

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Care of dying adults in the last days of life

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for care of dying adults in the last days of life. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source(s) referenced in this briefing paper is:

[Care of dying adults in the last days of life](#). NICE guideline NG31 (2015).

Update not yet scheduled. The guideline was published in December 2015.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the clinical care of adults (18 and over) who are dying, during their last 2 to 3 days of life. This is different from other important NHS initiatives about 'end of life care' which aim to improve care in the last year or so.

The focus reflects the scope of the primary development source which was produced in response to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. The need arose from an independent review of the Liverpool Care Pathway (LCP) which recommended that the LCP should be phased out by 2014.

The broader end of life care topic is covered by existing NICE guidance on [improving supportive and palliative care for adults with cancer](#), published in 2004. Separate NICE guidelines are in production that will cover [service delivery in relation to end of life care](#) and [end of life care for infants, children and young people](#). There is also an existing quality standard on [end of life care for adults](#) (QS13) that covers adults in the last year of life. This quality standard will complement QS13. It is expected that QS13 will be updated once all the new guidance has been published.

2.2 ***Definition***

Care of dying adults in the last days of life refers to the clinical care of people aged 18 years and over who have been judged by a multi-professional clinical team to be within 2 to 3 days of death.

This definition of care does not include service delivery (for example out-of-hours availability, or how services are structured); it excludes palliative care or end of life care before the last few days or hours of life; and it excludes care after death (such as care of the body, certification and bereavement).

2.3 ***Management***

Recognising when a person is entering the last days or hours of life is a challenge, even for experienced clinicians. As a result of the long experience of palliative care in people with cancer, the approach of death for someone with cancer can be easier to predict than other causes. For people dying as a result of conditions from which temporary remissions occur (such as heart failure); or for those with dementia, cognitive impairment or frailty, anticipating death can be more difficult. It is important to be able to recognise that a person may be recovering and may need a different course of management.

In the last days of life, provision of medically assisted hydration can be an important and comforting aspect of care. However, for some people it may be unnecessary or even harmful.

Managing symptoms such as pain, nausea, anxiety and breathlessness can be key to achieving a peaceful death. Current practice includes assessing and treating any reversible causes. Sometimes, it is necessary to use sedative doses of medications such as opioids, benzodiazepines, and major tranquillisers to control refractory symptoms and 'terminal agitation'. However, starting such drugs too early or using inappropriate doses can lead to undue sedation and prevent communication in the final days, and thereby cause distress for the person who is dying and those important to them.

A key approach to symptom control is the use of anticipatory or 'just in case' prescriptions. This allows the prompt alleviation of distressing symptoms by clinicians, including district nurses, without the delay associated with obtaining a new prescription. However, there has been some criticism of arrangements for storing and disposing of such medication in the community. There have also been reports that family members can sometimes perceive these drugs as hastening death.

2.4 National Outcome Frameworks

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 [The Adult Social Care Outcomes Framework 2015–16](#)

Domain	Overarching and outcome measures
<p>1 Enhancing quality of life for people with care and support needs</p>	<p>Overarching measure 1A Social care-related quality of life**</p> <p>Outcome measures People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</p> <p>1B Proportion of people who use services who have control over their daily life</p> <p>Carers can balance their caring roles and maintain their desired quality of life</p> <p>1D Carer-reported quality of life**</p>
<p>3 Ensuring that people have a positive experience of care and support</p>	<p>Overarching measure People who use social care and their carers are satisfied with their experience of care and support services</p> <p>3A Overall satisfaction of people who use services with their care and support</p> <p>3B Overall satisfaction of carers with social services</p> <p><i>Placeholder 3E The effectiveness of integrated care</i></p> <p>Outcome measures Carers feel that they are respected as equal partners throughout the care process</p> <p>3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for</p> <p>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help</p> <p>3D The proportion of people who use services and carers who find it easy to find information about support</p> <p>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual</p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>

<p>4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm</p>	<p>Overarching measure</p> <p>4A The proportion of people who use services who feel safe**</p> <p>Outcome measures</p> <p>Everyone enjoys physical safety and feels secure</p> <p>People are free from physical and emotional abuse, harassment, neglect and self-harm</p> <p>People are protected as far as possible from avoidable harm, disease and injuries</p> <p>People are supported to plan ahead and have the freedom to manage risks the way that they wish</p> <p>4B The proportion of people who use services who say that those services have made them feel safe and secure</p> <p><i>Placeholder 4C Proportion of completed safeguarding referrals where people report they feel safe</i></p>
<p>Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework</p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

Table 2 [NHS Outcomes Framework 2016–17](#)

Domain	Overarching indicators and improvement areas
<p>2 Enhancing quality of life for people with long-term conditions</p>	<p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p>Improvement areas</p> <p>Ensuring people feel supported to manage their condition</p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p>Enhancing quality of life for carers</p> <p>2.4 Health-related quality of life for carers**</p> <p>Enhancing quality of life for people with mental illness</p> <p><i>2.5 ii Health-related quality of life for people with mental illness**</i></p> <p>Improving quality of life for people with multiple long-term conditions</p> <p><i>2.7 Health-related quality of life for people with three or more long-term conditions**</i></p>

<p>4 Ensuring that people have a positive experience of care</p>	<p>Overarching indicators</p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>ii GP Out-of-hours services</p> <p>4b Patient experience of hospital care</p> <p><i>4c Friends and family test</i></p> <p><i>4d Patient experience characterised as poor or worse</i></p> <p><i>i Primary care</i></p> <p><i>ii Hospital care</i></p> <p>Improvement areas</p> <p>Improving hospitals' responsiveness to personal needs</p> <p>4.2 Responsiveness to inpatients' personal needs</p> <p>Improving the experience of care for people at the end of their lives</p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p>Improving people's experience of integrated care</p> <p><i>4.9 People's experience of integrated care**</i></p>
<p>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

3 Summary of suggestions

3.1 Responses

Twenty-two stakeholders responded to the 2-week engagement exercise between 3-17 June 2016.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been aggregated under broad headings and summarised in table 4 for further consideration by Committee. A visual summary of the suggestions by broad heading is given in figure 1 that follows the table.

Some stakeholders supplied general comments that did not identify specific areas for quality improvement. These comments are not shown in the summary table. However, full details of all the suggestions provided (including general comments) are given in appendix 3 for information. Each comment /suggestion has been given a unique reference number which is shown in table 4 so that the reader can link the summaries back to the specific comments in appendix 3.

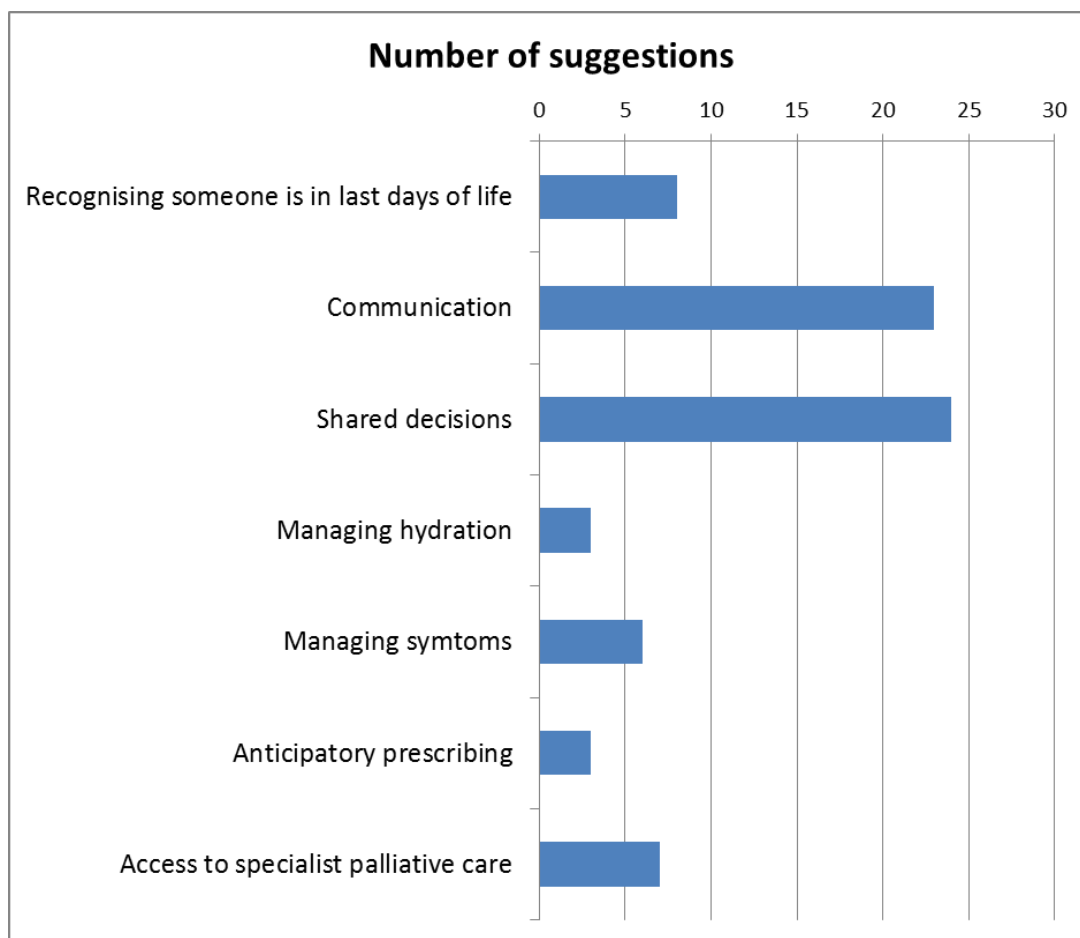
Table 4 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Recognising someone is in last days of life	APM (1), EPA (10), Hospice UK (17), RC (46), RCPsy (49), SCM 2 (57), SCM 3 (61), SCM 5 (70)
Communication <ul style="list-style-type: none"> • Telling the person they are dying • Preferences and needs of the person who is dying • Needs of families, carers and others • Sharing of information 	BTC (79), EPA (11), FICMICS (91), Hospice UK (18,19,20), LSCP (24), MC (27), NHSE (35,36), OPAA (38,39), RC (45,47), RPsy (50), SA (77,78), SCM 1(53, 54), SCM 2 (58), SCM 5 (71), TSL (83,86)
Shared decisions <ul style="list-style-type: none"> • Involving the person who is dying and those important to them • Exploring preferences and needs • Documenting decisions / care plans 	APM (2,5), BHANRPN (81), CoE (8), EPA (12), FICMICS (92,93,94), MC (27,29), NHSE (37), OPAA (40), RC (43,44), RCN (41), RCPsy (51), SCM 1 (56), SCM 2 (59), SCM 4 (67, 69), SCM 5 (71,72), TSL (84,85),
Managing hydration	APM (4), EPA (13), SCM 5 (73)
Managing symptoms <ul style="list-style-type: none"> • Administration of medication • Assessment of symptoms 	BPS (6), RCN (42), NHSE (34), SCM 1 (55), SCM 3 (62), SCM 5 (74),
Anticipatory prescribing	SCM 5 (74), EPA (14), SCM 3 (60)
Access to specialist palliative care	APM (3), BTC (80), Hospice UK (16), LSCP (21), MC (28), NHSE (33), SCM 1 (52),
Developmental areas <ul style="list-style-type: none"> • Complementary therapies • Earlier intervention • Improved recognition of spiritual, cultural and practical needs • Improved care of the deceased 	EPA (15), LSCP (26), SCM 5 (75)
Other <ul style="list-style-type: none"> • Care after death • Service delivery / joint commissioning and funding • End of life care for people with dementia • Frailty 	BGS (89,90), BPS (7), CoE (9), FICMICS (95), LSCP (22, 23, 25), MC (30, 31), NHSE (36), RCA (88), SA (76), SCM 3 (63, 64), SCM 4

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Suggested area for improvement	Stakeholders
<ul style="list-style-type: none"> • Education and training • Inequalities in end of life care • Nationally agreed ceilings of treatment • Organ donation • Symptom management for young adults 	(65,66,68), TSL (82)
<p>APM, Association for Palliative Medicine of Great Britain and Ireland BGS, British Geriatrics Society BHANRPN, The British Humanist Association/Non-Religious Pastoral Support Network BPS, British Pain Society BTC, The Brain Tumour Charity CoE, Church of England: Mission and Public Affairs Council EPA, EPA UK/EU FICMICS, Faculty of Intensive Care Medicine and Intensive Care Society Hospice UK LSCP, Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN MC, Marie Curie NHSE, NHS England OPAA, Older People's Advocacy Alliance RC, Resuscitation Council (UK) RCA, Royal College of Anaesthetists RCN, Royal College of Nursing RCPsy, Royal College of Psychiatrists SCM, Specialist committee member SA, Stroke Association TSL, Together for Short Lives</p> <p>Note: Both the Royal College of Physicians of Edinburgh and the Royal College of Physicians responded to the consultation by endorsing the comments of the APM. For the sake of brevity, the summary table above only shows the response of the APM. The BMA also submitted general comments which are listed in Appendix 3.</p>	

Figure 1: Chart of showing number of suggestions by area of improvement



Note: The chart does not show developmental areas or suggestions assigned to 'Other'.

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1701 papers were identified for this topic. In addition, 53 papers were suggested by stakeholders at topic and 16 papers internally at project scoping.

Of these papers, 3 have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

4 Suggested improvement areas

4.1 *Recognising someone is in the last days of life*

4.1.1 Summary of suggestions

Five stakeholders and three SCMs suggested that recognising that someone is in the last days of life, or that death is imminent, is a priority area for quality improvement. The full comments identified the importance of experienced professionals determining if someone is close to death; recognised that greater consistency is needed and that signs of imminent death can be misunderstood; and highlighted the need to record that it has been recognised that someone is dying. Early recognition that someone is dying was suggested as being important because it allows for better care, support and decision making; although one stakeholder felt that the last days of life was not timely enough.

4.1.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the Committee’s discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Recognising someone is in the last days of life	Recognising when a person may be in the last days of life NICE NG31 Recommendations 1.1.1 to 1.1.7

Recognising when a person may be in the last days of life

NICE NG31 – Recommendation 1.1.1

If it is thought that a person may be entering the last days of life, gather and document information on:

- the person's physiological, psychological, social and spiritual needs
- current clinical signs and symptoms
- medical history and the clinical context, including underlying diagnoses
- the person's goals and wishes
- the views of those important to the person about future care.

NICE NG31 – Recommendation 1.1.2

Assess for changes in signs and symptoms in the person and review any investigation results that have already been reported that may suggest a person is entering the last days of life. These changes include the following:

- signs such as agitation, Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions and progressive weight loss
- symptoms such as increasing fatigue and loss of appetite
- functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

NICE NG31 – Recommendation 1.1.3

Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering.

NICE NG31 – Recommendation 1.1.4

Avoid undertaking investigations that are unlikely to affect care in the last few days of life unless there is a clinical need to do so, for example, when a blood count could guide the use of platelet transfusion to avoid catastrophic bleeding.

NICE NG31 – Recommendation 1.1.5

Use the knowledge gained from the assessments and other information gathered from the multiprofessional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving.

NICE NG31 – Recommendation 1.1.6

Monitor for further changes in the person at least every 24 hours and update the person's care plan.

NICE NG31 – Recommendation 1.1.7

Seek advice from colleagues with more experience of providing end of life care when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has statements that address recognising that someone is dying. See Statements 1 and 11 in appendix 1.

4.1.3 Current UK practice

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) presents findings from an organisational audit and a casenote review of patients who had died in hospital. 96% of acute trusts participated, and the clinical audit covered a one month period and included 9,302 unique patient data sets. In terms of limitations, the audit only covers hospital settings. Deaths in hospital account for around half of all deaths in England.

The clinical audit found that in 83% of cases there was documented evidence that it was recognised that a patient was expected to die in the coming hours or days. When sudden and unexpected deaths are excluded, this proportion increases to 93% of cases.

In relation to the timeliness of recognition, the average (median) number of hours between the first documented evidence of the recognition that the patient was expected to die and actual death was 34 hours. For a quarter of patients, though, recognition occurred less than 11 hours before death. The relatively late recognition for this group is partly explained by the inclusion of patients who died soon after admission.

Recognition that someone was thought to be dying was reviewed regularly for 91% of patients. The audit also indicates that there is input from experienced staff in the recognition process (in 76% of cases a senior doctor was involved in recognising that a patient was dying).

In primary care settings, there is evidence that systems are in place to identify patients who need palliative care, but not necessarily people who are entering the last days of life. The Quality and Outcomes Framework (QOF) provides data sourced from GP practices. [QOF reporting for 2014/15](#) shows that:

- 98.5% of GP practices maintain a register of patients in need of palliative care.
- 96.7% of GP practices have regular multidisciplinary case review meetings where patients on the palliative care register are discussed.

4.1.4 Resource impact assessment

This area was not included in the resource impact report for the primary source guidance NG31. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.2 *Communication*

4.2.1 Summary of suggestions

Communication was one of the quality improvement areas most frequently identified by stakeholders. Sub-themes that emerged from the comments included:

Telling the person they are dying: Comments stated that such discussions are not always taking place; too many people are not being told; and yet individualised care and support are dependent upon it.

Preferences and needs of the person who is dying: Comments advocated understanding communication needs and preferences, with reference made to needs of people with specific conditions / illnesses, Advance Care Planning, Independent Advocacy Support, and DNACPR (Do Not Attempt Cardiopulmonary Resuscitation).

Needs of families, carers and others: Stakeholders suggested exploration of the needs and support of family member, carers and people important to those who are dying. According to some stakeholders, attention to this is often negligible or sub-optimal. One stakeholder suggested this is a concern for the person who is dying.

Sharing of information: Responses stated that systems and methods are needed to share information between professionals and across settings. Information to be shared includes prognosis, needs, preferences, and decisions.

The training and education, professionalism and competencies of staff to ensure the quality of communication were identified by several stakeholders. However, quality standards are based on the premise that those undertaking the actions described have sufficient and appropriate training and competencies to do so. Therefore quality statements usually do not address training and education.

4.2.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Telling the person they are dying	Communication NICE NG31 Recommendation 1.2.2, 1.2.3, 1.2.4, 1.2.5
Preferences and needs of the person who is dying	Communication NICE NG31 Recommendation 1.2.1, 1.2.5
Needs of families, carers and others	Communication NICE NG31 Recommendation 1.2.4
Sharing of information	Communication NICE NG31 Recommendation 1.2.6

Telling the person they are dying

NICE NG31 Recommendation 1.2.2

Identify the most appropriate available multiprofessional team member to explain the dying person's prognosis. Base this decision on the professional's:

- competence and confidence
- rapport with the person.

NICE NG31 Recommendation 1.2.3

Discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.

NICE NG31 Recommendation 1.2.4

Provide the dying person, and those important to them, with:

- accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
- an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
- information about how to contact members of their care team
- opportunities for further discussion with a member of their care team.

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NICE NG31 Recommendation 1.2.5

Explore with the dying person and those important to them:

- whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
- whether the dying person has understood and can retain the information given about their prognosis.

Preferences and needs of the person who is dying

NICE NG31 Recommendation 1.2.1

Establish the communication needs and expectations of people who may be entering their last days of life, taking into account:

- if they would like a person important to them to be present when making decisions about their care
- their current level of understanding that they may be nearing death
- their cognitive status and if they have any specific speech, language or other communication needs
- how much information they would like to have about their prognosis
- any cultural, religious, social or spiritual needs or preferences.

NICE NG31 Recommendation 1.2.5

Explore with the dying person and those important to them:

- whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
- whether the dying person has understood and can retain the information given about their prognosis.

Needs of families, carers and others

NICE NG31 Recommendation 1.2.4

Provide the dying person, and those important to them, with:

- accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism

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- an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
- information about how to contact members of their care team
- opportunities for further discussion with a member of their care team.

Sharing of information

NICE NG31 Recommendation 1.2.6

Discuss the dying person's prognosis with other members of the multiprofessional care team, and ensure that this is documented in the dying person's record of care.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has a statement that addresses communication. See Statement 2 in appendix 1.

4.2.3 Current UK practice

Discussion with the patients about their imminent death appears to be infrequent in hospital, but this is mostly a result of the patient not being able to have such a discussion. The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) found that only 20% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death. Of those where no documented discussion took place, reasons for not having a discussion included the patient not being conscious (44%); the patient having cognitive impairment (21%) and the patient dying suddenly (13%). In 17% of cases, however, there was no documented reason why such a discussion had not taken place. It is also important to recognise that a small, but important, proportion of patients (1%) did not want to be told they were nearing the end of their life.

In 95% of the cases where it had been recognised that the patient was likely to die, there was a documented discussion with those nominated as important to the dying person. In almost half of cases where there was not a documented discussion, there was no record of why this did not take place.

The audit also identified evidence that 32% of patients were given the opportunity to have their concerns listened to. For 52% of patients, there was a specific reason why there was no opportunity given, and these included the patient not being fully conscious and lacking mental capacity. However, for 16% of patients there was no record of such opportunity and no reason given for this not happening.

Of those who had their concerns listened to, 94% were given an opportunity to have questions about their concerns answered.

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For 80% of patients, it was reported that the nominated person(s) important to the patient had regular opportunities to discuss the patient's condition with a senior healthcare professional. On average, there were 2 of these discussions taking place in the last 24 hours of life.

In 38% of cases there was documented evidence in the last episode of care that the patient's spiritual, religious, cultural and practical needs had been discussed with the people important to them. In 54% of cases, the needs of persons important to the patient were considered.

Excluding the cases of sudden or unexpected deaths, the people important to the dying patient were notified of the imminent death in 84% of cases. Of those notified, 63% were recorded as being present at the time of death.

The organisational audit found that 35% of trusts were using electronic palliative care coordination systems.

The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved people's views on the quality of care provided to a friend or relative in the last 3 months of life. For the [2015 VOICES survey](#), data were collected from a sample of deaths registered between 1 January and 30 April 2015, and over 21,000 people responded to the survey.

The survey found that 79% of people caring for someone in the last two days of life felt they were kept informed about the condition and care of that person by healthcare professionals. Three quarters believed that they had enough time with staff to ask questions and discuss condition and care, and 86% understood the information they were provided with. All these responses varied across settings, with the highest values recorded for people who died in hospices and the lowest proportions recorded for people who died in hospital.

4.2.4 Resource impact assessment

This area was not included in the resource impact report for the primary source guidance NG31. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.3 *Shared decision making*

4.3.1 **Summary of suggestions**

Twenty-four suggestions were made which identified shared decision making, or communication and shared decision making, as a key area for quality improvement. Sub-themes that emerged from the comments were:

Involving the person who is dying and those important to them: Some comments emphasised the need for decisions to be taken in consultation with the person who is dying, and also those important to them. The role of Independent Mental Capacity Advocates was specifically raised by one stakeholder.

Exploring preferences and needs: Some stakeholders identified this in general terms whereas others were more specific about what should be explored, including place of death; the type of care someone wants to receive or refuse; advance statements or decisions; whether there is a lasting power of attorney; spiritual, emotional and cultural needs; and physical needs.

Documenting decisions / care plans: The importance of documenting decisions was emphasised by some stakeholders, with reference made by some to the documentation being in a care plan. Some comments identified what should be documented including decisions relating to DNACPR, implantable cardioverter defibrillator deactivation, withdrawal from life sustaining therapies, the setting / place of death, ceilings of treatment, and reference to mental capacity. The need for care plans to be tailored to individual needs, and also be based on the discussions that have taken place, was flagged by some stakeholders.

4.3.2 **Selected recommendations from development source**

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee’s discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Involving the person who is dying and those important to them	Shared decision-making NICE NG31 Recommendation 1.3.1, 1.3.5, 1.3.6, 1.3.7, 1.3.8
Exploring preferences and needs	Shared decision-making NICE NG31 Recommendation 1.3.2

Documenting decisions / care plans	Providing individualised care NICE NG31 Recommendation 1.3.4, 1.3.5, 1.3.6, 1.3.7, 1.3.8
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Involving the person who is dying and those important to them

NICE NG31 Recommendation 1.3.1

Establish the level of involvement that the dying person wishes to have and is able to have in shared decision-making, and ensure that honesty and transparency are used when discussing the development and implementation of their care plan.

NICE NG31 Recommendation 1.3.5

In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:

- personal goals and wishes
- preferred care setting
- current and anticipated care needs including:
 - preferences for symptom management
 - needs for care after death, if any are specified
- resource needs.

NICE NG31 Recommendation 1.3.6

Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multiprofessional care team.

NICE NG31 Recommendation 1.3.7

Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.

NICE NG31 Recommendation 1.3.8

While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.

Exploring preferences and needs

NICE NG31 Recommendation 1.3.2

As part of any shared decision-making process take into account:

- whether the dying person has an advance statement or an advance decision to refuse treatment in place, or has provided details of any legal lasting power of attorney for health and welfare
- the person's current goals and wishes
- whether the dying person has any cultural, religious, social or spiritual preferences.

Documenting decisions / care plans

NICE NG31 Recommendation 1.3.4

Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.

NICE NG31 Recommendation 1.3.5

In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:

- personal goals and wishes
- preferred care setting
- current and anticipated care needs including:
 - preferences for symptom management
 - needs for care after death, if any are specified
- resource needs.

NICE NG31 Recommendation 1.3.6

Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multiprofessional care team.

NICE NG31 Recommendation 1.3.7

Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.

NICE NG31 Recommendation 1.3.8

While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has statements that address shared decision making. See Statements 3 and 11 in appendix 1.

4.3.3 Current UK practice

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) found that only 4% of patients had made an advance care plan prior to admission. For 91% of patients it was taken into account when making decisions, and reviewed in 79% of cases.

The audit also found that there was a CPR decision in place for 94% of patients at the time of death. Discussion about CPR between the senior doctor and the patient was recorded in 36% of cases. The main reasons for discussions not taking place included the patient not being conscious (38% of cases) and the patient displaying a lack of mental capacity for the issue of CPR (34%). Discussion about the CPR decision with the nominated person important to the patient was documented in 81% of cases.

In 95% of cases when it was recognised that a patient was dying, there was discussion about this with a person important to the patient. In contrast, only 54% of case records showed that the needs of people important to the patient were asked about. Only in a third of all cases were needs of the nominated person identified or explored.

In two thirds of cases, records showed that there had been a holistic assessment of the patient's needs regarding an individual plan of care in the last 24 hours of life. Excluding sudden deaths and cases where a patient died within 24 hours of admission increased this proportion to 73%. There was wide variation between trusts on this measure (from under 30% to 100%).

The team caring for a dying person was aware of an individual plan of care in 56% of cases. At trust level this proportion varied widely; many trusts recording between 80%–100%, but many other trusts had a value below 40%. Where a team was aware of an individual plan of care, it was followed in 96% of cases and reviewed in 86% of cases.

The [2015 VOICES survey](#) reported that 69% of those bereaved considered that the emotional needs of the person who dies were considered and supported; and 58%

felt that the person's spiritual / religious needs were considered and supported. 69% reported that efforts were made to make sure the person was in the place they most wanted to be cared for.

The same survey showed that 86% of those bereaved felt that the carer / family were given enough help and support at the time of death.

The VOICES survey also asked respondents if the deceased had expressed a preference for where they would like to die. Most (60%) said the person had not expressed a preference. Of those where there was a preference, 81% believed the deceased had wanted to die at home; 8% said in a hospice; 7% in a care home and 3% in hospital. Respondents were asked if the patient had actually died in the right place. In hospices and at home more than 9 out of 10 people were believed to have died in the right place for them. 74% of respondents whose relative died in hospital believed that their relative died in the right place, despite only 3% of all respondents stating that patients wanted to die in hospital. Hospitals also have the highest proportion of respondents who felt the deceased did not die in the right place (17%).

4.3.4 Resource impact assessment

The resource impact report for the primary source guidance NG31 states that there may be costs associated with recommendation 1.3.4 in relation to equipment provision and staffing for care at night for the dying person. Providing additional support at home should help more people avoid going into hospital.

Investing in these areas could result in savings from reduced admissions to hospital for people in the last few days of life. As the current availability of these services varies across the country the resource impact could not be calculated.

4.4 *Managing hydration*

4.4.1 Summary of suggestions

Three stakeholders identified this as a key area for quality improvement. Stakeholders identified decisions relating to managing hydration as being complex and emotive. One stakeholder advocated the involvement of a senior clinician in such decisions, and another stated that medically assisted nutrition and hydration should be considered as medical interventions. The importance of ensuring that the person dying and the people close to them understand issues relating to hydration was reflected in comments.

4.4.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Managing hydration	Maintaining hydration NICE NG31 Recommendation 1.4.1 to 1.4.10

Maintaining hydration

NICE NG31 Recommendation 1.4.1

Support the dying person to drink if they wish to and are able to. Check for any difficulties, such as swallowing problems or risk of aspiration. Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person's care.

NICE NG31 Recommendation 1.4.2

Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed. Offer the person the following, as needed:

- help with cleaning their teeth or dentures, if they would like
- frequent sips of fluid.

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NICE NG31 Recommendation 1.4.3

Encourage people important to the dying person to help with mouth and lip care or giving drinks, if they wish to. Provide any necessary aids and give them advice on giving drinks safely.

NICE NG31 Recommendation 1.4.4

Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.

NICE NG31 Recommendation 1.4.5

Discuss the risks and benefits of clinically assisted hydration with the dying person and those important to them. Advise them that, for someone who is in the last days of life:

- clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems (see recommendation 1.4.9)
- it is uncertain if giving clinically assisted hydration will prolong life or extend the dying process
- it is uncertain if not giving clinically assisted hydration will hasten death.

NICE NG31 Recommendation 1.4.6

Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.

NICE NG31 Recommendation 1.4.7

When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:

- whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment
- their level of consciousness
- any swallowing difficulties
- their level of thirst
- the risk of pulmonary oedema

NICE NG31 Recommendation 1.4.8

Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.

NICE NG31 Recommendation 1.4.9

For people being started on clinically assisted hydration:

- Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
- Continue with clinically assisted hydration if there are signs of clinical benefit.
- Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

NICE NG31 Recommendation 1.4.10

For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life:

- Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
- Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death. For people being started on clinically assisted

4.4.3 Current UK practice

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) identified that:

- 66% of patients had their ability to drink assessed in the last 24 hours of life
- 39% of patients were documented as drinking in the last 24 hours
- 45% of patients had been supported to drink in the last 24 hours of life.
- 18% of patients had a 'nil by mouth' order

In relation to clinically assisted hydration (CAH), the audit results show that:

- 71% of patients had an assessment regarding the need for CAH between admission and the time of death
- 18% of patients had a documented discussion regarding drinking and the need for CAH
- for 39% of patients, discussions had taken place with nominated people
- 43% of patients had CAH in place during the last 24 hours of life

There was variation between trusts on the measures above. At trust level, the proportion of patients who had assessment for CAH ranged from less than 50% to 100%. The proportion of patients with CAH in place during the last 24 hours varied from 0% to 70%.

The audit also captured some information on mouth care. Two thirds of trust records showed there had been a holistic assessment of the patient's needs in the last 24 hours of life. Of the trusts that recorded a holistic assessment, mouth care was assessed in 82% of cases.

The [2015 VOICES survey](#) results suggest that people may be less likely to receive support drinking in hospital compared to other settings. Overall, 78% of bereaved people agreed that the person who died had been supported to drink or receive fluid if they wished in the last two days of life. This measure ranged between 70% for hospital settings to 90% for hospices.

4.4.4 Resource impact assessment

The resource impact report for the primary source guidance NG31 states that there may be costs associated with recommendation 1.4.8 in relation to providing subcutaneous assisted hydration to people in the community.

Investing in hydration support in community settings could result in savings from reduced admissions to hospital for people in the last few days of life. As the current availability of services varies across the country, the resource impact could not be calculated.

4.5 *Managing symptoms*

4.5.1 **Summary of suggestions**

Six stakeholders identified management of symptoms as a priority area for quality improvement. One stakeholder stated that when dying people are asked what matters most, this is their top priority.

Three stakeholders identified assessment of symptoms as specific area for quality improvement. Two stakeholders specified assessment of pain as the particular focus. The use of a behavioural pain assessment tool for patients who are unable to communicate was identified as the key area by one of these stakeholders.

One stakeholder identified the need for individualised prescribing based on the patient's current symptoms (as opposed to blanket prescriptions) as the as the specific area for quality improvement. Whilst this involves assessment, it also relates to administration of medicine; an area that two further stakeholders identified as a priority for quality improvement, with speed of access to medications referred to in the supporting comments. Administration of medication by the family / carer was the specific area for quality improvement flagged by one of these two respondents.

4.5.2 **Selected recommendations from development source**

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Administration of medication	Pharmacological interventions NICE NG31 Recommendation 1.5.1 to 1.5.9
Assessment of symptoms	Managing pain NICE NG31 Recommendations 1.5.12 to 1.5.14 Managing breathlessness NICE NG31 Recommendations 1.5.15 Managing nausea and vomiting NICE NG31 Recommendations 1.5.18 Managing anxiety, delirium and agitation NICE NG31 Recommendations 1.5.23 Managing noisy respiratory secretions NICE NG31 Recommendations 1.5.29

Administration of medication

NICE NG31 Recommendation 1.5.1

When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.

NICE NG31 Recommendation 1.5.2

When involving the dying person and those important to them in making decisions about symptom control in the last days of life:

- Use the dying person's individualised care plan to help decide which medicines are clinically appropriate.
- Discuss the benefits and harms of any medicines offered.

NICE NG31 Recommendation 1.5.3

When considering medicines for symptom control, take into account:

- the likely cause of the symptom
- the dying person's preferences alongside the benefits and harms of the medicine
- any individual or cultural views that might affect their choice
- any other medicines being taken to manage symptoms

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- any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

NICE NG31 Recommendation 1.5.4

Decide on the most effective route for administering medicines in the last days of life tailored to the dying person's condition, their ability to swallow safely and their preferences.

NICE NG31 Recommendation 1.5.5

Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.

NICE NG31 Recommendation 1.5.6

Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.

NICE NG31 Recommendation 1.5.7

For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.

NICE NG31 Recommendation 1.5.8

Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.

NICE NG31 Recommendation 1.5.9

Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

Assessment of symptoms

NICE NG31 Recommendation 1.5.12

Assess the dying person's level of pain and assess for all possible causes when making prescribing decisions for managing pain.

NICE NG31 Recommendation 1.5.13

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Follow the principles of pain management used at other times when caring for people in the last days of life, for example, matching the medicine to the severity of pain and, when possible, using the dying person's preferences for how it is given.

NICE NG31 Recommendation 1.5.14

For a person who is unable to effectively explain that they are in pain, for example someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management.

NICE NG31 Recommendation 1.5.15

Identify and treat reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion.

NICE NG31 Recommendation 1.5.18

Assess for likely causes of nausea or vomiting in the dying person. These may include:

- certain medicines that can cause or contribute to nausea and vomiting
- recent chemotherapy or radiotherapy
- psychological causes
- biochemical causes, for example hypercalcaemia
- raised intracranial pressure
- gastrointestinal motility disorder
- ileus or bowel obstruction.

NICE NG31 Recommendation 1.5.23

Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them. Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.

NICE NG31 Recommendation 1.5.29

Assess for the likely causes of noisy respiratory secretions in people in the last days of life. Establish whether the noise has an impact on the dying person or those important to them. Reassure them that, although the noise can be distressing, it is unlikely to cause discomfort. Be prepared to talk about any fears or concerns they may have.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has a statement that in part addresses management of symptoms. See Statement 11 in appendix 1.

4.5.3 Current UK practice

The [2015 VOICES survey](#) reported that 80% of bereaved people thought there was enough help with nursing care (including giving medicine) in their last 2 days of life for the person who died; 13% did not agree that this was the case.

Respondents were also asked if the person who died had sufficient pain relief in the last 2 days of life. 81% agreed with this statement; 10% disagreed. The proportion that agreed the person who died had sufficient pain relief was highest for people who died in hospices (92%) and lowest for those who died in hospitals (78%).

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) collected information on symptoms and their control in the last 24 hours of life. The proportions below relate to the proportion of patients that had the particular symptom present:

- 79% of patients had pain controlled
- 72% of patients had agitation / delirium controlled
- 68% had dyspnoea / breathing difficulty controlled
- 62% had noisy breathing / 'death rattle' controlled
- 55% had nausea / vomiting controlled
- 10% had other symptoms controlled.

Of patients that died in hospital, the audit showed that 31% had been reviewed by a member of the specialist palliative care team since admission; and 23% were reviewed in the last 24 hours of life.

Almost two thirds (65%) of medications that patients received were reviewed in the last 24 hours of life. In terms of administration route, in the last 24 hours of life:

- 30% of patients were taking oral medications
- 5% of patients had a continuous subcutaneous infusion of medication
- 2% of patients had been prescribed rectal medication.

4.5.4 Resource impact assessment

This area was not included in the resource impact report for the primary source guidance NG31. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.6 Anticipatory prescribing

4.6.1 Summary of suggestions

Three stakeholders identified anticipatory prescribing as a priority area for quality improvement. One stated that the prescribing should be individualised and based on assessment of likely symptoms of the patient. Benefits of anticipatory prescribing were identified by some stakeholders as including helping to cope in emergency situations out of hours, reducing stress and better confidence / reassurance for patients, their family and carers.

4.6.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 10 to help inform the Committee’s discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Anticipatory prescribing	Anticipatory prescribing NICE NG31 Recommendation 1.6.1 to 1.6.6

Anticipatory prescribing

NICE NG31 Recommendation 1.6.1

Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed.

NICE NG31 Recommendation 1.6.2

Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain). Discuss any prescribing needs with the dying person, those important to them and the multiprofessional team.

NICE NG31 Recommendation 1.6.3

Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.

NICE NG31 Recommendation 1.6.4

When deciding which anticipatory medicines to offer take into account:

- the likelihood of specific symptoms occurring
- the benefits and harms of prescribing or administering medicines
- the benefits and harms of not prescribing or administering medicines
- the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed
- the place of care and the time it would take to obtain medicines.

NICE NG31 Recommendation 1.6.5

Before anticipatory medicines are administered, review the dying person's individual symptoms and adjust the individualised care plan and prescriptions as necessary.

NICE NG31 Recommendation 1.6.6

If anticipatory medicines are administered:

- Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
- Adjust the individualised care plan and prescription as necessary.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has a statement that includes anticipatory prescribing, albeit not explicitly. See Statement 11 in appendix 1.

4.6.3 Current UK practice

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) collected information on whether anticipatory medication was prescribed for five key symptoms that could occur in the last hours or days of life. If results are restricted to those with known length of stay of 24 hours or more, the findings show that:

- 75% of patients were prescribed anticipatory medication for pain
- 66% of patients were prescribed anticipatory medication for breathing difficulties
- 66% of patients were prescribed anticipatory medication for nausea/vomiting
- 62% of patients were prescribed anticipatory medication for noisy breathing /death rattle
- 60% of patients were prescribed anticipatory medication for agitation/delirium

4.6.4 Resource impact assessment

This area was not included in the resource impact report for the primary source guidance NG31. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.7 Access to specialist palliative care

4.7.1 Summary of suggestions

Seven stakeholders identified access to specialist palliative care services out of hours, ‘when needed’ or ‘24/7’, across all settings as a priority area for quality improvement. There is significant variation in access to specialist care services across the country according to the comments received.

4.7.2 Selected recommendations from development source

Table 11 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 11 to help inform the Committee’s discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Access to specialist palliative care	<p>Recognising when a person may be in the last days of life NICE NG31 Recommendation 1.1.7</p> <p>Providing individualised care NICE NG31 Recommendation 1.3.9</p> <p>Pharmacological intervention NICE NG31 Recommendation 1.5.9</p> <p>Managing anxiety, delirium and agitation NICE NG31 Recommendation 1.5.28</p>

Access to specialist palliative care

NICE NG31 Recommendation 1.1.7

Seek advice from colleagues with more experience of providing end of life care when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

[Note for Committee: The [full guideline](#) (page 90) makes clear that this recommendation includes seeking advice from specialist palliative care teams: “The Committee made a separate recommendation around seeking advice from colleagues with more experience of providing end of life care and agreed this may

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include specialist palliative care teams or other relevant specialties whose input would reduce the uncertainty in recognising dying”.]

NICE NG31 Recommendation 1.3.9

Ensure that shared decision-making can be supported by experienced staff at all times. Seek further specialist advice if additional support is needed.

[Note for Committee: The [full guideline](#) (page 142) states that Committee considered “...specialist support to include any specialty who are able, because of their specialist experience, to aid shared decision making.” This recommendation therefore includes specialist palliative care, although not by name.]

NICE NG31 Recommendation 1.5.9

Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

NICE NG31 Recommendation 1.5.28

Seek specialist advice if the diagnosis of agitation or delirium is uncertain, if the agitation or delirium does not respond to antipsychotic treatment or if treatment causes unwanted sedation.

Overlap with existing quality standard

The [End of life care for adults](#) quality standard has a statement that addresses specialist palliative. See Statement 10 in appendix 1.

4.7.3 Current UK practice

The Royal College of Physicians [End of life care audit – Dying in hospital: National report for England 2016](#) collected information on specialist palliative care.

The organisational audit found that almost all trusts (97%) had their own specialist palliative care (SPC) service. Most trusts (70%) also used an SPC service that was located and funded outside of the trust. The availability and nature of SPC services varied widely:

- 11% of trusts offered a face to face 24/7 service
- 37% offered a face to face service 9am to 5pm, 7 days a week
- 39% offered a face to face service 9am to 5pm, Monday to Friday
- 11% of trusts did not indicate any offer of face to face SPC involving a doctor at any time

- availability of an out-of-hours telephone service was more comprehensive, with the majority of services providing this every day of the week.

The clinical audit found that almost a quarter of patients (23%) were reviewed by a member of the specialist palliative care team in the last 24 hours of life. The proportion reviewed was slightly lower for trusts without an onsite specialist palliative care unit (22%) compared to those that had such a unit (26%).

4.7.4 Resource impact assessment

This area was not included in the resource impact report for the primary source guidance NG31. It was not identified as an area that would have a significant resource impact (>£1m in England each year).

4.8 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 27 July.

Developmental areas / emergent practice

Stakeholders suggested areas of emergent practice that are underpinned by NICE guidance or NICE accredited guidance. The following suggestions are not specifically underpinned by current NICE guidance or are outside of the scope of this quality standard:

- Complementary therapies
- Earlier intervention by palliative care services (i.e. prior to the last 2-3 days of life)
- Improved recognition of spiritual, cultural and practical needs of dying people
- Improved care of the deceased immediately after death

Care after death

Three aspects of care after death were suggested: providing bereavement support to relatives after a person has died; using the views of the bereaved to improve services; and timely verification and certification of death. These areas are not addressed by the primary source guidance. There are statements in the existing end of life care quality standard that address care after death.

Service delivery / joint commissioning and funding

Co-ordinated care across the multiple services providing care to a dying person; multidisciplinary team management; logistics; access to multidisciplinary pain management services; access to palliative care services for people with stroke; and joint commissioning and funding were suggested as priority areas for quality improvement. Service delivery, funding and joint commissioning are outside the scope of the primary source guidance. Service delivery is the focus of the end of life care for adults in the last year of life: service delivery guideline that is in production.

End of life care in advanced dementia

A stakeholder suggested this area and stated that advanced dementia is often neglected and not recognised as a terminal condition. Palliative care needs of

patients with dementia are covered by the [dementia: support in health and social care](#) quality standard.

Frailty

One stakeholder suggested this area and stated that identification of people with frailty at the end of their life is crucial to their quality of life. The primary source guidance does not specifically address frailty.

Education and training

Education and training for non-palliative care specialists was suggested as a key area for quality improvement. For reasons stated in section 4.1.1, quality standards usually do not include statements on education and training.

Inequalities in end of life care

One respondent stated that experience of end of life care varied between people in different settings, with different conditions, and between different sub-groups of the population. There are no specific recommendations in the primary source guidance relating to this area, but one of the overarching objectives of the quality standard is to address inequalities and variations in practice.

National agreement around unified ceilings of treatment

Quality standards are designed to support local quality improvement. They do not cover national standards and national policy.

Organ donation

Not within the scope of the primary source guidance or the quality standard.

Symptom management for young adults

One stakeholder commented that symptom management for young people is different to that for older people. There are no specific recommendations that deal with young adults in the primary source guidance.

Appendix 1: End of life care for adults quality standard

Some of the areas suggested for quality improvement in this paper are, in part, addressed by NICE quality standard QS13 [end of life care for adults](#). However, QS13 covers people who are in the last 12 months of life and not just the last 2-3 days of life. The statements from QS13 are listed below so that the degree of overlap can be considered.

Statement 1. People approaching the end of life are identified in a timely way.

Statement 2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Statement 3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Statement 4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

Statement 5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Statement 6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Statement 7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Statement 8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

Statement 9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

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Statement 10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

Statement 11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

Statement 12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.

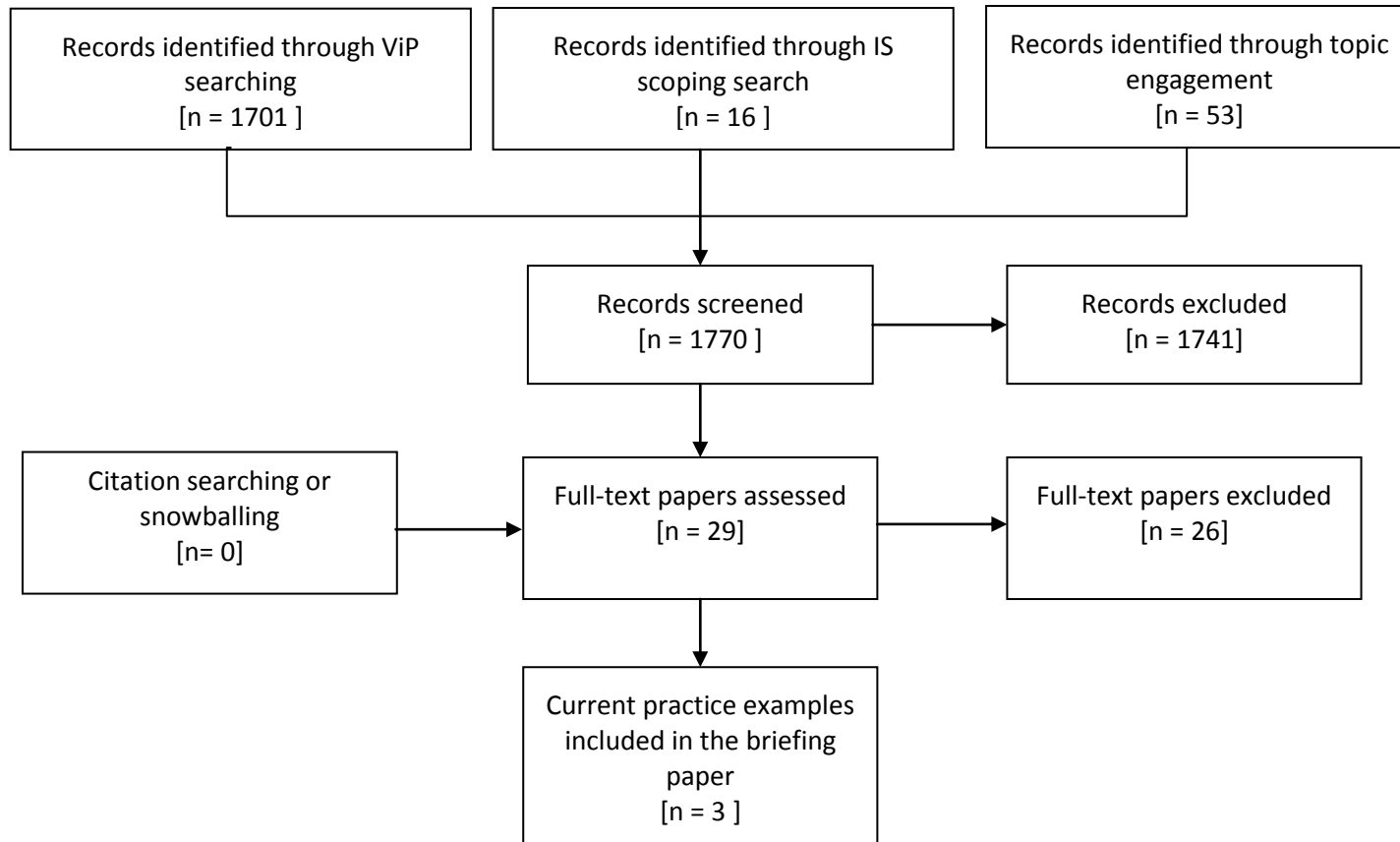
Statement 13. Families and carers of people who have died receive timely verification and certification of the death.

Statement 14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Statement 15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Statement 16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

Appendix 2: Review flowchart



Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Recognition of dying					
1	Association for Palliative Medicine of Great Britain and Ireland	Recognition of dying	<p>The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team, including the senior doctor & nurse responsible for the patient's care – senior leadership and accountability.</p> <p>It is crucial to communicate the recognition of dying to patients (where able) and those close to them.</p> <p>This should be underpinned by mandatory training / education about recognition of dying and communication skills for those frequently working with patients approaching the end of their lives.</p>	<p>To ensure that the diagnosis of dying is made by experience doctors / nurses who know the patient well</p> <p>Where avoidable, to prevent this diagnosis being made by junior staff or those who do not know the patient well</p> <p>To make sure that alternative diagnoses / treatments have been considered</p> <p>To ensure that this diagnosis and management plan is regularly reviewed by someone senior</p>	<p><i>Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020</i></p> <p><i>CQC Report: A different ending: Addressing inequalities in end of life care 2016</i></p> <p>https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals</p> <p><i>Parliamentary & Health Service Ombudsman: Dying without dignity 2015</i></p> <p><i>House of Commons Health Committee End of Life Care 2014-15</i></p> <p><i>NICE guidelines NG31 - Care of dying adults in the last days of life 2015</i></p> <p><i>Leadership Alliance for the Care of Dying People: One chance to get it right 2014</i></p>
10	EPA UK/EU	Recognising when a person may be in the last days of life	<p>Dignity and compassion are of the upmost importance at the end of life. There can be no dignity where there is a denial or a failure to recognise a very significant event in a person's life such as dying.</p> <p>There is good evidence to support the fact that the earlier it is recognized and</p>	<p>Complicated grief remains a major concern for people once their loved one has passed over. There is a greater risk of complicated bereavement when the bereaved did not have the opportunity to discuss death with the deceased before the death occurred.</p>	<p><i>Guidelines for the Assessment of Bereavement risk in family members of people receiving palliative care, Centre for palliative care, 2000.</i></p> <p>http://prc.coh.org/BereavGuidelines.pdf</p>

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			<p>communicated that a person is dying the more supportive it is for the person and those important to them as it gives everyone time to prepare and to say goodbye. People need time to reach a point of completion in their lives. For this reason it is important to recognize when a person is dying far earlier than in the last few days of life.</p>	<p>One of the reasons for complicated grief is that people often feel they did not have enough time to say everything that they needed to say and so spend years with unresolved grief.</p>	
17	Hospice UK	<p>People are recognised to be dying in a timely way, to allow preferences to be met in terms of how and where they wish to be cared for</p>	<p>Last days of life are often recognised too late – this does not allow time for affairs to be put in order, for conversations to happen or for people to leave hospital.</p>	<p>Closer engagement between palliative and care of the elderly teams in hospital and the community. Shared care models are leading to earlier recognition of dying in hospital and community.</p> <p>Care homes and hospices are also increasingly working together – evidence that dying patients are recognised</p>	
46	Resuscitation Council (UK)	<p>More frequent and consistent recognition that a person is dying, with documentation of that 'diagnosis' and the reasons for making it, and (also documented) explanation of the situation to the patient and those important to the patient.</p>		<p>The RCP Audit of end-of-life care in hospitals⁹ found that imminent death was recognised in 93% of people, but in many at a relatively late stage prior to death, leaving limited opportunity to plan and deliver good end-of-life care. Furthermore, only 25% of people had documented evidence that this situation had been explained to and discussed with the patient themselves. Recognising dying and being able to identify and</p>	<p><i>For example, please see refs 9 and 11 above.</i></p>

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				make the transition to changing priorities of care towards the end of life should be an integral part of training of all health professionals who may encounter and provide care for a person who is dying.	
49	Royal College of Psychiatrists	Problems are often seen when signs of imminent death are misunderstood by acute care clinicians. They may be referred to psychiatry liaison with depression etc. Better teaching and recognition is necessary.			
57	SCM 2	<p>RECOGNITION of situation (1.1.1)</p> <p>Although it may be difficult to predict with certainty it is vital to discuss the situation in a timely manner and to involve the appropriate people – viz the dying person, those important to them and suitably qualified staff</p>	<p>It is important to avoid any unnecessary investigations; to address symptoms appropriately; to allow the dying person the chance to discuss matters of concern; to inform those important to them who also may wish to discuss matters of concern and plan for the future.</p> <p>(Only 1% patients decline to know that they are dying but of course that should be respected)</p>	<p>These improvement issues are linked with why recognition is important (qv) The topics need sensitivity and staff with the appropriate experience and training.</p> <p>The LGBT community can encounter particular difficulties in end of life care.</p> <p>For many patients there is only one chance to get it right and how the situation is handled can have far-reaching effects for those important to them as well.</p>	<p><i>Please see CODA Guidelines 1.1.1 for supporting details</i></p> <p><i>Also National Council for Palliative Care project with Health Education England which is looking at new ways to build the End of Life Care workforce (Bulletin 10.06.16)</i></p> <p><i>Difficult Conversations (also in NCPC Bulletin 10.06.16)</i></p> <p><i>NHS England Specialist Palliative Care Information for Commissioners (see Template of questions for guidance)</i></p> <p><i>James Lind Alliance Palliative End of Life Care Priority Setting Partnerships also refer.</i></p>
61	SCM 3	Earlier diagnosis of	More informed decision making and		<i>RCP audit patients dying in</i>

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		dying	addressing fears and stress in both patients and families/carers		<i>hospital</i>
70	SCM 5	Recognition of imminent dying and the possibility of recovery	<p>Failure to recognise that a person is entering the last 2-3 days of life can lead to lost opportunities for communication and shared decision-making, as well as some people not dying in their preferred place. Conversely, declaring that a person is dying and failing to see the possibility or improvement or recovery could lead to inappropriately timed deaths.</p> <p>Recognition of dying and the possibility of even temporary improvement were highlighted in the NICE guideline NG31. It also stressed the importance of daily review of this status and the need to seek advice from more experienced colleagues if there is uncertainty.</p>	<p>The RCP audit of end of life care in hospitals (March 2016) showed that patients were recognised as dying on a median of 5 days into their final admission. After documented recognition, median time to death was only 34 hours.</p> <p>As a consequence of late recognition, only 25% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death.</p> <p>The opportunity to seek patients' own views on other aspects of their end of life care could have been missed.</p> <p>In some cases, late recognition led to some people important to the dying person failing to be informed in time.</p>	<p><i>See RCP audit of end of life care (March 2015).</i></p> <p><i>Also see 'More Care, Less Pathway (Neuberger review, 2013)</i></p>
Communication					
11	EPA UK/EU	Communication	The current recommendation is strong when it comes to content and methods of communication between health care teams and with the dying person and those most important to them. We acknowledge that	<p>A literature review found that:</p> <p>Communication and the relationship between caregivers</p>	<p><i>Remedios, C, Thomas K, and Hudson, P. (2011). Psychosocial and bereavement support for family caregivers of</i></p>

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			<p>aspects emphasised may relate specifically to weaknesses highlighted in the Liverpool Care Pathway For the Care of the dying Adult. We note in this area no mention on quality of communication.</p> <p>We recommend that everyone who is supporting the dying person be trained in self-reflection and self- awareness as to the impact of how we are on others. This requires training medical, nursing, allied health, carers, catering and domestic staff in how to deliver care without imposing on another.</p> <p>All staff and carers need to be supported to recognise their own discomfort around dying so that they do not impose their own fears and beliefs about dying onto another.</p>	<p>and health professionals were identified as key determinants in the adequacy of information provision (Docherty, et al., 2008). Dissatisfaction with communication was found in a number of studies, particularly in relation to the level of detail of the information provided and the limited opportunities for meetings or discussions (Docherty, et al., 2008). Where poor communication was experienced, relatives often reported feeling isolated, disillusioned, frustrated and distressed. This was also found to impact on their ability to handle situations (Andershed, 2006).</p>	<p><i>palliative care patients: A review of the empirical literature (2011). Centre for Palliative Care, St Vincent’s Hospital & Collaborative Centre of The University of Melbourne</i></p> <p>http://centreforpallcare.org/assets/uploads/Psychosocial%20and%20Behavioural%20Support%20Literature%20Review%202011%20.pdf</p>
18	Hospice UK	Information between health care, urgent care, social care and the patient needs to be simply and safely shared	People want to tell their story once. All providers need to know ACP preferences, up to date clinical condition, and plans for deterioration.	<p>Areas where there is high usage of systems such as Co-ordinate My Care (CMC) – are demonstrating key improvements in quality of care in terms of information sharing and preferences of location being met.</p> <p>http://hitconsultant.net/2016/06/09/future-health-index/</p> <p>Dixon, J., King, D., & Knapp, M.</p>	

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				<p>Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People. BMJ Support Palliat Care doi:10.1136/bmjspcare-2015-000971</p>	
19	Hospice UK	<p>All health and social care providers, in all settings, have the confidence, and competence to care and communicate compassionately and safely for dying patients in a person-centred way in their last days and hours.</p>	<p>Doctors and nurses are still often ill at ease in terms of talking about goals of care and the fact that time is short. Education and training needs to be systematically embedded in all undergraduate and post-graduate health and social care education. Hospices can help with this.</p>	<p>Doctors and nurses who have had specific training in end of life care (e.g. a hospice placement as a student or soon after qualifying, or close working with a hospital palliative care team) are much more at ease in terms of recognising dying and communicating compassionately.</p> <p>Caswell G, Pollock K, Harwood R, Porock D. Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. BMC Palliative Care. 2015;14:35. doi:10.1186/s12904-015-0032-0.</p> <p>Pollock K, Wilson E. Care and communication between health professionals and patients affected by severe or chronic illness in community care settings:</p>	

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				<p>a qualitative study of care at the end of life. Southampton (UK): NIHR Journals Library; 2015 Jul. (Health Services and Delivery Research, No. 3.31.)</p>	
20	Hospice UK	<p>Informal and family caregivers have their needs assessed and relevant support offered in the pre and post bereavement phase.</p>	<p>Attention to family needs is often negligible. Needs are not assessed in a structured way, and this can lead to a poor experience of care and a difficult bereavement.</p>	<p>Trials using a structured Carers Support Needs Assessment Tool (CSNAT) demonstrates that not only is the use of the tool therapeutic in itself, but that very simple needs are priorities for families (e.g. knowing what will happen next.)</p> <p>Aoun S, Deas K, Toye C, Ewing G, Grande G, Stajduhar K. (2015) Supporting family caregivers to identify their own needs in end of life care: Qualitative findings from a stepped wedge cluster trial. Palliative Medicine Online first:</p> <p>CSNAT is now recommended as the best carers assessment tool in Australian Blueprint for improving end of life care</p> <p>http://www.aci.health.nsw.gov.au/palliative-care-blueprint/the-blueprint/essential-components/essential-component-5</p>	

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24	Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN	Roll out of an effective electronic record for key information around palliative and end of life care that is accessible to all key stake holders from both health and social care	Evidence that effective electronic record sharing enhances care	Localities are struggling to get IT systems that “talk” to each other Information Governance requirements on smaller organisations can be overwhelming with no support to help them comply	
27	Marie Curie	Key area for quality improvement 1: Communication and decision-making	Dying people who have been clear that they want to understand their prognosis should be informed when time is short. This information should be communicated clearly and sensitively to them and the people who are important to them. Plans for care should be decided in consultation with the dying person and those important to them.	The Royal College of Physicians End of Life Care Audit Report (March 2016) shows only 25% of people who were recognised as being likely to die had documented evidence of a discussion with a healthcare professional about their likely imminent death. Overall, where there was not a documented discussion, there was no reason recorded in 17% of cases. https://www.rcplondon.ac.uk/news/new-rcp-end-life-care-audit-shows-steady-progress-care-dying-people	<i>The Leadership Alliance for Care the Care of Dying People set out 5 priorities of care for dying people in 2014. This document comprehensively sets out duties and responsibilities for health and care staff and should be reflected in NICE quality statements on this topic:</i> http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf
35	NHS England	Shared information which can be used to inform decisions about care and treatment, and coordinate care	Patients who are close to dying are often unable to communicate their priorities and preferences, nor to participate in shared decision making in a meaningful way. Often conversations have taken place with professionals prior to that stage, sometimes in a different care setting, but without systems that enable shared records and	There is evidence that the inadequacy of systems to share key information about the person’s condition, needs and preferences (e.g. through shared records across organisational boundaries) means that this information is not used to inform decisions about	Ref: <i>Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015</i> <i>The source guidance includes a recommendation (1.1.1) which</i>

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			<p>professional skills and attitudes which ensure these records (where they exist) are used fully, these patients' preferences cannot be known and taken into account in decisions and interventions for their care and treatment. Moreover, such a lack of shared record system reduces the ability of the system to ensure that care is coordinated and 'wrapped around' the person.</p>	<p>care and treatment which takes into account the person's needs and preferences, and which results in a lack of coordinated care for the person and those close to them. Whilst the capability to share records across a locality is a system issue, a quality statement which focuses on the care plan of the individual being informed by such information accessed through shared system could achieve this. Alternatively, a 'structural' QS could be more straightforward, as CCGs often provide leadership for ensuring that such electronic record sharing systems are provided across their locality.</p>	<p><i>focuses on the gathering of information, which could provide a useful starting point for this QS.</i></p>
36	NHS England	Needs of those close to the dying person	<p>This is an issue that is of concern to dying patients. We know that this continues to receive suboptimal attention, yet these people are often the main carer (thereby leading to consequences on their physical and mental health, employment, etc with potentially long term consequences), as well as undergoing their own process of loss and bereavement.</p>	<p>The End of Life Care Audit - Dying in Hospitals (2015) show that this is one of the areas that was least well documented (only 54% of records showed that the needs of people important to the dying person were asked about). We also know that when somebody dies at home, the main carer is often family or friends who live with, or close to, the person – the evidence that they have been offered a formal Carers Assessment or have their needs addressed remain patchy across the country.</p>	<p><i>Evidence sources:</i></p> <ul style="list-style-type: none"> • <i>The End of Life Care Audit – Dying in Hospital (2016), commissioned by NHS England and conducted by the Royal College of Physicians</i> • <i>Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015</i> <p><i>Information source:</i></p> <p><i>Ambitions for Palliative and End of</i></p>

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					<i>Life Care: a national framework for local action (2015).</i>
38	Older People's Advocacy Alliance	Being proactive about the promotion of independent advocacy support around end of life care.	Example: Many older people tell us that they are not aware of their rights around end of life care. Independent Advocacy support can help them to plan for a good death, to communicate their wishes, be aware of their rights and making informed choices. Compassion in Dying's End-of-Life Rights Advocacy pilot project in East London ensured over 2000 people were made aware of their rights at the end of life. Our stakeholders tell us that care will only be quality when we are comfortable with talking about end of life wishes, starting conversations about death, end of life, making plans and informed choices, these are all areas where advocacy support can improve outcomes.		<i>Our Cancer, Older People and Advocacy programme is supporting older people to make informed choices about their end of life wishes and care, as well as offering vital carer support. We share stories about the impact of advocacy at the end of life and end of life planning stage on our blog https://opaalcopa.org.uk/tag/end-of-life/</i>
39	Older People's Advocacy Alliance	Communication and person centred care.	People have different communication preferences in relation to how they are given and how their receive news of their prognosis. Our Older People's Cancer Voices project has heard from older people who feel the varying ways in which 'bad news' is being communicated impact on their/their loved ones experiences of end of life care.	The NICE guideline on care of dying adults also highlights communication issues: "Some health and care professionals are uncomfortable discussing how long someone has left to live, and sometimes do not have the skills and confidence to give difficult news or talk about the dying process. Adequate training and continued support is important to help health and care professionals to communicate sensitively and effectively".	<i>We think this training and support needs to be more than adequate, if older people are to feel comfortable talking about their wishes, and be clear with professionals how they would like news to be communicated then health professionals must be comfortable with working in a person centred, compassionate and confident way at the end of life.</i>

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45	Resuscitation Council (UK)	Advance care planning	There is recognition and recommendation that much more widespread advance care planning in all healthcare settings would improve the quality of end-of-life care in the last days of life, by supporting patients in identifying and understanding their priorities for their care and treatment, and by helping those close to patients to understand these, thereby enhancing a collaborative approach to high-quality care and avoiding potential for misunderstanding and false expectation when death is imminent.		<p><i>Please see for example:</i></p> <p><i>11. Ambitions for Palliative and End of Life Care:</i></p> <p><i>A national framework for local action 2015-2020</i></p> <p><i>National Palliative and End of Life Care Partnership</i></p> <p><i>www.endoflifecareambitions.org.uk</i></p> <p><i>Also:</i></p> <p><i>Transforming end of life care in acute hospitals (as listed in your topic overview).</i></p> <p><i>Decisions relating to cardiopulmonary resuscitation (ref 3 above).</i></p>
47	Resuscitation Council (UK)	Communication – ensuring that, at all levels of seniority and in all disciplines, health professionals who may encounter and provide care for a person who is dying have the training and skills to communicate sensitively and effectively with dying patients, those close to dying patients and all other health and care professionals who may be involved in caring for them.		This is a theme that runs through all the major audits, guidelines and reviews relating to the quality of end-of-life care, including those already referenced herein, Absent, inadequate or bad communication is the commonest cause of complaint about health care in general and about aspects of end-of-life care in particular. Widespread improvement in the quality of communication has huge potential to deliver a better end-of-life experience for dying people and those important to them. This should be part of a change of culture among health	<p><i>Please see (for example) references 1, 2, 3, 4, 7, 8, 9, 11 above</i></p>

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				professionals so that they all aim to play a positive part in delivering excellence in end-of-life care.	
50	Royal College of Psychiatrists	Too many patients who are dying or terminal with non cancer illness are not told. Eg cardiac cachexia and end stage cardiac and renal failure are not dealt with. Better understanding and teaching on non cancer terminal illness is needed.			
53	SCM 1	Discussion between patient and health professional about likely imminent death and patient priorities	Individualised care cannot be achieved without open discussion	End of Life Care Audit-Dying in hospital only 25% patients recognised as imminently dying had documented discussion around this between patient and health care professional (assumed patient responsive)	As above
54	SCM 1	Distinct exploration of family/carer support needs	Requires specific exploration of family needs, listening, acknowledging, providing information at a time of feeling anxious/fearful improves quality of experience of family and coping into bereavement	5 priorities of care NHS IQ End of life Care Audit-Dying in hospital	http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf
58	SCM 2	COMMUNICATION(1.2.1;1.2.2; 1.2.4) It is important to establish needs and expectations in this	It is important to identify the most appropriate team member, both to explain and discuss the prognosis so that the dying person and those important to them have the opportunity to air any anxieties and ask questions	As above, the appropriate experience and training are essential to such discussions. It is important to ascertain mental capacity (or who is acting as	<i>NICE CODA Guidelines 1.2.1, 1.2.2 and 1.2.4 refer here</i> <i>Also general NICE Guidance about Patient Experience in Adult NHS Services, and more particularly</i>

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		<p>regard, taking account of any cultural or other preferences, including whether the dying person wishes to have anyone important to them present when making decisions</p>	<p>It is also important to provide contact details for any further discussion that may be desired</p>	<p>advocate) and confirm the availability of any advance statement so that the dying person's wishes are respected.</p>	<p><i>about palliative care in http://cks.nice.org.uk/palliative-care-general-issues#!scenario:2?</i></p> <p><i>And NHS England Specialist Palliative Care Information for Commissioners regarding Multidisciplinary Teams</i></p>
71	SCM 5	<p>Communication with the dying person and shared decision-making, including with the people important to the dying person</p>	<p>Planning and delivering the best quality of end of life care and support for families and friends depends on good communication between all those involved. Shared decision-making in turn depends on good communication and regular review, in the light of changing circumstances.</p> <p>The NICE guideline NG31 stressed these areas and also recommended that the most appropriate people in the professional team should be identified for continuing communication. It stressed the need to explore the dying person's wishes and advance decisions in making decisions, eg DNACPR, hydration etc.</p>	<p>The RCP end of life care audit (2016) showed that patients were frequently not involved in their final decisions, especially regarding DNACPR.</p> <p>Only 32% of patients had opportunities to have their concerns listened to.</p> <p>Regarding the people important to the dying person, in only 38% of cases, was there documented evidence in the last episode of care that the patient's needs had been discussed with the people important to them.</p> <p>In total, only 54% of case records showed that the needs of persons important to the person were asked about.</p>	<p><i>See RCP audit of end of life care (March 2015).</i></p> <p><i>Also see 'More Care, Less Pathway (Neuberger review, 2013)</i></p>

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77	Stroke Association	Effective communication for those with palliative care needs	33% of stroke survivors are affected by communication problems, including receptive aphasia (difficulty understanding what is being said), expressive aphasia (difficulties expressing oneself), or a mix of the two. ¹	<p>Because of both the nature of a devastating acute stroke, and communication impairment caused by stroke, stroke patients who are dying may be unable to express their desires, wishes, and palliative care needs. Additionally, those who are in the final stages of life where stroke is a co-morbidity may have aphasia, and steps need to be taken to ensure they can be communicated with effectively. For example, those who have had a stroke often develop vascular dementia.</p> <p>Sentinel Stroke National Audit Programme data shows that, although many stroke survivors wish to die at home, this is only the case in a minority of cases. This may be the result of ineffective communication with stroke survivors; although we appreciate that communication with a stroke patient when their prognosis is very poor may be difficult, where death is prolonged efforts should be made to communicate with the patient to determine their wishes for the end of their life.</p>	<p><i>SSNAP data shows that, although many stroke survivors wish to die at home, this is only the case in a minority of cases.</i></p> <p><i>A recent Swedish study comparing end of life care for stroke and cancer found that those caring for stroke patients do not know how the patient is feeling in the week before they die; for example, if they are in pain. More information available here:</i></p> <p>http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0147694#sec008</p>
78	Stroke	Supporting family and	One in five stroke survivors are cared for by	Family, friends and carers may	<i>According to a recent report,</i>

¹ Stroke Association, 'State of the Nation', January 2016, <https://www.stroke.org.uk/resources/state-nation-stroke-statistics>

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	Association	carers at the end of a patient's life.	family or friends, and these carers may play a role in end-of-life decision making.	<p>find it difficult to understand the impact that a stroke has had on an individual, and may need to make difficult decisions about end-of-life care.</p> <p>NHS Quality Improvement Scotland has produced a best practice statement for end of life care for acute stroke. They point out that, because of the rapid onset of acute stroke, patients and carers require support in coping with the pace of events, and making decisions.²</p>	<p><i>relatives of stroke patients feel most discomfort when either excluded from decision making, or feeling overly responsible for making decisions about the end-of-life trajectory for stroke patients. Better communication between clinicians and family and friends is very important for improving end of life care, particularly around uncertainty. Further detail is available here:</i></p> <p>https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf</p> <p><i>A recent Swedish study has found that, in the event of stroke, family members are less likely to be offered bereavement support than in the case of cancer.</i></p> <p>http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0147694#sec008</p>
79	The Brain Tumour Charity	We would reiterate the guidance in NICE Guideline NG31 to discuss the dying person's prognosis with them as soon as it is recognised that they may be entering the last	Just 40% of people with a high grade brain tumour survive for one year or more after diagnosis, yet there is often a lack of preparation for end of life. In a survey of people with a brain tumour with a terminal prognosis 21% stated that they had made no plans for end of life and 28% had not received appropriate information about end	Evidence provided by the Royal College of Physicians and Marie Curie showed that in 17% of cases no reason had been given as to why no documented discussion had taken place in instances of people who were recognised as being likely to die	<ol style="list-style-type: none"> 1. <i>The Brain Tumour Charity. Losing Myself: The reality of life with a Brain Tumour [Internet]. 2015. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/</i>

² University of Glasgow, 'Best Practice Statement: End of Life Care Following Acute Stroke', December 2010, http://www.gla.ac.uk/media/media_181950_en.pdf

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		days of life	<p>of life care (1).</p> <p>NICE Guideline NG31 emphasizes that it is important for healthcare professionals to understand the needs and expectations of an individual in the last phase of end of life care. In 21% of cases where no documented discussion about likely imminent death took place with people recognised as being likely to die it was because of cognitive impairment (2). People with a brain tumour may experience rapid cognitive decline due to the nature of their prognosis. In light of this it is important that discussions happen as soon as possible.</p>	(2).	<p>2. Royal College of Physicians, Marie Curie. <i>End of Life Care Audit - Dying in Hospital: National Report for England 2016</i> [Internet]. <i>Healthcare Quality Improvement Partnership</i>; 2016. Available from: https://www.rcplondon.ac.uk/file/3338/download?token=9u-kTz2H</p>
83	Together for Short Lives	Professional openness and honesty	<p>Professionals working with people at the end of their life should be honest and open at all times.</p> <p>This may mean acknowledging professional uncertainty and planning for all possible outcomes. Families should not be given false hope but instead be given realistic expectations of what may happen.</p>	In talking with young people about their experiences of talking about death and dying to inform our joint booklet with the National Council for Palliative Care, young people spoke about the need to improve honest conversation about death and dying.	<p><i>Together for Short Lives (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions.</i> http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE_.pdf</p> <p><i>National Council for Palliative Care & Together for Short Lives (2015). Difficult Conversations</i> http://www.togetherforshortlives.org.uk/news/7838_difficult_conversations_for_young_adults</p>
86	Together for Short Lives	Support for family members	Family members should be supported, heard, kept fully informed and encouraged to continue their caring relationship with the		<p><i>Together for Short Lives (2015). Stepping Up.</i> http://www.togetherforshortlives.org</p>

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			<p>person throughout the end of life phase.</p> <p>Plans for after death care should be revisited and families provided with written information regarding the following;</p> <ul style="list-style-type: none"> • Registering the death • Procedure for cremation • Contact numbers for funeral directors • Advice on benefits and entitlements including help with funeral expenses. 		<p>uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf</p>
91	Faculty of Intensive Care Medicine and Intensive Care Society	Improve communication skills of key staff, and subsequently family feedback	End of life care is a frequent occurrence on the ICU. It is of paramount importance to patients and relatives.		
Shared decision making					
2	Association for Palliative Medicine of Great Britain and Ireland	Appropriate support to make choice of place of care, dying and death a real choice	<p>To enable patients and those close to them to feel able to be cared for and die in an appropriate setting of their choice requires coordination between health and social care staff (across primary, secondary, tertiary and voluntary sectors) to ensure easy and ready provision of and access to medication, equipment, nursing & medical care, carers / carer support / sitters.</p> <p>This would need to be supported by ease of funding of reasonable social care packages and national prescribing guidance with supporting data on safety of medications at the end of life (to reassure non-specialists)</p>	<p>To reduce avoidable hospital / emergency admissions in patients who are recognised to be dying.</p> <p>Lack of availability of commonly used medication at the end of life should not be a reason for an emergency admission. There needs to be availability of drugs in the community, either through support for community pharmacies to keep drugs or make a rota to do so, publication of out of hours pharmacies, or funding of acute trusts to supply commonly used drugs at the end of life out of hours/weekends.</p>	<p>As above</p> <p><i>NICE guidelines NG31 - Care of dying adults in the last days of life 2015</i></p>

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5	Association for Palliative Medicine of Great Britain and Ireland	DNACPR decisions and discussions	When it is clear a patient is dying and this is an irreversible process, they should be allowed to die naturally.	<p>So that patients are not offered CPR when it is clear it will provide no benefit and discussions should be focussing on dying and appropriate care at this time.</p> <p>There needs to be clear updated national guidance on CPR, legal decision making, treatment escalation and emergency healthcare plans to support clinicians.</p> <p>DNACPR and treatment escalation plans / emergency healthcare plans should be transferrable and recognisable across all settings.</p>	<p>As above</p> <p><i>NICE guidelines NG31 - Care of dying adults in the last days of life 2015</i></p>
8	Church of England: Mission and Public Affairs Council	Holistic support – spiritual and religious	<p>NICE Quality Statement 6 in 'End of Life Care for Adults' (2011/2013) recognises the importance of spiritual and religious care for adults approaching the end of their lives.</p> <p>Picker In-patient Surveys indicate the ongoing importance of religious care</p> <p>Article 9 of the Human Rights Act (1998) ensures freedom to manifest religion or belief 'in worship, teaching, practice and observances'. Article 2 of the UN Declaration to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms places responsibility on states to 'protect, promote and implement' religious freedoms and to take 'legislative, administrative and other</p>	<p>It is important to distinguish between spiritual care which can be of a generic nature and religious care which, while incorporating spiritual care, has elements of care specific to faith traditions. For many people approaching the end of life, it is essential that their religious needs are met in order for them to be cared for in a holistic manner.</p> <p>It is not clear that the need to protect and to promote religious care is uniformly well understood or applied in all NHS Trusts through adequate provision of</p>	<p><i>End of life care for adults: NICE quality standard [QS13]: Quality Statement 6 (2011, updated 2013)</i></p> <p><i>Religious need in the NHS in England: The contribution of Picker Inpatient Surveys (2010)</i></p> <p><i>The Human Rights Act 1998 (Article 9)</i></p> <p><i>Declaration on the Right and Responsibility of Individuals,</i></p>

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			<p>steps as may be necessary to ensure that the rights and freedoms referred to in the present Declaration are effectively guaranteed'</p>	<p>chaplains services in keeping with revised NHS England Chaplaincy Guidelines (2015) and the 2016 NHS Standard Contract, Service Condition 14: 14.1 The Provider must take account of the spiritual, religious, pastoral and cultural needs of Service Users.</p> <p>14.2 The Provider must have regard to NHS Chaplaincy Guidelines.</p> <p>This is a topic of ongoing concern for NHSE and the Chaplaincy Leadership Forum.</p>	<p><i>Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms. Adopted by General Assembly resolution 53/144 of 9 December 1998 (article 2)</i></p> <p><i>NHS Chaplaincy Guidelines 2015: Promoting Excellence in Pastoral, Spiritual & Religious Care</i></p>
12	EPA UK/EU	Shared decision-making	<p>Shared decision making is the cornerstone of patient-centred care.</p> <p>People have a right to choose where they want to die. With rights come responsibilities and it is the responsibility of all working with the dying person to provide dignified and compassionate care.</p> <p>A dying person has a right to choose the care they wish to receive. They also have a right to refuse any care.</p> <p>Decision-making needs to be supported and not worked against.</p>	<p>There is a major mismatch between people's preferences for where they would like to die and their actual place of death. Research shows that around 70% of people in the UK would prefer to die at home, around 50% currently die in hospital. This is often due to not having adequate provisions at home to care for the dying person.</p> <p>It is also due to not having adequate support to make preference-sensitive decisions.</p>	<p><i>According to a Cochrane review of 86 trials published through 2009, the use of patient decision aids for a range of preference-sensitive decisions led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided.</i></p> <p><i>Stacey D, Bennett CL, Barry MJ, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2011;10:CD001431-CD001431</i></p>

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29	Marie Curie	Key area for quality improvement 3: Social services	Social services need to be linked to the palliative care package in order to remove barriers which prevent dying people from being discharged into the community.	<p>In line with quality statement 8 in the NICE Quality Standard on end of life care for adults, dying people and the people important to them should expect to receive coordinated care, and to be able to be cared for in the place of their choice if appropriate.</p> <p>The May 2016 NAO report on delayed discharges from hospitals for older people shows that the number of delayed transfers of care has been 'increasing at an alarming rate'. https://www.nao.org.uk/report/discussing-older-patients-from-hospital/#</p> <p>Evidence from Marie Curie's discharge liaison services shows that people at the very end of life are being delayed in hospital or dying in hospital after they had been approved for discharge because a community care package could not be put in place.</p>	
37	NHS England	Holistic individualised plan of care	The care needs of a dying person encompasses not only symptom management (see above) but also their physical needs (including assessment of	Although this is an area that is improving, there is still evidence of variation in practice, particularly taking into account the holistic	<p><i>Evidence sources:</i></p> <ul style="list-style-type: none"> • <i>The End of Life Care Audit – Dying in Hospital (2016), commissioned by NHS England</i>

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			need and desire for food and drink), and emotional and spiritual wellbeing.	needs and the development and delivery on an individualised plan of care that is reviewed and revised regularly.	<p><i>and conducted by the Royal College of Physicians</i></p> <ul style="list-style-type: none"> • <i>Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015</i> <p><i>Information source:</i></p> <p><i>Ambitions for Palliative and End of Life Care: a national framework for local action (2015).</i></p>
40	Older People's Advocacy Alliance	Clarity about IMCA instruction.	IMCAs [Independent Mental Capacity Advocates] do really vital work around end of life decisions. The NICE guideline refers to the MCA, however explicit reference to the role of the IMCA in supporting quality end of life care is omitted.	We recommend that the quality standard refers to the role of statutory advocacy in supporting quality end of life care. This should be explicit about the role of the IMCA in obtaining information about the person's wishes, feelings, beliefs and values.	<i>Our recommendation supports the recommendation we outline above (key area #1) about raising awareness of the value of advocacy in supporting quality end of life care, planning and informed decision making.</i>
41	[Royal College of Nursing]	Clarification of the role of the Lasting Power of Attorney	For dying patients who are unable to communicate and who have appointed a lasting power of attorney for health, a quality standard should clarify that this appointed person is acting for the patient, and is the patient's voice.	Although the current NICE guidelines consistently state that health professionals should consult family or friends of the dying patient, in practice, it is the health professional who decides, not the patient's appointed representative who is best placed to know the patient's wishes. This	<i>NICE guidelines – Care of dying adults in the last days of life, points 1.25, 1.32, 1.33, 1.36, 1.52</i>

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				is evidenced by consistently poor satisfaction surveys of care of the dying.	
43	Resuscitation Council (UK)	Specific, timely, properly documented consideration and conversations with each individual (and/or their family or other representatives) about making a clear recommendation on whether or not CPR would be wanted or effective.	Failure to do this exposes a dying person to the risk that health professionals may attempt CPR when the heart and breathing stop, subjecting them to avoidable indignity at the end of life and exposing them to some risk that the heart and breathing may be restarted briefly and inflict prolonged or increased suffering without preventing an inevitable death.	<p>The systematic review of DNACPR decisions by the Warwick University team showed inconsistent policy and practice across the UK, failures to follow national guidance, poor communication, poor decision-making and poor documentation. Some examples have led to litigation and attention from the media and the public. There is also evidence that a DNACPR decision can lead to inappropriate failures to deliver other elements of good-quality care, and that CPR decisions should be discussed in the context of a person's overall goals of care.</p> <p>The national guidance from the BMA/RC (UK)/RCN recommends (as does GMC and other guidance) shared decision-making whenever possible, that those undertaking such discussions have the communication training/skills to do this well and that decisions and discussions are documented well.</p>	<p><i>Please see:</i></p> <ol style="list-style-type: none"> <i>Perkins GD, Griffiths F, Slowther A-M, et al. Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. DOI: http://dx.doi.org/10.3310/hsdr04110</i> <i>Fritz Z, Malyon A, Frankau JM, et al. (2013) The Universal Form of Treatment Options (UFTO) as an Alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders: A Mixed Methods Evaluation of the Effects on Clinical Practice and Patient Care. PLoS ONE 8(9): e70977. doi:10.1371/journal.pone.0070977</i> <i>The British Medical Association, Resuscitation Council (UK) and Royal College of Nursing. Decisions relating to cardiopulmonary resuscitation. https://www.resus.org.uk/publication/s/</i>
44	Resuscitation Council (UK)	Specific, timely, properly documented	To spare people risk and resulting pain and distress of repeated ICD shocks in the last	In developing national guidance ⁴ in relation to this topic the RC	<i>Please see:</i> 4. <i>Pitcher D, Soar J, Hogg K et al:</i>

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		<p>consideration and discussion with each person with an ICD (or CRT-D device) of whether or not - and if so exactly when - they wish to have the shock function of their device deactivated. There should be clear distinction between this decision and its timing, and any decision regarding CPR.</p>	<p>hours or days of their life.</p>	<p>(UK)/ BCS/NCPC Working Group encountered wide variation in practice and attitudes across the UK.</p> <p>There is international recognition in many publications of the importance of maintaining review of the risks and benefits of any active treatment as a person's needs and wishes change towards the end of their life.</p> <p>Many publications (e.g. 4–8) address specifically treatment from implanted devices, and some have included increasing recognition that discussion of the possible need for later withdrawal of treatment (by deactivation of the shock function of an ICD) should form part of the process of informed consent to implantation.</p> <p>The RCP Audit of end-of-life care in hospitals⁹ found that only 80% of NHS trusts reported having a policy on ICD deactivation towards the end of life.</p> <p>Despite this there is evidence from complaints, media reports (e.g. 10) and discussions with numerous healthcare providers</p>	<p><i>the CIED Working Group. Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care. Heart 2016;102:A1–A17.</i></p> <p>5. <i>Kinch Westerdahl A, Sjöblom J, Mattiasson AC, et al. Implantable cardioverter-defibrillator therapy before death: high risk for painful shocks at end of life. Circulation 2014; 129:422-429</i></p> <p>6. <i>Germanas Marinskis 1* and Lieselot van Erven² on behalf of the EHRA Scientific Initiatives Committee. Deactivation of implanted cardioverter-defibrillators at the end of life: results of the EHRA survey. Europace (2010) 12, 1176–1177 doi:10.1093/europace/euq272</i></p> <p>7. <i>Goldstein N, Bradley E, Zeidman j, Mehta D, Morrison R S. Barriers to Conversations about Deactivation of Implantable Defibrillators in Seriously Ill Patients. Results of a Nationwide Survey Comparing Cardiology Specialists to Primary Care Physicians.</i></p>

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				<p>that policy and processes vary hugely among healthcare economies/communities and that practice varies enormously according to the attitudes, skills and training of individual clinicians, rather than according to internationally recognised best practice.</p>	<p><i>J Am Coll Cardiol</i> 2009; 54: 371–373.</p> <p>8. Clark AM, Jaarsma T, Strachan P et al. <i>Effective communication and ethical consent in decisions related to ICDs.</i> <i>Nature Reviews Cardiology</i> 2011; 8: 1–12.</p> <p>9. Royal College of Physicians. <i>End of Life Care Audit – Dying in Hospital.</i> London: RCP, 2016.</p> <p>10. Carter C <i>Dying grandfather 'shocked back to life' 30 times.</i> www.telegraph.co.uk/health/healthnews/10991824/Dying-grandfather-shocked-back-to-life-30-times.html</p>
51	Royal College of Psychiatrists	<p>People with dementia admitted to hospital for acute illness when they have severe condition and should be managed at home or in care home. Better understanding of what is good for people as venue to die and the need for relative pulling back on interventions. Understanding that an acute hospital may be a</p>			

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		bad place to die particularly if you have dementia.			
56	SCM 1	Clear documentation around updating decisions around ceiling of treatment including resuscitation including use and reference to mental capacity/best interests framework	To ensure continuity of care across teams particularly if patients moving between care settings in last days of life and compliance with legal frameworks of mental capacity.	Variation observed across settings in which people are moved consistent with their wishes but treatment escalation communication does not reflect updated discussions/decisions,	
59	SCM 2	<p>SHARED DECISION-MAKING (1.3.3)</p> <p>Once more, this is linked with what has been highlighted previously, The levels of involvement desired by patients need to be clear to enable honest discussions to take place.</p>	<p>Such discussion may rest on whether the dying person has made any advance statements around care or is known to have given power of attorney.</p> <p>Care plans need to be in place but are likely to be limited without any such consideration.</p> <p>Unless there is transparency trust is eroded (and can be very hard to regain).</p> <p>The Voices survey found that 1 out of 10 bereaved people rated the quality of end of life care as poor; this means a significant number of dying people are affected annually, with residual effects for those who survive the death of a loved one.</p>	<p>Having a named lead healthcare professional is essential to ensure that all relevant parties understand the dying person's wishes concerning their care.</p> <p>Again, their contact details need to be noted so that any changes in the situation can be easily dealt with.</p> <p>More emphasis generally (with due explanation) on patients' preparing advance statements could help to avoid end-of-life crises and care uncertainties.</p> <p>These activities can depend on joined-up health care between the different NHS care systems, particularly between primary care providers and others.</p> <p>Ideally the relationship would have</p>	<p><i>Where staff would like help about how to proceed in these matters it could be useful to look at or direct those in their care as early as possible to the "Find Me Help" sections of http://www.help.dyingmatters.org as this is "the UK's most comprehensive directory of services for people in their last years of life, their families, carers and friends"</i></p> <p><i>The NHS New Care Models being developed in the Vanguard sites (as reported in June 2106) cover nine areas of support that include:</i></p> <ul style="list-style-type: none"> <i>* designing new care models</i> <i>* integrating commission and provision</i> <i>* empowering patients and communities</i> <p><i>To be effective there needs to be</i></p>

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				<p>begun much earlier than the last days of life via support provided by health care teams to the dying person and those important to them</p> <p>The NCPC maintains (from 2015 survey findings) that “very little is changing. What’s good remains good and what’s poor remains poor”....and that “the health and care system needs to listen to what bereaved people are saying consistently and clearly about quality and experience of end of life care”.</p>	<p><i>better integration of care and Health & Wellbeing Boards also have a role to play in their strategic plans.</i></p> <p>http://nationalsurveyofbereavedpeoplevoices/england/2015</p> <p><i>Integration, Quality and Choice were the key points of the Westminster Health Forum report on palliative care:</i></p> <p>http://www.westminsterforumprojects.co.uk/forums/showpublications.php?pid=1084</p>
67	SCM 4	Patient’s preferred place of death	<p>It is important to tailor palliative care to each individual person. This includes their preferred place of death.</p> <p>Providing individualised care, including their preferred care setting is recommended in the NICE guidelines.</p> <p>The Choice in End of Life Care Programme Board, 2015 also emphasises that a person is able to die in their place of choice.</p>	<p>It has been reported that a lower percentage of people die at home compared to the percentage of people who state home as their preferred place of death.</p> <p>It has been suggested, although there is limited evidence, that dying at home is less expensive than dying in a hospice or hospital.</p> <p>The National Survey of Bereaved People (VOICES) looked at the</p>	<p><i>Please see attached report – a guide for dying well at home</i></p> <p>http://www.scie.org.uk/publications/guides/guide48/costsofdyingathome.asp</p> <p><i>Please see attached NICE Guidelines – Care of dying adults in last days of life, 2015.</i></p> <p>https://www.nice.org.uk/guidance/N/G31/chapter/Recommendations</p> <p><i>Please see attached The Choice in</i></p>

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				<p>quality of care delivered in the last 3 months of life for adults who died in England. This survey showed that 93.3% of people who died at home and 93.6% of people who died at a hospice dies in the right place. This is compared to 73.5% of people who died in a hospital setting died in the right place, 16.5% did not die in the right place and 10% unsure.</p>	<p><i>End of Life Care programme Board, 2015</i> https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf</p> <p><i>Please see attached The National Survey of bereaved people (VOICES)</i> http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015#main-points</p>
69	SCM 4	Spiritual Care	<p>It has been recommended in the NICE Clinical Summary (July 2015) that patients and carers should have access to staff who supported their spiritual needs.</p> <p>This was based on guidance from NICE on improving supportive and palliative care for adults with cancer.</p>	<p>The National Survey of Bereaved People (VOICES) looked at the quality of care delivered in the last 3 months of life for adults who died in England. This reported significantly fewer people agreed that support and consideration for spiritual and/or religious needs was provided in comparison with other needs.</p>	<p><i>Please see attached guidance:- NICE (2004) Improving supportive and palliative care for adults with cancer (NICE guideline). Guidance on Cancer Services National Institute for Health and Care Excellence</i></p> <p>http://cks.nice.org.uk/palliative-care-general-issues</p> <p><i>Please see attached The National Survey of bereaved people (VOICES)</i> http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/</p>

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					england2015#main-points
72	SCM 5	Individualised plan of care	<p>The Neuberger review of the Liverpool Care Pathway found that great distress had been caused to families because of the perception that the LCP was used as a 'one-size-fits-all' and a blanket approach. It recommended that care plans should in future be personalised or individualised.</p> <p>These remarks were echoed by the One Chance to Get it Right document.</p> <p>The NICE guideline NG31 made several recommendations about individualised care planning, taking into account the dying person's wishes and preferences.</p>	<p>This is an important area because of the great distress felt by people who had been adversely affected by the LCP and its misuse as a blanket approach.</p> <p>The RCP end of life care audit (2016) showed that there had been a holistic assessment of the dying person's needs in 66% in the last 24 hours of life.</p> <p>There was also significant variation between hospital trusts in the proportion of patients who had an individual holistic needs assessment.</p>	<p>See RCP audit of end of life care (March 2015).</p> <p>Also see 'More Care, Less Pathway (Neuberger review, 2013)</p> <p>Also see 'One Chance to Get it Right' (2014)</p>
81	The British Humanist Association/Non-Religious Pastoral Support Network	<p>The provision, availability and access to like-minded non-religious spiritual care</p> <p>'Multidisciplinary teams should have access to suitably qualified, authorized, and appointed spiritual care givers and should also be aware of local community resources for spiritual care.</p>	<p>There is significant evidence that there is a need for appropriate like-minded spiritual care available to individuals in end of life care.</p> <p>The Palliative Care - General Issues document draws reference to the need to 'assess and individuals religious or spiritual needs'.</p> <p>When non-religious pastoral carers are available in institutions that provide palliative care, the spiritual care team is seen to better meet the needs of the patient</p>	<p>In line with the Equality Act 2010 there is a need to provide an equal spiritual care service to all individuals receiving palliative care and this includes those who have no religion.</p> <p>Most spiritual care teams, whilst offering support to all individuals, often only contain religious providers. The reason for this is that traditionally spiritual care/chaplaincy teams have traditionally been comprised of those who have be authorised by religious bodies</p>	<p>Research at Guys' and St Thomas hospital indicated that only 4% of chaplaincy team visits were to the non-religious. This suggests that this are not receiving an equal level of support as their religious counterparts.</p> <p>As the BHA are the only provider of authorised non-religious carers, we are aware of the limited number of individuals who are in place within palliative care teams.</p>

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			by increasing their level of choice.	Only for the last year and a half the BHA has been authorising individuals through its pastoral care induction programme, to provide spiritual care to the non-religious. As such, the availability of these carers is much lower than that of religious providers.	
84	Together for Short Lives	Choice of where to die	<p>End of life care should take place where possible wherever the person and/or their family choose. This may be home, hospital, hospice or other residential setting.</p> <p>The person should have access to 24-hour expert symptom management and palliative care.</p>	Despite the majority preference to die at home, we know that a large proportion (59%) of deaths from cardiovascular disease between 2004 and 2011 occurred in hospital.	<p><i>Together for Short Lives (2015). Stepping Up.</i> http://www.togetherforshortlives.org.uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf</p> <p><i>The Choice in End of Life Care Programme Board (2015). What's Important to Me: A Review of Choice in End of Life Care.</i> https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf</p>
85	Together for Short Lives	Emotional, cultural and spiritual needs	Professionals should be sensitive to the cultural and spiritual values and beliefs of families and should not obstruct the family's own preferences. It is always good practice to ask families directly about their beliefs, as these may be different from what is expected.	British Muslims are the second largest faith group in the UK. Data shows that the ethnic groups to Muslims belong suffer from life-limiting conditions more than other minority groups. South Asian groups, for example, have a 48% chance of having a life-limiting condition, whilst the national	<p><i>Together for Short Lives (2015). Stepping Up.</i> http://www.togetherforshortlives.org.uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf</p> <p><i>Hospice UK, Together for Short Lives, Woolf Institute (2015).</i></p>

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				average is 32%.	<i>Bridging the Gap: Strengthening relations between hospices and Muslims of Britain.</i> http://www.woolf.cam.ac.uk/uploads/Bridging%20the%20Gap.pdf
92	Faculty of Intensive Care Medicine and Intensive Care Society	Documentation of end of life treatment plans should be explicit			
93	Faculty of Intensive Care Medicine and Intensive Care Society	Treatments, patient and family experience should be broadly similar in the end of life care for patients being withdrawn from life sustaining therapies (organ support) regardless of location			
94	Faculty of Intensive Care Medicine and Intensive Care Society	DNACPR documentation should be completed using nationally agreed standards			
Managing hydration					
4	Association for Palliative Medicine of Great Britain and Ireland	Routine assessment of swallowing/hydration needs and provision	Wherever possible, patients should be supported to eat and drink as they wish in the last few days of life. However, this is sometimes not possible or is a complex decision.	When a decision about eating and drinking at the end of life is not straightforward or a decision to recommend the patient is Nil by Mouth or clinically assisted hydration / nutrition are being considered a senior clinician must be involved, supported by	As above <i>NICE guidelines NG31 - Care of dying adults in the last days of life 2015</i>

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				the multidisciplinary team as these decisions are complex and may be emotive.	
13	EPA UK/EU	Maintaining hydration	<p>The person who is dying and those who are important to them need to be aware that medically-assisted nutrition and hydration should be considered medical interventions rather than basic provisions of comfort. They also need to understand in full the affects of hydrating those who are dying and the complications that this can bring. Lay people are often unaware of the complications.</p> <p>It is essential that all those involved in the care of the dying person know that stopping fluids is NOT stopping care.</p>	Withholding food and hydration is a very emotive area for people so greater education is required for both health care professionals as well as lay people. There are many myths around it that need to be debased.	<p><i>Stopping artificial nutrition and hydration at the end of life</i> http://www.uptodate.com/contents/topping-artificial-nutrition-and-hydration-at-the-end-of-life</p>
73	SCM 5	Maintaining hydration	<p>The Neuberger review found that many families felt that the dying relatives had suffered from dehydration. On the other hand, there is evidence that over-hydration, especially with intravenous fluids, can be harmful to some.</p> <p>The NICE guideline NG31 made several recommendations regarding the assessment of hydration needs; encouraging and supporting dying people to drink naturally; and offering clinically assisted hydration (CAH) in all settings, where medically indicated and wished by the person.</p>	<p>The Neuberger review found many examples of perceived enforced dehydration by the inexpert use of the LCP.</p> <p>The RCP end of life care audit (2016) found that 37% of dying people had their ability to drink assessed; 39% were documented as drinking on the day they died; and 45% had support to drink.</p> <p>Nil by Mouth decisions were not usually shared with the dying person (23%) although 64% of people important to them had</p>	<p><i>See RCP audit of end of life care (March 2015).</i></p> <p><i>Also see 'More Care, Less Pathway (Neuberger review, 2013)</i></p>

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				<p>been informed.</p> <p>CAH was in place for 43% of patients who were dying.</p> <p>There was inter-hospital variation in the assessment for hydration and the provision of CAH.</p> <p>It is probable that people dying in the community and possibly in hospices will have reduced likelihood of being offered CAN.</p>	
Management of symptoms					
6	British Pain Society	Assessment of Pain	Pain cannot be adequately treated or addressed unless it is recognised. It is generally understood that pain in terminal illness is not adequately recognised and addressed	Pain Management is a basic human right	
34	NHS England	Symptom assessment and management	<p>To have symptoms well controlled is the top priority when dying people are asked about what matters most when they are dying (ref. Waghorn).</p> <p>In the 2015 ComRes poll, 'being pain free', 'being with family and friends' and 'retaining your dignity' were the top priority for most people.</p>	This remains a key quality improvement area – there is significant variation in outcomes for patients. The reasons are multifactorial – including having professionals who are able to recognise that the patient is uncomfortable, skilled in assessment, capable of addressing these through pharmacological and non-pharmacological means, able to recognise limitations of their skills and to request specialist level	<p>Ref: Waghorn M, Young H, Davies A, et al. <i>BMJ Supportive & Palliative Care</i> (2011). doi:10.1136/bmjspcare-2011-000041</p> <p>Ref: http://www.comres.co.uk/wp-content/uploads/2015/05/National-Council-for-Palliative-Care_Public-opinion-on-death-and-dying.pdf - see tables 11 and 12.</p>

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				help, access to specialist level palliative care advice and support when needed, access to medication and equipment in a timely away, etc. – but if a quality statement were to be developed focusing on the outcome for the person, the others would follow.	
42	[Royal College of Nursing]	Use of behavioural pain assessment tool for patients who are unable to communicate	For dying patients who are unable to communicate, a behavioural pain assessment tool should always be used to recognise subtle signs of pain or distress	Currently in many centres, pain assessment tools are used which rely on the patient being able to communicate with staff. If they are unable to do so, the score is left blank, which adversely affects the assessment score.	<p><i>An example of a well validated pain assessment tool is the PAINAD Scale:</i></p> <p><i>Warden V, Hurley AC, Volicer, L. (2003) Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. J Am Med Dir Assoc, 4 (1), 9-15</i></p>
55	SCM 1	Access to and training in use of medication that can be administered by family/carer if patient unable to tolerate oral route including sub-lingual, buccal, intranasal routes	To ensure timely access to medications to manage symptom distress	Rapid access to district nursing support can be compromised by absence of 24 hour service and or demands on service	
62	SCM 3	Prompt administration of medication	Too many delays in prescribing, procuring and administering appropriate medication. Introductions of Just in Case Bags/Boxes with appropriate training.		<i>RCP audit patients dying in hospital</i>
74	SCM 5	Individualised prescribing for current symptoms and anticipatory prescribing.	The Neuberger review found that many families perceived the dying person had important drugs withheld and also that they had undue sedation from painkillers and	The RCP end of life care audit found that medications for current symptoms and as required medications were prescribed to	<p><i>See RCP audit of end of life care (March 2015).</i></p> <p><i>Also see 'More Care, Less Pathway</i></p>

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			<p>other drugs.</p> <p>The NICE guideline NG31 made several recommendations about the need for individualised as opposed to blanket prescriptions. It was unable to make many specific recommendations for drugs or doses, because of lack of evidence.</p> <p>NG31 also recommends that anticipatory prescribing is individualised, based on an assessment of the likely symptoms of the patients.</p> <p>It also recommends regular review of prescribed and anticipatory medications.</p> <p>NG31 recommends that the team should seek expert help, including from specialist palliative specialist palliative care, if symptoms do not respond or if there are unacceptable side-effects.</p>	<p>different extents for different symptoms, suggesting a degree of individualisation.</p> <p>However, only 65% of medications had been reviewed in the last 24 hours of life.</p> <p>The RCP audit found that only 37% of hospital trusts had face to face specialist palliative care review Mon-Sun, 9-5; and only 11% had fully 24/7 face to face reviews.</p> <p>26 out of 142 hospital trusts had no level of specialist palliative care visiting at all.</p> <p>It is likely that the provision of out of hours specialist palliative care will be less in the community and care homes.</p>	<p><i>(Neuberger review, 2013)</i></p> <p><i>Also see 'One Chance to Get it Right' (2014)</i></p>
Anticipatory prescribing					
14	EPA UK/EU	Anticipatory prescribing	It is important to be prepared for as many eventualities as possible when it comes to the care of the dying. Often emergency situations will occur after hours where there	Not everyone needs medication at the end of life and for these people anticipatory prescribing is not required. However when the	<i>Scottish Palliative Care Guidelines</i>

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			is no access to immediate medical care or pharmacy. Anticipatory prescribing helps to reduce stress for all concerned.	dying person does require medications they often need it fast and this is important if we are to provide dignified care for the dying.	http://www.palliativecareguidelines.scot.nhs.uk/guidelines/pain/Anticipatory-Prescribing.aspx
60	SCM 3	Anticipatory prescribing for symptom management	Better management and confidence of managing symptoms for patients and reassurance for relatives/carers		<i>RCP audit patients dying in hospital</i>
Specialist palliative care					
3	Association for Palliative Medicine of Great Britain and Ireland	Availability, accessibility and coordination of specialist palliative care services	To support patients in the last few days of life there needs to be seven day access to specialist palliative care advice, including visits for those with physical and psychological distress. This needs to be available in all settings. So that care can be coordinated there needs to be IT support to join up communication about EOL phase. There need to be interfaces between EPaCCS systems and acute Trusts.	To ensure patients are cared for and die in the setting of their choice with appropriate support and symptom control (both physical and psychological symptoms).	<i>As above</i> <i>NICE guidelines NG31 - Care of dying adults in the last days of life 2015</i>
16	Hospice UK	Consistent and expert out of hours palliative support (overnight and weekends) available to patients dying in all settings.	24/7 advice to cover whole localities, available to GPs, paramedics, care homes and hospitals will ensure a better experience for all dying patients, and help to address the poor quality of pain control in the community. Hospices can help with this.	Royal College of Physicians/Marie Curie (2016) found that very few hospitals have access to OOH palliative support 24/7. The national survey of bereaved relatives confirms poor pain control in the last days of life at home.	<i>Royal College of Physicians/Marie Curie (2016) End of life care audit: Dying in Hospital</i> <i>Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015</i>

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				<p>Many 24/7 advice lines exist – often hosted by hospices. These are often not commissioned and are not known to all OOH services.</p>	
21	<p>Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN</p>	<p>7 day a week access to palliative care services</p>	<p>Good evidence that access to services 7 days a week is important to prevent hospital admission and improve the quality of care.</p>	<p>But what does a 7 day a week access look like in different scenarios</p> <p>What services are essential for 7 day a week working</p> <p>What models of provision work and are sustainable</p> <p>Funding needs clarifying as this is a mixed economy</p>	<p><i>National audit for hospitals 2016</i></p>
28	<p>Marie Curie</p>	<p>Key area for quality improvement 2: Service availability</p>	<p>Specialist palliative care services need to be available at short notice and must be capable of responding to complex needs, not only within specialist facilities, but also on general hospital wards and in the community.</p>	<p>NICE Quality Standard on end of life care for adults, Quality Statement 11 sets out that ‘Palliative care services should ensure provision to visit and assess people approaching the end of life face-to-face in any setting between 09.00 and 17.00, 7 days a week (provision for bedside consultations outside these hours is high-quality care), and provide specialist palliative care advice at any time of day or night, which may include telephone advice.’ We would expect this standard to be met as a minimum for people in the last days of life, who are likely to have complex needs.</p>	<p><i>RCP audit:</i> https://www.rcplondon.ac.uk/news/new-rcp-end-life-care-audit-shows-steady-progress-care-dying-people</p>

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				<p>However, the RCP end of life care audit found only 37% of Trusts meet this standard, and only 11% were able to offer specialist services 24/7.</p>	
33	NHS England	Access to specialist palliative care when needed	<p>Not all dying patients will need access to specialist palliative care, and some will be cared for by health professionals who need access to telephone advice from specialist palliative care without the need for face to face assessment. But a significant proportion of people require face to face assessment, and often ongoing advice and/or direct care, by specialist level palliative care teams.</p>	<p>This is a significant area of variation with great potential for quality improvement. There is good evidence that access to specialist level palliative care services remains patchy across the country. In some areas, specialist palliative care services are confined to weekday office hours; in many areas, telephone advice is available 24/7 but non-specialist health professionals appear not to be sufficiently aware of this availability, nor use this. So the issue is both the level of service provision (requiring resources and service design to be optimal) and awareness raising.</p>	<p><i>Evidence sources:</i></p> <ul style="list-style-type: none"> • <i>The End of Life Care Audit – Dying in Hospital (2016), commissioned by NHS England and conducted by the Royal College of Physicians</i> • <i>Office for National Statistics (2015) National Survey of Bereaved People (VOICES): England, 2015</i> <p><i>Information source:</i></p> <p><i>NHS England published information for commissioners about specialist level palliative care in 2016:</i> https://www.england.nhs.uk/wp-content/uploads/2016/04/specilst-palliatv-care-comms-guid.pdf</p> <p><i>This includes a recommendation to:</i> <i>“Provide medical and nursing cover to allow assessment, advice and active management seven days a week, and 24 hour telephone advice. This may require a collaborative arrangement between</i></p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>a number of service providers and joint commissioning, working towards provision of 24 hour access to specialist level palliative care advice from a consultant in palliative medicine, including face to face assessment where this is necessary.”</p>
52	SCM 1	<p>Access to face to face specialist palliative care assessment 7 days per week in all settings, if usual care team unable to manage symptoms adequately. In community dedicated palliative care rapid response service including equipment, nursing and care provision</p>	<p>Experientially there is good evidence that timely access to specialist palliative care has driven significant improvements in patient experience/comfort and bereavement in last days of life.</p>	<p>Quality statement 10 EOLC for adults NICE</p> <p>End of Life Care Audit- Dying in hospital (2016)</p> <p>From experience variations dependent on settings: care home, community and hospital dependent on commissioning arrangement.</p> <p>To optimise reach to patients in last days of life including sudden decline, requires community based rapid response to optimise quality of care and choice.</p>	<p>https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-10-specialist-palliative-care</p> <p>https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016</p>
80	The Brain Tumour Charity	<p>We would reiterate the guidance in NICE Guideline NG31 that the individual and family should be referred to 24/7 services</p>	<p>In a public poll commissioned by Sue Ryder 82% of respondents expected that support and advice should be available 24 hours a day for those who are dying (3). Access to face-to-face or remote support and advice in the last days of life can improve people’s experience of end of life care (4). Where appropriate this support may better enable a person to die in the place of their</p>	<p>Provision of 24/7 services is varied across the country. Just 8% CCGs commission 24/7 advice palliative care (3). An audit of end of life care found that 11% of trusts offered a face-to face 24/7 service (2). Out-of-hours telephone service is more comprehensive (2). With such</p>	<p>3. <i>Dying doesn't work 9 to 5 [Internet]. Sue Ryder. [cited 2016 Jun 16]. Available from: http://www.sueryder.org/how-we-help/policy-and-campaigns/our-campaigns/not-9-to-5/facts</i></p> <p>4. <i>NCPIC. Dying out-of-hours 24/7 care at the end of life</i></p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>choosing.</p> <p>NICE Guideline NG31 states that the provision of information about relevant out-of-hours services is an essential part of shared decision making. The Choice in End of Life Care Programme Board recommended that, “every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people’s choices and preferences” (5).</p>	<p>variation in provision is difficult to see how the guidance in NG31 could be followed across the board.</p>	<p><i>conference report [Internet]. 2011. Available from: http://www.ncpc.org.uk/sites/default/files/DyingOutOfHours_Conference_Report.pdf</i></p> <p>5. <i>What’s important to me. A Review of Choice in End of Life Care [Internet]. The Choice in of Life Care Programme Board; 2015. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf</i></p>
Developmental areas					
15	EPA UK/EU	Additional developmental areas of emergent practice	<p>Complementary therapies (CAM) are used by a large number of patients in palliative care clients.</p> <p>It is a dying person’s right to choose the therapies that they want. We cannot return to a dis-enabling approach to health care, where the consumer’s right to choose is not supported by treating medical teams.</p> <p>Complementary health practitioners are those that work in responsible relationship with conventional medicine, with a commitment to being involved in research, unified in the integrity of our intention to serve for public benefit.</p>	<p>CAM needs to have the same funding as the pharmaceutical industries to provide evidence of its effectiveness. We cannot afford to stop listening to any innovations that are anecdotally shown to work for people, especially with end of life care.</p>	

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26	Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN	<p>Additional developmental areas of emergent practice</p> <p>Early intervention by palliative care such as the Vanguard at the Chrisite where Palliative Care services are working at a much earlier phase of illness to improve symptoms and support for cancer patients</p>			
75	SCM 5	<p>Additional developmental areas of emergent practice:</p> <ul style="list-style-type: none"> • Out of hours specialist palliative care provision • Improved recognition of spiritual, cultural and practical needs of dying people • Improved care of the dying person immediately after death 			
Other					
7	British Pain Society	Access to Multidisciplinary Pain Management Services	The full range of treatments for pain cannot be delivered to appropriate patients without formal links with services – these should include psychological and interventional		

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			approaches for the relief of pain and suffering.		
9	Church of England: Mission and Public Affairs Council	Care after death – bereavement support	The points made above also apply to bereavement care for relatives.		
22	Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN	Clarity around the impact of Transform programme in hospitals and AMBER care bundle	Early recognition of the possibility that a person may be approaching the palliative phase of their illness enables them to have advanced care planning discussions and ceilings of treatment discussions	Lack of training in basic medical training or core medical training after qualification means that care still looks at treatment and control (rarely cure) more than palliation limiting early referral to palliative care services	
23	Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast SCN	National agreement around unified ceilings of treatment including DNACPR or allow natural death	On-going issues with ambulance services in particular around sudden unexpected deterioration of people known to have a life limiting illness	Shared understanding of phase of illness would mean clarity around appropriate care offered to patients	<i>Still a lack of understanding around Tracey judgement</i> <i>Lack of skill to have difficult conversations around a theoretical scenario</i>
25	Lancashire and South Cumbria Palliative and End of life Advisory Group for the North West Coast	Methods by which health and social care can be jointly commissioned and funded at end of life to smooth the final days / months of life out of hospital			

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	SCN				
30	Marie Curie	Key area for quality improvement 4: Views of bereaved people	The opinions of bereaved family and caregivers should be routinely collected to inform future regulation and delivery of services.	The most recent RCP audit found 20% of Trusts had not sought bereaved relatives' and friends' views about their services over the period of a year. This information plays a crucial role in driving service improvements. https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016	<i>RCP Audit collects data on different methods (p76).</i> https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016
31	Marie Curie	Key area for quality improvement 5: Logistics	All sites which provide care for dying people should enable and provide access to physicians, nurses and appropriate medicines.	Poorly controlled symptoms stemming from unavailability of trained staff or medications causes significant distress (PHSO report contains case study examples: http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity)	
63	SCM 3	Multidisciplinary team management	Needs joined up thinking using best available resources and healthcare professionals including specialist palliative care pharmacists, occupational therapists, social workers.		<i>Peer review palliative and end of life care National Cancer Peer Review</i>
64	SCM 3	Education and training for non-palliative care specialists	Everyone wants to do their best to ensure a comfortable and peaceful death but it is apparent that the knowledge and skills to ensure this are not always known or in place. More funding and recruitment for		<i>RCP audit patients dying in hospital</i>

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			palliative care multidisciplinary teams in hospital and community.		
65	SCM 4	Inequalities in end of life care - Experience of patients can be variable	<p>Good end of life care has been described in national standards and guidance, including from the National Institute for Health and Care Excellence (NICE).</p> <p>The National End of Life Care Programme aims to promote high quality, person-centred care for all adults at the end of life in all care settings.</p>	<p>A CQC overview report addressing inequalities in end of life care highlighted that there is a variation in experience of end of life care. In particular for patients with a non-cancer diagnosis or dementia, for patients from black and minority ethnic groups, for LGBT patients, for patients with a learning disability or mental health condition, and for homeless patients or patients in a secure or detained setting.</p> <p>Patients from these groups have unique needs and it was reported a lack of understanding about these needs is a barrier to people receiving good personalised care.</p> <p>A review of evidence into equity in the provision of palliative care in the UK also highlights how quality of care for people from different groups can vary; for example people from BME backgrounds were less likely to rate overall care as outstanding or excellent.</p>	<p><i>Please see attached CQC report addressing inequalities in the end of life care</i> http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf</p> <p><i>Please see attached review of evidence into equity in the provision of palliative care in the UK</i> http://www.pssru.ac.uk/archive/pdf/4962.pdf</p> <p><i>Please see attached NICE Guidelines – Care of dying adults in last days of life, 2015.</i> https://www.nice.org.uk/guidance/NG31/chapter/Recommendations</p>
66	SCM 4	Co-ordinated care	Palliative care patients often have complex needs and are looked after by multiple service providers.	Communication between the service providers needs to be improved to ensure good palliative care especially for patients in the community. Electronic Palliative	<i>Please see attached article about Co-Ordinate my Care</i> Smith, C (2012). <i>BMJ Supportive and Palliative Care Article : Feature</i>

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			<p>Integrated care across these service providers is vital to providing individualised care for each patient and ensuring their wishes are met e.g. preferred place of death</p>	<p>Care Coordination Systems (EPaCCS) can help this.</p> <p>The Department of Health End of Life Care Strategy (2008) recommended the development of electronic systems as a way of improving co-ordinated care for people at the end of their life, and for their families and carers.</p> <p>Currently in London an EPaCCS called “Co-ordinate My Care” is being used. This is a computerised care record that health professionals can access to review aspects of a patient’s care plan such as resuscitation decisions and preferences of care. This record can be accessed by specialist palliative care teams, GPs, London Ambulance and hospices.</p> <p>Available data suggests that the use of EPaCCS helps people to die in their preferred place of death, decreases the percentage of hospital deaths and increases in the percentage of deaths at home and in hospices. However the use of EPaCCS is still new and only one third of Clinical Commissioning Groups have an</p>	<p><i>Title: Coordinate My Care: A clinical service that coordinates care, giving patients choice and improving quality of life.</i></p> <p><i>Please see attached :- Department of Health. End of Life Care Strategy: promoting high quality care for adults at the end of their life. July 2008</i></p> <p><i>Please see attached the following report about the use of EPaCCS</i> http://www.nhs.uk/resources/publications/electronic-palliative-care-co-ordination-systems-(epaccs)-in-england.aspx</p>

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				operational system.	
68	SCM 4	Care after death – timely verification and certification	Timely verification of death and certification of death is an essential aspect of care after death. If there is a delay or problem with this it can add to family distress.	<p>Locally there has been incidents where verification +/- certification has been delayed or there has been confusion about whose role it is to do. This can add extra distress to an already grieving family.</p> <p>Ensuring family members and health professionals are aware whose role this is, and factoring in out of hours in this, can reduce any delay and improve care after death.</p> <p>The Medical Defence Union (MDU) analysed files regarding death certification over a five year period and reported that 16% of complaints were due to alleged delays in issuing certificates.</p>	<p><i>Please see attached guidance stating care after death includes timely verification</i></p> <p><i>Care after death: Guidance for staff responsible for care after death (2nd edition); Hospice UK, April 2015</i></p> <p><i>Please see attached link from the MDU</i></p> <p><i>http://www.themdu.com/guidance-and-advice/latest-updates-and-advice/last-rites-the-dos-and-donts-of-death-certificates</i></p>
76	Stroke Association	Improving access to palliative care at the end of life	Palliative care is an extremely important issue for stroke patients. Stroke is the fourth single largest cause of death in the UK, and 7% of all deaths in the UK are caused by a stroke. ³ 30% of those who have a stroke	Patients who have a diagnosis of stroke can be more likely to make the transition to palliative care than patients with other conditions. In one study focusing	<i>There is significant evidence to show that those who have a diagnosis of a condition other than terminal cancer can find it difficult to access palliative care. Please see a</i>

³ Stroke Association, 'State of the Nation', January 2016, <https://www.stroke.org.uk/resources/state-nation-stroke-statistics>

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			<p>die within 28 days, but little is known about the palliative needs of stroke patients.⁴</p> <p>According to the most recent SSNAP statistics about 5% of patients who have a stroke experience a stroke of such severity that a decision is made to palliate within 72 hours.⁵</p>	<p>on the transition to palliative care for older people in acute hospitals, the odds of a transition to palliative care were multiplied by an estimated 5.1 for patients with a cancer, by 8.0 for stroke diagnosis, and by 2.6 for a dementia diagnosis. However, patients with a cancer diagnosis are more likely to receive specialist palliative care than stroke patients.⁶</p> <p>Research suggests that most patients dying from stroke are not referred to specialist palliative care services, and can have unmet palliative care needs.⁷ The National Stroke Clinical Guideline recommends that stroke teams should facilitate access to expert and co-ordinated palliative care services.⁸</p>	<p>report from Marie Curie which explores this issue in more detail: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf</p> <p>This study of 191 stroke patients reported no referrals to specialist palliative care for that cohort: http://www.eapcnet.eu/LinkClick.aspx?fileticket=-608F2HB3-1%3D&tabid=625</p>
82	Together for Short Lives	Symptom management for young adults	Young adults are relevantly different from older adults in the way they metabolise medications.	Pain and symptom management of young adults is complex and members of the care team will	<i>Together for Short Lives (2015). Stepping Up.</i> http://www.togetherforshortlives.org .

⁴ Christopher R. Burton, Sheila Payne, Julia Addington-Hall and Amanda Jones, 'The palliative care needs of acute stroke patients: a prospective study of hospital admissions', *Age and Ageing*, 2010, Vol 39, No 5, 554-559.

⁵ Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, <https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx>

⁶ M Gott, C Ingleton, C Gardiner, N Richards, M Cobb, T Ryan, B Noble, M Bennett, J Seymour, S Ward and C Parker, 'Transitions to palliative care for older people in acute hospitals: a mixed-methods study', *Health Services and Delivery Research*, November 2013, Vol 1, No 11

⁷ Clare Jeffries, Cathy Shipman and Bee Wee, 'The role of specialist palliative care services in stroke – views from an acute stroke unit', *BMJ Supportive and Palliative Care*, 2012, Vol 2 (Supp 1):A1–A120

⁸ Royal College of Physicians, 'National Clinical Guidelines for Stroke' September 2012, <https://www.rcplondon.ac.uk/guidelines-policy/stroke-guidelines>

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>Young people with a life-limiting or life-threatening condition will also have been taking medication for a long period and may require higher dosages than adults at the end of life.</p>	<p>need access to expert advice when working with young adults and will require training to ensure their skills are maintained and developed.</p> <p>For example, young people usually require higher doses for analgesia.</p>	<p>uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf</p> <p><i>Together for Short Lives and The Rainbows Hospice for Children and Young Adults (2014). Basic Symptom Control in Paediatric Palliative Care.</i></p> <p>http://77.92.72.251/PPCSCM/PPCS/CM/PPCSCM.pdf</p>
88	Royal College of Anaesthetists	Suggest that the guidance should be considered for patients considered to be in the last 2 to 3 WEEKS of the end of life.	The advice contained in the document seems to be very good. However, we would suggest that the guidance should be considered for patients considered to be in the last 2 to 3 WEEKS of the end of life, not the 2 or 3 days' of the end of life stated, as we feel this is too late in the process		
89	British Geriatrics Society	End of life care in advanced dementia	<p>The key area for quality improvement is end of life care in advanced dementia.</p> <p>It is important as it is so often neglected and not recognised as a terminal condition as evidenced by National Voices;</p> <p>http://www.nationalvoices.org.uk/news-media/news-item/inequalities-end-life-care</p> <p>The Alzheimers Society also recognises the importance of end of life care in advanced dementia</p> <p>https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2709</p>		
90	British Geriatrics Society	Frailty	The other key area is Frailty. The identification of people with frailty who are at the end of life is crucial to their good		

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			<p>quality of life. The British Geriatrics Society has completed significant work in Frailty and has identified markers for severity.</p> <p>http://www.frailsafe.org.uk/ http://www.ncbi.nlm.nih.gov/m/pubmed/23456467/</p>		
95	Faculty of Intensive Care Medicine and Intensive Care Society	Consideration of organ donation, and appropriate referral to the specialist nurse for organ donation, should occur in all cases of withdrawal of life sustaining therapy.			
General comments					
32	NHS England	<p><i>Three critically important national reports/policy documents have been left out of Section 3.2 of the Topic Overview:</i></p> <ul style="list-style-type: none"> • <i>More Care Less Pathway: an independent review of the Liverpool Care Pathway (July 2013), which has the same status as the 2015 'Choice in End of Life Care' report, as they are both independent reports.</i> • <i>One Chance to Get it Right (June 2014) is the system wide response to 'More Care Less Pathway' – this response focuses specifically on care of dying people and NICE is a co-signatory organisation.</i> <p><i>Ambitions for Palliative and End of Life Care (Sept 2015) is the national framework for improving palliative and end of life care, and includes care of dying people.</i></p>			
48	Royal College of Physicians of Edinburgh	RCPE wishes to endorse the comments supplied separately by the Association of Palliative Medicine of Great Britain and Ireland.			
87	Royal College of Physicians	<p>The RCP is grateful for the opportunity to respond to the above consultation.</p> <p>We would like to endorse the comments submitted by the Association for Palliative Medicine</p>			
96	BMA	As you may be aware, over the past 18 months the BMA has undertaken a major new project, seeking views from our members and members of the public on several practical and ethical issues around end-of-life care and physician-assisted dying. We commissioned social			

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					<p>research experts TNS BMRB to design and conduct a series of 21 dialogue events across the UK, hearing from more than 500 doctors and members of the public. You can find out more about the project, and view our three-part final report at www.bma.org.uk/endoflifecare.</p> <p>The findings of our project led us to make various recommendations on end-of-life care, which are detailed in full in the third volume of our final report, of which I enclose a copy. These will be debated in some detail next week at our annual representative meeting (ARM), where we will be asking our members to give some indication of the areas they feel we should prioritise in taking work forward. I hope to be in a position to be able to share the outcomes of the discussion at our ARM with you at a later date.</p>