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 healthcare staff who see patients is needed to recognise who would benefit from specialist palliative care to treat the symptoms of advanced chronic disease.