

End of Life Care Strategy

Quality Markers and measures for end of life care



*'How people die
remains in the memory
of those who live on'*

Dame Cicely Saunders

Founder of the Modern Hospice Movement

June 2009

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End of Life Care Strategy

Quality Markers and measures for end of life care

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Executive summary

Introduction

- 1.1 The Department of Health published its *End of Life Care Strategy* in July 2008. During its development, the SHA End of Life Care Pathway Chairs identified that commissioners and providers needed support in delivering improvements in care. The resultant Quality Markers, contained in this document, are intended to meet this need.
- 1.2 The Quality Markers should ideally be read in the context of the *End of Life Care Strategy* and, in particular, of the care pathway it sets out.

Context

- 1.3 The *End of Life Care Strategy* and these Quality Markers operate within the usual devolved NHS system. This means that they are not mandatory. Individual organisations will need to decide which of the Quality Markers they wish to adopt, depending on their local needs and circumstances.
- 1.4 However, these Quality Markers will be of use for Primary Care Trusts (PCTs), who will want to work with their local partners to formulate their plans for end of life care, in particular with Local Authorities (LAs), building on their Joint Strategic Needs Assessment and the Local Strategic Partnership. PCTs may also wish to involve their Strategic Health Authorities (SHAs), as the local headquarters of the NHS, in formulating these plans.
- 1.5 Commissioners may wish to use the Quality Markers, and an expectation of improvement against them, in their contracting. This will provide incentives for providers to adopt them.
- 1.6 The Quality Markers may also provide a useful framework for boards of individual commissioner and provider organisations, when defining and tracking progress against their own action plans.

Structure of the Quality Markers

- 1.7 The document is laid out in sections for commissioners and providers. Each organisation will be able to extract the section that applies to them. Some sections are very short: for example, ambulance services have only six Quality Markers. The longest section applies to commissioners. This is because, through the commissioning process, they have a role in encouraging and quality assuring the markers which rest with other organisations.
- 1.8 The Quality Markers emphasise issues such as communication across sectors which are key to delivering a seamless service organised round the individual. These apply to all the organisations involved in providing care, so some markers are repeated across the sections.
- 1.9 For example, there are Quality Markers for a range of organisations on assessing and documenting a patient's needs and wishes at the end of life. That does not mean that each service will necessarily be beginning the process afresh. For example, where a patient already has a care plan, services should use it and amend it as required. However, each should be ready to start the process if that is what is needed for a particular individual.
- 1.10 The Quality Markers are based on the structures and processes of care that are most likely to yield good outcomes for people who are approaching the end of life, and their families and carers.
- 1.11 They are accompanied by suggested measures for assessment of compliance, which commissioners and providers should find helpful in their audit and evaluation of services.
- 1.12 The Quality Markers do not necessarily require new work or new thinking. Where organisations are already implementing the National Institute for Health and Clinical Excellence (NICE) guidance on supportive and palliative care for adults with cancer, or where they are already using the end of life tools (the Gold Standards Framework, Preferred Priorities for Care and the Liverpool Care Pathway for the Dying Patient), for example, they will already be compliant with many of these markers.

Intended audience

- 1.13 The Quality Markers have been designed to be especially helpful to commissioners of services, for both PCTs and LAs. PCTs have the lead role in commissioning end of life care services, but will need to work closely on this with LAs. PCTs may also need to work closely with one another when services are shared between specialist palliative care inpatient facilities such as hospices.
- 1.14 SHAs may also wish to consider how best to measure progress towards higher quality care. They may, for example, wish to ask individual PCTs to complete a self-assessment against the Quality Markers, and PCTs may in turn wish to ask providers to do the same. Alternatively, SHAs (and/or PCTs and LAs) may wish to institute some form of peer review appraisal process.
- 1.15 The regulators may also wish to make use of the Quality Markers when undertaking assessments of end of life care provision.

Future potential

- 1.16 We expect that the Quality Markers will develop and expand as the evidence base supports it and as the services and structures themselves develop.
- 1.17 We recognise that there are some gaps which we need to fill, such as bereavement and spirituality.
- 1.18 This first version of the Quality Markers emphasises structure and process. That reflects the stage we have reached on service development; but we have included measures for tracking impact and progress. We would like a future iteration of these Quality Markers to look at outcomes, including, for example, Patient Reported Outcome Measures.

Quality Markers and measures for end of life care – structure, process, audit

Introduction

- 2.1 The Department of Health published its *End of Life Care Strategy* in July 2008. End of life care is one of the eight principal care pathways identified in the NHS Next Stage Review. Work at national and SHA level was carried out iteratively, and they continue to support each other in implementation. As a result, care for people at the end of life is now established on the agenda for the NHS.
- 2.2 As part of the development work on the SHA visions for end of life care, which formed part of the NHS Next Stage Review, the SHA End of Life Care Pathway Chairs identified that commissioners and providers needed support in delivering improvements in care. They unanimously requested that a unified national approach should be taken to develop quality standards for care provided to people at the end of life. In response the Department of Health published and consulted on draft Quality Markers. The resultant Quality Markers need to be read in the context of the *End of Life Care Strategy* and, in particular, of the pathway it sets out. The rest of this document reflects the comments received.
- 2.3 The draft was generally well received. The main criticisms we heard from respondents were that:
 - unless the Quality Markers were made mandatory they would have limited effectiveness in raising quality;
 - there was too much emphasis on process and audit and too little on outcomes;
 - there were too many Quality Markers, and they were repetitive; and
 - dividing the Quality Markers by organisation would encourage silo working.

Context

- 2.4 The *End of Life Care Strategy* and these Quality Markers sit within the overall policy framework for the NHS and social care. This means that we are working within a devolved system; it would be inconsistent for the Department of Health to make these Quality Markers mandatory. It has to be a matter for individual organisations to decide which of the Quality Markers they wish to adopt, depending on their local needs and circumstances. PCTs will want to work with their local partners to formulate their plans for end of life care, in particular with LAs, building on their Joint Strategic Needs Assessment and the Local Strategic Partnership.
- 2.5 However, commissioners may wish to use the Quality Markers in their contracting which will provide incentives for providers to adopt them. Commissioners may also wish to build an expectation of improvement against the markers into their contracts; in addition, the Care Quality Commission may consider these useful in terms of its role in assuring the safety and quality of regulated end of life care services – if so, that would add emphasis to their value.
- 2.6 Equalities legislation places duties on public bodies, including the Department of Health and NHS organisations. Commissioners and others will wish to ensure that they take account of these duties in implementing the *End of Life Care Strategy*, including using these Quality Markers.
- 2.7 The Quality Markers will also provide a useful framework for boards of individual commissioner and provider organisations to use in order to define and track progress against their own action plans. This will fit directly back into implementation of the NHS Next Stage Review and its principles of assessing and delivering quality, including the core requirement to include the views of service users and carers.

Structure of the Quality Markers

- 2.8 Although the document taken as a whole is quite long, we have laid it out in sections for each commissioner or provider. Each organisation will be able to extract the section that applies to them. Some sections are very short: for example, ambulance services have only six Quality Markers. The longest section applies to commissioners. This is because, through the commissioning process, they have a role in encouraging and quality assuring the markers which rest with other organisations. World Class Commissioning should itself facilitate joined-up working.

- 2.9 One overarching principle defining high quality care is that services are co-ordinated around the patient. The Quality Markers emphasise issues such as communication across sectors that are key to delivering a seamless service. There are markers for a range of organisations on assessing and documenting a patient's needs and wishes at the end of life, but that does not mean that each service will necessarily be beginning the process afresh. For example, where a patient already has a care plan we expect services to use it and amend it as required. However, since different patients will come to this stage differently – patients with dementia or sensory or cognitive impairment will need different approaches from others, for example – the markers appear across the spectrum of services that may be involved in their care.
- 2.10 The Quality Markers are consistent with the holistic approach to care described in the *End of Life Care Strategy*, and are based around the whole systems framework and care pathway it sets out (refer to Annex A). They have been designed as a supportive guide, setting out what will be needed for high quality end of life care to be delivered from the perspective of both commissioners and providers (the NHS, and the voluntary and independent sectors).
- 2.11 The Quality Markers are based on the structures and processes of care that are most likely to yield good outcomes for people who are approaching the end of life, and their families and carers.
- 2.12 They are accompanied by suggested measures for assessment of compliance, which commissioners and providers should find helpful in their audit and evaluation of services. One such measure is the locality-wide register for patients approaching the end of life. It is hoped that this can be implemented in the future, and piloting work begins later in 2009. However, until the pilots are complete it would not be sensible to add to the detail for these Quality Markers.
- 2.13 The Quality Markers do not necessarily require new work or new thinking. Where organisations are already implementing the NICE guidance on supportive and palliative care for adults with cancer, or where they are already using the end of life tools (the Gold Standards Framework, Preferred Priorities for Care and the Liverpool Care Pathway for the Dying Patient), for example, they will already be compliant with many of these markers. If they are applied consistently and in the light of local needs and circumstances, however, they will help to ensure high quality end of life care services across the country.

Intended audience

- 2.14 The Quality Markers have been designed to be especially helpful to commissioners of services, both PCTs and LAs, as they begin to put into place services that address the direction of travel set out by World Class Commissioning, the SHA visions and the *End of Life Care Strategy*. PCTs have the lead role in commissioning end of life care services, but will need to work closely on this with LAs. PCTs may also need to work closely with one another when services are shared between specialist palliative care inpatient facilities (e.g. hospices).
- 2.15 As the headquarters of the local NHS, SHAs may also wish to consider how best to oversee and measure progress towards higher quality of care for all, irrespective of age, gender, disability, ethnicity, sexual orientation and religion or belief. For example, they may wish to ask individual PCTs to complete a self-assessment against the Quality Markers, and PCTs may in turn wish to ask providers to do the same. Alternatively SHAs (and/or PCTs and LAs) may wish to institute some form of peer review appraisal process.
- 2.16 The Quality Markers will also be of use to service providers as a guide to assessing their progress in delivering improvements in end of life care, including against the equality strands.
- 2.17 The regulators may also wish to make use of the Quality Markers when undertaking assessments of end of life care provision.

Future potential

- 2.18 Many respondents wanted the Quality Markers to expand into other topics, such as dementia and chronic obstructive pulmonary disease, and to cover other settings for care, such as prisons. There were also comments that we needed to cover bereavement and spirituality.
- 2.19 We recognise that there are some gaps which we need to fill: bereavement and spirituality are two, and we hope to address them in the next iteration. Other topics, such as specific conditions, may be useful to illustrate particular Quality Markers but the right place for those to be developed is within their own strategies.
- 2.20 We recognise that these Quality Markers emphasise structure and process. That reflects the stage we have reached on service development; but we have included measures for tracking impact and progress. In addition, local organisations can develop Patient Reported Outcome Measures (PROMs)

for end of life care. We would like future iteration of these Quality Markers to include PROMs. Suggestions from the consultation were that:

- pain and other symptoms should be controlled effectively;
- the individual, carers and family should feel well supported;
- the individual, carers and family should feel confident in the skills and knowledge of their health and social care professionals;
- the individual, carers and family should know who to contact in an emergency; and
- the individual should be able to die in their place of choice.

2.21 We do not see this as a once-and-for-all exercise. The Quality Markers will develop and expand as the evidence base supports it and as the services and structures themselves develop. For example, as PCTs develop as world class commissioners, commissioning for outcomes, they are unlikely to be engaged in detailed workforce planning as set out in Quality Markers 1.36 to 1.39. Similarly, once we have the outcomes from the locality registers pilots we shall be in a position to revisit the relevant markers.

2.22 The *End of Life Care Strategy* is about improving the quality of care and experience for all patients at the end of life, and their carers and families, regardless of their condition, setting, or social and personal circumstances. The Strategy emphasises the importance of listening to the needs and wishes of patients and carers, and of developing services which will allow those wishes to be met – such as developing 24/7 community nursing services to allow people to receive high quality care in their own homes, if that is their preference. Sometimes the main carer will be a child or a young person and the services will need to be sensitive to the particular issues which this may raise. These Quality Markers are about the quality of that care, regardless of which sector provides it or which setting the patient is in.

Related work programmes

- 2.23** In parallel with the development of these Quality Markers and measures of the structure and process of healthcare delivery, the Department of Health is working to develop a suite of outcome measures for end of life care. Headed by the existing Tier 3 Vital Sign on home deaths, these are likely to include:
- place of death (available from the Office for National Statistics);
 - audits of care given to recently deceased patients (such as the National Care of the Dying Audit – Hospitals, which is based on the Liverpool Care Pathway for the Dying Patient); and
 - surveys of bereaved relatives based on the successful Views of Informal Carers – Evaluation of Services surveys which have been used extensively in end of life care research studies.
- 2.24** End of life care is also a theme in the Department of Health's *Transforming Community Services* (TCS) strategy: these Quality Markers marry up with TCS's High Impact Changes and the Quality Framework for Community Services.
- 2.25** In parallel with development of these Quality Markers, a review is in train on cancer peer review for specialist palliative care measures.

Summary of the consultation

- 2.26** A summary of the response to this consultation is available on the Consultations website at www.dh.gov.uk/en/Consultations/Responsestoconsultations/index.htm

Impact assessments

- 2.27** The Department of Health carried out full impact and equality impact assessments on the *End of Life Care Strategy* as a whole. These Quality Markers were a commitment in the Strategy as one component of implementation, and are therefore covered in the existing impact assessments.

Top ten Quality Markers for providers

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

Annex A: Quality Markers

These good practice Quality Markers and suggested measures are set out in ten parts:

- Part 1: Quality Markers for commissioners
Depending on local commissioning arrangements these may be more attributable to a PCT, LA or SHA or a combination of organisations. Where they are about ensuring that local service providers themselves match Quality Markers, the recommended measures are given in Parts 2 to 9.
- Part 2: Quality Markers for primary care
- Part 3: Quality Markers for acute hospitals
- Part 4: Quality Markers for community hospitals
- Part 5: Quality Markers for care homes
- Part 6: Quality Markers for specialist palliative care inpatient facilities
e.g. hospices
- Part 7: Quality Markers for providers of specialist end of life care services in the community
- Part 8: Quality Markers for district/community nursing services
- Part 9: Quality Markers for ambulance services
- Part 10: Quality Markers for out of hours medical services

Part 1: Quality Markers for commissioners

Public awareness

PCTs to demonstrate the following.

- 1.1 They are aware of the views of their population, appropriately segmented, with regard to the delivery of care at the end of life.

Measure:

- Reports of surveys or focus groups related to the views of the local population regarding end of life issues.

- 1.2 They have a strategy for promoting public awareness with regard to issues around death, dying and end of life care.

Measure:

- The strategic plan for end of life care (see Quality Marker 1.4) includes actions to be taken to promote awareness of end of life issues.

Strategic planning

PCTs to demonstrate the following.

- 1.3 The needs of the local population, appropriately segmented, for end of life care have been appropriately assessed.

Measure:

- Availability of a needs assessment report.

- 1.4 They have developed a strategic plan for end of life care, which encompasses patients with all diagnoses and care provided in any setting and covers each step in the end of life care pathway.

Measures:

- Availability of a comprehensive strategic plan for the locality.
- Post-implementation evaluation of the strategic plan for impact and progress.

- 1.5 The strategic plan has been developed jointly with social care and the voluntary sector and takes account of the views of service providers and service users as well as those of the local population.

Measure:

- Written documentation of people/organisations involved in the development of the strategic plan.

- 1.6 The strategic plans for end of life care encompass the volume and quality of services delivered by different provider organisations, including care homes.

Measure:

- Comprehensive information on current service delivery by provider organisations is included in the strategic plan.

- 1.7 There are transparent funding mechanisms for end of life care services.

Measure:

- The strategic plan provides information on the funding arrangements for specific end of life care services that take account, where appropriate, of the relevant principles and undertakings in the Compact Funding and Procurement Code of Good Practice.

Identification, communication and care planning

PCTs to demonstrate that all providers have processes in place to do the following.

- 1.8 Identify those who are approaching the end of life.
- 1.9 Ensure that discussions with individuals regarding end of life issues are undertaken by appropriately trained workers.
- 1.10 Ensure that individuals' needs for care are appropriately assessed.
- 1.11 Ensure that individuals are offered a care plan. This is about identifying needs for care. Care plans apply to people with a long-term condition and, as they approach the end of life, should cover those care needs.
- 1.12 Ensure that individuals are offered an advance care plan. This is an advance wishes document that encompasses an individual's preferences for care, but can also cover practical aspects such as funeral arrangements. A high quality service will be sensitive to the different needs of different individuals. For example, individuals with dementia or cognitive or sensory impairment may need this at a different stage in their journey than others.

- 1.13 Ensure entry onto a locality-wide end of life care register, if available, or that there are other mechanisms for sharing information as required across sectors.¹
- 1.14 Ensure that individuals' preferences and choices are documented and communicated to appropriate professionals.

Local Authorities to do the following.

- 1.15 Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment and that support is offered pre- and post-bereavement.

[Measures for these markers are shown in Parts 2–10.]

Co-ordination of care across organisational boundaries

PCTs to demonstrate the following.

- 1.16 Mechanisms are in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.

Measures:

- Documentation of processes for transferring information about individuals who are approaching the end of life between primary care, social care, ambulance services, out of hours (OOH) providers, hospitals, care homes, specialist palliative care, etc.
- Audits of effectiveness of transfer of information (e.g. availability of care plans and Do Not Attempt Resuscitation (DNAR) status to OOH or emergency services).
- Audits of the proportion of people approaching the end of life with a documented key worker.

- 1.17 A locality-wide register of individuals approaching the end of life is maintained.

Measures:

- Existence of a locality-wide register.
- Proportion of deceased individuals who were entered onto the locality-wide register.

¹ Locality-wide registers for end of life care are to be piloted starting this year.

- 1.18** The register is available for all relevant health and social care professionals providing care for an individual patient.

Measure:

- Documentation of governance arrangements related to access to the end of life care register.

- 1.19** The register holds information regarding advance care plans, advance decisions and DNAR status of the individual, subject to their consent.

Measure:

- Contents of register (e.g. names of individuals, full care plans, organ donor status, DNAR status).

Availability of services

PCTs to demonstrate the following.

- 1.20** Essential services are available and accessible in the community 24/7 for all who need them to enable people to live and die in the place of their choice. These include:

- nursing services (including visiting and rapid response services);
- medical services;
- personal care services;
- access to pharmacy services; and
- access to equipment.

Measures:

- Documentation regarding community services and the proportion of the local population covered by these services.
- Timeframes for decisions on continuing care funding.
- Documentation of up-to-date available information for individuals, carers and families.
- Documentation of processes to access equipment.
- Audits of equipment use and provision (e.g. time from request to delivery).

- 1.21 Individuals at the end of life can be transferred quickly, within locally agreed timescales, by the effective commissioning of ambulance and other transport services.

Measure:

- Local commissioning contracts with ambulances and other transport services to include the locally defined transfer time requirement for individuals approaching the end of life.

- 1.22 There is appropriate provision of specialist palliative care services to meet the needs of the population. These will include:

- community palliative care services

Measure:

- Existence of a multiprofessional specialist palliative care team or teams covering the whole community and days/hours of working, e.g. provision of OOH services.

- hospital palliative care services

Measure:

- Existence of a multiprofessional specialist palliative care team in each acute hospital and days/hours of working, e.g. provision of OOH services.

- inpatient services (e.g. specialist palliative care services)

Measure:

- Numbers of specialist palliative care beds available per 100,000 population.

- 1.23 Individuals have access to advice from specialists in palliative care, irrespective of diagnosis or location. (The NICE guidance on supportive and palliative care for adults with cancer recommends that advice from specialist palliative care services should be available on a 24/7 basis.)

Measures:

- Documentation that specialist palliative care advice is available in all locations (e.g. home, care homes, prisons).
- Audits of specialist palliative care provision to care homes.

- 1.24 Processes are in place to facilitate urgent and safe discharge to the community of those who wish to die at home.

Measures:

- Documentation of processes to facilitate urgent discharge to the community (e.g. Hospital2Home schemes, discharge nurses for end of life care).
- Audits of numbers of patients discharged home to die and the outcome of these discharges (e.g. re-admission rates).

- 1.25** People approaching the end of life in care homes have appropriate access to 24/7 medical services.

Measure:

- Documentation of processes to access medical care both within normal working hours and OOH.

- 1.26** People approaching the end of life in care homes have access to community services including primary care services, equipment and pharmacy.

Measures:

- Documentation of processes for accessing equipment and drugs for individuals near the end of their lives.
- Use of equipment and drugs.

- 1.27** People approaching the end of life in care homes have the same level of access to specialist palliative care services as for those living at home.

Measures:

- Documentation of processes for accessing specialist palliative care services.
- Audits of number/proportion of deceased individuals who received specialist palliative care services.

Care in the last days of life

PCTs to demonstrate the following.

- 1.28** All care providers adopt a common approach to care for people in the last days of life.

Measures:

- Number/proportion of providers adopting a standardised approach (e.g. the Liverpool Care Pathway or equivalent).
- Number/proportion of individuals dying with the Liverpool Care Pathway (or equivalent) in place.

Care in the days after death

PCTs to demonstrate the following.

- 1.29** All providers have appropriate processes in place for verification and certification of death, and care after death, including viewing of the body and return of personal property.

Measures:

- Number/proportion of providers using the care after death module of the Liverpool Care Pathway (or equivalent).
- Number/proportion of individuals for whom the care after death module of the Liverpool Care Pathway (or equivalent) was used (including individuals who died suddenly).

- 1.30** All providers have assessed their current environments for care from the perspective of people at the end of life and their carers, and have incorporated plans for improvement into their formal estates strategies.

Measures:

- Audit of estates strategies.
- Audit of implementation of estates strategies.

- 1.31** That providers have assessed the needs and provision for bereavement services, including support for children.

Measures:

- Audit of provision and uptake of bereavement services.
- Audit of questionnaires assessing the experience of those using bereavement services and appropriate action taken.

Workforce planning

SHAs to demonstrate the following.

- 1.32** The utilisation of the Multi Professional Education and Training levy (MPET) budget is in line with the Department of Health's main expectations for the use of funding related to end of life care as set out in the annual service level agreement between the Department and SHAs.

Measure:

- The MPET investment plan sets out proposed levels of training and development relating to end of life care, and includes details of partnerships with commissioners, providers and assessors of services

(including training providers) in determining workforce development needs across health and social care.

- 1.33 Training commissioned for pre-registration and undergraduate students contains curriculum content relating to end of life care.
- 1.34 The end of life care training needs of workers (including those working in specialist palliative care services) within hospitals, community settings, care homes, hospices, ambulance services and other health and social care settings are incorporated into investment plans.
- 1.35 Training programmes are available and accessible to these workers and should take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.

Measure:

- Written evidence that training programmes relating to end of life care are available and accessible to health and social care workers.

PCTs to demonstrate the following.

- 1.36 Workforce requirements for specialist palliative care services have been appropriately assessed by the PCT and agreed with those responsible for workforce at SHA level.
Measure:
 - Written evidence that specialist palliative care workforce requirements have been agreed with the SHA.
- 1.37 All providers have processes in place to identify the development needs of all other workers (registered and unregistered, including volunteers) across health and social care who require end of life care related training. They should take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.
- 1.38 Training investment plans from providers should be assessed in partnership with the PCT and agreed with those responsible for workforce at SHA level.
- 1.39 All providers are aware of end of life care training available, and enable relevant workers to access or attend appropriate programmes dependent on their needs.

Measures:

- The local strategic plan encompasses a workforce development and investment plan that includes the development and training needs of GPs, hospital doctors, nurses, allied health professionals, ambulance staff, social workers, support workers, care home staff and others as appropriate to their local service.
- Documentary evidence of providers' training investment plans, including training and refresher courses.
- Written evidence that the training investment plans have been agreed with the SHA.

Monitoring

PCTs to demonstrate the following.

- 1.40** A coherent approach to data collection on end of life care is in place across the whole locality.

Measures:

- The strategic plan should include arrangements for data collection on end of life care issues by all providers. This should be proportionate to the nature and level of service provided.
- The information that providers are expected to collect on end of life care should be specified in local contracts or service level agreements.

- 1.41** Individual organisations monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

Measures:

- The number/proportion of general practices which provide data in line with local agreements.
- The number/proportion of care homes which provide data in line with local agreements.
- The number/proportion of hospitals which provide data in line with local agreements.
- The number/proportion of specialist palliative care inpatient facilities (e.g. hospices) which provide data in line with local agreements.
- The number/proportion of community palliative care teams which provide data in line with local agreements.

Part 2: Quality Markers for primary care

All GP practices to demonstrate the following.

- 2.1 They have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the practice.
- Post-implementation evaluation of the action plan for impact and progress.

- 2.2 They have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Whether the practice has adopted an approach to end of life care management (e.g. Gold Standards Framework/KITE or equivalent).
- Number/proportion of individuals whose preferred place for care has been recorded.
- Number/proportion of patients who die in their preferred place for care.

- 2.3 They have mechanisms in place to identify, assess and document the needs and preferences of carers of those approaching the end of life (Royal College of General Practitioners' Supporting Carers).

Measures:

- Number/proportion of individuals whose carer is recorded.
- Number/proportion of carers who have been referred for a carer's assessment and whose needs have been recorded.

- 2.4 They discuss and record the needs of those approaching the end of life at multi-disciplinary team meetings, preferably monthly but at a minimum quarterly (refer to the Quality and Outcomes Framework).

Measures:

- Audits of the proportion of deceased individuals who were discussed at a practice-level multidisciplinary meeting in the last year of their lives.²
- Protocols for sharing information with other health and social care professionals.

- 2.5 They provide information on individuals approaching the end of life proactively to OOH services (e.g. through the locality-wide register and/or through the extension of the Gold Standards Framework or equivalent).

Measures:

- Documentation of processes for informing OOH care providers regarding individuals at the end of life.
- Proportion of individuals entered onto a practice-based end of life care register for whom information was communicated to OOH providers.

- 2.6 They nominate a key worker for each person approaching the end of life.

Measures:

- Documentation that each person has been offered an appropriate key worker if required.
- Audits of the proportion of people approaching the end of life with a documented key worker.

- 2.7 They have processes in place to identify the training needs of workers linked to their practices, taking into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care, which can be assessed and agreed with the PCT.

- 2.8 They take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers.

² This will need to take account of the fact that not all deaths are predictable.

- 2.9 They are aware of end of life care training available, and enable relevant workers to access or attend appropriate programmes dependent on their needs.

Measures:

- Documentation showing processes for determining training needs and the training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.

- 2.10 They adopt a care pathway management approach when people are in the dying phase (e.g. through use of the Liverpool Care Pathway or equivalent).

Measures:

- Use of the Liverpool Care Pathway (or equivalent) for individuals dying in their homes.
- Number/proportion of individuals dying in their own homes with the Liverpool Care Pathway (or equivalent) being used.

- 2.11 They collate information on the quality of care provided to individuals after their death for audit purposes (e.g. using a tool such as the After Death Analysis from the Gold Standards Framework).

Measures:

- Number of individuals for whom audit data on end of life care is available from primary care.
- Participation in PCT audit of end of life care.
- Number/proportion of individuals who die at home.
- Number/proportion of individuals who die in their preferred place.
- Number/proportion of carers and family members who receive support following the death of a patient.
- Audit of complaints and compliments regarding end of life care.

Part 3: Quality Markers for acute hospitals

All acute hospital providers to demonstrate the following.

- 3.1 They have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the hospital.
- Post-implementation evaluation of the action plan for impact and progress.

- 3.2 They have a multidisciplinary specialist palliative care team (as defined in the NICE guidance on supportive and palliative care for adults with cancer).

Measures:

- Documentation of members of the hospital specialist palliative care team and hours of services.
- Documentation of OOH services.

- 3.3 They have effective mechanisms for identifying those who are approaching the end of life.

Measures:

- Availability of training for front-line hospital clinicians in identification of patients approaching the end of life.
- Number/proportion of front-line clinicians who have undergone formal training.

- 3.4 They offer care plans to all patients who are approaching the end of life.

Measures:

- Documentation of processes for assessing and recording needs for end of life care.
- Proportion of all deceased patients who had an end of life care plan (or documentation that a care plan had been offered but declined).

- 3.5 They have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Documentation of processes for assessing and recording preferences for end of life care.
- Audits of numbers of patients with a written record of their preferences for end of life care, such as Preferred Priorities for Care, advance care plans and advance decisions.

- 3.6 They have effective mechanisms for identifying the patient's preferred place of care and, where hospital is not the preferred place of death, they have procedures in place to discharge the patient in a safe and timely manner.

Measure:

- Audit the number of patients who achieve their preferred place of care. Correlate with the primary care audit. Feed back reasons for non-achievement to develop practice both within the acute trust and the PCT, and have remedial plans to address this.

- 3.7 They ensure that relevant information on patients approaching the end of life is entered into a locality-wide register (where available) or otherwise communicated to other health and social care professionals involved with the patient's care.

Measures:

- Number/proportion of deceased patients who were recorded on the locality-wide register.³
- Protocols for sharing information with other health and social care professionals.
- Reference Quality Marker 1.16 in terms of access to patient information on presentation at A&E.

- 3.8 They nominate a key worker for each patient approaching the end of life if required.

Measures:

- Documentation that each patient has been offered an appropriate key worker if required.
- Audits of the proportion of patients approaching the end of life with a documented key worker.

³ Locality-wide registers for end of life care are to be piloted starting this year.

- 3.9 They use a care pathway (such as the Liverpool Care Pathway or equivalent) for those who are dying and for care of the body after death.

Measure:

- Protocols for use of a recognised pathway (e.g. the Liverpool Care Pathway or equivalent) for dying patients and for use after death with patients who die suddenly.

- 3.10 They assess the needs of family and carers and provide them with appropriate support during the patient's time in hospital and in the period around death, if the patient dies in hospital.

Measures:

- Documentation of processes to ensure that the needs of carers are assessed, documented and addressed.
- Availability of workers with dedicated time for supporting carers reflected in their job plans.

- 3.11 They have designated suitable quiet spaces in wards for families and carers, which are specifically used for this purpose, and suitable places for families and carers to be seen post-bereavement to collect documentation and personal belongings.

Measure:

- Documentation of processes to ensure that the needs of families and carers are accommodated.

- 3.12 They have appropriate facilities for viewing the deceased.

Measures:

- Documentation of processes to ensure that there are suitable viewing facilities.

- 3.13 They communicate effectively with patients' GPs around end of life decisions and inform the general practice within 24 hours when a patient dies.

Measures:

- Relevant workers having documented responsibility for ensuring communication with GPs when end of life decisions are made and at the time of death.
- Processes for recording that communications have been made with GPs.
- Audits of communication.

- 3.14 They have mechanisms for auditing and reviewing quality of end of life care provided by the hospital.

Measures:

- Participation in national audits related to care of the dying in hospital (e.g. the Liverpool Care Pathway or equivalent).
- Evidence of local reviews of the quality of end of life care and resulting action plans.
- Audit of complaints and compliments regarding end of life care.

- 3.15 They have processes in place to identify the training needs of all workers (registered and unregistered) in the hospital that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.

Measures:

- Documentation showing processes for determining training, needs and the training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.
- Availability of 'foundation' programmes in end of life care for non-registered workers who may have to deal with patients approaching the end of life or just after death, or their families and carers.
- Number/proportion of workers attending such programmes.
- Availability of educational programmes related to end of life care for registered workers.
- Number/proportion of workers attending such programmes.

- 3.16 They take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers.

Measures:

- Availability of training programmes for workers involved in discussing end of life issues with patients and carers.
- Documentary evidence of workers who have received this training.

- 3.17 They are aware of end of life care training available (including training related to the Liverpool Care Pathway or equivalent), and enable relevant workers to access or attend appropriate programmes dependent on their needs.

Measures:

- Documentary evidence of workers who have received such training.
- Availability of educational programmes related to the introduction of the Liverpool Care Pathway or an equivalent pathway.
- Proportion of all hospital wards where patients may be expected to die in which the Liverpool Care Pathway (or equivalent) has been introduced.

Part 4: Quality Markers for community hospitals

All community hospitals which provide relevant services to demonstrate the following.

- 4.1 They have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the community hospital.
- Post-implementation evaluation of the action plan for impact and progress.

- 4.2 They nominate a key worker for each patient approaching the end of life if required.

Measures:

- Documentation that each patient has been offered an appropriate key worker if required.
- Audits of the number/proportion of patients approaching the end of life with a documented key worker.

- 4.3 They offer care plans to all patients who are approaching the end of life.

Measures:

- Documentation of processes for assessing and recording needs for end of life care.
- Number/proportion of all deceased patients who had an end of life care plan (or documentation that a care plan had been offered but declined).

- 4.4 They have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Documentation of processes for assessing and recording preferences for end of life care.

- Audits of number/proportion of patients with a written record of their preferences for end of life care, such as preferred priorities for care, advance care plans and advance decisions.
- Protocols for sharing information with other health and social care professionals.

4.5 Patients' needs for end of life care are assessed on an ongoing basis.

Measure:

- Documentation of processes to review patients' needs, including evidence of written record of assessment and review.

4.6 Patients who are dying are entered onto a care pathway.

Measure:

- Number/proportion of deceased patients for whom the Liverpool Care Pathway (or equivalent) was used.

4.7 Families and carers are involved in end of life care decisions to the extent that they and the patient wish.

Measures:

- Documented processes for involving families and carers in end of life care decisions.
- Audits of the care records of deceased patients assessing involvement of families and carers in end of life care decisions.

4.8 The quality of end of life care provided by the community hospital is audited and reviewed.

Measures:

- Documented processes to audit and review end of life care.
- Reports of audits/reviews.
- Audit of complaints and compliments regarding end of life care.

4.9 They have processes in place to identify the training needs of all workers (registered and unregistered) in the community hospital that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning, and symptom management) as they apply to end of life care.

4.10 They take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers.

- 4.11 All community hospitals are aware of end of life care training available (including training related to the Liverpool Care Pathway or equivalent), and enable relevant workers to access or attend appropriate programmes dependent on their needs.

Measures:

- Documentation showing processes for determining training needs and the training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.

- 4.12 Processes are in place to review all transfers into and out of community hospitals for patients approaching the end of life.

Measure:

- Documentation by community hospitals of patients who are transferred and admitted to hospital, with (as appropriate) date of transfer, date of return to community hospital and date of death.

Part 5: Quality Markers for care homes

All care home providers that provide services to people approaching the end of life⁴ to demonstrate the following.

- 5.1 They have developed an action plan for end of life care, that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the care home. This might include, for example, training, development and skills needs; use of an end of life care tool (the Gold Standards Framework, Preferred Priorities for Care, Liverpool Care Pathway or equivalents); regular contact with a medical practitioner; access to specialist palliative care advice.
- Post-implementation evaluation of the action plan's impact and progress.

- 5.2 That they have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Documentation of processes for assessing and recording preferences for end of life care.
- Audits of numbers of residents with a written record of their preferences for end of life care, such as preferred priorities for care, advance care plans and advance decisions.
- Protocols for sharing information with other health and social care professionals.

- 5.3 That residents' needs for end of life care are assessed and reviewed on an ongoing basis.

Measures:

- Documentation of processes to review residents' needs, including evidence of written record of assessment and review.
- There is written evidence of continuing assessment of changes in care needs as death approaches, including changes in the desired place of death.

⁴ Care homes need to consider end of life care from the point of view of residents who may have a year or more to live, rather than days or weeks.

- 5.4 That they nominate a key worker, if required, for each resident approaching the end of life.

Measures:

- Documentation that each resident has been offered an appropriate key worker if required.
- Audits of the proportion of residents approaching the end of life with a documented key worker.

- 5.5 That residents who are dying are entered onto a care pathway.

Measure:

- Number/proportion of deceased residents for whom the Liverpool Care Pathway (or equivalent) was used.

- 5.6 That families and carers are involved in end of life care decisions to the extent that they and the resident wish.

Measures:

- Documented processes for involving families and carers in end of life care decisions.
- Audits of the care records of deceased residents assessing involvement of families and carers in end of life care decisions.

- 5.7 That other residents are supported following a death in a care home.

Measure:

- Documented processes to support other residents following a death.

- 5.8 That the quality of end of life care provided by the care home is audited and reviewed.

Measures:

- Documented processes to audit and review end of life care.
- Results of surveys (or other assessments) of residents' views regarding the deaths of other residents.
- Reports of audits/reviews.
- Audit of complaints and compliments regarding end of life care.

- 5.9 That they have processes in place to identify the training needs of all workers (registered and unregistered) in the care home that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning and symptom management) as they apply to end of life care.

Measures:

- Documentation showing processes for determining training needs, and a training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.

- 5.10 That they take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers.

Measures:

- Availability of training programmes for workers involved in discussing end of life issues with patients and carers.
- Documentary evidence of workers who have received such training.

- 5.11 That all care homes are aware of available end of life care training (including training related to the Liverpool Care Pathway or equivalent) and enable relevant workers to access or attend appropriate programmes, dependent on their needs.

Measures:

- Availability of educational programmes related to the introduction of the Liverpool Care Pathway or an equivalent pathway.
- Documentary evidence of workers who have received such training.

- 5.12 That processes are in place to review all transfers into and out of care homes for residents approaching the end of life.

Measure:

- Documentation by care homes of patients who are appropriately transferred and admitted to hospital, with the date of transfer, the date of return to the care home and the date of death.

Part 6: Quality Markers for specialist palliative care inpatient facilities, e.g. hospices

All providers of specialist palliative care inpatient facilities need to demonstrate the following.

- 6.1 That they have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the specialist palliative care inpatient facility.
- Post-implementation evaluation of the action plan's impact and progress.

- 6.2 That they have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Documentation of processes for assessing and recording preferences for end of life care.
- Audits of numbers of patients with a written record of their preferences for end of life care, such as preferred priorities for care, advance care plans and advance decisions.
- Protocols for sharing information with other health and social care professionals.

- 6.3 That patients' needs for end of life care are assessed and reviewed on an ongoing basis.

Measures:

- Documentation of processes to review patients' needs.
- There is written evidence of continuing assessment of changes in care needs as death approaches, including changes in the desired place of death.

- 6.4 That they nominate a key worker, if required, for each patient approaching the end of life.

Measures:

- Documentation that each patient has been offered an appropriate key worker if required.
- Audits of the proportion of patients approaching the end of life with a documented key worker.

- 6.5 That patients who are dying are entered onto a care pathway.

Measure:

- Number/proportion of deceased patients for whom the Liverpool Care Pathway (or equivalent) was used.

- 6.6 That families and carers are involved in end of life care decisions to the extent that they and the patient wish.

Measures:

- Documented processes for involving families and carers in end of life care decisions.
- Audits of the care records of deceased patients assessing involvement of families and carers in end of life care decisions.

- 6.7 That they are responsive to emergency need and are able to admit patients 24/7.

Measure:

- Audit of admissions.

- 6.8 That the quality of end of life care provided by specialist palliative care inpatient facilities is audited and reviewed.

Measures:

- Documented processes to audit and review end of life care.
- Reports of audits/reviews.
- Audit of complaints and compliments regarding end of life care.

- 6.9 That they have processes in place to identify the training needs of all workers (registered and unregistered) in specialist palliative care that take into account the four core common requirements for workforce development (communication skills, assessment and care planning, advance care planning and symptom management) as they apply to end of life care.

Measures:

- Documentation showing processes for determining training needs, and the training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.

- 6.10 That they take particular account of the training needs of those workers involved in discussing end of life issues with patients and their families and carers.

Measures:

- Availability of training programmes for workers involved in discussing end of life issues with patients and their families and carers.
- Documentary evidence of workers who have received this training.

- 6.11 That they are aware of available end of life care training (including training related to the Liverpool Care Pathway or equivalent) and enable relevant workers to access or attend appropriate programmes, dependent on their needs.

Measures:

- Availability of educational programmes related to the introduction of the Liverpool Care Pathway or an equivalent pathway.
- Documentary evidence of workers who have received this training.

Part 7: Quality Markers for providers of specialist end of life care services in the community

All providers of specialist community palliative care services need to demonstrate the following.

- 7.1 That they have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the services.
- Post-implementation evaluation of the action plan's impact and progress.
- Audit of complaints and compliments regarding end of life care.

- 7.2 That multiprofessional specialist palliative care teams cover the whole community, including care homes and other residential care facilities.

Measure:

- Existence of a multiprofessional specialist palliative care team or teams covering the whole community 24/7, e.g. provision of out of hours services.

- 7.3 That specialist palliative care community services are available on the basis of need, not diagnosis.

Measure:

- Demonstration of case mix in the annual minimum dataset submission to the National Council for Palliative Care.

- 7.4 That specialist palliative care community services are available to visit and to assess patients 9am to 5pm, seven days a week.

Measure:

- Documentation of on-call rotas.

- 7.5 That specialist palliative care advice is available 24/7.

Measure:

- Documentation demonstrating the phone number of a specialist palliative care advice line.

- 7.6** That measures and processes are in place to ensure that a patient's wishes have been identified and, where possible, that patients who wish to die at home are able to do so. This will include, for example, the availability of suitably trained care workers or nurses at short notice; easy access to medicines and equipment; and mechanisms for rapid 'discharge to die' from hospital or hospice. This will require collaboration with other providers such as ambulance services, primary care and social services.

Measures:

- Operational policies in the community for 'discharges to die' and details of actual place of death and actual place of choice of death as part of annual activity reports.
- Audit of Preferred Priorities for Care/advance care planning.

- 7.7** That members of the community specialist palliative care team meet regularly as a multidisciplinary team to discuss the management of individual patients' care.

Measure:

- Documentation of multidisciplinary team meetings and attendees.

- 7.8** Community based specialist palliative care teams act as an educational resource for the training of generalist palliative care in the community, including GP practices, district nursing services, care homes and community hospitals (see Quality Marker 1.34, PCT requirement for education for workforce planning for non-palliative care specialists).

Measure:

- Availability of a strategic plan for the education of community based providers of end of life care.

Part 8: Quality Markers for district/ community nursing services

All district/community nursing services need to demonstrate the following.

- 8.1 That they have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the services.
- Post-implementation evaluation of the action plan's impact and progress.
- Audit of complaints and compliments regarding end of life care.

- 8.2 That the service has effective links with all local general practice and other providers (e.g. hospitals, care homes, hospices and community specialist palliative care teams) so that patients approaching the end of life in the community are effectively identified.

Measures:

- Documentation of processes to link with other end of life care providers.
- Audits of patients referred for end of life care and the timeliness of initial assessments by community nursing services.
- Attendance at multidisciplinary primary care meetings to discuss end of life care (as per the Gold Standards Framework).

- 8.3 That they nominate a key worker, if required, for each patient approaching the end of life.

Measures:

- Documentation that each patient has been offered an appropriate key worker if required.
- Audits of the proportion of patients approaching the end of life with a documented key worker.

- 8.4 That they have mechanisms in place to assess and document the needs of those approaching the end of life (e.g. use of the Gold Standards Framework or equivalent), and to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).

Measures:

- Number/proportion of nursing services that have adopted an approach to end of life care management (e.g. the Gold Standards Framework or equivalent).
- Number/proportion of individuals whose preferred place for care has been recorded.
- Number/proportion of patients who die in their preferred place for care.

- 8.5 That they have practical arrangements in place to support those dying at home or in a care home.

Measure:

- Proportion of cases with equipment, supplies and crisis boxes in place and out of hours sitting services available.

- 8.6 That they adopt a care pathway management approach when people are in the dying phase (e.g through use of the Liverpool Care Pathway or equivalent).

Measures:

- Use of the Liverpool Care Pathway (or equivalent) for patients dying in their homes.
- Proportion of patients dying in their own homes with the Liverpool Care Pathway (or equivalent) being used.

- 8.7 That the service is available 24/7 for patients approaching the end of life.

- 8.8 That workers providing out of hours services are competent in providing general palliative care, including symptom management, the use of syringe drivers, assessment of the need, communication skills and providing support both to the patient and to carers in relation to DNAR and advance decisions.

Measure:

- Documentary evidence of workers who require training, have received training and who have attended training courses, including refresher courses.

Part 9: Quality Markers for ambulance services

All ambulance service providers need to demonstrate the following.

- 9.1 That they have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the services.
- Post-implementation evaluation of the action plan's impact and progress.
- Audit of complaints and compliments regarding end of life care.

- 9.2 That they are able to respond to urgent calls to transfer patients at the end of life within locally defined timescales.

Measures:

- Whether services have a local policy on timeframes for the response to an end of life call.
- Audits of compliance with timeframes set out in that policy.

- 9.3 That they have mechanisms for identifying patients who are known to be approaching the end of life and who have expressed a wish to remain in their own homes or in a care home if that is their normal place of residence.

Measures:

- Audit of whether data provided by PCTs or other services for patients approaching the end of life has been uploaded onto ambulance systems.
- Audit of whether, for calls where information was uploaded and available, the crew took action in line with that information.
- Whether PCTs have a local policy on how crews should handle calls to patients who are at the end of life.

- 9.4 That they have processes to identify patients for whom a DNAR order has been signed.

Measures:

- Audit of whether data provided by PCTs or other services on patients with a DNAR order have been uploaded onto ambulance systems.
- Audit of whether, for calls where information was uploaded and available, the crew took appropriate action.
- Whether PCTs have a local policy on how crews should handle calls to patients with a DNAR order, taking into account national clinical guidelines.

- 9.5 That they take particular account of the training needs of those workers involved in discussing end of life issues with patients and their families and carers. (See Quality Marker 1.34.)

Measures:

- Documentation showing processes for determining training needs, and a training investment plan.
- Documentary evidence of workers who have received training, including refresher courses.

- 9.6 That they have processes to inform GPs where they have transferred a patient who is at the end of life to a hospital.

Measure:

- Whether ambulance data are shared with GPs.

Part 10: Quality Markers for out of hours medical services

All providers of medical out of hours services need to demonstrate the following.

- 10.1** That they have developed an action plan for end of life care that is congruent with the strategic plan developed for the locality by the PCT.

Measures:

- Availability of an action plan for end of life care for the services.
- Post-implementation evaluation of the action plan's impact and progress.
- Audit of complaints and compliments regarding end of life care.

- 10.2** That the Gold Standards Framework, Preferred Priorities of Care and Liverpool Care Pathway for the Dying or equivalent approaches have been adopted by all primary care providers, including out of hours services.

Measures:

- All those approaching the end of life are on a register.
- Medical services are available 24/7.

- 10.3** That medical practitioners providing out of hours service are competent in providing general palliative care, including symptom management, the use of syringe drivers, assessment of need, communication skills and providing support to both the patient and carers in relation to DNAR and advance decisions.

Measure:

- Documentary evidence of workers who require training, have received training and who have attended training courses, including refresher courses.

- 10.4** That medical practitioners have information on rapid access to other out of hours services such as specialist palliative care advice, symptom control drugs, rapid response nursing support and equipment necessary for symptom management.

Measure:

- Availability and audit of the above services.

- 10.5** That systems are established to ensure that up-to-date information is shared between daytime services and out of hours providers, across all care settings, including knowledge of the person's preferred place of care, advance care plan or advance decision, current drugs and emergency medication available at home or in the person's location.

Measure:

- Audit of the preferred place of care.

- 10.6** That a locally agreed palliative care formulary stock of drugs and equipment (such as catheters and syringe drivers) is readily accessible to all out of hours medical practitioners, with robust clinical governance standards in place to protect both patients and workers.

Measures:

- Audit of the outcome of out of hours services consultation.
- Evidence of a palliative care formulary and use of equipment such as catheters and syringe drivers.

Annex B: The End of Life Care Framework

The Quality Markers map onto the different elements of the End of Life Care Framework, which have been set out in the national strategy. These include the following.

- Raising public awareness about death, dying and end of life care issues.
- Local strategic planning.
- The end of life care pathway:
 - Identifying, and starting the conversation with, people who are approaching the end of life.
 - Assessing the needs of individual patients and carers and planning their care.
 - Co-ordination of care both within and between organisations.
 - Availability of services 24/7 with integrated service delivery of high quality care.
 - Review of individual patients' needs.
 - Care in the last days of life.
 - Care in the days after death.
 - Information and support for carers and families.
- Environments for care.
- Workforce development:
 - Communication skills.
 - Education and training in end of life care.
- Measurement of progress:
 - Markers for structure and processes of care.
 - Outcome measures.

Annex C: Glossary

Advance decision

(Previously known as a living will or advance directive.) An advance decision to refuse treatment is a decision to refuse a specific type of treatment at some time in the future. It will only be used if the person loses the ability to make their own decisions.

Advance care planning

A process of discussion between a person and those who provide care for them, for example nurses, doctors, care home managers or family members. It provides a mechanism for discussion of the person's views, preferences and wishes for their future care. Advance care planning is an entirely voluntary process, owned by the individual, and there is no pressure to undertake it if it is not desired.

Care homes

Community-based provision in the statutory, voluntary and independent sectors offering a range of short-term and long-term accommodation and care to adults with a variety of needs.

Care plan

A written document jointly agreed by the patient and professional. It is the tangible record of the process of care planning. It should allow a holistic approach to care, empowering individuals to bring all relevant areas of their life to the discussion. It can also help in the audit of service delivery.

Carer's assessment

Carers have a legal right to an assessment of their needs. The purpose of a carer's assessment is for the carer to discuss with social services what help they need with caring, as well as any help that would maintain their own health and balance caring with other aspects of life such as work, leisure, education and family commitments. Carers can be identified for this assessment by social services, GPs and through self-referral by carers themselves. Social services use the assessment to decide what help to provide.

Commissioners

Organisations responsible for commissioning health care services for populations, such as Primary Care Trusts, Local Authorities and Strategic Health Authorities.

Compact

The Compact between government and the voluntary and community sector was launched in November 1998. The Compact sets out the principles and undertakings that should underpin relationships between the voluntary and community sector and government, and is considered integral to increasing the involvement of patients and the public in health.

DNAR

Do Not Attempt Resuscitation.

End of life care

End of life care has been defined by the National Council for Palliative Care as 'care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

NCPC has further defined quality: 'A quality palliative and end of life care service for a population is one where all those with palliative and end of life care needs have such needs assessed and met in accordance with their priorities and preferences about when, how and where their care is delivered'.

End of Life Care Strategy

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Families and carers

Relatives and others close to the person approaching the end of life. Carers can include children and young people. 'Families' should be interpreted sensitively depending on the individual involved, and can include same-sex partners.

Generalist palliative care

Services in all sectors providing day-to-day care to patients with advanced disease and their carers, designed to alleviate symptoms and concerns, but not expected to cure the disease.

Gold Standards Framework

A systematic evidence-based approach to optimising the care for patients nearing the end of life in the community. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness.

www.goldstandardsframework.nhs.uk

Health and social care professionals

Professionals who provide usual care to the person approaching the end of life and their family as an integral part of routine practice, whatever the location.

Joint Strategic Needs Assessment

The Local Government and Public Involvement in Health Act 2007 places a duty on upper tier Local Authorities and Primary Care Trusts to undertake Joint Strategic Needs Assessment (JSNA). JSNA is a process that will identify the current and future health and well-being needs of a local population, informing the priorities and targets set by Local Area Agreements and leading to agreed commissioning priorities that will improve outcomes and reduce health inequalities.

www.dh.gov.uk/en/Managingyourorganisation/JointStrategicNeedsAssessment/index.htm

Key worker

A worker who, with the individual's consent and agreement, takes a key role in co-ordinating the individual's care and promoting continuity, ensuring the individual knows who to access for information and advice.

KITE ('Keep Improving the Experience')

The KITE standards are a set of 19 standards in cancer and palliative care for GP practices with the aim to 'keep improving the experience'.

Liverpool Care Pathway (LCP)

The LCP represents a continuous quality improvement programme for care of the dying. It transfers best practice for care of the dying in the hospice environment into other care settings, and a key feature of the LCP is that it empowers generic healthcare workers to deliver optimum care to dying patients, irrespective of diagnosis.

www.liv.ac.uk/mcpil/liverpool-care-pathway/

Local Strategic Partnerships

LSPs are non-statutory, multi-agency partnerships which match Local Authority boundaries. They bring together different parts of the public, private, voluntary and community sectors, allowing different initiatives and services to support each other.

MPET

Multi Professional Education and Training levy. It is a funding stream from the Department of Health that funds the additional costs to the NHS of supporting workforce training.

Multidisciplinary team

A group of health and social care professionals from a range of disciplines who meet regularly to discuss and agree plans of treatment and care for people with a particular problem, or in a particular location. Includes primary care teams, site-specific cancer teams, therapy teams and specialist palliative care teams.

NICE guidance on supportive and palliative care for adults with cancer

<http://guidance.nice.org.uk/CSGSP/Guidance/pdf/English>

Palliative care

Active holistic care of patients with advanced progressive illness, focusing on the management of pain and other symptoms and the provision of psychological, social and spiritual support.

People with sensory or cognitive impairment

People who, because of impairment in hearing, sight, speech, touch or cognition, may have difficulty communicating.

Preferred Priorities for Care

Preferred Priorities for Care (PPC, formerly known as Preferred Place of Care) is an advance care plan in which individuals can write down their preferences and priorities for care at the end of life in order to help prepare for the future.

www.endoflifecareforadults.nhs.uk/eolc/ppc.htm

Primary care

Services provided in community settings outside secondary care (including GP services, general dental, ophthalmic, mental health, learning disability and pharmaceutical services, community health and health promotion) with which patients usually have first contact.

Specialist palliative care

Services in all sectors that specialise in palliative care and which include consultants in palliative medicine, clinical nurse specialists in palliative care and a range of other specialist expertise.

Supportive care

Care that helps people approaching the end of life and their families and carers to cope with the end of life throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

Voluntary sector

Not-for-profit autonomous organisations involved in the delivery of health or social care services to people approaching the end of life and their carers. Many hospices sit within the voluntary sector.

Worker

Any person, including volunteers, providing care or services for the person approaching the end of life, their family or carers.

World Class Commissioning

World Class Commissioning is intended to deliver a more strategic and long-term approach to commissioning services, with a clear focus on delivering improved health outcomes.

www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm



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