staff talked of the importance of involving families to help understand the patient’s likes and dislikes, and to assist in finding the most beneficial onward care.

## Differences between Family Carers and Visitors

Some made a distinction between family carers and those willing to help out, and visitors who did not take part in any care, but did contribute to a noisy busy ward, which was not always seen as being dementia friendly. For those in Ipswich, there were concerns that open visiting presented such issues

> *“And we always used to say, if you’re going to be here at lunchtime you can help out with feeding; because that seems to be a problem as well. Not enough people to help with feeding the patients, if you’ve got quite a few, you know, you can’t do them all. But what you’ll find is, and I’ve done it myself, I’ve asked a relative before ‘oh if you’re staying over lunch, can you help feed?’ and I’ll get ‘No. I don’t know how to feed.” S15*

## Other

There were some concerns with family carer involvement, for example one person thought that sometimes carers needed to give staff space to provide care, and another pointed out that where there are issues within the family, this can have a negative effect on the patient.

## Theme 9: Staff issues and wellbeing

Staff were not asked directly about their mental health, although all were invited to describe what it was like to carry out their job.

### Depends on the Day

Several staff said that pressures of the job were dependant on the day and the role they were in. This can be down to fewer staff on the wards or care needs of patients. Staff on the wards were viewed as under more pressure than those in roles which had a varied portfolio on and off the ward.

### Work Pressures

In busy times, pressure increases and stress in staff rises. Patients were viewed as being increasingly complex with more distressed behaviours. Lack of staff was an issue raised several times.

One member of staff reported morale being very low especially on the wards.

Some people mentioned their coping strategies, trying think positively

> *“There's more working well than there isn't. If I focus too much on the stuff that isn't working well, I think it would be really demoralising, and we wouldn't keep a continuum behind it. And we need to keep positive and keep morale high on that. So, I try and really focus on what is within our group, what we can do rather than what we can't do” S9*

### Competing Priorities

Having competing priorities was raised as a difficulty many staff faced, making adherence to putting patients first a challenge at times.

Several staff mentioned the emotional load of their roles, talking of feeling sad about some patients’ situations, and others mentioned having a cry as a regular occurrence. However, there was also a significant amount of ***job satisfaction*** mentioned, despite the pressures.

> *“But obviously it's around selecting and making sure those patients are suitable to be looked after in a corridor. And sometimes the selection of patients means that isn't Possible. We have to pick somebody who's not ideal, but the most ideal person, which can be very, very hard. So obviously our job can be quite emotional. It's dealing with staff, with patients, with relatives. So, it's very, very challenging, but it's something that I greatly enjoy” S3*

## Theme 10: Dementia awareness and training

Staff were asked about training in dementia they had received, and how confident they felt about their dementia knowledge.

### Confidence and knowledge

Most healthcare staff said they felt they had largely received enough training and would be confident asking supportive colleagues for assistance if they were unsure. A common resource for additional specialist advice was the dementia specialist nurse leads. Several members of staff mentioned that they had additional knowledge of dementia through personal experience of family members.

> *"I am, yeah. And if I'm not sure about something, I'll come back and speak to [dementia nurse specialist]. And there's X here as well, who used to be a dementia nurse. And I'll ask them, but yeah, I do feel quite confident." S4*

### Amount of training

Training that staff had received varied, depending on their length of experience and role. The 2-day inhouse training was mentioned several times as valuable, but it was noted that this had stopped due to COVID, and again due to EPIC training. The availability of rooms for face-to-face training was cited as problematic.

> *"So your best time to do training is probably between sort of like March and November usually, but it's just been all squashed. So until that's up and running we've been basically, unless it's the odd like ad hoc on the wards, because we've just, you've got no rooms…But again, it's getting hold of staff that, like I said, they're taking staff off the wards for three days to do this Epic training. So it's just impossible at the moment, yeah" S11*

### Challenges in training

Training was valued highly by most staff. However, limitations included the time it took to attend courses, and the difficulties of putting new expertise into practise due to high workload. Online training was viewed by some as inferior to face-to-face training, although one member of staff did suggest that short, bite sized online training may be more practical for those for whom time away from the wards was challenging.

> *"So we've got the e-learning packages. So I've done the online e-learning and [dementia specialist nurse] runs her two day dementia study days… (finding time for training) isn't always possible for our HCAS and our nurses. And I know there's a lot of them who desperately want to do more training, but it's difficult*

> *for them to be released or they get told. Yes, you can go on it, but then it gets cancelled or there's a major staffing shortage" S14*

### Additional training required

Some staff had received minimal or no training, and this was the case especially for auxiliary staff. Several people suggested that additional training for people in roles such as ward clerks, ward hosts, cleaners, porters, security staff and consultants, would benefit from additional training in dementia awareness. For example, one said

> *"I think there is more training and support our staff could be given to give them more tools to be able, especially to manage conflict situations. And that isn't just our HCAS or nurses. I think also our consultants you know" S14*

A lack of training for new staff was also raised as a potential issue.

> *" I think if you've been here a while, it's sort of cemented into you, but when it comes to new staff, I don't know if there's enough. I don't know what their training is, the new healthcare assistants, what they have on dementia. There's always room to know more." S16*

# Discussion

### Overview of Staff Findings

The staff interviews illustrate the complexity of delivering dementia care within an acute hospital environment characterised by competing priorities, workforce pressures and increasing patient acuity. While staff expressed strong commitment to people living with dementia and derived considerable satisfaction from this work, the findings highlight structural and organisational constraints that limit the consistent delivery of individualised, dementia-friendly care. Across the 9 themes, tensions emerged between relational care and task-driven systems, reliance on carers and volunteers, and the emotional labour experienced by staff working in under-resourced settings.

### Theme 1: Ideas for Improving the Patient Experience

Staff articulated a wide range of practical, low-cost ideas to improve the experiences of patients living with dementia, with a strong emphasis on cognitive, social and environmental stimulation. Suggestions such as structured activities, use of sensory resources (e.g. Magic Tables) and social dining were seen as ways to reduce distress, boredom and responsive behaviours. These accounts align with evidence that meaningful activity and social engagement are central to maintaining wellbeing and reducing behavioural and psychological symptoms of dementia in hospital settings

(Kolcaba et al., 2006; Moyle et al., 2017). However, staff consistently highlighted that such interventions were constrained by time pressures and workforce limitations, reinforcing evidence that person-centred dementia care is highly dependent on staffing capacity and role flexibility (Alzheimer's Society, 2016). As such, access to volunteers or activity coordinators were seen as crucial to facilitating improvements. These data foreground the importance of organisational support for innovation in care delivery and lead into considerations of how valued and supported staff feel within the organisation.

### Theme 2: Feeling Valued within the Organisation

Perceptions of feeling valued varied across roles and contexts, with staff commonly reporting strong peer support and appreciation from patients and families, while organisational recognition was more inconsistent. Feeling valued by immediate colleagues emerged as a protective factor during periods of high pressure, echoing evidence that team cohesion and relational support are critical for staff retention and resilience (West, 2021). In contrast, some participants perceived dementia care to be insufficiently prioritised at organisational level, particularly during periods of system strain such as emergency department escalation. This tension reflects wider literature describing a disconnect between strategic priorities and frontline experiences in dementia care (Francis, 2013; NHS England, 2019). These perceptions of value and recognition provide important context for understanding staff motivation and shape how staff experience their work with people living with dementia, explored further in Theme 3.

### Theme 3: Working with Patients with Dementia

Most staff described working with people living with dementia as rewarding and meaningful, despite the inherent challenges. Positive descriptors such as “fulfilling” and “enjoyable” dominated narratives, indicating strong intrinsic motivation and alignment with caring values. Frustration arose primarily from systemic constraints, particularly limited time to provide relational, person-centred care. These findings align with evidence that staff attitudes towards dementia are often positive, but that task-driven acute care environments can inhibit the delivery of care that aligns with professional values (Clissett et al., 2013a; Turner et al., 2017). This mismatch between values and practice is known to contribute to moral distress and emotional strain, providing a bridge to staff reflections on the lasting effects of COVID-19 on care delivery and workforce culture.

### Theme 4: Lasting Effects of COVID

Staff accounts suggested that while operational processes had largely returned to pre-pandemic norms, COVID-19 continued to exert indirect effects on dementia care.

These included more risk-averse practices, reduced group activities, ongoing infection control vigilance and greater reliance on digital platforms for training and meetings. Staff also perceived patients as presenting with greater complexity, frailty and unmet needs, reflecting evidence of pandemic-related deconditioning and delayed access to care (Hanratty et al., 2020). Changes in workforce morale, turnover and volunteer availability were also noted, consistent with national reports on post-pandemic workforce strain (NHS England, 2021a). These enduring pressures contribute to a context of competing demands and resource constraints, which are explored further in Theme 5.

### Theme 5: Competing Challenges

Staff described navigating multiple, often competing challenges, including time pressures, staffing shortages, increasing patient acuity and bed pressures. Participants highlighted the difficulty of balancing organisational priorities with the needs of patients living with dementia, particularly when resources were stretched. Responsive behaviours were widely accepted as part of dementia care, yet staff acknowledged that limited time and staffing reduced opportunities for proactive de-escalation. These findings reflect broader evidence that systemic pressures in acute care disproportionately affect people with dementia, increasing risks of distress, adverse outcomes and fragmented care (Digby et al., 2017; Sampson et al., 2014). Such pressures also contribute to situations where restrictive or risk-focused responses are adopted, leading directly into the challenges surrounding the use of security personnel discussed in Theme 6.

### Theme 6: Security Use

The use of security personnel to manage distressed or aggressive behaviour was consistently described as a last resort, yet one that some staff felt was becoming more common. Participants expressed concern that the presence of uniformed security could exacerbate fear and distress for people living with dementia, particularly when personnel lacked dementia-specific training. These accounts align with literature cautioning against coercive or containment-based responses and emphasising the importance of understanding the unmet needs underlying responsive behaviours (Dewing & Dijk, 2016; NICE, 2018). Staff identified environmental factors, unmet basic care needs and staffing limitations as key contributors to escalation, reinforcing the need for preventative, relational approaches. These challenges highlight the broader emotional and ethical dimensions of dementia care and segue into the significant role staff play in supporting carer wellbeing.

### Theme 7: Carer Wellbeing

Supporting family carers was identified as a core, yet often under-recognised, component of staff roles. Staff frequently encountered carers at crisis point, with complex social issues such as burnout, safeguarding concerns and unmet community support needs becoming apparent during hospital admission. Acting as a listening ear and source of guidance placed additional emotional demands on staff, reflecting evidence that carers of people with dementia often reach hospital admission under significant strain (Manthorpe & Iliffe, 2020). These findings underscore the interconnectedness of patient, carer and staff wellbeing and align with policy calls for better integration between acute and community dementia support (World Health Organization, 2021). The extent of carer distress also shaped how carers became involved in care during admission, explored in Theme 8.

### Theme 8: Carer Involvement in Care

Staff largely viewed carer involvement as beneficial, particularly in supporting feeding, settling distressed patients and sharing personalised knowledge. Such involvement was seen to enhance patient wellbeing and, at times, reduce staff workload, echoing evidence that carers act as essential partners in dementia care (Røsvik & Rokstad, 2020). However, staff also identified tensions, including inconsistent expectations, reduced staff engagement when carers were present and challenges associated with open visiting policies. Distinctions were made between carers actively contributing to care and visitors whose presence increased noise and disruption, whilst leaving basic care such as feeding patients to careworn staff. These findings highlight the need for clearer guidance on carer involvement that balances partnership, boundaries and ward environment considerations, and they link directly to Theme 9 by illustrating how carer involvement intersects with staff workload, emotional labour and wellbeing.

### Theme 9: Staff issues and wellbeing

Although staff were not directly asked about their mental health, their accounts consistently highlighted the emotional labour and psychological demands of caring for people living with dementia in acute hospital settings. Participants described fluctuating pressures linked to staffing shortages, increasing patient complexity and competing priorities, with ward-based staff reporting particularly high levels of stress. Managing responsive behaviours, supporting families at crisis points and balancing organisational demands contributed to emotional fatigue, with some staff normalising distress as part of everyday work. Despite these challenges, many expressed strong professional commitment and job satisfaction, sustained through peer support, adaptive coping strategies and a focus on positive patient outcomes. These findings align with wider evidence that staff wellbeing is closely linked to workload, staffing levels and organisational culture, and that unaddressed emotional strain risks burnout, reduced morale and compromised care quality(Griffiths et al., 2018; West et al., 2017). The data underscore the importance of organisational approaches that prioritise staff wellbeing as a core component of safe, compassionate dementia care, consistent with national workforce strategies and the World Health Organization's emphasis on protecting and supporting the nursing workforce  (WHO, 2021; NHS England, 2021).

### Theme 10: Dementia awareness and training

Dementia awareness and training were viewed positively by staff, though confidence varied. This aligns with evidence showing that dementia education can improve staff knowledge and confidence, but overall gains are often modest without strong pedagogical design (Parveen et al., 2021). Training effectiveness is further limited by organisational barriers such as time pressures and inconsistent access, which mirror challenges described in the wider literature (Surr et al., 2020). Reviews also highlight that sustained improvements require interactive, person-centred teaching and supportive environments (Gkioka et al., 2020). These findings reinforce staff reports that training is valued but difficult to access and implement in practice.

### Conclusion

Collectively, the staff findings highlight that high-quality dementia care is not limited by willingness or compassion, but by structural, organisational and workforce constraints. Many staff demonstrated insight into what good dementia care requires, aligning closely with national policy and evidence, yet consistently described barriers to implementation. Addressing these gaps requires system-level commitment to dementia as a core priority, investment in relational roles, and recognition of the emotional labour inherent in this work.

# Section 8 - Carer Interviews

## Introduction

The Donabedian analysis highlighted a lack of patient feedback from patients and carers at ESNEFT relating to inpatients with dementia. DemFoCAS PPIE evidenced substantial difficulties experienced by patients and carers when a person with dementia is hospitalised. This reflects existing literature (Digby et al., 2017; Mukadam & Sampson, 2011), although, notably, there has been little research in the UK since the Covid-19 pandemic.

The purpose of this element of the project was two-fold. Firstly, to provide examples of carer experiences for spouses of people with dementia from the community covered by ESNEFT, thereby providing examples of retrospective patient feedback. Secondly, the study data will be presented in a separate research paper, adding to current literature and providing up to date research regarding the experiences of spousal carers of hospital stays.

## Method

### Design

The study used semi-structured interviews to explore experiences of spousal carers of people with dementia who had been admitted as inpatients.

### Participants

Participants were spousal carers for people with dementia who were inpatients at site A or B since 1/1/2023. Thirteen participants aged 61 to 89 were interviewed. See demographics table 10 and a summary of patients in table 11.

### Recruitment

The researcher recruited through visiting dementia cafes in person and by contacting dementia café organisers. Participant information sheets and consent forms were provided to carers who expressed an interest in taking part and preliminary date for interview was arranged. Participants were provided with ample time to ask questions before signing consent forms before each interview commenced.

## Ethics

Ethical approval was granted by University of Essex Research Ethics Sub-Committee 1, reference ETH2425-0298

*Table 10 Carer demographics*

| Carer No. | Ethnic origin | Age range | Gender | General Health | Disability/long term illness | Religion | Hospital |
|---|---|---|---|---|---|---|---|
| P1 | White British | 55 to 69 | Female | Good | None | None | Site A |
| P2 | White British | 70 to 74 | Female | Not bad for 73 | Thrombosis | Christian | Site B |
| P3 | White British | 80 to 84 | Female | Not bad for 80. Mentally 95%. Bad hip & back | None | Christian | Site A |
| P4 | White British | 85 to 90 | Female | Ok | Multiple disabilities | Christian | Site A |
| P5 | White British | 85 to 90 | Female | Reasonable | None | Christian | Site A |
| P6 | White British | 70 to 74 | Male | Pretty damn good | None | Christian | Site A |
| P7 | White British | 55 to 69 | Female | Fairly good | None | None | Site A |
| P8 | White British | 70 to 74 | Female | Excellent | None | Christian | Site B |
| P9 | White British | 70 to 74 | Female | Good | None | Christian | Site B |
| P10 | White British | 75 to 79 | Female | Hopefully good | None | Christian | Site B |
| P11 | White British | 85 to 90 | Female | Ok | None | Christian | Site B |
| P12 | White British | 85 to 90 | Female | Cancer being treated | Cancer | Christian | Site A |
| P13 | White British | 75 to 79 | Male | Totally knackered | Heart disease | None | Site B |

*Table 11 Summary of patients with dementia*

| Carer no. | Patient gender | Last admission | LoS (days) | Dementia diagnosis | Primary admission cause [1] | Yrs since diagnosis [2] | Current residence |
|---|---|---|---|---|---|---|---|
| **Site A** | | | | | | | |
| P1 | Male | Oct 23 | 16 | Fronto-temporal | Infection | 3.5 | At home |
| P3 | Male | Jun 24 | 3 | Alzheimer's disease | Infection | 4 | At home |
| P4 | Male | May 25 | 5 days | Alzheimer’s and vascular dementia | Diarrhoea, Infection | 2 | At home |
| P5 | Male | May 25 | 4-5 days each time | Alzheimer’s disease | Infection, unresponsive | 6-7 | Deceased |
| P6 | Female | Feb 24 | 10 days | Alzheimer’s disease | Extreme stomach pain | 6 | Deceased |
| P7 | Male | June 24 | 1 wk then 4 weeks | Vascular dementia | Infection, breathing difficulties | 5 | Deceased |
| P12 | Male | Nov 23 | 1 week | Alzheimer’s disease | Worsening health | Not known | Deceased |
| **Site B** | | | | | | | |
| P2 | Male | Dec 2023 | 8 days | Fronto-temporal | Fall | 3 | Deceased |
| P8 | Male | March 25 | 1 month | Alzheimer’s disease | Vomiting and lethargy | 5 | At home |
| P9 | Male | Mar 24 | 3 weeks | Parkinson's disease dementia | Fall | 3 | At home |
| P10 | Male | July 25 | 2 weeks | Alzheimer’s disease | Fall | 13 | Care Home |
| P11 | Male | Dec 23 | 1 week | Alzheimer’s disease | Constipation | 2 | Deceased |
| P13 | Female | May 25 | 1 night | Alzheimer’s disease | Infection | 4-5 | At home |

## Interviews

Interviews were mainly conducted in person (n = 11) and two online using Zoom. Most lasted approximately one hour, although one was 17 minutes due to time constraints and the longest interview was one hour 24 minutes. The length of the interviews and depth of discussion was often dependant on the location and time of the interview, with the shorter interviews being shortened due to activities or lunches being served at the dementia cafes. Several of the interviews were conducted in noisy environments.

A set of questions was produced as an interview guide and used in each interview. The first question asked about general family background, with subsequent questions enquiring about circumstances leading up to the participant's spouse going into hospital, and their subsequent experiences during and following the hospital stay. A full interview guide can be found in Appendix D.

# Findings

Interview transcripts were analysed thematically, using the project themes from PPIE in Phase 1 (figure 25).

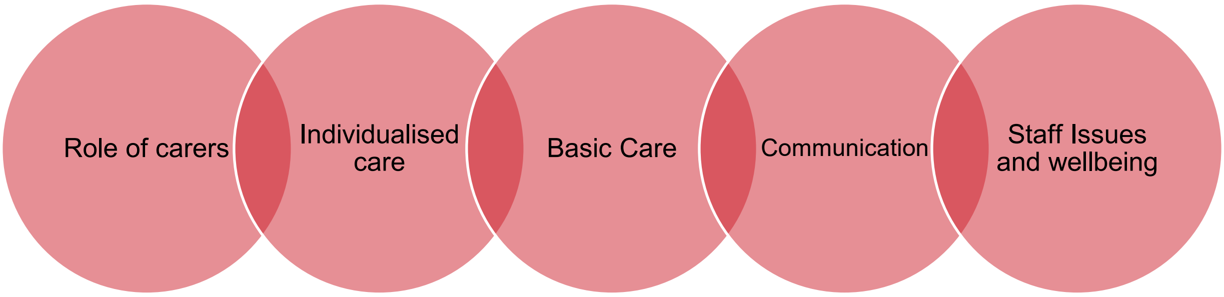


*Figure 25 DemFoCAS themes used to organise findings*

## Theme 1. Role of Carers

### Subtheme: Carer involvement

Carers saw themselves as playing several different roles while their partners were in hospital

**Speaking for the patient**. Several of the carers explained they saw their role as speaking on behalf of the patient, because communication was often difficult with patients, and the carers felt they knew their needs as well as, or better than the patient.

> *"I mean, at the time, I was just quite determined. And yeah, I mean, I was actually able to sort of stand there and fight his cause quite, quite well and sort of advocate for him" Carer 1*

> *"I was doing most of his answering for him anyway because he didn't have a clue and if you did ask him something, he didn't really know the answer anyway." Carer 7*

**Ensuring care was provided and alerting staff to problems.** By being present, the carers were able to notify when there were problems

> *"When the pain was starting again, I wasn't waiting. I was on their backs straight away." Carer 6*

Sometimes this was because the carer was assisting with personal care

> *"So I asked for a bowl and a towel to wash him. And when I took his shirt off, the whole of his back was covered in red spots. And I said, has anybody seen this? Nobody had seen it." Carer 9*

**Comfort, company and wellbeing.** Carers acknowledged the patients were often scared and confused and they were able to provide comfort

> *"When I used to go in there, I'd leave him for a little while and then I'd just touch his hand. And he put his hand out and put it on mine. And that was it. He was asleep again." Carer 12*

Wellbeing for the patient was often related to providing basic personal care

> *"I used to take razors in everyday…gave it to Harry, put it in his hand and he shaved himself. He's perfectly able. If I hadn't done that, he wouldn't have ever had a shave. Absolutely awful. I mean it makes you feel awful when you're all rough."*

For many of the carers, their present was crucial for the patient's wellbeing

> *"Because of my husband and the way, he felt about hospitals that he wasn't going to be able to handle it, and I needed to be with him. I needed to." Carer 2*

## Subtheme: Carer Challenges and Wellbeing

**Exhaustion.** The situation was challenging for the carers who were regularly exhausted from taking care of their spouses at home and spending time with them at hospital, most often with little sleep. In particular, the admission, when the patient was often most ill, was exhausting for the carer.

> *"But because I didn't want to leave him. I spent the night there. So and that's right. And I couldn't and I was trying, I was trying to put my head on his pillow like this…And then they said, right, we're moving him to another ward now. And I'd just dozed off! It was 4:00, I was like a zombie."*

This made it hard to cope with the demands of the hospital experience

> *"It's just so hard at the time and you're in a muddle…because there wasn't getting that much kip, for kickoff." Carer 6*

**Distress.** Carers were often upset by their spouses being in hospital

> *"Oh I was upset. Very upset, yeah. It broke my heart. Because it was bad enough under normal circumstances, but it was 100 times worse in hospital." Carer 3*

Some were distressed by the experience of their spouses being taken ill and admitted to hospital:

> *"We got on to [general] ward and his bed wasn't ready. So we were just there in the corridor. And I was just completely. I was. I mean, I was traumatised by what had happened in A and E." Carer 1*

Some carers were severely distressed by being separated from their spouses

> *"I'm utterly distraught. I did ring the Samaritans at 1:00 in the morning because I was so so upset because he needed to come out of hospital and I was fighting the social services." Carer 8*

**Feeling unwelcome or ignored.** The experience of being on the wards was often challenging, for example some of the carers said they felt they were unwelcome:

> *"I felt absolutely humiliated. I was only there as a helper. I wasn't getting in anyone's way." Carer 2*

Others felt when they tried to help their advice was ignored

> *"And so the nurse came with a pill and I said. He can't take pills. He'd either spit it out or chew it, and she said we'll try. And he spat it out about 5 times and then she decided that he needed liquid, for which I'd told her initially - he couldn't manage pills."*

## Subtheme: Fears and trust

The carers expressed various struggles with trust and fear.

**Fear of not being there.** Many of carers were fearful of leaving the patients in hospital for reasons such as fear of the patient being moved without the carer's knowledge:

> *"As I say, I just wouldn't trust them. I wouldn't know where to find her. If they move her, I wouldn't have known where to find her." Carer 6*

Another reason provided was that the patient may need the carer's help.

> *"But in hospital. Where I think they're most vulnerable because you can't be with them. I mean to leave him; it was worse than leaving a child. Because he couldn't express himself properly." Carer 3*

One carer reported an issue with a member of staff that subsequently made them scared of not being there, although this reduced when she got to know the staff.

> *"Yeah, I was constantly worried as to what was going on when I wasn't there, really. But once I got to know the nurses, it got easier" Carer 2*

Other carers were concerned generally for the patient's welfare:

> *"Yeah, I wouldn't have wanted to leave him on his own, even when he was asleep. I didn't want to leave him. I went downstairs. I think one day just to get him some sandwiches. Because not because I thought he would fall out of bed because he was too tired. I suppose I just wanted to make sure he was OK." Carer 10*

**Negative view of being in hospital.** There was a view from some that hospital care should be avoided at all costs in the future:

> *"He needed to go because he was in pain. And he needed to be checked to see if he'd broken anything. But I would fight tooth and nail for him going into hospital again." Carer 9*

For others, there was general view that a stay in hospital was detrimental:

> *“I didn’t want to, because everybody said it's the beginning of the end, if you go into hospital.” Carer 6*

One carer explained that people with dementia were particularly vulnerable in hospital:

> *“I just think if you have someone with dementia, don’t let them go into hospital. Because they’ll just go downhill.” Carer 11*

**Trust.** There was a level of distrust in many of the carers, for example some did not trust information they had been given

> *“Cos they kept saying to me, have them out of bed, get them walking about. And I still think it’s why he can’t now, because they didn’t try hard enough. But then I can’t call them liars, because I don’t know what happened before 11 o’clock.” Carer 10*

While some carer experiences led to distrust in hospital care.

> *“I think it just made me realise that you’ve just got to constantly watchful of what’s being done for everybody. You can’t, anymore, leave people, in the care of the hospital without constantly watching them. And asking questions.” Carer 11*

However, many comments from carers revealed an over-riding sense of trust in the staff, although the experience of hospital was still challenging

> *“I mean, I knew they would do their job. I was just worried anyway.” Carer 13*

There was also the view that hospital care was sometimes necessary and the best action:

> *“I didn’t want it. But you think it's the best thing it must be done because it's the best place to be if there's something wrong that needs treatment.” Carer 4*

## Theme 2: Individualised Care

The theme ‘individualised care’ relates to how the patient experience of hospital felt personalised to their needs. There were several carers who felt their loved one’s dementia was not always taken into consideration and healthcare staff did not always understand the patients well enough. For example, some felt it was not appreciated that patients did not understand their situation or information they were given.

> *"He just doesn't understand what they're saying. He doesn't' know what's going on." Carer 10*

Some of the carers felt staff misinterpreted behaviour. One said:

> *"But I didn't understand when they said they felt threatened because Justin was not a threatening person at all. I mean, whether they'd tried getting him back to bed and he had lashed out because I say he did lash out at me a couple of times, but I just thought. It made me think that it's not their fault, but I'm pretty sure nobody there was dementia trained. You know, because they just didn't understand what it was all about." Carer 7*

Two carers referred to the idea of individuals with dementia needing additional care and understanding.

> *"when you're fit and able, you know well, I know you're not going to be 100%, but you know, probably gone for an operation. Then it's fine. Because you're not needing that extra care. These people need it, it's not their fault you know, it's not like, you know, they'd say years ago they're senile. It is an illness as much as heart, cancer, whatever the dreadful things, it is an illness every bit as bad, but it's sometimes worse because they can't communicate" Carer 3*

### Subtheme: Patient Wellbeing

Most of the coding relating to individualised care centred around patient wellbeing in terms of their responses to being hospitalized. This has been organised into sections.

**Ward environment.** Some of the carers viewed the environment to be detrimental to patient wellbeing, and unsuitable for patients with dementia. Several were concerned there was no mental stimulation for them in the beds they were placed in. For example, one carer said:

> *"I went to see him once and he wasn't in the room I thought he was in and when I found him, he'd been put in a room all on his own with the door shut. Nothing to look at all. Nothing on the walls. Nothing, no music, nothing." Carer 11*

Another patient was in a bay but had little to look at, which the carer felt was affected his wellbeing. She said,

> *"He couldn't see the window very well from where he was, and there was one nurse, she used to keep pulling the privacy curtain across….And what he used to do was when he went to the toilet, he used to just stand and look out of the window. And he said to me oh I like to stand here for a little while. It's the only daylight I get to see. And he was in that corner for 16 days" Carer 1*

Where some carers found their spouses reacted positively to the care they received, with one saying their wife was "tickety boo!" (Carer 13), there were others who found patients were "confused" (Carer 1) or "Bewildered" (Carer 11). One described another patient being disruptive at night, and said her husband felt:

> *"... night was turning into day. It was disorientating him even more so. You know the best situation, for Alan was not being there." Carer 2.*

Another carer found the hospital experience particularly difficult. Although she was positive about the nursing care her husband received, she reported he had found being parted from her distressing, saying

> *"One of the nurses, he said he's been looking for you. He's been looking. He's even looked under the bed for you… Yeah, he was scared. He was scared. Yeah. He was scared. He thought I'd left him." Carer 3*

**Patients and Carers' combined Wellbeing**. It seemed that often the wellbeing of the patient related to the carers' wellbeing, with the patient's hospitalization being very much a shared experience. One carer said her husband's wellbeing was deteriorating after a prolonged stay. She said he was:

> *"Sad. Crying. We cried a lot together. Really cried… I just needed him to come back. To come home." Carer 8*

Often carers were protecting both their wellbeing and the patient's, with one explaining:

> *"So I felt that I needed to be there for him. Yeah, I wouldn't have wanted to leave him on his own, even when he was asleep... I suppose I just wanted to make sure he was OK" Carer 10*

# Theme 3: Basic Care

## Subtheme: Nutrition, Hydration and Toileting

The most common basic care issues related to nutrition and hydration. These have been summarised into four different areas:

**Help/Lack of help with hydration.** The majority of carers made comments related to hydration, with a common concern that staff did not ensure patients were drinking enough. Several of the carers explained their spouses needed to rely on others to ensure they were hydrated, as they were either not able to recognise thirst or act on it, even if well enough to do so.

> *“That he had been thirsty and nobody had offered him a drink. He wouldn't have been able to get one for himself it wouldn't have dawned on him. I mean, he would have known he was thirsty, but asking for a drink, you know it wouldn't have connected in his mind. You had to give him things, and you know, the same with eating.” Carer 5*

Some of the carers relayed instances of water being unreachable, even if the patient had wished to:

> *“One time they said he's not drinking very much. And I looked and I said, well, is there a wonder his table was at the side of his bed, not even anywhere near him. He'd got the water jug on it, no glass. And I said, even if he wanted to have a drink, how the hell is he supposed to get at it because he can't get out of bed. You know, someone's going to have to give him the drink. “ Carer 7*

**Carers’ involvement and expectations.** There was a perception by some of the carers that their spouses would not receive enough food and drink if they were not there to assist. One carer said:

> *“If we hadn't been there, he would have had no lunch. He might not have had anything to drink.” Carer 5*

There was also a lack of understanding what was expected;

> *“And if I'm honest, it didn't occur to me to say - tell me if you're not going to feed him and I'll come in at lunchtime and feed him. But nobody did, and they obviously didn't consider it important. The fact he hadn't eaten anything.” Carer 11*

Others, however, felt confident the staff were there to assist if required, for example one carer said:

> *"I always feed him. He can't feed himself. I'm pretty sure that if I wasn't there, they would have fed him. because they realised, he couldn't feed himself. But I was there to do it." Carer 10*

**Help/lack of help with food.** Several carers were concerned that not enough assistance was given with choosing and eating food.

A common concern was that food was left for the patient to feed themselves when they actually required help, and then taken away again if it was not eaten. For example, one carer said:

> *"I found out they brought the dinner in and people who couldn't feed themselves, it was just taken away if it was left. So, I used to go every day at lunchtime" Carer 12*

Alongside this concern was the belief that staff did not always understand patient needs:

> *"They used to put it on the thing across your bed, the table across your bed and leave you to it, working on the assumption that you could move forward and get your meal and eat it yourself. Which he obviously couldn't." Carer 2*

**Not understanding patients' needs/difficulties.** There were several comments relating to staff not understanding patient's ability to make informed choices. Reflected similar issues found in several interviews, one carer explained:

> *"I would have liked someone to know how little he really understood. How little he, I mean he doesn't ask for anything. He doesn't know he's thirsty… He doesn't say he's hungry or anything. I put food in front of him and most of the time, he'll eat it. Normally… If I said to him what do you want to eat? He doesn't know. And if they came round with a menu, handed him a menu and said what do you want to eat, he'd not know." Carer 4*

### Subtheme: Dignity

**Toileting.** The issue of incontinence, or not being able to reach the toilets in time was a common experience.

There were several reports of beds needing changing, which were sometimes sorted out quickly:

> *"And one day I went in and he'd had an accident. And brought his dinner in and I said he's had a bit of an accident. She said she'll be back in a minute. And she was." P12*

But sometimes this was not the case:

> *"And the next thing I know, the new nurse came in because these 2 have been told that Alan needed changing, we're not going to change it. They're going to leave it for the next lot. So, he was still waiting to be changed." Carer 1*

One carer was upset that her husband was provided with a bed pan, saying

> *"They made him use a bed pan. In bed. For both ends of going to the toilet. They never got him up at all. And he's physically fit. And I've put here (notebook) I am very upset and very worried about the situation." Carer 8*

**Dignity in general.** There were some views about more general aspects of dignity for patients with dementia. One carer said

> *"It's no different than if somebody's got cancer or had it is an illness. They're not just awkward old people, and there for the grace of God, how do any of us know how we're going to end up. And they need to be treated with some dignity, which they're not. " Carer 3*

## Subtheme: Mobility

The subtheme mobility relates to reports of how much time the patients were staying in bed, and their experiences of carers dealing with the consequences of being in bed for a prolonged period.

**Staying in bed too much.** Some of the carers were concerned patients were in bed for too much of their stay in hospital. One carer, whose husband had had a hip operation was concerned he was getting insufficient physiotherapy, saying:

> *"The main thing that I was really annoyed and upset about is just that I didn't feel any physio was going on… And they kept saying to me, even before his operation and after, they will be getting him up the day after his operation to try and get him to walk." Carer 10*

Another carer was concerned that leaving patients in bed was easier than encouraging mobility:

> *"Well because he can't speak for himself, it's a darn sight easier to be able to leave them in bed. Not out at all. And so it was a whole month, pretty much of being in bed." Carer 8*

**Pressure ulcers and infections.** The consequences of prolonged bed rest were commonly reported. Several carers described patients suffering with pressure ulcers.

> *"He'd got bed sores; he'd got ulcers because he wasn't getting out of bed. Four weeks laying flat on your back is like four months, apparently". Carer 7*

One of the carers reported her husband developed an infection, and was concerned that fewer staff on the wards was a contributing factor.

> *"Also, he had got a chest infection from lying around too much. And that was really what did for him in the end…. Basically, because he wasn't being moved. You know, everything was lying on his lungs. He wasn't, because there was, no, there's nobody there at the weekends to get them out of bed, you know, to even try to get him to walk." Carer 2*

**Losing mobility.** Another consequence of immobility in hospital was deconditioning, with patients being less mobile after discharge. One carer said:

> *"And then he was discharged home. And he went from the car with this zimmer and goodness knows what. It took him 30 minutes to walk down the garden path again, 30 minutes. He was in pain" Carer* 9

## Subtheme: Cleanliness

There were some positive comments from carers about basic cleanliness in the patients. One said,

> *"When I got there, they said they had washed him and that. He always looked lovely and clean. Lovely clean sheets" Carer 10*

However, there were some concerns from other carers, with one saying

> *"He's not had a shower. He's not had a hair wash; he's not had his bed sheets changed. All the time he was in there." Carer 8*

Another was concerned about general care, especially mouth care, which the carer was able to provide:

> *"Well, just sort of cleaning him up and giving him a shave. Cleaning his mouth. Cleaning his teeth. I don't know if they had cleaned his teeth at some point. But they certainly hadn't shaved him. Whether they had cleaned his teeth at some point during the day I don't know. I mean we didn't put a toothbrush or toothpaste in his toilet bag. But certainly, that first day they hadn't."*

# Theme 4: Communication

In the interpersonal communication theme, the carers reported aspects of communication across three subthemes. This theme is related to the subtheme 'Staff attitudes and culture' under theme 'Staff', with the main difference being this theme was more related issues about communication, rather than individual interactions with staff.

## Subtheme: Communication between staff and carers/families

The most common subtheme coded to related to communication issues the carers had experienced with staff. The overriding sense was many of the carers were confused about what was happening, who to talk to, and who people were on the wards. The main aspects of communication were as follows:

**Information not given or not understood**. Some issues were around not understanding what to do or where to find things. One carer said:

> *"Really, not many people tell you what to do. They don't tell you where the water machine is or the food is, or is there somebody who can sit with him while I go to the loo? You know, nobody offers you any particular information." Carer 2*

A further carer reported that the hospital had not informed them that their spouse had been distressed.

> *" But as I say the morning I got there and one of the nurses. He said he's been looking for you. He's been looking. He's even looked under the bed for you…So why didn't, because I phoned in the morning to see how he was. And they hadn't said, they hadn't told me or hadn't said, you know, come up because he's upset" Carer 3*

Some of the carers expressed being generally confused about everything, with one saying,

> *“Hadn’t got a clue. You were always wondering where you are in the system.” Carer* 6

Another said they found not knowing what the diagnostic situation was frustrating:

> *“Well, just because I didn't know what was going on, you know, I didn't know how long he was going to be in there, what was wrong with him…. but it's just the not knowing, so, you know, nobody giving you specific answers, you know, nobody. If they had just sat down for 5 minutes ago, and go right, We've done this. We've done that. You know, whatever, it might have been different, but.” Carer 7*

**Not knowing who people are and who to ask.** Several carers felt confused by who staff in the hospital were and who to ask for help. For example, one said:

> *“because you've got all these different people, haven't you on the ward, in all different uniforms and you see, I've never advocated for anybody before in hospital.” (Carer 1)*

Another carer felt there was no consistency as staff on the ward were changing so frequently,

> *“They don't tell you anything at the hospital. Every time you go there, you see somebody different. I always asked to speak to somebody who's in charge. You know, they usually say the person who's. looking after him is off today. And so and so and so is looking after him and then they really don't know anything about him. You don't get anywhere. One tells you one thing; another tells you another thing.” Carer 8*

## Subtheme: Staff / Patient Communication

The subtheme looking at communication between staff and patient showed diverse ways that dementia affected communication with patients.

**Communication requires an understanding of dementia.** There were several examples of incidences illustrating how patients with dementia require communication that is adapted for elements of dementia. One example was a patient being asked to explain why he was in hospital.

> *“You know that they have all these notes that they take and fill out all these books. And they never seem to look at them, you know, just come in. And how are you today? And, like, remind me again what you're in for? Well, he don’t know.” Carer 7*

A carer explained that staff did not appear to take the patient’s dementia into account when speaking to them.

> *“I mean they would come and speak to him as if everything was normal. I’d I have to say, he’s got dementia.” Carer 3*

In another interview, one carer reported that staff did not speak to the patient, saying:

> *“Otherwise, I don't remember them speaking to him at all. Apart from to say, would you like a coffee? And all he had to do was nod”*

**Positive communication meant the world.** Where carers reported seeing positive communication between the staff and patient, this was highly valued

> *“One night when I'd been visiting, the nurse came round to sort of, like, settle him down for the night, and she took so much care in just getting his pillows right. And I get emotional thinking about it now. Yeah, she took so much care. It meant the world. It meant the world.” Carer 1*

## Subtheme: Understanding patient behaviour

There were several references to the challenges of understanding the behaviours of patients.

**Understanding the individuality of dementia.** Some of the carers explained how their spouses could not communicate their problems. For example, one said:

> *“He doesn't know how to tell you if he's in pain. He can't tell you these things so why his legs collapsed we still don't know. They don't know. Why did it happen? We were never given an explanation of that.” Carer 2*

Another carer explained that interpreting the patient’s needs could be difficult as someone can present more able than they are.

> *“But the main thing is that when he's in hospital is about understanding his needs, and interpreting them, really. Because although he appears*

> *able, he's a lot less able than he appears, I think. So in hospital it's understanding what he needs. So normally that's my job. "* Carer 4

**Understanding responsive behaviour.** A few of the carers discussed how the behaviour of their spouses could be challenging. One explained that the patient may be challenging if they do not understand what is happening, saying:

> *"So hospital staff might be asking him to do things, and he might not be cooperating because he doesn't understand."* Carer 1

A carer explained there may be a simple explanation for her spouse's 'wandering':

> *"He was probably looking for me, but apparently, he used to wander and he'd go up towards the women, the nurses said we had to get security in cause we felt threatened. Well, Justin wasn't a threatening person, but I suppose because he wouldn't get into bed, you know, and he wouldn't do like, if because if I said Justin come back, he wouldn't do it do you I mean, so they got security in to watch him, which made me laugh, really."* Carer 7

**Carers can help.** Carers sometimes explained how they could help with some of the responsive behaviours. For example,

> *"The doctor said that Harry wouldn't take his medication… the doctor said that he, Harry, pushed him away. So, I said because it's quite possible he would if he's getting angry. And he doesn't want to be in there. So, I said to the doctor, can I give him his thyroxine tablets? …and the doctor said yes, so I just gave him his tablets, gave him a drink to wash them down. No problem. He took them."* Carer 8

However, one carer explained her suggestion that her husband had delirium was not accepted.

> *"He thought he was on a farm. He'd say look at that man over there. blah blah blah. He didn't realise they were patients in hospital. He was totally zoned out. It was definitely delirium. But that got poo pooed…I stopped the Gabapentin and Morphine. And my son said I've got my dad back."* Carer 9

## Theme 5: Staff Issues and Wellbeing

The staff theme brings together elements from the interviews reflecting the carers' experience of hospital staff.

### Subtheme: Not enough time

There were multiple references to staff being extremely busy.

**Empathy.** Carers showed significant empathy for the high workload of staff

> *"It's a very difficult situation. I know. I've been in that ward before. They've got so much to do, and so many different people coming and going all the time." Carer 2*

> *"And then they came back and but, oh, they were rushed off their feet. I don't know how they could stick it, really, you know." Carer 12*

**Explanation for shortcomings in communication.** Carers also indicated that their rationale for situations not going well was that staff were often too busy. For example, doctors were viewed as having too much to do.

> *"I think I asked what was happening and I think they must have said you'll have to wait for the doctor. And that's easier said than done. Well they're so busy aren't they." Carer 11*

It was also seen as a reason for communication with staff being difficult

> *"I mean they were pleasant, I'm not saying that, but there was nobody that I really got to speak because they were running around like, you know." Carer 4*

One carer suggested an alternative way of communicating with carers of patients with dementia, who were often not able to pass on information.

> *"They should be showing their relatives a booklet at the end of the bed that says so and so has been to see, and such and such been. Because they're stretched beyond capacity they haven't got the man power to keep you up to date on what's going on. You shouldn't have to keep fishing and fishing and fishing." Carer 9*

**Effects on basic care.** It was felt by some that staff being overworked was responsible for basic care sometimes not being achieved, for example ensuring patients had enough to drink.

> *“He wasn’t given drinks. And maybe they are just so short staffed they haven’t got time when someone is rushing past, to stop and give them a drink. I don’t know.” Carer 11*

There was one carer who felt that lack of time had a significant effect on personal care their spouse received:

> *“But it was the personal care that, you know, and I I'm not saying, I don't blame them because I know they all rushed off their feet and whatever, but it just felt so. like clinical like, in a cattle market, do you know what I mean? Because they just did what they had to do and that was it, you know, and even some of them were calling out and they just totally ignored them.” Carer 7*

### Subtheme: Not enough staff

A number of the carers felt there were insufficient staff.

**Staff not visible.** For some there was a perception that staff were often not visible or available to help, possibly due to high workload and pace of the ward. For example, one carer said:

> *“You never saw any staff. Anybody was just coming straight in and straight out.” Carer 11*

Staff’s availability was linked to both not enough staff and staff being too busy to be available to carers. When asked whether they talked to the nurses very much, one carer responded:

> *“They weren’t about. If you asked them, they were so busy.” Carer 7*

For another, it was linked to the time of year

> *“I mean it was difficult to see anybody really, as I say it was over Christmas and they were obviously short staffed and busy.” Carer 5*

There was also a carer who was helping other patients on the ward, who stated:

> *“I was only there as a helper. I wasn't getting in anyone's way. And yeah, all the time the other patients were coming walking up to me, asking me questions and help. I was helping them because there was nobody else on the ward.” Carer 2*

**Specialist Staff.** Some of the carers referred to the specialist dementia nurse team. One reported visits from dementia specialists, from EPUT, although they felt their spouse was too medically unwell to benefit.

> *"We did have a couple of visits from Some ladies. The dementia specialists. From Kingswood. Yes, they did make a visit. But as I said she was very, very poorly." Carer 6*

Three carers noted they were not able to contact someone from the ESNEFT team due to sickness, holiday, or reasons unknown:

> *"As I said, the downfalls was the dementia nurse, who we never got to see. Apparently she was off sick, so we never got to see her." Carer 1*

One carer made reference to a specialist dementia ward

> *"Apparently, they did have a ward with people with dementia. But it was full…. But whether it was any better, I don't know." Carer 11*

There was one comment relating to insufficient dementia nurse specialists

> *"I mean, how can you have one person in a hospital that size? It's criminal, I think. But all you hear about, you know, is the amount of people that there are with dementia. You can't tell me there's only a couple of people in there, at a time. It will. They'll put it all down to funding, won't they?" Carer 3*

Similarly, another carer explained the importance of having dementia specialist staff:

> *"They need a team in that understands dementia people. Understand what's going on and you know I wouldn't say be sympathetic but at least have somebody that says this is quite the norm and it's what people with this condition will do. It's what they're used to doing and you know and understand why instead of trying to battle against them try and work with them." Carer 7*

## Subtheme: Training/Dementia Awareness

**Lack of Dementia Awareness.** In the training subtheme, comments were mainly in relation to carers feeling staff did not understand dementia well enough, highlighting a need for increased dementia awareness. For example, one carer said:

> *"Well, I just think that some more knowledge about what dementia is like really, from the patient's point of view, you know the fact that you don't understand what's being said to you. And you may say one thing, when you don't mean it."* Carer 5

Another expressed a general lack of being able to understand patients with dementia were different.

> *"But no, you didn't feel that they knew how to cope with dementia. Not really. He was just another patient, you know. Just another sick person."* Carer 2

**Lack of dementia focused care.** Another element of the subtheme was the perception that care was not dementia focused enough, for example not enough extra care was provided. For example, one said:

> *"Well, when you've got someone with Alzheimer's, who can't talk, they should understand that and go over the top to help."* Carer 8

Another carer was concerned that staff were relaying information to the patient and not considering they would not remember and be able to tell the carer.

> *"It would have been good to have known what the doctor said when they came round (in EAU). It was no good them telling Cyril."* Carer 4

One carer suggested that dementia was not understood as an illness and patient behaviour was not always understood to be due to dementia. She said:

> *"You do need to have, especially. I know it's tight and I know they're hard work. But it's not their fault. It's no different than if somebody's got cancer or had it is an illness. They're not just awkward old people, and they're for the grace of God, how do any of us know how we're going to end up? And they need to be treated with some dignity, which they're not."* Carer 3

## Subtheme: Staff Attitudes and Culture

As interviews were with carers, most of this subtheme related to how they viewed the attitude of staff they came across, rather than culture.

**Helpful staff and positive reactions.** Across the interviews, there was a significantly positive regard for most staff. There were comments about staff being effective in difficult circumstances.

> *“It was mayhem everywhere and it's not the staff. The staff were wonderful. You know, I've. I've heard people say the nurses just stand there talking. They don’t. they're running around like bloody lunatics.” Carer 6*

Others just felt the staff overall were helpful to the patients and made carers feel reassured.

> *“It was just an infection. Yeah, but I just say, the staff were good to her… Yeah, yeah, a couple of them said It’s alright, don't worry, we’ll look after her.” Carer 13*

There were several reports of individual staff being particularly positive, for example one carer stated:

> *“There was a chap there called (Name) who was lovely. There's another, man, I can’t remember what his name was, but he was a lovely chap.” Carer 10*

**Negative perceptions**. A few of the carers reported feeling unwelcome on the wards, and worrying they were in the way of the staff:

> *“Yeah, I felt like I shouldn't have been there” Carer 2*

One carer was concerned the staff did not show enough compassion for the patients, saying:

> *“You know, you have all these adverts on television about how Alzheimer's is the biggest killer and all this, the compassion. It doesn't exist… Perhaps to say they don’t care is perhaps too strong, but it comes across as indifference ” Carer 3*

**Mixed responses to staff.** Many of the carers described a more mixed experience, with some staff viewed as more supportive than others, saying:

> *“But the sister who looked after me on the Monday and the Sunday was brilliant … because when she arranged for the transport, she arranged for the medication to be brought to me before I left on the Sunday” Carer 2*

Finally, one carer noted that her early difficulties with staff improved as she became more familiar with the hospital and its routines, suggesting that unfamiliarity with the setting can contribute to challenges in staff/carer interactions. She said:

> *“So, I think all of that was probably at the beginning. So it made me very unsure, but as I say, as time went on and I got to know the nurses and his nurses of the day, my confidence in them grew quite a lot and I built quite a good relationship with a couple of them …So by the end of it, I had a lot more confidence in them.” Carer 1*

# Discussion

The carer interviews produced extensive and detailed stories of patient hospitalisation. Using the DemFoCAS project themes as the basis for analysis ensured a continuation from the voices of carers and persons with dementia that took part in the PPIE workshops.

## Theme 1: Role of Carers

Carers viewed themselves as performing multiple, overlapping roles, such as advocate, interpreter, protector, and provider of emotional and practical support. This mirrors previous research showing that carers can act as patient experts, provide comfort to patients in hospital, especially when communication difficulties limit patients’ ability to express needs (Digby et al., 2017; Røsvik & Rokstad, 2020) and compensate for care gaps (Clissett et al., 2013b). However, carers also experienced distress themselves and were often exhausted from usual caring responsibilities and fearful of their spouse’s health outcomes. Further, the transition from carer at home to a more ambiguous role in the hospital often brought confusion and additional stress, often culminating in a fear of leaving their partner’s bedside. Role strain, emotional labour, and moral distress have been noted as significant contributors to caregiver burden during hospitalisation (Jurgens et al., 2012). Our findings reinforce this duality: carers enhance patient wellbeing and continuity of care, yet the lack of formal recognition of their role often amplifies stress and uncertainty.

## Theme 2: Individualised Care

Carers perceived wide variation in how well staff understood their relative's dementia, needs, and behavioural expressions. Several narratives described perceived misinterpretation of distress or non-cooperation, reflecting findings that hospital staff may struggle to differentiate dementia related behaviours from intentional resistance unless adequately trained (Clissett et al., 2013). This theme also highlights how hospital environments, for example noise, lack of stimulation, single isolated rooms, or constant activity, contributed to disorientation. The intertwining of patient and carer wellbeing was particularly pronounced; emotional responses were co experienced, reinforcing research that dementia caregiving is relational and that hospitalisation disrupts these relational supports. Our findings support calls for care models that embed carers as partners and draw directly on their knowledge of the person (Røsvik & Rokstad, 2020).

## Theme 3. Basic care

Across nutrition, hydration, mobility, and dignity, carers frequently identified gaps in basic care provision, and intervening when needed. These observations align with earlier studies indicating that people with dementia are particularly vulnerable to missed care, including feeding, toileting, and mobilisation, due to high staff workload and reduced capacity for self-advocacy (Clissett et al., 2013b). Carers' reports of dehydration risk, food left inaccessible, inconsistent assistance with toileting, and limited mobility resonate with research describing how task centred delivery can overlook cognitive impairment and fluctuating ability (Abbott et al., 2022; Røsvik & Rokstad, 2020). Person-centred care and focusing on positive relationships between patient and nursing staff should not be viewed as 'extras', but core working practices, as detailed in key nursing guidelines, for example, Kitson's Fundamentals of Care Framework (2014). Yet carers also described positive examples of attentiveness, highlighting variability across staff and shifts. These findings suggest that while individual staff demonstrate compassion and skill, systemic pressures, for example, pace of work, understaffing, and limited dementia specific expertise, can contribute to inconsistent basic care.

## Theme 4: Communication

Communication difficulties were frequently part of carers' experiences. Unclear information, rapid staff turnover, challenges identifying staff roles, and limited orientation to ward routines created confusion and distress. This is consistent with work showing that communication breakdowns contribute to family uncertainty and perceived loss of control in acute dementia care (Røsvik & Rokstad, 2020). The study also illustrates how communication with patients themselves is sometimes poorly adapted to cognitive impairment, reinforcing the need for dementia specific communication strategies. This is consistent with findings that positive instances, such as staff taking time to adjust pillows or speak gently, had disproportionate emotional impact, echoing research that small relational gestures can significantly enhance trust and reduce anxiety for both patient and carer (Dewing & Dijk, 2016; Spencer et al., 2013; Sunjaya et al., 2025).

## Theme 5: Staff Issues and Wellbeing

Carers' empathy for staff workload was notable, mirroring wider public awareness of strain on health services. Yet staffing pressures clearly affected visibility, availability, communication, and the delivery of basic care. Understaffing and high task demands in acute wards have been consistently identified as barriers to dignified, individualised care for people with dementia (Addis & Evans, 2025)Røsvik & Rokstad, 2020. The reported lack of access to dementia specialist teams — due to absence, limited capacity, or organisational gaps — reinforces the need for greater investment in expertise and training. These findings align with literature advocating for dementia skilled workforce development, environmental adaptation, and staffing models that account for the higher cognitive and relational care needs associated with dementia, e.g., specialist dementia units or embedded dementia champions (Gwernan-Jones et al., 2020; Spencer et al., 2013).

## Summary of Findings

Together, the themes point to a tension between carers' essential role in safeguarding patient wellbeing and the structural limitations of acute hospital environments. Carers provide expertise, vigilance, and emotional support that significantly mitigate risks for people with dementia, yet the hospital infrastructure does not consistently recognise or integrate them. Improving outcomes therefore requires both system-level solutions (staffing, training, communication processes, dementia friendly design) and relational solutions (partnership working, carer involvement policies, enhanced orientation/support for families).

### Limitations

The gender split was uneven, with only two out of 13 participants being men. This reflects the recruitment at dementia cafes where more women than men carers tend to attend.

Carers were often not sure which wards, or types of wards the patients were in. There was therefore no insight in the interviews as to whether care may have been different in wards more geared towards patients with dementia, where staff are more likely to have had more dementia training.

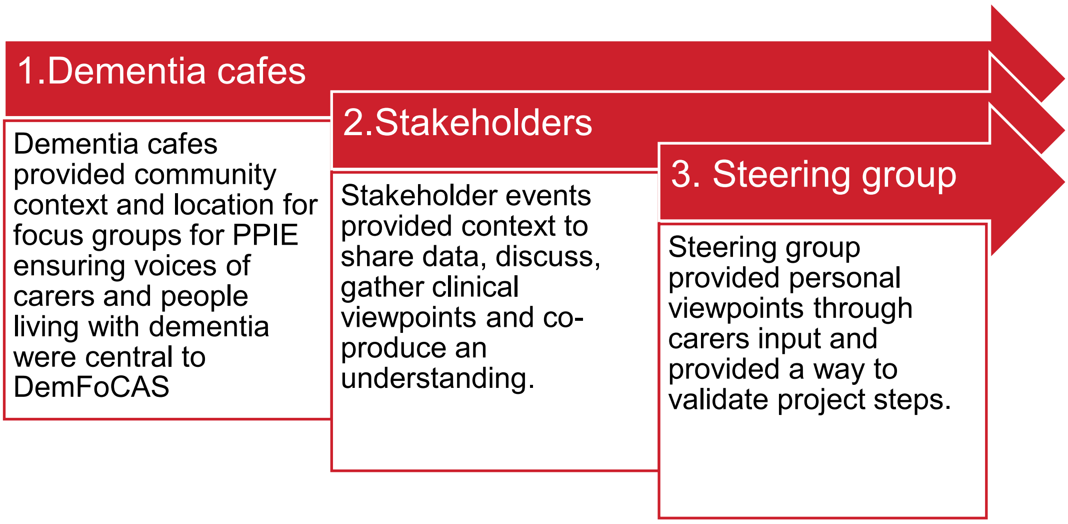
It should be noted that since the experiences of the carers, there has been a blanket introduction of 8am to 8pm visiting times.

# Section 9 – Core concepts

Section 9 brings together the key concepts and themes that emerged across the DemFoCAS project. The previous sections presented findings from multiple sources of evidence, including the systematic literature review (Section 4), mapping exercise (Section 6), staff perspective (Section 7), and carer interviews (Section 8). While each of these components provides valuable insight into dementia care within acute hospital settings, their combined interpretation offers a deeper understanding of how care is experienced, delivered and supported within ESNEFT.

This section therefore synthesises these findings to identify a set of core concepts that help explain the realities of dementia care in acute hospitals. These concepts highlight the relationships between organisational systems, staff practice, patient and carer experiences, and the wider care environment. Together they provide a framework for understanding the strengths, pressures and opportunities within the current system. The section also introduces the practical focus areas and "touchpoints" that link the project's findings to the recommendations presented later in the report.

Phase 1 of the project was concerned with establishing the main concepts and ideas that underpinned the project. This involved understanding research literature, wider and local context of the project, and through PPIE. This section shows how these concepts provided a thread through the whole project and these key elements – dementia cafes, stakeholders and steering group - steered the development of the key concepts as the project developed (figure 26).



1.Dementia cafes

Dementia cafes provided community context and location for focus groups for PPIE ensuring voices of carers and people living with dementia were central to DemFoCAS

2.Stakeholders

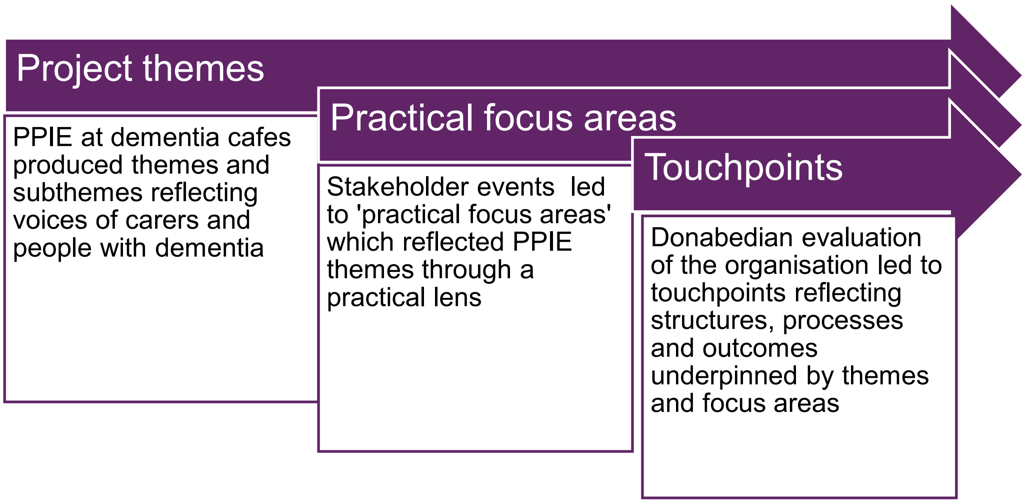
Stakeholder events provided context to share data, discuss, gather clinical viewpoints and co-produce an understanding.

3. Steering group

Steering group provided personal viewpoints through carers input and provided a way to validate project steps.

*Figure 26 Co-production elements*

Themes developed through our PPIE focus groups produced our key themes that provide a foundation for our project and ensure the voices of people with dementia and carers are present throughout. Stakeholders helped to mould these themes into practical areas to focus on. Themes and focus areas informed our Donabedian evaluation and provided a constant reference to stakeholders and community (Figure 27).



Project themes

PPIE at dementia cafes produced themes and subthemes reflecting voices of carers and people with dementia

Practical focus areas

Stakeholder events led to 'practical focus areas' which reflected PPIE themes through a practical lens

Touchpoints

Donabedian evaluation of the organisation led to touchpoints reflecting structures, processes and outcomes underpinned by themes and focus areas

*Figure 27 Development of concepts underpinning project*

The three-year project included multiple envelopes of work, all underpinned by our collaborative approach and project concepts and themes. The results of these workstreams have been collated and considered together to lead to recommendations (Figure 28).

*Figure 28 Findings from workstreams leading to recommendations*

# Public and Patient Involvement and Engagement (PPIE)

**PPIE: Developing the Initial Themes**

PPIE formed a critical starting point for the project. Focus groups held in dementia cafés brought together people living with dementia, carers and family members to discuss their experiences and perceptions of hospital care. These discussions generated a wide range of perspectives about admission to hospital, communication with staff, the hospital environment, and the challenges faced by both patients and carers during acute care episodes.

The focus groups highlighted both positive experiences and areas of concern, particularly around communication, continuity of care, and the recognition of individual needs. Importantly, these conversations ensured that the voices of people living with dementia and their carers informed the direction of the project from the outset.

The views shared during these sessions were organised into a set of themes and subthemes (Table 12). These themes provided an initial framework for understanding the key issues affecting dementia care in acute settings and ensured that the project remained grounded in lived experience throughout its development.

*Table 12 Themes and subthemes from PPIE with longer subtheme descriptions*

| Theme | Subthemes |
|---|---|
| **Role of carers** | • Carers should have their worries considered<br>• As a carer, hospitals can be challenging<br>• Carers should be allowed to be involved<br>• Carers should have extended visiting |
| **Individualised care** | • Older people and persons living with dementia should always be respected<br>• **Dementia is different for each person**<br>• Respecting diversity is important<br>• Patient wellbeing needs to be central to care |
| **Basic care** | • Patient dignity should always be prioritised<br>• Pay attention to the basics, such as cleanliness<br>• **Nutrition and hydration are key priorities**<br>• **Patients need to be kept safe**<br>• Mobility should be encouraged while someone is in hospital |
| **Communication** | • Good communication from hospitals to carers/families is essential<br>• **Staff / patient communication is extremely important**<br>• **Understanding patient behaviour should be a priority**<br>• Sharing information is crucial * |
| **Staffing issues and wellbeing** | • Staff don't have enough time<br>• More training is needed<br>• There are not enough staff<br>• Staff culture and attitudes are important |

*Subtheme was previously a separate theme

# Practical Focus Areas

The themes identified through the PPIE focus groups were presented at a stakeholder event in July 2023. Participants included clinicians, managers, service leads, and other professionals involved in dementia care across ESNEFT. During the event, participants explored the themes collectively and discussed the practical challenges associated with improving care in each area.

These discussions helped translate the broad themes arising from PPIE into more practical considerations relevant to service delivery. Stakeholders reflected on how organisational systems, staff roles, communication processes and environmental factors shaped the experiences described by patients and carers.

When the outputs of the stakeholder event were reviewed alongside the PPIE themes, it became clear that many of the issues identified were interconnected. For example, organisational systems and processes influenced how information was shared, how staff managed competing pressures, and how patients and carers were involved in decision-making. As a result, several of the themes overlapped or addressed similar underlying challenges.

Through further analysis and discussion within the DemFoCAS team, these ideas were refined and consolidated into five practical focus areas. These focus areas provided a clearer structure for the project's evaluation and helped guide the subsequent Donabedian analysis of structures, processes and outcomes within dementia care at ESNEFT.

Themes and subthemes were presented and discussed at a stakeholder event in July 2023. Ideas and challenges were discussed in relation to each theme (figure 29), asking how the themes can be addressed from practical perspective.

*Figure 29 Stakeholder event voices: Example Ideas and challenges*

The themes from the PPIE, and outputs from the stakeholder event were considered together. The DemFoCAS team found the ideas and challenges reached across themes and there was duplication. For example, systems and processes underpinned several of the themes, affecting how information was shared, staff pressures and how we support (or listen) to PLWD and their carers. Through careful consideration, the themes were represented through five practical focus areas (figure 30).

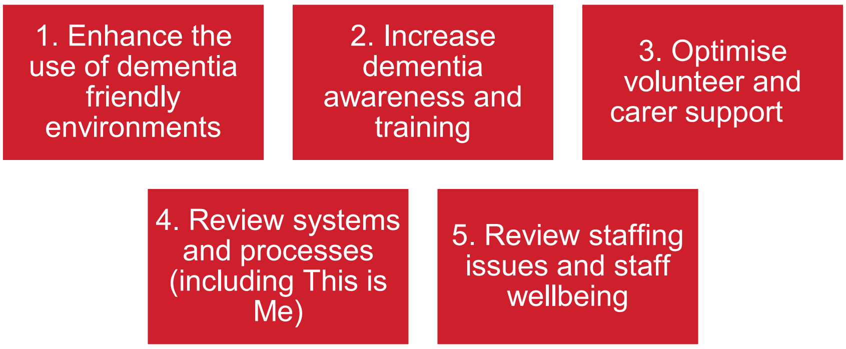


*Figure 30 Focus areas*

# Touchpoints

Using a Donabedian framework, the structures, processes and outcomes relating to care of patients with dementia in acute settings at ESNEFT were evaluated. This highlighted emerging touchpoint areas, as detailed in the progress report July 2024. Findings were presented to ESNEFT through report dissemination, and presentation at ESNEFT meetings including the Senior Nurse forum (figure 31). The draft touchpoint table is provided in appendix E.

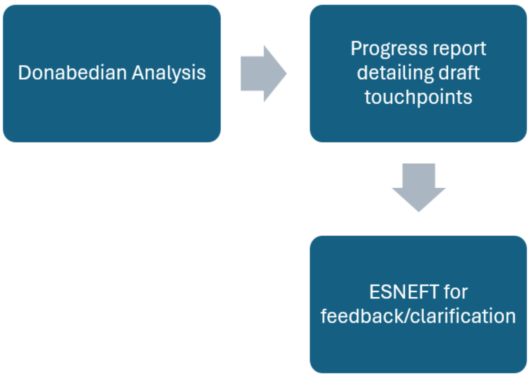


*Figure 31 Donabedian report pathway*

## Touchpoints to Field Work

Donabedian analysis revealed a lack of recent patient and carer feedback. The DemFoCAS team addressed this in two ways:

- Carer interviews – interviews with spousal carers from the community, whose spouses with dementia were hospitalised at ESNEFT acute settings since 2023 (Section 8)

- Patient/carer feedback – the mapping process included carer/patient stories. The method drew from a prior model carried out by ESNEFT, with carer/patients recruited during hospital spell, and interviewed 4 – 6 weeks following discharge (Section 6)

## Touchpoints to Recommendations

Draft touchpoints arising from the Donabedian analysis produced in 2024 were updated and re-addressed after fieldwork and consultation with ESNEFT and formed the basis of project recommendations in this report. Using the updated and expanded information, extensive discussions within the project team led to the touchpoints being combined, enhanced or in some cases removed, to result in our final recommendations.

## Project Components

The various components of the project and how they interconnect are shown in figure 32.

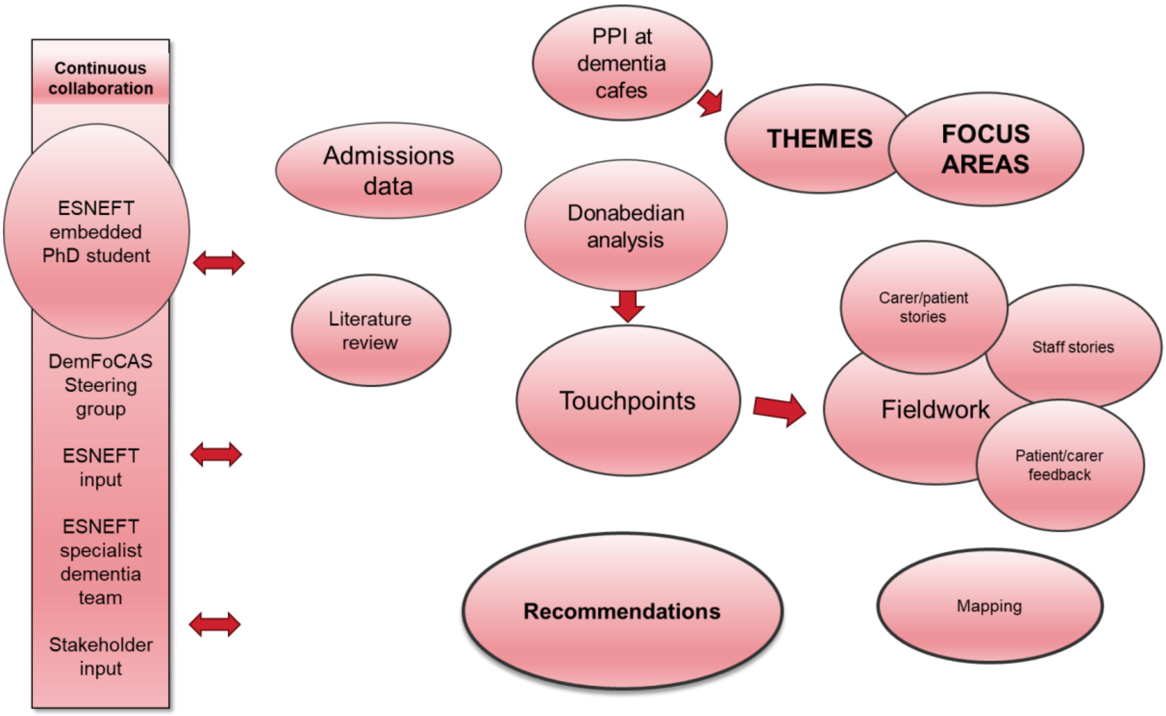


*Figure 32 DemFoCAS case diagram showing how aspects of the project interconnect*

# Methods

The use of multiple methods within the case study enabled the project to capture a rich and balanced understanding of acute care, patient/family/carer experiences and healthcare staff from several complementary angles. Focus groups and interviews provided in depth personal experiences, while process mapping offered a structured view of how services function in practice.

Quantitative analysis of admissions data provided a high-level profile. The coproduction approach through the steering group ensured that stakeholder perspectives actively shaped the work, and the Donabedian analysis added a systematic lens on healthcare quality across structures, processes and outcomes.

Finally, the systematic literature review grounded the findings in established evidence. Taken together, this broad methodological mix strengthened the validity of the insights by ensuring that different viewpoints, contexts and forms of evidence were considered (figure 33).

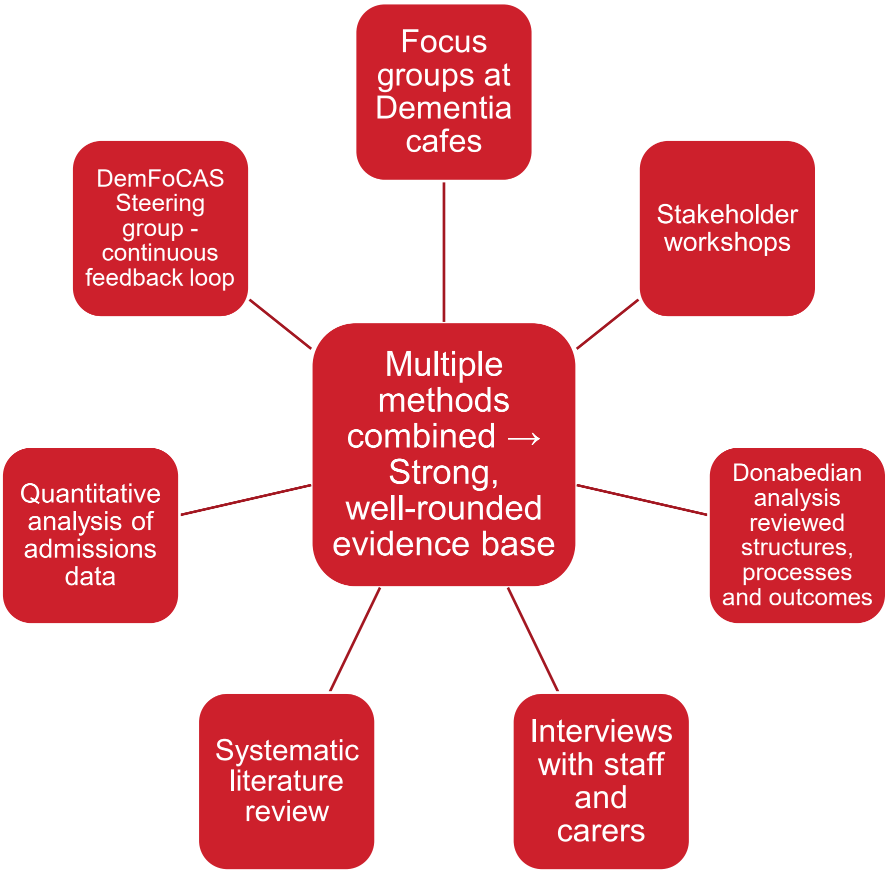


*Figure 33 Methods used in the case study*

## Summary

This section has shown how core concepts for the project were developed and how mixed methodologies, underpinned by the concepts, were used to produce a well-rounded evidence base. The evidence from the different elements of the project are combined in the following section, to show a clear pathway to recommendations.

# Section 10 – Findings and Implications for Practice

## Findings

The findings across the various elements (Donabedian analysis, systematic literature review, mapping exercise, staff perspectives, carer interviews) are brought together in this section by theme.

### Theme 1 – Role of Carers

**Carers being supported by staff**

Staff recognised that carers and families were often at crisis point when a person with dementia is admitted to hospital.

**Carers** reported feeling exhausted, stressed, and confused by the hospital environment and processes. However, those interviewed were not always at the level of 'crisis point' described by staff. This may reflect a tendency for staff to focus on those with the most complex needs, potentially overlooking the significant difficulties experienced by those with lower levels of complexity.

Findings from the **Donabedian analysis** indicated that feedback from carers and patients with dementia was not consistently or proactively collected across sites. Where feedback was gathered, there was limited clarity on how it was acted upon or embedded into service improvement. Carer interviews and mapping data highlighted experiences that may not be captured through formal mechanisms, including difficulties navigating the hospital environment and accessing information.

Carer information packs, including sources of support, guidance, and 'main family carer' badges, are in use at Ipswich Hospital and being introduced at Colchester. While these are positive developments, their impact is dependent on consistent communication and integration into wider processes, including feedback and engagement systems.

Overall, these findings suggest a need to broaden support beyond those in crisis, recognising that many carers experience distress and uncertainty during hospital admission. This may be addressed through more consistent communication, improved orientation, and standardised approaches to supporting carers.

### Carer Involvement in Care

**Staff** generally welcomed carer involvement in care, recognising the value of their knowledge of the patient, as well as their role in providing reassurance and supporting nutrition and hydration. However, some staff described tensions between staff expectations and carer perspectives.

**Carers** reported frustration with limited staff availability to support basic care needs, particularly at mealtimes. Some carers were unsure about how much to assist, expressing concern about “getting in the way” or not realising their involvement was encouraged.

Evidence from the **literature review** suggests that structured approaches to carer involvement, such as the TOP5 strategy, can improve patient outcomes, including reduced falls, improved communication, and better relationships between staff and carers (Isaac et al., 2018; Luxford et al., 2015).

These findings highlight the need for clearer communication and shared understanding of the carer role within acute care settings, alongside more structured approaches to involving carers in care delivery.

### Key Implications for ESNEFT – Carer Involvement

ESNEFT should adopt a more consistent and proactive approach to identifying, informing and supporting carers from the point of admission. This should include clear processes for recognising carers, providing orientation to the ward environment, and ensuring they know how to access information and support. Evidence consistently demonstrates that meaningful carer engagement improves patient safety, reduces adverse events, and enhances continuity of care, particularly for people living with dementia who may have impaired communication (Digby et al., 2017; Røsvik & Rokstad, 2020).

Clear guidance should be developed and communicated to staff and carers regarding the role of carers in care delivery, particularly in relation to supporting nutrition, hydration and patient reassurance. This would help reduce uncertainty, improve collaboration, and ensure carers feel confident and valued rather than unsure or excluded.

Carer feedback processes should be strengthened and standardised across sites, with clear mechanisms for capturing experiences and demonstrating how this feedback informs service improvement. This should include both formal and informal methods to ensure a wider range of experiences are captured.

Structured approaches to carer involvement (e.g. TOP5 or similar tools) should be embedded into routine practice and documentation, ensuring that carer knowledge is consistently used to inform care (Manthorpe et al., 2020; World Health Organization, 2021).

Finally, ESNEFT should continue to develop opportunities for carers to contribute to service development, training, and quality improvement activity, ensuring that changes to dementia care are informed by lived experience.

**Link to Recommendations**

This theme is addressed through recommendations focused on strengthening partnership working, communication, and system-level integration of carers:

- **Recommendation 5 – Assign a dementia care partnership and engagement lead**
- **Recommendation 6 – Embed carers and people living with dementia in strategic involvement**
- **Recommendation 7 – Enhance family and carer support through a dementia engagement framework**

These recommendations collectively aim to move carer involvement from informal and variable practice to a structured, supported and sustainable component of care delivery.

## Theme 2 – Individualised Care

### Improving Patient Experience

**Staff** recognised boredom and lack of stimulation as key factors contributing to confusion and unrest for patients living with dementia. This could escalate to responsive behaviours, sometimes resulting in the involvement of security staff to maintain safety. Suggested solutions were often practical and low cost; however, staff reported these were difficult to implement within current workload pressures.

Increased use of volunteers and activity co-ordinators was widely identified as the most effective approach, alongside initiatives such as social dining, which were being trialled in some areas.

**Carers** consistently described staff as busy, with limited time to provide one-to-one interaction or to get to know patients as individuals. This contributed to concerns about patient wellbeing, with carers reporting that patients were often upset, confused, or under-stimulated. Despite this, carers also highlighted examples of positive staff interactions, which were seen as highly valuable in reassuring both patients and families.

The **literature** supports the use of structured activities and therapeutic interventions to improve patient experience and reduce distress. Interventions such as cognitive stimulation therapy, music therapy, and the use of technological tools (e.g. PARO robotic devices) have been associated with improved wellbeing and more settled behaviour, although further high-quality research is needed (Cheong et al., 2016; Daykin et al., 2018; Kelly et al., 2021; McAulay et al., 2020; Tsuchiya et al., 2022). In addition, volunteer involvement has been shown to enhance care quality and may reduce the need for one-to-one supervision (Bateman et al., 2016; Blair et al., 2018). However, achieving this within acute settings requires deliberate system-level support to move beyond aspiration to consistent practice**.**

Wendy Mitchell's *What I Wish People Knew About Dementia* (2022) offers a compelling lived-experience perspective that closely aligns with national and local dementia care standards. Mitchell highlights the importance of clear, respectful communication; maintaining personhood and autonomy; recognising distress as a response to environment and interaction rather than "responsive behaviour"; and understanding how hospital routines, noise and lack of explanation can intensify fear and confusion. These principles are directly reflected in NICE dementia guidance (NG97; 2018; QS184; 2019), Care Quality Commission expectations relating to dignity, compassion and responsiveness (CQC, 2024), and the ESNEFT Dementia and Delirium Policy (2025), which promotes early identification, routine delirium screening, person-centred documentation (including *This Is Me*) and carer involvement throughout the inpatient journey.

The **Donabedian analysis** showed that volunteer numbers had dropped since COVID, although figures have increased significantly over the time of the

DemFoCAS project, and has included more volunteers specifically to help fill in ‘This is Me’s for patients with dementia.

**Key Implications for ESNEFT**

ESNEFT should prioritise the development of a more structured and sustainable approach to providing meaningful activity and stimulation for patients living with dementia. This should include expanding and embedding volunteer roles, with clear coordination and integration into ward teams, to support activities, social interaction, and completion of person-centred tools such as “This is Me”. Evidence indicates that when such tools are actively integrated into care processes, they support improved communication, reduce behavioural distress, and enhance patient dignity (Edvardsson & Nay, 2009)(Edvardsson et al., 2008; Royal College of Nursing, 2019).

Consideration should also be given to increasing access to activity co-ordinators or similar roles, particularly in areas with high numbers of patients with dementia. This would support more consistent delivery of low-level, high-impact interventions that improve patient wellbeing and reduce distress. Training alone is insufficient; it must be complemented by organisational practices that prioritise relational care alongside task completion. Embedding prompts within electronic records, handovers, and ward routines can support staff to consistently consider “who the person is” rather than focusing solely on clinical need. This aligns with evidence suggesting that person-centred care is most effective when supported by both cultural and structural enablers (McCormack & McCance, 2017).

Simple, ward-based approaches to improving stimulation such as social dining, access to music, and use of personalised activities should be standardised and supported within routine care, rather than reliant on individual staff initiative.

Finally, patient experience should be more routinely monitored in relation to wellbeing, engagement, and stimulation, ensuring that emotional and psychological needs are given equal priority to physical care. This is consistent with broader frameworks emphasising the measurement of relational and experiential aspects of care alongside clinical outcomes (World Health Organization, 2021).

**Link to Recommendations**

This theme of improving patient experience is addressed by:

- **Recommendation 3 – Develop a comprehensive dementia-friendly environment strategy**

- **Recommendation 4 — Develop a ‘care partners’ framework to broaden volunteer and family carer support**
- **Recommendation 7 – Enhance family and carer support through a dementia engagement framework**

These recommendations collectively support the integration of personalised care into routine practice through improved knowledge, skills, and use of patient-specific information.

## Staff Knowledge of Dementia

Staff knowledge and understanding of dementia emerged as a critical enabler of care quality, influencing communication, personalised care, and the ability to respond appropriately to distress and behavioural changes. Across data sources, there was clear recognition among staff of the importance of dementia-specific knowledge; however, the depth and consistency of this knowledge varied significantly across roles, departments, and levels of experience.

**Staff interviews** highlighted variability in confidence when supporting people living with dementia, particularly in managing responsive behaviours, understanding non-verbal communication, and adapting care approaches. While some staff demonstrated strong awareness and skill, others described reliance on general nursing knowledge or experiential learning, rather than formal dementia-specific training.

**Carers** frequently identified gaps in staff understanding, particularly where behaviours were misinterpreted as non-compliance or agitation rather than expressions of unmet need. This could lead to increased distress for patients and frustration for carers.

**The Donabedian analysis** identified inconsistencies in training provision, including variation in access, content, and uptake. While training was available, it was not always mandatory, role-specific, or reinforced in practice, limiting its overall impact.

This is Me’ was widely recognised as a valuable tool to support understanding of patient preferences and needs. However, staff noted that the benefit of these documents depended on them being actively used in care delivery. The introduction of EPIC has improved accessibility of these records, but consistent use in practice remains variable.

Evidence from the **systematic literature review** emphasises that dementia education alone is insufficient unless supported by organisational culture, leadership, and opportunities for reflective practice (Surr et al., 2017). It showed that person-centred care approaches, including staff training and the use of specialist dementia units, were associated with reductions in BPSD, agitation, and the need for antipsychotic prescribing (Allegri et al., 2022; Chenoweth et al., 2022; Graham et al., 2024; Tay et al., 2018; Sinvani et al., 2018). Specialist dementia teams also demonstrated lower reliance on benzodiazepines and PRN medications compared with standard care (Gilmore-Bykovsky et al., 2021; Shimomura et al., 2024; Travers et al., 2018). The findings from this study align with this, suggesting that while awareness of dementia is widespread, there remains a gap in embedding applied, practice-based knowledge within acute care environments.

Overall, the findings suggest that while awareness of dementia is widespread, there is a gap in embedding applied, practice-based knowledge within routine care.

### Key Implications for ESNEFT

ESNEFT should develop and implement a more consistent, role-specific dementia training strategy, ensuring that all staff have the skills required to support people living with dementia in acute settings. This should move beyond one-off training to include ongoing learning, practical application, and reinforcement within day-to-day practice.

Greater use of dementia specialist roles (e.g. dementia leads or liaison teams) should be prioritised to support ward staff, model good practice, and provide real-time guidance in managing complex situations.

The use of tools such as ‘This is Me’ should be standardised and embedded within routine care processes, with clear expectations that information is not only completed but actively used to inform care. Integration within EPIC provides an opportunity to support this consistency.

Finally, ESNEFT should strengthen how training and knowledge translate into practice by linking education to patient and carer experience, ensuring that improvements in staff knowledge led to measurable improvements in care.

### Link to Recommendations

This theme is addressed through:

- **Recommendation 1 – Increase dementia specialism across the Trust**

- **Recommendation 2 – Develop an integrated dementia-focused training strategy**

- **Recommendation 4 – . Develop a 'care partners' framework to broaden volunteer and family carer support**

- **Recommendation 6 – Embed carers and persons living with dementia in strategic involvement**

## Theme 3 – Basic Care

The provision of fundamental aspects of care including nutrition, hydration, personal hygiene, comfort, and mobility was identified as a key determinant of patient experience for people living with dementia. While staff consistently recognised the importance of these elements, their delivery was often challenged by the demands and pace of the acute hospital environment.

**Mapping data** highlighted variability in the consistency and quality of basic care. While some patients received attentive and responsive support, others experienced delays or unmet needs. This was particularly evident at mealtimes, where patients often required additional time, encouragement, and assistance, which was not always available.

Patients exhibiting responsive behaviours were perceived to be increasing. While recognised as part of dementia care, these behaviours were partly attributed to insufficient time for staff to provide appropriate support, leading to increased distress and confusion.

The use of security staff was described as a necessary last resort to maintain safety; however, it was also viewed as potentially detrimental to patient wellbeing. Concerns were raised regarding the intimidating nature of security presence and limited training in dementia and de-escalation techniques.

The use of boarding and frequent ward moves particularly at night was highlighted as negatively impacting patient and family experience. **Process mapping** identified that over 60% of patients were moved at least once during the night, despite ESNEFT dementia policy advising this should be avoided.

**Carers** frequently described stepping in to support basic care needs, particularly with feeding, hydration, and reassurance. While generally welcomed by staff, this raised concerns about equity for patients without carer presence. Carers also reported uncertainty about their role, indicating a lack of clear communication and expectations.

**Staff** identified competing priorities and staffing pressures as key barriers to delivering consistent basic care. Task-based care often took precedence over relational and supportive aspects, particularly where staff lacked confidence in adapting care for people living with dementia.

In addition, gaps in delirium screening were identified in some patients, increasing the risk of inappropriate or delayed care.

The **review of literature** highlights that failures in fundamental care are associated with poorer outcomes, including increased risk of delirium, malnutrition, and distress (Featherstone et al., 2019), emphasising the importance of consistent, dementia-informed approaches to care.

### Key Implications for ESNEFT

ESNEFT should prioritise strengthening workforce capacity and support at ward level to ensure that fundamental care needs particularly nutrition, hydration, and personal care can be delivered consistently and without delay, especially during high-demand periods such as mealtimes.

Clear expectations and guidance should be established regarding the role of carers in supporting basic care, ensuring that involvement is encouraged, communicated, and applied consistently, while maintaining equity for patients without family support.

Targeted training should be expanded to ensure all staff, including security personnel, are equipped with dementia awareness and de-escalation skills to reduce reliance on restrictive or distressing interventions.

Greater emphasis should be placed on adherence to ESNEFT dementia care policy, particularly in relation to minimising ward moves and boarding, and ensuring routine delirium screening is completed. Monitoring of these areas should be strengthened to support accountability and improvement.

Finally, practical, ward-level approaches to improving care—such as protected mealtime support and enhanced patient supervision—should be standardised to reduce variability in care delivery.

This aligns with evidence linking fundamental care delivery to broader measures of quality and safety in healthcare systems (World Health Organization, 2021).

### Link to Recommendations

- **Recommendation 1 – Increase dementia specialism across the Trust**
- **Recommendation 2 – Develop an integrated dementia-focused training strategy**
- **Recommendation 3 – Develop a comprehensive dementia-friendly environment strategy**
- **Recommendation 4 – Develop a ‘care partners’ framework to broaden volunteer and family carer support**
- **Recommendation 8 – Monitor optimal dementia care pathways according to dementia care policy**

# Theme 4 – Communication

## Communication between hospital staff, families and carers

**Carers** described feeling confused by the hospital environment and unclear about medical pathways and processes. Many reported not knowing who to approach for information, or what was expected of them during the admission. Feelings of exhaustion and worry often compounded this uncertainty. Carers interviewed for this project did not report receiving support from the specialist dementia team. Concerns were also raised regarding communication around discharge, including instances of patients being discharged earlier than expected or late at night.

**Staff** reported spending significant time supporting families, answering questions, and providing reassurance. There was clear empathy for the challenges faced by families, particularly in complex situations. The specialist dementia team, alongside discharge and community teams, were viewed as valuable sources of support; however, their limited capacity meant they were often only able to prioritise the most complex cases. While staff felt that families were generally appreciative, they also described occasional challenges, including frustration from families and difficulties managing expectations around visiting and care processes.

Findings from the **mapping exercise** reinforced these issues, highlighting communication gaps such as confusion around medication and difficulty identifying the appropriate person to provide information.

The **Donabedian analysis** indicated that feedback from carers was not consistently or proactively collected, suggesting that communication challenges may not be fully understood or addressed at a system level.

Evidence from the **literature review** indicates that involving carers more effectively in care and communication can improve trust, confidence in staff, and overall experience (Luxford et al., 2015).

### Key Implications for ESNEFT

ESNEFT should implement a more structured and consistent approach to communication with carers from the point of admission, ensuring that families are clearly informed about ward processes, care pathways, and who to contact for information.

Clear points of contact should be established for carers on each ward, reducing uncertainty about who to approach and improving continuity of communication.

Discharge communication processes should be strengthened to ensure that carers are informed, prepared, and involved in planning, with particular attention to avoiding unexpected or late discharges where possible.

The role and visibility of the specialist dementia team should be reviewed, ensuring that carers are aware of available support and that access is not limited solely to the most complex cases where possible.

Finally, ESNEFT should strengthen how feedback from carers is routinely collected and used, ensuring that communication issues are identified early and inform service improvement.

### Link to Recommendations

Issues raised regarding hospital and family communication are addressed through:

- **Recommendation 6** – **Embed carers and persons living with dementia in strategic involvement**
- **Recommendation 7 – Enhance family and carer support through a dementia engagement framework**

## Communication between Staff and Patients

**Staff** described caring for people living with dementia as highly rewarding but also associated with frustration due to workload pressures and limited time. Many reported feeling unable to spend sufficient one-to-one time with patients, which contributed to feelings of guilt. Responsive behaviours were viewed as an expected aspect of dementia care; however, increasing levels of agitation and aggression were reported, often linked to low staffing levels and reduced opportunities for meaningful interaction. Staff also described examples where effective communication approaches led to positive outcomes for patients.

Some staff expressed frustration when visitors did not participate in aspects of care, such as supporting patients at mealtimes. However, there was also evidence of unclear communication with families about how they could be involved, for example in relation to the use of activity resources such as ward-based trolleys.

Communication between security staff and patients was consistently viewed as challenging and, at times, detrimental to patient wellbeing. Concerns were raised regarding the lack of dementia-specific training and appropriate de-escalation approaches.

**Carers** reported that communication between staff and patients sometimes reflected a limited understanding of the impact of dementia, particularly where patients were expected to follow instructions or act independently beyond their abilities. This could lead to behaviours being misunderstood and, in some cases, escalation to the use of security staff, which was perceived as distressing for patients. However, carers also highlighted many examples of positive and compassionate interactions between staff and patients.

The **Donabedian analysis** identified gaps in dementia training provision, with training paused during and after COVID-19, and further impacted by the introduction of EPIC. As a result, a significant proportion of staff have not received Level 2 dementia training since 2020.

Evidence from the **literature review** indicates that dementia-friendly environments and staff training can improve communication and interactions with patients, leading to increased staff confidence and reductions in distress and responsive behaviours (Brooke & Semylen, 2019; Innes et al., 2016; Allegri et al., 2022; Chenoweth et al., 2022). Interventions such as music-based activities have also been shown to support positive engagement between staff and patients (Daykin et al., 2018; McAulay & Streater, 2020).

Overall, findings suggest that while many staff demonstrate compassionate and effective communication, this is not consistently supported by training, environment, or capacity within the current system.

### Key Implications for ESNEFT

ESNEFT should prioritise reinstating and strengthening dementia training across the workforce, ensuring that all staff have the skills to communicate effectively with people living with dementia, particularly in recognising and responding to responsive behaviours.

Additional targeted training should be provided for non-clinical staff, including security personnel, to ensure that all staff interacting with patients are equipped with appropriate communication and de-escalation skills.

Ward environments and routines should be reviewed to support more meaningful interaction between staff and patients, including protected time for engagement and the use of simple interventions such as activity resources and music to support communication.

Clearer communication should be established with families regarding how they can support patient interaction and care, ensuring that opportunities for involvement are understood and encouraged.

Finally, ESNEFT should ensure that communication practices are supported through both training and environment, recognising that effective communication is central to reducing distress, improving patient experience, and minimising escalation.

### Link to Recommendations

- **Recommendation 1 – Increase dementia specialism across the Trust**
- **Recommendation 2 – Develop an integrated dementia-focused training strategy**
- **Recommendation 3 – Develop a comprehensive dementia-friendly environment strategy**
- **Recommendation 6 – Embed carers and persons living with dementia in strategic involvement**

## Theme 5 – Staff Issues and Wellbeing

**Staff** interviews identified supportive colleagues as an important protective factor, particularly during periods of service pressure. Perceptions of feeling valued varied, with staff often reporting feeling appreciated by patients and families, but less consistently by the organisation. There were also multiple references to challenging communication with families, including occasional abusive behaviour from both patients and visitors.

Some staff reported that pressures within the emergency department could override ward needs, resulting in reduced staffing levels on wards and increased workload for remaining staff. There was evidence that morale was low in some areas, with several staff describing a decline since COVID-19. High workload, staff shortages, and competing priorities contributed to stress and, at times, feelings of inadequacy in being unable to provide the level of care they aspired to deliver.

Staff also reported that limited time with patients could contribute to increased distress and responsive behaviours, creating a cycle where workload pressures further impacted patient care and staff wellbeing.

**Carers** recognised the pressures staff were under and often expressed empathy, acknowledging that staff were doing their best in challenging circumstances. However, some carers reported difficulty accessing staff and occasional instances of reduced compassion, which were sometimes attributed to workload or limited dementia knowledge. One carer noted that relationships with staff improved over time as familiarity increased.

The **Donabedian analysis** indicated that staff sickness and overall wellbeing had improved since COVID-19; however, staffing levels remained below those required to meet patient acuity, particularly during the day. In addition, reporting of staffing shortfalls was inconsistent, limiting full understanding of workforce pressures.

Additional observations show that during the DemFoCAS project there have been several gaps in staffing due to sickness, turnover and annual leave within the dementia specialist nursing team, creating dementia support gaps and illustrating a lack of resilience in the team and points of system failure.

Evidence from the **literature review** suggests that targeted interventions can support staff wellbeing and confidence. Dementia-focused training programmes have been shown to reduce stress and improve confidence, while additional support through volunteers and carer involvement can help reduce workload pressures (Gilmore-Bykovskyi et al., 2021; Bateman et al., 2016; Luxford et al., 2015).

Overall, findings highlight the interdependence between staff wellbeing, workforce capacity, and the ability to deliver high-quality dementia care.

Approaches to improving staff issues and wellbeing include increasing support on the wards from volunteers, charity partnerships and carers. Increasing dementia specialist support would ease pressure on ward staff, and training in dementia could improve confidence and lead to more positive interactions with patients. Similarly, strengthening communication with families and carers would help them contribute more effectively to patient support.

**Key Implications for ESNEFT**

ESNEFT should prioritise the development of a clear and coordinated approach to workforce capacity and staff wellbeing, ensuring that staffing levels at ward level are aligned with patient acuity and care needs, particularly for patients living with dementia.

A structured staff wellbeing strategy should be strengthened, with a focus on supporting staff working in high-pressure areas, including access to psychological support, supervision, and opportunities for reflection.

Dementia training should be expanded as part of a wider approach to improving staff confidence and reducing stress, ensuring staff feel equipped to manage responsive behaviours and provide person-centred care.

Additional ward-level support should be developed through volunteers, carers, and specialist dementia roles to reduce pressure on staff and enable more time for patient interaction and care.

Finally, ESNEFT should improve the consistency and visibility of workforce data, including staffing shortfalls and wellbeing indicators, to better understand pressures and support targeted improvements.

**Link to recommendations**

This theme is addressed directly and indirectly through:

- **Recommendation 2 – Develop an integrated dementia-focused training strategy**
- **Recommendation 7 – Enhance family and carer support through a dementia engagement framework**
- **Recommendation 9 – Enhance workforce capacity and wellbeing through improved staff levels and a wellbeing strategy**

# System Context, Organisational and External Factors

The DemFoCAS project was undertaken during a period of significant organisational and system change across ESNEFT. Several contextual factors influenced both the delivery of the project and the environment in which findings should be interpreted.

A key development during this period was the implementation of the EPIC electronic patient record system. This required substantial staff training and adaptation to new processes, resulting in competing priorities and the temporary pause or deferring of some training programmes, including dementia education. While EPIC offers longer term benefits in improving the Trust's information, communication, assessment, recording keeping and access to patient information, its introduction impacted staff capacity during the project. It should be noted, however, by the end of the DemFoCAS project, evidence of improvements of record keeping, such as assessment scores, were already evident, beginning to address, for example, issues of inconsistent record keeping evidenced in the mapping phase of the project.

The project also took place in the context of ongoing recovery from the COVID-19 pandemic, alongside wider organisational changes including restructuring, personnel changes, industrial action, and evolving service pressures. These factors contributed to workforce challenges, variability in staffing levels, and constraints on time available for training and service development.

The project team maintained engagement with the Trust throughout, sharing findings through governance structures including the Delirium and Dementia Committee, Assistant Directors of Nursing, and the senior nurse linked to the project. This supported alignment with organisational priorities and ongoing developments. However, significant time was spent by the DemFoCAS team in the first year identifying contacts and understanding organisational structures. ESNEFT stakeholders were engaged and interested - attending events, meetings and interviews - but faced significant time pressures. As a result, deeper or more sustained involvement, such as reviewing detailed project documents, was difficult to secure due to competing clinical priorities.

Several operational challenges highlighted the presence of siloed ways of working within ESNEFT. Key staff involved in care of patients with dementia were not initially informed of the project during its early stages, and the DemFoCAS team was only invited to the dementia and delirium steering group (a key influential Trust forum), after the first year of activity. The Donabedian analysis in Phase 1 was also slowed by limited clarity around divisional roles and responsibilities, which made it difficult to identify appropriate information sources. Additionally, CPD-commissioned dementia training was not developed in partnership with the ESNEFT dementia specialist team, despite their central role in delivering dementia-focused education. These factors, whilst challenging to fully address in a large, complex organisation, highlighted a fragmented and disjointed management.

## Partnerships between Healthcare and Higher Education Institutions (HEIs)

### Clinician/PhD student

The embedded PhD student provided invaluable clinical insight, awareness of organisational pressures, and up to date knowledge of changing processes and new dementia related initiatives within ESNEFT. They eased navigation of governance processes and enabled access to clinical areas and staff. Although substantial challenges persisted (e.g. staffing shortages, operational pressures, sickness, restructuring and industrial action), the student's clinical expertise and established relationships helped mitigate their effects. This demonstrates how embedded clinical expertise is crucial for delivery of high-quality research in complex acute settings.

### NIHR Insight Programme

The student placement in phase 2 of the project was an example of the NIHR insight programme at the University of Essex. This helps build a sustainable, clinically embedded research workforce within ESNEFT by funding master's-level training and structured support, enabling health and social care professionals, particularly in dementia care, to develop research skills alongside clinical roles, translate evidence (e.g., DemFoCAS findings) into service improvements, foster innovation in practice and workforce development, and create a long-term pipeline into doctoral research that strengthens a research-active culture across the Trust.

To maximise the impact of future projects, they should formally include and cost clinical staff, allocating dedicated time (e.g. one day per month), for roles such as site co-ordinators. This would support organisational ownership, ground projects in practice, and support effective implementation, whilst strengthening collaboration with Higher Education Institutions (HEIs) to develop sustained, embedded programmes of research aligned with clinical and quality improvement priorities.

## Continuing professional development

The University of Essex has supported ESNEFT through delivery of a programme of 2-day workshops delivering training to clinical staff on responsive behaviour. This included Virtual Dementia Training (VDT), an immersive simulation designed to build understanding of the lived experience of dementia. This commissioned work illustrates how HEIs can provide practical, expertise-driven support and help buffer . logistical challenges associated with inhouse training. However, whilst valued by staff and is likely to have contributed to improved practise, the long-term impact depends on how learning is embedded in practice. Without structured reinforcement such as reflective supervision, alignment with policy, and integration into quality improvement training risks remaining experiential rather than leading to sustained change. Stronger HEI / healthcare partnerships should therefore ensure collaborative mechanisms are in place to support ongoing reinforcement and application in practice.

# Section 11 – Recommendations

## Introduction

Over the course of this three-year project, a great deal has changed within the Trust, across both sites and the wider system. We have updated our work as fully as possible as an external partner, drawing on regular staff contact, ongoing ESNEFT meetings, and stakeholder events. However, we recognise the Trust is a “live” organisation and many aspects of care delivery will inevitably have evolved in ways outside of the project. One of the most significant changes has been the implementation of the electronic patient record system (EPIC). As a result, some components of our work such as the processes documented in the 2024 progress report and the process mapping outlined in Section 6 reflect earlier workflows that have since shifted considerably following the introduction of EPIC. The DemFoCAS team acknowledges that parts of our recommendations, including potentially substantial elements, may already be in progress or partially addressed by the Trust.

## Guidelines/Strategy:

### Cross-mapping recommendations with dementia and older people policy priorities

The recommendations arising from the DemFoCAS project closely align with national and international policy priorities relating to dementia care, older people and the health and care workforce. Mapping findings to these frameworks demonstrates the project’s relevance, transferability and potential for system-level impact.

### Impact statement

By aligning its recommendations with established national and international dementia, ageing and workforce policies, the DemFoCAS project provides actionable, policy-relevant evidence to support service improvement, workforce development and strategic planning in acute hospital settings.

What follows is a presentation of the 10 recommendations, with rationale, objectives and mapped out across evidence, findings and key policies.

# Recommendation 1 – Increase dementia specialism across the Trust

| Recommendation 1 |
|---|
| **Rationale:**<br>- The current dementia specialist nursing team is one specialist nurse and one HCA per site. There is a lack of resilience in the team to cover sickness, turnover and leave.<br>- High workload and extensive responsibilities limit capacity, forcing the dementia specialist nurse team to prioritise only the most complex cases. This results in delayed audits, reduced support for less complex patients, and impacts staff morale and mental health, as reflected in staff interviews.<br>- The Dementia and Delirium Steering Group ensures multi-disciplinary oversight of dementia care across the Trust but currently meets quarterly.<br>- Carer interviews revealed gaps in staff dementia knowledge and non-dementia-friendly care, underscoring the need for comprehensive dementia awareness as prevalence rises.<br>- Carers interviewed were unaware of any involvement from dementia specialist staff, which may reflect indirect patient focused input or may relate to reduced team visibility linked to limited resilience.<br>- Cognitive champions across hospitals to enhance dementia care, share knowledge with staff, and cover gaps when specialists are absent.<br>- Dementia specialist support is largely limited to older adult wards, leaving patients on general and specialist wards at risk of receiving less skilled care. |
| **Objectives:**<br>- To increase resilience in the dementia specialist team<br>- To reduce workload in individual dementia team members to allow for more patients to be supported.<br>- To enhance dementia specialist knowledge throughout the Trust |

**Recommendation:**

The Trust should expand the dementia specialist team by enhancing its skill mix and exploring support from allied health professionals and trained generic staff, such as Assistant Practitioners or HCAs on apprenticeship programmes, to strengthen expertise, resilience, and succession planning. It should also identify other nursing and allied health professionals who can deputise in the absence of any dementia specialist team member. In addition, we recommend cognitive champions are trained and identified across the Trust.

**Focus area:** Relates to ‘Increase dementia awareness and training’

**Touchpoints:** 5

**Guidelines/Strategy:**

**Practice recommendations and policy**

Embedding person-centred dementia care in hospitals aligns with the WHO Global Action Plan on Dementia (2017–2025) (2017) and Global Strategic Directions for Nursing and Midwifery (2021–2025) (2021), which emphasise dignity, rights-based care, and compassionate leadership. In England, it supports the NHS Dementia Well Pathway (NHS England, 2022a) and DHSC Dementia 2020 Challenge (2015b), while partnering with carers reflects the NHS Long Term Plan’s commitment to their role in safe, high-quality care for older people with complex needs (2019).

# Recommendation 2 – Develop an integrated dementia-focused training strategy

**Recommendation 2**

**Rationale:**

- Current in-house Level 2 dementia training relies on 2-day workshops run by the specialist team, creating significant workload and making the programme vulnerable to disruptions from events like COVID, EPIC rollout, or winter pressures.
- EPUT provides training for its staff, including virtual dementia training (VDT) highlighting an opportunity to pool resources for wider training delivery. EPUT has also enabled Colchester Hospital staff to shadow their teams to enhance dementia knowledge.
- University of Essex training, commissioned through ESNEFT's CPD department, has trained 73 staff with 200 more planned. However, being delivered independently of the dementia specialist team limits their ability to assess impact or support participants.
- Previous ESNEFT 2-day workshops developed 'cognitive champions' who enhanced ward practice by raising awareness, educating colleagues, and promoting person-centred, dementia-friendly care.
- Incorporating lived experience enriches training. First-person accounts like Wendy Mitchell's What I Wish People Knew About Dementia (2022) offer valuable experiential insight.
- The lack of training since COVID, especially in light of the significant staff turnover has reduced the number of dementia skilled staff.

**Objectives:**

- To increase the level of dementia knowledge across the Trust, and work in partnership to pool resources.
- To centralise and co-ordinate dementia training across ESNEFT
- To assess dementia training impact through quality measures and audits aligned with NICE and ESNEFT policy

**Recommendation:**

Develop an overarching framework to strengthen ESNEFT's in-house dementia training, pool resources in partnership, and coordinate Trust-wide delivery. The framework should draw on multiple training sources, centrally managed by an ESNEFT training lead in collaboration with the dementia specialist team and key stakeholders. CPD-delivered training should be regularly evaluated, and the framework should align Virtual Dementia Training with the ESNEFT Dementia and Delirium Policy, NICE standards, and CQC domains.

**Themes:** This recommendation addresses multiple DemFoCAS themes of individualised care, basic care, communication and staff issues and wellbeing.

**Focus area:** This recommendation relates to 'Increase dementia awareness and training'

**Touchpoints:** Relates to touchpoints 9 and 10

**Guidelines/Strategy:**

**Education recommendations and policy**

The recommendation to embed dementia education across undergraduate, postgraduate and continuing professional development pathways aligns with the Royal College of Nursing Dementia Care Position Statement (2019) and the Health Education England Dementia Training Standards Framework (2018), which call for dementia knowledge to be a core competence across all staff groups, including non-clinical roles.

# Recommendation 3 – Develop a comprehensive dementia-friendly environment strategy

| Recommendation 3 |
|---|
| **Rationale:**<br>- Dementia friendly environments include clear layouts, good signage, colour coded wayfinding, low noise, soft lighting, access to suitable stimulation and social engagement for independence, dignity and wellbeing (Department of Health and Social Care, 2015a).<br>- ESNEFT is committed to dementia friendly environments through its dementia care policy (ESNEFT, 2025), and Ipswich Hospital follows the Suffolk Dementia Strategy 2024 - 2029 (Suffolk Dementia Partnership, 2024)<br>- ESNEFT's patient experience team uses the NHS 'ACE' (Assessment of Care Environments) tool for assessments. In conjunction with the dementia specialist team, they are working towards Alzheimer's Society accreditation.<br>- The dementia specialist team used the Kings Fund Dementia Friendly Environment Assessment Tool but audits were paused in 2025.<br>- Carers and staff reported environmental issues, including disorientation from surroundings, stress in single rooms lacking stimulation, noise from open visiting, and the need for more dementia-friendly rest areas or redesigned wards to support interaction. |
| **Objectives**:<br>- To have a comprehensive strategy across ESNEFT<br>- To co-ordinate funding for improvements and innovation. |
| **Recommendation:**<br>Develop a comprehensive dementia friendly environment strategy to co-ordinate efforts to make the hospital environment dementia friendly. This could include converting unused spaces to dementia friendly resting areas, installing 'bus stops' or similar, and producing guidelines for placement of patients with dementia. |
| **Themes:** 'Individualised care', 'communication' |

**Focus area:** ‘Enhance the use of dementia friendly environments’

**Touchpoints:** Previously touchpoint no. 6

**Guidelines/Strategy:**

This recommendation reflects NHS England priorities within the NHS Long Term Plan (2019), which emphasises early identification and improved care for people living with dementia. It is supported by National Institute for Health and Care Excellence guideline NG97 (2018) and QS184 (2019), alongside the NG86 (2012) regarding Patient Experience in Adult NHS Services, reinforcing the need for coordinated, person-centred care and consistent standards across services.

# Recommendation 4 – Develop a ‘care partners’ framework to broaden volunteer and family carer support

**Recommendation 4**

**Rationale:**

- Volunteers are an integral part of patient experience at ESNEFT. Numbers were depleted during and post COVID but have substantially increased over the duration of the DemFoCAS project.

- Carers and staff shared the viewpoint that more volunteer support would be beneficial to patients who are often lacking cognitive stimulation, which can in turn lead to patient agitation and confusion.

- Carers are often keen to be involved in supporting patients and the hospital. Carers often want to “give back”, an integrated carer support group should be formed to support other carers and families and encouraged to become future volunteers, when ready.

- Collaborative initiatives that include input from people with lived experience who bring perspectives that clinicians alone may omit.

**Objectives:**

- To increase volunteer numbers and expand their supportive activities

- To support and encourage carers to become involved in volunteering

**Recommendation:**

Develop a supportive care partners strategy which provides a framework to increase additional care support from carers, families and volunteers. This includes increasing volunteer numbers, broadening their involvement to different supportive activities and encouraging carers to become volunteers.

**Themes:** This recommendation reflect all project themes (role of the carer, individualised care, basic care, communication and staff issues and wellbeing)

**Focus areas:** Optimise volunteer and carer support

**Touchpoints:** Relates to touchpoint no. 11

**Guidelines/Strategy:**
This recommendation aligns with NHS England guidance on personalised care (2023b) and NHS Volunteer Responders Programme (2023a) , which promote the role of volunteers and community partners in supporting wellbeing. It is also supported by National Institute for Health and Care Excellence guideline NG97 (NICE, 2018), which emphasises meaningful activity and carer involvement in improving outcomes for people living with dementia.

# Recommendation 5 – Assign a dementia care partnership and engagement lead

| Recommendation 5 |
|---|
| **Rationale:**<br>▪ The Trust should continue to support initiatives that improve the experience of people living with dementia, their carers and families. While the Dementia and Delirium Steering Group provides a strong forum for coordination and discussion, the absence of a designated Trust-wide lead limits oversight and consistency. A named lead would strengthen coordination, accountability and delivery of dementia care improvements.<br>▪ Due to siloed working practices, many projects and initiatives are missed. Examples include the DemFoCAS project which was not known about by clinicians for some time; CPD training arranged independently, as well as local council and charity funded initiatives.<br>▪ Staff suggestions to improve experiences for patients with dementia include several centred around support from volunteers or activity co-ordinators.<br>▪ DemFoCAS introduced two dementia-support initiatives at Colchester Hospital: the Age Well East Sundowning Project, which ended early due to staffing issues, and an Alzheimer's Society initiative now integrated into the community dementia team.<br>▪ At Ipswich Hospital, support for people living with dementia and their families is provided by Shaftesbury Suffolk Memory and Dementia Support and Suffolk Family Carers, with referrals available for additional support.<br>▪ The DemFoCAS project identified no current initiatives that place activity coordinators on wards to provide therapeutic stimulation or support with basic care, e.g. eating representing a gap in patient-centred dementia care.<br>▪ This recommendation proposes appointing a named lead for each ward-based initiative to provide clinical oversight, support partner organisations, and offer on-site guidance to staff. |

**Objectives**:

- To collaborate with external partners and clinicians to develop effective and smoothly integrated partnership projects

**Recommendation:**

The recommendation is to assign a lead for ESNEFT who would be responsible for co-ordinating and integrating partnership projects which involve external parties, such as charities and local government, to provide on-ward support to patients and families. In addition, this role should include oversight of all dementia related projects across the Trust to ensure alignment, reduce duplication, and maintain a coherent strategic direction.

**Themes:** Links to themes ‘communication’ and ‘individualised care’

**Focus areas:** Relates to **‘**Optimise volunteer and carer support’ and ‘Review systems and processes’

**Links to other recommendations:** Related to recommendation 4

**Guidelines/Strategy:**

This recommendation reflects NHS England priorities within Integrated Care Systems (2022b) and the Health and Care Act (2022), which emphasise partnership working across health, social care and the voluntary sector. Establishing a dedicated lead supports system leadership, reduces fragmentation, and aligns with ICS guidance on place-based coordination and accountability.

# Recommendation 6 – Embed carers and persons living with dementia in strategic decision-making

**Recommendation 6**

**Rationale:**

- Involving people with lived experience, carers and families in care design and delivery ensures hospital services better meet the needs of those affected by dementia.

- Effective communication and management of dementia-focused care should be grounded in a collaborative approach

- Carers in the DemFoCAS steering group, PPIE workshops and carer interviews often expressed a desire to be heard, to be involved and to 'give back' to the NHS to improve care.

**Objectives:**

- To include early adoption of patient and public involvement and engagement (PPIE) in strategic dementia planning and decision-making.

- To co-designing and co-produced with individuals with dementia and carers

- To involve the voices of people with dementia and their carers in care.

**Recommendation:**

Adopt a collaborative approach to dementia care that embeds people living with dementia and their carers across training, care processes, feedback, and service improvement to ensure services remain relevant and experience led. This includes training, documentation, care processes, ongoing service improvements, patient feedback and volunteering roles.

**Themes:** Role of the carer, Communication, Individualised care

**Focus areas:** Involve people with lived experiences at all levels of decision-making.

**Touchpoints:** Extends 12

**Links to other recommendations:** Related to recommendation 7

**Guidelines/Strategy:**

This recommendation aligns with the NHS England Patient and Public Involvement and Engagement (PPIE) frameworks (2021b). It is also supported by National Institute for Health and Care Excellence guideline NG197 (2018), ensuring services are co-designed, person-centred and responsive to lived experience.

# Recommendation 7 – Enhance family and carer support through a dementia engagement framework

| Recommendation 7 |
|---|
| **Rationale:**<br>▪ Carers reported feeling exhausted, scared, and stressed, overwhelmed by the disorienting hospital environment and their loved one's admission, often feeling disconnected from staff and unsure how to seek support.<br>▪ ESNEFT's website can be confusing and difficult to navigate, often contains outdated information, and, whilst a valuable resource, is not dementia friendly.<br>▪ Carers and families often have their own health issues, and may themselves be living with dementia, so clear, dementia-friendly communication is essential for supporting them as well as patients.<br>▪ ESNEFT staff recognise that families are often at "crisis point" when a person with dementia is admitted and prioritise those in greatest need, yet the hospital environment remains confusing and challenging for many carers.<br>▪ Despite efforts to optimise discharge, early and collaborative communication with families remains a challenge, as highlighted in carer interviews and stories.<br>▪ Carer packs at Ipswich and more recently at Colchester contain useful information about community support and a feedback form for carers. |
| **Objectives:**<br>▪ To improve the carer/family experience through clearer and more accessible information<br>▪ To provide more orientation to families/carers so they know who to ask for what and what support is available<br>▪ To ensure families/carers understand how they can help provide care if they wish and know they can |

- To increase proactively collected patient/carer feedback and create a structure through which findings are reviewed in order to address issues as they arise and improve patient/carer experience accordingly
- To explore ways that further improvements can be made around admission avoidance
- To continue improving earlier discharge planning and optimise communication with families.

**Recommendation:**

Develop a dementia communication and family engagement framework in partnership with experienced carers, providing clear information to help families navigate the hospital and access support.

Standardise dementia-friendly discharge planning with early initiation, consistent family communication, and stronger community integration to ensure safe, timely discharges and reduce avoidable readmissions.

**Themes:** Role of the carer, communication

**Focus area:** 'Optimise volunteer and carer support', 'Review systems and processes'

**Touchpoints:** Relates to touchpoints 12, 13 and 14

**Links to other recommendations:** Related to recommendation 6

**Guidelines/Strategy:**

This recommendation reflects National Institute for Health and Care Excellence guidance CG138 (2012) and NG197 (Shared Decision Making; 2018), alongside NHS England commitments to carer inclusion (2022a). It also aligns with discharge and care planning standards outlined in the Hospital Discharge and Community Support Guidance, supporting carers as key partners in safe and effective transitions of care (Department of Health and Social Care, 2024).

# Recommendation 8 – Monitor optimal dementia care pathways according to dementia care policy

**Rationale:**

- The dementia care policy (ESNEFT, 2025) provides an important framework designed around national guidelines to help improve dementia care outcomes. The policy includes commitments to providing positive patient experiences and a dementia friendly care and environment.
- The mapping exercise showed that guidelines in the dementia care policy are not always followed. This is partly due to tools, such as the 4AT not being part of the care pathway documentation used by nursing staff. As this is integrated, and EPIC will allow easier, real-time documentation and ongoing record of assessments with be available.
- Mapping and staff interviews revealed continuing ward moves after 8pm, going against guidance in the dementia care policy (2022,2025)
- Ongoing audits are in place, and EPIC can now be used to integrate, monitor, and audit dementia and delirium care outcomes, with results feeding into the steering group. Assessment reports should be accessible to the dementia specialist team and senior clinicians to support guideline adherence and quality monitoring.

**Objectives:**

- To embed the dementia care policy into a continuous monitoring and development process to enhance care for patients with dementia
- To ensure that EPIC can provide reports to the dementia specialist nurses and senior clinicians in order to reduce time spent on collecting information and auditing manually.

**Recommendation:** Utilise the dementia care policy (ESNEFT, 2025) to monitor the care of patients with dementia, assess adherence to the policy, and identify areas for ongoing improvement. We recommend that EPIC reporting features enable the ESNEFT dementia nurse specialist team and a senior clinicians to monitor and audit features of the dementia care policy, so they can effectively shape, plan, and contribute to strategies for dementia care across the Trust.

**Themes:** Basic care, individualised care

**Focus areas:** 'Review systems and processes'

**Touchpoints:** Relates to touchpoint No. 4

**Guidelines/Strategy:**

Embedding dementia care within acute hospital governance frameworks supports broader healthy ageing agendas, including the World Health Organisation Decade of Healthy Ageing (2021-2030) (2020) , reinforcing the need for age-friendly health systems that meet the complex needs of older people.

# Recommendation 9 - Enhance workforce capacity and wellbeing through improved staff levels and a wellbeing strategy

| Recommendation 9 |
|---|
| **Rationale:**<br>- The Donabedian evaluation found that wards often operated with nursing levels below patient acuity and dependency needs. Gaps in retrospective reporting of hours make ongoing monitoring difficult, and findings require verification with ESNEFT senior nursing staff.<br>- Staff sickness and wellbeing since COVID showed some improvement, though challenges remained, and breaking this down by staff group would help clarify the impact on those caring for patients with dementia.<br>- In staff interviews, high workloads, persistent staffing shortages, and the emotional strain of being unable to support every patient were reported, with some noting low morale. Carers also expressed concern that staffing pressures hindered communication and the quality of care.<br>- Research shows that staff burnout in the NHS is often related to elements such as inadequate staffing levels, time pressures and psychological demands of their roles (Dall'Ora et al., 2020), showing the importance of investing time in looking after the workforce. |
| **Objectives:**<br>- Establish meaningful reporting and review protocols to improve nursing staffing levels.<br>- To increase staff support and ensure its effectiveness by consulting with staff in ways other than the annual staff survey. |
| **Recommendation:**<br>Review and enhance staffing-level reporting to provide accurate, meaningful data. Support the emotional and practical demands of dementia care through staff wellbeing initiatives, workforce development, interdisciplinary collaboration, and strengthened roles for dementia clinical nurse specialists, including links with community services and voluntary partners. In addition, staff should be routinely consulted about the effectiveness of these support measures, rather than relying solely on annual surveys, to ensure that interventions remain responsive to their needs. |

| |
|---|
| **Themes: Staff issues and wellbeing** |
| **Focus areas: Review staffing issues and wellbeing** |
| **Touchpoints: Relates to touchpoints 8, 18,19,20** |
| **Guidelines/Strategy:** Leadership development in compassionate, reflective practice aligns with the WHO Nursing and Midwifery Strategy (2021–2025) (2021), ICN (2025) definition of nursing, and the NHS England People Promise, all of which emphasise inclusive leadership, staff wellbeing, and reflective learning cultures as foundations for quality care. Positioning staff wellbeing as a patient safety and care-quality priority reflects the WHO Global Health and Care Worker Compact, the NHS People Plan, and The King’s Fund evidence linking workforce wellbeing to improved care outcomes. |

# Recommendation 10 - Embed clinically led dementia research and innovation within Trust strategy

| Recommendation 10 |
|---|
| **Rationale:**<br>▪ The systematic review found a major evidence gap in evaluating acute-setting innovations for people with dementia, with few rigorous studies and limited robust quantitative or theory-driven qualitative research. While service evaluations offer insights, more rigorous research (e.g., RCTs, high-quality qualitative studies) is needed to strengthen the evidence base and improve hospital experiences for patients, carers, and staff.<br>▪ Collaboration with a complex and fast paced organisation such as ESNEFT was often challenging due to clinical pressures and lack of costed clinical time for the project.<br>▪ The embedded PhD student provided key clinical insight and organisational knowledge that improved access and governance navigation, helping to offset operational pressures and demonstrating the essential role of embedded clinical expertise in delivering high-quality research in complex acute settings.<br>▪ The NIHR INSIGHT programme supports ESNEFT in developing a clinically embedded research workforce by funding master's-level training and structured support, enabling staff to build research skills, translate evidence into service improvements, and progress toward doctoral pathways.<br>▪ Include funded, dedicated clinical staff time (e.g., one day per month) in future projects would strengthen organisational ownership, anchor initiatives in practice, support effective implementation, and enhance HEI collaboration to deliver sustained, embedded research aligned with clinical and quality improvement priorities. |

**Objectives:**

- To support future research by ensuring projects include and embed clinicians whose time is costed into project budget and clinical time backfilled.

- To strengthen and sustain collaborative working between ESNEFT and the University of Essex.

- To ensure early involvement of people with lived experience, carers and families in the co-design and co-production of future research.

**Recommendation:**

Prioritise future research and establish dedicated, protected time for ESNEFT clinicians to work in partnership with University of Essex researchers, ensuring projects have embedded clinical expertise and the organisational support required for high quality delivery underpinned by people with lived experience.

**Themes:** All themes

**Focus areas:** All focus areas

**Guidelines/Strategy:**

Calls for post-Covid UK research on dementia care experiences directly address evidence gaps identified by the National Institute for Health and Care Research (Liu et al., 2021) and support the Alzheimer's Society research priorities (2025a), which highlight the need for contemporary, lived-experience-informed evidence to shape service design.

The emphasis on co-produced research aligns with National Institute for Health and Care Excellence dementia guidance in NG97 (2018) and NG197 (2021), which promotes shared decision-making and involvement of people living with dementia and carers in service evaluation and improvement.

# Section 12 - Future Directions and Next Steps

The DemFoCAS project provides a strong platform for sustained research, clinical academic development and service improvement within ESNEFT and beyond. The work has generated new knowledge, infrastructure and expertise which has strengthened partnerships and established a foundation for a coordinated programme of dementia and delirium research aligned with national priorities.

## Dissemination and Publication

Dissemination of the DemFoCAS project findings is an important next step to maximise impact both within ESNEFT and more widely. The project team has already begun sharing learning through local and national conference presentations, supporting knowledge exchange and engagement with wider clinical and academic audiences. In addition, outputs from the programme are being developed and progressed through academic publication, including peer-reviewed journal articles that are published, under review, or in preparation. This includes related work led by the team (e.g. Marrow et al., 2024) and a systematic review currently under review in the International Journal of Mental Health Nursing.

## Post-doctoral and NIHR-aligned Research Development

The project has generated important insights into dementia care in acute hospital settings and highlights clear opportunities for further research focused on implementation, sustainability and system-level improvement. A key strength moving forward is the clinical PhD researcher embedded within the project, who is well positioned to lead the next phase of research development at post-doctoral level. This role provides continuity between research and practice while strengthening clinical academic leadership within nursing and the allied health professions (AHPs).

An important priority will be the development of clinical research leadership, enabling the clinical PhD researcher to lead future grant applications and establish a sustained programme of dementia research linked to ESNEFT clinical priorities. This will involve building and strengthening collaborations with the University of Essex and other academic partners, while also developing partnerships with charities, voluntary organisations and industry partners working in dementia care. These collaborations will support the development of innovative research programmes, facilitate access to wider expertise and funding opportunities, and strengthen the Trust's position within national dementia research networks.

Future research development will involve close collaboration with clinical nurse specialist (CNS) dementia teams, community dementia services and voluntary sector partners involved in supporting patients within the hospital environment. Working across these clinical and community interfaces will be essential to ensure that future research is grounded in real service needs and supports continuity of dementia care across care settings.

Central to this work will be the continued engagement of the project's patient and public involvement and engagement (PPIE) group, including carers and people living with dementia. Their ongoing involvement will help ensure that research priorities, study design and interpretation of findings remain closely aligned with lived experience and patient-centred care.

Future research may focus on the implementation and evaluation of dementia-specific interventions in acute care settings, including specialist dementia units, delirium prevention strategies, workforce education, volunteer-based support programmes and models that strengthen carer involvement in hospital care. Particular attention will be given to understanding how these approaches can be implemented sustainably within routine practice and their impact on patient experience, safety and outcomes.

These priorities align closely with NIHR strategic themes in dementia, applied health research and workforce development. Potential funding routes include NIHR Post-Doctoral Fellowships, Programme Development Grants and collaborations with

Applied Research Collaborations (ARCs). Building on the partnerships established through this project, future work could involve multi-site studies, mixed-methods evaluations and implementation research examining dementia-friendly models of care across hospital systems.

The clinical PhD researcher will also play a key leadership role in developing grant applications, strengthening collaborations with the University of Essex and other academic partners, and building relationships with charities, community organisations and industry partners involved in dementia care innovation. Through these partnerships, the project will continue to situate dementia care provision within the wider Trust system while supporting future innovation and research.

## Developing Clinical Academic Pathways in Nursing and AHPs

The project has demonstrated the value of embedding research within clinical practice and engaging frontline staff in evidence generation. There is now an opportunity to build on this momentum by strengthening clinical academic pathways within ESNEFT, particularly for nurses and AHPs. With the growing emphasis on NIHR funding opportunities for nursing, AHPs and other health professionals, the NIHR Insight Programme provides an important entry route for early-career clinicians to develop research skills at Master’s level and explore clinical academic careers. Supporting staff to access this programme could help establish a pipeline of future doctoral and post-doctoral researchers within the organisation.

Future development should include structured mentorship, protected research time and closer alignment between Trust priorities and university partnerships. The clinical PhD researcher will play an important leadership role in mentoring emerging researchers, working alongside CNS dementia teams, community services and voluntary sector partners to identify practice-based research questions.

This collaborative model will also involve the PPIE working group of carers and people living with dementia to ensure that research priorities remain grounded in lived experience and service need. Strengthening these pathways will help embed a sustainable research culture within ESNEFT and support the development of nursing and AHP leadership in dementia and delirium research.

# Project Impact and Value to the Trust

## Organisational and Clinical Impact

The project has generated sustained organisational impact by strengthening awareness, engagement and collaboration around dementia and delirium care within ESNEFT. Close working with the Delirium and Dementia Committee and the senior nursing team has helped align the project with Trust priorities and supported the integration of research findings into discussions about service development.

The involvement of the Trust project link, Marie Alexander, has been central to maintaining strong connections between the research team and clinical services. This role facilitated communication across organisational levels and supported engagement with key clinical groups including dementia clinical nurse specialists, ward teams and community dementia services. The experience of this project highlights the value of dedicated clinical liaison roles in ensuring research is embedded within service priorities. Allocating protected time for such roles in future projects would help ensure that research activity is fully integrated within the Trust’s strategic research plans and supports the translation of findings into practice.

Partnership meetings with key stakeholders including frontline staff, carers, people living with dementia and voluntary sector representatives were a particular strength of the project. These meetings enabled meaningful co-production, ensured that lived experience informed interpretation of the findings and supported dialogue about how dementia care can be strengthened across the Trust.

The project has also strengthened collaboration between hospital services, voluntary projects operating within the hospital and community dementia teams. These relationships provide an important foundation for future service innovation and research development focused on improving the experience of hospital care for people living with dementia.

## Contribution to Evidence, Dissemination and Impact

The project has contributed to the growing evidence base on dementia care in acute hospital settings at local, national and international levels. Dissemination activities have included peer-reviewed publications, conference presentations and engagement with professional and research networks.

Within the Trust, findings have been shared through internal forums, clinical networks and stakeholder meetings involving dementia CNS teams, community services and voluntary partners. These activities have supported knowledge exchange and raised awareness of evidence-informed approaches to dementia and delirium care.

The project also strengthens links with wider dementia research and practice networks, supporting opportunities for collaboration and knowledge sharing beyond the Trust. Partnerships with the University of Essex provide a strong academic foundation for continued joint working, including student projects, doctoral supervision, post-doctoral research and future funding applications.

## Legacy and Sustainability

The legacy of the project lies not only in its findings but also in the relationships, infrastructure and research capacity it has helped to establish. By bringing together clinicians, researchers, patients, carers and voluntary partners, the project has created a collaborative platform for continued research and service development in dementia and delirium care.

Importantly, the project has supported the development of clinical academic leadership within nursing and AHP groups while strengthening connections with dementia CNS teams, community services and voluntary sector organisations. Continued engagement with the PPIE working group will ensure that future research remains grounded in the experiences and priorities of people living with dementia and their carers.

Overall, the project has delivered both immediate and longer-term value for the Trust by informing service development, strengthening research capacity and embedding partnership working. These achievements provide a strong foundation for future programmes of research aimed at improving care quality, patient experience and workforce development for people living with dementia.

## Logic Model: Future Research and Capacity Development

*Table 13 Research and capacity development*

| Inputs | Activities | Outputs | Short-Term Outcomes | Long-Term Impact |
|---|---|---|---|---|
| DemFoCAS findings and datasets | Development of post-doctoral research proposals | NIHR fellowship and grant applications | Increased dementia research activity within ESNEFT | Improved dementia and delirium care in acute hospitals |
| Clinical PhD researcher leadership | Collaboration with dementia CNS teams, community services and voluntary sector partners | Cross-sector research partnerships | Stronger integration of research with clinical practice | Sustainable dementia research programme within the Trust |
| Partnerships with Delirium and Dementia Committee and senior nursing team | Co-production workshops with staff, carers and people living with dementia | Stakeholder-informed research priorities | Research aligned with service needs and patient experience | Improved quality and person-centred care |
| PPIE group including carers and people with dementia | Ongoing involvement in study design, interpretation and dissemination | Co-produced research outputs | Greater relevance and acceptability of research | Dementia care innovation shaped by lived experience |
| NIHR training pathways (MSc Insight, doctoral routes) | Mentoring early-career nurses and AHPs | Clinicians entering MSc and PhD training | Growth of clinical academic workforce | Long-term nursing and AHP research leadership |
| University of Essex and research networks | Publications, conferences and knowledge exchange | Peer-reviewed outputs and collaborative grants | Increased national and international profile | ESNEFT recognised as a centre for dementia research and innovation |

# Conclusion

This project provides a comprehensive exploration of dementia care in acute hospital settings through the voices of staff and spousal carers. The findings reinforce that high-quality dementia care is not solely dependent on individual staff behaviours but is shaped by organisational culture, resources, environments and leadership. While examples of compassionate, person-centred care were evident, these often occurred despite systemic pressures rather than because of supportive systems.

The integration of staff and carer perspectives highlights the interdependence between workforce wellbeing and patient experience. Staff wellbeing emerged as a critical enabler of compassionate care, while carer involvement was shown to be essential for understanding patients' needs and maintaining continuity of care. These findings align with national and international policy priorities that position dementia care, workforce support and leadership as central to safe and effective health systems.

Overall, the project demonstrates the value of listening to lived experience and embedding PPIE within service evaluation and research designs. The insights generated provide a strong foundation for targeted improvements in practice, education, research and policy, and offer transferable learning for other acute care organisations.

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# Appendices

| Appendix | Title |
|---|---|
| A | Systematic literature review extraction table |
| B | Conventional Process Mapping - Example Patient Pathways |
| C | Staff Interviews – Guide/Questions |
| D | Appendix D: Spousal Carer Interviews - Guide/Questions |
| E | Table of Touchpoints from the Progress Report 2024 |

# Appendix A: Systematic Literature Review Extraction Table - Studies Included.

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| ***Quantitative studies*** | | | | | | | | |
| Allegri et al. | 2022 | Italy | "To evaluate whether a short training focused on improving dementia care practices of the hospital staff was able to counteract functional loss and to decrease negative outcomes at discharge Objective: "To evaluate whether a short training focused on improving dementia care practices of the hospital staff was able to counteract functional loss and to decrease negative outcomes at discharge among hospitalized older adults with cognitive impairment." | "A dementia care intervention for the hospital staff, called 'IDENTITA: Italian Dementia-Friendly Hospital Trial'" | Between groups design. Control group data were taken before the intervention. | "General Medicine, Surgery, and Orthopaedics Units of the Civic Hospital of Vigevano (Italy)" | 68 hospitalized participants aged 65 and over with cognitive impairment with a MMSE score of between 16 and 24. Control group n = 34, intervention group n = 34 | "Results: The intervention group demonstrated shorter hospital length of stay and a maintenance of the functional status at discharge compared to the control group. We observed no differences in cognitive ability between the two groups, and a trend towards a decrease of anxious symptoms in the intervention group compared to the control group.<br>Conclusion: The results suggest that an intervention, focused on improving dementia care practices in healthcare staff, has the potential to improve the outcomes for hospitalized older adults with cognitive impairment." |
| Blair et al. | 2018 | Australia | "Evaluate the clinical outcomes for patients with dementia, delirium, or at risk for delirium supported by the person-centered volunteer program in rural acute hospitals." | Volunteers were recruited and trained to assist with care, with a focus on nutrition, hydration, hearing and visual aids, activities and orientation. | Non-randomized controlled trial using historic patients as a control group | 7 acute rural hospitals in New South Wales. Sub acute wards were excluded from analysis | 270 patients received volunteer care, 188 historical control patients. Over 65, cognitive impairment as per MMSE or dementia diagnosis or have delirium or be high delirum risk factors. Excluded - challenging behaviours such as aggression (Safety). 35.9% of patients on intervention (IG) had dementia diagnosis on admission, 41.7% for control (CG). 22.3% IG and 26.9% CG had delirium diagnosis. | "Across all sites, there was a significant reduction in rates of 1:1 specialling and 28 day readmission for patients receiving the volunteer intervention. LOS was significantly shorter for the control group. There were no differences in other patient outcomes for the intervention and control groups.<br>Conclusion: The volunteer intervention is a safe, effective, and replicable way to support older acute patients with dementia, delirium, or risk factors for delirium in rural hospitals" |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
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| Chenoweth L; Williams A; Fry M; Endean E; Liu Z | 2022 | Australia | "This pilot study assessed clinical outcomes and quality care for persons with dementia in an acute hospital with PCC, compared with usual care". | Person centred care education intervention | Non-randomized, two-group (control and treatment) pre-post-intervention pilot study | Two wards (one acute aged care, one mixed surgical/medical) in a major tertiary hospital in NSW Australia. | Control participants (n = 21) were enrolled in months 1–4 and PCC intervention participants (n = 26) were enrolled in months 5–9. The intervention group participants had a confirmed dementia diagnosis, were aged 60 and above, self or proxy consent, no delirium, no unstable physical or psychiatric illness and not on end of life care. | "Compared with controls, at Time 2 PCC produced statistically significant improvements in behavioural/neuropsychiatric symptoms (adjusted p = .036) and care quality (adjusted p = .044). Where length of stay exceeded 8 days after baseline (Time 3), there was a sustained improvement in quality care (p = .007), but not in behavioural/neuropsychiatric symptoms (p = .27).<br>Conclusions: PCC can improve care quality for persons with dementia; nursing; agitation; paid caregivers with dementia and reduce behavioural /neuropsychiatric symptoms during short hospital stays." |
| Cheong et al. | 2016 | Singapore | "This pilot study evaluates the impact of a creative music therapy (CMT) programme on mood and engagement in older patients with delirium and/or dementia." | Creative music therapy | Pilot study. Observational study over a 3 month period. | 10 bed acute care unit for patients with delirium and or dementia | 25 patients with delirium and or dementia were recruited and observed. Recruitment was consecutive. Inclusions were "(i) diagnosis of dementia with or without delirium, (ii) age ≥ 65 years, (iii) no prior experience with CMT and willing to engage in music therapy intervention, (iv) absence of severe hearing impairment or able to hear using hearing aids, (v) not suffering from severely disruptive and combative behaviours that impair attention and engagement, and (vi) not medically unstable." | "As there has been little literature published hitherto on the effectiveness of music therapy for PtDD (patients with dementia or delirium) in acute hospital settings, the positive findings of this study are encouraging. Although the effects of CMT did not seem to extend beyond the period of music engagement, CMT can contribute to the overall well-being of PtDD if it is regularly scheduled into their daily routines or incorporated into other areas of care such as physical rehabilitation and nursing to increase patient compliance and cooperation." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
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| Fleiner et al. | 2017 | Germany | "The primary objective of this trial is to investigate the effects of a short-term exercise program on neuropsychiatric signs and symptoms in acute hospital dementia care. Effects on symptom dimensions as well as the use of psychotropic medication were analysed as secondary outcome measures." | Exercise programme. | Randomized control trial (random allocation into Intervention group and control group) - with the intervention group conducting a 2-week exercise program with four 20-minute exercise sessions on 3 days per week. CG received a social stimulation program in addition to treatment as usual. | LVR-Hospital Cologne - on 3 specialized dementia care wards in the Department of Geriatric Psychiatry | Intervention group (IG) N = 35, Control group (CG) N = 35 Mean age was 80 (SD = 6) years, 33 (47%) women. Participant included if: diagnosis of dementia (according to ICD-10); minimum length of stay of 1 week; no delirium present; written informed consent (from patient or guardian); ability to perform a screening test (Timed Up and Go Test).<br>the main exclusion which affected recruitment was the presence of delirium | Significant reduction of overall neuropsychiatric signs and symptoms for the IG compared to the CG after 2 weeks (intervention period). Underpowered.<br>"The exercise-carrousel program is easily applicable in hospital dementia care and significantly reduces neuropsychiatric signs and symptoms in patients suffering from predominantly moderate stages of dementia." |
| Fleiner et al. | 2020 | Germany | "To investigate the effects of a short term exercise program for patients with dementia on professional caregiver burden caused by neuropsychiatric symptoms of dementia. "the aim of this trial is to analyze whether or not, a structured exercise program effects professional caregiver burden caused by NPS" | Exercise programme. | RCT. Participants randomly assigned groups in the main study - Intervention group - 2 week exercise programme plus TAU, and control group 2 week social stimulation programme. Pre and post - 3 days before and after the intervention. Primary nurse assigned to each patient. A blinded investigator interviewed each primary nurse who applied the NPI variable tool. | LVR hospital Cologne - 3 specialist dementia wards | Participants were the primary nurses for each patient in the RCT reported in Fleiner et al., 2017 (IG N = 35, CG N = 35) | Showed a significant time effect for the intervention group but not the control. The study was underpowered. T0 showed no difference between the IG and CG but post intervention there were significant differences.<br>Conclusion: "The results of this trial reveal not only a clinically significant decrease of the NPS of patients but also a decrease of the perceived caregiver burden of these NPS. Along with growing evidence about the important role of physical activity in dementia care, the results of this trial further indicate to the necessity of implementing structured physical exercise programs in dementia care. " |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Graham et al. | 2024 | Australia | Objective: "To evaluate whether a hospital based dementia focused SCU (special care unit) reduces BPSD (behavioural and psychological symptoms of dementia) severity more than standard care" | Dementia focused special care unit | Single case nonconcurrent multiple baseline repeated measures study. Phenomenon was levels of BPSD, e.g. aggression and agitation | SCU in a Brisbane hospital, opened in 2020. | 392 participants standard care, 1055 SCU. Participants had dementia diagnosis and were admitted with BPSD, transferred to SCU after 4 days of regular care | Independent of other factors, older hospital patients living with dementia experienced significant reductions in the severity of aggression, neuropsychiatric symptoms, and agitation associated with an SCU compared with standard care. This was also associated with decreased odds of psychotropic medication use, patient-to-nurse violence, security callouts and physical restraint use. These findings contribute to growing evidence for implementation of dementia-enabling hospital designs and models of care for patients living with dementia. |
| Gustafsson et al. | 2017 | Sweden | "To assess whether comprehensive medication reviews conducted by clinical pharmacists as part of a healthcare team reduce drug-related hospital readmission rates among people with dementia or cognitive impairment". | Pharmacists part of healthcare team | "A randomized controlled study design was used to compare hospitalized patients obtaining usual care with those receiving additional standardized medication reviews performed by an experienced clinical pharmacist." | Acute internal medicine wards at two hospitals and an orthopaedic ward at a third hospital | 230 were randomized to intervention and 230 to control group by block randomization. Aged was 65 or over with dementia or cognitive impairment. | Participation of clinical pharmacists in healthcare team conducting comprehensive medication reviews did not significantly reduce the risk of drug-related readmissions in patients with dementia or cognitive impairment; however, post-hoc and subgroup analyses indicated significant effects favoring the intervention. These findings need confirmation in future studies. |
| Honda et al. | 2016 | Japan | "A multimodal comprehensive care methodology, Humanitude, with eye contact, verbal communication, and touch as its elements, was provided to three geriatric dementia patients for whom conventional nursing care failed in an acute care hospital." | "Humanitude" multimodal care methodology | Case series | Acute care hospital | All patients had advanced dementia with BPSD and identified as patients for whom conventional care had 'failed'. Failure of care was identified by patient's shouting, screaming, or abrupt movements of limbs. | "In our case series, conventional care was provided by less eye contact, verbal communication, and touch. The multimodal comprehensive care approach, Humanitude, decreased BPSD and showed success by patients' acceptance of care." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Isaac et al. | 2018 | Australia | The aim was to "investigate whether the TOP5 strategy to directly engage carers of persons with cognitive impairment during the hospitalisation of the patient<br>could improve the patient's hospital experience, and positively impact health service provision and outcomes, through reduced falls, length-of-stay (LOS), and allocation of one-on-one nursing care." The impact of the TOP5 intervention on carer and staff experiences was also investigated. | TOP5 | Pre post mixed methods design. Staff were surveyed pre intervention, 6m and 9m. Patient data post intervention was compared with baseline over 12months pre intervention. | 2 x acute geriatric wards in a teaching hospital in Western Sydney. Ward A 21 beds, Ward B 27 funded beds. Patients admitted to Ward B then Ward A if patient cannot be discharged within 72 hours. | "The numbers of patients admitted to Wards A and B with specific diagnosis-related group codes relating to cognitive impairment combined over the three study phases were: baseline (12 months): n=689; pilot phase (14 months): n=697; establishment phase (12 months): n=661". "43 carers completed surveys". "Health care staff were surveyed at three time points: pre-implementation (n=22), and at six months (n=11) and nine-ten months (n=7) after the initiative had commenced" | "The TOP5 initiative allows health professionals to effectively engage with carers to gain valuable non-clinical information to help personalise the care of their loved one (Luxford et al., 2015). The preliminary data reported here demonstrate the potential of this intervention to improve health outcomes for patients with cognitive impairment who are admitted to a large hospital, as well as reduce their associated costs of hospitalisation, and improve carer experiences and staff satisfaction." Significant reduction of falls, specialling but not LOS, nonsignificant reduction in complaints. Carers results included 90% felt TOP5 had positive impact on carer involvement, 80% felt patients benefitted, 75% said patients were calmer, 37% felt recovery was quicker. Low response from staff, but was general positive. though little or no difference in attitudes of staff to involving carers. 80% agreed or strongly agreed it was easier to relate to carers, increasing to 100% at 9-10 months. |
| Kelly et al. | 2021 | USA | Aim was to "evaluate the feasibility of PARO interventions for hospitalised older adults with dementia, determine the physiological effects and describe participant social-affected interactions." | PARO robotic seal. | Pilot study using a prospective descriptive design single group pre-post design | Acute hospital. | 55 participants receiving 1 - 5 interventions. 65+ dementia and/or delirium diagnosis with expected LOS of at least 2 days. Needed to be able to interact with the PARO. Mean age 85.5 (range 67-104). Participants were recruited from the orthopaedic, progressive cardiac care units and medical-surgical units. | "Although there were screening and implementation challenges, we established that PARO acute-care studies are feasible and acceptable. As such, this study lays the groundwork for future acute-care PARO research. Significantly, the participants' positive social and affective interactions hold promise for using the PARO as a non-pharmacologic treatment for improving the care of hospitalized patients with dementia." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Knight & Singh | 2016 | Wales | "The aim of this study is to investigate the incidence and outcome of IF (inpatient falls) prospectively in patients with dementia treated in single rooms compared with those with dementia treated in traditional multibedded wards" | Single rooms compared to multibedded rooms | Prospective observational study. Service evaluation. | 2 x Welsh hospitals, one new (2011) with 100% single room and one traditional. Acute and sub acute patients | Older patients with "known dementia" 100 consecutive patients across the two sites. | "In conclusion, this study has identified that hospital environment does have an impact on older people with dementia who could be at an increased risk of recurrent IFs if treated in single rooms compared with MB-Ws. Our study results indicate that recurrent IFs are correlated with a longer LoS and new care home placement, but no significant difference was observed in clinical outcomes in terms of hip fracture or mortality in the two hospital environments." |
| Lüdecke et al. | 2019 | Germany | "To identify factors that predict the quality of life (QoL) of patients with dementia in acute hospitals and to analyse if a special care concept can increase patients' QoL." | Specialist ward with dementia care concept | Non-randomised, case–control study | Two hospitals in Hamburg - one had implemented a dementia focused ward for internal medicine and the other just had a general medical ward (or internal medicine ward). | 333 in special care ward, 193 in control ward. Exclusion - not bed bound Inclusion - diagnosis of dementia. | "A special care ward will improve the quality of care and has a positive impact on the QoL of patients with dementia. Health policies should consider the benefits of special care concepts and develop incentives for hospitals to improve the QoL and quality of care for these patients." |
| Lukas et al. | 2022 | Germany | "To reduce the level of behavioral and psychological symptoms of dementia (BPSD) in an acute hospital environment through a stepwise procedure following by the initiation of a needs-oriented treatment." | Serial trial intervention | "An open, prospective, interventional study in form of an interperiod comparative design with a before-after comparison" | 3 wards - internal medicine, surgery, geriatric. | N = 53 before implementation, N = 54 after. Over 65, MMSE less or = 24. , minimum 4 day stay, exhibiting BPSD | "Even though the study ultimately failed to show a significant reduction in BPSD, the introduction of stepwise clarification of possible causes of BPSD, especially pain, demonstrates an attractive approach to BPSD management. STI seems to at least raise awareness of underlying causes of BPSD and increase the use of non-pharmacological interventions. In this respect, STI seems applicable and beneficial in the treatment of BPSD, also for hospitalized patients. Nevertheless, further studies need to follow to conclusively clarify the value of STI in an acute hospital setting." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Motzek et al. | 2016 | Germany | "To test 3 different types of environmental cues in double occupancy rooms of an acute care hospital. Cues were colour number and patient's name. Patient's name was subsequently dropped due to administration difficulties. | Environmental cues to aid orientation | Longitudinal nonblinded quasi experimental design. | acute geriatric ward with a capacity of 24 beds, being part of an acute hospital in Dresden. | 42 patients MMSE (score 24 or lower). 36 in analysis intervention group n = 14, control = 22 | "As this study indicated, the environmental cues color and number are helpful for these patients to identify their bed and wardrobe in the patient room. However, these cues were most effective from the third to the fifth day after admission. To sustain their effectiveness on patients' identification abilities during their hospital stay, we assume that an integration into the staffs' workflow is helpful. Thus, we recommend to discuss and to examine in future studies, whether a simple ongoing mentioning of the cues, embedded in the daily work of nurses and other staff, can further support the orientation abilities of patients." |
| Pitkänen et al. | 2019 | Finland | "The main aim of the present study was to explore the impact of physical exercise and music interventions on Neuro Psychiatric Symptoms (NPS), level of functioning and use of psychotropic medication in a replicated sample of patients with dementia on one acute psychogeriatric ward. We hypothesized that systematically including physical exercise and music interventions in the routine treatment of these patients would improve NPS and ADL and reduce the use of psychotropic medications" | Physical exercise and music | Observational intervention study, a benchmark controlled trial (BCT) | One acute psychogeriatric ward with 17 beds at a university hospital. | Control group n = 89, Intervention group n = 86. All had diagnosis of dementia. | "Although no differences were found between the study groups, analysis within the intervention group suggest that physical exercise may have some positive effects for both NPS and the level of functioning in some patients with dementia while no positive effects regarding music interventions were found."<br>"So far as we know, the current study established first-time evidence for the utility of implementing music and exercise interventions for routine treatment on an acute psychogeriatric ward" |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Shimomura et al. | 2024 | Japan | AIM: "to examine the influence of dementia-specialized care team on clinical outcomes for elderly inpatient among hospitalized older adults with cognitive impairment." | dementia-specialized care team. | Retrospective cohort study | Tertiary hospital in Japan | 16,237 patients in the preintervention period and 17,860 patients in the post-intervention period. Aged 65 + | "After the implementation of dementia-specialized care team, favorable outcomes such as a reduction in the use of hypnotics, the incidence of falls, and the length of hospitalization were observed. Introduction of the team and associated incentives may be effective in improving clinical outcomes in elderly inpatients." |
| Sinvani et al. et al. | 2018 | USA | "to investigate whether an innovative multicomponent model consisting of geographic cohorting, a multidisciplinary approach, patient engagement specialists (PES), and staff education would improve care of hospitalized older adults with cognitive" impairment. | Specialist dementia unit | One-year retrospective chart review with propensity score matching on critical demographic and clinical variables was used to compare individuals with cognitive impairment on intervention and non-intervention units. | Tertiary-care centre in hospital in New York area | Over 65 with cognitive impairment and behavioural symptoms. "476 of the 712 intervention visits were pair-matched with 476 of the 558 usual care visits." | "A multicomponent intervention of geographic cohorting, multidisciplinary approach, PES, and staff may offer a new paradigm in the management of hospitalized older adults with cognitive impairment." |
| Tay et al. | 2017 | Singapore | "AIM: To evaluate the effectiveness of an acute hospital dementia unit (Care for Acute Mentally Infirm Elders [CAMIE]) that adopts a PCC protocol." | CAMIE Unit Person centred care | Naturalistic cohort study | Hospital - a specialized unit for PWDs that adopts PCC. | 230 patients recruited over 6 months. 170 in CAMIE unit and 60 in conventional geriatric ward as controls) . All "suffered from confusion due to dementia, with/without delirium based on the confusion assessment method criteria, and concomitant acute medical problems." | "PCC for PWDs (persons with dementia) in acute hospitals not only improves clinical outcomes for patients but is also cost-effective. The results support the adoption of PCC on a wider scale for better care of PWDs." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Travers et al. | 2018 | Australia | "AIM was to a) educate and empower experienced hospital nurses to lead practice changes on their wards, in order to;<br>(b) improve the care of hospitalized patients with cognitive impairment by implementing best practices" | Education programme with Cogchamps | Observational between groups study comparing intervention hospital with control | 6 wards (four medical and two surgical) of a large tertiary referral hospital.<br>-<br>the Intervention Hospital (IH), in South-East Queensland, Australia,<br>Control hospital was similar setting 10km away | 34 registered nurses were trained as CogChamps.<br><br>181 patients observed, 130 in IH (intervention hospital; 500 observations), 51 in CH (Control hospital; 207 observations).<br>Patients had cognitive impairment which included dementia and delirium<br>8 patients max per day were observed. | "The CogChamps project demonstrates that nurse Champions can be effectively empowered to educate other nurses about dementia and delirium including the accurate recognition of delirium. Practice improvements were achieved for well-defined tasks (e.g. conducting a cognitive assessment) with clear targets, the nomination of those responsible for the task and where progress was measured. Thus, it is concluded that these elements are important when implementing practice changes. Although only modest improvements were demonstrated, these results suggest that using collective social education approaches shows promise and warrants further research. |
| Tsuchiya et al. | 2022 | Japan | "This study aims to assess the immediate effect of one-session cognitive stimulation intervention on the mood of patients with dementia in a hospital" | Cognitive stimulation therapy | Retrospective Single-Arm Cohort Study | Hospital | 33 female patients.<br>Diagnosis of dementia with mild to moderate dementia with MMSE of 10 or more | "This study is the first report to provide preliminary evidence that one-session CS intervention may have beneficial alterations in the moods of patients with dementia in a hospital. The comparison of the primary outcomes in patients with dementia before and after sessions showed a positive change, which may indicate an immediate improvement of pleasure." |
| Young et al. | 2017 | Wales | "To describe acutely unwell patients with dementia admitted to two different hospitals environments—single rooms and traditional MBW—and to study the clinical outcomes and predictors of adverse outcomes in these two environments." | Single rooms compared to multibedded rooms | Prospective observation study | Hospital | 100 patients with dementia, 50 at each hospital | "This observational study suggests hospital environments may affect clinical outcomes, with a significantly higher length of stay for acutely unwell patients with dementia admitted to single rooms as compared to those in MBWs. However, no other significant differences were observed in clinical outcomes in terms of inpatient mortality, inpatient falls, discharge to a new care home, or 30-day readmission." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| ***Qualitative studies*** | | | | | | | | |
| Brooke & Semlyen | 2019 | UK | "The aim of this study was to explore how dementia-friendly ward environments in an acute hospital impacted on the care nurses and health care assistants provided for their patients with dementia." | Dementia friendly ward | Service improvement | The study was completed across three wards within a District General Hospital (DGH) in England. | Participants were junior qualified nurses (n=17) and health care assistants (n=21). | "Dementia-friendly wards are an important and impactful way to improve care and the lived experience of people with dementia in the acute hospital setting, reducing confusion and creating a supportive space. Implementation of dementia-friendly ward environments leads to increased contact with patients, and increased person-centred care and possibly a reduction in harm. Provision of change management strategies in future implementations' may improve staff uptake." |
| Couzner et al. | 2022 | Australia | To " illustrate how the application of the principles of trauma-informed models of care by staff in geriatric inpatient care facilitated improved identification and response to trauma-related needs, and associated outcomes in terms of patient wellbeing, experiences of care, and behavior". | Trauma focused model of care | Case series | Acute hospital setting - inpatient non-psychiatric geriatric ward | 5 patients. Cases were selected where they illustrated how past psychologically traumatic events may be contributing to the symptom presentation of a person with dementia in an inpatient hospital setting. | "These cases illustrate that the principles of trauma-informed care can be successfully applied in the care of older adults by staff without formal mental health training. Trauma informed care is an innovative approach in geriatric medicine, and widespread adoption will require systems-level initiatives including staff training, processes to promote information. Much can be learned from mental health services and systems, where trauma-informed care is well characterized and from which toolkits for implementation are available. By improving staff skills and organizational systems, older trauma survivors can benefit from tailored, empowering care in which they feel safe and free of distress." |
| Hung | 2020 | Canada | "To generate greater understanding of technology adoption and to test strategies supporting virtual care interventions in hospitalised older people with dementia, such as the use of an iPad to connect them with their family members." | Virtual Care | Qualitative study using interviews, focus groups and observation | One mental health unit and two medical units at 2 large urban hospitals | 3 focus groups with 38 staff, 2 interviews with frontline nurses supporting patients with the iPad, 22 PLWD (persons living with dementia) observation & interviews, 3 interviews with stakeholders - patient, family, nurse leader representatives | "Using an iPad has the potential to enable hospitalized older people with dementia to connect with their family and take part in activities that promote person-centred care. This is particularly important when physical distancing leads to social isolation, such as during the COVID-19 pandemic." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Mandzuk et al. | 2018 | Canada | "The clinical question in our initiative examined how an older adult living with dementia, delirium or depression would respond to one-to-one personalized music sessions" | Personalised music sessions | Quality improvement initiative. | Acute care facility | 10 patients with dementia, delirium or depression. 90% dementia. Mean age 81, mean no of sessions was 7, range 1-10 | "Music can be a clinically significant activity for hospitalized adults with dementia. "When words fail, music provides a way for the person with dementia to connect with others and engage in memories and emotions" (Alzheimer's Society of Canada, 2017b ). This has been a remarkable journey. Whether older adults are in long-term care or acute care, this simple innovative strategy should be considered in your practice setting. It is a simple yet powerful intervention that can make a difference to older adults living with dementia. |
| Skingley et al. | 2021 | UK | "Aim: To describe and evaluate PIE implementation in three UK NHS regions". | PIE programme | A longitudinal mixed method design was used for multiple case studies - qualitative element is reported in this paper. | 10 wards in 5 NHS acute hospitals across 3 regions over a period of 18 months | 10 wards with substantial number of older people with dementia | "PIE has the potential to help staff improve person-centred care for people with dementia admitted to hospital wards. However, the evidence provided by this article is limited to 10 wards, of which only two fully implemented the programme." |
| ***Mixed methods studies*** | | | | | | | | |
| Appel et al. | 2021 | Canada | "The primary aim of the pilot study was to determine the feasibility of administering IVR therapy to inpatients at an acute care hospital in various stages of dementia, particularly those in moderate and advanced stages. This included assessing the tolerability or acceptability, comfort, and safety of the VR equipment and 360° | Virtual reality | Prospective longitudinal pilot study, not randomized or blinded. | Community teaching hospital linked to the University of Toronto. | 10 participants (8 female, mean age 86.5) age 65 + with dementia diagnosis | "These findings support conducting a large-scale RCT to investigate immersive VR therapy as a nonpharmacological intervention to manage BPSD in acute care hospitals. Particular interest should be given to people with more advanced stages of dementia (moderate to severe), as there are pervasive challenges in managing symptoms and improving the quality of life of these individuals using the current standard of care." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Appel et al. | 2024 | Canada | "The main objectives of this RCT were to evaluate the impact of VR therapy on BPSDs and associated patient outcomes during the hospital stay. Our secondary objectives were to report on the acceptability, safety, experience, and satisfaction with VR therapy among inpatients with dementia " | Virtual reality | Open label RCT with participants randomly assigned to either VR group or control | Community teaching hospital in Toronto Canada. | 69 participants randomly selected for intervention or control. Inpatients over 65 with dementia diagnosis recruited from hospitalist or medicine ward. | "Immersive VR therapy appears to have an effect on aggressive behaviors in patients with dementia in acute care. Although the randomized controlled trial was stopped before reaching the intended sample size owing to COVID-19 restrictions, trends in the results are promising. We suggest conducting future trials with larger samples and, in some cases, more sensitive data collection instruments." |
| Bateman et al. | 2016 | Australia | "The aim of the present study was to address the challenges faced by staff in an acute rural hospital in Australia when providing person-centred care for patients with dementia and/or delirium. This was done by training volunteers to provide personal support to these patients, then measuring the outcomes of this intervention." | Volunteers | Quasi-experimental pre–post design | A 63-bed rural acute hospital | Data for 64 patients who passed through the program; questionnaire data for 18 nurses and 18 volunteers. Patients were over 65 (or over 50 for aboriginal consent) plus dementia or delirium diagnosis, SMMSE score of <25/30 OR risk of delirium. | "It is feasible to introduce and then sustain a relatively inexpensive program to improve quality of care for people with dementia and/or delirium in an acute rural hospital. Reasons for the program’s effectiveness are canvassed in the paper, but further research is needed to investigate the effectiveness of a similar program in urban hospitals." |
| Daykin et al. | 2018 | UK | "This pilot study examined the impact of a ten week period of weekly participatory music in a 54 bed acute care service for older people in a UK hospital." "The study aims were not simply to generate positive examples of benefit of the intervention, rather to explore the impact of the music project more broadly, addressing what works and what does not work." | Music Therapy | Pilot study. Mixed method design - statistical analysis on routinely collected patient data and thematic analysis for interviews and observations made during 10 music sessions | Acute care service for older people in a UK hospital comprising of multiple wards. Secondary data were available for patients with dementia who had stayed on the wards. | Used 54 bed acute care service for older people in a UK hospital. Secondary data were available for 85 patients with dementia who had stayed on the wards during one of the two periods. The study population for the primary data study included 38 patients 12 staff members. | "Data from this limited pilot study suggest that music is a useful intervention for enhancing patient and staff experiences and improving care in acute dementia care environments. The suggestion that use of anti-psychotic drugs may be reduced when music is present warrants further research." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| Gilmore-Bykovskyi et al. | 2021 | USA | "The present project aimed to address gaps in hospital-based management of dementia-dementia related BE through the development of a nurse-led, multi-component decision support intervention to address both BE prevention and management." | PROACTIVE treatment approach. | Mixed methods quality improvement study | 20 bed general medicine inpatients unit in a Midwestern Veterans Affairs hospital, Wisconsin | Pre - 17 nurses, 9 nursing assistants<br>Patients Pre post n = 40/40. "confirmed (existing diagnosis) or suspected cognitive impairment due to dementia."<br>Post implementation Staff - 16 nurses, 5 nursing assistants | "Patients receiving the PROACTIVE Treatment Approach (N=40) had higher rates of acetaminophen use, shorter lengths of stay and lower use of 1:1 direct observation than the historical comparison group (N=40). Additional, more rigorous evaluation is needed to better determine optimal implementation strategies and intervention impact." |
| Innes et al. | 2016 | Malta | "To ascertain the experiences, attitudes and knowledge of staff working in two Maltese hospital wards and the observed experiences of people with dementia living there. To examine the impact of recommendations made in October 2011 for improving the psychosocial and physical environments of the wards 1 year later." | Improvements made to psychosocial and physical ward environment | Single group mixed method pre - post test evaluation study of 2 wards. | Hospital in Malta | Ward1 - recruited 5 patients (1 man) with dementia at T1 and 4 (2 men) at T2. Ward2 - 4 patients (women) at T1 and 3 (2 men) at T2<br>All ward staff also recruited. 74 | "This study demonstrates that small steps to developing the hospital work force are a key way to achieve change and improvement; however, wholescale change will require a holistic and whole systems approach to dementia care delivery in hospital wards." |
| Luxford et al. | 2015 | Australia | "To examine the impact of implementing a clinician–carer communication tool for hospitalized patients with dementia." | TOP 5 | Surveys with clinicians and carers. Time series analysis on patient outcomes | 53 wards over 22 hospitals (one control) in New South Wales (17 public, 5 private). Mix of medical, surgical and aged care wards | Surveys were returned by 798 clinicians, 240 carers and 21 local liaison staff involved in implementation | "Our findings indicate that the use of a simple, low-cost communication strategy for patient care is associated with improvements in clinician and carer experience with potential implications for patient safety. Minimally, TOP 5 represents 'good practice' with a low risk of harm for patients." |

| Author | Publication Date | Country | Aim/Purpose | Intervention brief | Design | Setting | Participants | Conclusions |
|---|---|---|---|---|---|---|---|---|
| McAulay et al. | 2020 | UK | "The purpose of the service evaluation was to gauge the level of attendance and feedback on Cognitive Stimulation Therapy as part of the patient's usual care in an inpatient setting" | Cognitive stimulation therapy | Service evaluation. Patient feedback forms given to each attendee after each session. 6 questions were asked with a Likert style answers plus a free text section for qualitative data | Hospital - focused on 2 wards were the CST is delivered | 51 feedback forms received. Dementia diagnosis and/or delirium, verbally communicate well, and well enough to be out of bed. | "The structured questionnaire, occupational therapist observations and feedback from other staff members suggest that attendance to the Cognitive Stimulation Therapy group was welcomed by the patients and had a positive effect on their quality of stay." |

# Appendix B: Conventional Process Mapping - Example Patient Pathways

The mapping exercise included process mapping for 18 patients, when patient notes for a single admission were examined in detail. This section includes four examples – two from each site, one with and one without dementia. Please note these are examples and have not been selected for comparison purposes, either between sites or between dementia and no dementia.

## Example 1: Patient 20878 Ipswich hospital -> Urinary Tract Infection -> dementia coded -> 5 days length of stay

**Diagnosis and Screening**

**Day 1**
82 y/o female admitted from care home to A&E with UTI

**Day 1**
Screening revealed: congestive heart failure, atrial fibrillation, migraine, hypertension and "dementia undiagnosed"

**Ward Moves**
26/03/23 @11.12 to A&E majors -> 26/03/23 @17.40 to Brantham assessment unit -> 26/03/23 @22.40 to Saxmundham ward -> 29/03/23 @00.00 to Stradbroke ward

**ADLS/Treatment/Communication**

**Day 1**
Husband acts as carer

**Day 1**
Performed blood tests and ECG

**Day 1-5**
Family supported, visited and were informed of care developments

**Day 1-5**
Patient was administered a sedative when she became agitated

**Day 1-5**
Patient pulls out catheter out often

**Day 3**
At one point hospital staff wanted to transfer patient to gastro bed – but no beds available there

**Day 3**
Patient developed a nose bleed

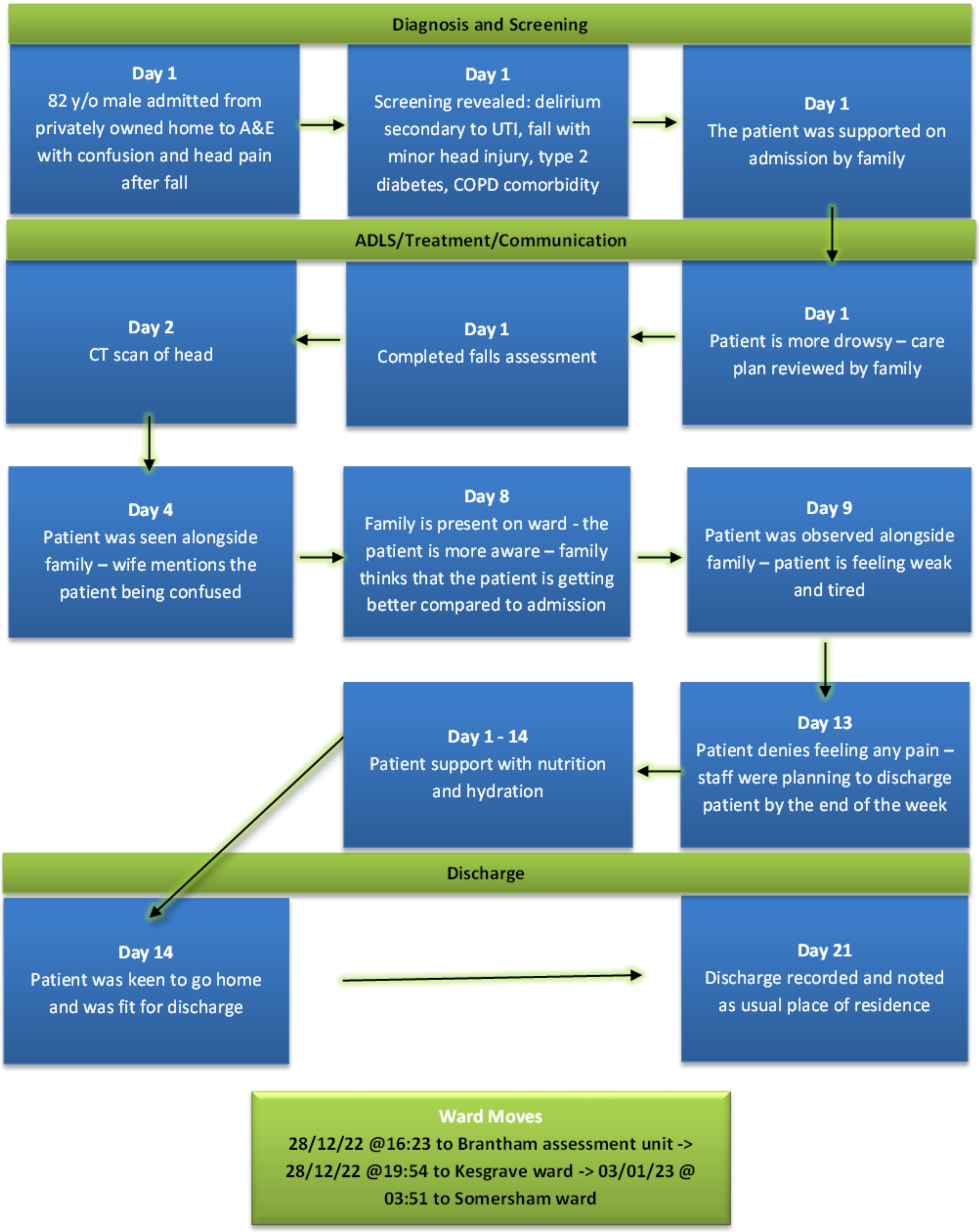
**Day 4**
A near end-of-life diagnosis was made

**Day 5**
"Hepatitis secondary to nitrofurantoin but no clear cause – sadly this has led to the patient's continued deterioration with acute hepatic failure"

**Discharge**

**Day 25**
Patient died: "multiorgan failure with a confounding effect of a probable dementia diagnosis and hospital acquired delirium."

## Example 2: Patient 15895 Ipswich hospital -> Delirium -> no dementia -> 21 days length of stay



**Diagnosis and Screening**

**Day 1**
82 y/o male admitted from privately owned home to A&E with confusion and head pain after fall

**Day 1**
Screening revealed: delirium secondary to UTI, fall with minor head injury, type 2 diabetes, COPD comorbidity

**Day 1**
The patient was supported on admission by family

**ADLS/Treatment/Communication**

**Day 1**
Patient is more drowsy – care plan reviewed by family

**Day 1**
Completed falls assessment

**Day 2**
CT scan of head

**Day 4**
Patient was seen alongside family – wife mentions the patient being confused

**Day 8**
Family is present on ward - the patient is more aware – family thinks that the patient is getting better compared to admission

**Day 9**
Patient was observed alongside family – patient is feeling weak and tired

**Day 13**
Patient denies feeling any pain – staff were planning to discharge patient by the end of the week

**Day 1 - 14**
Patient support with nutrition and hydration

**Discharge**

**Day 14**
Patient was keen to go home and was fit for discharge

**Day 21**
Discharge recorded and noted as usual place of residence

**Ward Moves**
28/12/22 @16:23 to Brantham assessment unit -> 28/12/22 @19:54 to Kesgrave ward -> 03/01/23 @ 03:51 to Somersham ward

## Example 3: Patient 1138 Colchester hospital -> dementia coded -> Tendency to fall -> 8 days length of stay

**Diagnosis and Screening**

**Day 1**
81 y/o male admitted from care home via (A&E) with confusion and fall

**Day 1**
Comorbidities include vascular dementia

Dementia alert on system

**Day 1**
The patient's daughter was present on admission

**Day 1**
Patient *'not tolerating ECG'. 'Patient not tolerating in depth examination '*

**Day 1**
The patient completed Mental Capacity Assessment – seen to have capacity

No mention of 'This is me' on file

**Ward moves**
Resus 23.08 @ 1527 >
Bay 03 23.08 @1539 >
Bay 13 23.08 @1631 >
EAU 23.08 @2011 >
Birch ward 24.08 @0053

**ADLS/Treatment/Communication**

**Day 1**
Patient left hospital and was detained by police

**Day 1 - 8**
Patient has guards present by bed

**Day 1 - 8**
Administered medication daily

**Day 1 – 8**
Patient's nutritional and hydration needs were met daily

**Day 2**
Staff member wrote: *'the residential home are unlikely to take *patient name* back given presentation'*

**Day 3**
Patient assaulted staff and service users (police, security, nurse) on day of discharge

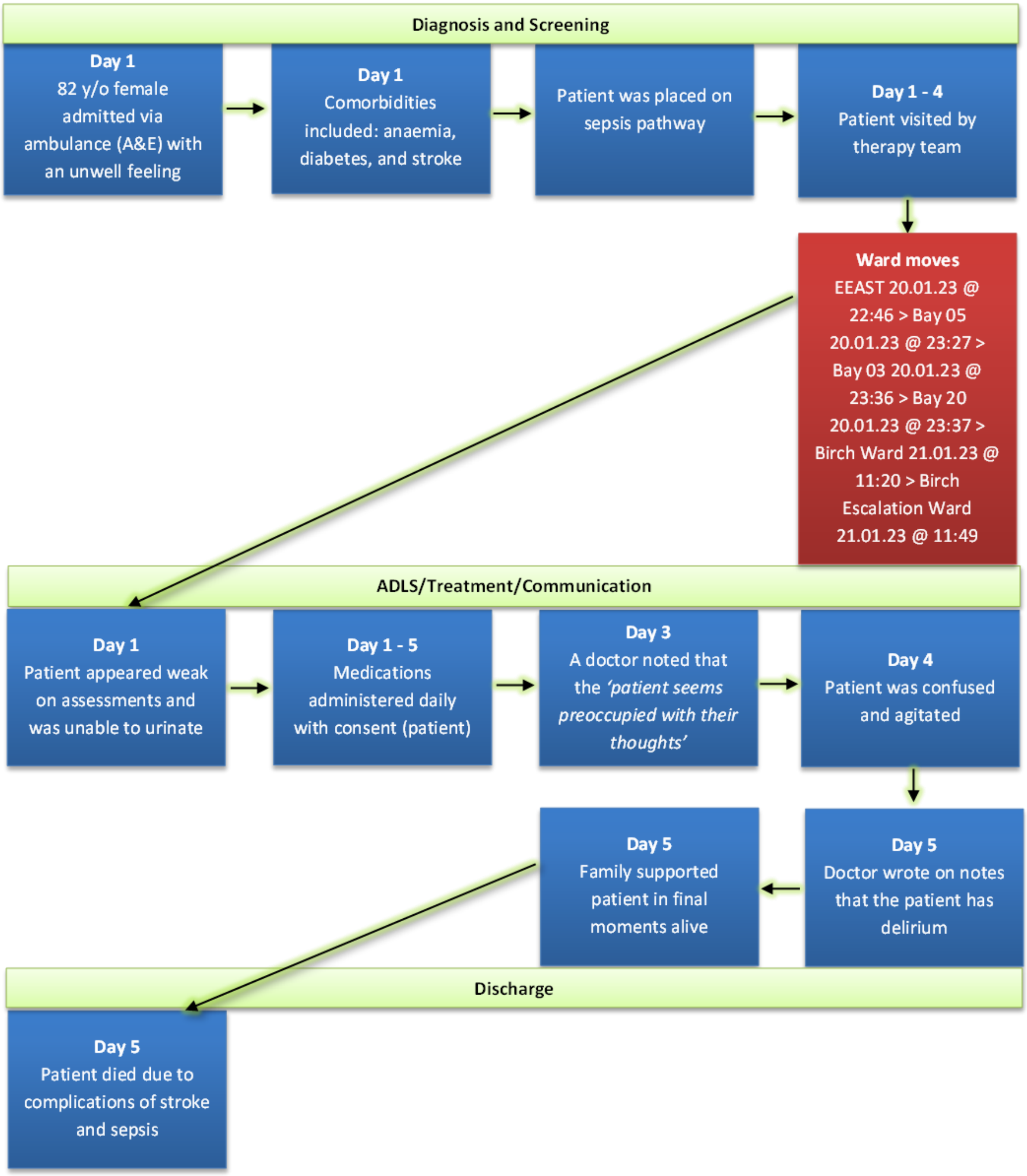
**Day 4**
Aggression shown to staff

**Day 7**
Verbal and physical abuse towards staff

**Discharge**

**Day 8**
Discharged to previous care home coded as usual place of residence

## Example 4: Patient 25195 Colchester hospital -> Delirium -> no dementia -> 5 days length of stay



**Diagnosis and Screening**

**Day 1**
82 y/o female admitted via ambulance (A&E) with an unwell feeling

**Day 1**
Comorbidities included: anaemia, diabetes, and stroke

Patient was placed on sepsis pathway

**Day 1 - 4**
Patient visited by therapy team

**Ward moves**
EEAST 20.01.23 @ 22:46 > Bay 05 20.01.23 @ 23:27 > Bay 03 20.01.23 @ 23:36 > Bay 20 20.01.23 @ 23:37 > Birch Ward 21.01.23 @ 11:20 > Birch Escalation Ward 21.01.23 @ 11:49

**ADLS/Treatment/Communication**

**Day 1**
Patient appeared weak on assessments and was unable to urinate

**Day 1 - 5**
Medications administered daily with consent (patient)

**Day 3**
A doctor noted that the *'patient seems preoccupied with their thoughts'*

**Day 4**
Patient was confused and agitated

**Day 5**
Doctor wrote on notes that the patient has delirium

**Day 5**
Family supported patient in final moments alive

**Discharge**

**Day 5**
Patient died due to complications of stroke and sepsis

# Appendix C: Staff Interviews – Guide/Questions

The following interview schedule was used for the interviews. Questions in bold reflect those suggested by the DemFoCAS steering group.

| **Questions** | **Prompts/follow ups** |
|---|---|
| 1. Firstly, please describe your role at ESNEFT and how you are involved in the care of patients with dementia? | |
| 2.Could you tell me a little bit about what it is like to do your role?<br>How do you feel about working with patients with dementia?<br>Were you particularly motivated to care for people with dementia? | Prompt to expand on motivations if required.<br>**How valued do you feel in your role?**<br>Please tell me about some challenges you have experienced in your role in relation to dementia care |
| 3. ESNEFT What would improve care for patients with dementia? | **Do you feel you have enough time to spend with patients to provide individualised care**? |
| **4. How much specialist training have you had in dementia?** | **How confident are you in your knowledge about dementia?** |
| 5. Obviously the impact of COVID-19 was immense. How much do you think COVID-19 still influences hospital care? How? | **How much has extended visiting of family carers influenced patient care and your role?** |
| 6. Anything else you would like to add? | |

# Appendix D: Spousal Carer Interviews - Guide/Questions

Participants were encouraged to tell their stories in their own way. The following questions were used as a semi-structed guide for the interviews:

1. Please could you start by telling me a little bit about yourself and (your spouse/partner)?

   Possible prompts: Check for general information such as family members, general lifestyle, how long married/together etc

2. Please can you tell me about the circumstances that led to (your spouse/partner) going into hospital?

   Possible prompts: How did you feel when you were waiting for the ambulance? What were you expecting to happen when the ambulance arrived? How did (spouse's name) react when the ambulance arrived?

3. What was it like when you got the hospital? What happened?

   Possible prompts: How long did you have to wait to see a doctor or until you knew what was happening? How were you and (spouse/partner) feeling?

4. Can you tell me what happened next, after (name) was admitted?

   Possible prompts: How were you feeling during this time? How did (spouse/partner) respond to the experience?

5. Can you tell me about your involvement in (name)'s care while they were in hospital?

   Possible prompts: How was your relationship with the staff? What was the ward like? Can you tell me about a typical day on the ward? What sort of visiting were you allowed to do? How did it feel when you were at home during this time and what was it like? How was the communication with the staff?

6. How do you think that your spouse/partner (name) felt about their time in hospital?

   Possible prompts: Can you give me some details about experiences that happened when (spouse/partner) was on the ward? How was communication with staff/doctors with you and (spouse/partner) How did (spouse/partner) behave in hospital compared to when they are at home?

7. What was your experience of the discharge process?

   Possible prompts: How involved were you? How did you feel about decisions that were made?

8. When you reflect on that time now, what comes to mind?

   Possible prompts: How do you feel (spouse/partner) has been affected by their hospital stay? How have you been affected? How has your relationship been affected?

9. Do you have anything else you would like to add?

# Appendix E: Table of Touchpoints from the Progress Report 2024

| No. | Description | Progress report Section title | Progress Report section no. |
|---|---|---|---|
| 1 | ESNEFT is still recovering from effects of COVID-19 with services, training, processes and patient support still affected in some areas. | Introduction | 3.1 |
| 2 | ESNEFT area has a high prevalence of dementia compared to national averages, especially in coastal regions. | ESNEFT structure and statistics | 5.1 |
| 3 | There are complex issues relating to identifying patients with dementia which can lead to difficulties comparing prevalence statistics. | ESNEFT structure and statistics | 5.1 |
| 4 | The ESNEFT Dementia care policy (2022) is due for review in 2025. | Guidance, care pathways and strategies | 5.2 |
| 5 | The dementia specialist team has a large range of responsibilities, and is small, with one dementia nurse specialist at each site. Colchester has 2 specialist consultants, Ipswich has 8 as reported in the NAD round 5. | Specialist dementia focused care and governance | 5.3 |
| 6 | Local audits for dementia friendly environments are currently on hold due to workload. This has been recognised and suggestion has been | Dementia friendly environments | 5.4 |

|  |  |  |  |
|---|---|---|---|
|  | made for an audit programme to be planned for financial year 2024/25. |  |  |
| 7 | The central dementia friendly strategy/plan for ESNEFT is currently unclear. | Dementia friendly environments | 5.4 |
| 8 | Staff pressures, sickness and wellbeing remain key challenges although are improving since COVID-19. | Staff overview, support, sickness and turnover | 5.5 |
| 9 | Difficulties re-establishing training programmes after COVID-19 are ongoing. | Staff training | 5.6 |
| 10 | ESNEFT management should support the training programme and ensure it can be delivered to all relevant staff and new skills can be implemented on the wards. | Staff training | 5.6 |
| 11 | Volunteer numbers are still low following a drop due to COVID-19. There are plans to recruit more volunteers to assist with mealtimes. Recruitment can be challenging. | Volunteering | 5.7 |
| 12 | A carer or patient group for dementia could be beneficial | Family carers<br>Patient and carer feedback | 5.8, 6.5 |
| 13 | Family carers could be helped to feel more confident about hospital care with increased communication through clear and easily navigable information on the ESNEFT website and exploring other ways to communicate ESNEFT hospital services to the community. | Family carers | 5.8 |
| 14 | ESNEFT website should be checked for being dementia friendly and updated information relating to carer | Family carers | 5.8 |

| | | | |
|---|---|---|---|
| | support and visiting information is needed. | | |
| 15 | There has been a notable reduction in percentage of patients with discharge planning in place within 24 hours between NAD round 4 (78.6% in Colchester and 80.8% in Ipswich) and round 5 (35% in Colchester and 16.5% at Ipswich). | Discharge planning | 5.9 |
| 16 | More information is needed regarding discharge planning at ESNEFT to understand when adhering to NHS guidelines is not possible. | Discharge planning | 5.9, 6.2 |
| 17 | Evolve notes relating to discharge planning were variable with some records missing. | Discharge planning | 5.9 |
| 18 | Wards are consistently operating with nursing staff levels below the hours needed for acuity and dependency levels of patients. | Staffing levels and patient safety management | 5.10 |
| 19 | For every month between Oct 22 and Sep 23, unregistered nursing staff during the day on wards at Colchester for older person's services were operating on an average monthly fill rate of less than 80%. | Staffing levels and patient safety management | 5.10 |
| 20 | Hours short (a calculation of the number of nursing hours short of requirements on wards per shift after individual patient needs are taken into account) are not reported retrospectively so a true picture of staffing levels is not monitored on an ongoing basis. | Staffing levels and patient safety management | 5.10 |
| 21 | In line with expectation from prior research, the length of stay for patients with a dementia diagnosis | Length of stay | 6.10 |

| | | | |
|---|---|---|---|
| | was significantly higher than for other inpatients. | | |
| 22 | Mean length of stay for inpatients with dementia was slightly longer at Colchester (10.4 days) than Ipswich (9.6 days). | Length of stay | 6.10 |
| 23 | There are discrepancies between NAD 5 data and ESNEFT inpatient admissions data which may be caused by lack of consistency in the way discharge destination is allocated on ESNEFT systems. | Discharge to care homes | 6.2 |
| 24 | Measurement of changes in patient cognition, functionality, wellbeing, ADLS and signs of deconditioning needs more review to assess. Implementation of the new integrated patient record (7 day) may affect assessments carried out. | Changes in cognition, ADLs and signs of deconditioning | 6.4 |
| 25 | Current understanding is there is no ongoing collection by ESNEFT of feedback from patients and carers regarding inpatient experiences to enable the service to respond to current issues around dementia care | Patient and carer feedback | 6.5 |
| 26 | Datix records show most falls are unwitnessed, although also mild, they can affect wellbeing. | Datix incidents | 6.6 |