NHS
England

COMMISSIONING PERSON CENTRED END OF LIFE CARE

A TOOLKIT FOR HEALTH AND SOCIAL CARE
UPDATED APRIL 2016

CLICK HERE TO START

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; and

- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

- We have also given due regard to the responsibility that CCGs have a duty to actively involve local people as stated in the Health and Social Care Act [2006 amended], 2012 Health and Social Care Act (amending the NHS Act 2006) c. 7 PART 1 Further provision about clinical commissioning groups Section 26 Section 14z(2)[1], Health and Social Care (Safety and Quality Act) 2015[2].

[1] http://www.legislation.gov.uk/ukpga/2012/7/section/26/enacted

[2] http://www.legislation.gov.uk/ukpga/2015/28/contents/enacted

This updated toolkit has a range of practical resources to support those involved in commissioning for person centred end of life care. It was revised in response to requests from commissioners and providers with many examples generously shared by colleagues around the country. Insight data from desktop research using for example, findings from the National Survey of Bereaved People (VOICES), accounts from people in care homes distilled from Care Quality Commission (CQC) reports, as well working through our partner organisations to access the views and opinions of people with life limiting conditions and carers with experience of end of life care, have been woven into the fabric of this toolkit.

This toolkit reflects the health and care landscape as it was in October 2015, building on prior improvement from an earlier strategy, opportunities and thinking from the NHS Five Year Forward View and Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020.

It supports delivery of the National Institute for Health and Care Excellence's (NICE) quality standard 13[3] for end of life care, NICE guideline NG31 Care of dying adults in the last days of life[4] and the five priorities identified in One chance to get it right[5], that collectively aim to ensure the right care in the right place at the right time with the right resource.

The toolkit is intended to be a supporting resource for those who may find it helpful. It is not new or additional guidance and is largely to guide generalist care.

We would like to thank the many people who shared their knowledge, insight and experience, and gave their time so generously.

HOW TO USE THIS TOOLKIT

To move through the toolkit you can use the 'next' and 'previous' buttons as well as the coloured section buttons at the side of each page.

To come back to this page click the **HOME** button.

[3] http://www.nice.org.uk/guidance/qs13

[4] http://www.nice.org.uk/guidance/ng31/chapter/context

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

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End of life care affects everyone, patients, their families and carers and practitioners alike, because death awaits us all. Care as we approach the end of our life has to matter to everyone – in health and social care and in the wider community. We all have a joint responsibility for providing the best support we can whether someone's death is sudden, very gradual or anticipated.

Health and social care commissioners have an essential role to play in ensuring that people who are approaching the end of their life receive high quality treatment, and care that supports them to live as well as possible until they die, and that when they die they are able to do so with their dignity maintained. Patients, carers and their families give us valuable insights into the services being commissioned locally. It is important that their voice is heard, and wherever possible, they are encouraged to actively engage with any planned changes so we can ensure that the changes we are planning will add value to the patient, and ensure they are at the centre of all we do.

Any commissioning plans must encompass good bereavement and pre-bereavement care, including care for children and young people.

Good commissioning, as shown opposite, places the individual at the heart of this process with services designed in consultation and in collaboration with people who use them, families and carers.

Care planning

My goals/ outcomes

PERSON CENTRED COORDINATED CARE

"I can plan my care with people who work together to understand me and my carer(s), allow me control and bring together services to achieve the outcomes important to me."

Information

Transitions

Communication

Decision making

Source: www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations

Throughout this toolkit we refer to people, their families, carers, other loved ones and communities to include people approaching the end of their life, those who are important to them and the wider community they live in.

Commissioning high quality end of life care presents particular challenges because of the need to coordinate and integrate the care commissioned and provided across health and social care settings. It also offers commissioners the opportunity to ensure services achieve desired outcomes, including avoiding unwanted admissions to acute care in the last year of life, meeting peoples' choices and improving the consistency and quality of care.

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KEY PUBLICATIONS

This toolkit is set in the context of the following key publications:

- Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020
- Every Moment Counts: A narrative for person centred care (March 2015)
- The Care Act (October 2014)
- NHS Five Year Forward View (October 2014)
- The Forward View into Action: Planning for 2015/16 (December 2014)
- One chance to get it right (June 2014)
- Actions for End of Life Care (November 2014)
- RCGP End of Life Care Commissioning Guide (April 2013)
- NICE guideline NG31 Care of dying adults in the last days of life
- NICE quality standard for end of life care for adults (August 2011)
- NICE guidance for commissioners on end of life care for adults (December 2011).

Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020[6]
Builds on the 2008 strategy and improvements that followed. Setting out six high level ambitions, it looks to integrated health and social care systems to work with people, as well as for people, to create new ways to build more effective systems of care, putting existing resources to more creative and effective use, aligning with changes flowing from the NHS Five Year Forward View[7].

Every Moment Counts: a narrative for person centred coordinated care for people near the end of life (March 2015)[8]
Draws on surveys, testimonies of bereaved carers, experience of end of life care charities and the reflections of professionals the CQC Chief Inspector of Hospitals, Professor Sir Mike Richards noted: "this clearly articulates the quality of care which everyone should be able to expect at the end of their life. We are using the narrative in our thematic review of inequalities and variation in End of Life Care[9] to describe what good care looks like, so that we can understand why people's experience of End of Life Care often falls short of this."

Care and Support Statutory Guidance (2014)[10]
Places new duties and responsibilities on local authorities to ensure people receive services that prevent needs escalating, receive appropriate care, get information around choice and support and have access to a range of providers.

There is also a new emphasis on supporting friends, families and individuals who care.

[7] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

[8] http://www.ncpc.org.uk/news/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations

[9] http://www.cqc.org.uk/content/identifying-variation-end-life-care-commissioning

[10] https://www.gov.uk/guidance/care-and-support-statutory-guidance

[6] http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

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NHS Five Year Forward View (2014)[11]
Calls for a more engaged relationship with people who use services to plan them, and a range of care models to support better integration of services across providers, with shifts of investment from acute to primary and community services. Several models have the potential to support improvement to end of life care.

One chance to get it right: Improving people's experience of care in the last few days and hours of life (2014)[12]
Sets out the approach to caring for dying people that health and care organisations and staff caring for dying people in England should adopt. The approach focuses on addressing five Priorities for Care.

Actions for End of Life Care (2014)[13]
Uses the House of Care model to set out NHS England's commitments to end of life care for adults and children and the range of actions to address these. Actions are aligned with existing plans and programmes of work within NHS England and partner organisations.

RCGP Commissioning Guidance in End of Life Care (2013)[14]
Provides guidance for GPs, Clinical Commissioning Group (CCG) advisers and commissioners on supporting better care for all people nearing the end of life. Includes many excellent tools and resources, with a local health, social care and third sector system improvement focus. It recognises commissioning end of life care involves leading change in the local health system and that improving quality of care can also lead to reduction in cost.
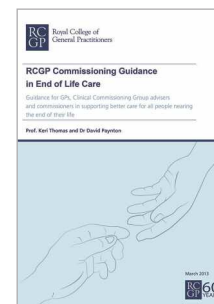
NICE guideline NG31 Care of dying adults in the last days of life[15]
This guideline responds to a need for an evidence based guideline for the clinical care of the dying adult throughout the NHS. It is focused on care needed when a person is judged by the multiprofessional clinical team to be within a few (two to three) days of death. It will also provide a baseline for standards of care in settings that specialise in caring for people who are dying, such as non NHS palliative care units and hospices.

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[11] http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

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

[13] http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf

[14] http://www.rcgp.org.uk/policy/~/media/Files/CIRC/EOLC/RCGP-EOLC-Guidelines-Apr-2013.ashx

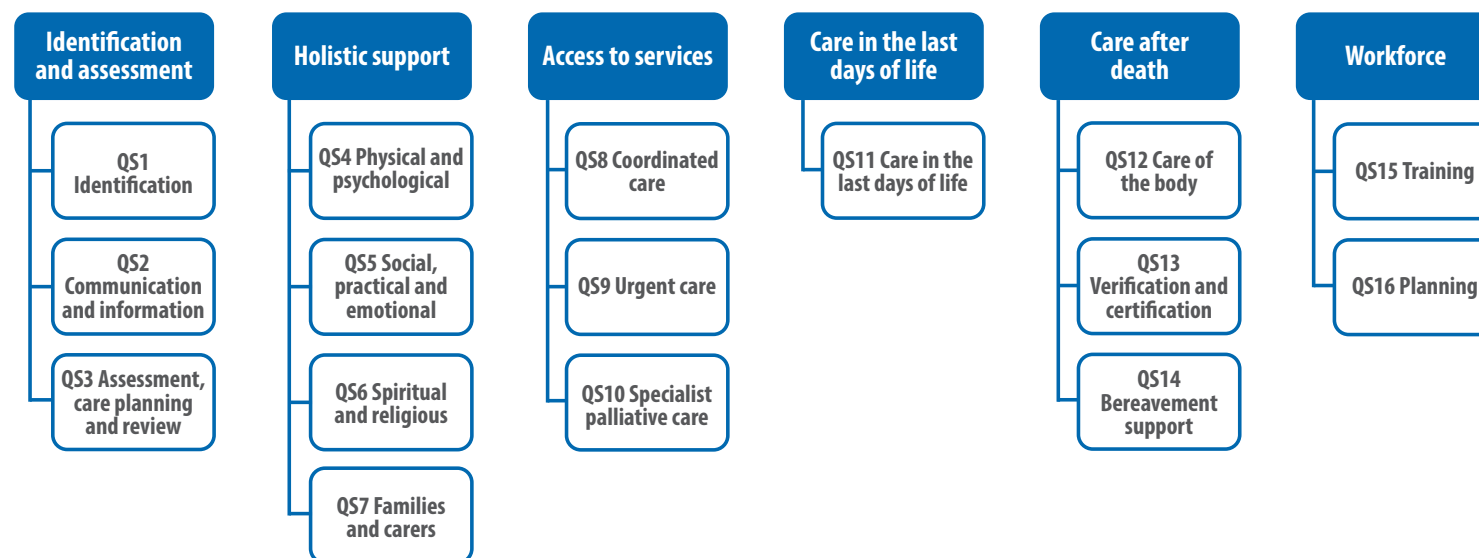[15] http://www.nice.org.uk/guidance/ng31/chapter/context

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NICE quality standard for end of life care for adults (2011)[16] 🖑
Defines clinical best practice with 16 quality statements of recommendations relating to end of life care.

See also NICE guideline CG 138 patient experience in adult NHS services: improving the experience of care of people using adult NHS services[17]. 🖑

See also the NICE into practice guide[18] 🖑 (updated September 2015) on how to use NICE guidance to achieve high quality care.

Identification and assessment	Holistic support	Access to services	Care in the last days of life	Care after death	Workforce
QS1 Identification	QS4 Physical and psychological	QS8 Coordinated care	QS11 Care in the last days of life	QS12 Care of the body	QS15 Training
QS2 Communication and information	QS5 Social, practical and emotional	QS9 Urgent care		QS13 Verification and certification	QS16 Planning
QS3 Assessment, care planning and review	QS6 Spiritual and religious	QS10 Specialist palliative care		QS14 Bereavement support	
	QS7 Families and carers				

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[16] https://www.nice.org.uk/guidance/qs13
[17] https://www.nice.org.uk/guidance/cg138
[18] https://www.nice.org.uk/article/pg1/chapter/1%20introduction%20and%20background

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GENERAL MEDICAL COUNCIL DEFINITION: END OF LIFE CARE

The General Medical Council (GMC) defines patients 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

(a) **advanced, progressive, incurable conditions**

(b) **general frailty and co-existing conditions that mean they are expected to die within 12 months**

(c) **existing conditions if they are at risk of dying from sudden acute crisis in their condition**

(d) **life threatening acute conditions caused by sudden catastrophic events.**

In GMC guidance the term 'approaching end of life' can also apply to extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

AMBITIONS FOR PALLIATIVE AND END OF LIFE CARE

The **six ambitions** articulated in the **'Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2010'[19]** are:

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
6. Each community is prepared to help.

To realise the ambitions eight foundations need to be in place to deliver rapid and focused improvement.

I. Personalised care planning
II. Shared records
III. Evidence and information
IV. Involving, supporting and caring for those important to the dying person
V. Education and training
VI. 24/7 access
VII. Co-design
VIII. Leadership

All six ambitions and eight foundations inform each of the following five commissioning stages.

As an example, the ambition for coordinated care would be part of a local vision and strategy, information gathered about it to establish a baseline and inform planning, be included as an outcome during procurement and continuously improved.
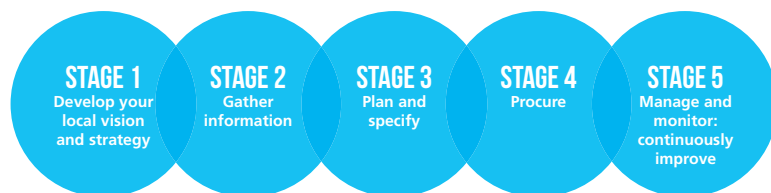
[19] http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

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The five interlinked stages of commissioning safe effective end of life care in this toolkit are:

STAGE 1 Develop your local vision and strategy

STAGE 2 Gather information

STAGE 3 Plan and specify

STAGE 4 Procure

STAGE 5 Manage and monitor: continuously improve

These stages will inevitably overlap. Commissioning is complex, involving a dynamic and continuous process of review and improvement to ensure alignment with changes to national policy, commissioning models, local demand, workforce changes and procurement options.

SECTION SUMMARY AND NEXT STEPS

Now the commissioning context is set, the first stage in this toolkit is to develop your local vision and strategy.

STAGE 1 – DEVELOP YOUR LOCAL VISION AND STRATEGY

Developing your local vision and strategy is the first stage in this toolkit. People with lived experience of end of life care have summarised[20] 👆 what good, coordinated, or integrated, care looks like to people near the end of life.

> **"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)."**

This powerful vision is one everyone involved in commissioning has the opportunity to translate into consistent local reality.

Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020, looks to "a world where improvement no longer comes about from central direction but local leadership, which is "vital for finding new ways of organising care and support for people" … "turning ambitions that should by now have been standard into a reality for all".

Fundamental to any commissioning plan for end of life care is a local strategy, jointly developed with local people and key partners, clearly setting out your vision for end of life care. This may be underpinned by local models like the North West End of Life Care Model[21]. 👆

The Transforming end of life care in acute hospitals: The route to success 'how to' guide[22] 👆 can also assist you by providing a platform for your local discussions with providers and other key partners.

Collaborative working across a geographical area with other CCGs, local authorities, health and wellbeing boards, education boards and the voluntary sector should help to achieve this. For an example click here[23]. 👆

Having time to network and build relationships across local health, care, research and education, can be a major help in developing cohesive strategies and plans and ensuring end of life care data, indicators and best practice models inform local Joint Strategic Needs Assessment (JSNA) and joint health and wellbeing, as well as research strategies.

The NICE quality standard 13 includes a clear quality statement that:

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

[20] http://www.nationalvoices.org.uk/node/1078

[21] http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/north-west-end-life-care-model/

[22] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-how-to-acute-hospitals.aspx

[23] http://www.miltonkeynesccg.nhs.uk/end-of-life-care-strategy/

One chance to get it right (2014)[24] focuses on improving people's experience of care in the last few days and hours of life in comprehensive detail. It sets out five Priorities for Care in the last days of life (see below), assessing and responding to the holistic and changing needs of individual dying people and their families.
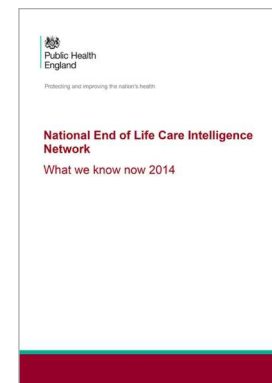
Priorities for Care of the Dying Person

Recognise
The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

Plan & Do
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Support
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Communicate
Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Involve
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

NATIONAL LEVEL RESOURCES TO SUPPORT DEVELOPMENT OF QUALITY SERVICES AND EXPERIENCES OF CARE

- **National guidance, research and directories**
  The NICE quality standard 13[25] for end of life care defines high quality end of life care and provides 16 specific, concise quality statements, measures and definitions

- NHS England Actions for End of Life Care: 2014–16[26] sets out NHS England's commitments to end of life care for adults and children and provides a framework using the House of Care[27] model approach

- **What we know now 2014 – National End of Life Care Intelligence Network (NEoLCIN), Public Health England**[28]
  The third 'What we know now' report shows the breadth of evaluation and research, including public knowledge and attitudes, specialist palliative care services, primary care, end of life care in care homes and social care support for dying people. It compiles key findings and information produced by the NEoLCIN and its partners during 2014. This is the first time research included has been gathered together in one place.

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

[25] http://www.nice.org.uk/guidance/QS13

[26] http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf

[37] http://www.england.nhs.uk/house-of-care/

[28] http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014

- The King's Fund Health and Wellbeing Board Directory map[29] 👆 provides details and contact information for health and wellbeing boards in England

- The National Council for Palliative Care (NCPC) Health and Wellbeing Board Vision for dying people (2014)[30] 👆 research found variation in how explicitly local health and wellbeing boards considered the needs of dying people and made recommendations for joint health and welling being strategies (JHWS) as a result

- **Person centred care**
  See the narrative for person centred coordinated care[31] 👆

- Department of Health key findings report of the Office for National Statistics Survey of Bereaved People (VOICES), 2014[32] 👆

- What's important to me: An independent review of Choice in End of Life Care (March 2015)[33] 👆 offers a blueprint for how greater choice in end of life care can be achieved. Advice is focused around a 'national choice offer' and steps and enablers that need to be in place

- **Commissioning including specialist palliative care (December 2012)**
  Commissioning guidance for specialist palliative care; helping to deliver commissioning objectives[34] 👆 includes an outline of what good palliative care looks like. See also Together for Short Lives[35], 👆 for a guide for CCGs to support commissioning transitions to adulthood for young people with life limiting and life threatening conditions between the ages of 13 and 25.

- **Condition specific**
  Public Health England's NEoLCIN's What we know now[36] 👆 section 4 on different disease groups (see pages 20, 21 and extracts below) highlights that

  "There is evidence to support the benefits of systematic evidence-based approaches, such as the Gold Standard Framework (GSF) **to improve end of life care through earlier identification, more person-centred assessment and effective care planning for people with end stage renal disease, chronic heart failure and chronic obstructive disease**" and

  "Only 20% of patients diagnosed with organ failure (heart, lung, liver or kidney) or dementia, either requested or were identified for palliative care before dying, compared to 75% of cancer patients."

[29] http://www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map

[30] http://www.ncpc.org.uk/sites/default/files/HWBs_Report.pdf

[31] http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf

[32] http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/index.html

[33] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf

[34] http://www.ncpc.org.uk/sites/default/files/CommissioningGuidancefor SpecialistPalliativeCare.pdf

[35] http://www.togetherforshortlives.org.uk/professionals/resources/7959_ transition_-_a_guide_for_clinical_commissioning_groups

[36] http://www.endoflifecare-intelligence.org.uk/resources/publications/what_ we_know_now_2014

Condition specific resources include:

- Out of the shadows: end of life care for people with dementia identified palliative and end of life care needs for people with dementia[37], potential solutions and best good practice examples

- End of life care in advanced kidney disease: a framework for implementation[38] (updated April 2015) identifies kidney specific end of life care aspects

- See also End of life care in heart failure: a framework for implementation[39] and neurological conditions[40]

Measuring experience of care

The NHS Outcomes Framework and the CCG Outcome Indicator set both include a measure on improving the experience of care for people at the end of their lives (bereaved carers views).

A more detailed guide to measuring experience of care in end of life care is available from the NHS Improving Quality website[41].

Also see the Health Foundations 'Helping measure person centred care'[42] and 'Measuring what really matters'[43].

- **Ensuring equality**
  In June 2013 Marie Curie published a report on Palliative and end of life care provision for our diverse communities. This includes people from different ethnic groups and with different religions, beliefs or non-beliefs in the UK[44] which provides an understanding of the nation's changing demographics, need for personalised services to best meet their end of life care needs and provide the diversity of our communities with the dignity and respect they need and deserve. Also see the follow up Next Steps report (2014)[45].

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[37] http://www.ncpc.org.uk/dementia

[38] http://www.nhsiq.nhs.uk/resource-search/end-of-life-care-in-advanced-kidney-disease-a-framework-for-implementation.aspx

[39] http://www.nhsiq.nhs.uk/media/2574509/end-of-life-care-in-heart-failure-framework-for-implementation.pdf

[40] http://www.ncpc.org.uk/neurological-conditions

[41] http://www.nhsiq.nhs.uk/media/2642618/eolc_measuring_experience_of_care.pdf

[42] http://www.health.org.uk/publication/helping-measure-person-centred-care

[43] http://www.health.org.uk/publication/measuring-what-really-matters-towards-coherent-measurement-system-support-person-centred

[44] https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf

[45] https://www.mariecurie.org.uk/who/plans-reports-policies/diversity-inclusion/research

- **Local Authority and Social Care**
  Supporting people to live and die well (revised January 2015)[46] 🖐 sets out a direction of travel for social care at end of life. See also *A good death: the role of the local authority in end of life care*.[47] 🖐

INVOLVING INDIVIDUALS, THEIR FAMILIES, CARERS, OTHER LOVED ONES AND COMMUNITIES

> "I think as a commissioner if you invest in a small number of really intensive relationships, you can get a huge amount from that. What you're trying to do is build each other's knowledge, skills and confidence in each other's areas, so you begin to talk each other's language. So patients [or carers] really begin to understand and help you problem solve things you're grappling with as a commissioner and at the same time you're trying to problem solve and deal with the things that they are trying to deal with in their day to day lives."

Luke O'Shea, Head of Integrated and Personal Commissioning and Person Centred Care, NHS England, Commissioning magazine

Many services have patient/resident/service user groups with whom commissioners should engage throughout the commissioning process. These include local hospices, care and nursing homes, Patient Advice and Liaison Services (PALS) and GP patient participation groups.

Engagement should also be meaningful and sustained as appropriate.

Commissioners have a legal duty to take account of the nine protected characteristics under the 2010 Equality Act: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation. In addition, commissioners of end of life care should pay due regard to the duty to involve people as per the Health and Social Care Act 2012 c. 7 PART 1 Further provision about clinical commissioning groups Section 26 4Z2.

Engagement should be across the diversity of all populations and communities.

In addition, commissioning benefits from being informed by people:

- Accessing homeless shelters or insecurely housed
- Released from custody
- Who use drugs and/or misuse alcohol
- In care and who have left care
- Whose life patterns include travelling
- Who may be dependent and live alone or in a care home
- With limited or no English.

[46] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-social-care-framework.aspx

[47] http://www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf

As well as people and their families who serve or have served in the Armed Forces[48]. Taking account of disability can include people living with dementia, a person with a learning disability or with autism.

However, any confidential personal information can only be used for commissioning purposes if there is a lawful basis.

> I live in a society where I get good access to care, regardless of who I am, where I live or the circumstances of my life
>
> Ambition 2: Each person gets fair access to care

PATIENT LEADERS

Patient leaders[49] bring a credible voice, and can work with system leaders to create a compelling case for change, giving the system 'permission to act'. Patient leaders can help to design services on the ground. When system leaders involve patient leaders and carers in this service design, they are able to focus more closely on what patients and carers want. More radically, commissioners may reduce the risk of future legal challenge about the decommissioning decisions they make in large scale procurements and transformation programmes, if they involve patient leaders armed with robust evidence of what matters to local patients and families. They can also have a role as 'champions' in their communities promoting broader social movement around health and wellbeing.

Following are web links and references to support individual and public participation in all stages of commissioning.

- Improving experience of care through people who use services, how patient and carer leaders can make a difference (August 2015)[50]

- Transforming participation in health and care (2013)[51] provides practical guidance to commissioners on how to improve individual and public participation in all stages of commissioning

- **Healthwatch**[52] Healthwatch England is the national consumer champion in health and care. It has significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. Its local reports can powerfully show lived experience of care to inform commissioning actions and developments. Local healthwatch[53] groups represent the voice of users and help to plan how best to meet the needs of their local population. An action sheet[54] for Healthwatch members outlines expectations of CCGs for engaging with service users

- NHS Network's Smart guides to Engagement Series[55] provide ten guides for commissioners with straightforward advice on all aspects of patient and public engagement

[48] http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/49469/the_armed_forces_covenant.pdf

[49] http://www.england.nhs.uk/wp-content/uploads/2013/08/imp-exp-care.pdf

[50] http://www.england.nhs.uk/wp-content/uploads/2013/08/imp-exp-care.pdf

[51] http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

[52] http://www.healthwatch.co.uk/about-us

[53] http://www.healthwatch.co.uk/strategy

[54] http://www.ncpc.org.uk/sites/default/files/Action%20Sheet%202%20-%20HealthWatch.pdf

[55] https://www.networks.nhs.uk/nhs-networks/smart-guides

- The NCPC guide to involving patients, carers and the public in palliative care and end of life care services[56] aims to help commissioners strengthen involvement in palliative and end of life care

- University of Westminster 2012 evaluation[57] of experience led commissioning for a end of life care project

- Coalition for Collaborative Care[58] brings together people, including people with long term conditions, and organisations from across the health, social care and voluntary sectors that are committed to making changes a reality

Remember to use simple language. Words like hospice care, specialist palliative care, and supportive care are not always familiar to everyone in local communities. See the GMC[59] for other examples.

Part of on-going participation could include asking a wide range of local people to work with you on communication materials setting out what people, family, friends, carers and other loved ones can reasonably expect from their health and care services, to provide personalised care as death approaches and afterwards.

Preferred Priorities for Care (2011)[60] and many other documents are available in an easy to read format[61] to make help and social care information more widely accessible.

SECTION SUMMARY AND NEXT STEPS

Having listened and connected, with an outline vision in place, the next step is to gather detailed local information to help turn the vision into reality.

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[56] http://www.ncpc.org.uk/sites/default/files/InvolvingPatientsCarersAndThe PublicInPalliativeCareAndEndOfLifeCareServices.pdf

[57] http://www.gtc.ox.ac.uk/images/stories/academic/elcreport2012.pdf

[58] http://coalitionforcollaborativecare.org.uk

[59] http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_glossary_ of_terms.asp

[60] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ppc.aspx

[61] http://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-upd-er-july-15.pdf

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This section provides information and resources to help identify demand, scope of current local service provision and gaps.

DEMAND

Commissioning plans and specifications must reflect the whole population's end of life care needs. They should be an integral part of JSNA profiles and health and wellbeing strategies in local communities. They should also align to plans for people with long term conditions, older people's services, including dementia and carers' support.

Approximately 1% of people on a GP's list will die each year and this equates to an average of 20 deaths a year. Around 70–80% of all deaths are likely to benefit from planned end of life care. The key to this approach is to identify those likely to be in their last year of life and to decide how best to reach them. Find essential guidance on the sensitive approach needed for this (August 2014) from Jane Cummings, Chief Nursing Officer[62]. All GP practices should have an agreed mechanism for identifying people approaching end of life – prognostic indicator guides[63] can assist with this process. Another approach is the surprise question "Would you be surprised if this patient were to die in the next six to 12 months?"

Remember to include social care data sources.

NATIONAL TOOLS WITH LOCAL DATA OR APPLICABILITY

- The NEoLCIN profiles[64] provide data on deaths, place of death and deaths by place and cause

- End of Life Care Profiles CCG level snapshots[65] launched by Public Health England, October 2015

- NEoLCIN modelling tools[66] provide a simulation of the likely end of life care needs for an average 200,000 population

- Quality and Outcomes Framework (QOF)[67] for performance on palliative care indicators at practice level (use of palliative care registers and regular multidisciplinary meetings to discuss cases)

- Hospital Episode Statistics (HES)[68] hospital mortality data gives the ratio between the actual number of patients who die after hospitalisation at a trust and the number expected to die on the basis of average England figures, given the anonymised characteristics of the patients treated there

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[62] http://www.england.nhs.uk/2014/08/20/jane-cummings-7

[63] http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

[64] http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/

[65] http://fingertips.phe.org.uk/profile/end-of-life

[66] http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/

[67] http://www.qof.hscic.gov.uk/index.asp

[68] http://www.hscic.gov.uk/SHMI

OTHER USEFUL NATIONAL REFERENCES FOR LOCAL USE

- NHS Atlas of Variation in Healthcare[69] 🖑 allows use of routinely available data to relate investment, activity and outcome to the whole population in need, not just those who happen to make contact with a particular service

- NHS England Long Term Conditions Dashboard[70] 🖑 provides comparative data on risk factors, prevalence, quality of life, quality of care, and economic impact relating to long term conditions

- Public Health England Older Peoples Health and Wellbeing atlas[71] 🖑 gives a snapshot profile of each local authority in England. More than 100 indicators organised into six themes:
  - Population Profile
  - Public Health Outcomes Framework
  - Hospital Stays in 65s and over
  - Deaths in 65s and over
  - Sensory Impairment
  - Social Care

- National Survey of Bereaved People (VOICES) (July 2014)[72], 🖑 provides results of the third survey of information on bereaved peoples' views on the quality of care provided to a friend or relative, in the last three months of life for England

- Commissioning Guidance for Specialist Palliative Care[73] 🖑 provides guidance around how much specialist palliative care is needed based on population size

- Case finding and risk stratification handbook[74] 🖑 (January 2015) provides practitioner insight into case finding

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[69] http://www.rightcare.nhs.uk/index.php/nhs-atlas/

[70] http://ccgtools.england.nhs.uk/ltcdashboard/flash/atlas.html

[71] http://www.wmpho.org.uk/olderpeopleatlas/

[72] http://www.ncpc.org.uk/news/national-survey-bereaved-people-voices-survey-%E2%80%93-comment-national-council-palliative-care

[73] http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialist PalliativeCare.pdf

[74] http://www.england.nhs.uk/wp-content/uploads/2015/01/2015-01-20-CFRS-v0.14-FINAL.pdf

ASSESS LOCAL SERVICES AND GAPS

Map the current scope and quality of health, social care, voluntary sector and community services in the area. See below for a sample visual map. Including funding sources here may be helpful.

HEALTH CONTRIBUTED FUNDING	NON RECURRING FUNDING	THIRD SECTOR FUNDING	NO PROVISION

SERVICE TYPE/AREA	CURRENT SERVICE PROVISION (BY FUNDING TYPE)

Use this to map any pathway interdependencies:

- Assess costs of current unwanted admissions to acute care
- Consider and model different service pathways.

Fully understand your baseline starting points in terms of data and lines of enquiry below.

- **Ensuring equality**
  Below are links from resources previously developed by the National End of Life Care Programme; although some of these resources may be a little out of date, there is still useful information available covering people with learning disabilities[75] (updated 2015), people who identify as lesbian, gay, bisexual and transgender (LGBT)[76] (June 2012), people who are homeless[77] (December 2010) and prisoners[78].

- People of different faiths, spiritual needs and none – see Birmingham St Mary's Hospice community project[79] and case study[80] on increasing awareness of palliative care

- Consider how to support and communicate with individuals who may have complete hearing loss with restricted mobility and live alone

- **Population profiles** by age, disease/s (including multiple long term conditions) gender, ethnicity (which may show variations in disease prevalence and trajectories), deprivation and risk. Consider carer profile and household occupancy (number of people living alone by gender and age)

- **Carers** – many people approaching the end of their life will be cared for and supported by family members and other carers, many of whom may have been carrying out that role some time. NHS England's Carer Principles[81] and self-assessment checklists provide an easy way to identify what already exists or to highlight areas that need further support and possible investment[82]

- Do local General Practices proactively identify people who may provide unpaid care and support for a relative, neighbour or friend? Do practices have a **carers register** (compiled with the consent of carers), offer registered carers flexibility with appointments or an increased possibility of making a home visit? Are people identified as carers offered a regular health check and if needed, a flu jab to look after themselves?[83]

- Could you as a commissioner influence local hospitals to offer free parking to carers?[84]

- Making full use of existing data sources and triangulation:
  - Are all local providers fully completing national data set returns, including full demographic data to identify if any communities may not be fully reached?
  - Use people's experience of services already in place: patient experience surveys, feedback, complaints. Are there any metrics for experience within these services and if so what are they telling you? What are the results of the VOICEs survey telling you? Also see 'Measuring experience of care in end of life care – an overview' (2015)[85]

[75] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-learning-disabilities.aspx

[76] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-lgbt.aspx

[77] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-hostels-and-homeless.aspx

[78] http://www.nhsiq.nhs.uk/media/2387182/rts-prisons-dec-14.pdf

[79] http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/11789/

[80] http://www.nhsiq.nhs.uk/media/2690832/casestudy_increasing_awareness_palliative_care_final.pdf

[81] http://www.england.nhs.uk/commissioning/comm-carers/principles/

[82] http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx

[83] http://www.nhsiq.nhs.uk/media/2535883/carers_case_study_-_health_and_wellbeing_checks_in_devon.pdf

[84] http://www.healthwatchdevon.co.uk/torbay-hospital-one-first-nationally-offer-free-parking-carers

[85] http://www.nhsiq.nhs.uk/media/2642618/eolc_measuring_experience_of_care.pdf

- **Triangulation** – getting a broader picture from overlapping data sources consider QOF data. Do the numbers of people on end of life care registers correlate with the numbers of people who may be in the last year of life?

- **Understanding local variation**
  Is there variation by:
  - General Practice, and if so are the reasons understood?
  - In referrals to services, for example by ethnicity, suggesting some populations are not being fully reached?
  - In access to care at home for people in isolated rural areas
  - How many practices hold regular multidisciplinary meetings to discuss the care of people on their supportive care register?

Quality assurance
Published Information sources can include the following.

- **Provider**
  - Board papers (including use of patient and carer "stories of care")
  - Governance and policies (including when last reviewed, non exhaustive list):
    - Being open and duty of candour, death of service user, drug errors, falls prevention, infection control information governance, nutrition and hydration, safeguarding, safety, incident reporting, Serious Incident requiring investigation management, tissue viability (pressure sores)
  - Provider and wider CQC end of life care reports

- Compliments and complaints – as at October 2015, two NHS England Quality Complaints Commissioning Toolkits are in development, one for acute and one for primary care. They are being developed in partnership with CCGs, the Parliamentary and Health Service Ombudsman (PHSO) and the CQC
- Contributions to national minimum data sets
- PLACE reports[86] – patient led assessments of the care environment, including dementia friendliness
- Quality Accounts
- Quality of Record Keeping Audits (including timeliness and accuracy)
- Staff surveys
- Staffing levels and turnover
- Anonymised reports on planned and completed training

- **Evidence of improvement programmes – examples include the following**
  - Always Events[87]
  - Point of care patient and family centred point of care, multidisciplinary quality improvement programme[88]
  - Transforming End of Life Care in Acute Hospitals Programme[89]

- **General Practice**
  - QOF Palliative Care Register and/or Interoperable Electronic Palliative Care Coordination Systems (EPaCCS) access
  - Carers Register
  - NHS Choices feedback

[86] http://www.england.nhs.uk/ourwork/qual-clin-lead/place/
[87] http://www.pifonline.org.uk/nhs-england-always-events-improvement-initiative/
[88] http://www.pointofcarefoundation.org.uk/What-We-Do/#PFCC
[89] http://www.nhsiq.nhs.uk/media/2477322/consideration_on_quality_assurance.pdf

- **Local system intelligence**
  - Local Authority Scrutiny reports
  - Local councillors and Members of Parliament
  - Local healthwatch consultation and reports
  - Quality Surveillance Groups
  - Risk summits[90]

- **Local media reporting**
  Is the local media monitored for reports of local end of life care experiences, and national media for possible local lines of enquiry/assurance.

- **Twitter feeds**
  Consider using a social media dashboard to consolidate and follow local Healthwatch and other relevant Twitter accounts, take into consideration your organisation's social media policy.

In addition to sources above, more real-time feedback can drive continuous improvement.

Patterns and processes – where and how are services provided across the locality? Below is a list of lines of enquiry to consider.

- **Structure**
  - Have you identified all services that would deliver the local vision of great care and know how many exist now?
  - How many are accessible 24/7, to avoid for example the distress of uncontrolled pain or symptons? Also consider criteria such as age or disease type
  - Are Hospice at Home services available?
  - Are there services which should be decommissioned?

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night

Ambition 4: Care is co-ordinated

- Are there new ways to deliver services?

- **Bed capacity and demand data**
  - What is the provision of beds within care homes, hospices or respite care? Keep in mind developing service arrangements based on outcomes for individuals, rather than for example, units of provision
  - Do these beds and access to them meet the identified population needs?
  - Are systems to access these beds clear and understood by all relevant staff?

- System resilience
  - How resilient are local services to unexpected changes in demand?
  - Are plans in place via the System Resilience Group (SRG) to address these and what is the impact on end of life care services?

[90] http://www.england.nhs.uk/ourwork/part-rel/nqb/

- **System links**
  - Are there ways local organisations could work together to deliver better services?
  - Are protocols in place to support lawful information transfer and integration between organisations e.g. information sharing agreements across health, social care and third sector organisations which set out the legal bases for sharing and ensure appropriate training and security, for staff and public confidence?
  - Are there strong links with care home providers and community based supported housing schemes?
  - Do local care homes have strong links to local GPs?
  - Do local acute trusts know the details general practices would find helpful in discharge letters, for example when a patient's recovery may be uncertain, or an advance care planning conversation has been started in hospital and needs follow up in the community on discharge?
  - How many people identified as benefitting from a fast track discharge **Fast Track** Pathway tool (Revised November 2012)[91] 🖰 for continuing care actually get this? It should be used where a person requires rapid access to continuing care because that person has a rapidly deteriorating condition and may be entering a terminal phase
  - Are there policies and procedures in place to support safe and effective care regarding advance care planning, decision making, equipment such as beds, syringe drivers and anticipatory prescribing? Are these services available seven days a week or 24/7 and do they work across the system?

- Are transitions and transfers between services mapped (for example transfer from a home setting in an ambulance to a place of care)?
- Are there death in transit plans developed and understood across health and social care?
- Are there robust systems in place to identify and support children who may be vulnerable, for example in the sole care of a grandparent who is living with a life limiting or terminal condition to protect the child or children's future life chances?

- **Equity**
  - Does service availability reflect local community profiles, so if needed, deaths can be certified in time to meet faith requirements and/or any overseas repatriation?
  - Have services been designed around only one disease, do they need to be reviewed for people with conditions other than cancer? Local clarity on relevant clinical coding can help identify the number of people living with specific conditions, including multiple ones. If not consistently recorded at the earliest possible stage, they may not be visible to commissioners
  - Are dementia friendly services, for example dementia friendly ambulances in place?
  - Do options for geographic place of care consider the impact on those close to an individual in households without access to a car, where local public transport is limited?

[91] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213140/NHS-CHC-Fast-Track-Pathway-tool.pdf

- **Experience of care**
  - When a person presents at Accident and Emergency (A&E) and is unexpectedly diagnosed with a terminal condition, is there an experience of care protocol including focus on communications skills?
  - Is there access to bereavement support for any one close to people who experience sudden and unexpected death?[92,] [93,] (see national Suicide Prevention Alliance and updated Help at Hand Guide with practical and emotional support for people affected by suicide) and for traumatic loss[94]
  - Do all locum staff including out of hours, who may be unfamiliar with the area, know how to verify a death at home?
  - Is there an agreed approach to ensure sufficient community nursing capacity to verify expected deaths in a timely manner?

In North West England an innovative nurse led bereavement service is transforming care across three acute hospital trusts (April 2014[95]). A matron describes the service and the impact the bereavement services has made (September 2011)[96].

See also Child Bereavement UK[97]. Supports families and educates professionals when a baby or child of any age dies or is dying, or when a child faces bereavement. They provide training to professionals, helping them to better understand and meet the needs of grieving families.

- **Workforce and volunteer support and resilience**
  How do local health and care settings ensure psychological safety, support and resilience for staff and volunteers who may provide care day in and day out? This may range from individual support through clinical supervision to communities of practice through networks or Schwartz rounds[98].

> Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and passionate care
>
> Ambition 5: All staff are prepared to care

Workforce capacity and capability

The **Health Education England Strategic framework** (2014–29)[99] outlines drivers for change in health and social care, likely impact on people and patients in the future and characteristics of the future workforce to meet those needs. The Health Education England workforce plan 2014–15[100] sets out how £5bn investment in education and training, due to start in September 2015, will support new models of care.

[92] http://www.supportaftersuicide.org.uk/help-is-at-hand

[93] http://www.nspa.org.uk/

[94] http://www.cruse.org.uk/traumatic-bereavement/traumatic-loss

[95] http://www.ehospice.com/uk/articleview/tabid/10697/articleid/9806/language/en-gb/providing-excellent-end-of-life-care-in-acute-settings-every-patient-every-time.aspx

[96] https://www.youtube.com/watch?v=Z60pnnpwmsU

[97] http://www.childbereavementuk.org/

[98] http://www.pointofcarefoundation.org.uk/Schwartz-Rounds/

[99] https://hee.nhs.uk/sites/default/files/documents/HEE%20Strategic%20Framework%20%202015%20Refresh%20Final%20document.pdf

[100] https://www.hee.nhs.uk/sites/default/files/documents/HEE-Workforce-plan-14-15.pdf

STAGE 2 – GATHER INFORMATION

Local Education and Training Boards (LETBs) should work collaboratively with commissioners, providers and other partners to deliver effective workforce planning for end of life care. This will collectively identify future staffing skills requirements (such as advance care planning, communication skills, shared decision making, and use of coordination systems), values and behaviours, as well as numbers. Palliative care should be integrated within workforce plans for the frail and older person.

An end of life care **training needs analysis** across the whole local health and care system can be useful or individual providers could be asked to do one. Use the 2012 guide to workforce development published by Skills for Care/Skills for Health[101].

Having a **diverse workforce** can help to meet the diverse individual needs of people and those who are important to them.

Questions to ask about training and development

- What training capacity is there across the system to deliver a rolling programme of training in different settings?

> Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and passionate care
>
> Ambition 5: All staff are prepared to care

- When social care is commissioned by, but not directly provided by local authorities, how is consistency in training managed so all care agency staff are equipped to deliver good end of life care?
- Is end of life care training included in local Health Education England budgets?
- Are all relevant staff aware of the Fast Track tool and how to use it?
- Do staff have access to e-ELCA, the e-learning programme for end of life care, and are they supported to use it?
- Is there access to continuing professional development for all staff and volunteers touched by end of life care?
- What end of life care knowledge, skills, experience and training do local junior doctors working in acute or community settings have?
- Does a local system training needs analysis identify staff for training who may not be immediately obvious, for example communication awareness for staff such as cardiac technologists who may support people with defibrillators? This can include support for staff who may have cared for individuals over a number of years

See **Appendix for Learning and Development resources**.

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[101] http://www.skillsforcare.org.uk/Documents/Topics/End-of-life-care/A-guide-to-workforce-development-for-end-of-life-care.pdf

Voluntary sector

Remember the valuable contribution the voluntary sector can have in supporting end of life care and individuals who are bereaved – see examples below.

- The Louise Hamilton Centre[102] 🖱 in Great Yarmouth as an example of an integrated service
- Derbyshire night sitting services (June 2014)[103] 🖱
- St Lukes' Hospice Plymouth project on maximising potential of volunteers (November 2014)[104] 🖱
- The Carers Trust[105] 🖱 who provide support, information, advice and services to carers across the UK

Also check local services' provision against the 'One chance to get it right' implementation guidance[106], 🖱 that sets out expectations to ensure the five Priorities for Care for people approaching the end of life can be delivered in a safe, effective and patient centred way in any setting.

Use **The NCPC 10 questions framework** (2013)[107] 🖱 to ask yourself:

Q1. Where are local people dying, and where are they being cared for before they die?

Q2. What are people saying about the quality of care they and their loved ones have received locally?

Q3. What local systems are in place to ensure that people who might be approaching the end of their lives have been identified and plans about their care can be coordinated?

Q4. What services are available locally "at any time of day and night" to enable people to be cared for in the place that they want to be?

Q5. What support is available locally for carers of people approaching the end of life, including into bereavement?

Q6. What is being done to ensure that local services are genuinely available and accessible to everybody in the local community?

Q7. What training in end of life care are local organisations giving their staff?

Q8. Has end of life care been identified as a local priority and who is providing local leadership and accountability?

Q9. What local activities are being undertaken to raise public awareness about death, dying and bereavement and build people's confidence in having discussions and making plans?

Q10. What steps are being taken to involve local people and those with personal experience in the way services are shaped and evaluated?

[102] http://www.palliative-care-east.org.uk/why-is-it-needed/

[103] http://www.northderbyshireccg.nhs.uk/press_releases/id/868

[104] http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/13191/

[105] http://www.carers.org/merger

[106] http://www.nhsiq.nhs.uk/media/2483141/0138_nhs_england-annex_e_s19.pdf

[107] http://www.ncpc.org.uk/sites/default/files/10%20Questions.pdf

WORKING ACROSS LOCAL HEALTH, CARE, THIRD SECTOR, RESEARCH AND EDUCATIONAL ORGANISATIONS

- What is in place, electronically or face to face, to help bring together all organisations in the area who can develop and improve end of life care?
- Is there a clear single page local system map for end of life care development?
- Is there a forum where local commissioners and providers can meet and discuss issues and challenges and plan collaboratively?
- Are agreements in place setting out the legal bases for sharing personal identifiable data and common commitments to training and security?

Consider how the local health and care economy can benefit from research[108] 🖐 and development in local

- Academic Health Science Networks[109] 🖐
- Collaborations for leadership in applied health research (CLAHRCs)[110] 🖐
- Strategic Clinical Networks

Also consider how commissioning can support contributions to research and research papers to develop care.

SECTION SUMMARY AND NEXT STEPS

Now you have built on your vision, with detailed local information and evidence, working across health, social care, education and research, the next stage is to Plan and specify.

[108] http://www.endoflifecare-intelligence.org.uk/resources/summit
[109] http://www.ahsnnetwork.com/
[110] http://www.clahrcpp.co.uk/#!clahrcs/cjg9
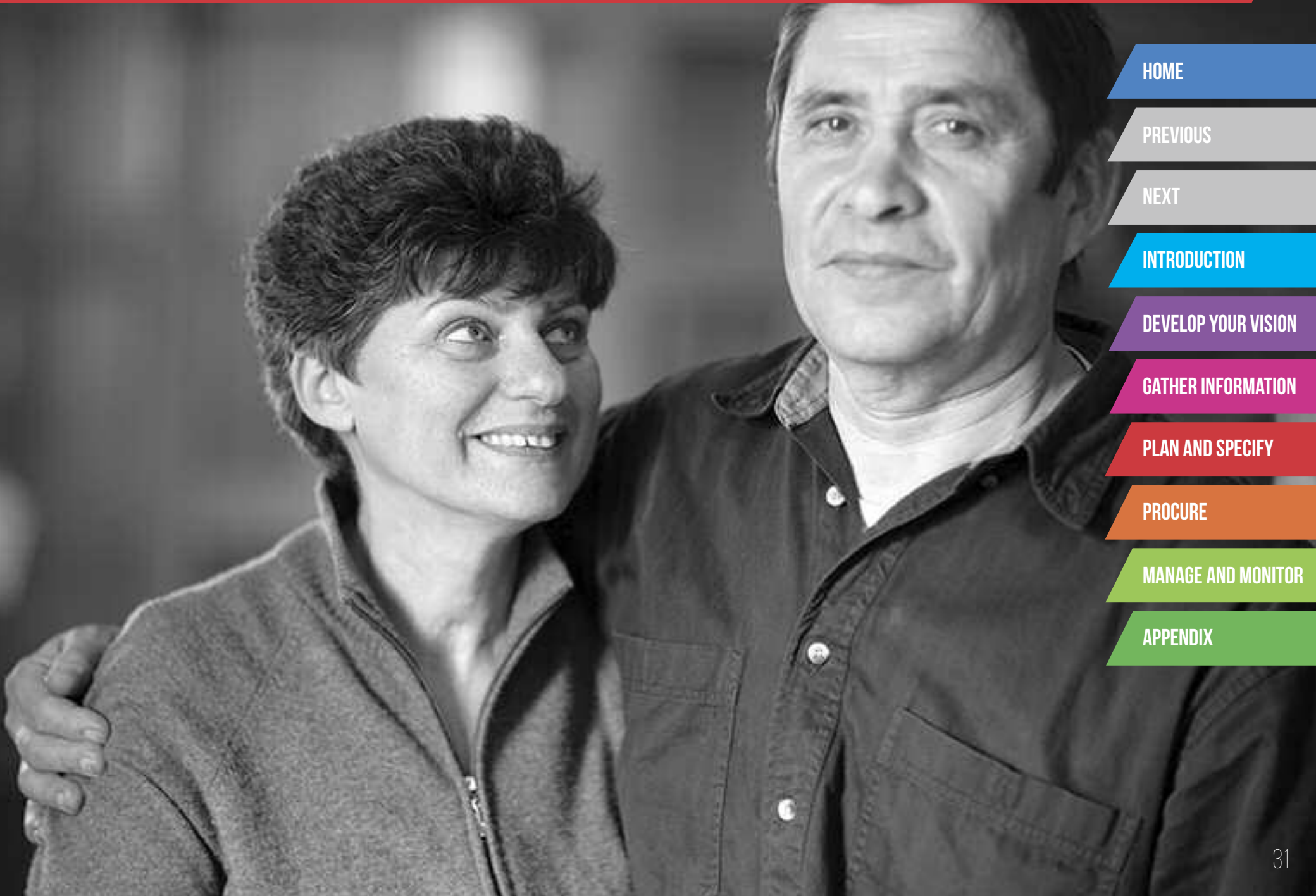
STAGE 3 — PLAN AND SPECIFY

This stage identifies outcomes needed to meet the needs and wishes of people approaching end of life and guidance on developing service specifications.

End of life care should be locally commissioned and locally provided across the whole spectrum of care from generic end of life care and support such as that delivered by primary care teams, non-specialist hospital teams and social care through to hospice care[111], and specialist palliative care services[112].

System Resilience Groups (SRGs)[113] provide a forum where all the partners across the health and social care system come together to plan and oversee the coordination and integration of year round services for patients. Provision for end of life care needs to be included in these plans.

OUTCOMES AND KEY INDICATORS

All service specifications should include **key indicators and quality outcome markers for measuring the provision of end of life care**. During 2015 NHS England plan to develop a set of basic metrics for end of life care.

Measurement for end of life care must reflect the whole population needs across the end of life pathway and link to planning for areas such as long term conditions, care of the elderly, dementia care and carers support.

TOOLS THAT SUPPORT QUALITY BENCHMARKING

- NICE quality standard QS13 on end of life care for adults[114]

- NHS Outcomes Framework 2014/15[115] sets out the high level outcomes and corresponding indicators used to hold NHS England to account for improvements in health outcomes

- Adult Social Care Outcomes Framework[116]

- The End of Life Care Strategy Quality Markers and Measures for End of Life Care (2009)[117]

- Marie Curie Cancer Care's Delivering Choice Programme[118]

- Considerations on assurance and quality improvement for care in the last days of life in acute hospitals[119]

- To assess costs associated with the range of service options see end of life care cost evaluation[120] and palliative care currency guide (March 2015)[121]

[111] http://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/2014-help-the-hospices-commissioning-survey-29-july-2014.pdf?sfvrsn=2

[112] http://www.ncpc.org.uk/sites/default/files/CommissioningGuidancefor SpecialistPalliativeCare.pdf

[113] http://www.england.nhs.uk/wp-content/uploads/2014/06/op-res-cap-plan-1415.pdf

[114] http://www.nice.org.uk/guidance/qs13

[115] https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015

[116] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/263783/adult_social_care_framework.pdf

[117] http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681

[118] https://www.mariecurie.org.uk/professionals/commissioning-our-services/partnerships-innovations/past/delivering-choice-programme

[119] http://www.nhsiq.nhs.uk/media/2477322/consideration_on_quality_assurance.pdf

[120] http://www.thewholesystem.co.uk/bespoke_project/reviewing-end-of-life-care-costing-information-to-inform-the-qipp-end-of-life-care-workstream

[121] http://www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-apprch-pallitv-care-fund.pdf

- The Health Foundation 'Helping measure for person centred care' (March 2014)[122] 👆 signposts research on commonly used approaches and tools to help measure person centred care. It includes a spreadsheet listing 160 of the most commonly researched measurement tools

THINK ABOUT MEASURES THAT WILL MEET OR EXCEED SERVICE EXPECTATIONS IDENTIFIED FROM YOUR STRATEGY AND PLANNING

Ensure:

- Every person on a practice supportive care register is offered at least one opportunity for a holistic needs assessment and the opportunity to document their wishes and preferences. Essential guidance on the sensitive approach needed is available, see www.england.nhs.uk/2014/08/20/jane-cummings-7

- Care is provided by health and social care staff with the right training and competencies relevant to their role to deliver high quality end of life care

- Peer support services in local communities is available to help people meet the social and emotional needs of those approaching end of life and their carers

- Clinical time is used effectively

- Patient information is shared when lawful, necessary and managed appropriately

- Remember that the duty to share information is as important for the care of the patient as the duty to protect patient confidentiality. Staff should be supported in sharing information lawfully, appropriately and securely as an integral part of delivering good care. See duty to share local policies and guidance.

- The experience of end of life care and pre/post bereavement care is a positive one for people, families, carers and staff (e.g. information given is clear, organisations providing care work seamlessly together, there are no unnecessary delays in appropriate place of care, equipment or medicines).

USEFUL REFERENCES

Commissioning Guidance for Specialist Palliative Care[123] 👆 includes population based workforce requirements based on current service models.

The Coalition for Collaborative Care publication 'A personalised care and support planning handbook' (January 2015)[124] 👆 has practical guidance, case studies and theory on how to introduce personalised care and support planning.

[122] http://www.health.org.uk/publications/helping-measure-person-centred-care/

[123] http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf

[124] http://www.england.nhs.uk/wp-content/uploads/2015/01/pers-care-guid-core-guid.pdf

LOCAL SERVICE SPECIFICATIONS

Overview

The service specification provides the platform for discussion and negotiation with providers. Local specifications should ideally drive a whole system approach that encourages providers to work together to deliver high quality integrated care and the availability of a range of services across the care pathway such as:

- Facilitation of discharge across the acute setting
- Rapid response services during periods out of hospital
- Use of effective patient held hard copy/electronic care records
- Centralised coordination of care provision in the community
- Use of an interoperable Electronic Palliative Care Co-ordination Systems (EPaCCS)
- Guaranteeing 24/7 care, seven days a week
- Improved links to out-of-hours and ambulance trusts
- Promotion of advance care planning by all staff for people living with long term conditions and dementia
- Inclusion of the Transforming end of life care in acute hospitals: The route to success 'how to' guide to help local providers raise standards in palliative and end of life care.[125]

Understanding the procurement approach is helpful at this stage. For example is the specification for a jointly commissioned generic end of life care service across health and social care, separate specifications for specialist palliative care, disease specific groups, hospices etc. or specialist commissioned services e.g. prisons?

[125] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-how-to-acute-hospitals.aspx

Where to start

Review current service specifications to identify amendments needed and where these are no longer appropriate, to develop new specifications, and define outcomes and indicators against which the service will be monitored. Develop them in partnership with providers such as hospices so contracts truly reflect the service provided.

Check all applicable service specifications contain a reference to end of life care. This should include management of transitions and coordination between pathways including mental health, children and young adults, long term conditions and carers. Clear service specifications will also be needed for the provision of and access to high quality generalist and specialist palliative care for those that require it. The new NHS standard contract (2015)[126] section SC34 requires providers to have regard to Guidance on Care of Dying People and maintain and operate a Death of a Service User Policy.

Things to consider when commissioning for outcomes

Each of the 16 NICE quality statements[127] for end of life care identified in the introduction is supported by numerous resources. For example, Planning for future care (revised 2012)[128] can help with initial conversations, while Preferred Priorities for Care (February 2011)[129] is a valuable advance care planning tool.

[126] http://www.england.nhs.uk/wp-content/uploads/2015/03/14-nhs-contrct-serv-conditions.pdf

[127] http://www.nice.org.uk/guidance/qs13

[128] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-planning-for-future-care.aspx

[129] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ppc.aspx

Personalised care and experience

- Personalised health and support planning – the Coalition for Collaborative Care handbook (January 2015)[130] ⊕ helps commissioners respond to expectations in respect of people with long term conditions set out in the Five Year Forward View and includes advance care planning

- Personal Health Budgets[131] ⊕ provide funds to support a person's identified health and wellbeing needs, giving people with long term conditions greater control over the healthcare and support they receive. Personal health budgets can pay for a wide range of items and services including therapies, personal care and equipment. Since 1 October 2014 people who are eligible for NHS continuing healthcare have the **right**[132] ⊕ to have a personal health budget

- Dignity – The NHS Confederation, Age UK and Local Government Association report on Delivering Dignity: Securing dignity in care for older people in hospitals and care homes[133], ⊕ provides guidance on commissioning dignity in care for hospitals and care homes. Use of the **Amber care bundle**[134] ⊕ for people whose recovery may be uncertain can contribute to this

Coordinated care and advance care planning

- Care coordination. Every General Practice and provider of end of life care should have an up to date system to share information about people approaching end of life through an EPaCCS[135] ⊕ An end of life care information standard SCCI 1580 supports consistency of data held and shared to co-ordinate the end of life care provided by the many organisations within a locality

- Preferred Priorities for Care and for place of death can change towards the end of life. It is essential any data sharing system can ensure entries are kept up to date to reflect this

- Commissioners are strongly advised to specify use of interoperable EPaCCS in their service contracts, and should monitor its use to ensure all patients who would benefit have their preferences recorded and reviewed on an EPaCCS. See the national information standard[136] ⊕ updated in September 2015 for guidance and Lessons Learned implementing an EPaCCS findings (August 2014)[137] ⊕

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[130] http://www.england.nhs.uk/wp-content/uploads/2015/01/pers-care-guid-supp-comms.pdf

[131] http://www.nhs.uk/choiceintheNHS/Yourchoices/personal-health-budgets/Pages/about-personal-health-budgets.aspx

[132] http://www.personalhealthbudgets.england.nhs.uk/_library/Resources/Personalhealthbudgets/2014/PBUnewsletterJan2014.pdf

[133] http://www.nhsconfed.org/~/media/Confederation/Files/Publications/Documents/Delivering_Dignity_final_report150612.pdf

[134] http://www.ambercarebundle.org/homepage.aspx

[135] http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/coordination-of-care.aspx

[136] http://www.endoflifecare-intelligence.org.uk/national_information_standard/end_of_life_care_coordination/

[137] http://www.nhsiq.nhs.uk/media/2511469/epaccs_lessons_learned.pdf

- 'Gentle Dusk' is a volunteer-led community based solution to raising awareness of end of life and improving end of life care planning. The work[138] includes volunteers who have been trained to become peer educators in planning for the last years of life. They deliver awareness-raising activities such as workshops, presentations, information stalls and also support individuals on a one to one basis to develop and record their plans

> I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in practical ways.
>
> Ambition 6: Each community is prepared to help

Levers and incentives

Consider Commissioning for Quality and Innovation (CQUIN) CQUINS, enhanced service arrangements and quality schedules within larger contracts as incentives and levers for change and quality improvement.

Recognise incremental, and lots of small improvements as well as large ones.

Health and care settings

Referenced earlier, "What we know now", includes comprehensive relevant research across different settings, to help commissioners identify local areas for continuous improvement.

- The route to success series[139] provides information on end of life care across various different settings like care homes, professional groups such as nurses or social workers and individuals e.g. people with learning disabilities

- The Housing Learning and Improvement Network (Housing LIN)[140] is a network of housing, health and social care professionals involved in planning, commissioning, designing, funding, building and managing housing with care for older people and produce a range of resources and fact sheets, several of which refer to end of life care. A factsheet (2015)[141] provides advice and examples of where housing organisations have improved the way they deliver their services for people at end of life

  See also www.housingforhealth.net case study[142] (on how home improvement agencies can support people approaching end of life for example, with changes to make a temporary downstairs bedroom)

- Single point of access – palliative care should be included in any single point of access service

- The Partnership for Excellence in Palliative Support (PEPS) service in Bedfordshire[143] coordinates palliative care across the county to ensure people have access to coordinated help and support that they may require in the future. PEPS provide a single 24-hour telephone point of access for palliative care services, involving joint working of 15 organisations in a 'hub and spoke' model

[138] http://www.gentledusk.org.uk/future-matters.html

[139] http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care/improvement-tools-and-resources/route-to-success-series.aspx

[140] http://www.housinglin.org.uk

[141] http://www.housinglin.org.uk/Topics/browse/CareAndSupportatHome/EndOfLifeCare

[142] http://www.housingforhealth.net/good-death-pilot-project-newcastle

[143] http://www.sueryder.org/how-we-help/care-services/PEPS

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OTHER REFERENCES

Example specifications:

- Hospice at Home[144] 👆

- Heywood, Middleton and Rochdale CCG service specification (Sept 2013)[145] 👆

- Hospice UK Commissioning into the future[146], 👆 Effective Cancer Commissioning in the new NHS, All Parliamentary Group report[147] 👆 and The NCPC Commissioning for Specialist Palliative Care[148]. 👆

Note: NHS England is currently developing guidance on service specifications for specialist palliative care.

The National Information Standard SCCI 1580 – renamed (September 2015) Palliative Care Co-ordination: core content[149] 👆 should be considered in conjunction with EPaCCS Recommended IT System Requirements[150]. 👆

[144] http://www.nahh.org.uk/component/docman/cat_view/23-service-specifications?Itemid=

[145] http://www.hmr.nhs.uk/attachments/article/286/PAPER%2011%20Palliative%20and%20End%20of%20Life%20Care%20Integrated%20Services.pdf

[146] http://www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care

[147] http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/APPG/BritainAgainstCancer2011/EffectiveCancerCommissioningintheNewNHS.pdf

[148] http://www.ncpc.org.uk/publication/commissioning-guidance-specialist-palliative-care-helping-deliver-commissioning-objectiv

[149] http://www.hscic.gov.uk/isce/publication/SCCI1580

[150] http://systems.hscic.gov.uk/qipp/library/epaccsreq.pdf

GENERAL QUESTIONS TO ASK YOURSELF ABOUT ANY SPECIFICATION

- Is it a clear and concise written document that explains what the commissioner/s wants and the provider/s can supply?

- Has it been reviewed by patient leaders?

- Are the outcomes you require clearly stated in the specification and are they person centred (e.g. having an individualised plan of care that includes explicit consideration of food, drink and symptom control or achieving choice of preferred place of care/death), rather than process/activity orientated and do these allow providers to innovate in providing solutions?

- Does the specification allow local provider innovation to achieve whole system outcomes? Improvement and innovation approaches may include:
  - **Improve**: advance care planning, fast track discharge, pain relief, 24/7 access to services/access to equipment
  - **Combine**: telecare, volunteers, communities, locality wide approach to continuing professional development
  - **Re-invent**: hospice at home, volunteers, telephone support, virtual ward approach
  - **Transform**: moving care closer to home.

- Is there a clear mechanism for measuring performance and outcomes in line with the health[151], 👆 social care[152] 👆 and public health[153] 👆 outcomes frameworks?

[151] https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014

[152] https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016

[153] https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency

- Does it facilitate joint working across social and health care?

- Is there a fit with current quality and regulatory requirements?

- Does it reflect what individuals, carers and families have said they need and include robust lawful measures for measuring experience?

- Does it encourage continuing professional development?

SPECIFIC QUESTIONS ABOUT END OF LIFE CARE

- How do providers show care is coordinated and preferences for care communicated across boundaries?

- What services are available in the community 24/7 to enable people to live and die in the place of their choice, and where appropriate, to support direct service providers?

- What access to specific end of life care education and training do staff working within provider organisations have?

- Skills for Health/Care[154]? 🖑 Have training needs been identified? How is this evidenced e.g. training needs analysis completed for relevant staff, rolling programme of training provided, impact of this on care evaluated?

- How do providers demonstrate that they take account of user and carer experience to inform service improvements? Use of real time measures and anonymised service user stories from patient/care opinion/family and friends test etc.

- How do providers continually improve practice and address known challenges – for example pain relief for people with dementia?

SECTION SUMMARY AND NEXT STEPS

Equipped with a good plan to help translate your vision into person centred end of life care, will help you during the next stage – Procurement.

[154] http://www.skillsforcare.org.uk/Documents/Topics/End-of-life-care/A-guide-to-workforce-development-for-end-of-life-care.pdf

INTRODUCTION

Procurement is the term used to carry out commissioning decisions. It may be done in many ways including in-house provision, partnership arrangements or collaboration with other agencies including the voluntary sector.

Procurement offers the opportunity to develop a coalition of providers (e.g. hospices) and/or one lead provider acting as prime contractor on behalf of the coalition. Whatever the model, it will have to be supported by your health and wellbeing boards as being in the best interests of people and the local community.

Commissioners may wish to extend and/or enhance existing contracts through contract variations and agreements, open or restricted tendering exercises, prime provider model or the any qualified provider[155] procurement model. Others may wish to consider different models for different services and take account of service improvement.

Think about how you work together with **patient leaders**. In a CCG procurement programme, patient leaders were given a 20% stake in the decision making process. 'This all centres around the commissioning bit of being the stakeholder, saying that patient representation will have a formal percentage of the decision making stake'[156].

CCGs in Staffordshire and Stoke on Trent aim to appoint a **Prime Provider** to be responsible for managing contracts for each of the whole cancer and end of life care experience from beginning to end. Their website[157] provides information on the procurement process and governance arrangements.

In Kent[158] **GP hubs are being piloted** so that practices can become the primary commissioners for people with complex health needs, using the Year of Care capitated budgets (July 2014)[159].

Where NHS commissioners are party to the same contract as a local authority, the **NHS Standard Contract**[160] must be used. From 2015 the standard contract includes a requirement for providers to have due regard to guidance on care of dying people. Where there is a pooled budget in place and the local authority has been formally designated as "lead commissioner" and will therefore hold the contract on its own, there is no requirement to use the Standard Contract.

Contracting, procurement and commissioning will continue to evolve and mature at a rapid pace. The **Five Year Forward View** outlines several new models of care provision which will have a significant impact on future commissioning and procurement for end of life care. **Monitor's paper 'Reforming payment systems'**[161] provides an insight into new models aligned to the Five Year Forward View plan.

The £3.8bn **Better Care Fund**[162] is a pooled budget that shifts resources into social care and community services to enable more people to get joined up personalised care closer to home.

[155] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216137/dh_128462.pdf

[156] http://www.england.nhs.uk/wp-content/uploads/2013/08/imp-exp-care.pdf

[157] http://staffordshirecancerandeol.com/procurement

[158] http://www.nhsiq.nhs.uk/media/2606994/southend_-_commissioning_and_payment_mechanisms.pdf

[159] http://www.nhsiq.nhs.uk/media/2518638/exploring_the_commissioning_of_personalisation.pdf

[160] http://www.england.nhs.uk/wp-content/uploads/2015/03/14-nhs-contrct-serv-conditions.pdf

[161] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/381637/ReformingPaymentSystem_NHSEMonitor.pdf?utm_medium=email&utm_source=The+King%27s+Fund+newsletters&utm_campaign=5071556_HMP+2014-12-

[162] http://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/

STAGE 4 — PROCURE

SERVICE SCOPE

Commissioners may commission services such as specialist palliative care independently, or alternatively commission across the whole spectrum of end of life care seeking lead providers to coordinate integrated care.

Services commonly commissioned includes the following:

Acute hospital care

Allied Health Professionals, nurses, social workers, doctors, chaplains, health and social care workers, volunteers etc.

Benefits advisors

Bereavement services

Care coordination

Carer support e.g. sitting services support

Community hospitals

Community services

Domiciliary care

Palliative care information and advice services/telephone helplines

Education and training for staff

Equipment suppliers timely delivery and collection

Hospice care — inpatient, hospice at home and day hospice

Interpretation services

Independent providers of care homes, nursing homes, residential homes and care at home

Night sitting services

Out-of-hours

Patient advocacy

Pharmacy suppliers including access to 24/7 palliative care drugs

Psychology services

Rapid response services e.g. Marie Curie

Respite care

Social workers

Specialist palliative care including 24/7 access, specialist nurses

Spiritual care services

Telephone services[163]

Voluntary sector

[163] http://www.sueryder.org/how-we-help/care-services/PEPS

STAGE 4 – PROCURE

Considerations for commissioning end of life care.

Purpose	Aim
Service scope	Geography, exclusions, user groups
Service delivery	Location, hours of access, response times, care pathways, discharge processes, staffing, information sharing
Quality assurance	User involvement, quality indicators, performance monitoring, equality, staff training, audit, safety
Activity plan	Planned improvements
Cost	Value for money

Service delivery and scope – additional headings to consider/cover

- Interdependencies
- Whole system relationships
- Continuous improvement
- Data collection and monitoring
- Data transfer *(information sharing)*
- Evidence base

- Innovation and research and development
- Referral routes (including DNA management) *(pathways)*
- Transfers of care on discharge *(discharge process)*

To specify and procure effectively commissioners need to follow a clear process, and work with local health and social care providers from all sectors to develop and agree a service specification/ service level agreement, tailored to supporting people with end of life care needs.

FUNDING AND TARIFF

Developing a new approach to palliative care funding (March 2015)[164] 🖰 offers a meaningful tool to support service planning and commissioning. It provides a 'currency' based on packages of care that are similar in terms of resource need and clinical input. The currency is not mandatory and will be further tested and refined during 2015/16. Public Health England and NHS England are working together to develop a dataset to support palliative care outcomes and the new currency.

[164] http://www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-apprch-pallitv-care-fund.pdf

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Personal health budgets are a way to enable people to buy goods and services not normally commissioned by the NHS. The voluntary sector[165] 🖱 can support CCGs in this process.

The September 2014 Nuffield report, **'Exploring the cost of end of life care'**[166] 🖱 found that even when costs in other sectors – social care, primary and community care were considered, Marie Curie patient costs were around £500 less per person. It builds on a prior 2012 study[167] 🖱 and suggests cost savings might be available if community-based support were made more widely available to help people to die in their own homes, where that was their preference.

In September 2012 a study[168] 🖱 reviewed potential benefits and costs associated with implementing EPaCCS.

OTHER USEFUL RESOURCES

Thanks for the Petunias (May 2011)[169], 🖱 a guide to support effective commissioning and development of non-traditional providers (NTPs), to support people with long term conditions in a local health economy from the Long Term Conditions Year of Care Commissioning Programme.

SECTION SUMMARY AND NEXT STEPS

Now you have a good evidence based specification/s, building on the local vision for great person centred end of life care, it is important to consider continuous improvement and assurance. These are covered in the next stage.

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[165] https://www.england.nhs.uk/healthbudgets

[166] https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/why-work/our-impact/2014-nuffield-report.pdf

[167] http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing

[168] http://www.thewholesystem.co.uk/wp-content/uploads/2014/07/EoLC_QIPP_Costings_Report.pdf

[169] http://personcentredcare.health.org.uk/sites/default/files/resources/thanks_for_the_petunias_-_a_guide_to_developing_and_commissioning_non-tradition al_providers_to_ssm_for_people_with_ltcs.pdf

STAGE 5 – MANAGE AND MONITOR: CONTINUOUS IMPROVEMENT

INTRODUCTION

This stage looks at the services provided and how to continue to improve them. All services need to be safe, of the highest quality, clinically effective, provide a good patient/service user experience, and offer value for money as well as performing to the contract and delivering national and local quality standards.

Collect data and measure performance and outcomes against contracts in a similar way to that used for all health and social care.

MEASURE PERFORMANCE AND OUTCOMES

End of life care is now one of the eight core services the CQC routinely inspect in acute hospitals. It is also incorporated into its inspection approach in the other settings where it is delivered.

The CQC use the evidence collected to reach judgements about the quality of care. It publishes reports about the services it inspects on its website.

After each inspection, it produces a report. In most cases the reports include ratings, which show its overall judgement of the quality of care.

These reports set out its findings on what each of the five key questions mean for the people who use the service. The CQC describe the good practice it finds, as well as any concerns it has, clearly setting out any evidence about breaches of regulations.

It also makes recommendations to help the care provider improve their rating. The care provider must respond to areas of concern identified, develop an action plan to address

them and make improvements. CQC will follow up on any action it tells care providers to take, follow up may be by contacting the care provider or visiting the service to carry out a focused inspection.

When the CQC inspect acute hospital trusts, specialist mental health services and community health services, its inspection findings are discussed at a **quality summit**. This is a meeting with the care provider and partners in the local health and social care system.

In 2015/16 the Royal College of Physicians are due to undertake the **national audit of end of life care in hospitals**.

Once a service has been commissioned it is important commissioners continually monitor and review services being delivered. This should include recognising and valuing consistent delivery of good and great care.

In addition, it should include systems to manage when performance is poor and failing to meet outcomes, identified in the contract negotiation rounds, which could mean decommissioning them.

As well as the sources mentioned earlier, real time intelligence can include:

- 'Walking the pathway' to see just how the service is operating, including weekends and bank holidays

- With permission, thinking about using a mobile phone to photograph, for example, rest areas for friends, families and those who are important to people, or mortuary viewing facilities

- Seeing routine audits, as they are completed

- Friends and family test

- Findings from Overview and Scrutiny Committees in local government[170] 🖑

- Feedback direct from people with experience of services including real time measures of patient/carer experience such as Patient Opinion[171] 🖑 and Care Opinion[172] 🖑

- Use of the Fast Track Tool[173] 🖑 for continuing care discussing any concerns over its use with organisations, clinicians and teams separately from decision making in any individual case.

REVIEW

In addition to setting out reporting frequency and format, set out your outcomes and key indicators and keep reviewing them.

EFFECTIVE USE OF LOCAL RESOURCES

- Appropriate use of hospital beds, numbers of avoidable admissions

- Some CCGs commission end of life care services from care homes by ensuring use of General Practice palliative care registers, training, education and support to identify those at the end of their life and reduce unwanted admissions and increase the proportion dying in their preferred place of care

- The Transforming end of life care in acute hospitals: The route to success 'how to' guide[174], 🖑 can be a useful resource to enable local acute providers and other partners to raise standards of care and ensure resources are used effectively

WORKING TOWARDS PERSON CENTRED OUTCOMES MEASURES

Think about outcomes – are they what matter to individuals? As a result of good nutrition and hydration policies, training and staff awareness, can a person at end of life enjoy, for example, the first of the summer fruit from their allotment brought in by a family member?

> My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.
>
> Ambition 3: Maximising comfort and wellbeing

AMBITIONS FOR PALLIATIVE AND END OF LIFE CARE

This toolkit includes resources to help realise the six ambitions included in the framework:

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**
6. **Each community is prepared to help.**

[170] http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN06520

[171] https://www.patientopinion.org.uk

[172] https://www.careopinion.org.uk/

[173] http://www.nhsiq.nhs.uk/media/2455484/supportsheet14_ajr_updated_28_oct.pdf

[174] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-how-to-acute-hospitals.aspx

To realise the ambitions eight foundations need to be in place to deliver the rapid and focused improvement the partnership outlined:

I.   Personalised care planning
II.   Shared records
III.   Evidence and information
IV.   Involving, supporting and caring for those important to the dying person
V.   Education and training
VI.   24/7 access
VII. Co-design
VIII. Leadership.

Below are examples of the types of evidence which might give assurance the five Priorities for Care at end of life are being met.

Priorities for Care – Recognise, Communicate and Involve

There is an appropriate correlation between the number of local deaths and the number of individuals who are supported by interoperable EPaCCS registers, (remembering that for people with some conditions this may be over a number of years and may change).

Clinical quality of record keeping audits show all individuals who could benefit from advance care planning in an acute setting have been identified, and if a conversation/s is not appropriate the reason why not is recorded in the care record.
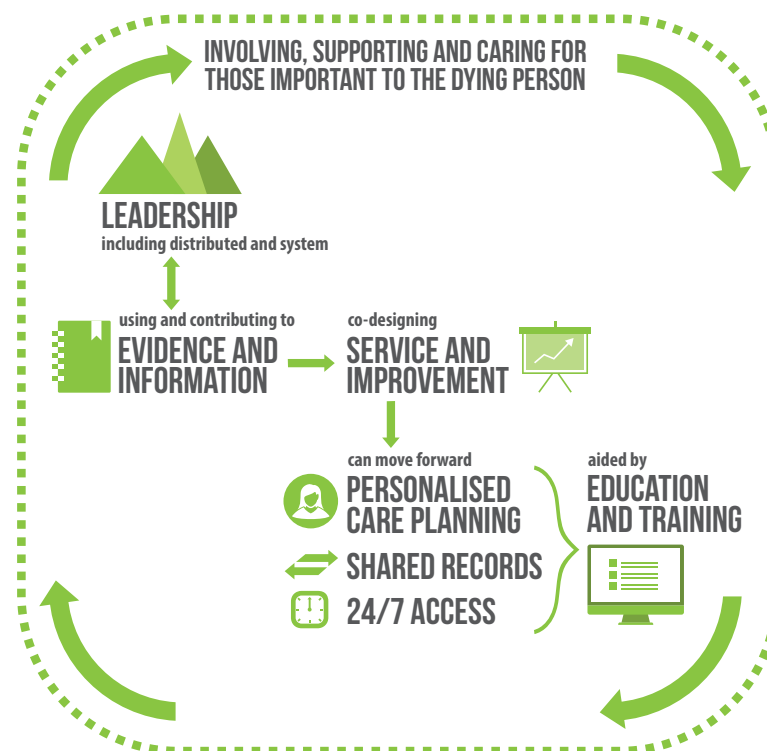
Priorities for Care – Support

Individuals, carers and families feel they have been treated with dignity and respect.

Individuals report there is sufficient quiet, calm space for personal conversations, evidenced by for example, local Healthwatch reports.

Priorities for Care – Plan and do

An individual's preferences for place of care are met.

Individuals have had their individual hydration, nutrition and pain relief needs met.

Individuals are seen and treated as a person – for example by a hospital porter on his way in to work taking the time to buy a foreign language newspaper for a patient.

Individuals identified for fast track discharge have had any equipment, home adaptations and medicines promptly in place, including over weekends or bank holidays.

CONTINUALLY WORKING WITH PROVIDERS TO SUPPORT QUALITY SERVICES

If providers face unexpected in year cost pressures, how can you as a commissioner, work with them to minimise the impact on services and support clinical and other end of life care staff have their needs heard, and met, at trust board level against competing demands?

If there are challenges with for example consistent access to drugs, perhaps for supply chain or cost reasons, how can you as a commissioner work to support providers to address this? A standard measure of provision might be the availability of "Just in Case" medications for people identified as Amber or Red on the Gold Standards Framework (GSF) rating.

CONTINUALLY IMPROVE

Keep up a process of monitoring population needs assessment and evaluating experiences of care. Repeat service user/carer consultation.

Be alert to on-going local population changes.

Pay particular attention to social inclusion e.g. people who are insecurely housed and those whose first language is not English. How do you know that individuals with a learning disability, autism or with mental health needs are receiving respectful and appropriate care?

SECTION AND TOOLKIT SUMMARY

You have listened and continue to listen. You have got a solid evidence and reference base, working with patient leaders, this informed your local strategy and specification approach. You continually look at how these lead to individuals, families, carers, other loved ones and communities getting consistent person centred care that matters to them, regardless of who they are, where they live or the circumstances of their life.

SHARE YOUR SUCCESS

Why not share your learning and contribute to continuous improvement? Maybe your work and your colleagues can inspire others through a case study, research contribution or presentation.

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USEFUL RESOURCES

END OF LIFE CARE SPECIFIC

Transforming end of life care in acute hospitals: The route to success 'how to' guide[175]

This e-publication supports NHS England's Action for End of Life Care 2014–16. It is part of an existing suite of documents that set out a wider ambition to develop a vision for end of life care beyond 2015. This version of the guide, following the withdrawal of the Liverpool Care Pathway, marks a significant milestone in improving end of life care for patients and their families. It builds on legacy work from NHS Improving Quality and provides practical advice and support for frontline clinicians and leaders on 'how to' identify, lead and implement change for themselves to improve their local services in collaboration with their local partner organisations across their community.

Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020[176]

Builds on the 2008 strategy and improvements that followed. It sets out six high level ambitions, and looks to integrated health and social care systems to work with people as well as for people, to create new ways to build more effective systems of care,

putting existing resources to more creative and effective use, aligning with changes flowing from the NHS Five Year Forward View[177].

Every Moment Counts: a narrative for person centred coordinated care for people near the end of life (March 2015)[178]

Draws on surveys, testimonies of bereaved carers, experience of end of life care charities, the reflections of professionals. The CQC's Chief Inspector of Hospitals, Professor Sir Mike Richards noted: "this clearly articulates the quality of care which everyone should be able to expect at the end of their life.

"We are using the narrative in our thematic review of inequalities and variation[179] in End of Life Care to describe what good care looks like, so that we can understand why people's experience of end of life care often falls short of this."

What's important to me: A review of Choice in End of Life Care (2015)[180]

Calls for a new 'national choice offer in end of life care' to be established, backed up by an additional £130 million from the next spending review. It also calls for a new right in the NHS Constitution for everyone to be offered choice in their end of life care, and for these choices and preferences to be recorded in their own

[175] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-rts-how-to-acute-hospitals.aspx

[176] http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

[177] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

[178] http://www.ncpc.org.uk/news/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations

[179] http://www.cqc.org.uk/content/identifying-variation-end-life-care-commissioning

[180] http://www.ncpc.org.uk/news/choice-review-published

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personal plan of care, implemented or adapted to suit local contexts of care.

Act and Early to avoid A&E (June 2011)[181] 🖑
Advises commissioners on actions to commission effective end of life care.

Advance Care Planning: a guide for health and social care staff (revised August 2014)[182] 🖑
Provides guidance about this area of practice for all health and social care staff responsible for the care of people affected by life limiting or life threatening illness. Written to complement the guidance aimed at doctors, published in 2010 by the GMC, 'Treatment and care towards the end of life: good practice in decision making'.

**updated version of Advance Care Planning: a guide for health and social care staff - revised August 2014 **

This guide covers:

the importance of assessing a person's capacity to make particular decisions about their care and treatment and of acting in the best interests of those who are assessed as lacking capacity to make these decisions

the differences and relationship between care planning and advance care planning.

Capacity, care planning and advance care planning in life limiting illness
A Guide for Health and Social Care Staff

Sharing successful strategies for implementing 'Supporting people to live and die well: a framework for social care at the end of life' (2013)[183] 🖑
Has a number of ideas and innovative approaches to end of life care.

The National Audit Office end of life care report (2008)[184] 🖑
Found some people receive high quality end of life care, but there is room for improved coordination between health and social care services in planning and delivery.

University of Southampton Health Sciences End of Life Care[185] 🖑

Public Health England: Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK[186] 🖑

Treatment and Care Towards the End of Life (GMC 2010)[187] 🖑

National Council for Palliative Care[188] 🖑

Association of Palliative Medicine[189] 🖑

Hospice UK[190] 🖑

COMMISSIONING AND CONTRACTING

Contracting for Outcomes – A Value Based Approach[191] 🖑

Older people living with frailty[192] 🖑

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[181] http://www.ncpc.org.uk/sites/default/files/AandE.pdf
[182] http://www.nhsiq.nhs.uk/resource-search/publications/eolc-ccp-and-acp.aspx
[183] http://www.nhsiq.nhs.uk/8502.aspx
[184] http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

[185] http://www.southampton.ac.uk/healthsciences/business_partnership/services/eolc.page
[186] http://www.endoflifecare-intelligence.org.uk/resources/publications/palliative
[187] http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp
[188] http://www.ncpc.org.uk
[189] http://apmonline.org
[190] http://www.hospiceuk.org
[191] http://outcomesbasedhealthcare.com/portfolio/contracting-for-outcomes-a-value-based-approach/
[192] http://www.camdenccg.nhs.uk/publications/camden-ccg-listening-events-november-2013

Long Term Conditions Year of Care Commissioning Programme[193] 👆
The programme aims to transform the quality of care for people with complex care needs. It supports commissioners and providers to develop and implement funding models so an annual budget for individuals with complex care needs can be used to commission tailored, joined-up packages of care.

DATA AND INTELLIGENCE

The National End of Life Care Intelligence Network[194] 👆
Aims to improve the collection and analysis of information about end of life care services. This intelligence can help drive improvements in the quality and productivity of services.

The network's website includes:

- End of life care profiles – data and statistics on end of life within each local authority area broken down by age, gender, place of death and cause of death
- Resources – data, reports, analysis and links to other useful sources of information
- Data sources – a guide to key health, social care and related data sources in the field
- Advice and information – signposting to advice and information for individuals, their relatives and carers.

LEARNING, DEVELOPMENT AND TRAINING

Training resources:

- e-learning modules e-ELCA[195] 👆 – free access to health and social care organisations. A core learning package to deliver five Priorities for Care is under development

- 'Care to Learn'[196] 👆 – The NCPC developed an end of life care programme relevant to all staff caring for people at the end of life, in particular those working in social care including care homes, housing organisations, other community settings and hospitals. As at October 2015 it was being revised and unavailable

- E-GP e-learning for general practice[197] 👆 – jointly developed with the RCGP and Health Education England, section 3.09 provides 10 e-learning modules covering end of life care

- 'Dying Matters' three day training course[198] 👆 and DVD training for GPs[199] 👆

- Gold Standards Framework training programmes[200] 👆 (primary care, care homes, acute hospitals, community hospital, domiciliary care, integrated care, hospice plus clinical and spiritual care)

- Macmillan Cancer Support Learn Zone[201] 👆 – free and easy access to a wide variety of learning resources, online courses and professional development tools

[193] http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/ltc-year-of-care-commissioning-model.aspx
[194] http://www.endoflifecare-intelligence.org.uk

[195] http://www.e-lfh.org.uk/programmes/end-of-life-care
[196] http://www.ncpc.org.uk/care-learn-training-0
[197] http://www.e-lfh.org.uk/programmes/general-practitioners
[198] http://dyingmatters.org/event/embracing-dying-three-day-training-course
[199] http://dyingmatters.org/gp_page/dvd
[200] http://www.goldstandardsframework.org.uk/training-programmes
[201] http://learnzone.org.uk/about

- Skills for Care[202] 👆 do not deliver training but have produced a number of resources to support those working in adult social care to develop their skills and knowledge in this area

- Year of Care Partnership Programme[203] 👆 – focus on care planning.

Note: During 2015 Health Education England plan to evaluate and review their education and training programme. e-ELCA is also updating their core training packages.

End of Life Care for All (e-ELCA)[204] 👆
The e-ELCA programme was commissioned by the Department of Health and delivered by e-Learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland. It aims to enhance the training and education of health and social care staff involved in delivering end of life care and has over 150 interactive sessions. As at October 2015, these are free to access by health and social care staff and focus on:
- Advance care planning
- Assessment
- Communications skills
- Symptom management, comfort and wellbeing
- Social care
- Bereavement
- Spirituality.

There is also an integrated learning module which covers specific settings and conditions.

LONG TERM CONDITIONS

House of Care model[205] 👆
NHS England and partners are using this model as a checklist/metaphor for these building blocks of high quality person centred coordinated care. The house relies on four key interdependent components, all of which must be present for the goal, person centred coordinated care, to be realised. Includes tools and case studies to support effective commissioning.
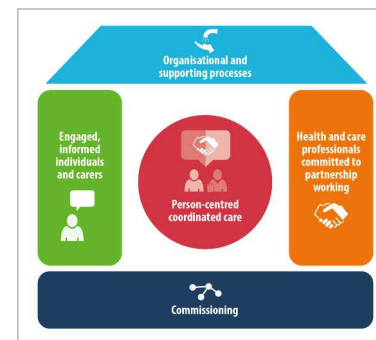
Personalised care for people with long terms conditions (2015)[206] 👆
Three 'service components' or 'handbooks' to provide practical support for good long term conditions management.

[202] http://www.skillsforcare.org.uk/Skills/End-of-life-care/End-of-life-care.aspx
[203] http://www.yearofcare.co.uk/about-us
[204] http://www.e-lfh.org.uk/projects/e-elca

[205] http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/house-of-care/house-care-mod/
[206] http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/ltc-care/

Joining up health and social care personal budgets – Key points on implementation, NHS Confederation (January 2015)[207]
Briefing paper relevant to leaders and managers considering how to join up personal budgets in health with personal budgets in social care. Includes practical examples.

Carers – NHS England Commitment to carers[208]
Sets out a series of 37 commitments from NHS England to support carers, reflecting what NHS England heard from carers at engagement events. Also see NHS England's Commitment to Carers End of Year Progress Summary 2014/15.[209]

The Health Foundation: Person centred care[210]
Provides a range of resources, blogs and publications to help organisations focus on developing a more person centred healthcare system, where people are supported to make informed decisions about, and successfully manage their own health and care, and choose when to invite others to act on their behalf.

Prioritising person centred care, National Voices (2014)[211]
Evidence from systematic reviews of ways to make person centred care happen placing people at the forefront of their health and care. It ensures people retain control, helps them make informed decisions and supports a partnership between individuals, families and services.

POLICY AND CONTEXT

Equality Act (2010)[212]

Health and Social Care Act (2012) with duties to reduce health inequalities[213]

Health and Social Care (Safety and Quality Act) 2015[214]

Human Rights Act[215]
See link for CQC equalities and human rights duties impact analysis for provider handbooks for residential adult social care, community based adult social care and hospices.

Mental Capacity Act (2005)[216]
Provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. The code of practice[217] provides practical advice on implementation and examples of best practice.

Health and Care system explained (March 2013)[218]
An overview of the structure of health and social care systems in England. See also The King's Fund alternative guide to the new NHS[219].

NHS England – guidance on Equality and Health Inequalities duties for commissioners[220]

[207] http://www.nhsconfed.org/resources/2015/01/joining-up-health-and-social-care-personal-budgets
[208] http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf
[209] https://www.england.nhs.uk/wp-content/uploads/2014/05/comm-carers.pdf
[210] http://personcentredcare.health.org.uk
[211] http://www.nationalvoices.org.uk/evidence
[212] http://www.nhs.uk/NHSEngland/thenhs/equality-and-diversity/Pages/equality-and-diversity-in-the-NHS.aspx
[213] https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets
[214] http://www.legislation.gov.uk/ukpga/2015/28/contents/enacted
[215] http://www.cqc.org.uk/sites/default/files/20141008_asc_provider_handbook_equality_impact_analysis_final.pdf
[216] http://www.legislation.gov.uk/ukpga/2005/9/contents
[217] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf
[218] https://www.gov.uk/government/publications/the-health-and-care-system-explained/the-health-and-care-system-explained
[219] http://www.kingsfund.org.uk/projects/nhs-65/alternative-guide-new-nhs-england
[220] https://www.england.nhs.uk/ourwork/gov/equality-hub/legal-duties

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QUALITY IMPROVEMENT

Compassion in Practice[221]

The NHS Change Model[222]
A simple framework to support sustainable change and transformation within and beyond organisations. It has eight components each supported by a wide range of practical resources like self-assessment tools, e-learning modules and case study examples.

A directory of organisations, groups and teams that support innovation, improvement, leadership development and systems leadership, issue 2[223]

Improvement Leaders Guides[224]

Guide to quality improvement methods[225]

NHS Improving Quality[226]
The Transform programme aims to improve the quality of end of life care within acute hospitals across England. It focuses on both quality of care provided by acute hospitals, as well as the important role they have, as one of many organisations that may provide care for people who are approaching end of life.

The programme encourages hospital trusts to develop a strategic approach to reach their aim to improve the quality of care. This includes:

- Involving patients, carers and the public
- Developing staff skills, competencies and confidence through education and development
- Quality assurance, measurement and evaluation.

[221] http://www.england.nhs.uk/wp-content/uploads/2012/12/compassion-in-practice.pdf
[222] http://www.nhsiq.nhs.uk/capacity-capability/nhs-change-model.aspx
[223] http://www.nhsiq.nhs.uk/resource-search/publications/a-directory-of-organisations,-groups-and-teams-that-support-innovation,-improvement,-leadership-development-and-systems-leadership.aspx
[224] http://www.nhsiq.nhs.uk/capacity-capability/advancing-change/publications.aspx
[225] http://hqip.org.uk/resources/guide-to-quality-improvement-methods/
[226] http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx

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