Planning for the End

A review of the quality of care provided to adult patients towards the end of life

NCEPOD

Improving the quality of healthcare

PLANNING FOR THE END

A review of the quality of care provided to adult patients towards the end of life

A report published by the National Confidential Enquiry into Patient Outcome and Death (2024)

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EXECUTIVE SUMMARY

Each year over 600,000 people die in the United Kingdom and many of these deaths occur in hospital, despite the majority of people saying that they would prefer not to die there. Approximately 70% of people die from long-term health conditions that often follow a predictable course, with death anticipated well in advance of the event. The annual number of deaths in the United Kingdom is predicted to rise to 736,000 by mid-2035. Therefore, the provision of care at the end of life must meet the needs of the population.

The quality of care provided towards the end of life for adults with a diagnosis of dementia, heart failure, lung cancer or liver disease were reviewed. The sampling period of death or final admission (for community deaths) was between 1st April 22 and 30th September 22. Data included 701 clinician questionnaires and the assessment of 350 sets of case notes. In addition, organisational data were kindly supplied by the National Audit of Care at the End of Life (NACEL).

★ Palliative care is not just about end of life care

Not enough patients had access to early palliative care alongside existing treatments to improve symptoms and quality of life.

135/439 (30.8%) patients had parallel planning.

During the final admission, the specialist palliative care team were involved in the care of 230/446 (51.6%) patients.

Where a parallel planning approach was not taken, this linked to room for improved clinical care for 58/140 (41.4%) patients.

★ Normalise conversations about death and dying

Death and dying was not discussed as often as it could have been. More people need to have their end of life care wishes recorded.

169/233 (72.5%) patients did not have their preferences for care at the end of their life recorded.

Communication was an area for improvement and of good practice. This included how patients and their families were included in decisions about care being provided, and advance care plans.

★ Have a named care co-ordinator

Care co-ordinators are an accepted standard in cancer services but were less common for other advanced chronic conditions.

There was documentation of a lead person in the records of 257/396 (64.9%) patients.

When a lead person was documented, specific end of life documentation was used in 162/243 (66.7%) patients, compared with 44/134 (32.8%) where there was no lead person documented.

★ Provide specialist palliative care services in hospitals and in the community

Specialist palliative care services were not always available in hospitals nor involved when needed.

Seven-day specialist palliative care services were available in 125/210 (59.5%) hospitals.

120/290 (41.4%) patients without parallel planning had specialist palliative care input, compared with 94/130 (72.3%) who did.

For 77/444 (17.3%) patients specialist palliative/end of life care input could have been better.

★ Palliative and end of life care should be a core competency for all healthcare staff

Training to identify when palliative or end of life care will help was not always provided or available.

Training in end of life care was included in the induction programme in only 137/214 (64.0%) hospitals and in mandatory or priority training in 110/214 (51.4%) hospitals.

Training in end of life care for all healthcare staff is needed to recognise who would benefit from specialist palliative care to treat the symptoms of advanced chronic disease.

RECOMMENDATIONS

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These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations in this report support those made previously by other organisations, and for added value should be read alongside:

- NICE Guideline [NG31], Care of dying adults in the last days of life, 2015
- NICE Quality Standard [QS144], Care of dying adults in the last days of life, 2017
- NICE Guideline [NG142], End of life care for adults: service delivery, 2019
- NICE Quality Standard [QS13], End of life care for adults, 2021
- Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026
- Universal Principles for Advance Care Planning
- NHS England, Service specifications for palliative and end of life care: Adults
- Quality statement for palliative and end of life care for Wales, 2022
- National Audit of Care at the End of Life (NACEL)
- Leadership Alliance for the Care of Dying People – One Chance to Get it Right

	The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives. The results which should be presented at quality or governance meetings, and action plans to improve care should be shared with executive boards. Suggested target audiences are listed under each recommendation
1	Ensure that patients with advanced chronic disease have access to palliative care alongside disease modifying treatment (parallel planning) to improve symptom control and quality of life. ***Primary target audience:*** *Integrated care boards and commissioners, hospital executive boards* ***Supported by:*** *Palliative care services, clinical directors, medical directors and directors of nursing, hospice services and local authorities, primary care, community care including care homes, nursing homes and social care* *This aligns with NICE Guideline [NG142], End of life care for adults: service delivery, 2019*
	RATIONALE and IMPLEMENTATION SUGGESTIONS
	Rationale: Palliative care should not be associated only with end of life care. Earlier non-specialist palliative care will support people to make sure their life before death is comfortable and their wider needs are being met, while their underlying illness is still being treated. In addition to specialist palliative care, non-specialist palliative care should be a core competency for all healthcare staff. **Implementation:** Building this approach into normal hospital processes, such as a box on an admission proforma may help identify patients in need of palliative care and embed it into clinical practice. The *statutory guidance for integrated care boards* and *NHS England » Service specifications for palliative and end of life care: Adults* may help.

2

Normalise conversations about palliative/end of life care, advance care plans, death and dying. As a trigger to introduce a conversation which includes the patient and their family/carers, consider:

- The surprise question “*Would you be surprised if this patient died within the next 12-months?*” This can be used across all healthcare settings; and/or
- Recurrent hospital admission of patients with advanced chronic disease.

Primary target audience: *Patients and their families/carers, all healthcare professionals, specifically members of the clinical team treating the underlying disease, primary care, community care including care home and nursing home staff*

Supported by: *Palliative care services, clinical directors, medical directors and directors of nursing, hospice services and social care*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: These are tools designed to help identify people who will benefit from proactive discussions about their care and to identify their wishes, such as treatment escalation decisions, especially if they are approaching the end of their life. The ‘surprise question’ is a non-challenging way for clinicians to consider the possibility of patients being in the last year of life. Although the focus might be the advanced chronic disease, other factors, such as comorbidities/age/frailty/poor physiological reserve can influence a person’s needs towards the end of life.

Implementation: By recurrent admission we mean more than once, so this could be set, for example, as two unplanned admissions in the previous 12 months for the same index condition or frailty.

Implementation: The conversations can be used as an opportunity to document an advance care plan.

3

Ensure all patients with an advanced chronic disease are allocated a named care co-ordinator.

Primary target audience: *Medical directors and directors of nursing in integrated care boards, health boards and trusts*

Supported by: *Palliative care services, clinical directors, primary care, hospice services and social care*

This aligns with NICE Cancer Service Guideline [CSG4] Improving Supportive and Palliative Care for Adults with Cancer

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: Care co-ordinators or key workers can help a patient, and their family/carers navigate the health and care system in hospital, the community and at home. They can help the patient and their family/carers access services to control symptoms, secure fast-track funding, and apply for benefits etc. The care co-ordinator may change but they should hand over to the next care co-ordinator.

Implementation: Clinical nurse specialists in cancer services would be a model to replicate.

4

Provide specialist palliative care services in hospitals and in the community, to ensure all patients, including those with non-malignant diseases receive the palliative care they need.

Primary target audience: *Integrated care boards and commissioners*

Supported by: *Medical directors, directors of nursing, the Association for Palliative Medicine of Great Britain and Ireland, hospice services, primary care, and community care*

This aligns with recommendations from the National Audit of Care at the End of Life

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: While early access to non-specialist palliative care and end of life care should be available to all who need it, specialist palliative care services should also be available when a patient's symptoms cannot be adequately controlled. We acknowledge the workforce issues that surround this, and local solutions will vary, some implementation suggestions are listed here.

Implementation: Formal links with hospice services, increased use of clinical networks or partnerships between healthcare providers and commissioners to share knowledge, skills and advice may help.

Implementation: One example of a current system involves an integrated inpatient palliative and end of life care jointly resourced by the NHS and the local hospice. The service was consultant nurse-led and had a dedicated discharge co-ordinator.

Implementation: Dual training of clinical nurse specialists, e.g. respiratory and palliative care.

Implementation: Multidisciplinary teams including consultants in palliative medicine and palliative care clinical nurse specialists, sufficient to provide a seven-day face-to-face service, 8.00am-4.00pm or equivalent, in line with the *NICE Cancer Standards 2004* could be applied to non-cancer conditions.

Implementation: Measure the number of cancer and non-cancer patients receiving specialist palliative care e.g. those coded on hospital systems or recorded on a cancer or palliative care registry. This would provide a baseline of current productivity to highlight where the gaps in service are.

5

Train patient-facing healthcare staff in palliative and end of life care. This training should be included in:

- Undergraduate and postgraduate education; and
- Regular training for patient-facing healthcare staff

Primary target audience: *Medical schools, schools of nursing and university departments who provide training for nurses, pharmacists, allied health professionals, primary care, community care including care homes, nursing homes, social care, post-graduate deaneries, medical directors and directors of nursing*

Supported by: *Executive boards, integrated care boards and commissioners, Care Quality Commission, Health Inspectorate Wales, Regulation and Quality Improvement Authority Northern Ireland*

This aligns with recommendations from the National Audit of Care at the End of Life

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: This training will help patient-facing healthcare staff understand the importance of recognising the need for, and early introduction of palliative care for advanced chronic diseases as well as when to involve specialist palliative care teams. Training should highlight the benefits of symptom control as well as care at the end of life.

Implementation: Embed palliative care and end of life care training as a core competency for patient-facing healthcare staff. A similar example would be *Basic Life Support (BLS)* training.

Implementation: Training requirements should be agreed through objective setting in appraisals. The frequency of this training might vary between different staff groups but should ensure a basic level for most patient-facing healthcare staff and enhanced training wherever possible.

Implementation: Focused training to a level appropriate to the job role with a clear job description and agreed core competencies may provide support for specialist palliative care teams.

6 Ensure that existing advance care plans are shared between all providers involved in a patient's care.

This aligns with recommendation 2 from the NCEPOD report looking at the in-hospital care of out of hospital cardiac arrests – Time Matters

Primary target audience: *Integrated care boards and commissioners*

Supported by: *Palliative care services, clinical directors, medical directors and directors of nursing, primary care, ambulance trusts, care home and nursing home providers, hospice services, social care, local authorities, patients, carers and family members*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: Documents frequently stay in one place if a patient is transferred, meaning their wishes are often not followed. This includes sharing of documents such as ReSPECT forms – *Resuscitation Council UK*, and universal / advance care plan / treatment escalation plans.

Implementation: Use electronic records or send the document with the patient when they are transferred, with consideration given to third sector (hospice), private (care and nursing home) and local authority providers.

7 Raise public awareness to increase the number of people with a registered health and welfare lasting power of attorney (LPA) well before it is needed.

Primary target audience: *Department for Health and Social Care, Welsh Government, Department of Health Northern Ireland, Office of the Public Guardian, the Office of Care and Protection*

Supported by: *Royal colleges, patient support groups, third sector organisations, hospice services, primary care, community care including care homes, nursing homes and social care*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Rationale: Early conversations are important to ensure that people's wishes are always considered specifically should they lose mental capacity to make their own decisions. Appointing trusted people to be an advocate when people cannot speak for themselves should be a normal part of this conversation.

Implementation: Information about a lasting power of attorney can be found here: *www.gov.uk/power-of-attorney.* This information could be provided to patients in GP practices, when people are admitted to hospital, hospice, care home or nursing home. Information could be provided by will-making services, or registrars when people get married/register a birth. A media campaign is needed, similar to organ or blood donation, to raise awareness.

FOREWORD

Of all the topics covered by NCEPOD reports, care at the end of life must be the most relevant to the largest number of people. It is not the first review to look at this,[1-9] yet there still remains room for improvement. The report highlights the importance of normalising conversations about death and dying while anticipating and meeting the needs of those in the last months of life.

The study looked at the end of life care provided to a sample of people with common conditions, however, the findings apply to deaths from most causes. It highlights that people with conditions other than cancer are less likely to receive specialist palliative care. As the proportion of patients dying from non-malignant causes increases, appropriate end of life care for all patients who need it is increasingly important. Almost a third of people admitted to hospital as an emergency are in their last year of life, and most have recent hospital contact offering multiple opportunities to discuss wishes, prognosis, symptom control and end of life care. These were frequently missed.

Death is inevitable but not always predictable. Healthcare professionals and families often avoid discussing death with people who are seriously unwell. However, thinking about death and discussing it with loved ones or healthcare professionals will not make it more likely or bring it closer, but it can make a difference to the care delivered in the final months of life. There is definitely such a thing as a good death, and it's something we can all work towards.

Healthcare professionals should consider, "*Would I be surprised if this patient died in the next 12-months?*" If the answer is no, think about what can be done to prepare the patient for a good death.

The report shows the importance of early involvement of specialist palliative care teams to improve the patient's quality of life, help support loved ones, and ultimately make a good death more likely. A quarter of people did not receive the end of life care they needed and the 2004 NICE guidance for 'round-the-clock' access to specialist palliative care advice is still not being met.[10] Investment in specialist palliative care and hospice provision would help address some of the deficiencies of the current system, however, specialist palliative care input for all patients is not always practical or necessary. Training is needed to allow patient-facing healthcare professionals to recognise when a patient might be coming to the end of their life and understand when specialist palliative care input is indicated. A quarter of hospital induction or mandatory training did not cover end of life care, which I hope will be reviewed in the light of this report.

There were examples of good practice highlighted which must be acknowledged. These included having an integrated palliative and end of life care team, involving palliative care specialists in multidisciplinary team meetings, and parallel care planning for those patients with serious conditions. These are good examples that could be used to stimulate local Quality Improvement projects on review of this report.

I'd like to thank the National Audit of Care at the End of Life (NACEL) for sharing their data, which has saved time and ensured that this report complements the excellent work they are doing to improve the quality of care, reduce unwarranted variation and health inequalities at the end of life. My thanks also go to the NCEPOD trustees, staff, clinical co-ordinators, study advisors, reviewers, clinicians, local reporters and ambassadors, without whom this work would not have been possible.

Dr Suzy Lishman CBE, NCEPOD Chair

INTRODUCTION

Each year over 600,000 people die in the United Kingdom[11] and many of these deaths occur in hospital, despite the majority of people saying that they would prefer not to die there.[5] Approximately 70% of people die from long-term health conditions that often follow a predictable course, with death anticipated well in advance of the event.[12] The annual number of deaths in the United Kingdom is predicted to rise to 736,000 by mid-2035.[13] Therefore, the provision of care at the end of life must meet the needs of the population.

The World Health Organization has defined palliative care as: '*An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial, and spiritual*'.[14] High-quality palliative care has a positive impact on patients and their families. Long-term conditions that are life-limiting represent an opportunity for palliative care to control symptoms and reduce suffering.

In 2008 the first national strategy for end of life care in England emphasised the importance of patient choice in terms of place of care alongside equity, cost effectiveness, planning for future increases in population and quality of care.[1] This strategy highlighted the variation in the quality of care delivered and received.

In 2014, the Leadership Alliance for the Care of Dying People published '*One chance to get it right*', which outlined five principles to guide the delivery of high-quality end of life care: recognising imminent death; communication with the patient; communication with the family; the needs of families; an individual plan of care.[15]

In 2016 the Care Quality Commission's report '*A different ending: Addressing inequalities in end of life care*' highlighted variation in the quality of end of life care experienced by patients from minority backgrounds.[4] In the same year, the National Survey of Bereaved People (VOICES) highlighted much good practice but also a lack of continuity and communication between providers.[5] These issues also align with NICE guideline NG31 (2015) and NICE quality standards QS137 and QS144.[6-8]

In 2021 the National Palliative and End of Life Care Partnership; a partnership of national organisations with experience of, and responsibility for, palliative care and end of life care, refreshed the '*Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026*'. The framework sets out six ambitions for palliative care and end of life care: each person is seen as an individual; each person gets fair access to care; maximise well-being; care is coordinated; all staff are prepared to care; each community is prepared to help.[16]

The National Audit of Care at the End of Life, (NACEL)[9] has reviewed compliance with published standards and guidelines during the final admission of patients who died in acute and community hospitals in England and Wales. Whilst the quality of care has improved in many areas, there remains room for improvement: for example, in the provision of a seven-day specialist palliative care service, the use of individual care plans and in identifying the needs of those close to the patient.

To add to the data provided by the NACEL audit, this study focused on hospital care provided in the last six-months of life as well as on the final admission. It was designed to identify opportunities to improve the provision of palliative care earlier in the disease trajectory and the impact of this on care at the end of life.

WHAT PEOPLE SAY

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‘My father was diagnosed with lung cancer and just four weeks later passed away at home … However, it wasn’t easy to make happen and was extremely challenging to manage as a family. The care he required often left us feeling overwhelmed and bereft … There is not enough support to make end of life at home feasible for everyone and for those that do make this happen the experience could be so much more improved.’

Hayley

‘I suffer from an incurable condition and it worries me greatly what will happen to me at the end of my life. I have been advised to make a living will to cover this exact issue. We are all human beings who deserve dignity and respect regardless of our circumstances.’

Anonymous

‘My Mum died in a hospice, and the care was wonderful, however she had wanted to get home, and a bed was installed, but it was not possible to put a care package in place in enough time for her to get there.’

Anonymous

‘Hospitals are busy sterile places, with set routines and often understaffed, not a place anyone would choose to die. If there is time and a choice, it should be made available. It would also free up much needed bed space for the next patient in need.’

Sacha (whose Mum died from cancer)

‘Making someone’s last wishes happen is the most dignified and compassionate thing you can do. I am an oncology/chemotherapy nurse and have seen patients plan their last days and the calmness and peace they achieve cannot be ignored. Each person is unique, each death is unique.’

Diane, an oncology nurse

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CHAPTER 1: METHODS AND DATA RETURNS

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Study Advisory Group

A multidisciplinary group of clinicians was convened to define the study aim and objectives. The Study Advisory Group (SAG) comprised a bereaved carer, representation from the National Audit of Care at the End of Life (NACEL), Hospice UK, Northern Ireland Hospice, Marie Curie, Sue Ryder and Macmillan Cancer Support, along with healthcare professionals from palliative medicine, specialist palliative care pharmacy, nursing, speech and language therapy, occupational therapy, anaesthesia and physiotherapy. This group steered the study from design to completion.

Study aim

To identify and explore areas for improvement in the end of life care of adults with advanced illness, focussing on the last six-months of life.

Objectives

To explore the clinical and organisational structures in place for the provision of care for patients at the end of life, reviewing the last six-months of life with a focus on:

- Management of multiple admissions
- Informed choices
- Assessing adequate communications with the patient, and their family and/or carers
- Use of evidence recorded from discussions and decision-making
- The extent to which patients' wishes and preferences were achievable
- Advance care planning discussions, and their quality
- Prompt recognition of the dying patient
- Evidence to support advance care planning in achieving key quality outcomes
- Treatment, escalation decisions and support for people at the end of their lives.

Study population and case ascertainment

Inclusion criteria

All patients aged 18 or over who died in hospital between 1st April 2022 and 30th September 2022 with one or more of the following conditions: dementia, heart failure, lung cancer and liver disease. A sample of people who died in the community was also identified. These were patients admitted to hospital during the study period with one of the included diagnoses who were subsequently discharged and died within six-months.

Exclusion criteria

Death due to suicides, homicides, or self-harm related
Death due to trauma, drowning, drug overdose or poisoning

Hospital participation

Data were included from NHS hospitals in England, Wales, and Northern Ireland.

Data collection – peer review

Identification of a sample population

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined time period. From this initial cohort, a maximum of eight patients were randomly selected from each hospital for inclusion in the study.

Questionnaire

One clinician questionnaire was used to collect data for this study. This questionnaire was sent electronically to the consultant responsible for the care of the patient at the time of their final admission to hospital.

Case notes

Copies of the case notes were requested from secondary care providers for peer review. These encompassed case notes from the final admission and the prior hospital contacts in the six-months preceding the final admission.

Peer review of the case notes and questionnaire data

A multidisciplinary group of case reviewers comprising consultants and trainees from palliative care medicine, elderly medicine, acute medicine, general medicine, intensive care medicine, anaesthetics, clinical nurse specialists, specialist pharmacy and speech and language therapy were recruited to peer review the case notes and associated clinician questionnaires.

Using a semi-structured electronic questionnaire, each set of case notes was reviewed by at least one reviewer within a multidisciplinary meeting. A discussion, chaired by an NCEPOD clinical co-ordinator took place at regular intervals, allowing each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion. In addition to assessing various aspects of care they were also asked to assign an overall quality of care grade:

- **Good practice:** A standard that you would accept from yourself, your trainees and your institution
- **Room for improvement:** Aspects of **clinical care** that could have been better
- **Room for improvement:** Aspects of **organisational care** that could have been better
- **Room for improvement:** Aspects of **both clinical and organisational care** that could have been better
- **Less than satisfactory:** Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution
- **Insufficient data:** Insufficient information submitted to NCEPOD to assess the quality of care.

National Audit for Care at the End of Life (NACEL) - organisational data

To reduce data burden, and improve efficiency, organisational data collected for NACEL in 2022 was provided. NACEL review the end of life care in hospital for any cause of death. The NCEPOD dataset included four conditions and reviewed previous hospital contact in addition to the final admission.

Information governance

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006

(PIAG 4-08(b)/2003, App No 007), and the Code of Practice on Confidential Information. Each patient was given a unique NCEPOD number.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free-text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. As the methodology provides a snapshot of care over a set point in time, with data collected from several sources to build a national picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies have been used throughout this report to illustrate themes. The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

Data analysis rules

- Small numbers have been suppressed if they risk identifying an individual
- Any percentage under 1% has been presented in the report as <1%
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

The findings of the report were reviewed prior to publication by the SAG, case reviewers and the NCEPOD Steering Group, which included clinical co-ordinators, trustees, and lay representatives.

Data returns

Clinical data

During the six-month study period, the initial patient identification spreadsheet data recorded 16,657 deaths where lung cancer, dementia, heart failure or liver disease were the primary diagnosis in the final hospital admission. In total, 9,373/16,657 of these were deaths in hospital. Figure 1.1 shows the sampling for inclusion in the study.

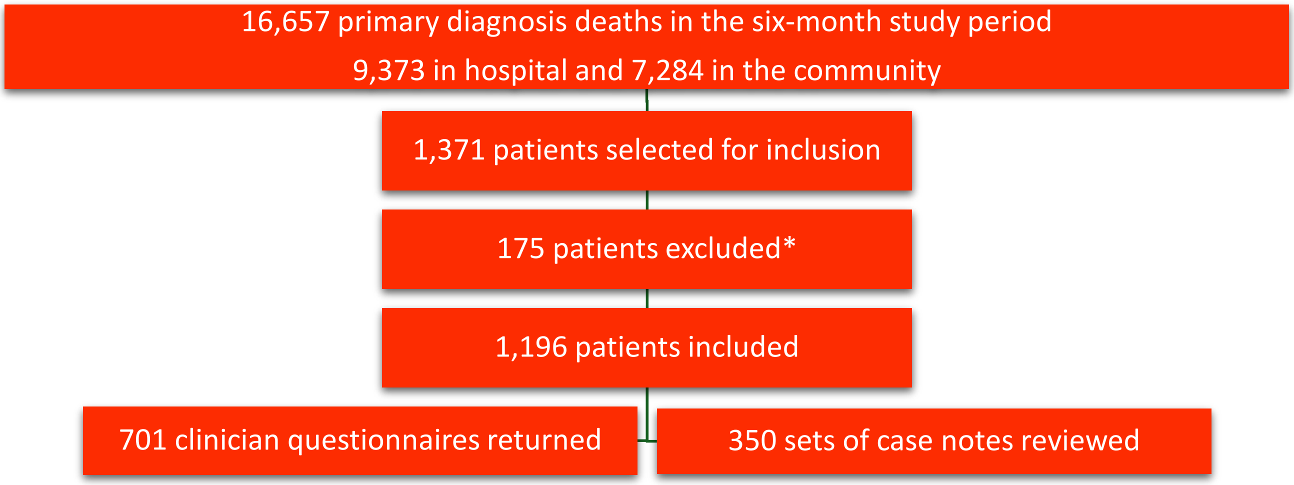

Figure 1.1 Data returned

**The most common reasons for exclusion were that the patient did not have a diagnosis of lung cancer, dementia, heart failure or liver disease.*

CHAPTER 2: STUDY POPULATION

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Four different diagnoses were chosen for inclusion in this study due to their different disease trajectories and the different demographics of the patients with these conditions. Inequalities in access to palliative and end of life care for patients with dementia and non-malignant conditions have been reported.[17,18] It is important to address these inequalities as advances in the identification of early-stage cancers and improved cancer treatments mean that the proportion of deaths from non-malignant disease is increasing.[19]

Initial sample

Of the 16,657 patients identified during the six-month study period with one of the primary diagnoses, the most common diagnosis was heart failure (7,264/16,657; 43.6%). The patients with liver disease were on average younger than the patients in the other three groups (with a mean age of 61.6 years, median 61.0 years) (T2.1).

Table 2.1 Age (years) of the study population by primary diagnosis

	Lung cancer	Dementia	Heart failure	Liver disease
Median	74.0	85.0	84.0	61.0
Mean	72.5	84.8	82.2	61.6
Number of patients	5,134	1,390	7,264	2,869

Patient identifier spreadsheet data

Overall, 9,373/16,657 (56.3%) patients died in hospital. A hospital death was more likely for those who died of liver disease and heart failure than lung cancer or dementia (T2.2).

Table 2.2 Location of death by primary diagnosis

	Location of death				
	Hospital		Community		
Diagnosis	Number of patients	%	Number of patients	%	Total
Lung cancer	2,208	43.0	2,926	57.0	5,134
Dementia	633	45.5	757	54.5	1,390
Heart failure	4,617	63.6	2,647	36.4	7,264
Liver disease	1,915	66.7	954	33.3	2,869
Total	**9,373**	**56.3**	**7,284**	**43.7**	**16,657**

Patient identifier spreadsheet data

There were 9,282/16,390 (56.6%) patients who had been admitted to hospital in the six-months before death. People with dementia were the least likely group to have been admitted (603/1,344; 44.9%), and the most likely were those with lung cancer (3041/5051; 60.2%) (T2.3). It is worth noting that hospital admission data do not include patients who presented to the emergency department and were not admitted or those who attended outpatient appointments.

Table 2.3 Hospital admissions in the six-months before death by primary diagnosis

	Hospital admission with six-months of death				
	Yes		No		
Diagnosis	**Number of patients**	**%**	**Number of patients**	**%**	**Total**
Lung cancer	3,041	60.2	2,010	39.8	5,051
Dementia	603	44.9	741	55.1	1,344
Heart failure	4,020	55.9	3,170	44.1	7,190
Liver disease	1,618	57.7	1,187	42.3	2,805
Total	**9,282**	**56.6**	**7,108**	**43.4**	**16,390**

Patient identifier spreadsheet data

Sampled patient group for review

From the initial larger dataset, a smaller sample of patients was selected for an in-depth review based on having had previous admissions to hospital. The detailed data presented in this report are therefore from a subgroup which differs slightly from the initial dataset (F2.1). Some patients had been diagnosed with more than one included condition. As a result, 754 diagnoses were reviewed in the 701 included patients. The largest overlap between groups was between dementia and heart failure, where there were 24 patients with both conditions. This overlap would be expected as vascular disease contributes to both heart failure and dementia. Much of the data presented in this report separates the diagnosis groups to help describe where there are differences in the provision of care as well as where the improvements needed apply to all patients.

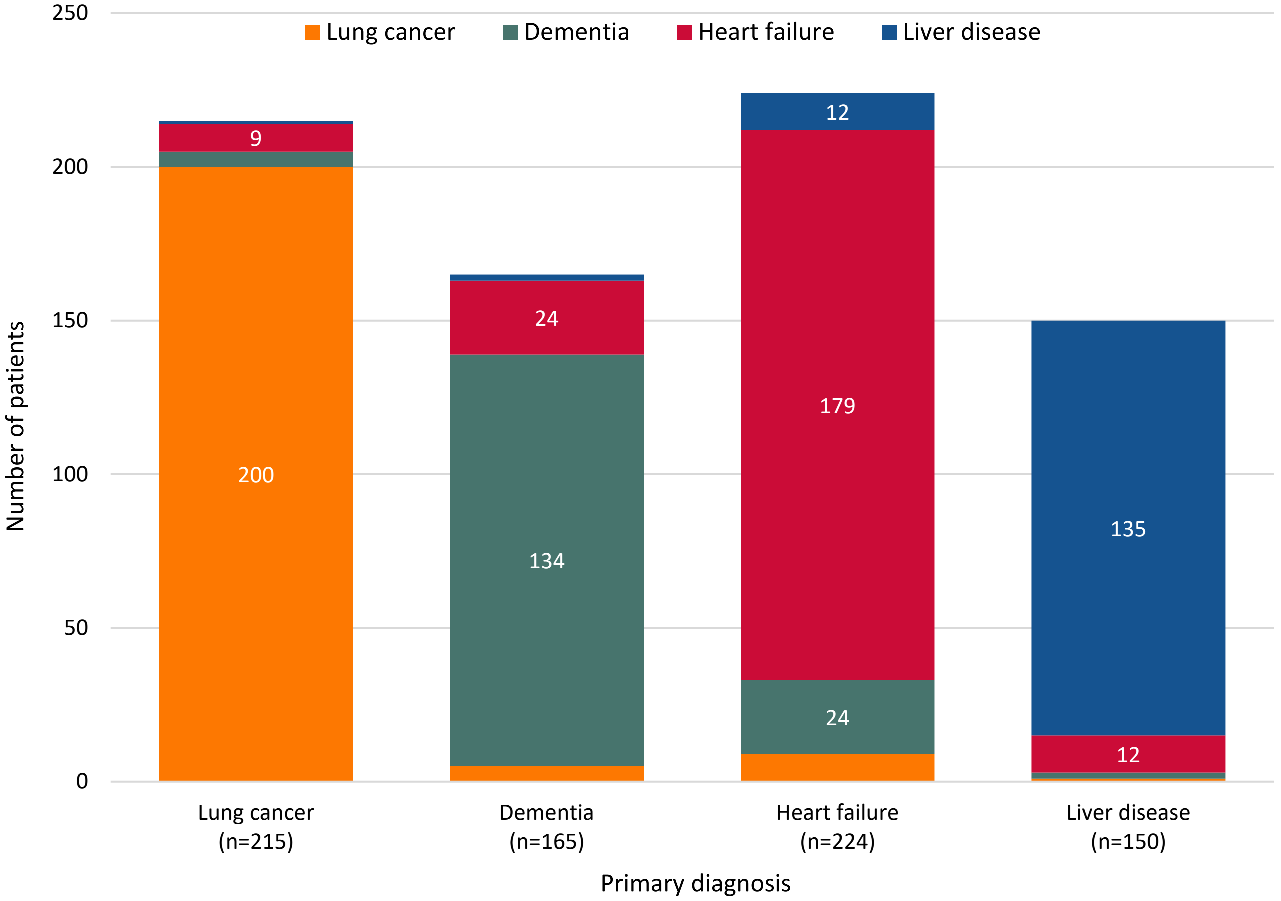

Figure 2.1 Primary diagnosis and multiple diagnoses

Clinician questionnaire data

As with the initial dataset, the patients with dementia (median age 86.0 years) and heart failure (median age 83.0 years) were generally older than those with lung cancer (median age 73.0 years), and those with liver disease (median age 64.0 years) (F2.2).

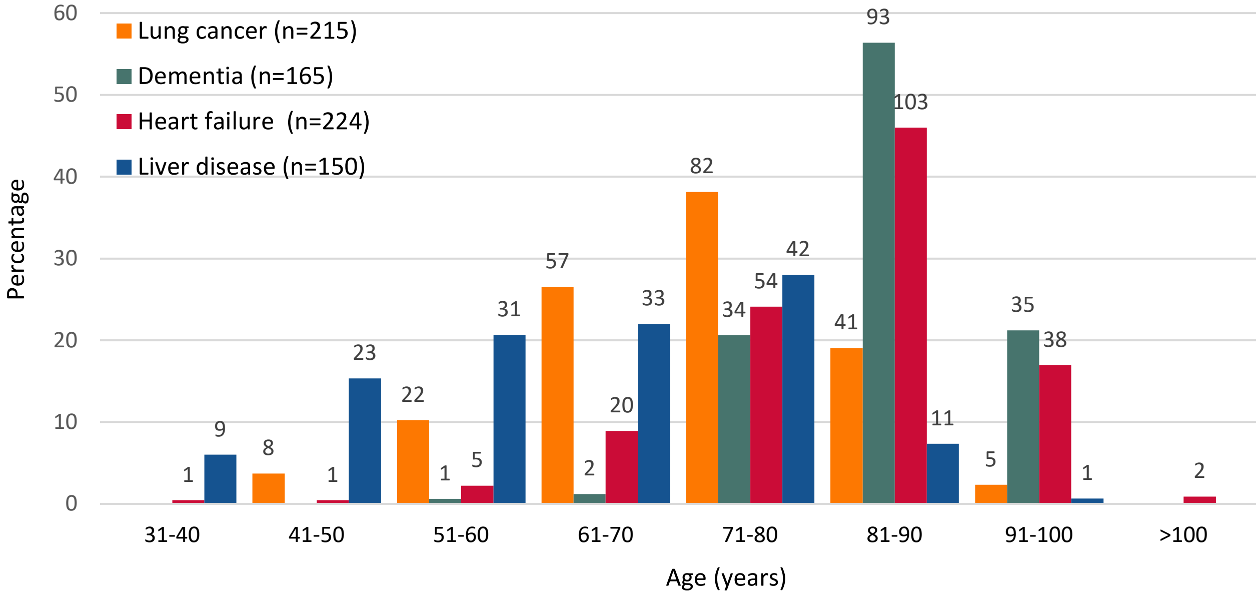

Figure 2.2 Age range by primary diagnosis
Clinician questionnaire data

Of the 701 patients included in the study, 316/701 (45.1%) were women. Ethnicity was identified for 635 patients and 608/635 (95.7%) were identified as white British or white other. Of the remaining 27 patients, 24/635 (3.8%) were Asian or Asian British. United Kingdom census data from 2021 showed that 81.7% of the population was white and Asian ethnic groups were the second largest percentage (9.3%).[20] Minority ethnic groups were therefore under-represented in the study population. There was no clearly identifiable explanation for this difference.

The Rockwood clinical frailty scale (9-point scale) was developed to describe the overall functional status of patients aged 65 years or older.[21] The Royal College of Physicians Acute Care Toolkit recommends using a system such as the clinical frailty scale to ensure that older people with frailty who attend hospital are consistently identified.[22] The Karnofsky performance status scale (10-point scale) is commonly used to record the level of physical functioning in cancer patients.[23] Both of these scales were used to describe the functional status of patients included in this study (APPENDIX).

There were differences in the frailty scores between the patients with different conditions (F2.3). Of the patients with dementia, there were 97/149 (65.1%) (unknown in 16) with a frailty score of 7-9 (at least severely frail), and no patients with a score of 0-3 (managing well or better). The group of patients with liver disease were more likely to be managing well (22/113; 19.5%) and had the lowest percentage with severe frailty (31/113; 27.4%) (unknown in 37).

There was a similar pattern for the Karnofsky performance score (F2.4), with a tendency for patients with liver disease to have a better (higher) performance score (median score 60). Those with dementia were more likely to have a worse (lower) performance score (median score 40). The groups of patients with heart failure and lung cancer both had a median score of 50.

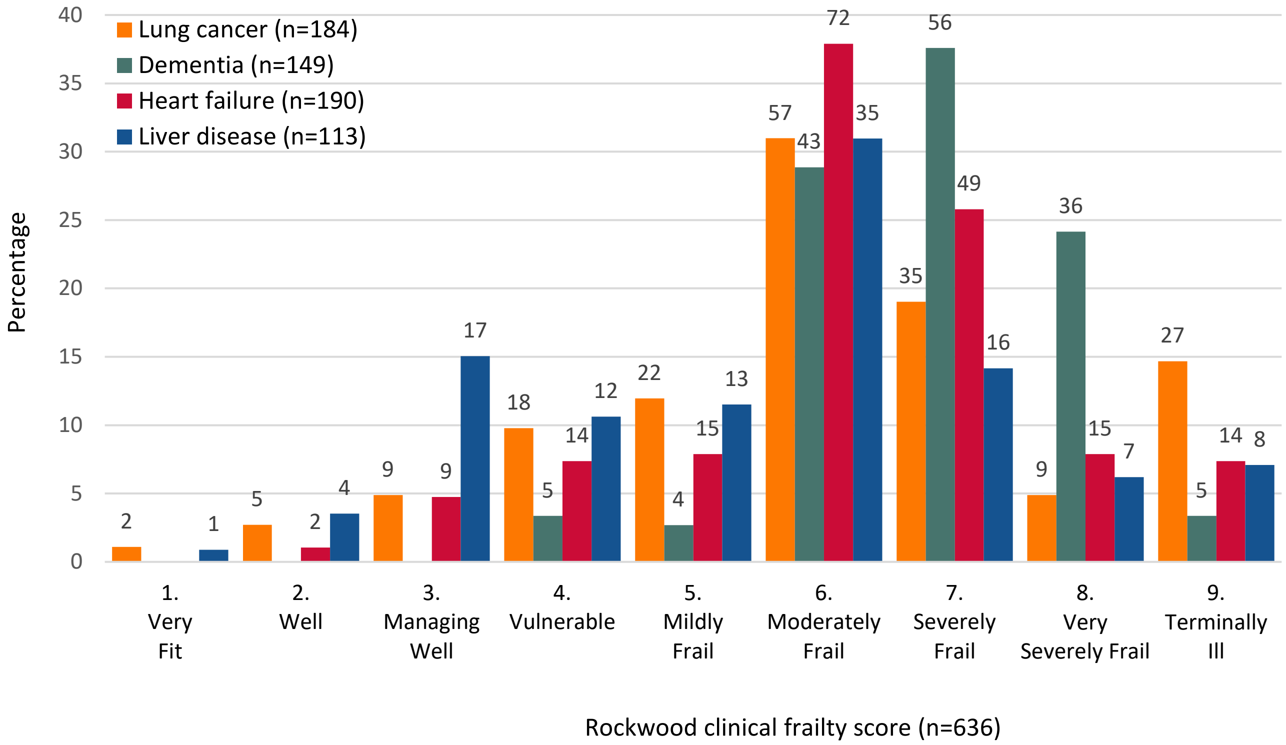

Figure 2.3 Rockwood score and diagnosis groups
Clinician questionnaire data

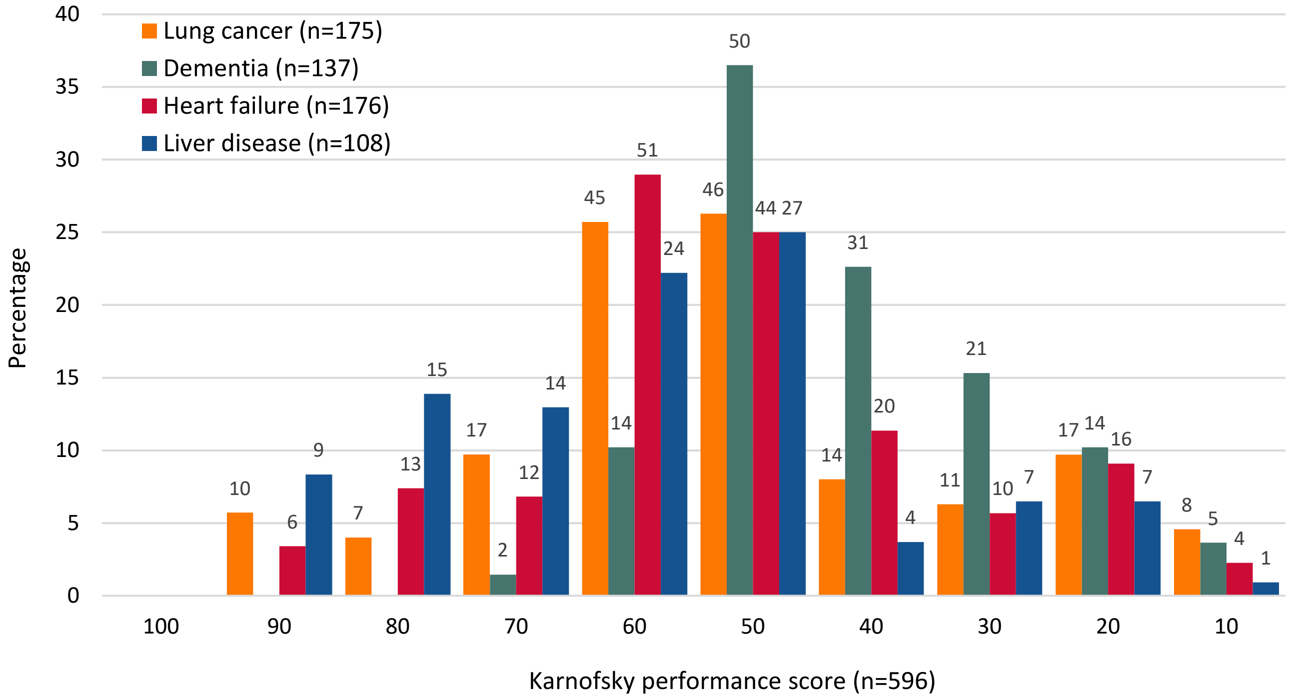

Figure 2.4 Karnofsky score
Clinician questionnaire data

From the clinical questionnaire data, 490/701 (69.9%) patients died in hospital. There were 79/701 (11.3%) people who died at home and 40/701 (5.7%) who died in a hospice. A further 51/701 (7.3%) patients died in a care home and for the 41/701 (5.8%) people who died in the community the exact location was not known as no clinical records were available at the time of death. Of the peer reviewed sample of patients, 274/350 (78.3%) died in hospital and the remaining 76/350 (21.7%) died in the community.

Patients with liver disease most commonly (124/150; 82.7%) died in hospital. There were some differences between the diagnostic groups in the next most common location of death. Of the patients with lung cancer, 63/215 (29.3%) died in their own home (37) or a hospice (26), while 30/165 (18.2%) of those with dementia died in a care home (T2.4).

Table 2.4 Location of death by primary diagnosis

	Lung cancer		Dementia		Heart failure		Liver disease	
Location of death	**Number of patients**	**%**	**Number of patients**	**%**	**Number of patients**	**%**	**Number of patients**	**%**
Hospital	121	56.3	111	67.3	173	77.2	124	82.7
Own home	37	17.2	9	5.5	25	11.2	9	6.0
Hospice	26	12.1	4	2.4	5	2.2	7	4.7
Care home	14	6.5	30	18.2	10	4.5	2	1.4
Unknown (community)	17	7.9	8	4.8	11	4.9	8	5.3
Total	**215**		**165**		**224**		**150**	

Clinician questionnaire data

Clinicians reported that informal, or family support was provided for 402/560 (71.8%) patients (unknown in 141). Clinicians also reported that 158/481 (32.8%) patients were receiving care at home prior to their final hospital admission (T2.5). If care arrangements are already in place prior to hospital admission, it may be easier to re-establish them than to arrange a new package of care, helping to facilitate discharge from hospital when the end of life is approaching. People who died in the community were more likely to have organised care in place (60/132; 45.5%) than those who died in hospital (98/349; 28.1%) (T2.5).

Table 2.5 Organised domiciliary/home care in place for this patient

	Hospital		Community		All	
	Number of patients	**%**	**Number of patients**	**%**	**Number of patients**	**%**
Yes	98	28.1	60	45.5	158	32.8
No	251	71.9	72	54.5	323	67.2
Subtotal	**349**		**132**		**481**	
Unknown	60		30		90	
Total	**409**		**162**		**571**	

Clinician questionnaire data

A health and welfare lasting power of attorney (LPA) can be put in place to allow for decisions to be made if a patient does not have the mental capacity to make their own decisions. It is designed to ensure that a person's prior views are considered. In conditions such as dementia, loss of mental capacity is predictable. Patients with advanced liver disease can develop encephalopathy, which although potentially reversible, can reduce their ability to engage in conversations about their care. Having an LPA in place can therefore be of particular help in decision-making for these patient groups. There was a documented health and welfare lasting power of attorney in place for 41/444 (9.2%) patients, of which 27 were for people with dementia (unknown in 257).

CHAPTER 3: PROVISION OF PALLIATIVE CARE SERVICES

(BACK TO CONTENTS)

Hospice UK estimates that one in four people do not receive the care they need at the end of their life.[24] Using population data in England over a two-year period, it has been estimated that 69-82% of people who die need palliative care.[25] Data from the initial dataset indicated that palliative care input was provided (coded) for 3,614/9,007 (40.1%) patients who died in hospital. These data suggest there may be a need to increase palliative care provision by between 70 and 100%.

Palliative care services were originally introduced to focus on patients with a predictable course of deterioration, particularly cancer. Although they are most effective when introduced early and not simply at the end of life. Patients with frailty, respiratory conditions, dementia and neurological diseases remain less likely to receive hospice care,[24] and from the initial dataset in this study it could be seen that palliative care for patients in hospital was more commonly coded for those with lung cancer (1,292/2,138; 60.4%). Patients with liver disease (562/1,817; 30.9%), heart failure (1,499/4,466; 33.6%) and dementia (261/586; 44.5%) had a lower frequency of palliative care coding (T3.1).

Table 3.1 Coded palliative care input (deaths in hospital)

	Coded palliative care input				
	Yes		No		
Diagnosis	**Number of patients**	**%**	**Number of patients**	**%**	**Total**
Lung cancer	1,292	60.4	846	39.6	2,138
Dementia	261	44.5	325	55.5	586
Heart failure	1,499	33.6	2,967	66.4	4,466
Liver disease	562	30.9	1,255	69.1	1,817
Total	**3,614**	40.1	**5,393**	59.9	**9,007**

Patient identifier spreadsheet data

Organisation of specialist palliative care services - National Audit of Care at the End of Life (NACEL)

These organisational data are from the 2022 National Audit of Care at the End of Life (NACEL).[9] It should be noted that the data are from England and Wales and do not include Northern Ireland.

The national framework for end of life care sets an ambition to ensure that each person gets fair access to care.[17] Provision of specialist palliative care services is known to vary across different geographical locations, with rural areas being served less well than urban communities.[26,27]

Data for NHS acute and community hospitals at the time of this study showed that there was onsite access to a specialist palliative care service in 161/214 (75.2%) hospitals and access for a further 49/214 (22.9%) hospitals offsite. All the 160 acute hospitals were able to access specialist palliative care services (T3.2).

Table 3.2 Access to specialist palliative care

	Acute		Community		Total	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes - onsite	146	91.3	15	27.8	161	75.2
Yes - offsite	14	8.8	35	64.8	49	22.9
No	0	0.0	4	7.4	4	1.9
Total	**160**		**54**		**214**	

NACEL organisational data

Guidance designed to improve access to palliative care for patients with cancer, published in 2004,[10] recommended that access to specialist palliative care advice was available on a 24-hour, seven days per week basis. The importance of access to such palliative care has also been highlighted again more recently.[28] However, there was still a gap in provision identified at the time of this study. Seven-day specialist palliative care services were only available in 125/210 (59.5%) hospitals (T3.3). Telephone access to the service was available in 191/209 (91.4%) hospitals (T3.4).

Table 3.3 Face-to-face specialist palliative care service available 8 hours/day, 7 days/week

	Acute		Community		Total	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes	105	65.6	20	40.0	125	59.5
No	55	34.4	30	60.0	85	40.5
Total	**160**		**50**		**210**	

NACEL organisational data

Table 3.4 Telephone specialist palliative care service available 24 hours/day, 7 days/week

	Acute		Community		Total	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes	149	93.1	42	85.7	191	91.4
No	11	6.9	7	14.3	18	8.6
Total	**160**		**49**		**209**	

NACEL organisational data

Specialist palliative care input is not needed for every patient nor is it feasible within current resources. Treating the symptoms of advanced chronic diseases is the responsibility of condition-specific specialist teams. It is therefore important to provide general training in both palliative care and end of life care for healthcare staff, to improve the ability to recognise who would benefit from specialist palliative care, both for control of symptoms and at the end of life, to recognise when the end of life is approaching, and to improve practical aspects of care delivery.

Training should be embedded at all levels starting with undergraduates. Regular updates to maintain essential competency are often built into mandatory or priority training in hospitals. For example, basic life support is a core competency and training for both palliative care and end of life care could be given a similar priority. However, training in end of life care was included in the induction programme in only 137/214 (64.0%) hospitals and in mandatory or priority training in 110/214

(51.4%) hospitals. There were 55/214 (25.7%) hospitals where this training was not included in the induction programme nor in priority training which is a missed opportunity (T3.5).

Table 3.5 End of life care training included in induction and/or mandatory/priority training

	Acute		Community		Total	
	Number of hospitals	%	Number of hospitals	%	Number of hospitals	%
Yes	126	78.8	33	61.1	159	74.3
No	34	21.3	21	38.9	55	25.7
Total	**160**		**54**		**214**	

NACEL organisational data

Both acute and community hospitals had similar levels of training in communication skills in place (159/213; 74.6%). There was also a similar frequency with which the views of bereaved families were sought about the end of life care provided (137/211; 64.9%).

CHAPTER 4: PREVIOUS HOSPITAL CONTACT

(BACK TO CONTENTS)

About 30% of patients who are admitted to hospital as an emergency are in their last year of life.[29] Specialist palliative care input can improve symptom control as well as care at the end of life, and has also been shown to reduce overall healthcare costs.[30] This study was designed to look at hospital contacts in the six-months prior to death including outpatient appointments, emergency department attendances and admissions. Data collection aimed to complement the National Audit of Care at the End of Life,[9] which looks at the final admission.[9] The aim was to identify opportunities to improve access to and delivery of specialist palliative care in the months before death.

The study sample was biased to include more patients with previous hospital contact to enable a full review of care received. A greater proportion of patients selected for case review had a previous hospital contact compared with the data received from the clinical questionnaires alone (T4.1).

Table 4.1 Previous contact with this hospital in the six-months prior to the index admission

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	559	82.3	314	92.1
No	120	17.7	27	7.9
Subtotal	**679**		**341**	
Unknown	22		9	
Total	**701**		**350**	

Clinician questionnaire data and reviewer assessment form data

Previous hospital contact was most commonly through emergency admission (430/559; 76.9%) (T4.2). There were also 208/559 (37.2%) patients who attended outpatient clinics. Similar numbers attended the emergency department but were not admitted (64/559; 11.4%) or were admitted electively (69/559; 12.3%). Therefore, during the natural course of these patients' illnesses there were multiple opportunities to discuss their wishes, have realistic conversations about prognosis, and introduce treatments aimed at symptom control and quality of life. The main opportunities for earlier specialist palliative care input sat within emergency care pathways and when they attended outpatient appointments.

Table 4.2 Types of previous contact

	Number of patients	%
Emergency (non-elective) admission(s)	430	92.5
Outpatient appointment(s)	208	44.7
Elective admission(s)	69	14.8
Emergency department attendance (not admitted)	64	13.8
Other	26	5.6

Answers may be multiple; n=559
Clinician questionnaire data

Patients with dementia were the least likely to have hospital contact in the prior six-months which may reflect the challenges of navigating the practical aspects of attending hospital. It may also reflect the fact that these patients have plans in place to prevent hospital attendance more frequently than those with other conditions (T4.3). Contact occurred in only 98/156 (62.8%) of this patient group, compared with at least 85% of all other diagnosis groups (lung cancer 190/211; 90.0%, liver disease 130/149; 87.2%, heart failure 183/213; 85.9%). Outpatient review was most common in the group with lung cancer (102/190; 53.7%) and least common in those with dementia (11/98; 11.2%) (F4.1).

Table 4.3 Contact with hospital in the six-months prior to index admission by diagnosis

	Lung cancer		Dementia		Heart failure		Liver disease	
	Number of patients	%	Number of patients	%	Number of patients	%	Number of patients	%
Yes	190	90.0	98	62.8	183	85.9	130	87.2
No	21	10.0	58	37.2	30	14.1	19	12.8
Subtotal	**211**		**156**		**213**		**149**	
Unknown	4		9		11		1	
Total	**215**		**165**		**224**		**150**	

Clinician questionnaire data

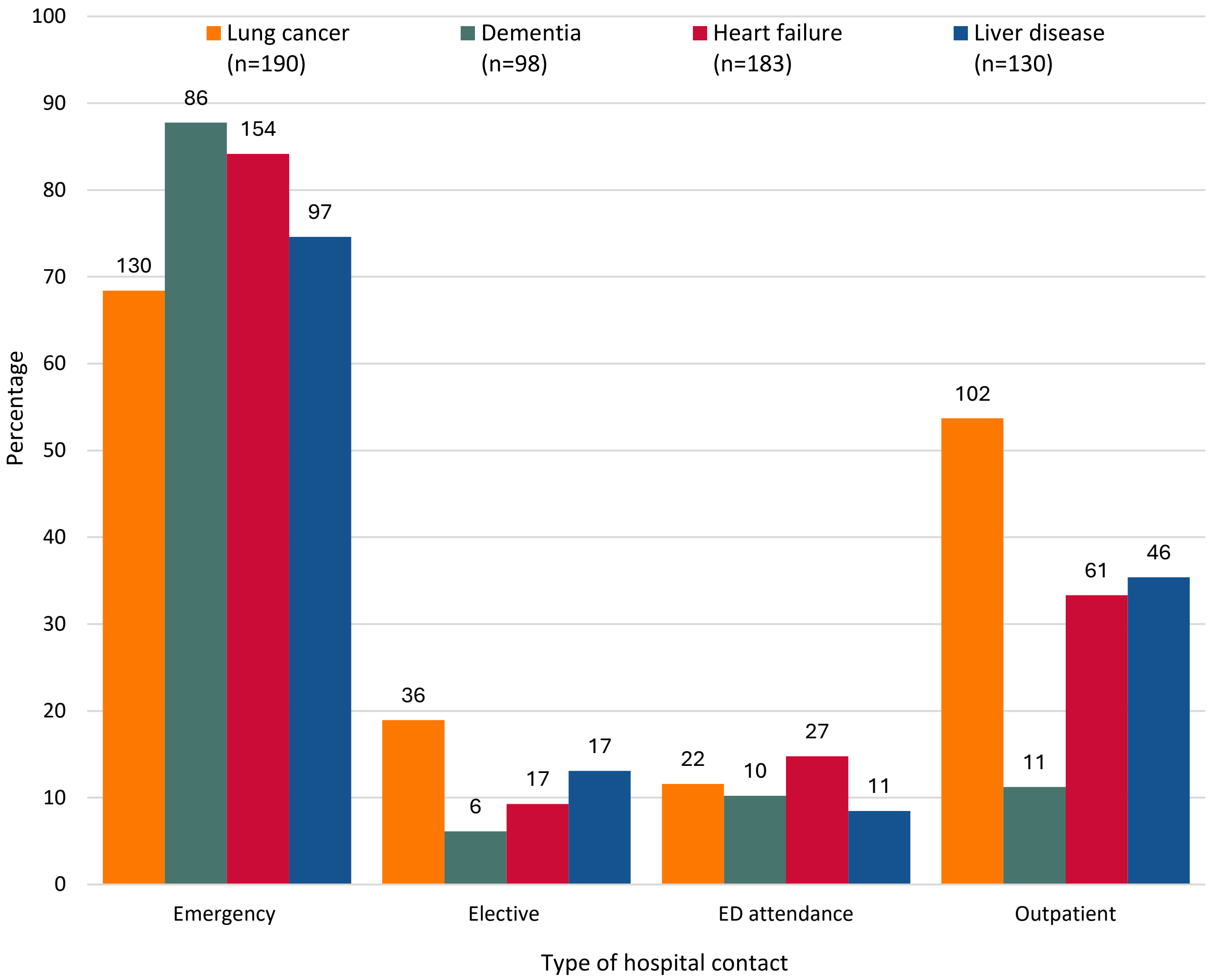

Figure 4.1 Types of previous hospital contact by diagnosis

Clinician questionnaire data

Data from the clinician questionnaire showed that during the previous hospital contact, death in the next six-months was anticipated in most patients (483/559; 86.4%) (unknown in 142).

Where death was anticipated, there were opportunities to improve end of life care in the six-months prior to death for 139/444 (31.3%) patients (T4.4). However, the reviewers believed that opportunities were missed more frequently, occurring in 153/285 (53.7%) patients. They reported that more opportunities were missed in the patients who died in hospital (126/219; 57.5%) than in those who died in the community (27/66; 40.9%) (T4.4). Possibly as clinicians within their own hospitals often accept the limitations in care, or do not see them as they are too close to the situation.

Table 4.4 Missed opportunities during previous hospital contact

	Clinicians' opinion All deaths		**Reviewers' opinion In hospital**		**Reviewers' opinion In the community**		**Reviewers' opinion All deaths**	
	Number of patients	**%**	**Number of patients**	**%**	**Number of patients**	**%**	**Number of patients**	**%**
Yes	139	31.3	126	57.5	27	40.9	153	53.7
No	305	68.7	93	42.5	39	59.1	132	46.3
Subtotal	**444**		**219**		**66**		**285**	
Not applicable	76							
Unknown	39		22		7		29	
Total	**559**		**241**		**73**		**314**	

Clinician questionnaire and reviewer assessment form data

According to the clinicians who looked after the patients, opportunities were missed more frequently in patients with dementia (31/81; 38.3%) and heart failure (53/146; 36.3%) than in those with lung cancer (52/165; 31.5%) and liver disease (19/88; 21.6%). The most common areas for improvement identified were specialist palliative care input, treatment limitation decisions and communication (T4.5). For 77/444 (17.3%) patients specialist palliative/end of life care input could have been better.

Table 4.5 Areas that could have been improved

	Number of patients	**% (of 444)**	**% (of 139)**
Specialist palliative/end of life care input	77	17.3	55.4
Treatment/intervention limitation decisions	66	14.9	47.5
Communication with patient/family	58	13.1	41.7
Discharge arrangements for support in the community	42	9.5	30.2
Investigation limitation decisions	29	6.5	20.9
Medicines management	18	4.1	12.9

Clinician questionnaire data

The reviewers also identified missed opportunities in each of the diagnosis groups (F4.2). This was the case in 46/72 (63.9%) patients with heart failure. Heart failure is a condition that often has a period of recovery after an acute deterioration. This leads to a greater focus on long-term disease management than on palliative care - a good reason to use a parallel planning approach. There were also missed opportunities in 25/48 (52.1%) patients with dementia, 50/101 (49.5%) of those with lung cancer and 24/49 (49.0%) patients with liver disease (F4.2).

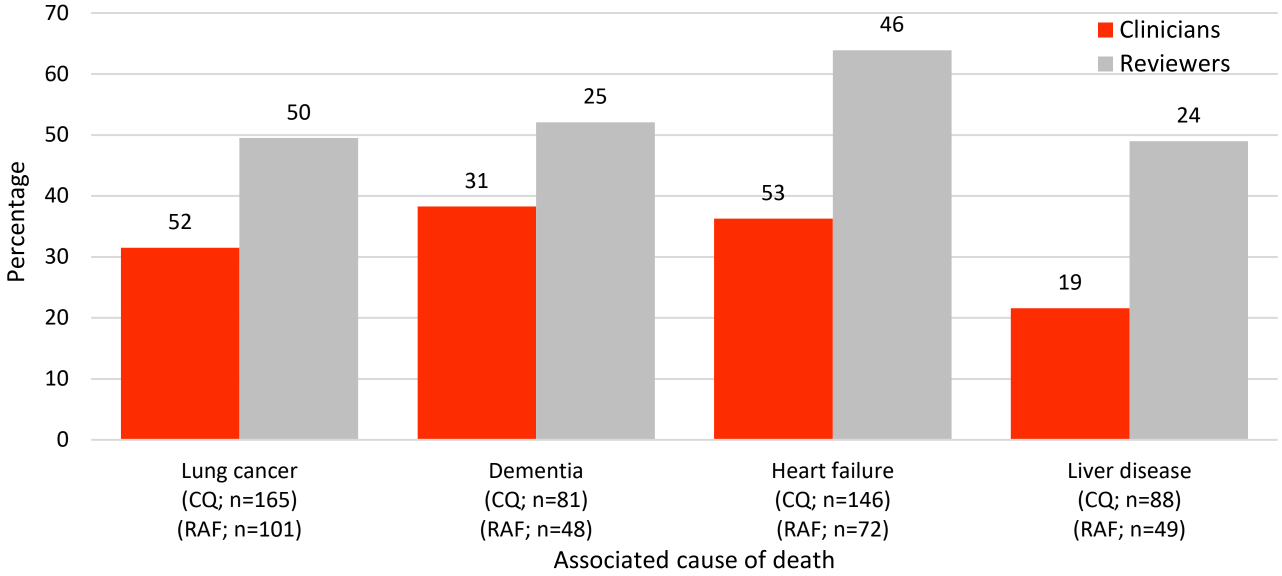

Figure 4.2 Missed opportunities by diagnosis
Clinician questionnaire (CQ) and reviewer assessment form (RAF) data

The areas for improvement identified by reviewers were the same as those identified in data from the clinical questionnaire. Figure 4.3 shows that the areas for improvement applied to all the diagnosis groups. When compared with Figure 4.4, it suggests that improvement is needed in the same areas of practice for patients who are in the last six-months of their life, regardless of the underlying diagnosis.

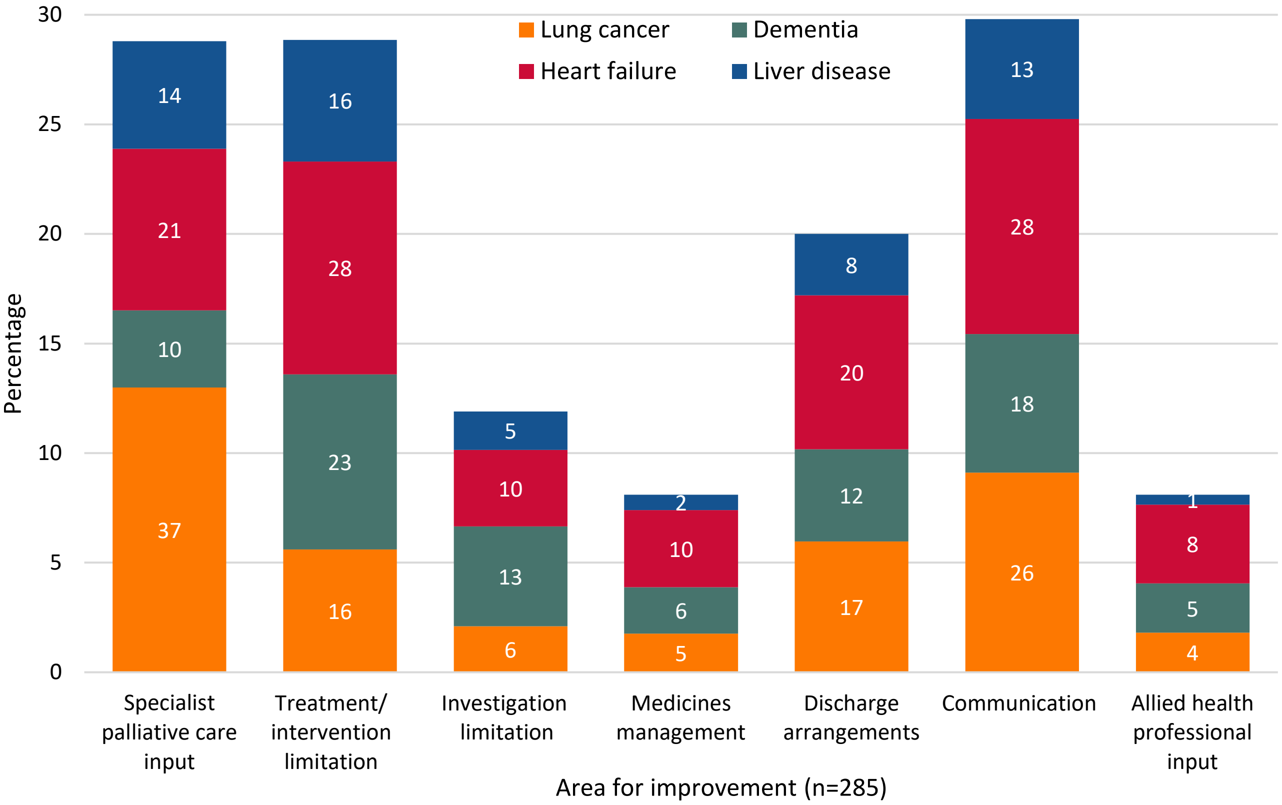

Figure 4.3 Areas for improvement by diagnosis for patients with previous contact
Reviewer assessment form data

Case study 1

An older patient with both advanced dementia and lung cancer was resident in a care home. They experienced breathlessness and were seen in an emergency department and discharged. A DNACPR (do not attempt cardiopulmonary resuscitation) order was agreed but no wider plan was made. The patient was readmitted a few weeks later with further deterioration. The admitting team considered this was a general deterioration and discharged them back to the care home for end of life care.

The reviewers considered that the final admission was avoidable, that death was predictable and that there was room to improve planning for palliative care in the previous attendance.

Good practice in end of life care

There were areas of good practice in end of life care identified for 282/441 (63.9%) patients. This represented more than 50% of patients in each of the diagnostic groups (F4.4).

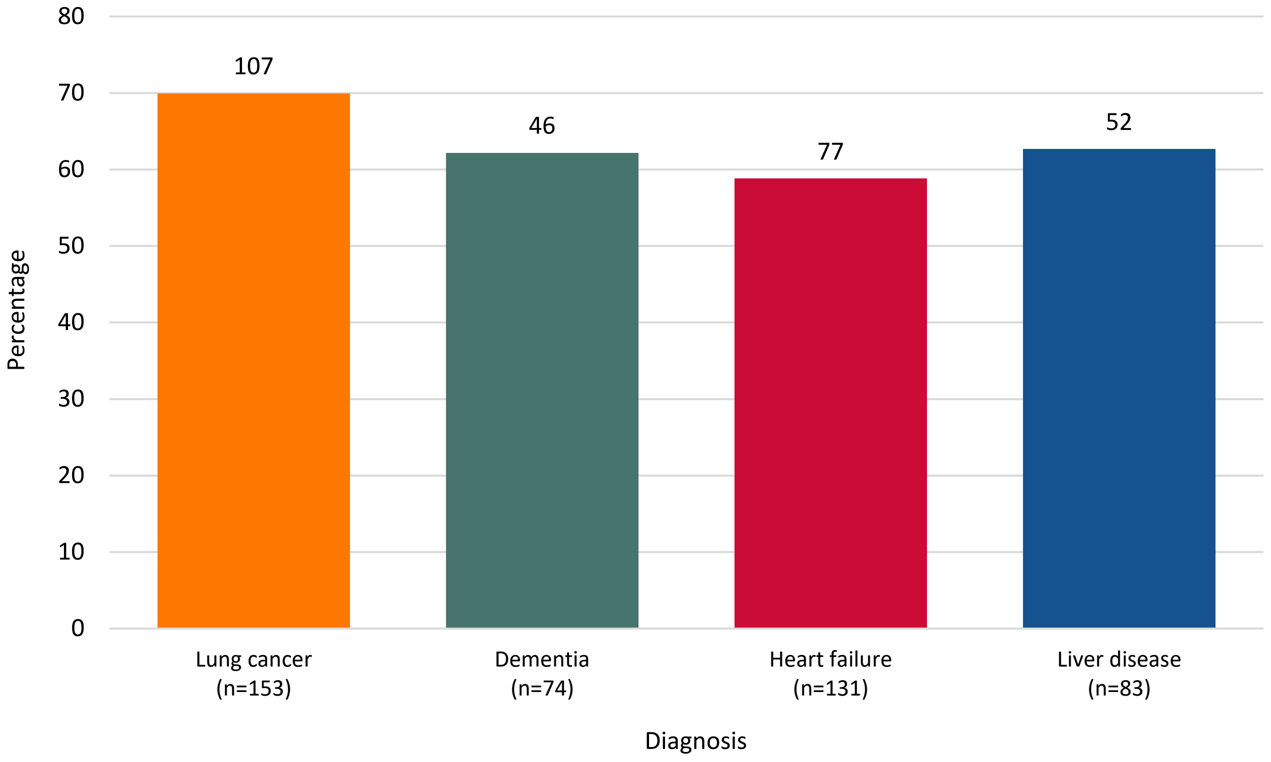

Figure 4.4 Areas of good practice by diagnosis

Clinician questionnaire data

The clinicians and reviewers were asked to provide a free text summary of areas identified for improvement and areas of good practice. Commonly the same themes arose in both, indicating the variability of care provided at the end of life, where improvements are required, and that good practice is possible.

Examples of what could be improved:

- Improved involvement of specialist palliative care teams
- Earlier identification that the end of life was approaching, and use of advance care planning including documentation of decisions about treatment escalation
- Parallel care planning (specialist treatment of the underlying condition alongside specialist palliative care input)

"Being able to offer specialist palliative care input for planning/symptom control while actively treating patients with advanced decompensated liver disease in view of the unpredictable nature of the disease. There are a lot of fluctuations and a risk of sudden deterioration meaning we are often too late to make plans with the patient."

"Advance/future care planning is not taking place on a big enough scale for people with advanced frailty in the community. It is also not being addressed effectively in hospitals, e.g. prior to discharge from hospital. This process takes significant time for sensitive discussion and healthcare professional resource makes this a huge challenge."

"We need better access to palliative care services. The current service is under-resourced meaning patients often wait several days before palliative care review. In my view, fast-track discharge ought to be within 24 hours, not three days, and funding should be organised once the patient is in the community."

"We need improved links with community teams. Too many people are still coming to hospital with terminal disease where death is expected, who die within days of admission."

Examples of good practice:

- Care co-ordinated by the specialist team (for 23 patients)
- Appropriate use of advance care/treatment escalation plans/ReSPECT process (61 patients)
- Referral to, and involvement of the specialist palliative care team (127 patients)
- Early identification of end of life (42 patients)
- Appropriate treatment/medication (26 patients)
- Parallel care planning (nine patients)

"We have a responsive palliative care service, supported by specialist nurses, and an online referral system. Additionally, we operate a monthly departmental multidisciplinary team (MDT) meeting, for patients with advanced cirrhosis, attended by a palliative care consultant, to discuss advance care planning for patients in our service who are deemed at risk of death, using the Bristol scoring tool and Supportive and Palliative Indicators Tool to objectify this. We can flag up patients through the MDT meeting who need advance care planning."

"The respiratory nurses in this area work very well as do the community cardiac failure nurses."

"We have an integrated inpatient palliative and end of life care team half resourced by the NHS and half by the local hospice. The service is consultant nurse-led and has a dedicated discharge co-ordinator. We also have a dedicated consultant nurse-led end of life care unit which meets the needs of patients dying in hospital. This has released over 1,000 bed days in the last 18 months."

"End of life care is well provided for within our organisation to ensure dignity and wellbeing of patients at the end of life. It encompasses proactive engagement, communication and co-ordination with the end of life care team and palliative care services. Families are involved at the outset; advance care planning is encouraged, and staff are educated on ethical considerations."

Communication and shared decision-making

Communication with patients, families and between clinical teams was also highlighted as an area both of good practice and where improvement was needed. This often related to how patients and their families were included in decisions about the care being provided and about future planning, including advance care plans.

The benefits of shared decision-making are highlighted in general guidance as well as specifically in guidance related to end of life care.[31,32] There were 169/233 (72.5%) patients who did not have their personal preferences for care at the end of their lives recorded (T4.6). Failure to discuss care with patients and their relatives can lead to clinical uncertainty, and often, unhelpfully aggressive treatments which can be more distressing for patients. The reasons that these conversations do not take place are likely to be complex. Additional data showing delayed recognition of approaching death during the final admission are presented in chapter 5.

Accurate prediction of outcome is difficult in individual patients and even in hospice patients. It has been previously reported that doctors are systematically overoptimistic about survival, overestimating this by a factor of more than five.[33]

Table 4.6 Appropriate recording and communication of patient's preferences for end of life care

	Number of patients	%
Yes	64	27.5
No	169	72.5
Subtotal	**233**	
Not applicable	45	
Unknown	36	
Total	**314**	

Reviewer assessment form data

When patients and their families are not involved in planning for their future care, this increases the likelihood of poor satisfaction with care, mistrust, and loss of confidence in health care professionals. It also increases the likelihood of death in hospital. An approach is needed that acknowledges that patients with advanced disease may be in the last years of life, even if the immediate outcome is uncertain. Starting a conversation about a patient's wishes and supporting them to plan the care they wish to receive is key to improving care, and care at the end of life. This is of particular importance for patients with dementia who are likely to lose the mental capacity to make decisions for themselves. Patients with liver disease also often present with encephalopathy, reducing their ability to be involved in decisions.

Different approaches have been used to help introduce conversations about advance care planning when patients would benefit from these. The AMBER care bundle was developed to improve care for patients whose recovery is uncertain.[34] The 'surprise question': "*Would you be surprised if this patient died within the next six (or twelve) months?*" is another tool that can help clinicians to identify patients with both cancer and advanced chronic disease who are in the last phase of life and who might therefore benefit from specialist palliative care input.[35] However, this question is not a good tool for predicting survival in an individual.[36]

The reviewers found just 26/287 (9.1%) patients where they were surprised that the patient died within six-months of the last hospital contact (T4.7). There was no difference between the different primary diagnosis groups. Using the 'surprise question' may be of some value in introducing conversations about advance care planning and general or specialist palliative care.

Table 4.7 Were you surprised that the patient died within six-months since the last contact

	Number of patients	%
Yes	26	9.1
No	261	90.9
Subtotal	**287**	
Unable to answer	27	
Total	**314**	

Reviewer assessment form data

Recognising that death is likely within a few months represents an opportunity to discuss patients' wishes, to address their symptoms as well as their wider needs and to plan how they would like care provided at the end of life. There were 60/285 (21.1%) patients who had a record in their notes during a previous contact suggesting that they were in the last 12-months of their life (T4.8). For ten of these patients, it was not possible to discuss their wishes, while of the remaining patients, 34/46 (73.9%; 4 unknown) had their wishes discussed.

For patients who had not been identified as being in the last 12-months of life, only 21/174 (12.1%) had their wishes discussed. Of those who were identified as dying, 24 people died in the community. Together these data suggest that earlier identification of patients approaching the end of life (or delivering palliative care alongside treatment of the underlying condition) can facilitate preferred place of death outside of hospital.

Table 4.8 During previous contact with this hospital, it was recorded that the patient was in the last 12 months of their life

	The patient was in the last 12 months of their life						
	Yes		No				
The patient's preferences were sought	Number of patients	%	Number of patients	%	Subtotal	Unknown	Total
Yes	34	73.9	21	12.1	**55**	9	**64**
No	12	26.1	153	87.9	**165**	4	**169**
Subtotal	**46**		**174**		**220**	**13**	**233**
Not applicable	10		22		**32**	13	**45**
Unknown	4		29		**33**	3	**36**
Total	**60**		**225**		**286**	**29**	**314**

Reviewer assessment form data

Case study 2

A severely frail older patient with cirrhosis was admitted to hospital with pneumonia. Ward based care was agreed as a ceiling of treatment and documented in a treatment escalation plan. The patient had been admitted on three previous occasions in the preceding five months. They deteriorated over 12 days in hospital, were then seen by the specialist palliative care team, and died 48 hours later.

The reviewers recognised that clinicians might not be surprised by this patient's death although on admission it might not have been completely predictable. They commented that the increasing frequency of admissions together with severe frailty meant the disease trajectory was clear and was a missed opportunity to involve specialist palliative care sooner.

The reviewers were able to rate discharge planning for end of life care at the time of the previous admission for 171 patients (51 not applicable, 92 unable to rate). They rated it as good for 46/171 (26.9%), adequate for 60 (35.1%), poor for 63 (36.8%) and unacceptable for two patients.

Reasons given for poor ratings again focused on patients with advanced life limiting diseases for whom an advance care plan would have been appropriate but for whom the focus remained on acute treatments. Where care was rated as good, this reflected good, honest communication with patients and families, involvement of community teams including specialist palliative care, and advance care planning addressing the patient's overall clinical needs.

CHAPTER 5: FINAL ADMISSION

(BACK TO CONTENTS)

When they are asked, the majority of people say that they would prefer to die at home.[37,38] Bereaved relatives are more likely to rate death in hospital as less than good.[5] The likelihood of a death in hospital also increases with higher levels of social deprivation.[39] Supporting people to achieve death outside of hospital is therefore important in the delivery of high-quality end of life care that is aligned with patients' wishes, this will in turn improve the experience of bereaved relatives and potentially reduce inequalities.

Identifying approaching death and addressing uncertainty

Both the reviewers and the clinicians found that during the final admission to hospital, the patient's death was anticipated in more than 80% of cases (T5.1). This is in line with the National Audit of Care at the End of Life (NACEL) 2022 report, which found that 87% of patients who died during the final admission were recognised as dying.[9]

Table 5.1 The death was anticipated

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	374	84.0	214	82.9
No	71	16.0	44	17.1
Subtotal	**445**		**258**	
Unknown	44		16	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

However, in planning both palliative and end of life care, it is important to recognise that although patients might have an advanced chronic disease, accurate prediction of when death will occur is challenging. Prediction may become easier when patients are within three months of death. Prescribing patterns have been used as a surrogate predictor in patients with cancer.[40]

There was frequently evidence that recovery was uncertain (T5.2). This was identified in 224/271 (82.7%) cases reviewed and in 300/450 (66.7%) clinician questionnaires (T5.2). Delay in recognising that the patient was dying was found in 113/265 (42.6%) patients who died in hospital. This meant that early opportunities to involve specialist palliative care and plan for end of life care were missed.

Table 5.2 Evidence that recovery was uncertain

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	300	66.7	224	82.7
No	150	33.3	47	17.3
Subtotal	**450**		**271**	
Unknown	39		3	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

Both the uncertainty about recovery and the delay in recognising that patients are dying help to explain why the focus of care often remains on active treatments until death is imminent even when a palliative approach would be appropriate. The result is that patients frequently do not benefit from the full range of specialist palliative care interventions designed to improve care and quality of life in the months before death.

An approach that can help to provide appropriate palliative care in the context of ongoing uncertainty (and the late involvement outlined above) is to introduce palliative care alongside active treatment. The term parallel care planning is used in paediatric care to describe this.[31,41] Parallel care planning was used in the care of 135/439 (30.8%) patients and 87/228 (38.2%) of the peer-reviewed cases (T5.3). There is therefore considerable room to increase the use of this approach to address uncertainty, while still ensuring that palliative care is provided when needed.

Table 5.3 Evidence of parallel care planning

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	135	30.8	87	38.2
No	304	69.2	141	61.8
Subtotal	**439**		**228**	
Unknown	50		46	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

Data from the clinician questionnaire highlighted one of the benefits of parallel care planning as 94/130 (72.3%) patients with parallel care planning had specialist palliative/end of life care team input compared to 120/290 (41.4%) where parallel care planning was not used (T5.4).

Table 5.4 The specialist palliative/end of life care team was involved in the patient's care during the admission

	Specialist palliative care involvement						
	Yes		No				
Parallel care planning	Number of patients	%	Number of patients	%	Subtotal	Unknown	Total
Yes	94	72.3	36	27.7	130	5	135
No	120	41.4	170	58.6	290	14	304
Subtotal	**214**	**51.0**	**206**	**49.0**	**420**	**19**	**439**
Unknown	16		10		26	24	50
Total	**230**		**216**		**446**	**43**	**489**

Clinician questionnaire data

The final admission was considered to be appropriate by the reviewers for 282/332 (84.9%) patients. However, in 50/332 (15.1%) cases reviewed they considered the admission was not appropriate. They also thought that 111/324 (34.3%) of the final admissions could have been avoided. There were 55 patients where the final admission was considered appropriate but still avoidable (41 patients died in hospital and 14 in the community) (F5.1).

Clinicians were able to identify 107/636 (16.8%) admissions they considered avoidable in their own hospitals. The main reasons were: poor assessment (which led to failures in recognition of decline), a lack of community support and a lack of pragmatic conversations with relatives and care homes.

Understanding the reasons for avoidable final admissions is important as it will help to identify areas for improvement in the future. Appropriate but avoidable admissions are likely to reflect the need for earlier or more proactive planning for end of life care, again supporting a parallel care approach.

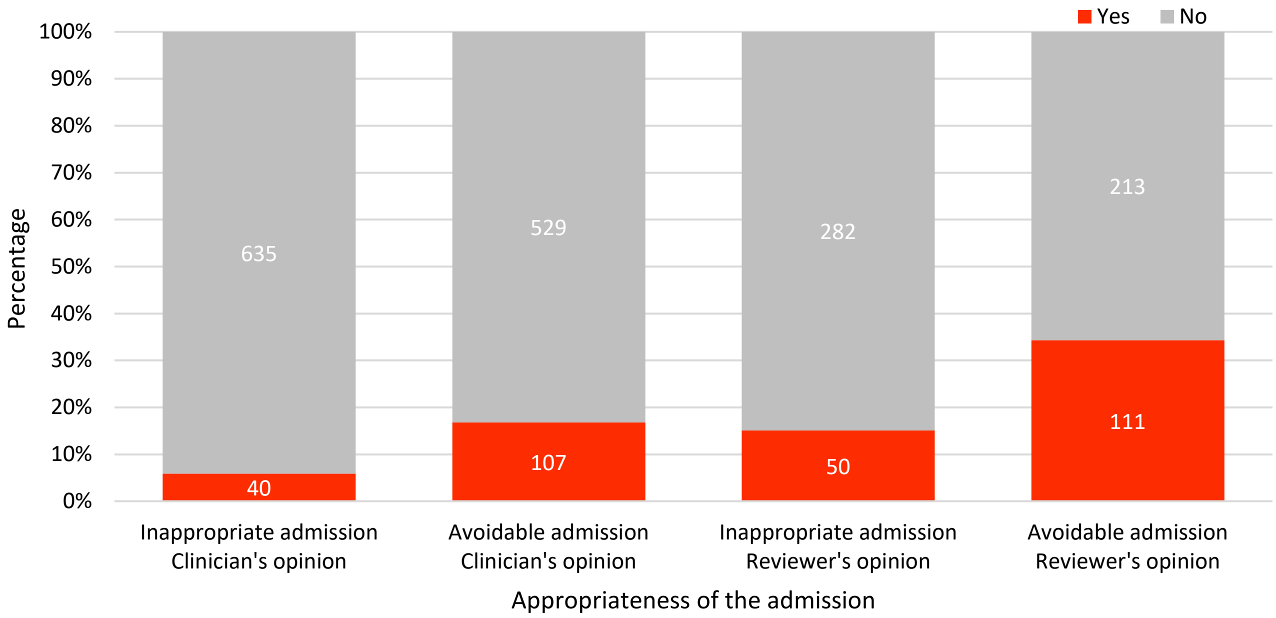

Figure 5.1 Inappropriate and avoidable final admissions

Clinician questionnaire data and Reviewer assessment form data

Case study 3

An older patient with advanced lung cancer and a treatment escalation plan in place had stated a wish to die at home. They deteriorated on a Friday evening with severe pain and breathlessness. Local services were not able to provide medications to achieve symptom control at home. The patient was admitted to hospital and died over the weekend.

The reviewers considered that this was a potentially avoidable admission. They commented that this was a common scenario and illustrated how investment in seven-day services in the community could improve the quality of care at the same time as saving the cost of a hospital admission. Earlier introduction of medications for symptom control might also have been helpful.

The importance of earlier introduction of palliative care was further emphasised by the impact of missed opportunities to improve palliative care during previous hospital contacts (discussed in chapter 4) on avoidable admissions. Both the clinicians in hospitals and the case reviewers identified the final admission was avoidable (F5.2).

Earlier involvement of specialist palliative care services has the potential to achieve the preferred place of death more frequently for patients, to reduce inappropriate hospital admissions, as well as helping to address the wider needs of the patients.

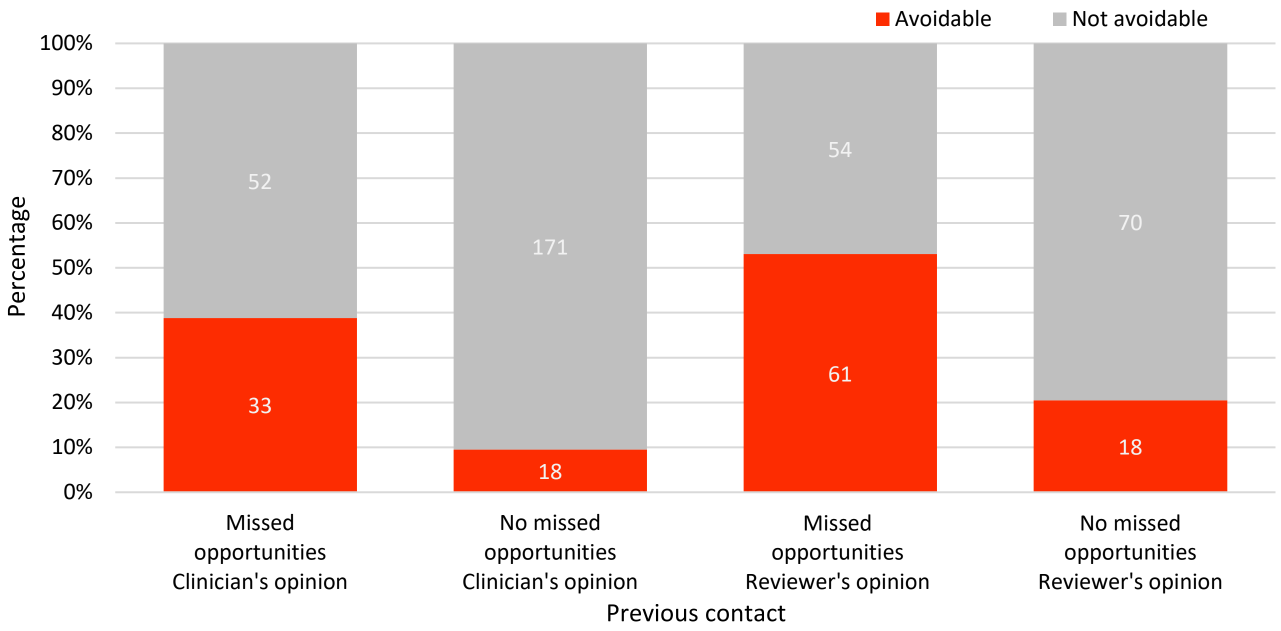

Figure 5.2 Missed opportunities during previous hospital contact and avoidable final admissions
Clinician questionnaire data and reviewer assessment form data

Investigations, treatment and medicines management
Guidelines recommend reviewing treatments in adults approaching the end of their life at the point where the provision of ongoing treatment outweighs the benefit.[6] Overtreatment was identified in 62/342 (18.1%) compared with undertreatment in 15/337 (4.5%) (F5.3). Similarly, the reviewers considered that more patients experienced over investigation (44/343; 12.8%) than to under investigation (19/341; 5.6%). This highlights the importance of reviewing the priorities of care, including investigation and treatment, to improve care at the end of life.

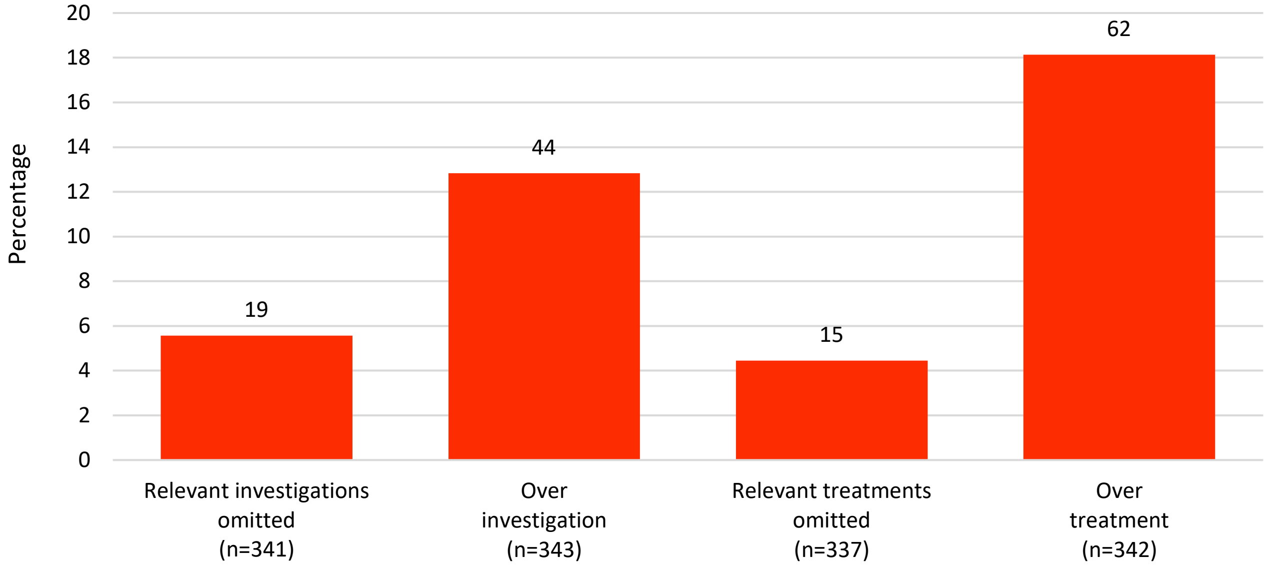

Figure 5.3 Under and over treatment/investigation
Reviewer assessment form data

It has also been recommended that an acute crisis in an older person with frailty should prompt a structured medication review including a focus on inappropriate prescribing.[22] Of the patients with a frailty score of 2-5, 10/98 (10.2%) were given treatments that reviewers thought should have been omitted (T5.5). This was the case in 52/224 (23.2%) of those who were at least moderately frail (Rockwood score of 6 or more). This confirms the value of the frailty score as a measure to highlight the need to review treatments. Frailty, combined with advanced chronic disease, might also be used as a prompt to consider involvement of the specialist palliative care team.

Table 5.5 Treatments given that should have been omitted

	Yes		No		
Rockwood score	**Number of patients**	**%**	**Number of patients**	**%**	**Total**
2		0.0	5	100.0	5
3	2	10.5	13	89.5	19
4	5	13.2	33	86.8	38
5	3	8.3	33	81.7	36
6	16	20.3	63	79.7	79
7	20	21.3	74	78.7	94
8	12	30.8	27	69.2	39
9	4	33.3	8	66.7	12
Unable to ascertain	0		20		20
Total	**62**	**18.1**	**280**	**81.9**	**342**

Reviewer assessment form data

Case study 4

A severely frail patient with advanced dementia was admitted to hospital with seizures six times in their last six-months of life. A CT scan of the brain was performed on five of the six admissions, including two just one week apart. On the final admission the patient was treated with broad spectrum antibiotics 'to cover for sepsis'. They developed a sacral pressure ulcer and clostridium associated colitis before end of life treatment was introduced.

The reviewers thought that this patient was over-investigated and over-treated, generally by relatively junior clinical staff. If end of life care had been considered at an earlier stage, the complications of treatment and possibly hospital admissions could have been avoided.

In the last few days of life, guidelines also make recommendations about medication management as well as non-pharmacological approaches.[31] In addition to stopping any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm, drugs that are likely to help control symptoms should be prescribed.

There was room for improved prescribing to control symptoms, (intended to make patients more comfortable) in 32/232 (13.8%) patients (T5.6). More could have been done to stop medications appropriately in 49/213 (23.0%) patients (T5.7). Stopping long-term treatments is appropriate as they are unlikely to benefit an individual with limited life-expectancy. This reduces the potential for side effects as well as reducing costs.

Table 5.6 Appropriate medications for symptom control

	Number of patients	%
Yes	200	86.2
No	32	13.8
Subtotal	**232**	
Not applicable	92	
Unknown	26	
Total	**350**	

Reviewer assessment form data

Table 5.7 Medications stopped appropriately as the patient deteriorated

	Number of patients	%
Yes	164	77.0
No	49	23.0
Subtotal	**213**	
Not applicable	99	
Unknown	38	
Total	**350**	

Reviewer assessment form data

As people approach the last few days of life, an individualised approach for those likely to need symptom control should involve the prescription of anticipatory medications.[31] Such medications were prescribed in 220/277 (79.4%) patients where it was possible to identify this. The value of this approach was highlighted by the fact that where anticipatory medications were prescribed, these were administered in 158/178 (88.8%) patients (unknown in 42).

The reviewers considered that there was room to improve the use of end of life anticipatory medications in 66/235 (28.1%) cases they reviewed. The reviewers were unable to comment for 38/76 people who died in the community as data on anticipatory medications were not available as frequently in this group (T5.8). These data suggest that for some patients, where symptoms persisted, better use of medication would have alleviated those symptoms. This points towards the ability to provide a good death for more patients than is currently achieved.

Table 5.8 Room for improvement in the use of end of life anticipatory medications

	Hospital		Community		All	
	Number of patients	%	Number of patients	%	Number of patients	%
Yes	60	30.5	6	15.8	66	28.1
No	137	69.5	32	84.2	169	71.9
Subtotal	**197**		**38**		**235**	
Unknown	77		38		115	
Total	**274**		**76**		**350**	

Reviewer assessment form data

Where there was a delay in recognising that the patient was dying (F5.4), this was associated with a much more frequent finding that treatments could have been omitted (37/110; 33.6% vs 16/150; 10.7%), and that anticipatory end of life medications could have been better used (42/74; 56.8% vs 17/116; 14.7%). The reviewers were also of the opinion that death could have been achieved in a location other than hospital in a greater proportion of these patients (57/101; 56.4% vs 59/136; 43.4%). This further highlights how early involvement of specialist palliative care teams and parallel care planning has the potential to improve clinical practice at the end of life.

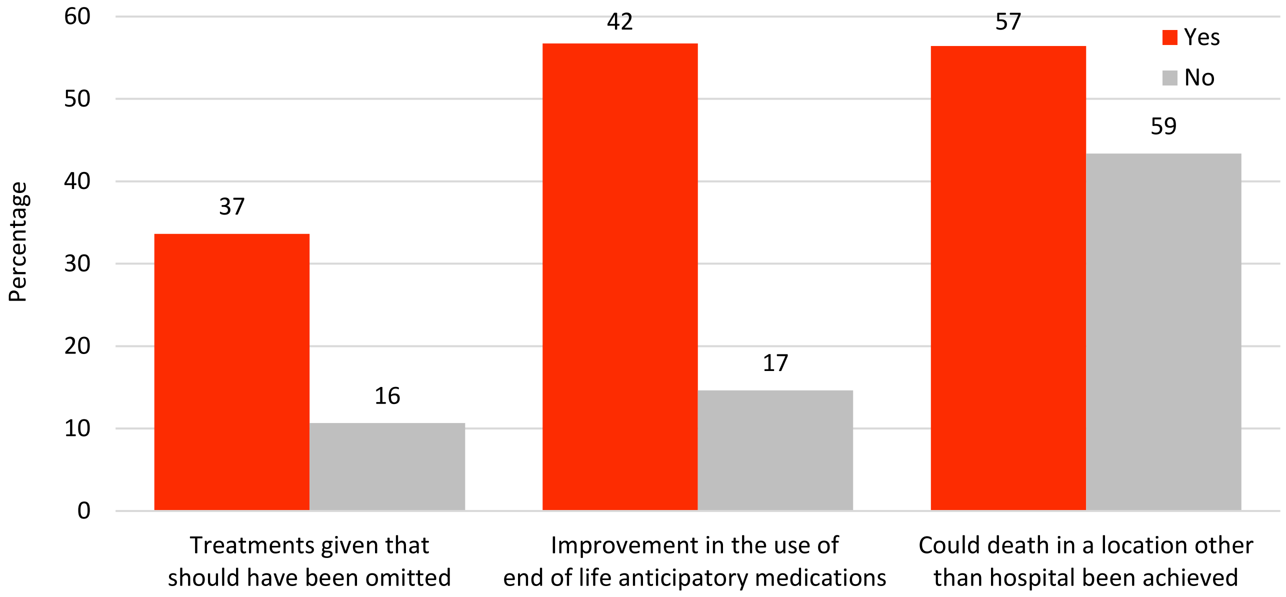

Figure 5.4 Delay in recognition of dying and areas for improvement
Reviewer assessment form data

Case study 5
A patient with advanced liver disease was admitted to hospital four times in a two-month period. On the final admission to hospital, while the patient was unconscious with encephalopathy they developed skin damage due to the trauma of being turned in bed. Bleeding after regular blood tests was also noted. After more than a week in the final admission, end of life care was initiated, and the patient died within 24 hours.

The reviewers thought that there was a delay in recognising that the patient was dying and that the previous admissions represented missed opportunities to discuss prognosis and the patient's wishes.

Specialist palliative care and documentation

The definition of 'palliative' is to ease the symptoms of (a disease) without curing it. Palliative care support for patients in the last months, days and hours of life is a priority to enhance the quality of life for patients and those close to them. Holistic personalised end of life care should consider the patient's goals and wishes, preferred care setting, physical care needs including preferences for symptom management together with cultural, religious, social and spiritual needs.[6]

As already noted, uncertainty about death and delay in recognition of approaching death are common. Data from this study showed that the median length of stay on the final admission was 12.0 days (mean 17.2 days) and that the median time before death that the specialist palliative care team was involved was 4.0 days (mean 5.6 days). This suggests that patients did not get the full benefit of palliative care for control of their symptoms.

Documentation such as an end of life care plan can help to prompt and organise discussions to cover all aspects of care for the patient with those close to them. End of life documentation was used in 237/434 (54.6%) of the patients who died in hospital and in 105/258; (40.7%) reviewed cases (T5.9).

Table 5.9 Specific end of life documentation was used

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	237	54.6	105	40.7
No	197	45.4	153	59.3
Subtotal	**434**		**258**	
Unknown	55		16	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

It is important to include both patients and their families in discussions about their wishes. To do this, they need to be aware that death is approaching. These conversations can sometimes be distressing so a sensitive approach is required. It will sometimes not be possible to have these discussions with patients when their medical condition prevents this (for example patients with liver disease and encephalopathy, and confusion or a reduced level of consciousness, or those with advanced dementia who lack mental capacity and cannot engage in a meaningful conversation). National audit data have consistently shown that the majority of patients are offered these discussions (90% in the latest audit).[9]

There was a record that the patient was offered information that they were dying in only 168/405 (41.5%) of the patients who died in hospital (T5.10). Of those who were not offered this information, 99/237 (41.8%) had a mental capacity assessment (and 61 of these did not have mental capacity). There were an additional 28 patients who did not have a mental capacity assessment and who had an underlying diagnosis of dementia. The inability of some patients to engage in conversations about end of life care when death is approaching again highlights the importance of introducing advance care planning and palliative care into conversations at an earlier stage, often in parallel with other active approaches to treatment. Factors that affect mental capacity are less likely to apply to patients' families, and as a result, these conversations were able to be held more frequently. The next of kin or family were offered information about the end of life approaching in 400/451 (88.7%) cases (T5.10).

Table 5.10 Documented that the patient/ patient's next of kin/family were informed the patient was dying

	Patient		Next of kin/family	
	Number of patients	%	Number of patients	%
Yes	168	41.5	400	88.7
No	237	58.5	51	11.3
Subtotal	**405**		**451**	
Unknown	84		38	
Total	**489**		**489**	

Clinician questionnaire data

Guidelines recommend that a systematic approach is used to identify adults who are approaching the end of their life.[7] Sharing this information across the health and care system is valuable to ensure that advance care plans including patients' wishes are taken into account when providing care. Data from the clinician questionnaire showed that 84/336 (25.0%) patients who died in hospital were on a palliative care register prior to the final admission. This included 31 with lung cancer, 21 with heart failure, 16 with dementia and 19 with liver disease. The clinician who responded was also not able to identify if the patient was on a palliative care register in 153/489 (31.3%) cases. This suggests that there is a need to improve the availability of this important information. During the final admission, the specialist palliative care team were involved in the care of 230/446 (51.6%) patients and 142/263 (54.0%) of the reviewed cases (T5.11).

Table 5.11 Specialist palliative/end of life care team was involved in the patient's care during the admission

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	**%**	**Number of patients**	**%**
Yes	230	51.6	142	54.0
No	216	48.4	121	46.0
Subtotal	**446**		**263**	
Unknown	43		11	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

Of the patients previously on a palliative care register, 69/80 (86.3%) had the specialist palliative care team involved in their final admission, compared with 93/237 (39.2%) who were not on a register (T5.12). It is therefore important to have a way of identifying patients early on so that they are known to those who can provide specialist palliative care when needed.

Table 5.12 The patient was on a palliative care register vs specialist palliative care involvement on the final admission

	Specialist palliative/end of life care team was involved in the patient's care during the admission						
	Yes		**No**				
The patient was on a palliative care register	**Number of patients**	%	**Number of patients**	%	**Subtotal**	Unknown	**Total**
Yes	69	86.3	11	13.8	**80**	4	**84**
No	93	39.2	144	60.8	**237**	15	**252**
Subtotal	**162**		**155**		**317**	**19**	**336**
Unknown	68	52.7	61	47.3	**129**	24	**153**
Total	**230**	**51.6**	**216**	**48.4**	**446**	**43**	**489**

Clinician questionnaire data

Overall input from specialist palliative care was more common for patients with a diagnosis of lung cancer (83/114; 72.8%) than for those with dementia (49.0%), heart failure (42.6%) or liver disease (39.6%) (F5.5). This was similar to the distribution of patients already known to the specialist palliative care service before admission, recognising the fact that not all chronic diseases are given the same priority for palliative care as cancer.

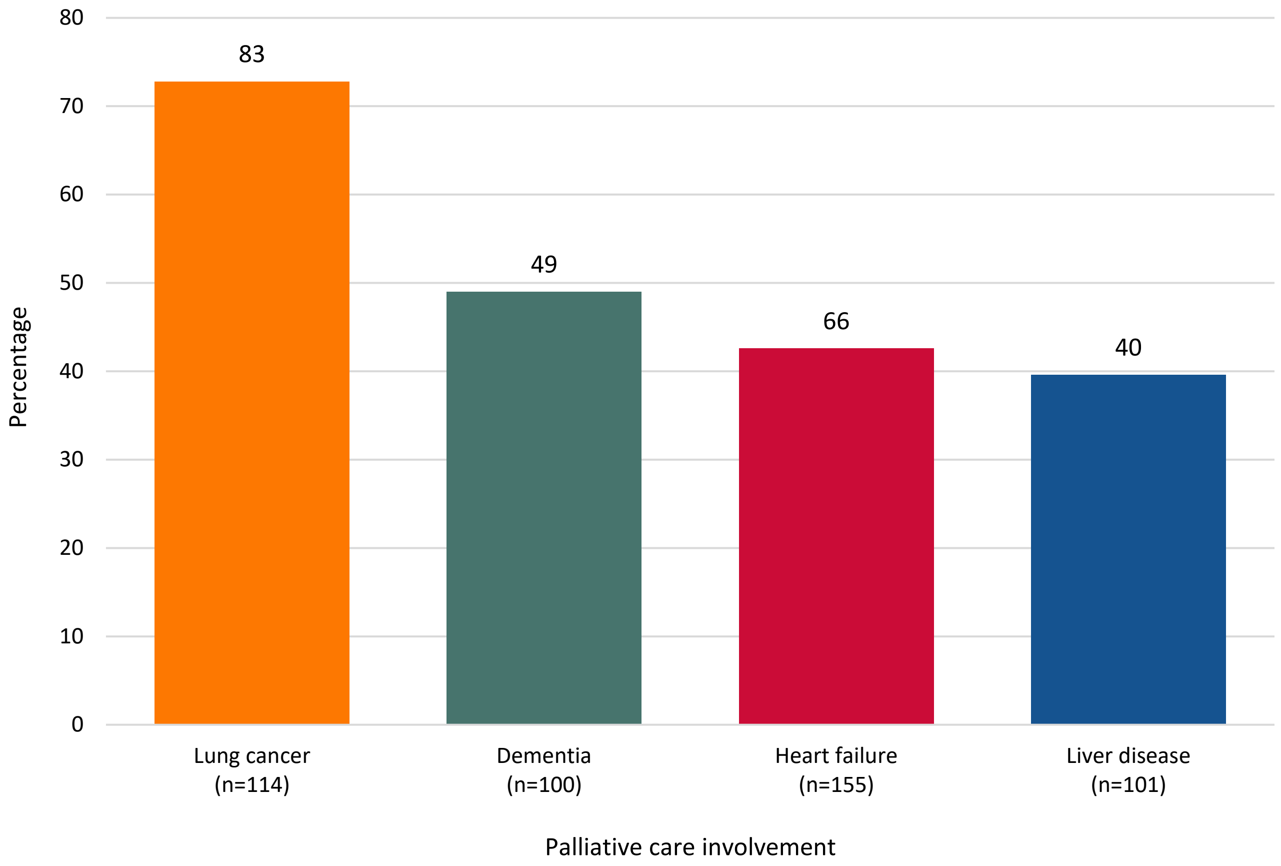

Figure 5.5 Specialist palliative care involvement during the final admission by condition/disease
Clinician questionnaire data

A greater proportion of the people who died in the community were on a palliative care register (62/106; 58.5% vs 84/336; 25.0%). Of the patients on a register, 62/146 (42.5%) died in the community. This compared with 44/296 (14.9%) of those who were not on a register (T5.13). This highlights that there are patients for whom the system works. Being on a register was more likely to result in the patient being able to die in the community, and care that aligns with patients' wishes.

Table 5.13 The patient was on a palliative care register vs location of death

	In hospital		In the community	
	Number of patients	**%**	**Number of patients**	**%**
Yes	84	25.0	62	58.5
No	252	75.0	44	41.5
Subtotal	**336**		**106**	
Unknown	153		84	
Total	**489**		**190**	

Clinician questionnaire data

These data suggest that identification of the approaching end of life and early involvement of specialist palliative care improves the palliative care and support at the end of life. In the context of the uncertainty already described the use of parallel care planning earlier in a disease trajectory will facilitate this. The data also suggest that identifying patients who are approaching the end of their lives can make an important contribution to ensuring that they do not die in hospital, when this aligns with their wishes.

Case study 6

An older patient with advanced heart failure was admitted with abdominal pain and severe breathlessness. No treatable cause of pain was found but it was recognised that they were dying from heart failure. During an admission five-months previously, the specialist palliative care team had discussed and documented an advance care plan. Both the cardiology and specialist palliative care teams saw the patient within six hours during the final admission. In line with previous discussions, the patient was discharged home to die with community support.

The reviewers considered that this was a good example of the benefit of early involvement of specialist palliative care and effective parallel care planning. The advance care plan helped the clinical team to provide timely care aligned with the patient's wishes.

Co-ordination of care is important and, in some services, patients with cancer, heart failure, dementia and liver disease can all have specific arrangements where a 'key worker' leads the co-ordination of care focused on their specific needs. This supports the patient and their family/carers. There was documentation of a lead person in the records of 257/396 (64.9%) patients (T5.14).

Table 5.14 A specific end of life document was used

	Yes		No				
Nominated lead person documented	**Number of patients**	**%**	**Number of patients**	**%**	**Subtotal**	**Unknown**	**Total**
Yes	162	66.7	81	33.3	243	14	257
No	44	32.8	90	67.2	134	5	139
Subtotal	**206**	**54.6**	**171**	**45.4**	**377**	**19**	**396**
Unknown	31		26		57	36	93
Total	**237**		**197**		434	**55**	**489**

Clinician questionnaire data

When a lead person was documented, specific end of life documentation was used in 162/243 (66.7%) patients, compared with 44/134 (32.8%) where there was no lead person documented (T5.14). The specialist palliative care team was also more likely to be involved in the care of those with an identified lead (146/244; 59.8%), than in those without (50/137; 36.5%) highlighting their benefit to the patient's care (T5.15).

Table 5.15 The specialist palliative/end of life care team was involved in the patient's care during the admission and whether there was a nominated lead for palliative care

	Yes		No				
Nominated lead person documented	**Number of patients**	**%**	**Number of patients**	**%**	**Subtotal**	**Unknown**	**Total**
Yes	146	59.8	98	40.2	**244**	13	257
No	50	36.5	87	63.5	**137**	2	139
Subtotal	**196**	**51.4**	**185**	**48.6**	**381**	**15**	**396**
Unknown	34		31		65	28	93
Total	**230**		**216**		**446**	**43**	**489**

Clinician questionnaire data

Case study 7

A young patient with metastatic lung cancer presented to the emergency department with severe chest pain. Following investigation, a cardiac cause was ruled out and a presumptive diagnosis of further metastatic spread of the cancer was made. In discussion with the patient and their next of kin an advance care plan was made, led by a lung cancer clinical nurse specialist. The patient was discharged home and died 10 days later with support from the GP and community specialist palliative care team who had received copies of the advance care plan and knew the patient's wishes.

The reviewers considered that this demonstrated that a 'lead' person facilitated good planning and communication to improve a patient's end of life care.

When the specialist palliative care team was involved in care during the final admission, specific end of life documentation was used in 151/211 (71.6%) patients, compared to 74/208 (35.6%) when they were not involved (T5.16). These data suggest that both an individual who takes a lead role and involvement of the wider palliative care team can improve aspects of the delivery of palliative care.

Table 5.16 Specific end of life documentation was used

	Yes		No				
Specialist palliative/end of life care team involved during the admission	**Number of patients**	**%**	**Number of patients**	**%**	**Subtotal**	**Unknown**	**Total**
Yes	151	71.6	60	30.9	**211**	19	230
No	74	35.6	134	69.1	**208**	8	216
Subtotal	**225**	**53.7**	**194**		**419**	**27**	**446**
Unknown	12		3		15	28	43
Total	**237**		**197**		**434**	**55**	**489**

Clinician questionnaire data

Treatment escalation decisions

Treatment escalation decisions are part of the advance care planning process. The ReSPECT and treatment escalation plan forms were developed to facilitate escalation decisions including decisions about cardiopulmonary resuscitation.[42] A ReSPECT (or equivalent) form was in place for 234/389 (60.2%) patients who died in hospital and 88/136 (64.7%) people who died in the community (T5.17). A treatment escalation plan was in place for 312/415 (75.2%) patients who died in hospital, and for 106/156 (67.9%) people who died in the community.

Table 5.17 The patient had a ReSPECT (or equivalent) form in place

	In hospital		In the community	
	Number of patients	**%**	**Number of patients**	**%**
Yes	234	60.2	88	64.7
No	155	39.8	48	35.3
Subtotal	**389**		**136**	
Unknown	100		54	
Total	**489**		**190**	

Clinician questionnaire

Where possible, patients should always be involved in decisions about the care they receive including planning for future care in the event of deterioration. Mental capacity can vary depending on the complexity of the decision being made. There were 312/489 (63.8%) patients whose mental capacity was assessed as part of the decision-making process about advance care planning. Of the patients who did not have mental capacity, 113/231 (48.9%) died in hospital and 23/77 (29.9%) patients died in the community (T5.18).

Table 5.18 The patient had mental capacity

	In hospital		In the community	
	Number of patients	%	Number of patients	%
Yes	118	51.1	54	70.1
No	113	48.9	23	29.9
Subtotal	**231**		**77**	
Unknown	2		2	
Total	**233**		**79**	

Clinician questionnaire data

Patients with dementia were most likely to have their mental capacity assessed during the final admission (T5.19). Dementia is known to lead to reduced mental capacity, whereas the other disease processes are not, yet the need to assess mental capacity is not exclusive to people with dementia.

Table 5.19 A mental capacity assessment was undertaken in relation to the advance care planning

	Mental capacity assessment undertaken						
	Yes		No		Subtotal	Unknown	Total
Diagnosis	Number of patients	%	Number of patients	%	Number of patients	Number of patients	Number of patients
Lung cancer	86	63.7	49	36.3	**135**	65	**200**
Heart failure	81	62.3	49	37.7	**130**	49	**179**
Liver disease	59	57.3	44	42.7	**103**	32	**135**
Dementia	74	75.5	24	24.5	**98**	36	**134**

Clinician questionnaire data

A health and welfare lasting power of attorney, allowing for decisions to be made if a patient does not have the mental capacity to make their own decisions, was in place for only 20/102 (19.6%) patients without mental capacity (T5.20).

Table 5.20 The patient had the mental capacity to sign a power of attorney document

	Yes		No				
Health and Welfare Power of Attorney	Number of patients	%	Number of patients	%	Subtotal	Unknown	Total
Yes	9	7.4	20	19.6	29	0	29
No	112	92.6	82	80.4	194	3	197
Subtotal	**121**		**102**		**223**	**3**	**226**
Unknown	53		42		95	1	96
Total	**174**		**144**		**318**	**4**	**322**

Clinician questionnaire data

Discharge from hospital and death in the community

In the context of the uncertain outcome and the delay in recognising approaching death already described, ongoing active planning including hospital discharge would be expected. This is an important part of parallel care planning. Death may still occur in hospital before discharge due to rapid deterioration or delay in discharge while plans are being made. Other reasons for death occurring in hospital rather than another location include patient choice, and the ability of local services to deliver the necessary level of care outside of a hospital. The 2023 NACEL audit reported that 64% of 11,067 hospital staff who completed a survey knew how to respond to requests from dying people and/or those important to them to die outside of the hospital setting.[9]

Of the patients who died in hospital, data from the clinician questionnaire showed that the aim was to discharge them in 190/442 (43.0%) cases (T5.21). The reviewers identified that there was a plan to discharge the patient from hospital in 115/237 (48.5%) cases.

Table 5.21 There was an aim to discharge the patient from hospital

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	190	43.0	115	48.5
No	252	57.0	122	51.5
Subtotal	**442**		**237**	
Unknown	47		37	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

Delayed discharge was not the main explanation, only being reported for a minority of patients. The reviewers found a delay in discharge in 46/252 (18.3%) patients (T5.22).

Table 5.22 Evidence of delay in discharge

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	37	8.1	46	18.3
No	418	91.9	206	81.7
Subtotal	**455**		**252**	
Unknown	34		22	
Total	**489**		**274**	

Clinician questionnaire and reviewer assessment form data

When patients were not discharged to die in a place other than hospital, the main themes identified by reviewers were a failure to recognise and plan for impending end of life (both during the current and previous admissions) and a lack of resources to support care in the community. A small number of patients deteriorated more quickly than expected so discharge was not possible.

This study showed that there was considerable potential to achieve death in a location other than hospital. The reviewers thought that this was possible in 122/244 (50.0%) patients, while clinicians considered this was possible in 100/429 (23.3%) (T5.23).

Table 5.23 Death in a location other than hospital could have been achieved

	Clinician questionnaire		Reviewer assessment form	
	Number of patients	%	Number of patients	%
Yes	100	23.3	122	50.0
No	329	76.7	122	50.0
Subtotal	**429**		**244**	
Unknown	60		30	
Total	**489**		**273**	

Clinician questionnaire and reviewer assessment form data

Deaths in the community

Death at home or in the community rather than in an acute hospital setting is often stated as a priority by people who are approaching the end of life. Measures that help to achieve this are therefore of great importance. Any examples of good practice that help to achieve patients' wishes are also opportunities to learn and improve the system.

Of the 190 people who died in the community, the clinician involved in their care stated that at the time of hospital discharge, death was anticipated in 121/164 (73.8%). Continuing healthcare funding arrangements are in place to facilitate rapid access to care outside of hospital for people identified as approaching the end of their life. This approach was used to facilitate the discharge in 43 of these patients (T5.24).

Table 5.24 Continuing healthcare funding (or equivalent) was used to facilitate the discharge

	Number of patients	%
Yes	43	55.8
No	34	44.2
Subtotal	**77**	
Unknown	44	
Total	**121**	

Clinician questionnaire data

Examples of good practice that enabled the discharge

Of the deaths that occurred in the community where it was possible to comment, the clinician who looked after the patient identified areas of good practice that enabled the discharge in 85/101 (84.2%) patients.

The principal areas of good practice identified by the reviewers that enabled patients to be discharged to the community were:

- Recognition of approaching end of life
- Acknowledging the patient's wishes
- Communication with relatives
- Assessment of the patient's needs, and
- Liaison with community services.

CHAPTER 6: OVERALL QUALITY OF CARE

(BACK TO CONTENTS)

The overall quality of care was good in 125/341 (36.7%) patients (unable to rate overall care in 9). There was room for improvement in clinical aspects of care (clinical only and clinical and organisational) in 174/341 (51.0%) patients and in organisational aspects of care in 92/341 (27.0%) (organisational only and clinical and organisational). Care was rated as less than satisfactory for 16/341 (4.7%) patients (F6.1).

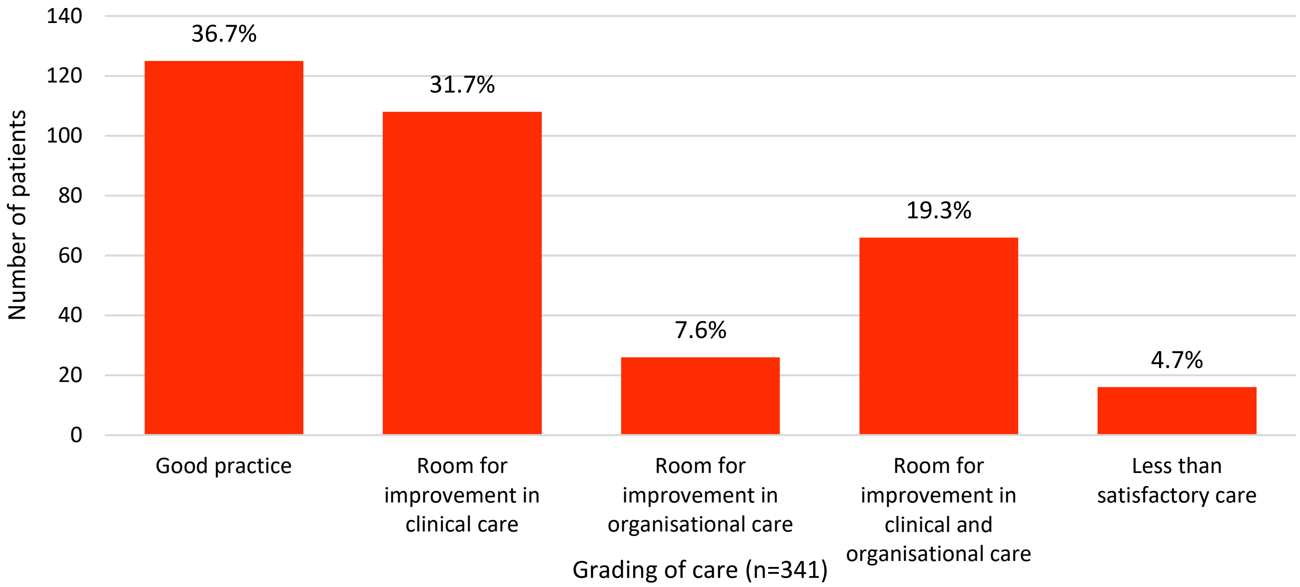

Figure 6.1 Overall quality of care

Reviewer assessment form data

The reviewers were more likely to rate the care of those who died in the community as good compared with those who died in hospital (40/76; 52.6% vs 85/274; 31.0%) (F6.2).

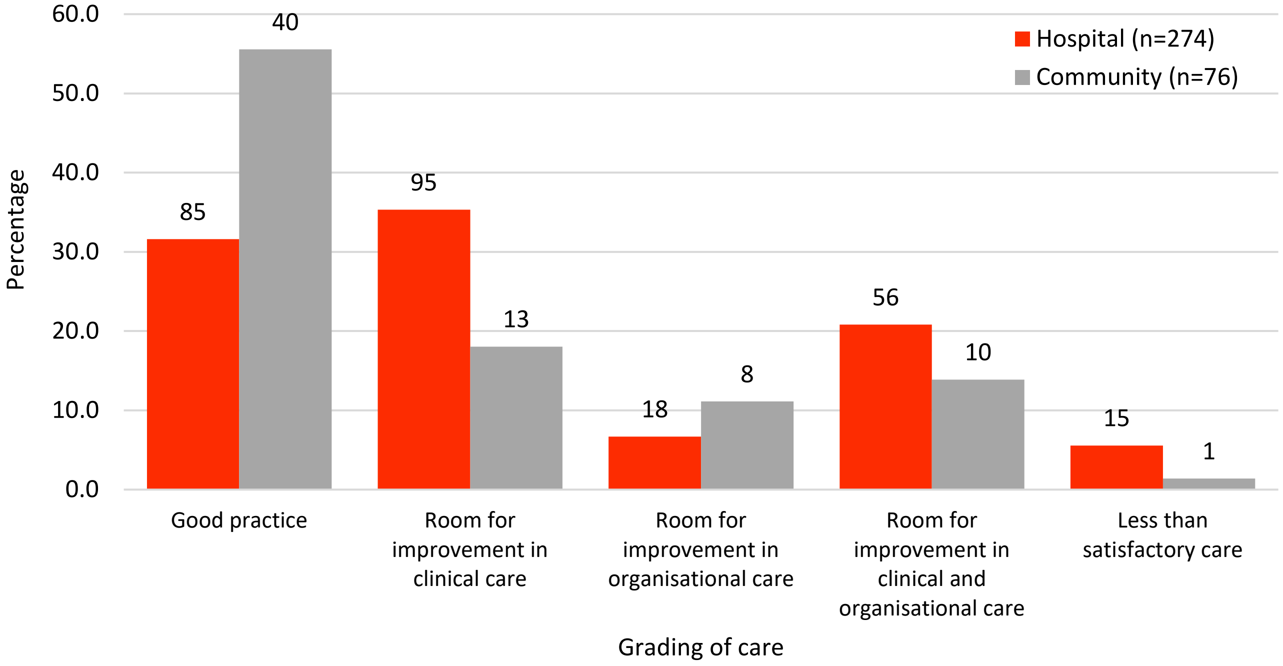

Figure 6.2 Overall quality of care and location of death

Reviewer assessment form data

Where parallel care planning had taken place, the reviewers were also more likely to rate the care received as good (37/84; 44.0%) compared with 30/140 (21.4%) when this approach was not used. It was also associated with room for improved clinical care for 58/140 (41.4%) patients where a parallel care planning approach was not taken (F6.3).

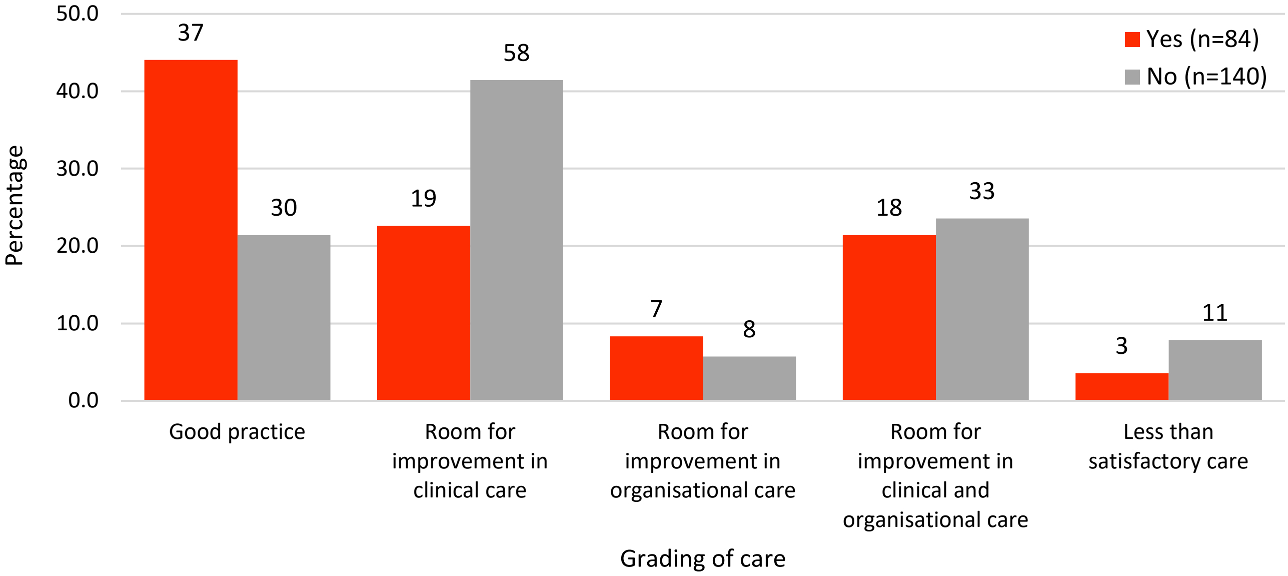

Figure 6.3 Overall quality of care and parallel care planning
Reviewer assessment form data

Of the 258 patients who died in hospital, the care was rated as good in 54/140 (38.6%) when the specialist palliative care service was involved in their care, compared with 24/118 (20.3%), when they were not involved (F6.4).

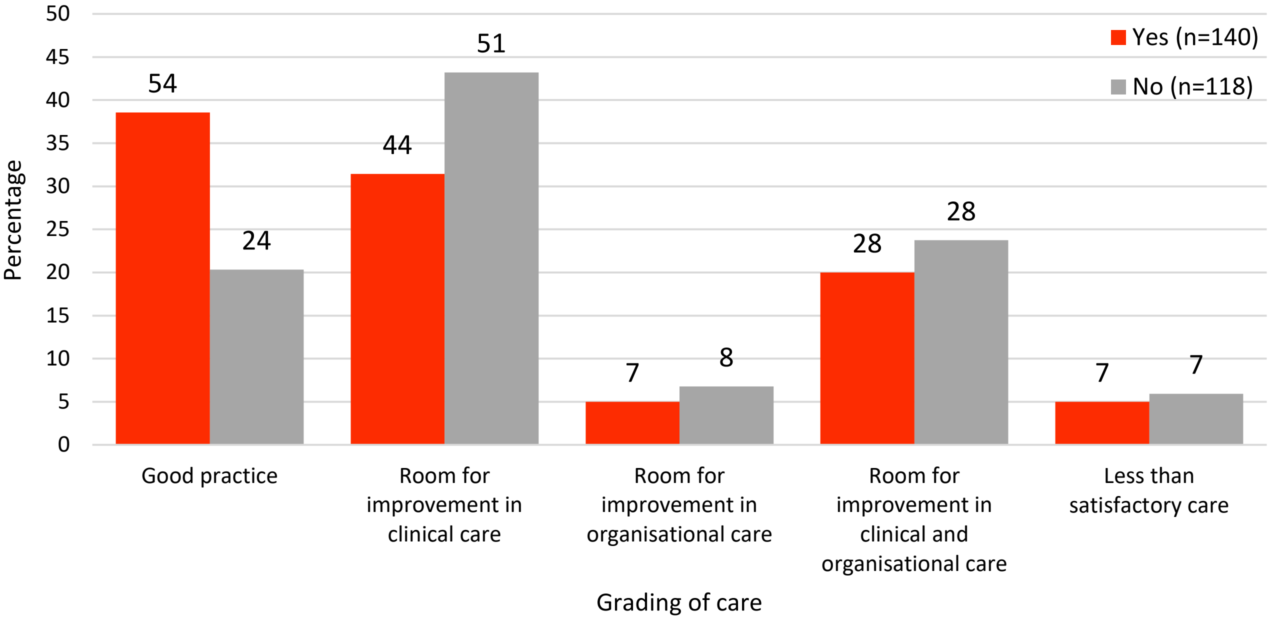

Figure 6.4 Overall quality of care and specialist palliative care involvement
Reviewer assessment form data (258 deaths in hospital*)*

These data suggest that involvement of specialist palliative care services, the use of a parallel care approach to treatment, and achieving death outside of hospital can all result in improved care of patients with advanced diseases.