Strategic clinical networks
Clinical senates

NHS

Thames Valley & Milton Keynes Strategic Clinical Networks –

Summary –End of Life Care Recommendations

September 2016

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)

Personalised Care Planning

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

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

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

- 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
  - http://www.dyingmatters.org/
  - Marie Curie End of Life Care Atlas
  - PHE EOL Profiles
  - Kings College London(2016) Introducing the Outcome Assessment and Complexity Collaborative Suite of Measures
  - NHS England CCG outcomes indicator set – June 2016

Shared Records

- 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.

24/7 access

- 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

- 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/ (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/

Leadership

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/
- http://www.londonscn.nhs.uk/publication/commissioners-checklist-for-end-of-life-care/
- RCGP EOL Commissioning Toolkit