Information for commissioning end of life care
National End of Life Care Programme
The care of all dying patients must improve to the level of the best

## Contents

- **Background**
- What is end of life care
- The role of commissioners
- The End of Life Care Pathway
- What will good commissioning for end of life care look like?
- Commissioning and accountability relationships
- The lead commissioner
- Strategic health authorities
- Primary Care Trusts and local authorities
- Practice based commissioning
- The commissioning process for end of life care
- Patient and public involvement
- Strategic planning
- Continuing health care commissioning
- Managing demand and performance
- Useful references
- Key questions to ask about the Service Level Agreement
- Key questions that commissioners may wish to ask providers regarding end of life care

- **Contributors**

- **Useful links**

- **Appendix A - Generic example service specification for commissioning end of life care for social and health care commissioners**
  
  - 1. Description of the service to be jointly provided
  - 2. National drivers
  - 3. Places where services are to be provided
  - 4. Environmental factors
  - 5. Duration
  - 6. Description of eligible service user
  - 7. Service user access to services
  - 8. Timing of referrals and of access
  - 9. Explanation of how providers will seek to meet service users needs
  - 10. Number of people who may be referred for access to the services and during what periods
  - 11. Special delivery requirements
  - 12. Special equipment to be used
  - 13. Special personnel requirements
  - 14. Key performance indicators

- **References (endnotes 1-12)**
Background

The Department of Health, National End of Life Care Strategy (DH NEoLC Strategy) published in July 2008 sets out the key priorities for improvement in end of life care over the next ten years and is focussed on the care of adults above the age of 18 years.

‘The aim of this strategy is to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.’


Driving up the quality and availability of end of life care which is responsive to patient’s needs and choices is a key role for commissioning. Development of a clear commissioning framework that aligns to national quality markers should be in place across all care delivery settings and deliver consistent end of life care pathways across all end of life care service providers including the following:

- identification of the end of life phase
- timely conversations about end of life care
- assessment and care planning
- co-ordination and registration
- integrated service delivery
- review
- last days of life
- care/support after death bereavement
- support and information for patients and carers

What is end of life care?

The phase ‘end of life’ ends in death. Definition of its beginning is variable according to individual patient and professional perspectives. In some cases it may be the patient who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient. In all cases, subject to patient consent, the beginning is marked by a comprehensive assessment of supportive and palliative care needs.

End of life care 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 patient 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.
This information is intended for:

- Primary Care Trusts (PCT’s)
- practice based commissioners
- mental health service commissioners
- older people service commissioners
- long term condition service commissioners

and will support the commissioning of a whole-systems approach to end of life care. This focuses on delivery of a high quality, individualised service to meet the physical, emotional, spiritual and social needs of all people in their end of life phase and their carers. It supports delivery of the DH NEoLC Strategy and the end of life care policy set out in, Department of Health’s, *Building on the Best*¹ and *Our health, our care, our say*² and *High Quality Care for All*³ that end of life care services need to be commissioned to ensure that all people suffering from a life limiting illness are supported to enable them to have more choice over where they are cared for, and die.

People frequently require care from multiple services and they may need or want to transfer between locations (home, hospital, care home, hospice etc). Co-ordination of care is often fragmented. People who are approaching the end of life need access to care and support 24 hours a day, 7 days a week. Building service capacity in the community will be important to ensure that services are timely and responsive to avoid the patient being admitted to hospital rather than being cared for in their normal place of residence (home or care home).

The evidence suggests that most, but not all, people would prefer not to die in a hospital – although this is in fact where most people currently do die.

**The role of commissioners**

The core responsibility for commissioners is to commission high quality safe services that are tailored to the needs of individual patients and to do so in a way that maximises value for money. In essence this means buying healthcare services for their defined population from a range of providers. PCTs should do this in conjunction with practice-based commissioners (PBCs) and commissioning colleagues from other sectors including local authority (LA) and the voluntary sector.

Commissioners need to specify clearly what needs to be in place to deliver good quality end of life care for their populations. They should also work to ensure that there is sufficient spread of care service providers available to deliver this, paying particular attention to access to specialist palliative care services, hospice beds, bereavement services, pharmacy services, equipment, spiritual care and access to information.

Attention is also required to ensure access to general medical and nursing services, out of hours’ services and rapid response to maintain continuity of care, thereby supporting the patient’s preferences and choice.

Commissioners also have a key role in the performance management of service delivery in line with agreed outcome measures and are required to understand the roles, responsibilities and governance arrangements of existing structures for example, clinical networks.
The End of Life Care Pathway

The DH NEoLC Strategy sets out a nationally agreed generic pathway for end of life care services:

Step 1 Discussions as the end of life approaches
Step 2 Assessment, care planning and review
Step 3 Co-ordination of individual patient care
Step 4 Delivery of high quality services in different settings
Step 5 Care in the last days of life
Step 6 Care after death

Underpinned throughout by:

- spiritual care
- support for carers and families
- information for patients and carers

![End of Life Care Pathway Diagram]

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<td>Delivery of high quality service in different settings</td>
<td>Care in the last days of life</td>
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- Open, honest communication
- Identifying triggers for discussion
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers
- Strategic coordination
- Coordination of individual patient care
- Rapid response services
- High quality care provision in all settings
- Acute hospitals, community, care homes, Extra care housing hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation
- Recognition that end of life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Department of Health (2008), National End of Life Care Strategy
The development of a strategic commissioning framework and good co-ordination across organisations is needed to support each of the above steps. Recognising that some services may require regional commissioning eg ambulance services and that PBC clusters may commission local services eg a rapid response team. The commissioning framework should be underpinned by the key principles and outcome measures across the whole end of life care pathway.

However, it is acknowledged that, locally, the detail will differ. Many different factors may affect a person’s needs and preferences for care. These include:

- the nature of the condition or conditions from which they are suffering
- their social circumstances, eg whether they live alone or with others, the proximity of close family, in sheltered accommodation, in a care home, hostel etc
- deprivation and pre-existing vulnerabilities: such as, mental health and learning disabilities
- experiences of health care to date, particularly in relation to the deaths of others
- approach to life and psychological well-being
- cultural factors
- spiritual/religious beliefs

The commissioning of integrated services is an essential element in the end of life care pathway. Individual patients and their families/carers may need access to a complex combination of different services, including:

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<td>community and voluntary sector support</td>
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Services need to be commissioned across a number of different settings – hospital, community, care home or hospice. On some occasions they will also be needed in other locations such as prisons and hostels for the homeless.

PCTs may wish to identify funding to support the provision of end of life care from budgets across health and social care services in order to support joint commissioning and investment across the whole pathway of care. The development of a personalised approach to the delivery of adult social care in line with ‘putting people first’ will impact on how people access services tailored to their individual needs in the future.

Clear partnership arrangements with charities and other voluntary sector providers will be needed to ensure that the balance of resource investment is appropriate to ensure support across all areas.

**What will good commissioning for end of life care look like?**

At a national level, good commissioning of end of life care services will be achieved when the following, outlined in the DH NEoLC Strategy, can be demonstrated:

- all patients approaching the end of life, and their carers:
  - have their physical, emotional, social and spiritual needs and preferences
  - assessed by a professional or professionals with appropriate expertise
  - have a care plan
  - have their needs, preferences and care plan reviewed as their condition changes
  - have access to bereavement support
  - know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff
  - maintain dignity and respect for the individual

- all the services the person needs are effectively co-ordinated across the sectors
- there is optimal delivery of care across all relevant services in hospitals, hospices, and care homes and in the community
- there is good quality care in the last days of life
- there are effective processes for the verification and certification of death, and care after death
- the quality and effectiveness of care can be robustly measured
- there are equalities in access to and provision of end of life care services

World Class Commissioning (WCC) means that local strategic plans will set out priorities and steps towards achieving the above. These outcomes should underpin the commissioning, specification and contracting process for end of life care providers.
Commissioning and accountability relationships

The choice of commissioner(s) of the service is for local determination. One of the local NHS organisations or the (LA) may take on this role on behalf of all of the others. The responsible organisation could therefore be within the NHS or a LA providing some of the services whilst commissioning others.

The lead commissioner

Where an organisation is interested in providing services to more than one commissioner, commissioners might wish to work collaboratively with a single lead commissioner acting on behalf of all others in order to streamline the contracting arrangements. The commissioners would agree between themselves how to contract with that provider and the provider will then be required to deal with only one commissioner. It would also be important to ensure that where a lead commissioner is identified the supporting infrastructure is in place across the agreed partners commissioning teams.

There are also likely to be existing structures, groups/bodies/clinical networks, which will already be supporting development of related services eg supportive or palliative care. It is important that, wherever these structures are in place, commissioners understand the related roles and responsibilities. A memorandum of understanding between parties may be needed to ensure clarity and accountability across boundaries.

The terms of reference, links and connections for existing commissioning groups may need to be adjusted to reflect the role of networks. Membership and representation may also need to be reviewed to ensure it includes representatives from pharmacists, providers, trusts and community case managers, LA, out of hours providers, ambulance services and the voluntary sector.

All related services may be commissioned as a whole but patients may move from a long term conditions pathway eg cancer requiring supportive care to the end of life care pathway. It will therefore be important to establish the key triggers/criteria and decision making regarding the beginning of the end of life care phase across the range of specialities including cancer, cardiac, respiratory, renal, neurological and dementia. It will also be important to consider both older people and older teenagers (ie in terms of transition to adult services) in planning end of life care services. Commissioners should be aware of the strategy set out in Better Care: Better Lives6 which addresses children’s palliative care services.
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Strategic health authorities

Working in consultation/collaboration with PCTs and LAs, Strategic Health Authorities (SHAs) will wish to determine whether strategic plans should be developed at single PCT level or by consortia of PCTs. Either way, they will want to ensure that local strategic plans cover the whole of their population. SHAs will wish to satisfy themselves that an inclusive approach has been taken in the development of local plans and, for example, that they:

- cover each step in the care pathway
- reflect the needs of the population and the local decisions about priorities based on the identified needs
- will enable more patients to live and die in the place of their choice
- will support a shift in the balance of care from the acute sector to the community, with 24 hour medical and nursing services available to patients in all locations
- include effective arrangements to coordinate individual patient care
- take into account training and other workforce development requirements
- include a performance management framework setting outcome measures against the national end of life care pathway
- demonstrate effective engagement with service users, clinicians and providers in redesigning services

Workforce development will be one of the major cost drivers for improving end of life care. SHAs will want to take into account additional workforce development needs arising from their local end of life care strategies in devising and monitoring their training and development plans.

Primary care trusts and local authorities

The WCC Programme identifies a vision for healthcare commissioning and what it will deliver, ‘Adding life to years, and years to life’. In the context of end of life care services this is about ensuring that individuals and their carers experience the highest quality of life during their end of life phase. WCC positions LAs and PBCs as key partners within PCTs. It is important that commissioners for end of life care services work collaboratively with all key partners

Currently PCTs are most usually responsible for commissioning end of life care health services, working closely and in partnership with LAs. Services should be commissioned against the agreed end of life care pathway. The pathway crosses a number of organisations and potential service providers and it is essential that commissioning, and service provision, is co-ordinated. Strategic co-ordination at the local level may be led by PCTs working in partnership with local authorities, and should involve close cooperation with all relevant service providers, clinicians and service users.

The LA may provide a range of services that help support people in their own homes eg home helps, meals on wheels and assisted technology loans etc. Redesign of end of life care pathways could increase demand for these services with additional resource implications. In addition, LAs may need to adapt or reconsider existing provision of nursing home, respite care and social services support. Further work will be required in modelling capacity and demand for end of life care services across a community and the use of personalised budgets will need to be considered.
This may be further supported by an understanding of the localised population based needs assessment and public health data.

This will require PCTs and LAs to work together to achieve improved health and well-being outcomes for their populations, and should be based on a sound Joint Strategic Needs Assessment (JSNA).

The JSNA will be the means by which PCTs and LAs identify the future health, care and wellbeing needs of local populations and will help set the strategic direction of service delivery to meet those needs. Work on the JSNA will inform the local Sustainable Communities Strategy and will impact on priorities and targets in the Local Area Agreement which will be the main local service planning and delivery agreement.

**Useful resource:**
Capacity to Care a Data Analysis and Discussion of the Capacity and Function of Care Homes as Providers of End of Life

**Practice based commissioning**

High Quality Care for All® encourages PBCs to use NHS funds more flexibly to provide a better response to individual's needs. PBCs are influential in developing services locally, both in influencing the commissioning discussion, as providers of services and as key contacts with users of services. PBCs should be represented on commissioning groups/boards and all should sign up to the local strategic plan. One area where PBCs may have a key role is in supporting those approaching the end of their lives and those who care or them, to remain at home if that is their wish. This could include rapid access to pharmacy and equipment services, emergency respite care, help with personal care, shopping and housework, bereavement care and support for carers, family members and close friends.

**The commissioning process for end of life care**

The overall purpose of WCC is to contribute to the achievement of the goals of the health system. These are also reflected in the vision set out in the DH NEoLC Strategy services:

- good health outcomes
- high quality and safe care
- good access
- responsive and patient-centred care
- equity and fairness
- contained costs
- efficient use of resources
The care of all dying patients *must improve to the level of the best*

The diagram below outlines the process for commissioning world class end of life care services and is followed by a description of each step.

**Patient and public involvement**

The needs and wants of the public, patients and users should be at the heart of the commissioning process. Different kinds of users should be identified together with the means of empowering them. Patient voice should be embedded throughout the commissioning cycle at planning, tendering, choosing providers, procurement, monitoring performance and evaluation. A local strategy should be developed that addresses why, when, where and how to involve users in commissioning to ensure maximum value. Capacity for user involvement should be built in by ensuring that:

- the system as a whole has capacity to respond to user views
- commissioners and providers have the capacity to carry out user involvement
- users have the capacity to get involved
- user and carer involvement is efficient and effective
Where commissioners intend to make significant changes to a patient pathway, particularly where this involves moving services out of secondary care, public consultation is a necessary part of the commissioning process. The commissioner should be aware of the demographics of the population, key influences upon public opinion and key local groups and individuals who should be actively managed through the consultation process. These might include local MPs, support groups, key players within the local voluntary sector and patient group leaders.

Commissioners may wish to establish links to existing voluntary sector groups, service network user groups and engage via the local involvement networks to understand current views about existing services and the communities’ priorities for improvement.

Whilst it is important to record and understand the views of the public, WCCs also have a responsibility to market their intentions in a way that properly explains the broader advantages of a change in services to the community as a whole and promotes any benefits of redesign including financial and individual patient experience. It is therefore imperative that a communications and publicity plan is drawn up in advance of commencement of formal consultation.

**Useful resource:**
Real involvement: working with people to improve services

**Strategic planning**

**Step 1 - Assessment of needs**
The Operating Framework 2007/08 asked PCTs, working with LAs, to conduct a baseline review of local end of life care services to support the implementation of the DH NEoLC Strategy. Guidance for the review is set out in Operating Framework 2007/08: PCT Baseline Review of Services for End of Life Care. The purpose of the review was to allow local services to identify gaps in their services and obtain a much clearer view of local need, to inform local commissioning activity. This was strengthened further in the Operating Framework for 2008/09 which stated that a key element of the DH NEoLC Strategy will be to improve people’s access to high-quality services, close to their homes, and that central to the delivery of this change will be the development of rapid-response services and co-ordination centres. (The outline costs are mapped in the impact assessment for the DH NEoLC Strategy).

**Step 2 - Review current service provision**
Local strategic plans will be guided by the outcome of JSNAs that all PCTs and LAs are now required to produce from April 2008.

**Co-ordination across health and social care is the key** to developing a sound local strategic plan.

The end of life care pathway provided in the DH NEoLC Strategy provides an agreed high level generic pathway.

This will need to be further developed at a local level, setting out the range of services provided at each step.
There are a number of national levers to support re-design of end of life care pathways, these include: (Department of Health)

- High Quality Care for All (2008)
- Patient Choice (2005)
- Our Health, our care, our say (2006)
- Commissioning Framework for Care Closer to Home
- Carers Strategy (2008)
- NHS Operating Framework (2009/10)
- Gold Standard Framework, Liverpool Care Pathway of the Dying and Preferred Priorities for Care
- National Audit Report - End of Life Care (2008)

Commissioners and providers debate and agree priorities, pathways and audit mechanisms and PBCs put forward effective alternative services. In reviewing services and re-designing pathways it will be important to ensure that the patient’s care plan is owned and co-ordinated by a nominated person within the care pathway, and that the care plan is regularly reviewed and updated in partnership with the patient. In addition, the needs of the carer should be reviewed at regular intervals to negate the need for emergency admission of the patient due to carer fatigue. Department of Health (2008)12

End of life care services are complex. Service users and carers must be clear about the nature of this care and how the arrangements differ from other services e.g. intermediate/or continuing care. It should also be clear (between NHS, LA, commissioner and provider) from the outset who is responsible for meeting the cost of various elements of the overall end of life care pathway. This will also include transport arrangements.

Some examples of service delivery models to be considered by commissioners can be found at:

www.endoflifecareforadults.nhs.uk
www.endoflifecareforadults.nhs.uk/eolc/SS18.htm

Appendix A provides a generic example of an end of life care service specification

Step 3 - Decide priorities
It will be important when in discussion with LA about JSNA priorities and in discussions about spending priorities within PCTs that costs and savings information is available to support cases for re-design where appropriate. The specific costs of end of life care services can be difficult to identify within the costs of care services in total. However, the costs of under-occupancy of care home beds, for example, can be calculated. Inappropriate admissions into services such as acute and intermediate care may need to be addressed through the pathway re-design for end of life care.
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Continuing health care commissioning

All continuing health care commissioning for individuals with end of life care needs should reflect best practice in wider end of life care policy.

The fast-track tool is in place to enable quick interim decisions to be made about entitlement to continuing health care for individuals with a rapidly deteriorating condition who may be entering a terminal phase.

A key purpose of the fast-track tool is to facilitate individuals to be able to be in their preferred place of care as soon as possible. In the weeks after use of the fast-track tool, it may be appropriate for PCTs and LA to carry out a full assessment together. This may lead to a change in responsibility for funding the support. Wherever possible, support should be commissioned in such a way that, even if responsibility for funding passes to a LA, it should not make a significant difference to the provision or style of the care provided.

Therefore commissioning should enable choice based on individual need.

Careful decision making is essential to avoid undue distress that might result from a person moving in and out for continuing health care eligibility in a very short period of time.

It is important that the views of users and carers, together with the outcomes of any surveys, are taken account of in the development of strategic plans. The following is a list of potential stakeholders who should be taken account of in the development of commissioning plans.

Key stakeholders will include:

Services

• ambulance/transport service
• primary care teams and services
• community nursing services
• intermediate care services
• social services
• older peoples services (including LA)
• equipment
• occupational therapy
• psychological support services
• information services
• respite care
• speech and language therapy
• physiotherapy
• day care
• pharmacy
• financial advice
• dietetics
• carer support services
• bereavement support
• funeral directors
• coroners
• spiritual care/chaplaincy services
• medicines management
• acute sector services
• emergency services eg police and fire

Professionals
• allied health professionals
• GPs
• secondary care clinicians
• clinical networks
• nurses and HCAs
• social service staff
• voluntary Sector

Providers
• NHS palliative and specialist palliative care service providers, including NHS hospices
• care homes
• community hospitals
• emergency and urgent care services
• out of hours service providers
• prisons/hostels
• extra care housing

Third sector
• charities/voluntary organisations, including hospices

Users
• expert patient/carer scheme
• support groups

Commissioners
• older people’s services commissioner
• long–term conditions commissioner
• mental health services commissioner
• HIV services commissioner

Development of local strategies should take account of any new developments or influences and expected changes in public attitudes and behaviour.
Specifying outcomes and procuring services

The views of patients and the public should be taken account of in specifying required outcomes from services commissioned from providers and that they should be involved in procurement through the assessment and selection of providers bidding for contracts.

Step 4 - Specify services

When designing care pathways closer to home it is also important to understand the financial implications for existing services such as LA services, third sector organisations, medicines management and existing community services. These may need investment or re-design to support the new pathway for end of life care services. Commissioners will also want to work in partnership with all key stakeholders to ensure service users views and clinical advice drives continuous improvement.

Step 5 - Shape structure of supply

PCTs signal the strategic direction of end of life care services in the local prospectus and develop service specifications and support proposals as appropriate. They will need to work with NHS Trusts, Foundation Trusts, GP practices, neighbouring PCTs, LA, private and third sector providers to ensure best services for local people.

Commissioners may choose to work collaboratively with LA and/or commissioners from other local PCTs in order to contract services that represent value for money. The lead commissioner will negotiate on behalf of others but contracts will be signed up to by all.

Commissioners should be clear about the services to be provided and the appropriate qualifications and standards that the services should adhere to. Schedules of anticipated activity should be included and monitored with providers at regular intervals. In addition, contracts should include detailed key service performance indicators that represent clinical effectiveness, value for money and user satisfaction.

PCTs and LAs should be mindful of the importance of the Impact/Compact on Relations between Government and the voluntary and community sectors in England when commissioning with the voluntary sector. Any new services contracted for from a voluntary sector organisation which are agreed as part of a local strategy, should be paid for, in full, by the statutory sector. This ensures a fair playing field for all providers and fair and transparent commissioning and procurement.

Managing demand and performance

Commissioners operationalise service level agreements and contracts through provider end of life care teams/GPs/MDT leads. Activity schedules will be included and will need to be monitored to assess need/demand for services and monitor performance of providers. Modelling may be undertaken based on local population and demographics.
Useful references:


Step 6 - Managing demand and ensure appropriate access to care
Establish strategies for care and resource utilisation to ensure that patients receive the most appropriate care in the right setting, ensuring that resources are used as effectively as possible.

Step 7 - Clinical decision making
Working with social services and other agencies where appropriate, individual needs assessments are carried out and patients and carers are advised on choices available.

Step 8 - Manage performance (quality, performance, outcomes)
Commissioners of end of life care services need to work to an agreed measurement framework aligned to the National End of Life Care Quality Markers to monitor and assess the impact of investment and outcomes achieved. Quality should be integral in all of the measures within the framework. The framework will be individual for each PCT and will directly reflect the service model commissioned. It is suggested that the framework is based on five domains - patient experience, organisational, clinical, activity and resource utilisation.

Below are examples of how the metrics could be applied to end of life care services.

- **Patient experience**
  Measured through carer and patient experience/satisfaction; including meeting the cultural and religious needs of the population also measured by looking at actual outcome for patient compared to care plan intentions.

- **Organisational**
  Measured through successful partnership working between acute trusts, PCT, Hospice at Home, hospices, LA nursing homes and extra care housing.

- **Clinical**
  The new care pathway should result in fewer unexpected exacerbations and/or symptoms and more planned interventions. Clinical audits of outcomes can be undertaken.
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- **Activity**
If successful, the new care pathway should allow for fewer deaths in hospital and more deaths at home. In addition, there should be fewer emergency admissions of people in their end of life phase. Deaths within 14 days of admission to hospital should be significantly reduced. Audits can be undertaken of the spread of the three tools, LCP, PPC and GSF.

- **Resources**
Measures should be identified which ensure that value for money is obtained when commissioning effective services.

Local end of life care/palliative care, trust end of life care team, Multi Disciplinary Teams (MDTs) and PBC monitor services against quality outcomes set out in Service Level Agreements (SLAs) and contracts and report to PCT contract lead. The PCT team assures quality to Trust Board where collective performance across the pathway will be reviewed and compared with outcomes of any national audits.

**Key questions to ask about the Service level Agreement**

1. Is it a clear and concise written document that explains what the commissioner wants and what the provider can supply?
2. Does it detail the processes that will be used by both parties?
3. Is there a clear mechanism for measuring performance?
4. Does it try to re-invent the wheel?

The following links may be useful to commissioners:


www.institute.nhs.uk/world_class_commissioning/world_class_commissioning/world_class_commissioning_home.html

www.ic.nhs.uk/commissioning

The PCT annual report/prospectus can be used to demonstrate progress to the public.
Key questions that commissioners may wish to ask providers regarding end of life care

1. What mechanisms are in place to identify patients who require end of life care?
2. How do providers demonstrate that care is co-ordinated across boundaries?
3. What percentage of patients are cared for by an MDT?
4. What percentage of patients have a completed care plan identifying their preferred priorities for care?
5. What services are available in the community 24/7 to enable people to live and die in the place of their choice?
   - a. nursing services including rapid response services
   - b. single point of contact
   - c. medical services
   - d. personal care services
   - e. access to pharmacy services and medicines out of hours
   - f. access to equipment required in the home without delay
   - g. what is the process for fast tracking continuing care?

Contributors

The National End of Life Care Programme team would like to acknowledge the contribution of the Department of Health, commissioning work group, the end of life care service specification working group and individual commissioners in producing this information for commissioning end of life care services.
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Useful links

NHS National End of Life Care Programme
www.endoflifecareforadults.nhs.uk/eolc/

Department of Health, National End of Life Care Strategy (2008)

Marie Curie Delivering Choice Programme
www.deliveringchoice.mariecurie.org.uk

Gold Standards Framework
www.goldstandardsframework.nhs.uk/

Liverpool Care Pathway of the Dying patient (LCP)
www.mcpcil.org.uk/liverpool_care_pathway

Preferred Priorities for Care
www.endoflifecareforadults.nhs.uk/eolc/ppc.htm

The ‘Commissioning Framework for Health and Well-Being’ sets out the eight steps that Health and Social Care should take in partnership to commission more effectively.

It is aimed at commissioners and providers of services in health, social care and local authorities. It is part of the White Paper, our health our care our say implementation.

Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own
www.opsi.gov.uk/si/si2000/20000617.htm

The Cancer Commissioning Toolkit is a “one stop solution” for access to cancer commissioning information to inform decision making. This toolkit brings together information from a range of different sources, in a user friendly format
www.cancertoolkit.co.uk

The guidance contains suggestions for questions which commissioners can ask service providers and advice on how to interpret data. It contains information which may be useful to commissioners regarding end of life care.

Integrated care network
www.networks.csip.org.uk/icn/
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Appendix A

Generic example service specification for commissioning end of life care for social and health care commissioners

This is a broad framework for health social care, voluntary and independent service delivery, to develop joint local end of life care service specifications. It could also be used to negotiate the range of service to be provided by care homes. It recognises the importance of both medical and social models of care as an important part of the approach.

1. Description of the service to be jointly provided
The aim of the service is to improve end of life care for all irrespective of diagnosis and seeks to provide greater choice for people in their place of care and death.

This is underpinned by people having access to high quality end of life care and being able to actively participate in decisions about where they wish to live and die.

Fundamental to this is early identification; assessment of need; implementing an advance care plan; an ongoing assessment co-ordination; communication and co-ordinated multi-agency approach to care. Care must be provided by a competent trained workforce.

2. National drivers
The outcomes have been informed by current national guidance

Department of Health:
National End of Life Care strategy (July 2008)
High Quality Care for All (2008)
Our health, our care, our say (2006)
Our health, our care, our community (2006)
NICE guidance supportive and palliative care for cancer patients (2004)
Mental Capacity Act (2005)
Commissioning a patient led NHS (2005)
Standards for better health (2004)
National Minimum Standards and supporting regulations (2008)
National Service Frameworks (2007)
• older people
• renal part II
• cancer plan
• long term conditions
Building on the best choice responsiveness and equity (2003)
New Ambitions in Older Age (2006)
National Stroke Strategy (2007)
2.1 Outcomes

- individualised care
  - people being treated as an individual with dignity and respect incorporating physical, psychological, social, practical and spiritual care needs
  - relatives and carers to feel welcome and engaged in care
  - initial and ongoing assessment
- organisational arrangements
- integration of health, housing and social care service delivery
- use of integrated governance to promote safe care
- workforce planning, reconfiguration and link to training and development
- reduction in the number of emergency admission for acute care for those who have expressed a wish to die at home or their normal place of residency
- reduction in the number of people transferred from care homes to acute care in the last week of life
- agreed patient transfer protocol for end of life care
- people receive improved palliative care services

3. Places where services are to be provided

Care is provided in support of people’s preferred choice where possible and if this cannot be achieved the reasons are clearly stated and the next best option considered.

4. Environmental factors

- environment is safe and clean
- providers should comply with the relevant standards as laid out by Health Care commission and/or Commission for Social Care Inspection and/or Patient Environmental Action team and all other legislative requirements

5. Duration

Individualised care plans should enable an individual to be supported 24/7

6. Description of eligible service user

All adults nearing the end of life irrespective of diagnosis, in a defined locality of the service (HRG and tariff linkage explanation to be included)

7. Service user access to services

- clear directory of services
- access to core services
- access to specialist palliative care services
- access to other relevant specialist services

8. Timing of referrals and of access

- protocol for referrals to services
- agreed response time from referral for differing elements of palliative care services
- agreed criteria for access
9. Explanation of how providers will seek to meet service users needs
   • methods for seeking people’s views in planning and delivering services and the outcomes
   • single written plan signed up to by providers and service users within agreed budgets

10. Number of people who may be referred for access to the services and during what periods
    Useful sources of information may include population based needs assessment, Office of National Statistics
    and Public Health information to draw rough estimates of likely need for planning purposes?

11. Special delivery requirements
    • An agreed care pathway has been developed for front line staff eg care workers which includes support
      from other health and social care professionals, access to expert knowledge education and training
    • The pathway should have explicit decision making appropriate to the stage of the condition, including
      out of hours support from primary care to specialist palliative care, ambulance services and NHS Choices.
    • This should be supported by locally agreed integrated policies and procedures.
    • There needs to be clear protocols to support residential home staff and extra care housing staff in caring
      for people at the end of their lives to prevent them being moved eg access to nursing care.
    • In reach clinical support and access to advice 24/7 for care homes and extra care housing.
    • Shared records across all care providers. Single assessment should support this element.
    • Evidence of application of NICE guidance (palliative and supportive care) and all relevant NSFs.
    • Consideration is given to the use of tele care/tele medicine.

12. Special equipment to be used
    • core and specialist equipment is defined
    • referral systems are clear
    • delivery times for urgent and less urgent items are agreed
    • schedules to include maintenance servicing and replacement
    • out of hours is included for urgent items

13. Special personnel requirements
    Access to specialist palliative care personnel for non cancer service users

14. Key performance indicators
    Monitoring and evaluation of the joint commissioning agreement/service specification
    • evidence of joint health and social care commissioning
    • evidence of clinical engagement in the commissioning process
    • evidence of user involvement in the commissioning process
    • evidence of attainment of Standards for Better Health
    • evidence of provider quality assurance processes
    • definition of number of eligible service users
    • evidence of actual numbers of service users who have accessed services
    • evidence of number of service users with an individualised care plans
    • evidence of reduced number of emergency admissions
    • evidence of roll out of end of life care models in locality*
    • evidence of patient safety measures/models eg care bundle approach
    • audits eg admission rates to acute care, place of death, carer’s survey
* The criteria for the roll out of an end of life care model tool within a service is as follows

GSF - that a register which identifies palliative care patients and a multi-disciplinary meeting has been established
LCP - that the pathway has been implemented
PPC - that the tool has been implemented

References

3 Department of Health. (2003). Building on the best: Choice, responsiveness and equity in the NHS.