End of life care

Sustainability and Transformation Partnership support tool

West, North and East Cumbria

Why is Palliative and End of Life Care important?

Improving palliative and end of life care (EoLC) will play an important role in the successful delivery of many Sustainability and Transformation Partnership (STP) priorities, in particular those highlighted in the Next steps on the NHS Five Year Forward View such as mental health, cancer, urgent and emergency care, as well as improving financial sustainability.

In 2015, more than half a million deaths were registered in England: 28,189 more than 2014, the largest percentage increase (5.6%) since 1968. The majority (24,201) of these additional deaths were people aged 75 and over[1]. Research suggests that improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could translate to a potential reduction in hospital costs and therefore reinvestment of £180 million per annum[2] as well as improving patient choice.

There is significant variation and therefore opportunity to improve the commissioning and delivery of services that support people at the end of life across health and care systems. Focussing on improving care for people at end of life will not only improve outcomes and experience for patients, it will also improve health and care flow, reducing the pressure on ambulances, urgent and emergency care and hospital beds through timely and appropriate responses to urgent unscheduled needs in their usual place of care.

Focussing on those at the end of life will also help to reduce unnecessary and unwanted admissions and improve early supported discharge to a place of care that best meets the needs of the patient, therefore reducing the likelihood of unnecessary re-admission, clinically unnecessary occupied bed days and improve patient experience. Better care coordination and shared records contribute significantly to facilitating an efficient flow of patients and communication between the hospital and their home, which is also better for the patient.

1. Office for National Statistics, 2015 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/provisionalanalysisofdeathregistrations/2015
2. Hughes-Hallett, Craft, Davies. 2011. Palliative Care Funding Review

Did you know?

The voluntary sector are important partners in meeting EoLC needs, both as providers and funders of care. Across the country, the hospice sector, for example, invests over £1 billion of charitable funding in local communities to meet palliative care needs[3].

If recent mortality trends continue, 160,000 more people in England and Wales will need palliative care by 2040[4].

10% of people receiving hospice care that have engaged in ACP die in hospital compared to 26% of those who have not engaged in ACP[5].

Approximately 30% of people in the last year of life use some form of Local Authority funded social care[6].

If access to community-based EoLC improved, £104 million could be redistributed to meet people's preferences for place of care by reducing emergency hospital admissions by 10% and the average length of stay following admission by three days[7].

Hospital costs are by far the largest cost elements of EoLC with care in the final three months of life averaging over £4,500 per person who died. The bulk of this cost is due to emergency hospital admissions where hospital costs increase rapidly in the last few weeks of life[8].

Economic evaluation of Electronic Palliative Care Co-ordinated Systems (EPaCCS) indicates financial savings can be made where these systems are in place to share EoLC records – recurrent savings after four years c£270k for a population of 200,000 people[9].

Advance Care Planning (ACP) improves EoLC and patient and family satisfaction and reduces care home admissions, stress, anxiety and depression in surviving relatives[10].

Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%)[11].

*Other useful information: National Survey of Bereaved People (VOICES): England, 2015 - Quality of care delivered in the last 3 months of life for adults who died in England.

3. Hospice UK (2016) Hospice Accounts: Analysis of the accounts of UK charitable hospices for the year ended 31 March 2015. London: Hospice UK
4. BMC Medicine article - https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2
5. Age UK 2017 report - ref: NHS South West review of 960 records in last 2.5 years
6. Bardsley, M., Georghiou, T. and Dixon, J. (2010). Social care and hospital use at the end of life. The Nuffield Trust.
7. National Audit Office (2008) End of Life Care. National Audit Office. https://www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf
8. Nuffield Trust report: https://www.nuffieldtrust.org.uk/news-item/further-evidence-on-the-cost-of-end-of-life-care-outside-of-hospital-new-nuffield-trust-analysis
9. Economic Evaluation of EPaCCS - Early Implementer Sites. 2013. NHSIQ. http://www.slideshare.net/NHSIQ/economic-evaluation-of-the-electronic-palliative-care-coordination-system-epaccs-early-implementer-sites
10. Age UK 2017 report - ref: NHS South West review of 960 records in last 2.5 years
11. National Survey of Bereaved People (VOICES): England, 2015

West, North and East Cumbria Sustainability and Transformation Partnership (STP)
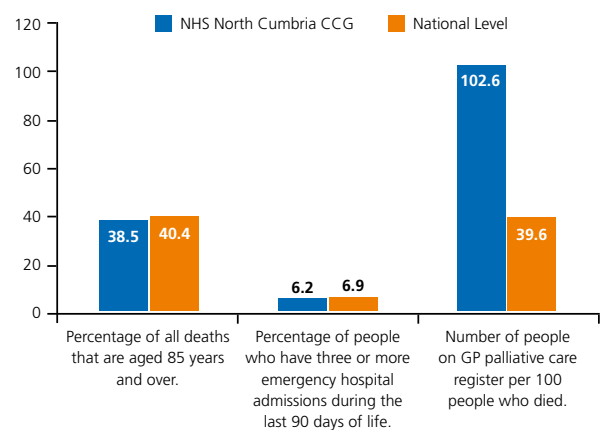
This information and data pack was produced collaboratively by NHS England, Public Health England (PHE) and the Care Quality Commission (CQC). It contains a sample of end of life care metrics, which may be of interest to you and could help support local decision making. Following these metrics you will find information on the outcome of CQC inspections of end of life care services in your STP area.

A full list of the end of life care metrics can be accessed here, where you will find PHE's End of Life Care STP Data Tool and metadata guide.
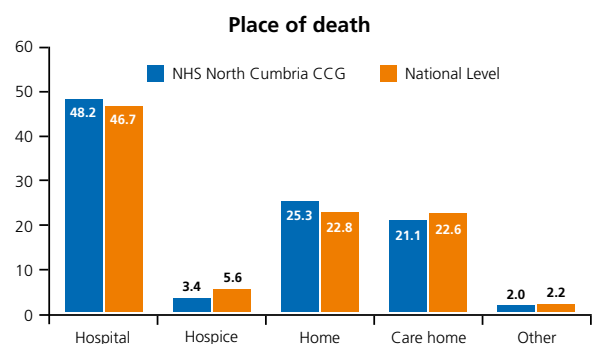
In your STP, there were 3,511 deaths in 2015, which is 0.71% of the national number of deaths.

Some key metrics that can help to understand how your STP compares with the National indicators are shown in the following charts:

The chart to the right compares data for your STP area with national data on a) the percentage of all deaths that occur in people aged 85 or over; b) the percentage of people who have three or more emergency hospital admissions during the last 90 days of life; c) Number of people on GP palliative care register per 100 people who died.
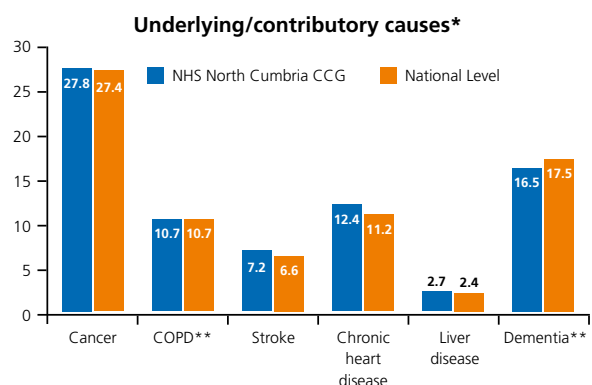

The percentages of deaths in different locations are shown in the chart to the right.

Place of death

To the right is a comparison of the underlying causes of death for your STP area compared with national levels (as a percentage of total deaths).

* Totals may exceed 100% as more than one factor can contribute towards the death of a patient.

** COPD and Dementia look at both underlying and contributory causes.

Underlying/contributory causes*

Outcomes of CQC inspections of end of life care service in your STP area

The table below illustrates the outcomes of CQC inspections of end of life care services in your STP area. It is possible that not all end of life care services for NHS acute hospitals or community providers are captured, although all NHS acute trusts and most community health providers have now been rated.

*Data up-to-date as of 18 June 2017

	Inadequate	Requires improvement	Good	Outstanding	Not formally rated	Number of services rated
NHS acute hospitals (2 services)	0%	0%	100%	0%	0%	2
Community (1 service)	0%	100%	0%	0%	0%	1
Hospices (3 services)	0%	0%	67%	0%	33%	3

Useful contact details:

Key contacts	Email details
Palliative and EoLC network (Northern England)	Louise Watson: Louise.watson19@nhs.net (SCN Project lead) Adrienne Moffett: adriennemoffett@nhs.net (Managerial lead) Alexa Clark: alexa.clark@nuth.nhs.uk (Clinical lead)
NHS England's National Palliative and End of Life Care team	england.endoflifecare@nhs.net

The below table outlines how EoLC can support delivery of key priorities identified in STP plans (shown here as themes in the far left hand column). It contains strategic information on how each theme links to national evidence and policy and outlines operational advice on 'what good looks like'. The column on the far right provides information, updates and signposting to available tools and resources which support delivery of the priority.

	STRATEGIC	OPERATIONAL	
Themes appearing in STPs	Strategic case: links to national evidence and policy	What a good model should include	What support is available?
1. Transformation of services	There are lots of examples of good practice across the country from an EoLC perspective that could support wider outcomes and improvements at system and provider level. Ambitions for Palliative & EoLC: national framework for local action [see report and slide pack] sets out the components needed to deliver good palliative and EoLC across a local system to improve care, quality and efficiency. A self-assessment tool is available to identify gaps. The 2016-17 Mandate to NHS England sets out that there should be an increase in people dying in their place of choice, with an emphasis on home. Key points are continued in the 2017-18 Mandate to NHS England which emphasises choice in EoLC, expansion of Personal Health Budgets, delivery of the choice commitment and inclusion of metrics in CCG IAF. The government's response to the Choice Review into EoLC sets out a 6 point EoLC commitment that everyone should expect as they approach the end of life. CCG IAF includes metrics relating to EoLC to support measurement of progress in local areas.	• Hospital improvement programme enablers can be adopted to improve recognising and managing uncertain recovery, discharge to home, care co-ordination, Advance Care Planning (ACP), and improve care of the dying adult. • Best practice is identified and shared through national and local networks and communication mechanisms. • Shared electronic records and a well-integrated system of communication and coordination across professional and organisational boundaries spanning the whole of the local health and care economy, including the voluntary sector.	• Resources, tools and case studies are now available on the 'Knowledge Hub' for palliative & EoLC. • NHS England (NHS E) National Palliative and EoLC network has a role in identifying and sharing best practice. Network leads are in place across the country – see contact details above for more information or email england.endoflifecare@nhs.net. • NHS E hold monthly webinar series on different topics. Contact england.endoflifecare@nhs.net for more details. • A self-assessment framework has been developed for localities to conduct gap analysis against the Ambitions Framework. • This 'Transforming end of life care in acute hospitals: The route to success 'how to guide'' aims to improve the quality of EoLC within acute hospitals across England. • NHS Improvement (NHS I) has launched an EoLC Improvement Collaborative to support Trusts improve care during 2017, with support from regional quality leads and specialist nurse advisor. • NHS E, via HQIP has commissioned a 5 year National audit of care of the dying adult for hospitals.

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			• Core educational framework and case studies of good practice and webinars are available on NHS Employers website.
			• An EoLC Charter has been developed by London's Directors of Adults Social Services.
2. Financial efficiency	There is significant variation and therefore opportunity in the commissioning and delivery of services that support people at the End of Life across health and care and through charitable organisations to ensure best outcomes and value are achieved. The Palliative Care Funding review concluded that improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could translate to a potential reduction (and therefore reinvestment) in hospital costs of £180 million per annum[1]. Studies estimate that costs in the last year of life are 30% lower for patients in receipt of palliative care[2]. The voluntary sector is an important local partner, and invests over £1billion a year in meeting palliative and EoLC needs[3]. Research study concludes that Marie Curie community-based palliative nursing service shows a potential cost savings of £500 per person compared to usual death[4].	• There is a clear understanding of all the services available locally and benchmarking of outcomes and cost against other areas. • Use of local data on EoLC to improve the quantitative and qualitative analysis of care provided. • Commissioning models and incentives focussing on outcomes and supporting providers to work together to co-ordinate care. • Services across the health, social care and voluntary sectors work together to meet local needs efficiently and effectively.	• The RightCare Commissioning for Value pack for Long Term Conditions includes financial and quality data relevant to EoLC and comparison with nearest neighbours. • Currencies for Specialist Palliative Care can be implemented to understand case complexity within and across different settings – separate set for adults and children/young people. • Multispecialty Community Provider framework. • Commissioning toolkit for person centred end of life care is available for commissioners • PHE Health Economics Report 'Understanding the health economics of palliative and end of life care' and end of life care analytical toolkit and user guide is available here. • NICE has produced a resource impact template (EoLC for infants, children and young people with life-limiting conditions) which can help CCGs to calculate their own potential resource savings. More information is available here. • Together for Short Lives have produced guidance on the commissioning of children's palliative care.

1. Hughes-Hallett, Craft, Davies. 2011. Palliative Care Funding Review https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf
2. National Audit Office (2008) End of Life Care. National Audit Office. https://www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf
3. Hospice UK (2016) Hospice Accounts: Analysis of the accounts accounts of UK charitable hospices for the year ended 31 March 2015. London: Hospice UK
4. Georghiou T, Bardsley M. 2014. Exploring the cost of care at the end of life; Research report. Nuffield Trust

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	Evaluation of Midhurst Macmillan Specialist Palliative Care Service, consisting of early referral programme and MDT of Specialist Palliative Care professionals linking with primary care, community services, social services, care organisations and voluntary bodies estimate costs could be reduced by 20% in last year of life[5].		
	Economic evaluation of Electronic Palliative Care Co-ordinated Systems (EPaCCS) indicates financial savings can be made where these systems are in place to share EoLC records – recurrent savings after four years c£270k for a population of 200,000 people[6].		
	The Transforming End of Life Care at UCLH business case includes evidence that costs of care are higher when a patient receives EOLC in hospital rather than at home and that costs in the last six months of life are £2,000 less for those patients with a Coordinate My Care (CMC) record, the majority of whom die outside hospital. For nursing home residents cost of death in hospital is over £4,200 higher than that of dying in the nursing home[7].		
	A review by the National Audit Office estimated that if there was better access to community based EoLC, £104 million could feasibly be saved from cancer patients alone as a result of fewer emergency admissions and reduced length of stay (National Audit Office, 2008).		

5. Thiel V, Sonola L, Goodwin N, Kodner D., 2012. Midhurst Macmillan Community Specialist Palliative Care Service: Delivering end-of-life care in the community. London: The King's Fund.

6. Economic Evaluation of EPaCCS - Early Implementer Sites. 2013. NHSIQ. http://www.slideshare.net/NHSIQ/economic-evaluation-of-the-electronic-palliative-care-coordination-system-epaccs-early-implementer-sites

7. Transforming End of Life Care at UCLH – becoming business as usual

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	Evaluation of a Marie Curie Nursing Service (MCNS) found that people who received the service were found to be significantly more likely to die at home (78%) compared to those who received usual care (35%), and were less likely to have an emergency admission at the end of life (12% compared with 29%)[8].		
	Data analysis collected pre and post implementation of the AMBER care bundle and last year of life project demonstrates a reduction in the number of admissions from 19 to 7 and a reduction in the number of bed days from 569 (£147,940.00) to 19 (£4,940) for those identified in the last year of life over a 6 month period post-implementation of AMBER care bundle[9].		
	Nuffield Trust research report shows evidence that hospital costs are by far the largest cost elements of end-of-life care with care in the final three months of life averaging over £4,500 per person who died. The bulk of this cost is due to emergency hospital admissions. Hospital costs increased rapidly in the last few weeks of life[10].		
	NICE calculate that commissioning and providing EoLC to children and young people across a population of 1.5million delivers a net saving worth £701,000 in released resources.		
	A personal health budgets evaluation (2009)[11] shows their potential to help meet the current financial challenges facing the system.		

8. Chitnis X and others (2012) The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life
9. Taylor V (2014) Last Year of Life Project (Pilot) Supplementary Report, University of Manchester
10. Shifting the balance of care - Great expectations. URL address: https://www.nuffieldtrust.org.uk/files/2017-02/shifting-the-balance-of-care-report-web-final.pdf
11. Personal Health Budgets evaluation - available at: https://www.phbe.org.uk/index-phbe.php

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	The evaluation showed that personal health budgets are cost-effective, and that they tended to improve or maintain people's outcomes while reducing their costs or being cost-neutral.		
	For some groups, for example people with the highest levels of need, these impacts were more pronounced, with a personal health budget being associated with a £3,100 reduction in annual spend per person.		
	Cost-savings from early palliative care accrue due to both reduced length of stay and reduced intensity of treatment, with an estimated 63% of savings associated with shorter length of stay. A reduction in day-to-day costs is observable in the days immediately following initial consult but does not persist indefinitely[12].		
	By 2040, annual deaths in England and Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659).		
	If recent mortality trends continue, 160,000 more people in England and Wales will need palliative care by 2040. Healthcare systems must now start to adapt to the age-related growth in deaths from chronic illness, by focusing on integration and boosting of palliative care across health and social care disciplines[13].		

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12. Cost analysis of a prospective multi-site cohort study of palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from? Can be found at: http://journals.sagepub.com/doi/pdf/10.1177/0269216317690098
13. BMC Medicine article - https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2

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Themes appearing in STPs	**Strategic case: links to national evidence and policy**	**What a good model should include**	**What support is available?**
3. Prevention and self-management	Evidence shows that Advance Care Planning (ACP) improves EoLC and patient and family satisfaction and reduces stress, anxiety and depression in surviving relatives[14]. Evidence from 38 studies indicates that on average 33–38% of patients near the end of life received non-beneficial treatments, rather than informed discussions about options and impact to support real shared decision-making[15]. A study of English cancer carers found that of 5,271 people who registered the death of a relative to cancer in May 2015, over 90% reported spending time on care-giving in the last 3 months of the decedent's life, contributing a median 69 hours 30 min of care-giving each week. Those who reported details of expenditure (72.5%) spent a median £370 in the last 3 months of the decedent's life[16].	• Patients and staff are supported through training and behaviour change techniques to talk about and plan for death earlier. • Patients are supported to discuss and record preferences and treatment goals. • Patients are supported to develop a personalised care and support plan which is reviewed to keep it up to date, and shared with those who need access to it. • Personal Health Budgets are considered. • Carers are supported and involved to the extent that they, and the patient, wish.	• A Patient empowerment film has been published on NHS Choices, to support patients with their medical consultations. • Follow / join in with the campaign to promote the EoLC commitment #EolCommitment. • Learning from PHB pilots will be produced and shared (report due Autumn 2017) with tools and guidance delivered though 2017/18. • Support and information on carers assessment is available here. • Personalised Care Planning templates and guidance, including templates for advance care plans, emergency care and treatment plans, etc. • All of me - Sanjay talking about his experiences has been produced by London ADASS. • End of life care: why talking about death and dying matters. • Range of resources on the London ADASS EoLC webpage.

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14. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ 2010; 340 doi: http://dx.doi.org/10.1136/bmj.c1345 (Published 24 March 2010)Cite this as: BMJ 2010;340:c1345

15. M Cardona-Morrell, JCH Kim, RM Turner, M Anstey, IA Mitchell, and K Hillman: Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. International Journal for Quality in Health Care Advance Access published June 27, 2016

16. A national post-bereavement census survey of cancer carers' hours of care and expenditures - found at: http://journals.sagepub.com/doi/pdf/10.1177/0269216317690479

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Themes appearing in STPs	**Strategic case: links to national evidence and policy**	**What a good model should include**	**What support is available?**
4. Primary and community care	83% of GPs list giving more time to terminally ill patients as a top priority for general practice in terms of improving EoLC, but many say that they lacked the time and resource to deliver this[17]. Focussing on improving and co-ordinating EoLC across primary and community care will reduce duplication and demand for individual services and improve ability for staff to care for people as they approach the end of life.	• People approaching the end of life are identified early to discuss options and preferences and develop a care and support plan. • People at end of life with non-cancer conditions are on the palliative care register and part of MDT discussions. • Integrated community based teams have training and support to identify and provide care for people at end of life. • Named care co-ordinators and/or care navigators are offered to people at the end of life where their care involves multiple services.	• Quality Outcomes Framework shows the number of patients on a palliative care register within a GP practice and whether they are being reviewed on a regular basis – also comparison between patients with a cancer, as opposed to non-cancer conditions on the register. QOF 15/16 data can be found here. • Learning and information on the New Care Models available here. • Use of prompts such as Supportive and Palliative Indicators Tool (SPICT) to identify people at risk of deteriorating or dying. • Care co-ordination models for end of life care (available here). • CIE/NCPC video - 'Talking about the words we use' is aimed at practitioners and asks them to consider whether the words they are using are clear and convey compassion. • NHS England and partners have published a series of quick guides to support the transformation of urgent and emergency care services out of hospital and to support local health and care systems. The guides provide practical tips, case studies and links to useful documents, which can be used to implement solutions to commonly experienced issues. • UCL Partners have developed a suite of educational materials including a 17 minute film 'You Matter-End of Life Care in the Community'. The six sets of structured educational material include preparing for a death in the community and recognition of deterioration, prognostication, bereavement, cultural and spiritual issues. Effective communication, making a plan of care, physical care and advance care planning are also covered.

17. Marie Curie and Royal College of GPs survey. October 2016. https://www.mariecurie.org.uk/media/press-releases/gps-call-for-more-time-with-terminally-ill/147700#_ednref1

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Themes appearing in STPs	**Strategic case: links to national evidence and policy**	**What a good model should include**	**What support is available?**
5. Urgent and emergency care	Focussing on people at end of life in acute care initiatives will improve care and flow, and reduce the pressure on Ambulances, A&E and Hospital beds through timely and appropriate response to urgent unscheduled needs in their usual place of care; it will also aid the prevention of unnecessary unwanted admissions and improved early supported discharge to a place of care that is right for the patient and their family and therefore reduce re-admission. Care Coordination and shared records can also contribute significantly to facilitating discharges from the Acute Sector thereby reducing occupied bed days.	• Clinical Advice Hubs are developed that include access to Specialist Palliative Care advice. • 24/7 Specialist Palliative Care is available to ensure appropriate and timely advice on symptom and EoLC management. • Shared Electronic Records are available that provide details about people's EoLC preferences (EPaCCS) and their personalised care and support plan). • Named care co-ordinators are identified in the patient record. • Discharge assessment processes specifically consider the needs of people at End of Life. • Medications and equipment are available in the community and accessible when needed.	• EPaCCS implementation guidance. • The Summary Care Record (SCR) is promoted as the minimum requirement to enable electronic sharing of end of life care preferences. SCR additional information is activated where an EPaCCS solution is not in place. • Specialist Palliative Level Care information for commissioners sets out what good SPC looks like from a system perspective. • Discharge to assess and a Discharging from hospital into the care sector 'Quick Guides' set out case studies and interventions that can be adopted. • The national CQUIN scheme supports the delivery of clinical quality improvements and drives transformational change - there is a national CQUIN for 2017-19 to support proactive and safe discharges. • The resus council has published a ReSPECT document and process for emergency care and treatment planning. More information found here. • UCL Partners have developed a suite of educational materials including a 17 minute film 'Milestones-Care in the last days of life in hospital'. The educational material can be used to teach the following aspects of end of life care: recognition of deterioration, effective communication, making an individualised plan of care, physical care at the end of life. • Royal College of Emergency Medicines Best Practice Guidelines: end of life care for adults in the emergency department.

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6. Cancer	The National Cancer Strategy sets out how we in England could achieve the very best cancer outcomes by 2020 and advises that the recommendations of the EoLC independent choice review are implemented.	• A holistic needs assessment at diagnosis should identify EoLC (likely 1 year maximum prognosis). • Staff are supported to talk earlier about stopping treatment and options for end of life care patients. • Patients and staff are aware of the 6 point EoLC Commitment and are supported for these to be honoured.	• Macmillan's Holistic Needs Assessment template.
7. Mental health	Place of death profile for people who have died with dementia is markedly different compared with the general population. For those aged 65+, the majority of deaths with a mention of dementia occurred in care homes (58%) and less than a tenth of people with dementia die at home, this is significantly lower than those dying with other conditions[18].	• Early Advance Care Planning for people with dementia. • Specific adjustments for and approaches to EoLC for people with Mental Health conditions are applied (to achieve parity of esteem).	• Dementia Care Planning templates and guidance available here.
8. Reduce inequalities in health outcomes	Significant inequalities exist in EoLC as identified in the CQC thematic review for people with non-cancer conditions, those with LD, in secure and detained settings and the homeless. Improving EoLC for these groups will improve outcomes and value[19].	• Needs of people at EoLC in secure and detained settings are addressed. • Specific adjustments and approaches to EoLC for people with Learning Disabilities are applied. • Specific adjustments and approaches to EoLC for people who are homeless are applied. • Staff are able to support people at EoLC from different diverse groups including culture and sexuality as well as sensory losses.	• A 'Community of Practice' exists for EoLC secure & detained settings – for more information email england.endoflifecare@nhs.net. • Learning Disabilities & EoLC 'quick guide' of resources (due August 2017). • PHE has developed EoLC profiles for CCG's - These profiles draw together a wide range of information to give an overview of variations in cause and place of death, by age and sex, for each clinical commissioning group (CCG) in England: Fingertips EoLC Profiles and an Atlas of Variation.

18. Public Health England. Dementia intelligence network. 2016 http://www.yhpho.org.uk//resource/view.aspx?RID=237895
19. CQC thematic review http://www.cqc.org.uk/content/different-ending-end-life-care-review-0