South East London Integrated Care System

Palliative and End of Life Care (PEOLC)

NHS South East London

Overview of our current system

Death and dying are inevitable.
In 2022 10,211 people died in South East London. 5,121 of these people died in hospital, for many, if they had been asked where they would want to die, they would have chosen a setting outside of hospital. It is estimated that around 50-75% of deaths are 'amenable to palliative care', but at present it is not clear what proportion of people are referred for support. At any one time, nationally, it is estimated that one third of people who are in hospital today will die in the next year, many of these admissions might have been avoided with proactive open communication and personalized care planning.
Palliative and end of life care must be a priority across services and care pathways. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preference and wishes.

Strengths / opportunities

- We have a well established PEoLC group and CCPL leads in most boroughs
- New London universal care plan (UCP) well utilized in many parts of the system and opportunities to further embed this.
- Bexley in particular has had success in 'finding their 1%' of people likely to die in the next year. Of these patients, almost 70% have a personalized care plan. There is scope to learn from this work and achieve similar results for the relevant % across other boroughs
- We have almost completed work to define a core offer for community Specialist Palliative Care providers;
- Pilot project to support patients and their families transitioning from CYP to adult EoL services
- Significant opportunity to address inequalities in many areas, starting with people with LD
- Projects started to implement End of Life Care virtual wards into wider acute/community pathways
- We have excellent services locally and a world leading PEoLC research institute

Challenges

- There are significant gaps in workforce across generic EoL (GP, DN, hospital, care home) and specialist palliative care (SPC) services. Where we have workforce, they may lack confidence on EoLC.
- Local SPC provision is reliant on significant charitable funding which may present problems in the current cost of living crisis (also a strength)
- There are significant inequalities in access to care – and much work to be done, e.g. moving away from a white-European approach to death and dying
- Our data is not joined up and so we are not able to fully understand pockets of excellent or weak performance.

What we've heard from the public

We have heard that the priorities for our patients are "to manage and choose the support" they need and to be empowered to begin planning at an earlier stage through honest conversations including families so people can understand their choices. We have also heard the need to better integrate care between services and to ensure seamless access to advice, care and treatment out of hours, including access to medications so people do not have to go into hospital. Social isolation was an issue for some. We are keen to progress more integrated engagement with our communities building on best practice across the UK, such as compassionate communities and death literacy.

PEOLC - Our vision and objectives

Our vision

Our vision is to ensure that people of all ages at the end of their lives* are identified early so that they can be supported to make informed choices, receive 24/7 care in the place of their choice and that they receive the best quality, personalised care, with people close to them supported by people who are empowered, skilled, confident and timely.

Our key objectives – what we want to achieve over the next five years

Our key objectives align to the National Palliative and End of Life Care 22-25 strategic priorities of accessibility, quality and sustainability.

Accessibility

- People likely to be in the last year of life are identified as early as possible
- All patients in the last year of life are offered a Personalised Care and Support Plan (PCSP)
- High quality care and advice is accessible 24 hours a day, 7 days a week for patients, family, carers and professionals in all settings
- There is equitable access to PEOLC for all, focusing on underserved populations

Quality

- Patients receive standardized and high-quality Palliative and End of Life Care irrespective of age, condition or diagnosis
- There is a confident workforce with the knowledge, skills and capability to delivery high quality Palliative and End of Life Care
- End of Life Care is seen as everyone's business, with patients identified and support through effective multi-disciplinary teams

Sustainability

- Specialist palliative care services, including hospices, are sustainable in the longer term, with sufficient NHS investment to achieve this.
- We have sufficient SEL specialist palliative care workforce to meet patient need and future demand, and non-specialist staff supporting end of life care patients feel confident and supported to deliver effective end of life care.
- We have thriving neighbourhood-based support which maximises the role of neighbourhood and third sector organisations in delivering support to patients, families and carers (e.g social prescribing and compassionate neighbours)

** n.b: Although we are generally talking about 'last year of life' there will be some people where a palliative care approach may be earlier. For others, they may be identified in the very last weeks, days or hours.*

PEOLC - Our priority actions

Our priority actions – what we will do

1. **Proactive and personalised care** - We will improve early identification of people approaching end of life and ensuring proactive, personalized care and support planning.
2. **Improve our service offer** - We will ensure PEoLC services are accessible 24/7 for patients, carers and professionals in all settings that are rated as 'good' or above across all areas of SEL
3. **Improve access** - We will identify groups who are marginalized and improve access for these groups
4. **Workforce** - We will support our workforce to have the confidence and skills they need to provide end of life care and work with the People programme to ensure that has End of Life Care is integrated into all health and care career pathways in SEL.
5. **Population Health Management** - We will use population health management approaches to ensure that EoLC is integrated into the model of care for all population groups, starting with the frail elderly and those with long term conditions.
6. **Compassionate communities** - We will work alongside our communities to support the development of compassionate communities with citizens who have a growing confidence and understanding about death, dying and loss.

PEOLC – Our progress to date

Key Successes in Delivery in 2023/2024

- Roll-out of the Universal Care Plan in South East London including integration into the majority of SEL clinical systems.
- Movement to an aligned Marie Curie contract within South East London (for 5/6 boroughs)
- Development of a specialist palliative care core offer by the Community Palliative Care Providers
- Piloting improvements to accessing palliative care medicines in the out of hours period
- Development of Palliative and End of Life Care Virtual Wards in some LCPs
- South East London Palliative and End of Life Care Network day with a focus on health inequalities
- Completion of a project to improve transitions from children to adults Palliative and End of Life Care services
- Development of shared SEL-wide outcomes for Palliative and End of Life Care

Key Challenges to Delivery in 2023/2024

- Lack of clarity around changes to the commissioning arrangements for Children and Young People's Palliative Care
- Ensuring the quality of Universal Care Plans and integration with the EPIC clinical system
- Challenging financial context across Palliative and End of Life Care
- Inefficient and fragmented out of hours support
- Recruitment and retention challenges across the workforce
- Variability in service offer and funding levels across LCPs
- Capacity available across the system to support planning, contracting and transformation

Learning and Implications for Future Delivery Plans

- Plans need to be better targeted to reflect capacity constraints
- Workforce development and retention needs to be a key priorities to support delivery

PEOLC priority action 1 – proactive and personalised care

Proactive and personalised care

Improving early identification of people approaching end of life and ensuring proactive, personalised care and support planning

How we will secure delivery

Actions for 24/25

- Funded place based projects to improve identification of patients in last year of life and increase use of advance care planning.
- Share learning from projects to agree standardization where appropriate
- Improve quality of records and utilisation of the Universal Care Plan
- Deliver integration of the Universal Care Plan with EPIC.
- Test approaches to integrate Palliative and End of Life Care provision into multiple Long Term Condition and Frailty integrated neighbourhood team models.
- Grow and improve MDT/ Gold Standard Framework meetings in LCNs with palliative care involvement

Actions for 25/26

- Test project ECHO (Extension of Community Healthcare Outcomes) model in SEL
- Mainstream integration of Palliative and End of Life Care planning within integrated neighbourhood teams
- Explore options for improved identification of people at end of life in hospital (find your third)

Intended outcomes in 5 years time

- Increased % of people identified as being in their last year of life on practice registers and Increased number of people with Personalised Care and Support Plan(PCSP)/UCP. (moving to England average of 1%)
- Increased % of people who die in their preferred place of death.
- A 10% reduction in the % of deaths with three or more emergency admissions in the last year of life
- Increased numbers of people referred to community SPC by 2027.
- Increase in time from referral to death in community SPC services by 2027.

PEOLC priority action 2 – improve our service offer

Name of priority action

Services which are accessible 24/7 for patients, carers and professionals in all settings that are rated as 'good' or above across all areas of SEL

How we will secure delivery

Actions for 24/25

- Complete gap analysis of current provision against the SEL specialist palliative care core offer.
- Review outputs of CYP transition pilot project against future commissioning plans.
- Complete a review of out of Hours services for people at EoL and identify opportunities for improvement
- Test further improvements to access to end of life care medications, particularly out of hours
- Ensure safe transition of Children's Palliative Care commissioning from NHS England, work with LCPs to establish approach for 25/26.

Actions for 25/26

- Mainstream improvements to access for end of life care medications, particularly out of hours
- Understanding and quantifying distance to travel to level up all provision to meet the core offers
- Review Children's Palliative Care provision and develop a core SEL offer
- Implement improvements to Out of Hours End of Life Care services (ensuring alignment with Integrated Urgent Care services)

Intended outcomes in 5 years time

- Delivery of core standards and outcomes across all specialist palliative care providers through the implementation of core offers
- Improved experience for children, families and carers transitioning from CYP to adult end of life care services.
- All patients (adults and children) to have access to palliative care support to optimise symptom control and relieve pain 24 hours a day, 7 days a week
- All patients, families, carers and professionals have access to specialist palliative care advice 24/7 days a week
- A single point of referral for specialist palliative care services is in place (at an appropriate geography) which provides triage, assessment and coordination of care needs
- All patients have access to hospice beds, acute and community specialist palliative care services, hospice at home services and ambulatory care services.
- Families have access to bereavement services and carer support services which meet local population need
- Good access to appropriate palliative care medicines in the community by working with community pharmacy to support peoples end of life care plans

PEOLC priority action 3 – improved access for marginalised groups

Improved access for marginalised groups

Identify groups who are marginalized and improve access for these groups

How we will secure delivery

Actions for 24/25

- Co-design pilots to improve end of life care for two underserved population groups for potential testing through health inequalities programme
- Review use of Universal Care Plan across inequalities groups and identify ways to better equalise access
- Targeted communications and engagement with underserved population groups to improve knowledge of services available

Actions for 25/26

- Work with the London Universal Care Plan programme on a plan to improve patient accessibility of the plan for all the population taking into account digital exclusion and language barriers etc
- Implementation of health inequalities pilots (subject to funding)
- Organise system-wide learning events to review missed opportunities for palliative and end of life care for patients who experienced 3 or more emergency admissions in the last three months of life

Intended outcomes in 5 years time

- Developed data in identifying areas of focus among underserved population
- Increase in fair and equal access to quality palliative care especially among underserved populations
- A reduction in variation in access to specialist end of life care services for patients from underserved populations
- A reduction in variation in patients identified as being in the last year of life from underserved populations
- A reduction in variation in the number of patients who have been offered a personalised care and support plan from underserved populations
- A reduction in variation in the % of patients who die in their preferred place of death across underserved populations
- A reduction in the number of patients from underserved populations who experience 3 or more emergency admissions in the last three months of life

PEOLC priority action 4 – workforce

Workforce

Support our workforce to have the confidence and skills they need to provide end of life care and work with the People programme to ensure that has End of Life Care is integrated into all health and care career pathways in SEL.

How we will secure delivery

Actions for 24/25

- Develop virtual training products to be made avaliable to all SEL practitioners, intially focussing on early identification of people at EoL.
- Implement a training scheme for band 5 nurses with an interest in EoLC to help them develop their palliative care knowledge and skills. This will aim to support 24 Band 5's from all settings.
- Consider opportunities via the NHS Long Term Workforce Plan to support further workforce initiatives across End of Life Care, engagement with the SEL People Programme.

Actions for 25/26

- Development of additional modules as part of the virtual training platform.
- Implementation of new recruitment and retention projects aligned to the NHS Long Term Workforce Plan.
- Explore joint recruitment/ rotation models across the Palliative and End of Life Care system

Intended outcomes in 5 years time

- Increase in confidence in the workforce with knowledge, skills and capability to deliver high quality PEoLC - number of staff trained in PEoLC
- Developed implementable SPC workforce plan across CYP/ adult
- Developed Education and Training Strategy which will include training and resources, prioritisation of staff groups/ topics and scoping for additional investment
- Improved confidence in managing end of life care staff reported as a result of training – via staff survey
- Alignment between capacity and demand for the specialist palliative care workforce

PEOLC priority action 5 – population health management approaches

Population health management approaches

We will use population health management approaches ensure that EoLC is integrated into the model of care for all population groups, starting with the frail elderly and those with long term conditions.

How we will secure delivery

Actions for 24/25

- Continue to implement whole system integration approaches in service provision -integrating EoL SME into LTC/ frailty management
- Develop a Palliative and End of Life Care dashboard based on the SEL outcomes framework
- Ensure SPC advice and guidance is integrated into the development of multi-disciplinary team approaches so that patients are supported holistically regardless of where they treatment is being managed.
- Share learning from initial End of Life Care virtual wards across SEL, and consider opportunities to further development the model.

Actions for 25/26

- Further development of Palliative and End of Life Care data tools, moving on to the development of new indicators where data is not readily available within the system (i.e patient and staff experience)
- Develop specification for the population health management tools required by front-line professionals and neighborhood teams to deliver the model of care
- Embed outcomes into SPC services and ensure reporting captures this

Intended outcomes in 5 years time

- As near to real time data flow between providers involved in the delivery of End of Life Care
- A detailed understanding of population segmentation within end of life care and the needs of those segments.
- Articulated and shared care pathways for all population segments
- A PEoLC dashboard is in place with timely activity and quality related data
- Patient and carer reported improvement in the integration and personalisation of care
- Staff reported improvement in feeling support to deliver the care that they wish to
- Improved symptom control and relief of pain
- Increase in the number of patients dying in their preferred place of death

PEOLC priority action 6 – develop compassionate communities

Develop compassionate communities

We will work alongside our communities to support the development of compassionate communities with citizens who have a growing confidence and understanding about death, dying and loss.

How we will secure delivery

Actions for 24/25

- Continue an events programme aligned to Dying Matters week to engage interested citizens in talking about death dying and loss
- Development of patient and carer stories to share with a) communities b) health and care professionals c) system leaders – what matters to me, what good eolc looks like.
- Development of a compassionate communities pilot in SEL to start in 2024/25 (rebalancing death and dying)
- Expand utilisation of patient-led access to the London Universal Care Plan
- Bid for funding to support Compassionate Community development in 25/26

Actions for 25/26

- Develop guides and resources on developing compassionate communities in South East London
- Work with, and map, community assets that can support communities outside of statutory services.
- Establish partnerships with key community institutions to develop a year of Compassionate Communities events

Intended outcomes in 5 years time

- Increase in people coming forward to share their story
- Increased understanding and empathy with EoLC experiences for a broad range of people
- Communities involved in co-production of services that meet their needs
- Increase in self referral

PELOC enabler requirements

Workforce

- Ongoing development of SEL PEoLC leadership team
- Clinical and Care Professional Leadership roles in each borough with sufficient resource and support to joint up professionals across boundaries.
- More joined up working between leadership roles across workstreams – cross working with other programmes
- Better utilization of additional role reimbursement scheme (ARRS) roles towards EoLC
- Support from the People Board and Programme to understand and act on future workforce, training and education needs for the EoLC workforce
- Access to a consistent training and education package around EoLC care, including advanced care planning, where uptake can be monitored
- Modelling and workforce planning tools
- Workforce Wellbeing for both NHS trust and non-NHS trusts staff
- Investment in care home staff training

Digital

- Investment to test remote monitoring and digital technologies to support workforce efficiency and improve patients care
- Seeing each other's records -as appropriate
- Development of webpage
- Remote monitoring kit for Virtual Wards and observations of people at home
- Improvements in IT equipment, in particular for domiciliary care – to enable measurement of outcomes
- Enabling digitally able community patients to self-report PROMs
- Ongoing renewing of kit
- Support to care homes, social care and children hospice providers to overcome barriers that are restricting access to the London Urgent Care Plan
- Videos for training

Estates

- Improvements to primary and community care estate to support the development of integrated neighbourhood teams for End of Life Care.
- Investment in WiFi infrastructure within our estate

Data

- Integrated data across primary, community, acute and social care providers
- Population health management dashboards for end of life care which meets the needs of front-line professionals, neighborhood teams, Local Care Partnerships and ICB teams
- Dashboard to monitor and track outcome measures and key performance indicators
- Regular, automated data flows relating to staff capacity, training and education
- UCP data
- Support to implement the community services dataset across our hospices