

**NHS England
Specialist Level Palliative
Care:
Information for
commissioners
April 2016**



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Part One

1. Background

This guidance has been prepared by expert reference groups supported by NHS England, and led by the National Clinical Director for End of Life Care, in response to requests by commissioners, service providers and clinicians for a clear description of what should be provided in terms of specialist level palliative care for people with progressive, life-limiting illness who have complex needs, and/or those whose usual care teams require the expert advice, guidance and support of those with specialist knowledge and skills in palliative care.

It was developed following wide engagement with commissioners, service providers, clinicians and people with personal experience based on an earlier draft service description (2014), and further engagement with commissioners and service users in late 2015 and early 2016.

Throughout this document, the term 'person' refers to people with progressive life-limiting illness to reflect the wide range of settings where specialist level palliative care is provided. This includes people with cancer and the growing number with life threatening non-cancer conditions and comorbidities that limit their life. Involving the person in decision making is key to delivering care. Part of this process is telling them about how their information will be used. An assumption is that the person's family, carers and those important to them are included in decision making to the extent that the individual wishes them to be. This document applies mainly to adults, but includes TYA (Teenage and Young Adults) and young people undergoing transition into adult services.

This guidance document is intended as a framework from which local services can be shaped. It aims to encourage and support dialogue between commissioners and service providers about what is required to meet the needs of adults in their locality who require specialist level palliative care. In many instances, such commissioning may require collaboration between a number of commissioners and service providers to achieve this in a coordinated way, avoiding unnecessary duplication.

Although the sample specification has been developed using an NHS template, its content can be used by other commissioners as appropriate and it aims at all times to acknowledge the integrated multi-agency and cross sector nature of commissioning and delivery of specialist level palliative care services and support, which includes the NHS, Local Authorities and the voluntary sector. The specification may be appended to the NHS Contract.

Due to its nature, palliative care services have to deal a number of complex issues around the use and sharing of patient information. Examples include capacity and sharing with carers and family members. This complexity needs to be considered to help deliver the best service possible for patients. Please do remember the following when designing your service specification:

- Consider the needs and flows of patient data at the earliest possible stage

- The law, principles and policy of information governance set out the steps that will need to be taken to enable appropriate information sharing
- Engaging, informing and enabling patients is vital both generally and specifically for the use and sharing of patient data

For further information, you may wish to contact your local information governance resource for assistance. The latest Information Governance guidance, support and news is available from the Information Governance Alliance, visit <http://systems.hscic.gov.uk/infogov/iga> for more information.

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it;
- Given regard to the need to reduce inequalities between individuals in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this might reduce health inequalities.

To provide clarity for commissioners, for the purposes of this document, the more common term of 'Specialist Palliative Care' is referred to as 'Specialist Level Palliative Care'. Similarly 'Generalist Palliative Care' is referred to as 'Core Level Palliative Care' to highlight the universal need for a basic or core level of palliative and end of life care for all those facing progressive life-limiting illnesses.

2. Information for Commissioners about Specialist Level Palliative Care

People who face progressive life-limiting illness, with or without comorbidities, require different levels of health and social care at different points in their illness. Apart from care and treatment that is specific to their underlying condition(s), they are likely to have needs that are often referred to as palliative or end of life care, especially as they approach the last year(s) of their lives. Throughout the trajectory of their illness, sometimes episodically, sometimes for prolonged periods, they may require expert assessment, advice, care and support from professionals who specialise in palliative care. These professionals work as part of multidisciplinary teams providing the service directly to the person with need, and those important to them, and/or supporting other care teams to do so.

Specialist level palliative care services are therefore an integral and core part of resourcing care for people who have been assessed as having more complex or complicated palliative care needs. Commissioners may find that they need to work with a range of providers to secure these specialist resources, including services for the homeless, gypsy and traveller communities, those in secure and detained

settings, and people within mental health care settings. To be effective and efficient these services need to be commissioned and offered in a way that is comprehensive and coordinated. In most localities this is likely to require collaboration and cooperation between a number of service providers and commissioning which encourages, facilitates and supports that way of working.

Many staff currently working within a specialist level palliative care service hold joint NHS and voluntary sector contracts, or work for a service through a service level agreement (SLA) with the employing service, which cover services in the community, residential facilities, hospices and acute hospitals simultaneously. Formal arrangements ensure that they come together to plan and provide a holistic service to a person with specialised level palliative care needs following referral and assessment.

Commissioners may wish to note that specialist palliative care providers within hospices, whether NHS or voluntary sector, make significant funding contributions to the delivery of specialist level palliative care services through raising charitable funds. Reflecting this provision in activity modelling and making this explicit in the contract will help to make it clear – for all parties - the scope and focus of the contract and what deliverables the commissioner may expect. Many of these organisations also provide services that are additional to specialist level palliative care e.g. lymphoedema services, which will need to be commissioned separately.

2.1 Specialist Level Palliative Care (SLPC) Services

Specialist level palliative care is required by people with progressive life-limiting illness, with or without comorbidities, where the focus of care is on quality of life and who has unresolved complex needs that cannot be met by the capability of their current care team. These needs may be physical, psychological, social and/or spiritual. Examples include complex symptom, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions.

Specialist level palliative care is delivered by a multidisciplinary team (MDT) of staff with the requisite qualifications, expertise and experience in offering care for this group of people, to support them to live as well as possible during their illness ensuring their comfort and dignity are maintained as they come to the end of their lives. Input from specialist level palliative care professionals to the care of a person must be based on the needs of the person and not the illness they have.

The Specialist Level Palliative Care (SLPC) MDT works with the person to develop their individualised plan of care, including where they prefer it to be delivered. This plan is regularly reviewed to reflect the changing needs of the person and to ensure that care is provided by the most suitable health or social care professional(s). This may be facilitated through shared service agreements. The main components of specialist level palliative care include, but are not limited to:

- in depth specialist knowledge to undertake assessment and management of physical, psychological and spiritual symptoms to reduce symptoms, suffering and distress;
- supporting analysis of complex clinical decisions-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment;

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- providing care and support to those important to the person receiving care, including facilitating bereavement care; and
- providing specialist advice and support to the wider care team who is providing direct core level palliative care to the person.

A specialist level palliative care service is usually provided in three main ways:

- **Specialist level palliative care liaison work to support the person's care by their usual caring team:** this may be undertaken in the hospital or in the community, but both involve the clinical responsibility remaining with the person's key consultant/GP. A specialist assessment can be undertaken leading to recommendations for care that may be provided directly to the person or carried out by the usual caring team who retain clinical responsibility. The person's needs should be reviewed at MDT meetings constituted to consider all specialised level aspects of their care which includes as necessary a palliative care specialist contribution into the meetings held by the usual caring team. Examples may include disease specific multidisciplinary meetings (MDMs) in hospital, Gold Standard Framework of Supportive Care meetings in primary care, and individual review meetings in residential facilities.
- **Specialist level in-patient palliative care:** this may be delivered in beds in a palliative care unit in hospital or a hospice, or may be delivered by the expert team in the person's usual place of residence in some rural localities. The person's needs are assessed and their care is planned and delivered by medical, nursing and other care staff who specialise in palliative care. Arrangements should be in place for specialist level support to the wider care team at all times (24/7). The service should have access to all essential specialists to constitute a specialist level palliative care team.
- **Specialist level out-patient services:** people may have their needs assessed and their care planned by specialists working in out-patient clinics or Day Centres in a variety of settings. Specialist level palliative care out-patient clinics and therapies may be provided by relevant clinicians expert in palliative care from medicine, nursing, Allied Health Professionals, as well as psychology, spiritual advisors or social work that match both the needs of the person and people important to them and their carers. Clinical accountability and responsibility for the coordination and delivery of the person's individualised care plan is shared between the specialist clinician and the person's primary care team in this situation, and clearly agreed arrangements must be in place.

The specialist level palliative care multidisciplinary team also plays a lead role in developing best practice in palliative and end of life care and contributing to the delivery of education, training and continuing professional development to the wider workforce, and time is required for undertaking these well.

It is important that the evidence base for best practice is maintained and extended through an active engagement and contribution to Clinical Research Networks and National Audits. Specialist level services are expected, as a mark of their

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specialisation to participate in a rolling programme of evaluation using validated patient and colleague-centred outcome measures to demonstrate their effectiveness in direct and indirect care. Commissioners may wish to take account of the resources needed for these activities within the service specification agreed locally.¹

Regardless of the service model, to be considered as a provider of specialist level palliative care, the following specialists must be included in the SLPC MDT leading the service:

- Consultants in Palliative Medicine – who may provide clinical leadership across a number of locality teams. In some exceptional circumstances services are currently led by other medical staff with considerable experience in palliative care who may not be on the specialist register or hold a CCT (Certificate of Completion of Training) in Palliative Medicine. This situation is likely to be historic and may be acceptable in local circumstances at present, however as future opportunity arises the appointment of a Consultant in Palliative Medicine should be made.
- Nurses specialising in palliative care – where a nurse is leading a service or has a role with a significant autonomous advisory component, such as in community settings, hospital palliative care teams or nurse-led outpatient clinics, it is expected that the nurse would be at the level of Clinical Nurse Specialist (CNS) in palliative care or consultant nurse in palliative care. These nurses may have lower grade nurses responsible to, or supervised by, them to support the delivery of services. In other settings such as palliative care in-patient units, nurses who have received specialist level palliative care training will be part of the SLPC MDT.
- Within a locality the SLPC MDT should have formal arrangements in place (e.g. SLAs) to include input from the following professionals/services, who must have specialist skills and experience in palliative care:
 - Physiotherapists;
 - Occupational Therapists;
 - Social Workers;
 - Spiritual and psychological services (level 3 or 4).
- The SLPC MDT should also have formal access to advice and input provided by the following professional groups with specialist knowledge:
 - Dieticians;
 - Speech and Language Therapists;

¹ It is important to recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons. These may include historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect. It is vital that these services are not destabilised and so this sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working. Commissioners can play a pivotal role in bringing providers together and facilitating such dialogue where this is not already happening.

- Pharmacists; and
- Specialists in interventional pain management.

2.2 Core Level Palliative Care Provision

All professionals and staff in health and social care have a role in the effective provision of palliative and end of life care services across all care settings. The SLPC MDT are expected to proactively support, advise, assist and guide education and training to these staff.

Professionals and staff working in services providing core level palliative and end of life care make an important contribution and may be specialists in other disciplines and services; however unless they are led by a SLPC MDT they cannot be considered to provide a specialist level palliative care service.

2.3 Other Palliative Care Services

Palliative care services whether specialist level or not, may also offer other services funded and commissioned through other mechanisms, for example:

- Lymphoedema services
- Bereavement support
- Complementary and comfort therapy
- Creative therapies

3. Links to national work

3.1 Ambitions for Palliative and End of Life Care

The National Palliative and End of Life Care Partnership published 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020' in September 2015. It is aimed at local health, social care and community leaders. It builds on the Department of Health's 2008 National Strategy for End of Life Care and the NHS Five Year Forward View. It responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012. It encompasses all elements of palliative and end of life care for all age groups within its scope.

The Ambitions framework underpins the contribution of specialist level palliative care services as an integral part of the overall care in meeting the person's changing needs as their illness progresses, and those of families, carers and those important to the person, and other professionals who have primary responsibility for a person's direct care.

The overarching vision of the Ambitions framework is:

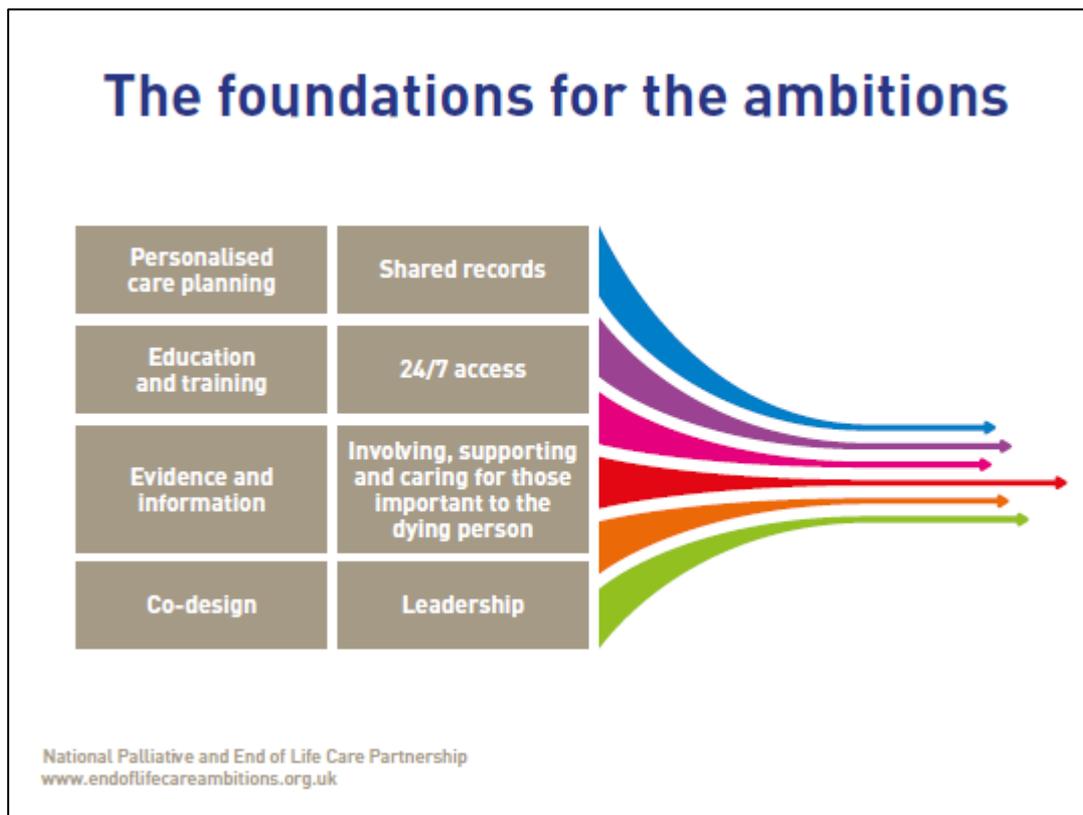
“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).²”

The Ambitions framework sets out six ambitions to make that vision a reality:



² National Voices and the National Council for Palliative Care (NCPC) and NHS England (2015). Every Moment Counts: A narrative for person centred coordinated care for people near the end of life. London: National Voices. Available at: www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-of-life-calls-brave-conversations (accessed on 9 Mar 2016).

These ambitions have to be underpinned by eight foundations, all of which need to be in place to deliver rapid and focused improvement:



For each ambition a number of 'building blocks' have been identified of particular relevance to that ambition.

To support commissioners and demonstrate the relevance of the descriptors, links have been made to the Ambitions framework within the specialist level palliative care service description in Sample Schedule 2.

3.2 Palliative Care Currencies

An independent Palliative Care Funding Review (PCFR) reported in July 2011 on proposals for a per-patient funding model, with tariffs based on case complexity and other factors. A pilot data collection was undertaken to address the lack of robust cost and activity data within the sector. The data collection was based upon phase of illness, functional status, problem severity and family care giving strain. The findings from the pilot data collection supported those made in a similar programme in Australia.

The data collection was undertaken to gather a better understanding of the resources utilised in the provision of palliative care services. The analysis of these data enabled a set of palliative care currencies (units of healthcare that are clinically similar and have broadly similar resource needs) to be developed. These are being tested in a number of sites across England during 2015/16, following which a definitive set of

currencies will be published. There is no tariff (prices) linked to these currencies at present. The currencies will be an important requirement, whatever funding model is used for palliative care in the future.

Further details can be found in the document NHS England 'Developing a new approach to palliative care funding' March 2015. <http://www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-approch-pallitv-care-fund.pdf>.

3.3 Palliative Care Clinical Data Set

NHS England has collaborated with the National End of Life Care Intelligence Network, two voluntary sector partners (Hospice UK and National Council for Palliative Care) and an academic partner (Cicely Saunders Institute) to develop an individual level palliative care clinical data set. The project, led by Public Health England (PHE), piloted the technical aspects of the data set with a small number of palliative care organisations around the country in 2015/16. This data set, and guidance for its use, will be made available for use by clinicians, service providers and commissioners in 2016. Although this will be a voluntary process for localities, its use will minimise the burden of data collection as the data items are aligned with data required to support the use of palliative care currencies as well as individual level clinical outcomes.

3.4 Links to other documents and sources of support:

- *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* (Sept 2015). National Palliative and End of Life Care Partnership: www.endoflifecareambitions.org.uk
- *Quality Standard QS13 End of Life Care for Adults* (Nov 2011). NICE: <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13>
- *One Chance to Get it Right: Improving people's experience of care in last few days and hours of life* (June 2014) [see Annex E for guidance to commissioners and service providers]. Leadership Alliance for the Care of Dying People: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf
- *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives* (December 2012). Developed in collaboration with: Association for Palliative Medicine of Great Britain and Ireland, National Nurse Consultant Group (Palliative Care), Marie Curie Cancer Care, National Council for Palliative Care & Palliative Care Section of the Royal Society of Medicine: <http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf>
- *Compassion in Practice* (December 2012). NHS Commissioning Board: <http://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf>
- *Actions for End of Life Care: 2014-16* (November 2014). NHS England: <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

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- *Guidance on Equality and Health Inequalities duties for commissioners* (December 2015). NHS England:
<https://www.england.nhs.uk/ourwork/gov/equality-hub/legal-duties/>
- *Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK* (June 2013). Public Health England:
<http://www.endoflifecare-intelligence.org.uk/resources/publications/palliative>
- *Treatment and Care Towards the End of Life* (May 2010). GMC:
http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
- Reports and statistics relating to palliative care. Public Health England:
<http://www.endoflifecare-intelligence.org.uk/search/palliative+care>
- National Council for Palliative Care <http://www.ncpc.org.uk/>
- Association of Palliative Medicine <http://apmonline.org/>
- Hospice UK <http://www.hospiceuk.org/>

Part Two

1. Sample Schedule 2 Specification

SCHEDULE 2 – THE SERVICES

A. Service Specifications³

Mandatory headings 1 – 4: mandatory but detail for local determination and agreement

Optional headings 5-7: optional to use, detail for local determination and agreement.

All subheadings for local determination and agreement

Service Specification No.	
Service	Specialist level Palliative Care
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

Local detail should be added below the mandatory **green** headings. Text in **red** is guidance for commissioners and should be deleted before the service specification is included in an NHS Standard Contract. Text in **black** is suitable for inclusion in the NHS Standard Contract but may be varied locally by commissioners.

³ This is a sample specification, it is not mandatory.

1. Population Needs

1.1 National/local context and evidence base

National

People who face progressive life-limiting illness, with or without comorbidities, require different levels of health and social care at different points in their illness. Apart from care and treatment that is specific to their underlying condition(s), they are likely to have needs that are often referred to as palliative or end of life care, especially as they approach the last year(s) of their lives. Throughout the trajectory of their illness, sometimes episodically, sometimes for prolonged periods, they may require expert assessment, advice, care and support from professionals who specialise in palliative care. These professionals work as part of multidisciplinary teams, providing the service directly to the person and those important to them and/or supporting others to do so.

Specialist level palliative care services are therefore an integral and core part of resourcing care for these people. Many commissioners may find that they need to work with a range of providers to secure the specialist resources to provide the required services, including services for the homeless, gypsy and traveller communities, those in secure and detained settings, and people within mental health care settings. To be effective and efficient these services need to be commissioned and offered in a way that is comprehensive and coordinated. In most localities this is likely to require collaboration and cooperation to meet need in a way that is effective, efficient, sustainable and supports continuing quality improvement.

The Specialist Level Palliative Care (SLPC) MDT works with the person to develop their individualised plan of care, including where they prefer it to be delivered. This plan is regularly reviewed to reflect the changing needs of the person and to ensure that care is provided by the most suitable health or social care professional(s) and this may be facilitated through shared services agreements. The main components of specialist level palliative care include, but are not limited to:

- in depth specialist knowledge to undertake assessment and management of physical, psychological and spiritual symptoms to reduce symptoms, suffering and distress;
- supporting analysis of complex clinical decisions-making challenges where medical and personal interests are finely balanced by applying relevant ethical and legal reasoning alongside clinical assessment;
- providing care and support to those important to the person receiving care, including facilitating bereavement care; and
- providing specialist advice and support to the wider care team who is providing direct core level palliative care to the person

A specialist level palliative care service is usually provided in three main ways:

- **Specialist level palliative care liaison work to support the person's care by their usual caring team:** this may be undertaken in the hospital or in the community, but both involve the clinical responsibility remaining with the

person's key consultant/GP. A specialist assessment can be undertaken leading to recommendations for care that may be provided directly to the person or carried out by the usual caring team who retain clinical responsibility. The person's needs should be reviewed at MDT meetings constituted to consider all specialised level aspects of their care which includes as necessary a palliative care specialist contribution into the meetings held by the usual caring team. Examples may include disease specific multidisciplinary meetings (MDMs) in hospital, Gold Standard Framework of Supportive Care meetings in primary care, and individual review meetings in residential facilities.

- **Specialist level in-patient palliative care:** this may be delivered in beds in a palliative care unit in hospital or hospice, or may be delivered by an expert team in the person's usual place of residence in some rural localities. The person's needs are assessed and their care is planned and delivered by medical, nursing and other care staff who specialise in palliative care. Arrangements should be in place for specialist support to the wider care team at all times (24/7). The service should have access to all essential specialists to constitute a specialist level palliative care team.
- **Specialist level out-patient services:** people may have their needs assessed and their care planned by specialists working in out-patient clinics or Day Centres in a variety of settings. Specialist level palliative care out-patient clinics and therapies may be provided by relevant clinicians expert in palliative care from medicine, nursing, Allied Health Professionals, as well as psychology, spiritual advisors or social work that match both the needs of the person and people important to them and their carers. Clinical accountability and responsibility for the coordination and delivery of the person's individualised care plan is shared between the specialist clinician and the person's primary care team in this situation, and clearly agreed arrangements must be in place.

Commissioners should allow for the lead role the SLPC MDT has in developing best practice in palliative and end of life care and contributing to the delivery of education, training and continuing professional development to the wider workforce. It is important that the evidence base for best practice is maintained and extended through an active engagement and contribution to Clinical Research Networks and National Audits. Specialist level services are expected, as a mark of their specialisation to participate in a rolling programme of evaluation using validated patient and colleague-centred outcome measures to demonstrate their effectiveness in direct and indirect care.

The underpinning evidence base for this specification includes:

- National End of Life Care Strategy (2008);
- NICE Quality Standard for End of Life Care for Adults (Nov 2011);
- One Chance to Get it Right: Improving people's experience of care in last few days and hours of life (June 2014). Leadership Alliance for the Care of Dying People;

- Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020 (2015).

Commissioners should recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons. These may include historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect. It is vital that these services are not destabilised and so this service specification is an indicator for a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working. Commissioners also play a pivotal role in bringing providers together and facilitating such dialogue where this is not already happening.

Local

Local strategies, responses to national guidance, data (including patient experience or VOICES-SF surveys) and narrative to be inserted here.

Local commissioning arrangements can be usefully framed around the ambitions and their foundations for palliative and end of life care set out in the part 1 guidance.

Data relating to local context may be contained in the CCG Outcomes Tool in the NHS Outcomes Framework across domains 2 to 5 – SLPC services are not specifically mentioned however some of the indicator set under domain 2 'Enhancing quality of life for people with long term conditions' may be applicable and domain 4 'Ensuring that people have a positive experience of care' has a specific outcomes indicator 'Improving experience of care for people at the end of their lives'.

It would be beneficial for the service specification to be linked to other local plans, e.g.:

- **Joint Strategic Needs Assessment (JSNA);**
- **public health;**
- **workforce planning;**
- **community adult health services;**
- **cancer;**
- **learning disabilities;**
- **dementia;**
- **continuing care;**
- **urgent and emergency care; and**

- **primary care.**

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions: <ul style="list-style-type: none"> • Ensuring people feel supported to manage their conditions; • Improving functional ability in people with long term conditions; • Reducing time spent in hospital by people with long term conditions; • Enhancing quality of life for carers. 	Y
Domain 3	Helping people to recover from episodes of ill-health or following injury: <ul style="list-style-type: none"> • Improving outcomes from planned treatment. 	Y
Domain 4	Ensuring people have a positive experience of care: <ul style="list-style-type: none"> • Improving the experience of care for people at the end of their lives. 	Y
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm: <ul style="list-style-type: none"> • Reducing the incidence of avoidable harm. 	Y

2.2 Local defined outcomes

Specialist level palliative care is commissioned and delivered across both health and social care. Inclusion of the Adult Social Care Outcomes Framework Domains and Indicators may be useful.

Local specific outcomes and performance measures are agreed between the commissioner and service providers based on existing local performance and baseline data. Suggested measures could be aligned to the six ambitions in the ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’. For example:

- **Evidence of a personalised approach to care, e.g. as measured through using person-centred outcome and experience measures.**
- **Evidence of steps taken to establish the extent to which the service provides fair access, and any measures taken to improve this.**
- **Evidence of effective efforts on maximising the person’s comfort and wellbeing using established validated outcome measures, e.g. the Integrated Palliative Outcome Scale (IPOS).**

- **Extent to which the service provider engages with local systems to share information that supports better coordination of care, e.g. through participation in Electronic Palliative Care Coordinating Systems (EPaCCS) or equivalent as they are established.**
- **Evidence, using outcome measures, of education and training, other staff support measures and appraisal systems for own staff, and contribution to the education and training of wider palliative and end of life care teams in the locality.**
- **Evidence of actions that the service has taken, or plans to take, in relation to community engagement and understanding of palliative and end of life care.**

Also:

- **CQC requirements – Provider Handbook Measures;**
- **NICE guidance and quality standards, in particular:**
 - **NICE Supportive and Palliative Care for Adults with Cancer (2004) – note: currently being revised to cover adults with all conditions (anticipated Jan 2018);**
 - **NICE Clinical Guidelines for Care of the Dying Adult (2015);**
 - **NICE Quality Standard for End of Life Care (2011).**

3. Scope

3.1 Aims and objectives of service

‘I can make the last stage of my life as good as possible because everyone works together confidently to help me and the people who are important to me, including my carer(s)’ Extract from ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020 (2015)’

Specialist level palliative care is delivered across settings where people have need and includes acute, hospice and community settings extending to marginalised groups such as the homeless, gypsy and traveller communities, those in secure and detained settings, and individuals within mental health care settings. Those working in these specialist level palliative care services have specialist qualification, skills and experience to provide clinical leadership and deliver care both directly and indirectly. They provide direct specialist level palliative care to people, their carers and those important to them, related to need. Indirectly they also provide clinical support, advice and education to other professionals to deliver core level palliative and end of life care.

The objectives of the service are to provide people in need of specialist level palliative care wherever they are with access to timely and sometimes repeated

and/or ongoing expert assessment, advice and care, based on the best levels of evidence available.

3.2 Service description

These should be worked through and adapted to available or planned local services because they may result in additional resource and cost pressures to services provided by small hospices and charities. Not all services are funded through the NHS, nor are all NHS services fully funded through statutory resources.

The service characteristics are structured below to make the links to ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015- 2020’ more explicit:

1. Each person is seen as an individual;
2. Each person gets fair access to care;
3. Maximising comfort and wellbeing;
4. Care is coordinated;
5. All staff are prepared to care; and
6. Each community is prepared to help.

The service will:

Service Characteristic	Link to Ambitions Framework
REFERRAL	
1. Have defined referral criteria which include specialist level palliative care for: <ol style="list-style-type: none"> a. the person with progressive life-limiting illness, with or without comorbidities, where the focus of care is on quality of life, including complex symptom control; b. the person with unresolved complex needs that cannot be met by the capability of the current team. These needs may be physical, psychological, social and/or spiritual. Examples include complex symptom, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions. 	Ambition 2
2. Have a referral process which includes a system for prioritisation that is auditable and linked to patient outcomes.	Ambitions 2 and 4
3. Accept referrals based on need rather than disease label.	Ambition 2
ASSESSMENT AND CARE	
4. Provide medical and nursing cover to allow assessment, advice and active management seven days a week, and 24 hour telephone advice. This may require a collaborative arrangement between a number of service providers and joint commissioning, working towards provision of 24 hour access to specialist level palliative care advice from a consultant in palliative medicine, including face to face assessment	Ambitions 2, 3 and 4

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where this is necessary.	
5. Have timely access to medication and equipment to meet the needs of the person.	Ambitions 2, 3 and 4
6. Work in partnership with people, those important to them and their carers to develop and support personalised care planning, including identifying and recording personal preferences, and helping them navigate to services that will deliver the required information and care, at any time of day or night that that is needed.	Ambitions 1 and 4
7. Identify and assess the needs of those important to the person, including psychological and social needs, and provide support, preparation for the caring role at whatever level is required to be undertaken, and facilitate access and signposting to other services, including pre-bereavement and bereavement.	Ambitions 1, 3 and 6
8. Be responsive to age, culture, faith and ideology, disability, sexuality and gender issues in relation to palliative care, dealing with them in a sensitive and inclusive way, including access to advocacy, translation and interpretation services.	Ambitions 1 and 2
9. Use a multi-disciplinary approach to care, with a competent workforce with recognised expertise in specialist level palliative care that uses evidence based best practice. People must be reviewed, and discussed by the multidisciplinary team regularly, as defined by local operational policy.	Ambitions 3 and 5
COORDINATION AND PARTNERSHIP WORKING	
10. Work in partnership with other services to meet the person's needs, ensuring that assessments and personalised care planning are reliably communicated and coordinated with other services involved with the person in a timely fashion.	Ambitions 1 and 4
11. Access and use an electronic palliative care coordination system to facilitate this coordination, as such systems become available locally, and where the individual agrees to its use.	Ambitions 1 and 4
12. Have a defined operational policy for multi-disciplinary and partnership working to include arrangements for multidisciplinary team meetings, and communication across care settings and organisational boundaries within a quality and governance framework.	Ambition 4
LEADERSHIP AND GOVERNANCE	
13. Have specialist level palliative care clinical leadership at strategic level (e.g. Senior Management Team level within organisations).	Ambition 5
14. Have a suitably resourced quality, IT and governance framework, which should include: <ul style="list-style-type: none"> a. audit and Quality Improvement methodology; b. patient centred outcome and experience measures and user feedback; c. data collection and sharing to aid service; improvement at local and national level; d. adequate access to electronic clinical information, including pathology and imaging; e. arrangements for engagement in research in line with the service's objectives; and f. arrangements for all staff and volunteers to be appropriately 	Ambitions 1, 2, 4, 5 and 6

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trained and supported to give competent, reliable, confident and compassionate care.	
15. Be configured and established to lead and/or contribute to the delivery of education, training and continuing professional development (CPD) to the wider workforce regarding best practice in palliative and end of life care.	Ambition 5
16. Use the growing evidence base to enable the development of innovative practice.	Ambitions 3 and 5
17. Contribute to, and encourage, public understanding, involvement and engagement in developing compassionate communities, including local awareness, practical support and planning for future care.	Ambition 6

Staffing required to support the service description:

To provide a safe and effective specialist level palliative care service it must be adequately resourced to meet the characteristics of the service commissioned, taking into account the need for 24/7 cover, and cover for study leave, holidays and other absences.

There is no solid evidence or benchmark on staffing levels and ratios for commissioners and service providers as these are dependent on the model of service commissioned, local circumstances and resources already in place. Currently data that link staffing levels to outcomes are not available. Locally, staffing levels must be based on an assessment of the known and growing unmet needs of the population for these services, its geographical spread and locally available case mix data.

Staffing levels need to be adequate to allow specialist staff to undertake activities and CPD to maintain their own skills commensurate with their role and responsibility. If the SLPC MDT members have multiple employment contracts there will be a need to ensure that these activities are formalised and coordinated, and the responsibility appropriately shared between the organisations involved.

Specialist level palliative care is delivered by a multidisciplinary team (MDT) of staff with the requisite qualifications, expertise and experience in offering care for people with progressive life-limiting illness, with or without comorbidities, to support them to live as well and as long as possible during their illness ensuring their comfort and dignity are maintained as they come to the end of their lives.

Regardless of the service model, to be considered as a provider of specialist level palliative care, the following specialists must be included in the SLPC MDT leading the service:

- Consultants in Palliative Medicine - who may provide clinical leadership across a number of locality teams. In some exceptional circumstances services are currently led by other medical staff with considerable experience in palliative care who may not be on the specialist register or hold a CCT (Certificate of Completion of Training) in Palliative Medicine. This situation is likely to be

historic and may be acceptable in local circumstances at present, however as future opportunity arises the appointment of a Consultant in Palliative Medicine should be made.

- Nurses specialising in palliative care – where a nurse is leading a service, or has a role with a significant autonomous advisory component, such as in a community or hospital liaison settings or nurse-led outpatient clinics, it is expected that the nurse would be at the level of Clinical Nurse Specialist (CNS) in palliative care or consultant nurse in palliative care. These nurses may have lower grade nurses responsible to, or supervised by, them to support the delivery of services. In other settings such as in-patient units, nurses who have received specialist level palliative care training will be part of the SLPC MDT.
- Within a locality the SLPC MDT must have formal arrangements in place (e.g. SLAs) to include input from the following professionals/services who must have specialist skills and experience in palliative care:
 - Physiotherapists ;
 - Occupational Therapists;
 - Social Workers;
 - Practitioners with recognised post graduate qualifications in psychological care and experience at level 3 and 4;
 - Practitioners with spiritual care experience at level 3 or 4.
- The SLPC MDT must also have formal access to advice and input provided by the following professional groups with specialist knowledge:
 - Dieticians;
 - Speech and Language Therapists;
 - Pharmacists; and
 - Specialists in interventional pain management.

There must be adequate administrative and secretarial support for the SLPC MDT so that professionals can carry out their work efficiently and effectively, and data collected for service monitoring, audit and quality purposes.

It should also be recognised that as specialists, the SLPC MDT has obligations, not only to provide education and training for the wider workforce delivering core palliative care, but also to support and contribute to education and training at pre-qualifying and post-qualifying levels, especially in medicine, nursing and allied health professions. The time and resources needed to carry out these obligations fully should be taken into account in discussions about commissioning for service, and education and training.

3.3 Population covered

This specification is for individuals who meet the agreed referral criteria for

specialist level palliative care services (see Service Characteristic Para 1 above). Reference should be made to geographical boundaries such as areas covered by GPs or CCGs

3.4 Any acceptance and exclusion criteria and thresholds

The providers of specialist level palliative care services will have clear acceptance criteria that are transparent and made clear to referrers.

Commissioners may wish to insert locally agreed referral mechanisms and thresholds that are audited regularly.

Commissioners may wish to consider:

- **What happens to those instances where people are not eligible for referral;**
- **What information is needed locally on services available and how they are accessed;**
- **Support for integrated cross sector/agency working.**

3.5 Interdependence with other services/providers

Services required by people in need of specialist level palliative care span different sectors and settings. Providers shall adopt an integrated approach to planning, contracting and monitoring service delivery across all health and social care sectors.

The NICE quality standard requires that services are commissioned from and coordinated across all relevant agencies, including specialist level palliative care, and encompasses all phases and complexities of palliative and end of life care. To implement the services, the provider shall work with other health and social care professionals in an integrated way to ensure people with specialist level palliative care needs and those important to them and their carers receive joined-up and streamlined services tailored to their needs.

The following should represent local services covering the geographic area.

In the delivery of this integrated service, key interdependencies are for example:

- Primary and Community Providers – GPs, district nurses, and out of hours services;
- The cross service and sector Integrated Multi-disciplinary Team;
- The Rapid Response Team;
- Adult Social Care services – both in hours and out of hours;
- Other providers of Palliative and End of Life Care services: statutory and voluntary;
- Providers of Acute Care;
- Urgent and Emergency Care services, including 111 and ambulance services;

- Providers of Paediatric Palliative Care;
- Public Health;
- Providers of services for individuals with long-term conditions.

4. Applicable Service Standards

4.1 Applicable national standards (e.g. NICE)

NICE Quality Standard QS13 *End of Life Care for Adults* (Nov 2011) covering the full spectrum of palliative and end of life care is available at:

<http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13>

The standard “provides health and social care workers, managers, service users and commissioners with a description of what high-quality end of life care looks like, regardless of the underlying condition or setting. Delivered collectively, these quality statements should contribute to improving the effectiveness, safety and experience of people approaching the end of life and, their families.

The quality standard requires that services are commissioned from and coordinated across all relevant agencies, including specialist palliative care, and encompass the whole end of life care pathway.”

The 16 statements which make up the Quality Standard are (Statement 10 specifically covers SLPC):

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

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

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

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

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

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

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

Statement 8. People approaching the end of life receive consistent care that is

coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

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

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

[N.B. Reminder from Information Governance team: Information about people approaching end of life is shared outside their MDT only with explicit consent or as a proportionate response to a pressing public interest need]

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

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

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

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

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

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

NICE is in the process of updating its 2004 service guidance for palliative care, but will extend this to people with all conditions (not just cancer as was in the 2004 guidance). The expectation is that this will be published in January 2018.

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

Treatment and Care Towards the End of Life (May 2010). GMC.

This guidance provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives:

http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (Sept 2015). National Palliative and End of Life Care Partnership:

www.endoflifecareambitions.org.uk

One Chance to Get it Right: Improving people's experience of care in last few days and hours of life (June 2014) [see Annex E for guidance to commissioners and service providers]. Leadership Alliance for the Care of Dying People:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

NHS Services, Seven Days a Week – Clinical Standards - NHS England

<https://www.england.nhs.uk/ourwork/qual-clin-lead/7-day-week/>

4.3 Applicable local standards

5. Applicable quality requirements and CQUIN goals

5.1 Applicable Quality Requirements (See Schedule 4A-D)

5.2 Applicable CQUIN goals (See Schedule 4E)

6. Location of Provider Premises

The Provider's Premises are located at:

7. Individual Service User Placement