Planning for the End

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

SUMMARY

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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Cohort: Patients aged 18 or over who died in hospital between 1st April 2022 and 30th September 2022 with one or more of these conditions: dementia, heart failure, lung cancer or liver disease.

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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 patient-facing 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 who see patients 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.

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.

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.

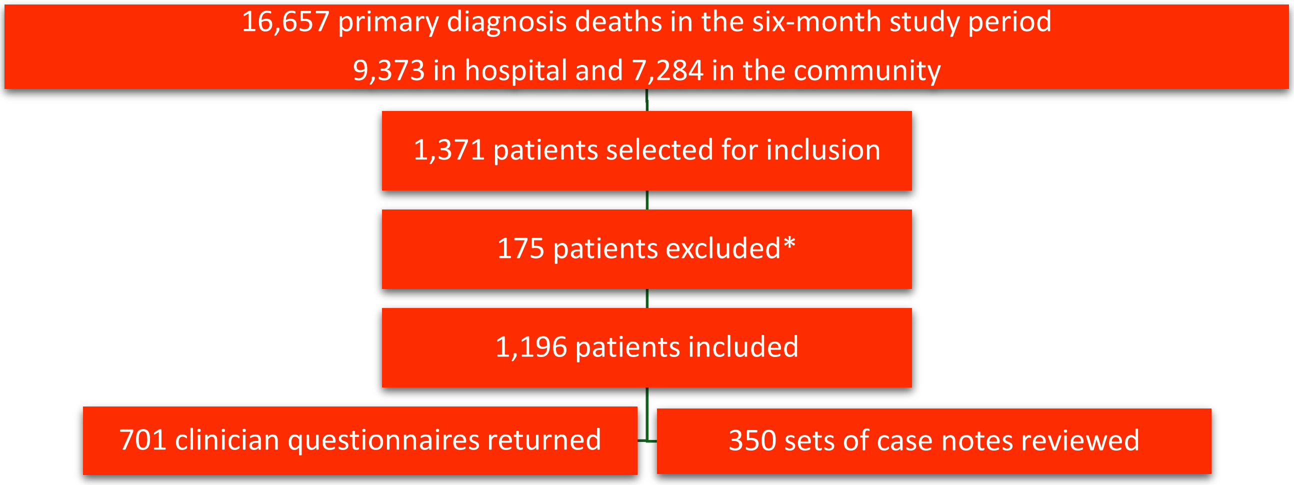

Figure 1.1 Data returned

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

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.

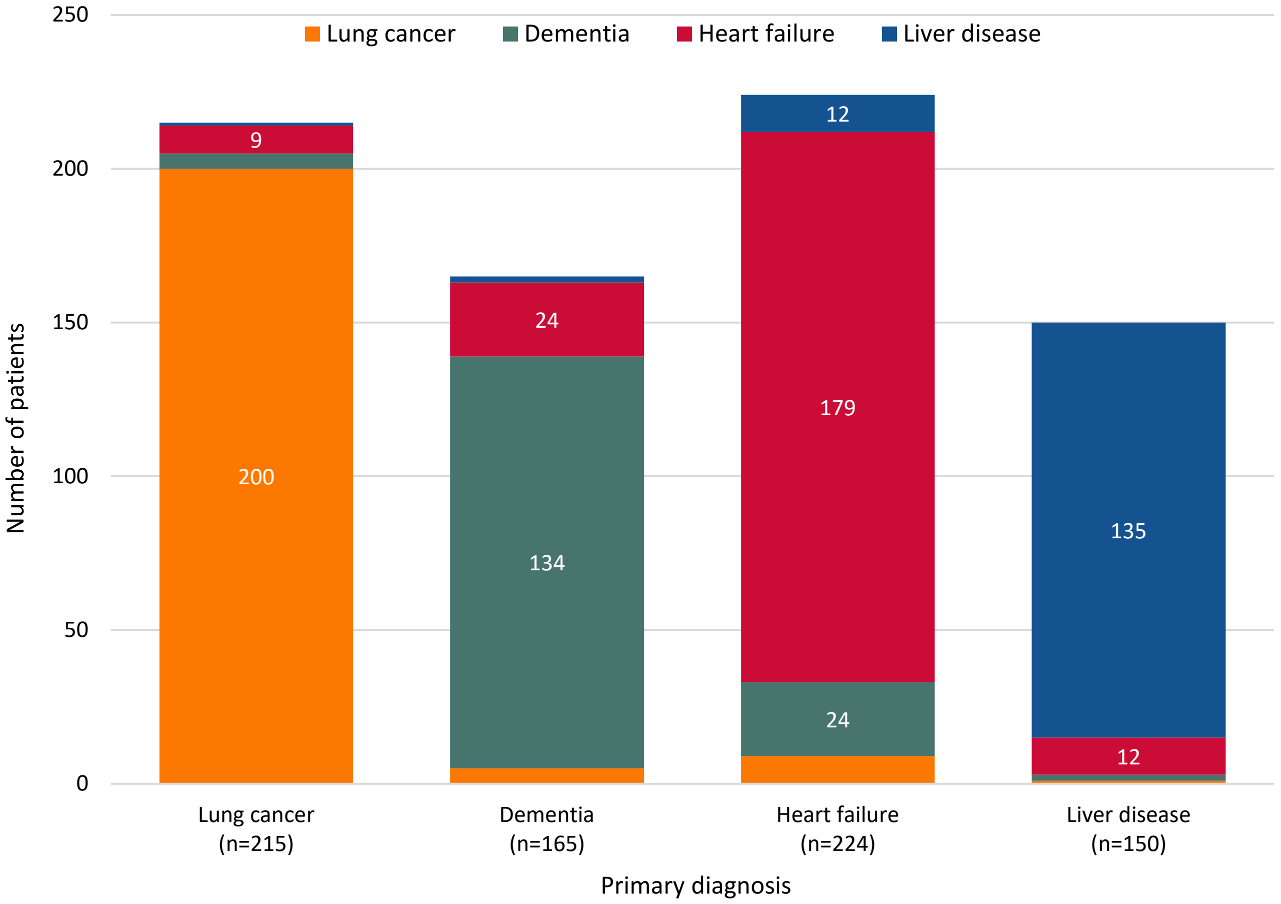

Figure 2.1 Primary diagnosis and multiple diagnoses

Clinician questionnaire data