Commissioning Guidance: Thames Valley & Milton Keynes Strategic Clinical Network

End Of Life Care

September 2016
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The wider guidance – System working as core

We trust you will find this commissioning guidance for the End of Life Care agenda in Thames Valley and Milton Keynes for 2016/17 useful.

This year there are two main differences in our approach:

• We heard from you that it was a valuable resource which would be made more valuable by bringing together the advice from our partners as well. This now includes support and guidance from PHE, the Oxford AHSN and HEE.
• This year as well as bringing you this guidance as a web portal which aims to be intuitive, convenient and more detailed - we are able to provide pdf copies of the guidance which should aid accessibility and provide an opportunity to print and share should you so wish.

While the Guidance is segmented by the clinical areas covered by the SCN, we would like to stress some underlying principles:

• Prevention is a key priority for all and is everyone’s responsibility. We are pleased to partner with PHE and bring their message to you with ideas for what needs to be addressed, examples of how it can be done and the potential gain from the initiatives.
• The integration of mental and physical health is key to providing holistic patient-centred care. This is gaining traction in clinical areas such as perinatal mental health, cardiovascular disease and serious mental illness, the entire long term condition agenda and end of life care.
• With the significant proportion of health care burden on patients and the system related to long term conditions, the importance of the TV LTC transformational programme cannot be overemphasised. The traction that programme has gained in primary care now needs to be firmly embedded and systematised.
• The current push for system working gives us all the opportunity to contribute in different ways and at varying levels towards the same aim. We hope this guidance will provide an opportunity to connect widely and pose questions, share good practice and offer practical solutions. Your SCN leads contact details can be found at the end of this guidance (alongside your other clinical network leads)
Ambitions for Palliative and End of Life Care

A new approach to End of life Care. A new approach to End of life Care services

- End of life rarely suddenly happens, more commonly there is a trajectory from living well with illness to a focus on dying well.
- Care is holistic from time of diagnosis and services integrated and coordinated.
- Access to end of life services can increase, dependent on the needs of the patient and those important to them.
- Bereavement is an essential part of end of life care.

There is an opportunity to plan for all non curable illnesses and for all people.
Ambitions for Palliative and End of Life Care

- Each person is seen as an individual
- Each person gets fair access to care
- Maximising comfort and wellbeing
- Care is coordinated
- All staff are prepared to care
- Each community is prepared to help

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<thead>
<tr>
<th>Personalised care planning</th>
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<td>Co-design</td>
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Choice Review

- The report, *What’s important to me: A review of Choice in End of Life Care* calls for a new ‘national choice offer in end of life care’ to be established.
- It calls for everyone to be offered choice in their end of life care, and for these choices and preferences to be recorded in their own personal plan of care.
- For 24/7 end of life care for people being cared for outside hospital to be in place across England by 2019.
- For everyone in need of end of life care to have a named senior clinician responsible for their care and preferences and their own care coordinator.
- For a clear policy to make access to social care for people at the end of life fast and free.
- For more honest and open communication about end of life issues, with better support for health and care professionals and increased awareness raising amongst the public.

- [The Government response to the Choice Review](#)
- [Modelling the options of choice](#)
Personalised Care Planning

Everybody approaching the end of their life should be offered the chance to create a personalised care plan. Opportunities for informal discussion and planning should be universal. Such conversations must be ongoing with options regularly reviewed. [http://endoflifecareambitions.org.uk/](http://endoflifecareambitions.org.uk/)

Every year approximately half a million people die in England. This is expected to rise by 17% by 2030, with a significant increase in the proportion who are aged over 85 years. For at least three quarters of these deaths it is not sudden but is expected, providing opportunity to plan. (Actions for End of Life Care: 2014-16, NHS England)

A recent ComRes public opinion survey showed that only 7% of British adults had written down their wishes or preferences about their future care, should they be unable to make decisions for themselves.

### Table 16

<table>
<thead>
<tr>
<th>Q3 Which, if any, of the following have you yourself done? Base: All respondents</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>Unweighted base</td>
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<tr>
<td>2015</td>
</tr>
<tr>
<td>Weighted base</td>
</tr>
<tr>
<td>NET: Any</td>
</tr>
<tr>
<td>Written a will</td>
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<tr>
<td>Registered to become an organ donor or have an organ donor card</td>
</tr>
<tr>
<td>Talked to someone about my funeral wishes</td>
</tr>
<tr>
<td>Talked to someone about my own end of life wishes</td>
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<tr>
<td>Asked a family member about their own end of life wishes</td>
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**Written down any of my wishes or preferences about my future care, should I become unable to make decisions myself**

| | Unweighted base | Weighted base | 2015 | 141 | 54 | 87 | 5 | 10 | 12 | 22 | 22 | 70 | 48 | 40 | 20 | 33 | 19 | 35 |
| Written down any of my wishes or preferences about my future care, should I become unable to make decisions myself | 141 | 54 | 87 | 5 | 10 | 12 | 22 | 22 | 70 | 48 | 40 | 20 | 33 | 19 | 35 |

**Initiated a conversation with my GP about my end of life wishes**

| | Unweighted base | Weighted base | 2015 | 22 | 13 | 9 | 2 | 4 | 3 | 2 | 5 | 8 | 8 | 1 | 5 | 1 | 1 | 1 | 1 |
| Initiated a conversation with my GP about my end of life wishes | 22 | 13 | 9 | 2 | 4 | 3 | 2 | 5 | 8 | 8 | 1 | 5 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
Evidence of Best Practice

The Parliamentary and Healthcare Ombudsman report in 2015 found many of the cases reviewed included a failure to link the person’s needs with the services being provided.

This was especially true of cases where care was provided in more than one setting or by a combination of providers in the community and/or hospitals.

**These cases showed people tending to have a poorer experience than they should have at the end of their lives. In particular, the person’s wishes are not always taken into account.**

This, as well as a lack of resources for community palliative care, can also mean that people often do not die where they want to.

In “A different ending: Addressing inequalities in end of life care” there is a draft of good practice highlighting what constitutes outstanding care planning for those nearing or at the end of life.

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**Best Practice Case Study – a Lancaster GP Practice rated as Outstanding**

- Patients were offered conversations around EoLC planning including DNACPR, Priorities of care, wishes and preferences
- 98% of patients who should have been on the EoLC register were on the register
- 85% had documentation regarding ACP for managing further deterioration
- 81% of these patients died out of hospital
- Palliative care register was changed to a supportive care register, to include frail elderly, and earlier stage dementia
- Monthly MDT meetings to discuss register and care of these patients
- Evidence of in house EoLC training, including difficult conversations
Commissioner Recommendation

Commissioners need to be assured that all providers have robust systems to evidence the following foundations for End of Life care as defined in ‘Ambitions for Palliative and End of Life Care- a national framework for local action 2015-2010’.

To promote the development of advanced care plans- developed with the patient and encompassing the patient’s wishes and preferences, and including:

• preferred place of care
• CPR decisions
• communications with those important to the patient
• a clinical escalation plan

Evidence should be provided to commissioners that these plans are shared across all providers (e.g. via EPACCS)

Assurance can be gained through the providers demonstrating comprehensive education and training strategies (see Education & Training section), use of local contracts (e.g. DES, CES) and through feedback from service users.
Education & Training

It is vital that every locality and every profession has a framework for their education, training and continuing professional development to achieve and maintain competence and allow expertise and professionalism to flourish. [http://endoflifecareambitions.org.uk/](http://endoflifecareambitions.org.uk/)

Health Education England recognises that end of life care is everybody’s business and as such the generalist and specialist workforce need to be trained and supported accordingly. Access to relevant end of life care training enables patients to receive high quality end of life care and to be supported in achieving their individual wishes and preferences of care.
Education & Training

There is little evidence across Thames Valley, or within localities, that comprehensive Training Needs Analyses are being undertaken. National policy and research demonstrate the need for comprehensive education & training:

- Advanced Communication Skills and Sage and Thyme training have nationally been recognised as good models of communication skills training. [http://www.sageandthymetraining.org.uk/evidence-and-links](http://www.sageandthymetraining.org.uk/evidence-and-links)
- A literature review, conducted into Dementia awareness training which is applicable to end of life care education, found that a minimum of half a day of training was needed to change practice: [http://www.leedsbeckett.ac.uk/pages/what-works/](http://www.leedsbeckett.ac.uk/pages/what-works/)

<table>
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<tr>
<th>Between 1st April 2014 &amp; 31st March 2015 did formal in house training include /cover specifically communication skills training for.....</th>
<th>Medical staff</th>
<th>Nursing (registered)</th>
<th>Nursing (non registered)</th>
<th>Allied Health Professionals</th>
</tr>
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<tbody>
<tr>
<td>National Results ( % )</td>
<td>63%</td>
<td>71%</td>
<td>62%</td>
<td>49%</td>
</tr>
<tr>
<td>Buckinghamshire Healthcare NHS Trust</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Frimley Health NHS Foundation Trust</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Milton Keynes Hospital NHS Foundation Trust</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>Oxford University Hospital NHS Trust</td>
<td>No</td>
<td>No</td>
<td>No</td>
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</tr>
<tr>
<td>Royal Berkshire NHS Foundation Trust</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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Health Education England note that most localities have access to Sage and Thyme communications courses, and all have access to Advanced Communication Skills courses, funded by HEE TV. National Care of the Dying Audit of Hospitals (2016) undertake training audits across all acute units (including in-house) highlighted the following for our region.
Good practice across the region

- Berkshire CQUIN – the community provider is supporting the identification of patients in the last year of life. Community staff are receiving training from Hospice Consultants to support prognostication.
- Buckinghamshire Directed Enhanced Service plus (DES+) scheme.
- West Berkshire CES requires 1 GP per practice must evidence attendance at relevant training and dissemination within practice.
- TVSCN delivering End of Life Care workshops supported by Health Education England.
- Sage & Thyme courses are delivered across Oxford & Berkshire. These courses are accessible to all health and social care providers including care homes.
- Joint working with further education colleges to deliver QCF qualification in EoLC for non-registered staff.
- OUHFT, in conjunction with Sobell House Hospice, delivering EoLC induction workshops for hospital Health Care Assistants.
Impact on training programmes for staff

HCA induction programme, OUHFT, Oxford
“Training has improved confidence and competence to discuss EoLC with patients and professionals”

Sage & Thyme Training (Berkshire)
“As the result of the training I am more likely to:
• Allow patients to talk more before I answer
• Help person involved to identify who they want to help them
• Communicate better with patients, and in my day to day life”

Comments from TVSCN End of Life Care workshops
• “Good to see a multidisciplinary approach/focus to these issues; I will look at PAINAD the other observational pain score validated for use in dementia”
• “For a newly qualified GP this is brilliant”
• “I will try to introduce earlier discussions and look at different ways of exploring discussions”
• “I loved the opening questions and will use them in the future - Its heartening to see the humanity, kindness and compassion is very much alive in this area of NHS work”
• “Very helpful to get updates and share experiences with peers”
• “Helped with how to communicate in EoLC to get better dialogue”
• “Made me aware that I need to be open to having these difficult conversations and be comfortable with them”
Impact on training programmes for staff (continued)

Resources for Education & Training
Much specific End of Life Care training is delivered through ad hoc, locally developed sessions, predominantly delivered by specialist palliative care services. These training days need to be supported by CCGs.

Thames Valley Strategic Clinical Network & Health Education England Thames Valley will provide 5 half-day workshops on End of Life Care 2016/2017, open to all clinicians.

Hospices providing courses and study days open to all:
• Sobell House, Oxford: http://sobelleducation.org.uk/
• Sue Ryder, Nettlebed & Reading: http://www.sueryder.org/how-we-help/education-and-training
• Rennie Grove: http://www.renniegrove.org/healthcare-professionals/education-programme
• Willen Hospice: http://www.willen-hospice.org.uk/how-we-care/For-Clinicians/learn-with-us
• St Christophers Hospice, Sydenham: http://www.stchristophers.org.uk/education/

Other courses available:
• Macmillan Cancer Support: http://learnzone.org.uk/ NB: some courses are only available to Macmillan Professionals.
• National e-learning (eELCA): http://www.e-lfh.org.uk/programmes/end-of-life-care/

Specialist Palliative Care Workforce;
• Training and development of the specialist Palliative workforce in Medical, Nursing and Allied health is supported by courses delivered via Higher Education Institutions and the Medical Deanery. PG Cert and Masters courses are provided by Oxford Brookes University, Coventry University and University of West London.

Further opportunities:
• HEE have commissioned NCPC to review the Skills and Competency Framework for EoLC (report due Spring 2017)
Commissioner Recommendation

To be assured that all providers have a skilled, competent workforce as evidenced by:

• robust systems and plans for needs assessment and training of the workforce.
• undertaking annual training needs assessment
• support for delivery of EoLC courses and ensure staff across all providers have access to this training.
• engaging with HEETV and the training programmes provided
• identifying training and education leads who prioritise EoLC for the whole workforce

Key areas include:

• Caring for people in accordance with their personal preferences – provide training in communication, Advance Care Planning, identification and prognostication
• Maximising comfort and wellbeing – provide training in assessment, symptom control, psychological and emotional support, carer assessment
• Delivering the 5 Priorities of Care for the Dying – provide training in the provision of individualised plans of care with explicit consideration of food and drink, symptom control and the provision of psychological, social and spiritual support

Useful tools to monitor progress:

• NHS Improvement provide helpful advice about how training can be delivered to all health providers: https://improvement.nhs.uk/
Evidence & Information

Comprehensive and robust data are necessary to measure the extent to which the outcomes that matter to the person are being achieved. This, alongside strengthening the evidence base, will help to drive service improvements. http://endoflifecareambitions.org.uk/

It is appreciated that there is paucity of local data and the amount of national evidence available for End of Life care is also limited. Because of the lack of local data, CCGs should make arrangements to collect data that they consider necessary to be assured that patients are receiving a quality end of life service from its providers.
EOL National Hospital audit 2016 – Nearly half of all deaths in England occur in hospitals – 223007 out of a total of 469,975 in 2014. For this reason, trust boards, managers and clinicians should recognise that a core responsibility of hospitals is to deliver high-quality care for patients in their final days of life and appropriate support to their families, carers and those close to them. Government policy in recent years has reinforced this requirement.

The importance of good end of life care cannot be overestimated. In the majority of cases, people receive end of life care that is caring and compassionate – but people from certain groups in society may experience poorer quality care because providers and commissioners do not always understand or fully consider their specific needs. 


A different ending: End of life care review -The importance of good end of life care cannot be overestimated. In the majority of cases, people receive end of life care that is caring and compassionate – but people from certain groups in society may experience poorer quality care because providers and commissioners do not always understand or fully consider their specific needs. Following the recommendation of more care, less pathway, the independent review of the Liverpool Care Pathway, CQC looked at ‘how dying patients are treated across various settings’. In particular, they focused on people who may be less likely to receive the good end of life care that they need.

http://www.cqc.org.uk/content/different-ending-end-life-care-review

National End of Life Intelligence Network -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. http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx  http://www.endoflifecare-intelligence.org.uk/resources/tools/

VOICES SURVEY-The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved people’s views on the quality of care provided to a friend or relative in the last 3 months of life, for England. The survey has now been run for 5 years and was commissioned by the Department of Health in 2011 and 2012, and NHS England from 2013. It is administered by the Office for National Statistics (ONS).


National Voices- This is the fourth of National Voices’ narratives on person- centred coordinated care. This narrative has been jointly published by National Voices and the National Council for Palliative Care. The narrative describes some critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers and families. http://www.nationalvoices.org.uk/pages/every-moment-counts-narrative-person-centred-coordinated-care-people-near-end-life
Living and dying with dementia in England: Barriers to care – Patients with dementia do not always receive a good level of care as the Marie Curie report suggests. It states that over the coming decades, the number of older people living in the UK is likely to rise considerably. By 2030, the proportion of the UK aged over 85 is set to double and as a result we are likely to see a significant increase in the number of people living and dying with dementia. To date much of the focus has been on living well with dementia, with little focus on the experiences of people with dementia nearing the end of their lives. For too long, the dying phase of dementia has been the forgotten aspect of what has been referred to as a ‘silent epidemic’.


EOL National Hospital audit 2015 -It has been designed to ensure that the priorities for care of the dying person outlined in the document ‘One Chance to Get it Right’ are monitored at a national level. National audit data will support end of life care commissioners, service providers and policymakers to audit the care and to facilitate quality improvement initiatives. The audit highlighted variation across trusts, need for workforce training and the variability and poor access to 24/7 specialist palliative care.

https://www.rcplondon.ac.uk/projects/end-life-care-audit-dying-hospital

A review of choice in end of life care has made great strides forward in recent years, in particular following the publication of the End of Life Care Strategy in 2008. However, we know that too many people still do not receive good quality care which meets their individual needs and wishes. For example, only just over half of respondents to the National Survey of Bereaved People (VOICES-SF) felt that their relative had died in a place of their choice. At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035.


End of Life Care rating maps – The data shown in these maps is from CQC inspections published up to 25 April 2016, for acute hospitals, community hospitals and independent hospices, respectively.

http://www.cqc.org.uk/content/end-life-care-ratings-maps

Other useful links

End of Life Care profiles: http://fingertips.phe.org.uk/profile/end-of-life/data#page

National End of Life Care intelligence Network: http://www.endoflifecare-intelligence.org.uk/home

Specialist Level Palliative Care: Information for Commissioners: https://www.england.nhs.uk/resources/resources-for-ccgs/#palliative

Nice Guidance for end of life care: https://www.nice.org.uk/guidance/ng31
Commissioner Recommendation

To define relevant information and evidence and create a cross provider person-centric data set for EoLC.

• The tools and references included in the TVSCN guidance can assist CCGs in deciding on the type of information they should collect.
• To compile a comprehensive dashboard which will provide an easy indicator as to the appropriateness and quality of End of Life Services.
• To connect with the End Of Life network to keep up to date with developments across the country. TVSCN generalist and specialist clinical leads work with the National team and are able to share good practice and new developments.
• To engage with the TVSCN activities, such as the Commissioner Forum, which provides an opportunity to share thinking, look to support and help from peers in overcoming barriers and challenges.
Co-design

End of life care is best designed in collaboration with people who have personal and professional experience of care needs as people die. http://endoflifecareambitions.org.uk/

Evidence
- Patients who are at end of life and their carers /families don’t feel listened to.
- Significant variation in care and patient/carer experience demonstrated by National Voices.
- Patients and their families/carers don’t feel they are given choice at end of life.
- Significant Inequalities in end of life care dependent on diagnosis, deprivation, learning disability and dementia.

Learning from good practice across the patch
- Berkshire West CCG Federation –locality steering group including patient and carer representation are currently developing 24/7 helpline and “Just in Case” medicines.
- Reading Borough Council End of Life working Group –Public Awareness Campaign and Workshop with the public took place in June 2016.
- Sonning Common GP Practice Matters of Life and Death Workshop –this Berkshire Practice ran a successful workshop for the public in May 2016 attended by over 100 people –they plan to run more over the coming year.
- Finity –www.finity.org.uk A Buckinghamshire based constituted community voluntary organisation running workshops for the public who want to think and talk about death and dying
- EOLC – co-design model
Commissioner Recommendation

To increase public awareness and debate on death and dying and talking about wishes (Consider working with the Dying Matters Coalition, promotion of Dying Matters Week /local Death Cafes /Serious Illness Conversation).

Local health and social care leaders work with the local charitable providers of hospice and palliative care to better understand the needs in their communities –specialist palliative care and hospices have huge amounts of data which could support CCG and HWB in development of strategies.

To ensure patient/ carer representation through:

- Core membership on Locality Groups /Steering Groups
- Linking with Healthwatch, Patient Voice Groups, local GP Practice PPGs, CCG Board Lay members
- Use of charitable palliative care providers as a conduit to direct engagement with people facing the end of their lives and their families
- Developing robust ways to measure/assess experience –consider using /adapting National VOICES Survey for local use
- Explore development of Personal Budgets to enable patients and carers have choice at end of life

Useful Tools

- Marie Curie End of Life Care Atlas
- PHE EOL Profiles
- Kings College London(2016) Introducing the Outcome Assessment and Complexity Collaborative Suite of Measures
Shared records

“To ensure the plan can guide a person centred approach it has to be available to the person and with their consent, be shared with all those who may be involved in their care.”

http://endolifecareambitions.org.uk/

All electronic systems for sharing health related preferences must encompass the recording and sharing of preferences at the end of life. The widespread use of electronic systems should be encouraged across health and social care providers in the statutory, voluntary and private sector – stakeholders should include;

GPs | GP Out of Hours | 111 Services | Care Homes | Specialist Palliative Care
---|---|---|---|---
GP Practices | Acute Trust | Ambulance Services | District Nursing | Community Trust
A vital part of an electronic sharing system is the adoption of an integrated electronic palliative care record to support achievement of preferred place of death (82% of those who recorded their preference achieved this). In 2013 the implementation of electronic palliative care records stood at:

- www.endoflifecare-intelligence.org.uk
There are examples where the implementation of EPaCCs has been a qualified success. In London, “Co-ordinate my Care” (CMC) has had great success as the outcomes highlight.

Further information on EPaCCs can be found at the NHS Improvement website.

**Best Practice – Co-ordinate my Care (CMC), London**

- Patients with CMC personalised urgent care plans: 22,119
- Deaths recorded: 9,322
- Patients who died in their preferred place: 79%
- Actual place of death: 17% died in Hospital i.e. 83% died outside of hospital
- Death in Usual Place of Residence (home, care home)
  - National data for London 16% (2011)
  - CMC – 65.1% (2015)

Costs- £2,100 saving per patient who dies with CMC care plan i.e. cost savings of £23.3 million

Learning from our colleagues:

- As developments are ongoing within local CCG boundaries around shared data, the need to widen data sharing to include other partners pan-Thames Valley & Milton Keynes such as NHS 111, SCAS etc. is required. Any planning or operational developments should incorporate wider regional shared data requirements.
Commissioner Recommendation

CCGs have a plan in place to implement and roll out EPaCCS as a matter of urgency, ensuring all key providers have access to information held.

These plans are
- Reviewed against the national specification- ensuring it conforms to all aspects and amending and refined if necessary.
- Looking beyond their boundaries and work closely with SCAS and 111 provider and out of hours GP services to make sure all systems are joined up and talk to each other.
- Drawing on the information and data gathered through the adoption of a shared record to contribute to local assurance of EoLC services
- Able to demonstrate how quality improvement methodology results in consistent improvement with long term benefits.
- Include measures of success such as:
  - Percentage of patients who have completed ACP by diagnosis
  - Difference in place of death for patients with completed ACP according to diagnosis
  - Hospital usage of people who have completed ACP compared to those who have not- length of stay, number of days in hospital in the last year of life, number of emergency admissions and cost of hospital care in the last year.
When we talk about end of life care, we have to talk about access to 24/7 services as needed, as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for ‘opening hours’.

http://endoflifecareambitions.org.uk/

Evidence for 24/7

24/7 care is recognised as a cornerstone of palliative and end of life care best practice and vital to enabling people to die at home if they wish to do so.

The NICE quality standard for end of life care includes the need for provision of 24/7 holistic support, co-ordinated care, urgent care and access to specialist palliative care.

The Ombudsman review ‘Dying without dignity’ highlighted that ‘People who are dying as well as their carers suffer because of the difficulties in getting palliative care outside normal working hours.’

End of Life Care Audit, Royal College of Physicians, 2016: https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals

*Hospice at home services regard 24/7 services, operating 365 days a year, to be a core element of their service [http://www.nahh.org.uk/about-hospice-care/service-specifications]

"We also considered several cases where people who were dying had extremely poor experiences in getting support outside normal working hours. This can be because emergency medical services are often under pressure out of hours, and many specialist palliative care services are not able to provide round-the-clock availability."

24/7 Access (continued)

Best Practice Study – Sue Ryder Bedfordshire PEPS

- An initiative known as Partnership for Excellence in Palliative Support (PEPS) is a co-ordination service in Bedfordshire aims at coordinating the multiple services involved in the care of a patient at the end of their lives.
- 50% of calls to the Sue Ryder 24-hour palliative expert support service in Bedfordshire come outside normal working hours.
- PEPS co-ordinates care between 15 different organisations, providing a single point of contact via a 24-hour telephone service, improving care for the individual, their family and carers.

Case study: Sue Ryder Partnership in Excellence for Palliative Support (PEPS)

Sue Ryder’s PEPS service in Bedfordshire is a partnership of 15 organisations which supports the patient and their family to stay in their preferred place of care. It has been in place for three years and evidence shows that nearly half (46%) of patient and carer calls were made ‘out of hours’ (after 5pm, before 9am). Of these, 79% of ‘out of hours’ calls were made by a relative or carer and 21% by the patient. In the year to May 2014, the service avoided 166 hospital admissions. Since January 2014, the local ambulance provider has worked closely with PEPS to change ambulance service patient pathways and ways of working. Under these arrangements, when a call is made to an ambulance, crews are able to see if a person is known to the PEPS service via their computer aided dispatch system and contact PEPS for further information (e.g. on preferred place of care or DNACPR status) once the crew has attended the call as normal and stabilised the patient. PEPS can then coordinate the patient’s care in the community according to clinical need and patient preference. A minimum of two admissions a week are being avoided in this way through closer working with the ambulance service.

Best Practice Case Study – The Gold Line

The Gold Line, an innovative out-of-hours service for dying people and their carers

- Round-the-clock access to help, support and reassure patients, carers and families
- Increased patients dying at home from 23% (England average) to approx. 40% (Gold Line patients)
- 2/3rds of calls received by the Gold Line are out of normal working hours
- The Gold Line delivers end of life care, provided by Airedale NHS Foundation Trust with support from Sue Ryder nurses by providing a 24/7 helpline to those patients with serious illness who may be in their last year of life. The service allows patients to access help and support via the phone or ‘Skype’ nurses any time, day or night. Not only does this provide peace of mind for patients, but may also contribute to avoided admissions
- Further information can be found at http://www.airedale-trust.nhs.uk/yourhealth/services-and-support/gold-line/ and the video below
Commissioner Recommendation

- To map the availability of community nursing, specialist palliative care, night sitting services in the CCG area.
- To ensure patients and families are informed and know how to access direct support.
- To gain feedback from providers about quality of current out of hours workload by:
  - Regularly review calls to ambulance, 111, OOH GP services from patients in last year of life
  - To analyse complaints and ensure lessons learnt change commissioning practice

Useful TOOLS- when considering 24/7 provision
- End of Life Care profiles
- Specialist Level Palliative Care: Information for Commissioners
Involving, supporting and caring for those important to the dying person

Families, friends, carers and those important to the dying person must be offered care and support. They may be an important part of the person's caring team, if they and the dying person wish them to be regarded in that way. They are also individuals who are facing loss and grief themselves. [http://endoflifecareambitions.org.uk/](http://endoflifecareambitions.org.uk/)

Evidence:
Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people.

It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide.

End of life care is a recurring theme in the Ombudsman's Casework. (“Dying without Dignity”).

Key themes around poor recognition of dying and care planning, communication, symptom management feature repeatedly in the 12 case studies.

With right care and treatment, peoples' suffering can be avoided or lessened, as can the anguish their relatives and carers experience subsequently.'

The national survey of bereaved relatives provides important insight into the consideration services give to their needs alongside the care given across all care settings to the patient. This is a valuable national resource providing information about the support given to those important to the patient.

For example, only just over half of respondents to the National Survey of Bereaved People (VOICESSSF) felt that their relative had died in a place of their choice (attached)
[National Survey of Bereaved People (VOICES): England, 2015](http://endoflifecareambitions.org.uk/) High quality end of life care is possible
To understand, review and ensure that the views of relatives inform services.

To ask providers ‘How engaged are relatives in co-design of services?’

To consider implementing VOICES survey across the CCG once central funding ceases in 2017

To request service providers submit feedback from relatives about their experiences of care

Review access to bereavement support

Ensure communities are aware of end of life and bereavement services

To review the Do Not Attempt Cardiopulmonary resuscitation (DNACPR) documentation in light of the new national ReSPECT paperwork. [https://www.resus.org.uk/consultations/respect/](https://www.resus.org.uk/consultations/respect/) (Anecdotal evidence from Thames Valley has highlighted that poor documentation leads to patients being resuscitated when it was against their wishes)

Useful tools:

- Good death wheel – A tool used to explore what a good death means for patients with dementia and their families
- Find me help – map of EOL services across UK [http://findmehelp.org.uk/](http://findmehelp.org.uk/)
The leadership of Health and Wellbeing Boards, CCGs and Local Authorities are needed to create the circumstances necessary for action. Clinical leadership must be at the heart of individual service providers. [http://endoflifecareambitions.org.uk/](http://endoflifecareambitions.org.uk/)

Nationally, 73% of CCGs have an End of Life Strategy. In Thames Valley we are pleased to report that 100% of our CCGs have an End of life strategy, either in place or being refreshed. This is a testament to the end of life leadership locally, both in CCGs and in the SCN.
Leadership (continued)

For Health and Wellbeing Boards, TV is in a similar position as our counterparts nationally with only about half including the needs of dying adults and children in their key strategies.

The data from 2014 is below:

- Those Health and Wellbeing boards where green show have a specific mention of End of Life and how it fits into the overall strategy.
- Where the colour is Orange it means that the strategy considers related issues or groups (e.g. supporting older people), but not end of life care directly.
- Finally, Red indicates that there is no specific mention of End of Life Care in the published strategy.
- Where it is indicated as unpublished it means that no strategy is available in the public domain.

Learning from Local Best Practice.

Reading Borough Council and the Berkshire West CCGs in the locality are committed to End of Life Care and have a comprehensive webpage setting out their work programme and objectives
Leadership (continued)

Best Practice Case Study – Leading for End of Life Care

CCG Checklist for improvement
Stage 1 – Develop your local vision and EOLC strategy
National level resources to support development of quality services Strategy based on Ambitions framework
Involving individuals, their families, carers and other loved ones and communities Patient leaders Section stage summary and next steps.

Stage 2 – Gather information
Demand and analyse National tools with local data or applicability Other useful national references for local use Assess local services and gaps Working across local health, care, third sector, research and educational organisations Section stage summary and next steps

Stage 3 – Plan and specify
Outcomes and key indicators, Tools that support quality benchmarking, Think about measures, Useful references, Local service specifications, Other references - General questions to ask yourself about any specification - Specific questions about end of life care Section stage summary and next steps

Stage 4 – Procure
Introduction, Service scope and commission with clear service specifications, Services commonly commissioned, Funding and tariff, Other useful resources, Section stage summary and next steps

Stage 5 – Manage and monitor: continuous improvement
Introduction, Measure and monitor performance and outcomes, Review, Effective use of local resources, Working towards person centred outcomes measures, Ambitions for Palliative and End of Life Care, Continually working with providers to support quality services, Continually improve, Section and toolkit summary, Share your success!
All Trust Boards, CCG and HWB have a Board level lead for End of Life care with clear lines of accountability.

Recommendations include:

• Operational plans make a commitment to improve end of life care
• Local DES & DES plus incentives are in place for EOLC
• Local councils and Health and Wellbeing boards have EOL Operational Groups
• Local arrangements exist for a lead organisation, to oversee the integration of EOL initiatives
• Alignment with LTC/Urgent Care Programmes to acknowledge that ‘Dying doesn’t work 9-5’
• Robust contractual arrangements with third sector
• Link with CCGs across TV Network through Commissioner Forums to share good practice
• Cross organisational leadership and collaboration through local steering group
• Think wider –STP footprint –to enable work to happen at scale.

Useful tools

• One chance to Get it Right Recommendations
• https://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value/
• RCGP EOL Commissioning Toolkit