

Commissioning Guidance for Specialist Palliative Care:

Helping to deliver commissioning objectives

**Developed in collaboration with:
Association for Palliative Medicine of Great Britain and Ireland
Consultant Nurse in Palliative Care Reference Group
Marie Curie Cancer Care
National Council for Palliative Care
Palliative Care Section of the Royal Society of Medicine**

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Executive summary

Currently, about 355,000 people across England need end of life care each year, a substantial proportion of whom will need specialist palliative care because of the level of complexity of their needs.

The purpose of this document is to provide commissioners with key information to help them commission specialist palliative care, as a specific component of the whole spectrum of palliative and end of life care service provision. Commissioning specialist palliative care can help commissioners achieve a number of wider commissioning goals, especially in relation to Domains 2 and 4 of the NHS Outcomes Framework and in delivering the QIPP indicators for end of life care.

Specialist palliative care is delivered across primary and secondary care, and is provided by teams based in, and funded by, both the NHS and the voluntary sector. Commissioning an integrated service for patients with progressive, advanced disease, and their families, must take into account local variations in service provision and funding streams.

Currently specialist palliative care is provided to an estimated 160,000 - 170,000 people across England annually. Historically, the larger proportion of these people will have advanced cancer, but those with end-stage organ failure, neurodegenerative diseases and advanced dementia also need comprehensive and timely access to specialist palliative care. Their unmet needs will require identification and addressing.

Our ageing population, with the inevitable increase in co-morbidity, and rising expectations and aspirations for high quality care towards the end of life by both public and professionals, means that the demands on both generalist and specialist palliative care will increase. The only certain prediction about how much specialist palliative care is needed in the future is that it will rise.

This document sets out the factors that commissioners need to consider in commissioning specialist palliative care, sources of information and data that could help them (recognising the limitations in current availability of robust data), how value and impact might begin to be measured, and some early evidence of the potential for cost reduction and cost avoidance.

Introduction

The purpose of this document is to provide commissioners with key information that may be helpful in commissioning specialist palliative care as distinct from generic end of life care, for which commissioning guidance already exists. By commissioning specialist palliative care, commissioners should also be able to achieve a number of wider commissioning goals, such as a reduction in unnecessary hospital admissions.

Specialist palliative care is a diverse discipline that takes place across many different settings and is provided by teams based in the NHS and in the voluntary sector. Variations in scope and setting result in a range of local arrangements for the delivery of specialist palliative care.

What this guidance covers

The terminology which has grown up in this area is poorly understood and lacks clarity. Terms such as hospice care, palliative care, supportive care, specialist palliative care, generic or general(ist) palliative care, end of life care etc are not always used clearly or consistently – see Glossary (page 27) for full definitions.

This guidance relates specifically to **Specialist Palliative Care (SPC)**, its role in delivering and supporting the spectrum of palliative and end of life care and how, by commissioning SPC, commissioners may meet a number of wider commissioning objectives.

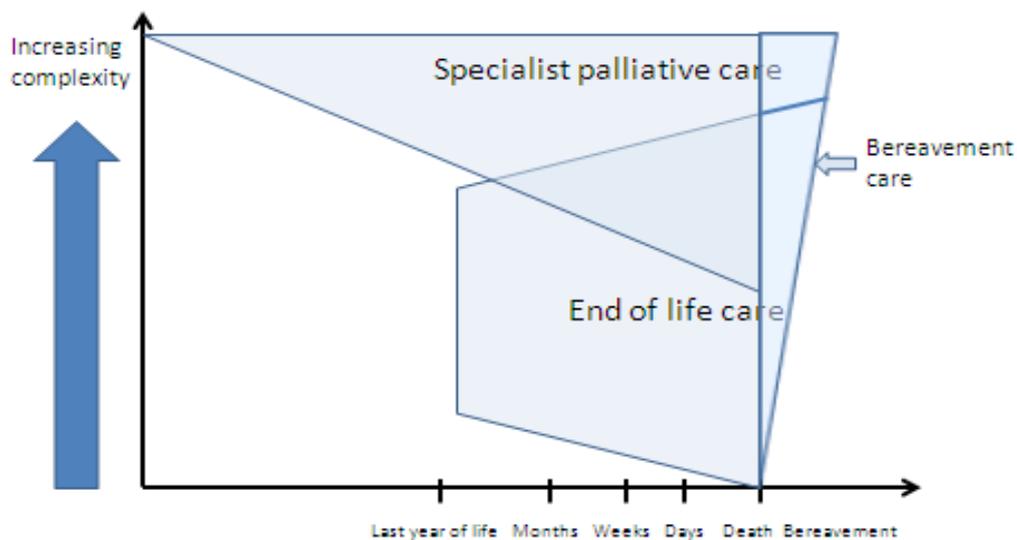
What is specialist palliative care?

Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support ...

(Tebbit, National Council for Palliative Care, 1999)

The relationship between SPC and end of life care is illustrated in Figure 1 below:

Figure 1: Relationship between specialist palliative care (SPC) and end of life care



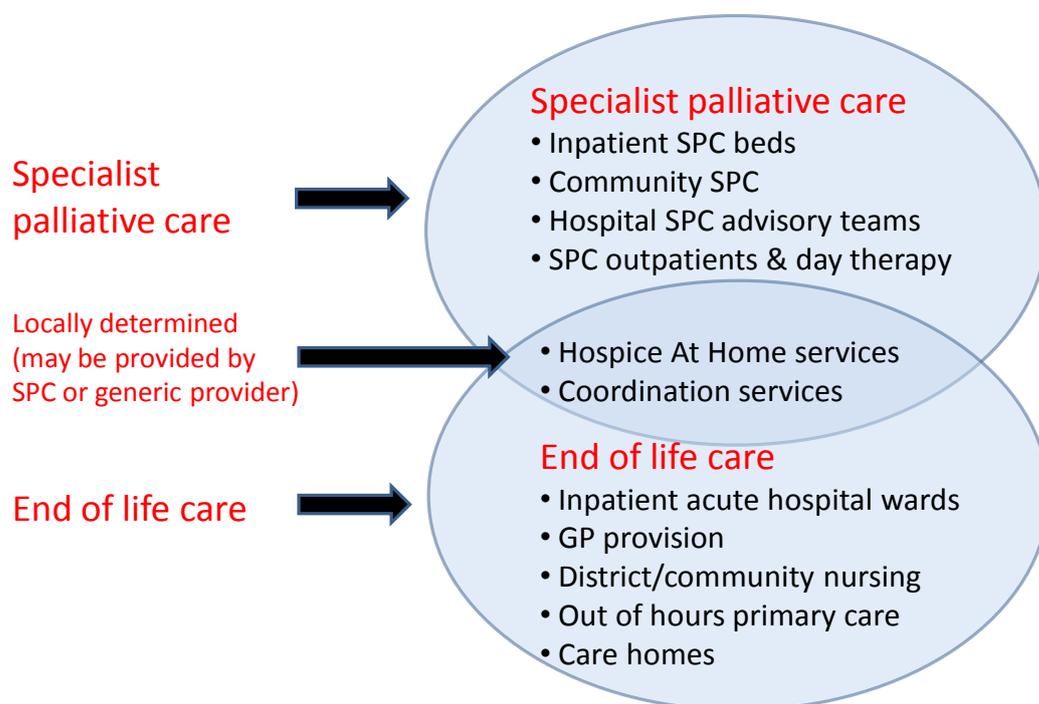
There are no nationally agreed criteria for accessing SPC (see ‘Referral criteria for Specialist Palliative Care’: page 13), but a common theme is that of complexity. Complexity is not only about the patient’s level of need. It also reflects the inter-relationship between the complexity of the patient need and the confidence and skills of the non-SPC practitioner (either in primary or secondary care).

Depending on local variations, commissioners may wish to commission SPC on its own, or to commission across the whole spectrum of palliative and end of life care, seeking lead providers to coordinate integrated care. Whatever the model used locally, SPC is a necessary component of service provision and needs to be explicitly commissioned.

Variation in service provider

The diagram below illustrates the way services might provide different types of care, as decided by local negotiation. This is intended to be illustrative rather than comprehensive, and specialist palliative care providers may be involved in providing, or leading the provision of, some aspects of end of life care:

Figure 2: Different types of care provision



Orientation

SPC is not only about providing care for people in their last year of life, but with approximately 1% of the UK population dying each year, it is critically relevant to the delivery of end of life care for this group of people.

The majority of those dying will be older people suffering multiple co-morbidities, the predominant causes of death being cardiovascular disease, chronic lung disease and cancer. The needs of such patients in the last phase of life will be for a combination of health and social care services. These will be

met by a diverse range of providers and informal unpaid carers (family and friends). General practitioners and district nurses provide the backbone of health care services at home.

Frequently those with the most difficult and complex problems, some of whom will be younger people, will require SPC provided by multi-professional teams of individuals who have had specialist training in this area. SPC teams also act as major sources of advice, support and education to others involved in providing this care.

Historically, most patients referred to SPC services have had a diagnosis of cancer. Increasingly patients with non malignant disease are being referred to SPC too. The extent to which this happens and the range of diagnoses covered, vary considerably depending on local negotiations e.g. some SPC providers will care for the elderly frail with multiple co-morbidities, but many are not commissioned or resourced to do so. Patients in the last phase of life (whatever their diagnosis) have a common set of needs across physical, psychological, social and spiritual domains which the model of holistic, multidisciplinary care that SPC represents can meet.

Because of the difficulty of prognostication and reticence on the part of healthcare professionals and/or patients to discuss the possibility of death and dying, the last phase of life is frequently identified or accepted late in the illness trajectory or indeed only after marked deterioration or even death. Often, the problems patients and their families experience in the dying phase have been longstanding and/or predictable, and the more complex of these could have benefited from interventions from SPC experts at an earlier stage. If patients are to have the opportunity to fulfil their wishes or preferences about their place and manner of dying, and if the preference of the majority for home death is to be achieved, then the possibility of death and dying must have been identified and discussed well ahead of time. This is an area in which SPC experts have played an important direct or supportive role e.g. helping to anticipate needs through Gold Standards Framework meetings in primary care.

What can specialist palliative care offer

In terms of national drivers for quality improvement, the key contributions that SPC can make are in the following areas:

Meeting the NHS outcomes framework

Domain 2: Enhancing quality of life for people with long-term conditions:

- 2.1. Ensuring people feel supported to manage their conditions, through direct support of these people as well as acting as a source of help and advice for GPs, district nurses and other generalist practitioners, for example through SPC involvement in general practice-based multidisciplinary meetings about patients and their carers, such as the Gold Standards Framework meetings. This may help to prevent unnecessary admissions to hospitals.
- 2.2. Improving functional ability in people with long terms conditions, through optimising symptom management, providing specialist rehabilitation, giving emotional support and encouraging self-management.
- 2.3.i Reducing time spent in hospital by people with long-term conditions, through optimising symptom management and encouraging self-management.
- 2.4. Enhancing quality of life for carers, by including carers in the holistic care model that is practised as a fundamental aspect of SPC.
- 2.6. Enhancing quality of life for people with dementia, through helping to enhance symptom management, emotional support and caring for the carers, in conjunction with generalists and dementia specialist teams.

Domain 4: Ensuring that people have a positive experience of care:

4. 1. Improving people's experience of outpatient care, through ensuring that SPC needs of patients in the community are met in a timely way, and pre-empting and minimising crises.
- 4.2. Improving hospitals' responsiveness to personal needs, by working with hospital teams to encourage person-centred care, especially for those suffering from advanced progressive illness.
- 4.6. Improving the experience of care for people at the end of their lives, through the provision of SPC directly to people, as well as acting as a source of help and advice to generalist practitioners.

Helping to deliver QIPP indicators for End of Life Care

1. Improve scores on the Death in the Usual Place of Residence indicator.
2. Reduce the number of hospital admissions of 8 days or more, which end in death.
3. Reduce emergency admissions in the last year of life.

SPC can help commissioners to achieve their overall commissioning goals in terms of developing community services to support quicker and more effective discharge from hospitals and reducing unplanned crisis admissions, with a better trained workforce, and delivering dignity in care (see <http://dignityincare.org.uk>). SPC has a long tradition of delivering services both in acute hospitals and community settings, so it is used to the concept of integrated care, and bridging the gap and influencing care in both environments.

The first national VOICES survey, undertaken by the Office for National Statistics on behalf of the Department of Health, showed that quality of care, being treated with dignity and respect, and pain relief, were all best achieved in hospices, so there is much that SPC can offer in helping to improve patients' experiences across all settings (see <http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf>).

What a good quality specialist palliative care service should include

The configuration of SPC may vary from locality to locality but commissioners should expect the following to feature as part of an effective SPC service:

The Specialist Palliative Care team

- Multi-professional teams whose members should have had training and experience in SPC, some of whom should be accredited specialists (e.g. consultants: see Appendix A, page 31).
- The National Advisory Committee on Palliative Care, the Council of Europe, National Institute for Clinical Excellence, and the Cancer Peer Review programme have all defined staff requirements for SPC teams:
 - physicians and nurses as core specialists, with physiotherapists, occupational therapists and social workers as part of the core team
 - pharmacists, dieticians, lymphoedema specialists, psychologists, administrative support, chaplains or spiritual care professionals, are required as part of the team, possibly as part-time or extended team members
 - given the high level of SPC involvement in education and training (both to SPC teams and to provide specialist support to general palliative care), educators, trainers, and information specialists, are often part of the SPC team.

(see section on 'How much SPC is needed': page 15 for further details)
- Access to an adequate number of dedicated beds in SPC units, staffed by medical and nursing staff, in adequate numbers and skill mix to provide 24 hour care.
- Rapid access to basic and specialist equipment, and to medications for patients.

Specialist Palliative Care activities

There should be 24 hour access to SPC advice, delivered by phone as a minimum. In addition, SPC:

- Undertakes detailed, specialised and holistic assessments of the needs of the patient across physical, psychological, social and spiritual domains.
- Provides expert management of complex symptoms.
- Provides advice in situations of ethical complexity.

- Delivers direct clinical care in partnership with colleagues in primary, secondary and social care.
- May provide care in any setting, including: hospital; community (including care homes); hospice inpatient units; hospital inpatient units; day therapy; outpatient clinics.
- May undertake case management/case leadership (if this is not already and appropriately undertaken by another professional).
- Attends the range of multidisciplinary team meetings in secondary care (for example, lung and other specific cancer type meetings).
- Attends multidisciplinary community meetings (for example Gold Standards Framework meetings and, in some areas, disease-specific meetings such as for COPD).
- Supports colleagues, patients and carers with advice and information on palliative care issues.
- Facilitates education and training across a variety of topics and according to local need, such as symptom control, advance care planning, support for the use of tools such as integrated care pathways for the last days of life, communication skills training, etc. (delivered by most, but not all providers).
- Supports/undertakes research (undertaken by a minority of services, in line with the recommendations by the National Cancer Research Institute and partners – see <http://www.ncri.org.uk/default.asp?s=1&p=7&ss=4>).

Referral criteria for Specialist Palliative Care

There are no nationally agreed criteria for accessing SPC but a good service should have written criteria which include the following (see examples^{1, 2}):

1. The patient has active, progressive advanced disease, a limited prognosis, and the focus of care is on quality of life, for example:
 - Potentially fatal conditions where treatment has changed from curative to palliative intent, e.g. cancer, multiple co-morbidities where curative treatment is no longer possible
 - Complex symptom control issues during treatment
 - Treatment available to prolong life but prognosis is uncertain, e.g. advanced chronic obstructive pulmonary disease, advanced heart failure
 - Palliative treatment from the outset with no cure available, e.g. motor neurone disease, multiple systems atrophy, advanced dementia.

2. The patient has unresolved complex needs that cannot be met by the caring team. These needs may be physical, psychological, social and /or spiritual. Examples may include complicated symptoms, difficult family situations, or ethical issues regarding treatment decisions.
3. Patient consent for referral (where the patient has capacity for this consent).

How much specialist palliative care is needed?

Estimations of SPC need can be derived from the numbers of deaths and patterns of prevalence of palliative care concerns (epidemiological approaches), or from current provision and recommendations (comparative and normative approaches)³.

Numbers of deaths and prevalence of palliative care needs

A starting point for understanding the need for SPC is the number of deaths⁴. In England, approximately 500,000 people die each year. Not all have palliative care needs prior to death, because their death may be unexpected and unpredictable, or from an external cause (such as accidents, homicide, suicide, etc). It has been estimated that about 25% of all deaths in England are unexpected deaths from acute causes⁵⁻⁷. Many patients with chronic disease may also die unexpectedly and it has been suggested that this could increase the proportion of unexpected deaths to 40%⁸.

The main disease groups identified as needing palliative care are⁹:

- advanced cancers
- end stage organ failures (heart failure, respiratory disease, renal failure, and liver failure)
- neurodegenerative diseases, such as motor neurone disease, multiple systems atrophy, Parkinson's disease, Huntington's disease
- advanced dementia/Alzheimer's

If these conditions are identified from among all deaths, then this represents **63% of all deaths** (personal communication, Verne, South West Public Health Observatory). However, several of these conditions (e.g. dementia, renal failure, Parkinson's disease) are under-ascertained as a cause of death. The Palliative Care Funding Review report recommends between **69% and 82% of deaths** are likely to have preceding palliative care needs¹⁰. **This suggests that about 355,000 new people annually need end of life care, of which the more complex will need specialist palliative care.**

How much specialist palliative care is currently delivered?

Using the Minimum Dataset for SPC, published by the National Council for Palliative Care¹¹, there is evidence that, in England:

In-patient specialist palliative care beds

About 40,800 new people (incident population) and 46,800 in total (prevalent population) are admitted to specialist inpatient beds per annum. This represents a total of 641,160 SPC bed days per annum (or 13.7 days per in-patient per annum).

Community specialist palliative care

Between 92,800 and 95,600 new people (incident population) and 135,000 in total (prevalent population) are seen by community services per annum for home care and/or Hospice at Home. This represents a total of 10,666,000 'community care days' per annum (which equate to an average of between 111.6 to 114.9 days per new patient per annum). During this community care, each patient has an average of 1.99 face-to-face contacts, 3.23 telephone contacts, and 5.23 contacts in total.

Specialist palliative day therapy

About 18,500 new people (incident population) and 33,500 in total (prevalent population) are seen by specialist palliative day therapy services per annum. This represents a total of 6,077,009 'day therapy days' per annum (which equate to an average of 180.6 days per patient per annum). On average, 19.0 sessions of day therapy are attended per patient per year, and this includes 17.9 face-to-face consultations per patient per year. Of these face-to-face consultations, an estimated 11.9 are delivered by medical, nursing, allied health professionals, social workers and psychologists (the remainder is delivered by spiritual care providers, complementary therapists, or 'other' professionals).

Specialist palliative care delivered by hospital advisory teams

Between 89,350 and 100,000 new patients (incident population) and between 98,780 and 110,550 in total (prevalent population) are seen by hospital support/advisory teams annually, across England. This represents a total of

about 375,365 contacts (an average of 3.8 contacts per patient per year). Almost all of these are seen by specialist doctors, nurses and social workers.

Outpatient specialist palliative care

About 35,102 new patients (incident population) and about 61,742 in total (prevalent population) are seen for SPC outpatient appointments in hospices and hospitals annually, across England. This represents a total of 109,813 face-to-face attendances (either first attendances or follow ups) and 66,115 'non-clinic' face-to-face contacts. On average, this represents 1.8 outpatient clinic visits per patient per year, plus 1.1 other 'non clinic' face-to-face contacts per patient per year. 46,517 outpatient contacts are estimated to be face-to-face medical contacts, and 83,095 are estimated to be face-to-face non-medical contacts by nursing, physiotherapy, occupational therapy, social work, or psychology professionals (contacts with spiritual care providers, complementary therapists, or 'other' professionals, are excluded).

It is difficult to judge how much national provision of SPC there is, because the categories listed above (in-patient SPC beds, community SPC, hospital SPC, and outpatient SPC) will to some extent overlap, and the size of this overlap is not known. If we assume (conservatively) that all patients who receive day care and outpatient SPC are also seen by community SPC, and about 50% of patients admitted to SPC beds or seen by hospital SPC teams are new to SPC, then we can estimate **about 160-170, 000 new patients receive SPC annually.**

In summary:

It is estimated that about 355,000 people need end of life care each year across England

The most complex of these will need SPC

The allocation of end of life/SPC provision is determined locally

Currently, SPC is provided to about 160-170,000 people annually (estimated)

Those with advanced cancer are much more likely to be referred to SPC

Unmet SPC need is likely to exist among those with non cancer conditions and among older people

Modelling tools are available on the National End of Life Care Intelligence Network website, to enable commissioners to apply estimates to their local population, and project expected numbers of deaths/palliative care need for the future (see

http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/default.aspx). Other useful data sources about the full spectrum of end of life care include:

- National End of Life Intelligence Network (<http://www.endoflifecare-intelligence.org.uk/home.aspx>)
- The Palliative Care Funding Review (<http://palliativecarefunding.org.uk/PCFRFinal%20Report.pdf>)
- HES Online (<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937>)
- The Palliative Care Funding pilots (<http://www.dh.gov.uk/health/2012/03/palliative-care-pilot-sites-announced/>)
- Electronic Palliative Care Coordination Systems (EPaCCS) data reports (including Coordinate My Care) (<http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard>)

National and international recommendations about specialist palliative care provision

Recommendations for the minimum requirements of specialist palliative care provision are summarised on the next page.

Although the most recent available, these recommendations are already several years old, and do not accommodate the changing demographics and patterns of death being experienced in the provision of health care. Nor do they take into account local variations which will influence the provision that needs to be commissioned, e.g. urban or rural factors, historical provision, and balance of SPC and end of life care provision available.

The less end of life care provision there is (or the more fragmented it is) in any setting, the more SPC will be required (see section on 'The potential for cost reduction and cost avoidance': page 23).

These recommendations also do not reflect the impact of changing expectations which are hard to measure at this stage. These include: availability of seven day face to face assessments by SPC clinicians, and capacity of SPC to support care closer to home and dying in the person's usual place of residence.

Per population of 250,000, the MINIMUM requirements are:

- Consultants in palliative medicine – 2 whole time equivalent (WTE)
- Additional supporting doctors (e.g. trainee/specialty doctor) – 2 WTE
- Community specialist palliative care nurses – 5 WTE
- Inpatient specialist palliative care beds – 20-25 beds with 1.2 nurse : bed ratio

Per 250-bed hospital, the MINIMUM requirements are:

- Consultant/associate specialist in palliative medicine – 1 WTE
- Hospital specialist palliative care nurse – 1 WTE

The following caveats apply to the above MINIMUM recommendations:

- Hospitals with cancer centres and tertiary referrals for other conditions will require more than the above minimum requirements
- Each specialist palliative care team will require input from a multi-professional team including occupational therapists, physiotherapists, social workers, chaplaincy and administration, as a minimum. Data for recommending minimum requirements is not currently available.
- These figures do not take into account the education and training responsibilities, nor any sub-specialisation role required locally
- These recommendations are from the last decade and are largely based on cancer requirements only
- The rapidly ageing population and increasing focus on non-cancer and multiple comorbidities means more, not less, specialist palliative care provision will be needed
- Local considerations (rural/urban, ethnicity, deprivation, mixed funding streams, etc.) need to strongly inform what SPC is commissioned
- These recommendations will be updated as new evidence and data arise.

See Appendix B, page 36, for detailed recommendations from different sources¹²⁻¹⁵ which have been used to draw up these recommendations.

What is currently happening in the system?

SPC in England is currently provided through a combination of statutory (National Health Service) and voluntary sector provision¹¹, with adult hospices receiving on average 34% of their funding from the NHS^{16,17}. However, provision does not reflect patterns of need¹⁷ **and, in addition**; there is considerable inequity of provision¹⁷. The recent independent review of palliative care funding in England identified more than 30-fold variation in NHS spend on SPC, ranging from £186 to £6,213 per death, although most PCTs (61%) spent less than £1,000 per death¹⁰.

Commissioners can obtain details and benchmark the performance of their own local area against previous Strategic Health Authority, Primary Care Trust and national averages using the following data sets:

- The Minimum Data Set (National Council for Palliative Care) via <http://www.ncpc.org.uk/mds>
- End of Life Care Quality Assessment (ELCQuA) self assessment data. The tool can be found at <http://www.endoflifecare-intelligence.org.uk/resources/tools/elcqua.aspx>
- National VOICES survey of bereaved people (<http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf>). PCT level data from this first survey is available in the autumn of 2012. A toolkit for the design and planning of locally-led VOICES end of life care surveys may be found at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128787
- Analysis of returns monitoring new investment in End of Life care services (Department of Health). Data for 2010/11 can be found at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130336
- National End of Life Care Intelligence Network Profiles for PCTs and Local Authorities (data of social care expenditure in addition to demographic data) http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx

Future Developments

Other relevant data that should be available in the future include the results of two pilots examining payment by results in SPC, and the Department of Health Palliative Care Funding Review pilots.

The potential for cost reduction and cost avoidance

SPC can deliver both improved outcomes for patients and families, and potential cost reductions within health systems, but it is important to note that services do not operate in isolation: for example, for care at home to be of the highest quality, specialist (and generalist) palliative care needs to work in conjunction with fully supported community services. Much of the available data focuses on end of life care and is not specific to SPC. Commissioners and providers will need to agree both what weight to place on them and how much SPC services can influence these components.

Health care costs increase steadily in the last three years of life with highest expenditures in organ failure (chronic heart failure, COPD, end stage renal disease, and other organ failure) and other terminal illness (cancer, motor neurone disease, and other neurodegenerative conditions). In the last three months of life, total health care costs almost triple in organ failure and other terminal illness¹⁸. Inpatient hospital stays account on average for 33% of the mean total cost per patient in the last weeks of life¹⁹. 90% of terminally ill patients are hospitalised in the last year of life¹⁸. Reasons for unplanned admissions are the absence of 24 hour response services, the absence of timely access to advice and medication, and the lack of prompt access to services in the community^{18,19}.

Early integration of palliative care in the disease trajectory has been advocated for a long time as an answer to meet patients' needs, reduce hospital admissions and also to reduce overall healthcare costs. Comparison of studies is challenging as they often report different types of palliative care interventions (multi-professional, nursing only, counselling only etc.), use different primary outcomes (patient-related, carer-related, service use-related etc.), and have methodological weaknesses²⁰. Despite these limitations, a systematic review on cost and non-clinical outcomes indicates that SPC is associated with fewer hospitalisations, fewer intensive care hospital days and lower overall costs²¹. Those studies which do not show a cost saving are at least cost neutral when SPC is provided²¹.

More recent and robust studies underline improved patient and carer outcomes and reduced costs when palliative care is provided early in the disease trajectory. A study comparing early diagnosed metastatic non-small-cell lung cancer patients to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone, showed that the

intervention group not only had better quality of life and reduced symptom burden but also less aggressive care towards the end of life and longer survival²². However, this was conducted in the USA and generalisability of findings to the UK remains uncertain. A short-term palliative care intervention in multiple sclerosis patients showed reduction of caregiver burden and cost savings of about £1,800 after 12 weeks follow-up including inpatient care and informal care costs²³.

Measuring value and impact

Outcomes have not, historically, been included in the range of data collected about SPC, but our view is that commissioners should, over time, adopt assessment measures (both process and outcome) in collaboration and discussion with providers so that the most accurate 'tools' are used to both reflect the activity that has been commissioned locally and to measure the value and impact of SPC (not just end of life care). Such tools might include, for example, the 'phase of illness' descriptors recommended by the Palliative Care Funding Review¹⁰, as well SPC support for the collection of more generic end of life indicators, but note that SPC teams may need funding and time to be able to develop these. Ultimately any tools used should include patient-centered outcome indicators. Repeated measures may then be assessed internally over time and externally between providers and against national benchmarking (with appropriate case-mix adjustment).

Commissioners may wish to access the following sources and types of information:

- The Minimum Data Set (National Council for Palliative Care), via <http://www.ncpc.org.uk/mds>
- National VOICES survey of bereaved people(<http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf>).
- National Care of the Dying Audit – Hospitals, which can be found at <http://www.liv.ac.uk/media/livacuk/mcpcil/documents/NCDAH-GENERIC-REPORT-2011-2012-FINAL.doc-17.11.11.pdf>
- Quality Accounts from NHS providers covering safety, patient experience and clinical effectiveness. See <http://www.dh.gov.uk/health/category/policy-areas/nhs/quality/quality-accounts-quality/>
- End of life care for adults quality standard(National Institute for Health and Clinical Excellence) which can be found at <http://guidance.nice.org.uk/QS13>
- Data on local preferences and place of death in regions within England for 2010 is available <http://www.csi.kcl.ac.uk/localpref.html>
- The percentage of people locally on the Electronic Palliative Care Co-ordination Systems (EPaCCS). For details see <http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard>

- Local data on the proportion of people dying on an Integrated Care Pathway
- Local patient and carer satisfaction survey data
- The National Cancer Peer Review process for SPC services will be publically available in the near future

A systematic review of outcome measures is available at

<http://www.csi.kcl.ac.uk/files/Guidance%20on%20Outcome%20Measurement%20in%20Palliative%20Care.pdf>

Glossary

End of Life Care

Care which 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.

Source: National Council for Palliative Care 2006

General(ist) Palliative Care

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

Adapted from: Improving Supportive and Palliative Care for Adults with Cancer, 2004

Hospice care

A hospice is not just a building; it is a way of caring for people. Hospice care aims to improve the lives of people who have a life-limiting or terminal illness, helping them to live well before they die. Hospice care not only takes care of people's physical needs, but looks after their emotional, spiritual and social needs as well. It also supports carers, family members and close friends, both during a person's illness and during bereavement.

<http://www.helpthehospices.org.uk/about-hospice-care/what-is-hospice-care/>

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Source: World Health Organisation 2003

Specialist Palliative Care

Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support...

Source: Tebbit, National Council for Palliative Care, 1999

Supportive care

This is care which helps people with cancer and other life-threatening illnesses and their families to cope with the disease and its treatment throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

Adapted from: Improving Supportive and Palliative Care for Adults with Cancer 2004

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References

1. EllenorLions Hospices. Referral criteria for EllenorLions Hospices Adult Specialist Palliative Care services. www.ellenorlions.org/pdfs/Referral%20Criteria%20-%20Adult.pdf (accessed 25th October 2012).
2. Yorkshire Cancer Network Sub-Regional Palliative and End of Life Care Group. Agreed Eligibility for Referral to Specialist Palliative Care, 2005
3. Higginson IJ. Health Care Needs Assessment: Palliative and Terminal Care. In: Stevens A, Raftery J, editors. Health Care Needs Assessment. Oxford: Radcliffe Medical Press; 1997.
4. Higginson I. Palliative and Terminal Care: Health Care Needs Assessment. Oxford: Radcliffe Medical Press; 1997.
5. Blackmore S, Pring A, Verne J. Predicting death: Estimating the proportion of deaths that are 'unexpected'. London, UK: National End of Life Intelligence Network, 2011.
6. Pring A, Verne J. Deaths Registered as Occuring Elsewhere: final report. London, UK: National End of Life Intelligence Network, 2011.
7. Osinowo A. External Causes of Death. London, UK: National End of Life Intelligence Network, 2011.
8. Omega, the National Association of End of Life Care. End of life care in primary care: national snapshot of end of life care. 2009.
9. Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential palliative care population. *PalliatMed*. 2005;19 (7):556-62.
10. Hughes-Hallet T, Craft A, Davies C, Mackay I, Nielsson T. Palliative Care Funding Review: Funding the Right Care and Support for Everyone. 2011.
11. National Council for Palliative Care. National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS Full Report for the year 2008 - 2009. London: National Council for Palliative Care, 2010.
12. Finlay I. Implementation of Palliative Care Report: Palliative care services funding 2008 to 2009. 2008.
13. Payne S, Radbruch L. White Paper on standards and norms for hospice and palliative care in Europe: Part 1. *European Journal of Palliative Care*. 2009;16 (6): 278-89.
14. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 2. *European Journal of Palliative Care*. 2010;17 (1): 22-33.
15. Consultant Physicians working with patients: The duties, responsibilities and practice of Physicians in Medicine. (5th edition) Royal College of Physicians, 2011.
16. Help the Hospices. Help the Hospices. Hospice accounts – Analysis of the accounts of UK independent voluntary hospices. 2010.
17. National Audit Office. End of Life Care. The Stationery Office, London. 2008.
18. Fassbender K, Fainsinger RL, Carson M, Finegan BA. Cost trajectories at the end of life: the Canadian experience. *J Pain Symptom Manage*. 2009;38(1):75-80.
19. Dumont S, Jacobs P, Fassbender K, Anderson D, Turcotte V, Harel F. Costs associated with resource utilization during the palliative phase of care: a Canadian perspective. *Palliat Med*. 2009;23(8):708-17.
20. Zimmerman C, Riechelmann R, Kryzanawska M, Rodin G, Tannock I. Effectiveness of specialised palliative care: a systematic review. *JAMA*. 2008;299(14):1698-709.
21. Smith TJ, Cassel JB. Cost and non-clinical outcomes of palliative care. *J Pain Symptom Manage*. 2009;38(1):32-44.

22. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-42. Epub 2010/09/08.
23. Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *J Pain Symptom Manage*. 2009;38(6):816-26.

Appendix A

The Role of the Palliative Medicine Consultant

(published by APM, Nov 2012: www.apmonline.org)

Executive Summary

Palliative medicine consultants are essential members of the multi-professional palliative care team. Their unique knowledge and skills ensure the very best outcomes and experience for our patients and their families. Their roles in leadership and education promote quality, efficiency and productivity.

This document describes the role of palliative medicine consultants in hospitals, independent and NHS hospices and the community. It has been prepared to aid and inform non-palliative medicine appraisers; employers, including NHS Trust and hospice senior executives; and commissioners of palliative care services. It develops the definition of the role from the Association of Palliative Medicine Strategy 2008-2010 (1) (Box 1). As such it includes roles which are specific to palliative medicine consultants as well as those which may be shared by other medical consultants, and other members of the specialist palliative care team.

Box 1

“The core role of the palliative medicine physician may be defined as the medical assessment of distress, symptom management and end of life care for patients with complex clinical needs due to advanced, progressive or life threatening disease. They provide medical leadership within palliative care services and hold clinical responsibility for the treatment of patients in their care. Areas of responsibility include ensuring good quality, efficiency and equitable access to services, advising on strategic planning including commissioning of services, and developing strategies for research, education and training in relation to specialist and generalist palliative care.” (APM Strategy 2008-2010(1))

1.0 Clinical expertise

Consultants in Palliative Medicine are required to complete extensive assessed medical training through their undergraduate, general medical and specialty training, and to meet the criteria for inclusion on the specialist register. They are essential members of the specialist palliative care team as a result of being expert in assessment, diagnosis and treatment of patients with a wide range of medical conditions (2). There is evidence that medical consultant delivered care improves patient outcomes (3).

Box 2

“The unique skill of the consultant physician is the ability to diagnose and make clinical decisions in difficult, complex and uncertain circumstances. Development of this skill takes comprehensive and thorough learning, time and experience. It is more than a collection of competencies. It reflects, individually and collectively, a culture of striving for excellence that has been built up over centuries.”

Royal College of Physicians 2011 Consultant Physicians Working With Patients (4)

- Consultants in Palliative Medicine are most often the responsible clinicians for inpatients in NHS and independent palliative care units and provide 24/7 cover in this respect
- They are the responsible clinician for patients in palliative care beds in acute centres
- They often provide 24/7 medical advice to professionals caring for palliative care patients in the hospital and community
- Consultants in Palliative Medicine often provide continuity of patient care through joint posts across hospice, hospital and community
- Consultants may be the most appropriate clinician on the team to communicate effectively with senior medical colleagues including other consultants and GPs, particularly in relation to complex or unusual cases
- Patients and their families perceive consultants to be the experts and need access to them for skilled conversations about treatment, prognosis or place of care

They have particular expertise in:

- Assessing complex symptoms from an understanding of underlying pathological (disease) processes
- Assessing and supporting patients who are dying and their families
- Assessing palliative care patients with acute clinical deterioration who may have a reversible condition
- Formulating evidence-based and individualised management plans including identifying appropriate investigations and involving other specialists
- Giving advice to other clinicians in hospital and community on the basis of knowledge and skills in ethical decision making including withdrawal and withholding of treatments, and advance decisions
- Taking responsibility for difficult clinical decisions by balancing risk, benefits and patient choice
- Assessing the appropriateness for specialist palliative care services for patients including understanding typical disease trajectories and the impact of comorbidities and prognosis, especially in non-malignant diseases and long-term conditions
- Drug treatments including a thorough knowledge of how they work (pharmacokinetics and pharmacodynamics) including the effects of organ failure, adverse effects and assessing new drug treatments
- Taking responsibility for prescribing drugs for unlicensed indications on the basis of the evidence base and current guidelines

- Shared care of patients with other medical teams including joint clinics in specialities such as oncology, respiratory, cardiac and renal diseases, dementia and progressive neurological conditions
- Promoting shorter stays in hospital or hospice

2.0 Leadership

- Clinical leadership of multi-professional specialist palliative care teams
- Operational leadership and management of specialist palliative care services
- Leading service developments and change initiatives such as reducing length of stay by rapid discharge pathways and reducing inappropriate admissions
- Strategic leadership and development of local services in hospice and community settings, or as lead clinician/member of the hospital palliative care team
- Strategic contribution to local commissioning groups/Clinical Commissioning Groups/health boards
- Strategic leadership within local networks such as palliative care and cancer alliances
- Leading and supporting the development of specialist palliative care services in and across all settings
- Providing clinical leadership and service development for end of life care services in acute centres and in the community
- Supporting the development of generalist palliative care provision and services in hospital, care home and community, with particular focus on community provision out of hours
- Supporting the appraisal process of specialty staff grade and associate specialist doctors (SSAS doctors)

3.0 Clinical Governance

- Participating in and leading on local and national audit
- Making a major contribution to the management of clinical risk and patient safety from their medical perspective
- Contributing to the development of local and national policy and guidance eg NICE guidance
- Leading and participating in local, regional and national quality assurance processes eg Cancer Peer Review
- Responding to national audits and reports eg NCEPOD, Dr Foster, NICE guidance
- Leading on governance issues relating to appraisal and revalidation for palliative medicine colleagues.
- Participating and leading on quality improvement initiatives such as the End of Life Care CQUIN.
- Involvement in and response to concerns and complaints around end of life care in the acute sector

4.0 Education

- Planning and delivery of undergraduate medical education in aspects of palliative care, end of life care, communication skills, and ethics
- Involvement in examinations and tutoring of medical undergraduates
- Palliative care and end of life care teaching to doctors in training in all specialties, including an important role with GP trainees
- Curriculum development and training of palliative medicine trainees which requires consultants to demonstrate their competence as clinical and educational supervisors
- Teaching GPs and other primary care staff
- Educating hospital doctors in palliative and end of life care (5)
- Developing educational resources eg e-ELCA (End of Life Care programme within e-Learning for Healthcare) on-line learning
- Supporting the continuing development of palliative care nurse specialists for example as nurse prescribers.
- Supporting the professional development of SSAS doctors

5.0 Research

- Formulating research proposals and developing and implementing research projects and programmes
- Linking with academic centres to support local research studies and promote multicentre research
- Supporting the research of others including offering recruitment to trials for patients in their care
- Applying their specific training in research methods and practice and their applicability to palliative care
- Bringing an awareness of Good Clinical Practice in research including consent to research and other ethical issues

Workforce Issues

The current number of full time equivalent (FTE) consultants in palliative medicine equates to 1.56 for every 250,000 population. However, analysis of current working patterns demonstrates that this workload does not allow sufficient time for continuing professional development, audit, research and clinical governance The Royal College of Physicians suggest that this level should be increased to 2 (FTE) consultants for every 250, 000 population, not including the time spent in extended managerial roles such as Medical Director (4).

Future increases in workload are expected as a result of:

- An increase in the number of dying patients as a result of the growing population

- The increasing life span of patients with advanced disease requiring longer periods of specialist palliative care
- Increasing referral of patients with non-malignant diseases
- Increasing complexity of medical treatments in advanced disease and increasing comorbidities
- An increasing role in the supportive care of patients receiving potentially curable therapies for cancer and non-malignant diseases
- Increased patient and carer expectation of medical treatments in advanced disease
- Increases in Palliative Medicine consultant outpatient episodes (6)
- Significant changes in commissioning structures and processes which call for high quality clinical engagement between providers and their commissioners
- The centrally led focus on increasing and improving delivery of End of Life care services into the future including a focus on limiting inappropriate admissions to hospital for patients at the end of life

References

1. The Association for Palliative Medicine of Great Britain and Ireland. Palliative Medicine in Supportive, Palliative & End of Life Care: A Strategy for 2008 to 2010. APM 2008
2. National Institute for Clinical Excellence. Guidance on cancer services; improving supportive and palliative care for adults with cancer: The manual. London: NICE, 2004
3. Academy of Royal Medical Colleges The benefits of consultant delivered care. 2012 London, UK <http://www.aomrc.org.uk/about-us/news/item/benefits-of-consultant-delivered-care.html> (accessed 25/06/12)
4. Consultant Physicians working with patients: The duties, responsibilities and practice of physicians in medicine. (5th edition) Royal College of Physicians 2011
5. Improving End-of-Life Care: Professional development for physicians. RCP 2012
End of Life Care Strategy - promoting high quality care for all adults at the end of life DOH 2008
6. Medical Specialty Workforce Factsheet: Palliative Medicine. Centre for Workforce Intelligence 2010
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277 (accessed 01/09/12)

Appendix B

Data to support recommendations for SPC provision

Detailed data extracted from various sources to support recommendations for SPC provision. These are set out under the headings of specific components of SPC provision. Most SPC services provide more than one component of service, and also provide varying levels of on-call cover, education and training support and other strategic contributions, which are not included in the data below. Local variations in both generalist end of life care and SPC provision must be taken into account when using the data below. Some of this data is drawn from European recommendations which reflect very different health service systems and cultural expectations.

In-patient specialist palliative care beds

- Between 16-18 in-patient SPC beds per 250,000 population¹².
- Considering predominantly the needs of cancer patients: a minimum of 12.5 palliative care beds for 250,000 population i.e. one bed per 20,000 population. Considering the needs of both cancer and non-cancer patients, and the growing prevalence of advanced chronic diseases, a minimum of 20-25 palliative care beds for 250,000 population^{13,14}.
- One consultant for each 20 specialist in-patient palliative care (hospice) beds, including outpatient and day care provision¹², or at least 3 physicians (consultant and other grades) per every 20 specialist inpatient palliative care beds (with at least one whole time SPC physician for every 5-6 beds)^{13,14}.
- One SPC nurse to oversee each 7.5 hospice beds, whether in-patient or Hospice At Home – note that additional nursing will be needed to provide the nursing care¹².
- Within palliative care units or hospices, nursing staff ratios for the provision of nursing care of at least 1 nurse per bed, but preferably 1.2 nurses per bed are recommended^{13,14}.

Community specialist palliative care

- At least 2 whole-time equivalent (WTE) community-based consultants in palliative medicine for 250,000 population¹⁵.
- At least 5 SPC nurses per 250,000 population¹².
- 10 to 12 full time professionals, including predominantly nursing and physician time, and with social worker and administration support, for every 250,000 population, with 24 hour and 7 day per week provision for support^{13,14}.

Specialist palliative care delivered by hospital advisory teams

- One consultant per 850 District General Hospital beds¹².
- One SPC nurse per 300 District General Hospital beds¹².

- At least one hospital palliative care support team (minimum one physician and one nurse, with SPC training) should be available for a hospital with 250 beds^{13,14}.
- Large secondary care hospitals and hospitals accepting tertiary referrals and management may need additional SPC professionals, including sub-specialisation roles and provision of additional support and education.

Additional recommendations

- Each consultant (whether community, hospital or hospice based) needs support from a minimum of one matching doctor, either trainee or staff grade or clinical assistant¹².

This document should be referenced as:

Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012. Guidance document published collaboratively with the Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK.

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