1. **What is the report looking at/what is the project measuring?**	Medical and Surgical Clinical Outcome Review Programme Planning for the End *A review of the quality of care provided to adult patients towards the end of life*
2. **What countries are covered?**	England, Wales and Northern Ireland
3. **The date the data is related to**	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.

No.	**Recommendation**	**Evidence in the report which underpins the recommendation**	**Guidance available**
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*	**CHAPTER 4** 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. **CHAPTER 5** 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). **CHAPTER 5** 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). **CHAPTER 6** 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).	NG31 Care of dying adults in the last days of life NG142 End of life care for adults: service delivery QS13 End of life care for adults QS144 Care of dying adults in the last days of life Quality statement for palliative and end of life care for Wales Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) Universal Principles for Advance Care Planning Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 NHS England » Service specifications for palliative and end of life care: Adults

2	Normalise conversations about palliative 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*	**CHAPTER 4** 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. **CHAPTER 4** **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) **CHAPTER 4** 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. **CHAPTER 4** 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 palliative care.	NG31 Care of dying adults in the last days of life QS144 Care of dying adults in the last days of life NG142 End of life care for adults: service delivery QS13 End of life care for adults Quality statement for palliative and end of life care for Wales Universal Principles for Advance Care Planning Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

		CHAPTER 4 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 (F4.5). 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** 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. **CHAPTER 5** 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. **CHAPTER 5** 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).	

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*	**CHAPTER 5** 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). **CHAPTER 5** 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).	CSG4 Improving Supportive and Palliative Care for Adults with Cancer Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 NHS England » Service specifications for palliative and end of life care: Adults
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*	**CHAPTER 3** 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). **CHAPTER 3** Seven-day specialist palliative care services were only available in 125/210 (59.5%) hospitals (T3.3). **CHAPTER 4** The most common areas for improvement identified were specialist palliative care input, treatment limitation decisions and communication (T4.5). For	NG142 End of life care for adults: service delivery NG31 Care of dying adults in the last days of life Quality statement for palliative and end of life care for Wales Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) NHS England » Service specifications for palliative and end of life care: Adults

		77/444 (17.3%) patients specialist palliative/end of life care input could have been better. **CHAPTER 5** 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). **CHAPTER 5** 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. **CHAPTER 6** 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).	
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*	**CHAPTER 3** 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 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	The End-of-life Care for All (e-ELCA) Curriculum for Palliative Medicine Training Northern Ireland Hospice Training and Education End of life and palliative care toolkit RCGP NHS England » Service specifications for palliative and end of life care: Adults

	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*	not included in the induction programme nor in priority training (T3.5).	
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*	**CHAPTER 5** 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). **CHAPTER 5** 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.	Resuscitation Council UK Recommendation 2 from the NCEPOD report looking at the in-hospital care of out of hospital cardiac arrests – Time Matters Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 Palliative and End of Life Care Standard - PRSB (theprsb.org) NHS England » Service specifications for palliative and end of life care: Adults
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*	**CHAPTER 2** 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 5 PAGE 44** 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).	www.gov.uk/power-of-attorney