

End of Life Care for Children and Young People in Kent and Medway

May 2019



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Executive Summary

Background

The need for end of life care services for children and young people (C&YP) is increasing nationally. Although many life-limiting and life-threatening conditions (LLCs) are rare, medical advances have led to better recognition and diagnosis of these conditions amongst C&YP (now almost 400 conditions), and better treatments have led to more C&YP living longer with their condition(s), with more complex health needs. There is increasing pressure on acute and community services to deliver good-quality, clinically effective care to C&YP and their families, in the context of financial and workforce challenges and the struggle to recruit and retain nurses in the NHS. As a result, palliative and end of life care for C&YP has been identified as a priority in the recently published NHS Long Term Plan and a new service model is currently under development by NHS England.

A Children and Young People's Palliative Care Network has been formed in Kent and Medway as a proactive response to the escalating need for services across the area, to ensure co-ordinated and equitable provision of high-quality and clinically effective end of life care. Up until now, prevalence of LLCs amongst C&YP in Kent and Medway has not been estimated and service provision has not been comprehensively mapped.

Aims

The aims of this Needs Assessment were to:

- estimate the prevalence of LLCs amongst C&YP in Kent and Medway.
- describe this population by age, gender, diagnostic category, deprivation, and Clinical Commissioning Group. Other analyses included hospital admissions per person by age, CCG and diagnostic category, and location of death.
- map current end of life care service provision in Kent and Medway to identify gaps and areas for improvement.
- support the Kent and Medway Children and Young People's Palliative Care Network in the development of the strategy for end of life care for C&YP.

Methodology

The need for end of life care services for C&YP in Kent and Medway was estimated by identifying all children and young people resident in Kent and Medway with a LLC. C&YP were defined as people aged 28 days to 19 years and perinatal conditions were omitted to reflect the main population accessing community end of life care services. LLCs were defined using a customised coding framework of ICD-10 codes, derived by Fraser, L. et al, 2016 (Appendix A). Two cohorts were identified:

- Cohort 1** C&YP who were coded with a diagnosis of a LLC during an admission to a Kent and Medway hospital in financial years 2014-15 to 2017-18 and who were alive as of August 2018 (identified using secondary care service activity data linked to the Kent Integrated Dataset). Quarter of birth (as opposed to date of birth) is stored in the dataset, therefore under three-month-olds were excluded.
- Cohort 2** C&YP who died in calendar years 2006 to 2017 and who had a LLC stated as the cause of death or a contributing factor on the death certificate (identified using the Primary Care Mortality Dataset).

Service provision in the community was mapped against the NICE Quality Standard for Palliative Care for Infants, Children and Young People (September 2017). Analysis of service activity data was attempted, which was only available for two community providers. In addition, the data was incomplete and only limited conclusions could be drawn.

Conclusions

The Need for End of Life Care Services

- C&YP who may benefit from end of life care services constitute a small portion of the Kent and Medway population. Over a four-year period, there were 1,415 living individuals with an LLC in Kent and Medway, and over a 12-year period 279 C&YP died from or with an LLC in Kent.
- Despite the cohort being small, the need for end of life care services in hospital and in the community is increasing. Yearly rates of living C&YP with an LLC have significantly increased since 2014-15 and yearly death rates from LLCs have been declining since 2008.
- This cohort creates a large burden on acute trusts and some community services. We estimate that the living C&YP with an LLC had approximately 5,000 hospital admissions over a four-year period. 15-19-year-olds with a haematological condition had the highest number of admissions per person to Kent and Medway hospitals.
- The number of C&YP requiring EOLC services at any one time is relatively small, however as this number increases, so too does the unpredictability and end of life trajectory of these individuals.

- The highest rates of LLCs amongst living and deceased cohorts were seen in the 1-4y age band. Prevalence of LLCs amongst living 15-19-year-olds is growing the most rapidly.
- More males were affected by LLCs than females in the living and deceased cohorts. This gap is widening amongst living C&YP.
- Swale, Thanet and Medway had the highest rates of LLCs amongst living C&YP and West Kent had the lowest rate. Rates of LLCs have increased in all CCGs since 2014-15; the rate in Swale is growing most rapidly.
- Ashford and Dartford, Gravesham and Swanley had the highest death rates from LLCs. There was a decline in death rates across all CCGs except Ashford, where the death rate increased.
- Amongst living C&YP, higher rates of congenital LLCs were seen than any other diagnostic category across all CCGs. The most common cause of death was cancer.
- A higher rate of LLCs was seen in the most deprived decile than the least deprived decile for both cohorts.
- There has been a general increase in hospital deaths from LLCs since 2008 and a general decline in hospice deaths from LLCs since 2011. Most hospital deaths from LLCs were in Kent and Medway hospitals. The majority of these were at William Harvey and Medway Maritime Hospitals.

Service Provision

EOLC service provision across Kent and Medway is incredibly complex, with multiple commissioning bodies and community providers delivering end of life care to C&YP. The needs of the population and service provision have gone unmapped, allowing services to evolve organically without adequate strategic planning and leaving some areas with overlapping service provision and other areas with gaps. The roles and responsibilities of providers within the system as a whole are not clear, making it difficult for providers to efficiently co-ordinate with each other and map out clear patient pathways. Nursing teams deliver the best quality care they can to as many C&YP and families as they can, within worsening financial, organisational and cultural constraints. However, this complex and fragmented system is ill-equipped to cope with the growing need for services in its current form. The main areas highlighted for improvement are outlined below.

- Equity of service provision: some providers struggle to deliver 24-hour EOLC to C&YP and families who need it, increasing the burden on acute services. There is currently a gap in out-of-hours service provision for some cancer patients in West Kent.
- Nursing team capacity: funding challenges and difficulty in recruiting specialist nurses are contributing to inadequate capacity and difficulty in delivering equitable, high-quality end of life care to those who need it. This has a profound effect on the provision of out-of-hours services and can lead to inappropriate hospital admission and prolonged hospital stay.
- Commissioning arrangements: arrangements have evolved organically, making roles and responsibilities and patient pathways unclear. Some providers do not have formal commissioning arrangements for end of life care, and some rely on outdated

specifications which no longer reflect the CCG's expectations of what the service should deliver or the current service delivery.

- Co-ordination of care: co-ordination between providers who share caseloads can be difficult, as not all providers have a formal commissioning arrangement or adequate capacity. Confusion around roles and responsibilities of teams and referral criteria impacts upon acute services and patient pathways.
- Nursing team training: there is variability in training levels of nursing staff within the hospice setting, in Children's Community Nursing Teams, and on paediatric wards. This had a stark impact on patient pathways and community team involvement, as nurses on the wards lacked confidence in having difficult conversation with families.
- Medical support: there is no Specialist Paediatric Palliative Care Team (SPPCT) or Paediatric Intensive Care Unit in Kent and Medway, alongside a shortage of SPPC consultants in tertiary centres in London. There is also variable local OOH medical support across the area with the necessary expertise in end of life care.
- Bereavement services: There is a lack of knowledge around locally commissioned bereavement services, as well as inadequate service-specific bereavement support for families after an unexpected death.
- Service activity data: not all providers record service activity and some teams lacked the necessary staffing and/or knowledge to pull relevant data out of the systems, causing gaps and significant delays in data collection and analysis.

Recommendations

To cope with the changing landscape of end of life care, services need to be well-placed with adequate funding and capacity, with special consideration given to cohorts in greatest need. Specific recommendations are outlined below.

- C&YP from deprived backgrounds require specific consideration when planning services. Transition services are also vital. In light of the rapid increase in LLCs amongst 15-19-year-olds, as their needs fall somewhere between those met by children's and adults' services.
- Careful EOLC service planning in Swale is required, in light of the rapid increase in LLCs amongst living and deceased C&YP.
- Although congenital conditions are the most prevalent LLCs amongst living C&YP, C&YP with haematological conditions have very high admission rates per person but deaths amongst this cohort are low. Secondary care services planning is vital to cope with the increase in future admissions.
- It is vital that commissioners are identifiable and map out the services needed to meet the needs of their populations. In the long-term, commissioning arrangements should be revised, requiring intensive involvement of all commissioners and service providers (community and acute) across Kent and Medway and London. In the immediate term, commissioners need to clarify roles and responsibilities and consider collaboration between teams to ensure out-of-hours on-call rotas are adequately staffed. Particular attention should be paid to cancer patients in West Kent.

- Referral criteria of community teams should be clarified with paediatric ward teams.
- All acute trusts across Kent and Medway and London should be engaged with to provide more frequent training sessions in end of life care.
- Commissioners should also ensure providers are aware of local commissioned services, including bereavement support.
- All providers should collect service activity data in a consistent way that can be shared easily between providers and commissioners. Potential benefits include wider scope for research and better-quality, cost-effective clinical care by targeting populations in greatest need.

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Abbreviations

NHSE	NHS England
CHC	Continuing Healthcare
ACP	Advanced Care Plan
EOLC	End of life care
OOH	Out-of-hours
LTC	Long-term condition
ICD-10	International Classification of Diseases, 10th Revision
CCG	Clinical Commissioning Group
K&M	Kent and Medway
CDOP	Child Death Overview Panel
LSCB	Local Safeguarding Children Board
DGS	Dartford, Gravesham and Swanley
PCN	Palliative Care Network
DNAR	Do Not Attempt Resuscitation
STRS	South Thames Retrieval Service
KID	Kent Integrated Dataset
PCMD	Primary Care Mortality Dataset
QEQM	Queen Elizabeth Queen Mary
HDU	High-Dependency Unit
NICU	Neonatal Intensive Care Unit
SCBU	Special Care Baby Unit
PICU	Paediatric Intensive Care Unit
MTW	Maidstone Tunbridge Wells
DNT	Diana Nursing Team
KCHFT	Kent Community Health NHS Foundation Trust
COAST	Children's Outreach and Specialist Team
MCH	Medway Community Healthcare
GOSH	Great Ormond Street Children's Hospital
WKCCG	West Kent CCG
WTE	Whole Time Equivalent
NELFT	North East London NHS Foundation Trust

1 Introduction: Palliative Care for Children and Young People

Palliative care is a multidisciplinary team (MDT) approach to help people with life-limiting conditions (conditions which will lead to premature death) and life-threatening conditions (curable conditions that may lead to premature death) live as well as they can until they die. It combines physical, psychological, emotional, social and spiritual aspects of care and aims to improve quality of life, relieve pain and other distressing symptoms, and help people die with dignity. It includes symptom management, anticipatory planning and complexity and crisis provision, as well as a support system, not only for people during their illness, but also to families and caregivers during treatment, the dying process and in bereavement.

Palliative care for children and young people (C&YP) differs from adult palliative care in a number of ways. It is defined by the World Health Organisation as a field involving giving support to the family, beginning when illness is diagnosed, and continuing regardless of whether a child receives treatment directed at the disease¹. Care can be given at any time during a person's illness, including antenatally, and is not dependent upon diagnosis or prognosis. Children spend up to five times longer on average under the care of the palliative team than adults. Many children have several episodes where it appears that they have reached end of life, creating unpredictability during their care and difficulties in EOLC service planning². Robust advanced care planning and 24-hour nursing care are therefore crucial parts of service provision. Not only can some illnesses behave differently in children, children also experience a variety of complex and rare illnesses not seen in adults, with some C&YP lacking a formal diagnosis. Serious illness is not a "normal" condition for most children and decisions are often made by caregivers on behalf of young children, presenting further unique challenges in caring for children and supporting families³. As a result, specialist paediatric palliative care teams (SPPCTs) play a more central role in palliative care for C&YP than for adults. Currently, there are less than 20 specialist paediatric palliative care consultants (SPPCCs) across the UK and C&YP and their families often rely on SPPCT telephone advice, given either directly, or via local paediatric teams in secondary care, Children's Community Nursing Teams (CCNTs) and hospice teams. However, similarly to adults, a large portion of services are managed by voluntary sector organisations and their commissioning arrangements with the NHS have traditionally varied substantially.

C&YP who may benefit from palliative care services have a variety of life-limiting or life-threatening conditions (LLCs), which can be broadly divided into four categories⁴:

¹ World Health Organization, <http://www.who.int/cancer/palliative/definition/en/>

² National Institute of Clinical Excellence guideline [NG61], End of life care for infants, children and young people with life-limiting conditions: planning and management, December 2016

³ Get Palliative Care, <https://getpalliativecare.org/whatis/pediatric/adult-vs-pediatric-palliative-care/>

⁴ Together for Short Lives, <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/categories-of-life-limiting-conditions/>

- **Category One:** life-threatening conditions for which curative treatment may be feasible but can fail (e.g. cancer). Access to palliative care services may be necessary when treatment fails.
- **Category Two:** conditions where premature death is inevitable (e.g. cystic fibrosis). These children may require long periods of intensive disease-directed treatment in between long periods of relatively good health.
- **Category Three:** progressive conditions without curative treatment options (e.g. Batten disease).
- **Category Four:** irreversible but non-progressive conditions, causing severe disability and leading to susceptibility to health complications and premature death (e.g. cerebral palsy).

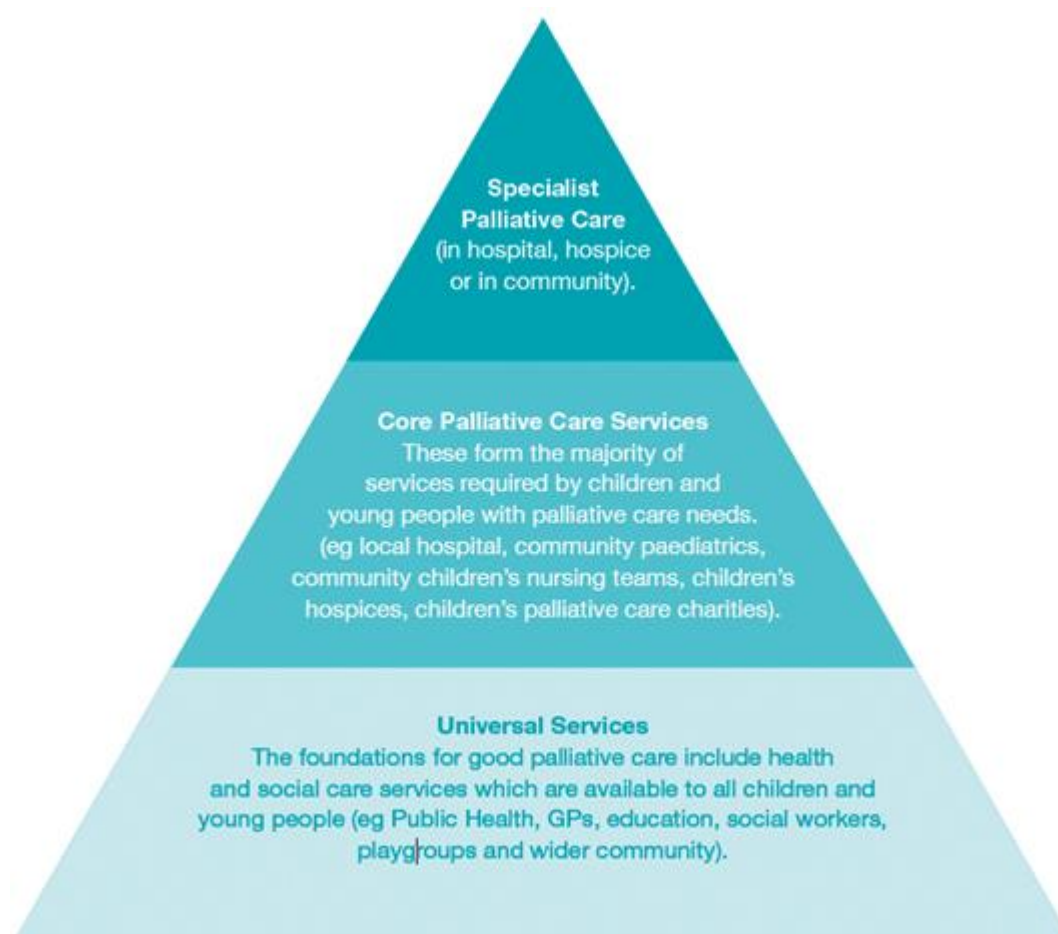
These C&YP often overlap with C&YP with severe disability and complex needs. C&YP may also have more than one LLC and will have varying requirements for palliative care services, owing to the nature and severity of the condition and the wishes of the child or young person and his or her family.

1.1 Service Provision

Palliative care for C&YP is delivered by universal services (available to all C&YP), core services (the majority of services required by C&YP with palliative care needs, including local hospitals, community paediatrics, CCNTs and hospices) and specialist services (SPPCTs led by consultants trained in paediatric palliative medicine in hospital, hospice or in the community) (Fig. 1). Outlined by Together for Short Lives in 2018, this three-tier model has been included in the NHS England (NHSE) service specification for children's palliative care, currently under development⁵. The integrated service model is a whole systems approach to ensuring services in all tiers are available to C&YP in need, and that all providers work in a coordinated way to create a seamless patient pathway, without compartmentalisation.

⁵ A Guide to Children's Palliative Care 4th Edition, Together for Short Lives, 2018

Fig. 1 Three-tier model of palliative care service provision⁶.



Source: Developing a Commissioning Model for CYP Palliative & End of Life Services, NHS England, 2018

There is a wide range of types of care provided to C&YP with palliative care needs. As part of universal services, all C&YP should have access to the Healthy Child Programme, primary care services including dental care, wider community services including playgroups, and be signposted to appropriate support from the local authority, including social care and housing. Core services provide targeted and skilled support to C&YP with an identified health need and are usually accessed via referral or emergency admission. They are delivered by hospitals, community paediatricians, CCNTs, children's hospices, therapy teams, psychological support teams, bereavement support teams, respite and wellbeing teams, special educational needs coordinators and young adult teams. Core services vary according to local arrangements and are usually delivered using a MDT approach, involving health professionals from primary and secondary care (who do not have specialist training in paediatric palliative medicine), allied health professionals (e.g. physiotherapists, occupational therapists and psychological support), pharmacists, social care practitioners, education professionals, Continuing Healthcare (CHC) teams and assessors, and family representatives. Types of care provided by core services broadly includes ongoing review,

⁶ Developing a Commissioning Model for CYP Palliative & End of Life Services, NHS England, 2018

symptom control (planned, as part of an Advanced Care Plan (ACP), or unplanned, if the child or young person is in crisis or has deteriorated), physical therapy (e.g. physiotherapy), creative therapy (e.g. art/music therapy), complementary therapy, psychological support, transition support to adult services and bereavement counselling. Short Breaks (respite care) are also offered by hospices, CCNTs and Short Break providers to provide respite in varying circumstances. Standard Short Breaks involve help by trained support staff whilst families who care for C&YP with complex health needs spend time away from caring duties. They range from a few hours in the home to longer stays in a special Short Breaks unit or hospice. Specialist Short Breaks are also offered to provide urgent additional care in an appropriate setting for highly complex or technology-dependent C&YP, either at home, hospice, hospital, or long-term care facility.

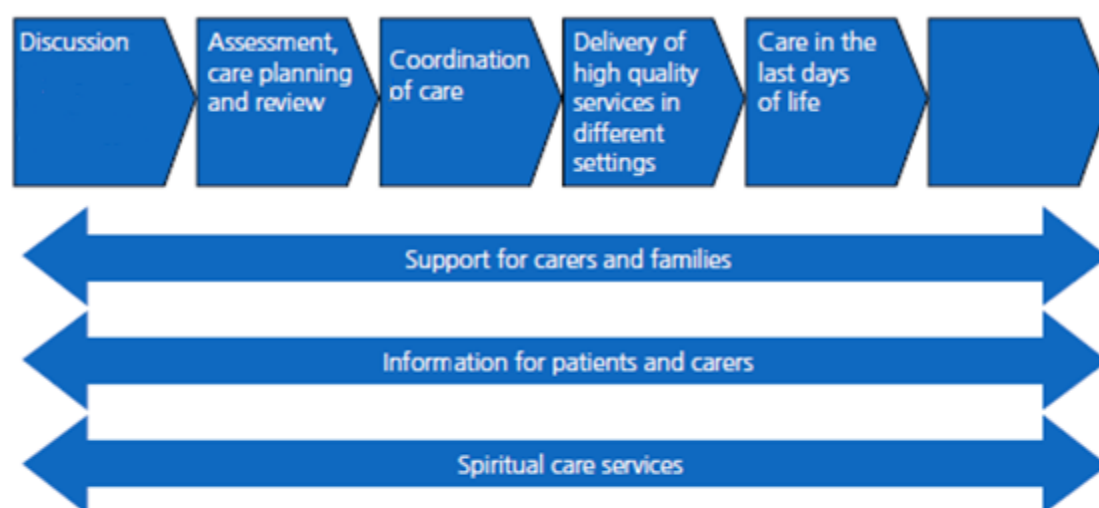
Specialist services include SPPCTs based in hospitals (tertiary centres), hospices and the community and are led by consultants with specialised training in paediatric palliative medicine. They are supported by specialist nurses, pharmacists and psychologists and provide expert care and support to C&YP and their families. A SPPCT is usually only involved when the needs of a child or young person become more complex as his/her condition progresses and/or when non-specialist involvement as part of core services becomes more complex. In addition to the care offered by core services, SPPCTs offer advanced symptom management, knowledge of the death and dying process, an understanding of rare diseases and 24-hour on-call support. SPPCTs will often lead MDT meetings and provide over-arching support for core service teams for advanced care planning, fast-track discharge and education and training programmes.

If the needs of a child or young person cannot be met by universal, core or specialist services, they may be eligible for NHS CHC funding, usually used to fund prolonged hospice admissions or packages of care at home. Each child or young person is assessed by the CCG CHC team via a MDT approach. All C&YP who receive CHC funding have the right to have a Personal Health Budget, which can be used to fund single teams of carers to build relationships and trust with families, respite provided by carers already known to families, or creative therapies to improve psychological wellbeing.

1.2 End of Life Care for Children and Young People

End of life care (EOLC) is an important part of palliative care. The term has previously been defined as care provided in the last 12 months of life, however this can be incredibly difficult to predict for C&YP at risk of sudden deterioration. It generally describes care given to those whose death is recognised as potentially imminent, those expected to die within months or years due to advanced, progressive incurable conditions, and those at risk of dying from a sudden acute crisis or event in an existing LLC. For some people, the appropriate start for EOLC might be at the time of diagnosis of a condition which normally carries a poor prognosis or after the birth of an extremely premature neonate whose prognosis is very poor⁶. Importantly, EOLC can take place in a variety of different settings, including in hospital and in the community, and all C&YP and their families should be supported to be cared for and die in their place of preference. Key aspects of EOLC have been outlined by the Department of Health End of Life Care Strategy, 2008⁷, outlined below (Fig. 2).

Fig. 2 End of Life Care Pathway (adapted from Department of Health End of Life Care Strategy, 2008)⁷.



Source: End of Life Care Strategy Promoting high quality care for all adults at the end of life, Department of Health, July 2008

1.2.1 Identification and Discussion

Stigma around palliative care, death and dying can mean that some families and clinicians only consider palliative care as a last resort when other options have failed. Some families may not accept valuable palliative care support offered to them, particularly at earlier stages of the child or young person's illness. Healthcare and social care staff are required to have open and honest discussions with C&YP and families, either when they are approaching end of life (which may be months or years away), or when they are at risk of

⁷ End of Life Care Strategy Promoting high quality care for all adults at the end of life, Department of Health, July 2008

sudden deterioration and death. This requires the necessary knowledge, skills and attitudes, stemming from good training.

1.2.2 Advanced Care Planning

All people approaching end of life need to have their needs assessed and wishes discussed, including those of their families and caregivers, as appropriate. This includes an advanced decision if they wish to refuse treatment if they lack capacity for that decision in the future, systems in place to get early help to avoid a crisis or during an emergency, management of life-threatening events including resuscitation, ceiling of treatment and organ and tissue donation. C&YP and families are also empowered to make choices regarding the place of care and place of death, which can include a variety of settings, such as hospitals, hospices, and a person's home. These decisions should be clearly documented in an ACP and subject to regular review by the MDT, including the child or young person and their family or caregiver, and should be available to all who are involved in their care, crucially including out-of-hours (OOH) services.

1.2.3 Coordination of Care

All people approaching end of life need to receive coordinated care across different services and sectors. This is particularly important for handovers between the community sector, secondary and tertiary care (during the day and night) and between children and adult services. Each member of the team should be aware of the ACP, including the child or young person's and his/her family's needs.

1.2.4 Delivery of High-Quality Services in all Locations

Services need to be provided in a variety of settings including hospitals, in the community, in care homes, sheltered and extra-care housing, hospices and ambulance services. Each service should satisfy the NICE Quality Standards, 2017⁸. C&YP and families are empowered to make decisions regarding place of care and place of death. Home-based care can be preferable to hospital care for some families and has been linked with improved patient experience.

1.2.5 Care in the Last Days of Life

Healthcare staff should identify the dying phase and review wishes for place of death, resuscitation and organ donation. Symptom control is provided, and information and support are given to both the child or young person and his/her family and caregiver, including access to spiritual care services.

⁸ National Institute of Clinical Excellence Quality Standard [QS160], End of life care for infants, children and young people, September 2017

1.2.6 After Death

Verification of death or coroner's referral should take place in a timely fashion and families and caregivers should always receive care and bereavement support.

1.2.7 Families and Caregivers

Information and support should be provided throughout the EOLC pathway, including after death.

1.2.8 Education, Training and Continuing Professional Development

It is paramount that healthcare and social care staff have the necessary knowledge, skills and attitudes for EOLC, including identification of the end of life phase, communication with families, and good quality clinical care. This is particularly important in avoidance of unplanned admissions for symptom-control. EOLC needs to be embedded into inductions, training curricula, Continuing Professional Development and appraisals.

2 Escalating Need

2.1 The UK

Although many LLCs are rare, the prevalence of C&YP with an LLC is rising and is now higher than that of other long-term conditions (LTCs), including diabetes mellitus⁹. Medical advances have led to the recognition and diagnosis of more LLCs (now over 400) and better treatments have led to more children and young people living longer with their condition(s), often with more complex health needs. This has increased the need for palliative care services in terms of capacity and the types of services offered, whilst maintaining good-quality care.

Previous estimates of national prevalence of LLCs have shown an increase from 10 per 10,000 in 1997 to 12 per 10,000 in 2003 to 16 per 10,000 in 2007¹⁰¹¹¹². The study in 2007 used death certificate data and is likely to have underestimated the burden of disease. A prevalence study in 2012 using inpatient hospital episodes and International Classification of Diseases, 10th Revision (ICD-10) disease codes to identify LLCs showed an increase from 25 per 10,000 in 2000-1 to 32 per 10,000 in 2009-10. The greatest prevalence was shown in children under 1-year-old, accounted for by congenital abnormalities. There was an increase in prevalence in all age groups, with the greatest increase amongst 16-19-year-olds, supporting prolonged survival time rather than rising incidence as the main driver of rising prevalence. There was also an excess prevalence amongst ethnic minority groups, especially in deprived areas, highlighting the importance of considering these groups when planning services to meet the increasing need¹³.

Delivering good-quality care is becoming increasingly difficult, owing to financial and workforce cuts and the struggle to recruit and retain nurses in the NHS. Nationally, fewer nurses are carrying out care for a record number of patients, with 40,000 nursing vacancies in England reported for 2017¹⁴¹⁵¹⁶. 45% of the current nursing workforce are over 45 years-old and 28% of nurses from overseas leave within two years of appointment. 25% of nurses are away from their workplace at any one time, owing to sickness, maternity leave,

⁹ Royal College of Paediatrics and Child Health, 2014

¹⁰ Baum, D., H. Curtis, and E. S, A guide to the development of children's palliative care services. 1997, Association for Children with Life-threatening or Terminal Conditions and Their Families and the Royal College of Paediatrics and Child Health

¹¹ A guide to the development of Children's Palliative Care Services: Report of the Joint Working Party. 2003, Association for Children with Life-threatening or Terminal Conditions and Their Families and the Royal College of Paediatrics and Child Health

¹² Cochrane, H., S. Liyanage, and N. R, Palliative Care Statistics for Children and Young Adults. 2007, Department of Health

¹³ Fraser, L. et al, Rising National Prevalence of Life-Limiting Conditions in Children in England. 2012, Pediatrics 10.1542/peds.2011-2846

¹⁴ Frontline First: The Fragile Frontline, Royal College of Nursing, 2015

¹⁵ Safe and Effective Staffing: the Real Picture, Royal College of Nursing, 2017

¹⁶ Nursing and Midwifery Council, <https://www.nmc.org.uk/about-us/reports-and-accounts/registration-statistics/>

compassionate leave, annual leave or study leave, creating a discrepancy between staffing levels on paper and in reality. Considering the increasing demand and struggling workforce, palliative and EOLC for C&YP has been identified as a priority in the recently published NHS Long Term Plan¹⁷. The current NHS Children's Hospice Grant of £11 million per year is projected to increase to £25 million by 2023-24 by match-funding Clinical Commissioning Groups (CCGs) which commit to increasing investment in local services, including children's hospices. NHSE are also currently developing a new service model for palliative and EOLC for C&YP, involving stakeholder engagement workshops.

2.2 Kent and Medway

Comprehensive prevalence of LLCs amongst C&YP in Kent and Medway (K&M) has not been previously reported. The 2006 government document 'Working Together to Safeguard Children' (revised in March 2015) stipulated the need for Child Death Overview Panels (CDOPs) to collect and review information about each child death (up to, but not including, 18 years-old, not including stillbirths and planned terminations) on behalf of the Local Safeguarding Children Board (LSCB)¹⁸. Including all-cause mortality, Kent CDOP reports over the last three years have shown a general increase in the number of deaths and death rate of C&YP¹⁹ (Table 1). Reports have also shown a small increase in the number of expected deaths (expected or anticipated within 24 hours of the event), particularly amongst non-neonates (Fig. 3)²⁰.

The number of expected neonatal deaths was not reported prior to 2016-17. It is important to note that the CDOP reviews cases from previous years due to prolonged time awaiting inquest outcomes, therefore unexpected deaths tend to be over-estimated and the data does not show accurate trends.

¹⁷ NHS Long Term Plan, January 2019, www.longtermplan.nhs.uk

¹⁸ Working together to safeguard children: A guide to inter-agency working to safeguard and promote the welfare of children, HM Government, March 2015

¹⁹ Kent Safeguarding Children Board Child Death Overview Panel Annual Report 2017-2018

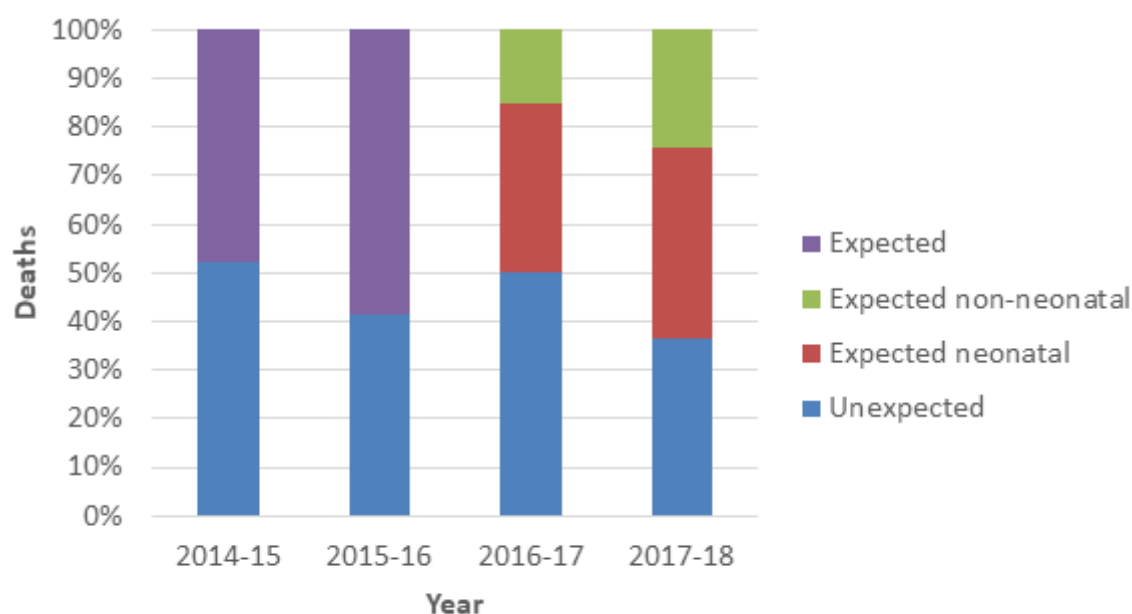
²⁰ Kent Safeguarding Children Board Child Death Overview Panel Annual Report 2016-2017

Table 1 Deaths (0-17 years) in Kent by age band and year (1st April to 31st March) (adapted from¹⁹. Death rates were calculated using data from the Office of National Statistics²¹.

Age	2015-16 (%)	2016-17 (%)	2017-18 (%)
0-27d	41 (51)	50 (49)	54 (53)
28-364d	18 (22)	27 (26)	14 (14)
1-3y	9 (11)	6 (6)	7 (7)
4-10y	6 (8)	6 (6)	6 (6)
11-17y	6 (8)	13 (13)	21 (20)
Total deaths	80 (100)	102 (100)	102 (100)
Deaths per 10,000 relevant population	2.4	3.1	3.0
Neonatal deaths per 1000 live births	2.4	2.9	3.1

2.2.1 Causes of Death

Fig. 3 Expected and unexpected deaths (0-17 years) in Kent by year (1st April to 31st March)¹⁹. The number of expected neonatal deaths was not reported prior to 2016-17.

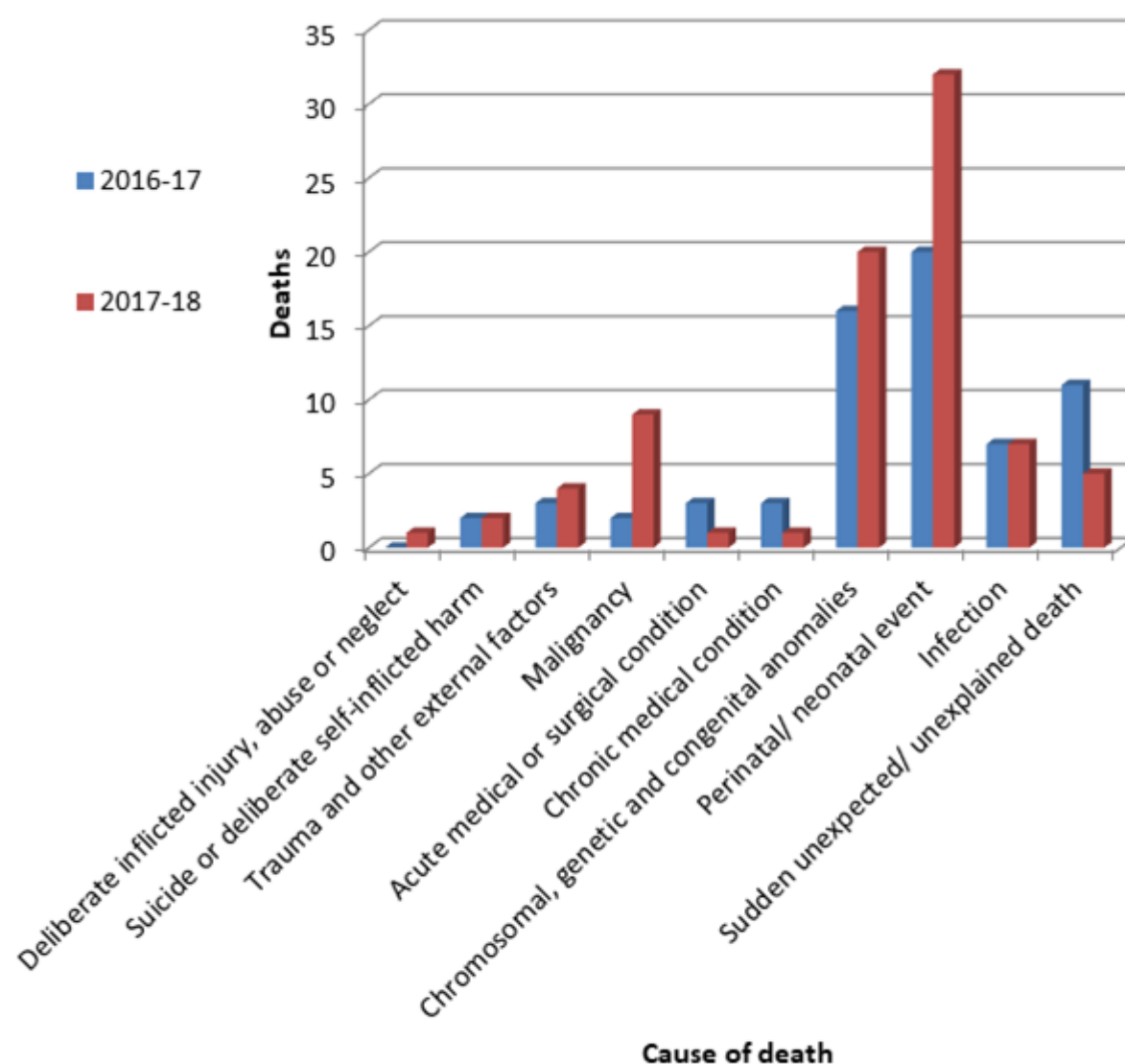


Source: Kent Child Death Overview Panel Annual Report 2017-18

²¹ Office for National Statistics, <https://www.ons.gov.uk>

Causes or contributors of death in cases reviewed and closed at CDOP in 2016-17 and 2017-18 are shown in Fig. 4. There is a notable increase in deaths from malignancy, chromosomal, genetic and congenital abnormalities and perinatal/neonatal events between years. It is important to note that there was a greater number of very premature births and neonatal death reviews in 2017-18, which could account for the large increase in perinatal/neonatal events.

Fig. 4 Deaths (0-17 years) in Kent by cause of death in 2016-17 and 2017-18 (1st April to 31st March)¹⁹.

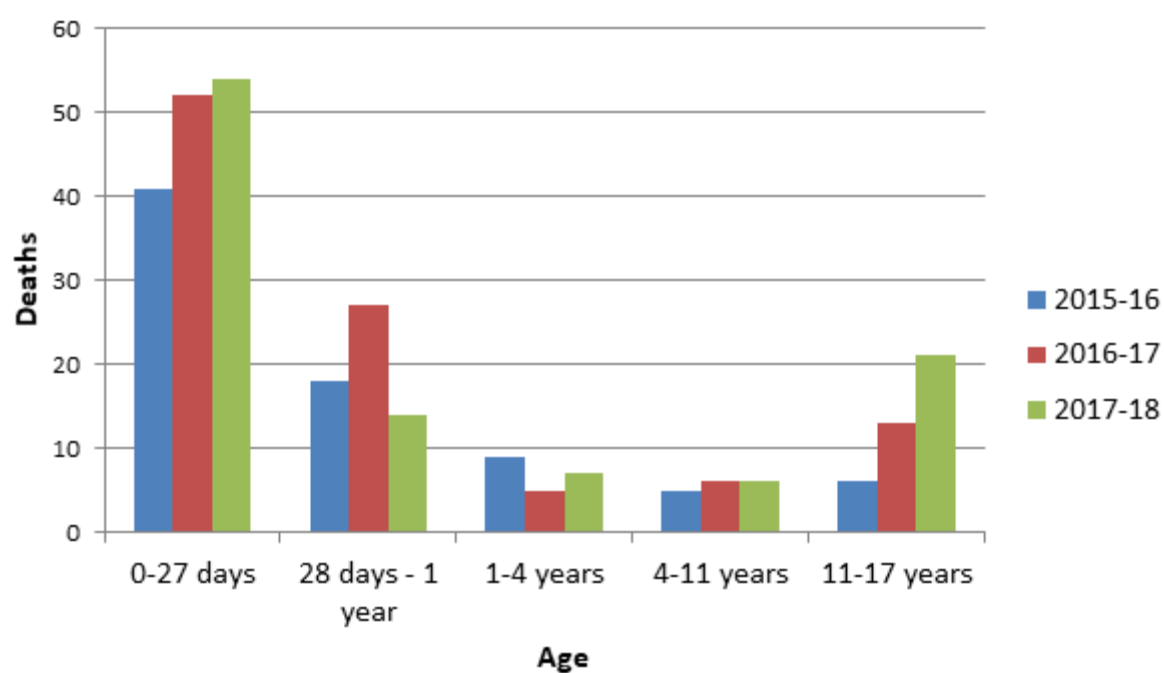


Source: Kent Child Death Overview Panel Annual Report 2017-18

2.2.2 Deaths by Age

Neonatal deaths (0-27 days) remained the highest portion of child deaths in 2017-18 (53%) and have increased from 2.4 to 3.1/1000 live births between 2015-16 and 2017-18 (Table 1). The greatest increase in deaths across the three-year period is seen amongst 11-18-year-olds (Fig. 5). Ten deaths from this age-group were from LLCs or natural causes, which increased from six in the previous year, reflecting the national prevalence data.

Fig. 5 Deaths (0-17 years) in Kent by age band and year¹⁹.



Source: Kent Child Death Overview Panel Annual Report 2017-18

2.2.3 Deaths by Clinical Commissioning Group

Kent is a large county with seven CCG areas. Death data of C&YP by CCG from the Kent CDOP is shown in Table 2.

Table 2 Deaths (0-17 years) in Kent by Clinical Commissioning Group in 2017-18 (1st April to 31st March), adapted from¹⁹. Death rates were calculated using data from the Office of National Statistics²¹. Total population excluding neonates was estimated using total population – 1/12(annual live births). *Suppressed data <4

Clinical Commissioning Group	Deaths (0-17 years) 2017-18					
	Total deaths	Deaths per 10,000 population	Neonatal deaths	Neonatal deaths per 1000 live births	Total deaths excluding neonates	Deaths per 10,000 population excluding neonates
Ashford	4	1.3	*	*	*	*
Canterbury & Coastal	12	3.1	*	*	8	2.1
Dartford, Gravesham & Swanley	18	3.0	12	4.0	6	1.0
South Kent Coast	19	4.7	7	3.2	12	3.0
Swale	12	4.5	6	3.3	6	2.3
Thanet	9	3.0	7	4.4	*	*
West Kent	28	2.5	16	2.7	12	1.1
Kent	102	3.0	54	3.1	48	1.4

In 2017-18, South Kent Coast and Swale had the highest death rates and Ashford had the lowest. Thanet and Dartford, Gravesham and Swanley (DGS) had the highest neonatal death rates and Ashford had the lowest. When neonatal deaths are excluded, South Kent Coast had the highest deaths rates and Ashford had the lowest.

2.2.4 Service Provision

EOLC service provision in K&M is complex. Numerous service providers cover a large geographical area, offering variable services with overlapping organisational boundaries. Funding for these services varies and comes from a combination of sources, including the NHS, local authority and charity/fundraising. CCG commissioning arrangements also vary significantly across the area. A Children and Young People's Palliative Care Network (PCN) has been formed in K&M as a proactive response to the escalating need for EOLC services for C&YP, to ensure co-ordinated and equitable provision of high-quality and clinically effective EOLC across the area. With an intended core membership of doctors, nurses, specialist pharmacists, therapists and other professionals, including CCNTs and commissioners, the PCN aims to promote partnerships to increase service provision across the region without the constraints and complexities of organisational boundaries, using an MDT approach. Service provision in K&M and areas for improvement highlighted by service providers and commissioners are outlined in Section 5.

3 Estimating Need

3.1 Methodology

The need for EOLC services for C&YP in K&M was estimated by identifying all C&YP resident in K&M with an LLC. C&YP were defined as people aged 28 days to 19 years to reflect the main population accessing community EOLC services in K&M. LLCs were defined using a customised coding framework of ICD-10 codes, derived by Fraser, L. et al, 2016 (Appendix A)²². Two cohorts were identified:

- Cohort 1** C&YP who were coded with a diagnosis of an LLC during an admission to a hospital in K&M in financial years 2014-15 to 2017-18 and who were alive as of August 2018 (identified using secondary care service activity data linked to the Kent Integrated Dataset (KID)).
- Cohort 2** C&YP who died in calendar years 2006 to 2017 and who had an LLC stated as the cause of death or a contributing factor on the death certificate (identified using the Primary Care Mortality Dataset (PCMD)).

Prevalence of LLCs and death rates were calculated by age, gender, diagnostic category, deprivation, and CCG. Other analyses include hospital admissions per person by age, CCG and diagnostic category, and location of death. Perinatal conditions were omitted.

3.2 Limitations

Limitations of the dataset for cohort 1 were as follows:

- Secondary care data from London trusts is not linked to the KID, therefore the dataset only includes admissions to K&M trusts. In specialties such as oncology, care is heavily led by tertiary centres and C&YP being admitted only to London trusts will not have been included in the dataset.
- Primary care data was not included in the dataset, therefore C&YP with an LLC managed only by their general practitioner have not been identified.
- Numbers and prevalences could not be looked at by ethnicity, owing to lack of data linked to the KID.
- Quarter of birth (as opposed to date of birth) is stored in the KID, therefore under three-month-olds were excluded. Infants under three months-old were estimated by identifying those whose first admission end date was within three months of the quarter of birth and excluded. The number of infants 3-12 months-old has been underestimated as a result.
- Perinatal diagnostic category was excluded as these conditions mainly affect neonates and infants in acute care.

²² Children in Scotland requiring palliative care: identifying numbers and needs (the ChiSP Study), Journal of Pain and Symptom Management, December 2016, Volume 52, Issue 6, e132-e133

Limitations of the dataset for cohort 2 were as follows:

- Death data after 2017 was not available, therefore cohort 2 was identified looking at data from calendar years, as opposed to financial years.
- Death data for Medway residents is not accessible to the Public Health Observatory, therefore cohort 2 only includes deceased Kent residents. The KID does not include detailed death data of K&M residents; therefore cohort 2 data could not be analysed in the same detail as cohort 1.
- The numbers of deceased C&YP were low in some categories and were therefore amalgamated or suppressed to avoid identification of individuals. Statistical significance was difficult to achieve, and error bars have therefore been omitted.

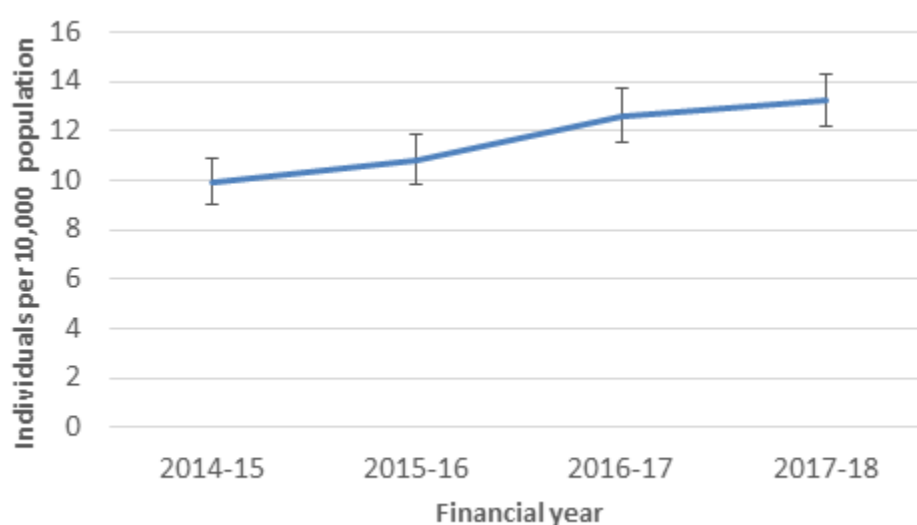
3.3 Cohort 1: Living Children and Young People with a Life-Limiting or Life-Threatening Condition

Supplementary tables including numbers of individuals and rates are shown in Appendix B.

3.3.1 Overall Trend

Fig. 6 Living individuals with a life-limiting or life-threatening condition per 10,000 population by financial year (Table B1).

NB. Individuals with multiple admissions across financial years are counted once in each financial year.



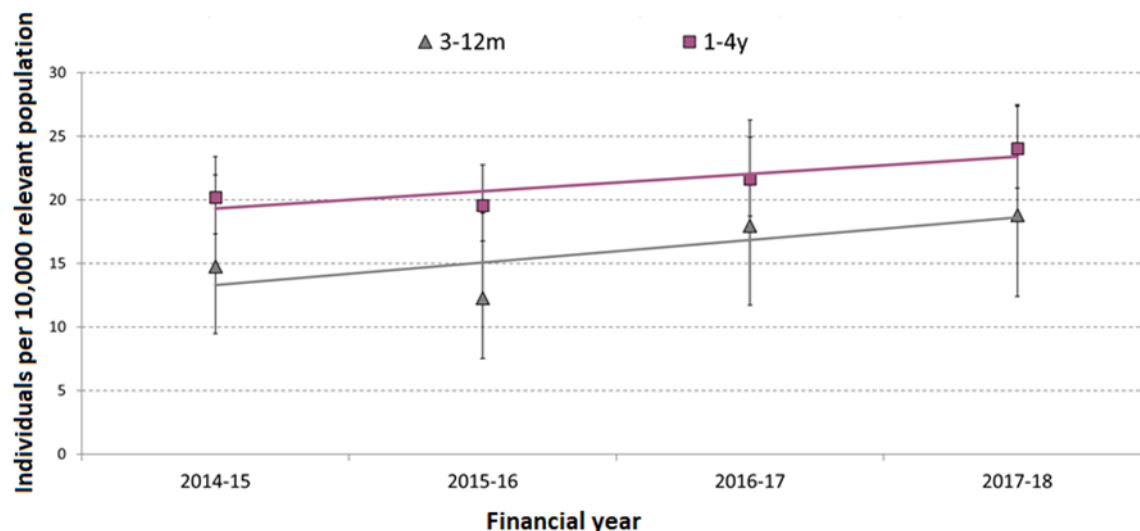
Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 1- key points:

- There were 1,415 living individuals with a LLC over the four financial years combined; there were 580 in 2017-18 alone.
- The rate of living individuals with a LLC has increased significantly since 2014-15.

Fig. 7 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population by age band and financial year (Table B2).

NB. Individuals with multiple admissions across different financial years are counted in each financial year.



3.3.2 Age

Fig. 8 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population, shown by age band and financial year (Table B2).

NB. Individuals with multiple admissions across different financial years are counted in each financial year.

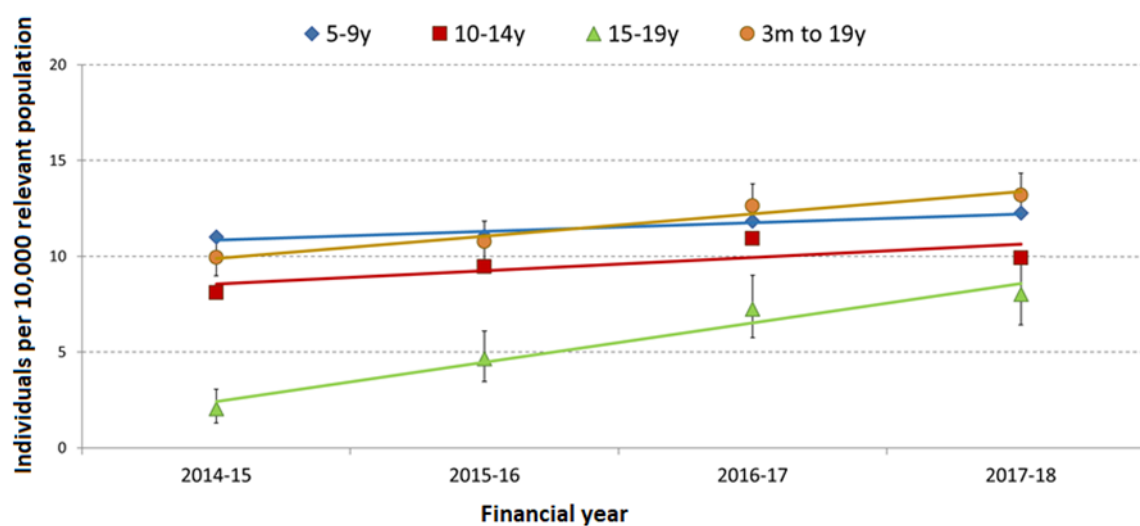
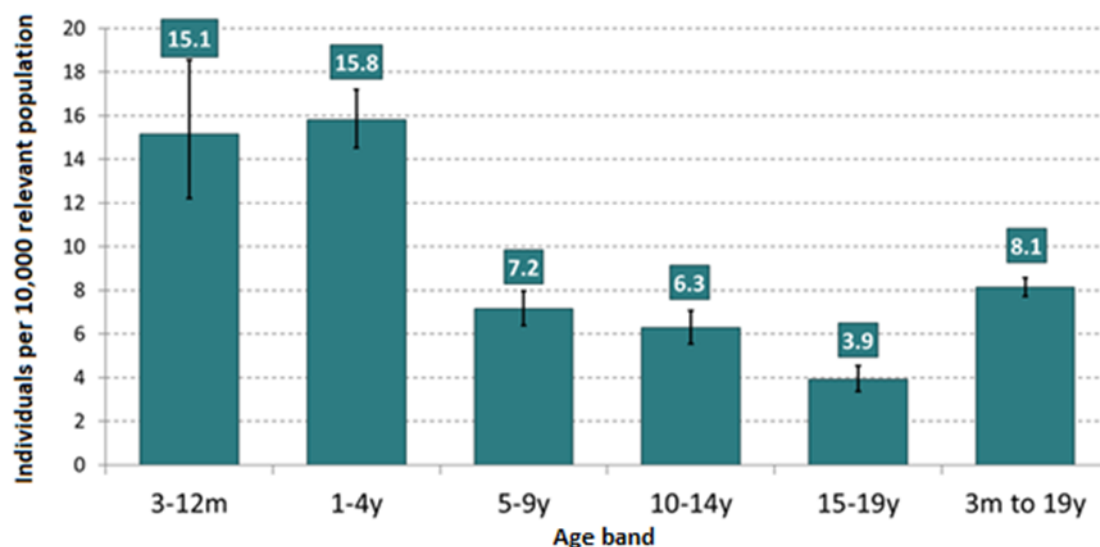


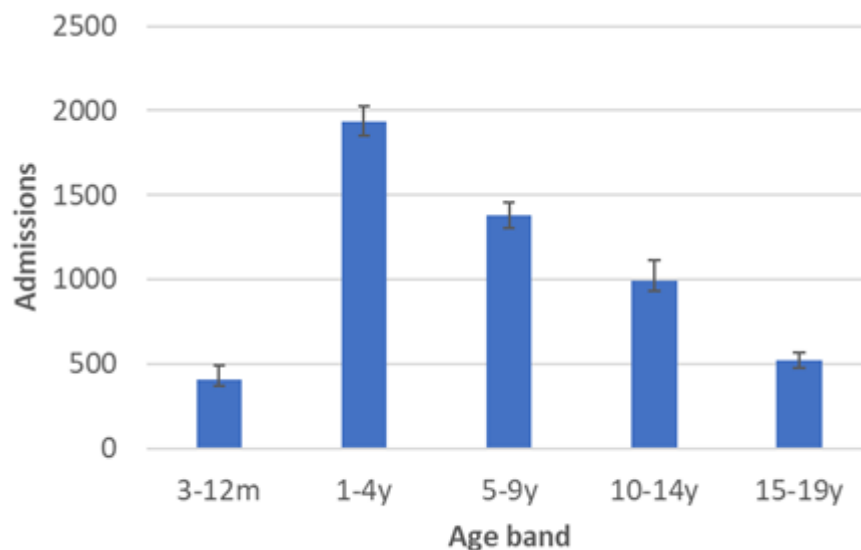
Fig. 9 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population from 2014-15 to 2017-18 (combined), shown by age band (Table B2).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 10 Kent and Medway hospital admissions of living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined), shown by age band (Table B6).

NB. Admissions at different ages are counted in each age band. Suppressed data has been omitted.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

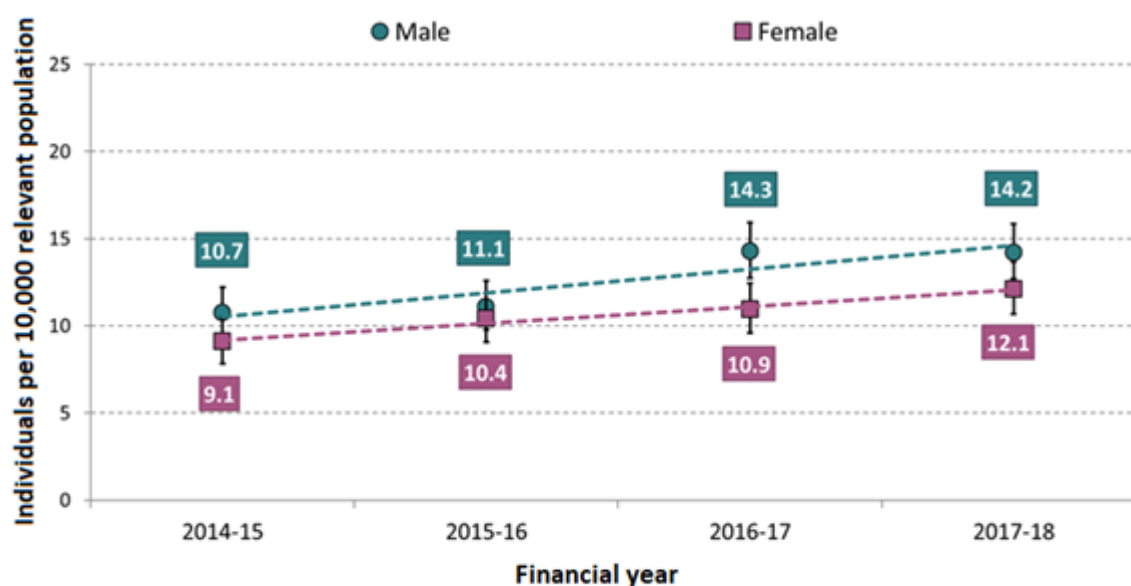
Box 2 - key points:

- Over the four financial years combined, the rate of living individuals with a LLC was significantly highest in the 1-4y age band, and significantly lowest in the 15-19y age band.
- The rate of living individuals with a LLC each year since 2014-15 was consistently highest in the 1-4y age band, and lowest in the 15-19y age band.
- The rate of living individuals with a LLC has increased in all age bands since 2014-15, with the greatest acceleration seen in the 15-19y age band.
- Living individuals aged 1-9 years had the greatest number of admissions

3.3.3 Gender

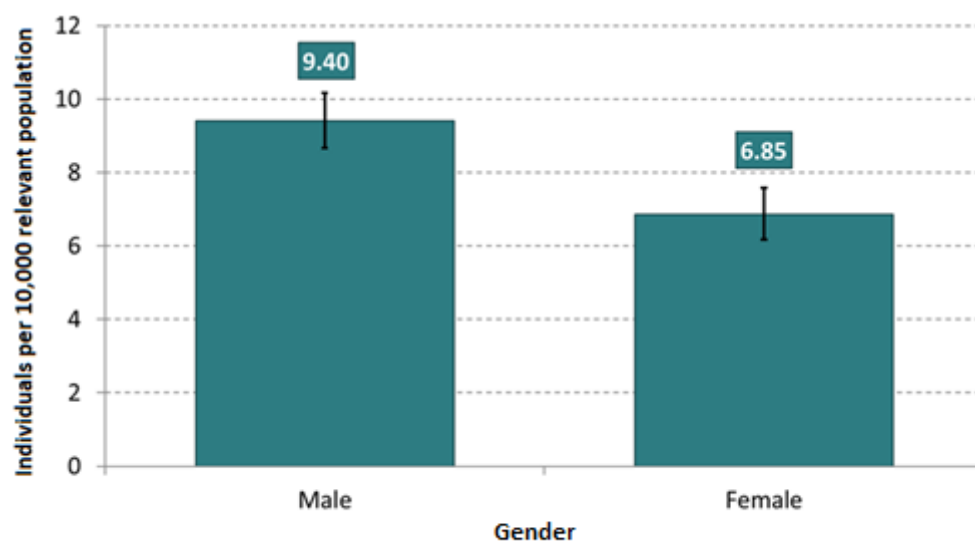
Fig. 11 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population by gender and financial year (Table B3).

NB. Individuals with multiple admissions across different financial years are counted in each financial year.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 12 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population from 2014-15 to 2017-18 (combined), shown by gender (Table B3).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

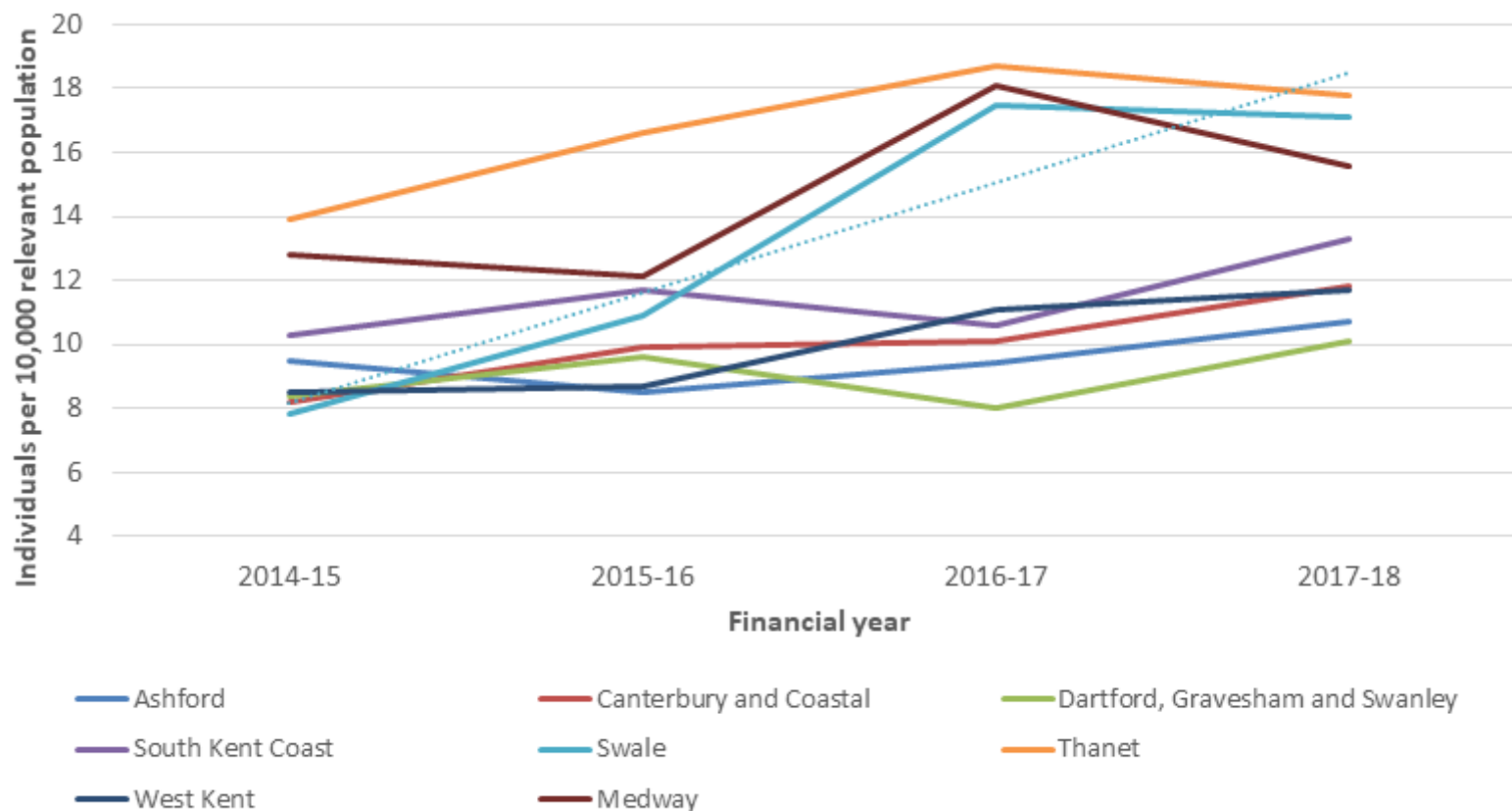
Box 3 - key points:

- The rate of living individuals with an LLC was significantly higher amongst males than females over the four financial years combined.
- The rates of living individuals with an LLC each year since 2014-15 have been consistently higher amongst males than females. This is only significant for 2016-17.
- The rates of living individuals with an LLC have increased amongst males and females since 2014-15, with a greater acceleration seen amongst males.

3.3.4 Clinical Commissioning Group

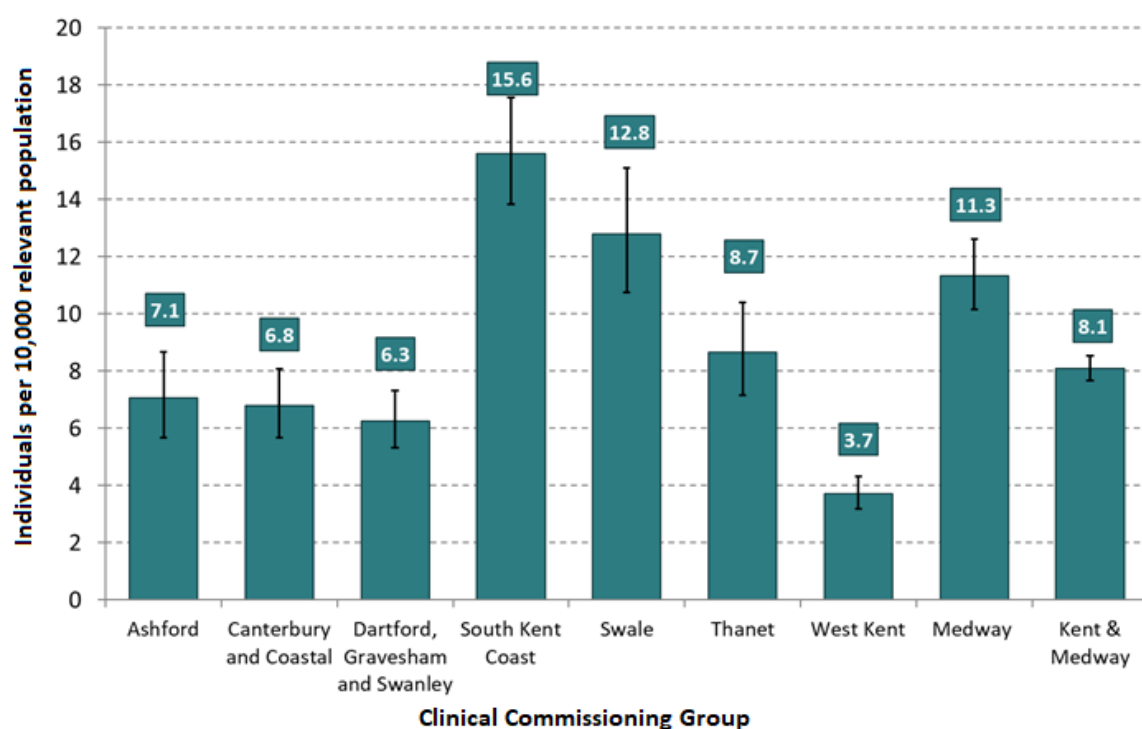
Fig. 13 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population by Clinical Commissioning Group and financial year (Table B4). A trendline for Swale is shown.

NB. Individuals with multiple admissions across different financial years are counted in each financial year



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 14 Living individuals with a life-limiting or life-threatening condition per 10,000 total population from 2014-15 to 2017-18 (combined), shown by Clinical Commissioning Group (Table B4)



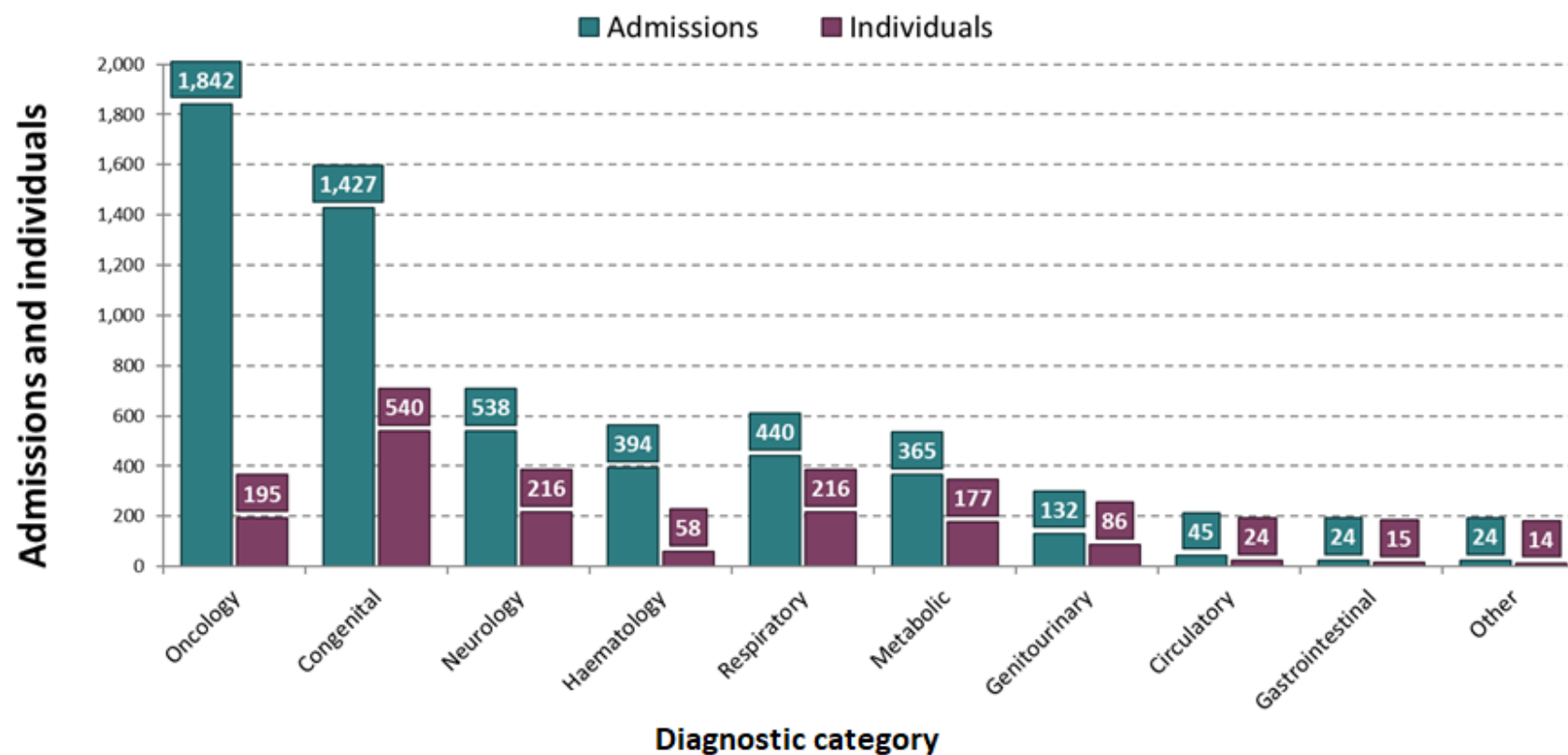
Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb-19

Box 4 - key points:

- The highest rates of living individuals with an LLC each year since 2014-15 are seen in Thanet. The highest rates since 2016-17 are seen in Swale, Thanet and Medway. Rates in these areas have been higher than K&M since 2015-16.
- The rates of living individuals with an LLC have generally increased across all CCGs since 2014-15, with the greatest acceleration seen in Swale.
- Over the four financial years combined, the rates of living individuals with an LLC is significantly highest in South Kent Coast, Swale and Medway, and significantly lowest in West Kent.

3.3.5 Diagnostic Category

Fig. 15 Living individuals with a life-limiting or life-threatening condition and admissions to a Kent and Medway hospital from 2014-15 to 2017-18 (combined), shown by diagnostic category (Tables B5 and B6).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb-19

Table 3 Admissions per living individual with a life-limiting or life-threatening condition to a Kent and Medway hospital from 2014-15 to 2017-18 (combined), shown by diagnostic category and age band. *Suppressed data

NB. Admissions at different ages are counted in each age band. Individuals with more than one LLC are counted in each relevant diagnostic category

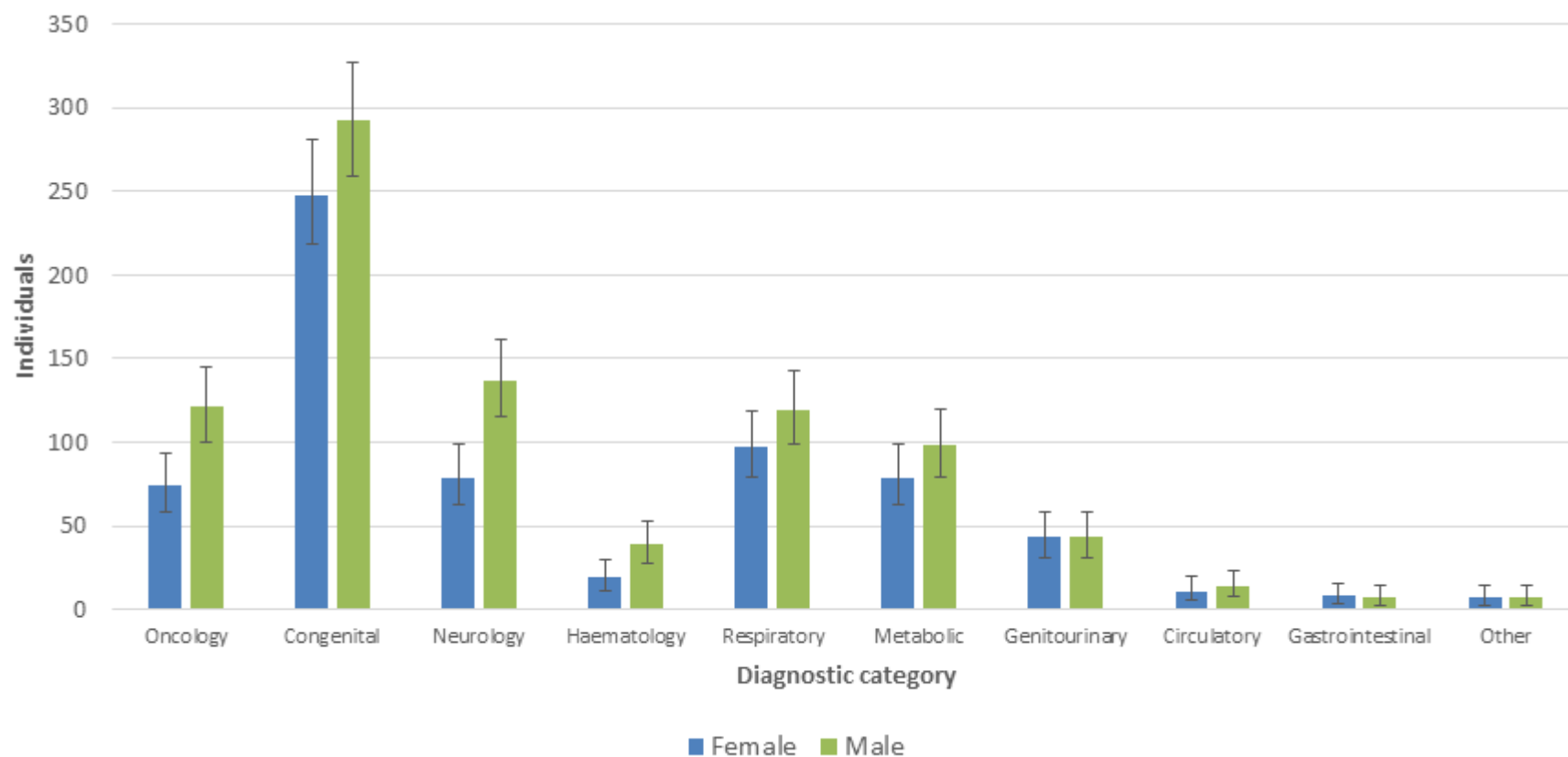
Age band	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Circulatory	Gastrointestinal	Other	Total
3-12m	2.2	1.6	1.7	3.7	1.4	1.6	1.0	1.0	0.0	3.0	1.6
1-4y	5.5	2.1	2.2	2.5	1.4	1.7	1.2	1.5	1.1	2.0	2.5
5-9y	4.4	1.9	1.6	4.1	1.3	1.5	1.3	1.0	1.0	1.2	2.5
10-14y	4.5	1.9	1.5	4.4	1.4	1.5	1.2	1.0	1.8	1.3	2.3
15-19y	3.5	1.5	1.3	9.8	1.5	1.5	1.8	2.0	1.4	1.3	2.2
Admissions: Individuals	9.4	2.6	2.5	6.8	2.0	2.1	1.5	1.9	1.6	1.7	3.4

Box 5- key points:

- Amongst living individuals with a LLC over the four financial years combined, the most common conditions were congenital; the least common conditions were circulatory, gastrointestinal and other.
- Living individuals with oncological and haematological LLCs had the greatest number of admissions per person over the four financial years combined; those with genitourinary, gastrointestinal and other LLCs had the least number of admissions per person.
- Amongst living individuals with an oncological LLC, those in the 1-4y age band had the greatest number of admissions per person. Amongst living individuals with a haematological LLC, those in the 15-19y age band had the greatest number of admissions per person.
- Living individuals in the 1-4y age band were most likely to be admitted for an oncological condition, in the 5-14y age band were most likely to be admitted for an oncological or haematological condition, and in the 15-19y age band were overwhelmingly most likely to be admitted for a haematological condition.

Fig. 16 Living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and gender (Table B7)

NB. Individuals with more than one condition are counted in each relevant diagnostic category.

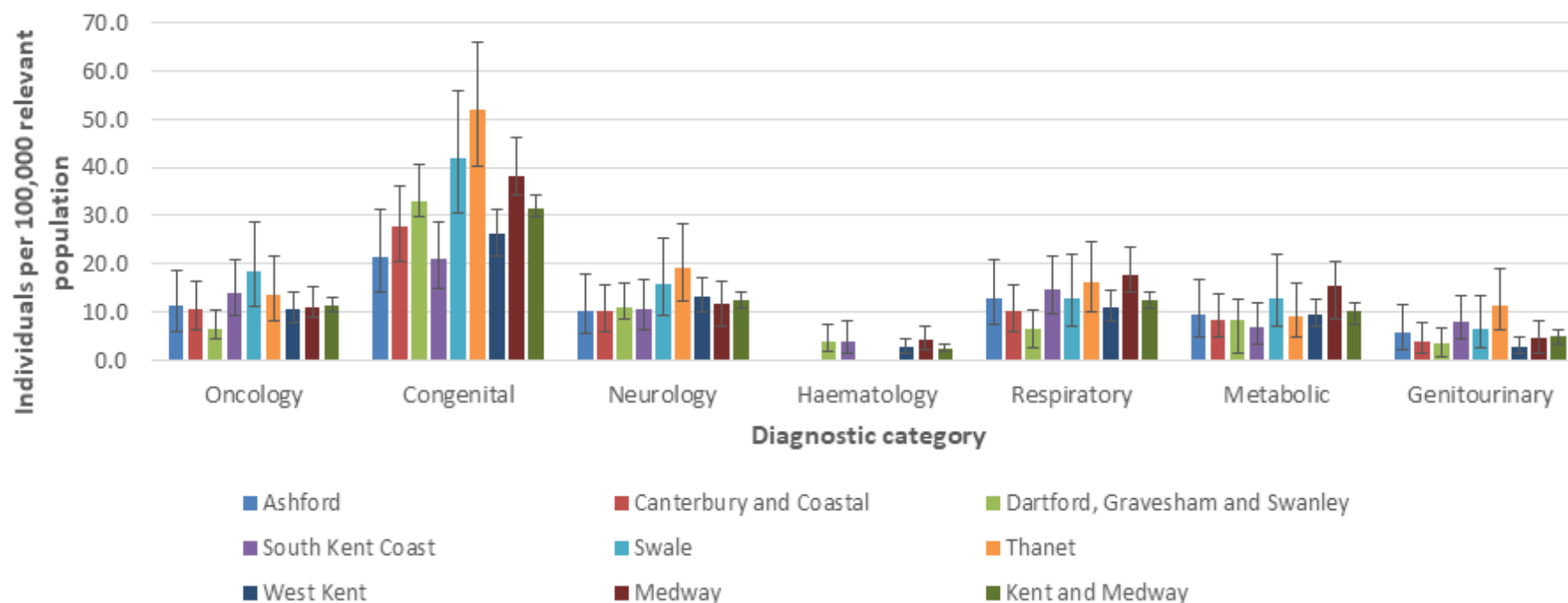


Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 6 - key point:

- Over the four financial years combined, there were more living males than females with LLCs across all diagnostic categories, except genitourinary, gastrointestinal and other. This difference was significant for oncological and neurological conditions.

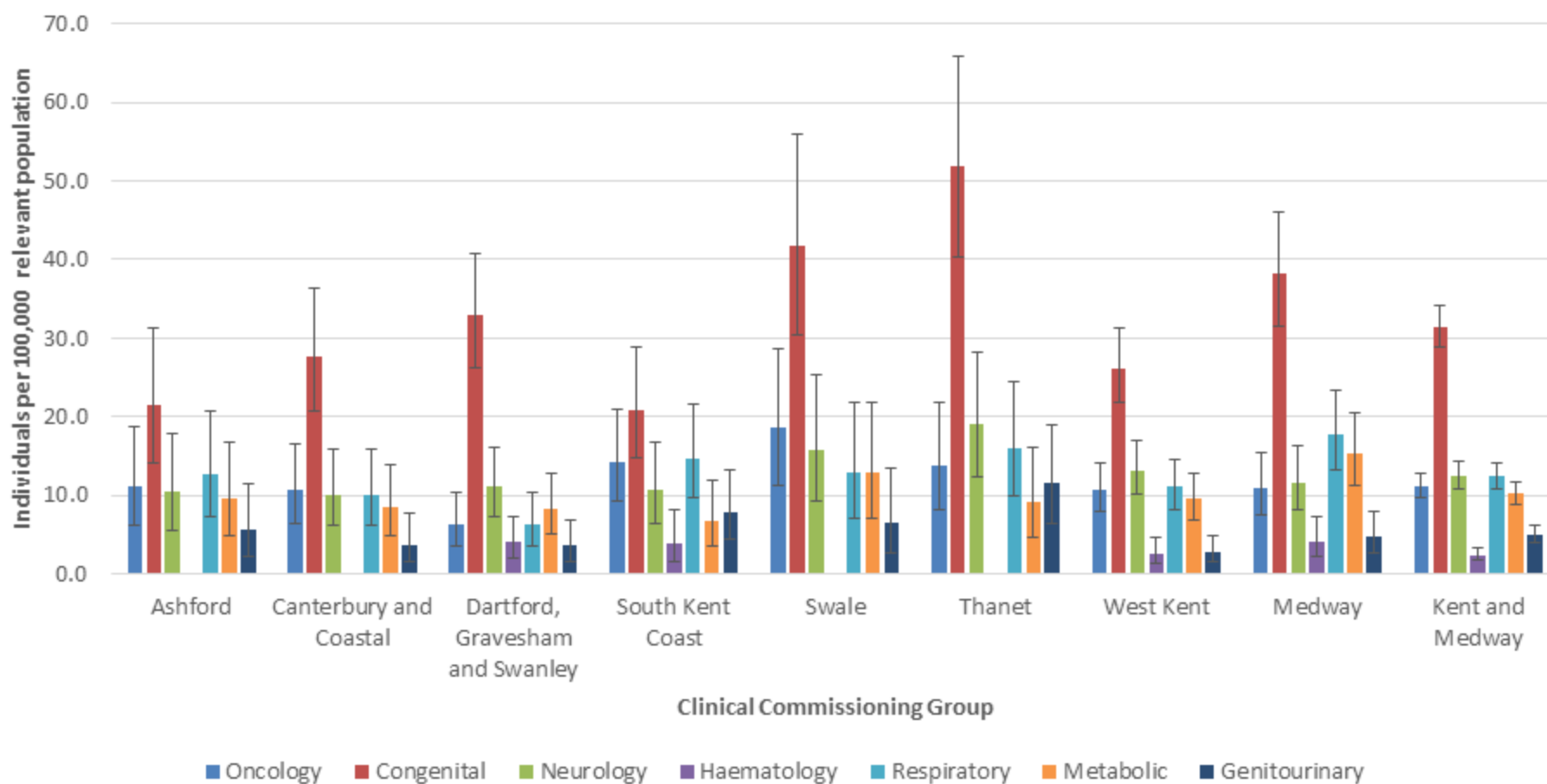
Fig. 17 Living individuals with a life-limiting or life-threatening condition per 100,000 relevant population from 2014-15 to 2017-18 (combined), shown by diagnostic category and Clinical Commissioning Group (Table B9). Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Individuals with more than one condition are counted in each relevant diagnostic category. Only individuals with a coded CCG are included. Individuals who moved CCG are counted in each CCG area.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 18 Living individuals with a life-limiting or life-threatening condition per 100,000 relevant population from 2014-15 to 2017-18 (combined), shown by diagnostic category and Clinical Commissioning Group (Table B9).

NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Individuals with more than one condition are counted in each relevant diagnostic category. Only individuals with a coded CCG are included. Individuals who moved CCG are counted in each CCG area



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Table 4 Admissions per living individual with a life-limiting or life-threatening condition to a Kent and Medway hospital from 2014-15 to 2017-18 (combined), shown by diagnostic category and Clinical Commissioning Group. *Suppressed data

NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Individuals with more than one condition are counted in each relevant diagnostic category. Only individuals with a coded CCG are included. Individuals who moved CCG are counted in each CCG area.

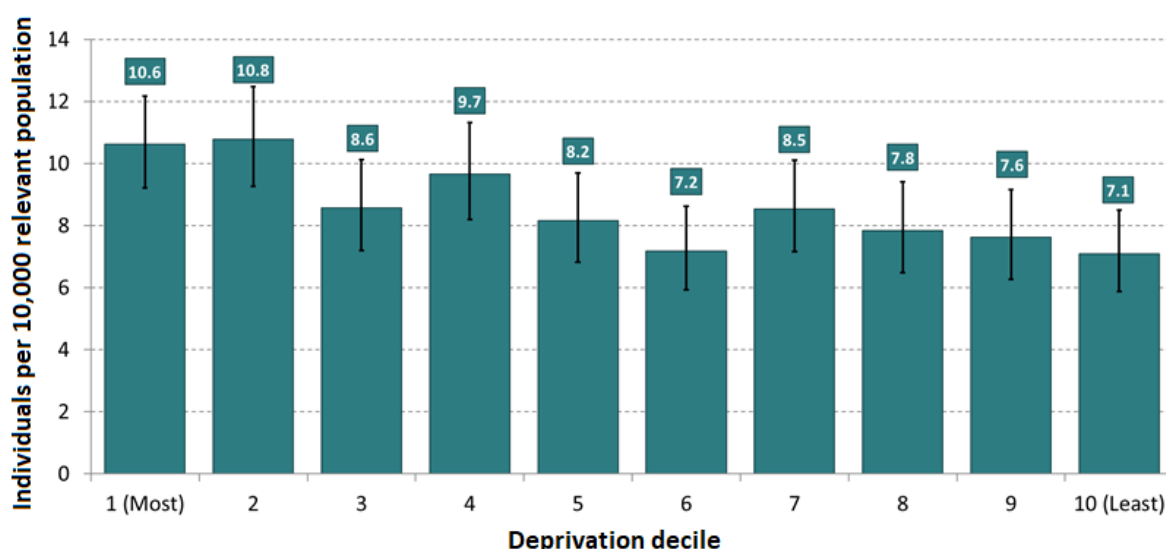
Clinical Commissioning Group	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Total
Ashford	7.3	1.8	2.8	*	1.9	1.2	1.7	3.2*
Canterbury and Coastal	11.8	2.8	1.8	*	1.9	1.7	1.3	4.2*
Dartford, Gravesham and Swanley	5.0	3.9	2.9	11.3	1.3	2.0	1.4	3.7
South Kent Coast	11.0	2.2	2.4	3.4	2.5	1.5	1.1	3.7
Swale	11.7	2.2	2.1	*	1.9	2.4	2.0	3.9*
Thanet	9.3	2.5	3.3	*	2.0	1.7	2.3	3.2*
West Kent	8.3	2.6	2.0	2.5	1.8	2.6	1.3	3.1
Medway	10.7	2.1	2.9	8.0	2.3	2.1	1.4	3.4

Box 7- key points:

- Over the four financial years combined, there were more living individuals with a congenital LLC in each CCG than any other condition. This was significant in Canterbury and Coastal, DGS, Swale, Thanet, West Kent and Medway.
- The highest rates of living individuals with a congenital LLC over the four financial years combined are seen in Thanet, followed by Swale and Medway. The rates in Thanet were significantly higher than K&M.
- The highest rates of living individuals with an oncological LLC over the four financial years combined are seen in Swale. The rates in Swale were only significantly higher than in DGS.
- Admissions per person for oncological LLCs are highest in Canterbury and Coastal, Swale, South Kent Coast and Medway. Admissions per person for haematological LLCs are significantly highest in DGS.

3.3.6 Deprivation

Fig. 19 Living individuals with a life-limiting or life-threatening condition per 10,000 relevant population from 2014-15 to 2017-18 (combined), shown by deprivation decile (Table B11).



Source: Kent Integrated Dataset. Prepared by KPHO (MP) Jan 2019

Box 8- key point:

- The rate of living individuals with a LLC over the four financial years combined was significantly higher amongst those in the most deprived decile than the least deprived decile.

3.4 Cohort 2: Deceased Children and Young People with a Life-Limiting and Life-Threatening Condition

Supplementary tables including numbers of individuals and rates are shown in Appendix C.

3.4.1 Overall Trend

Fig. 20 Death rates per 100,000 relevant population from a life-limiting or life-threatening condition by calendar year of registration (Table C1).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

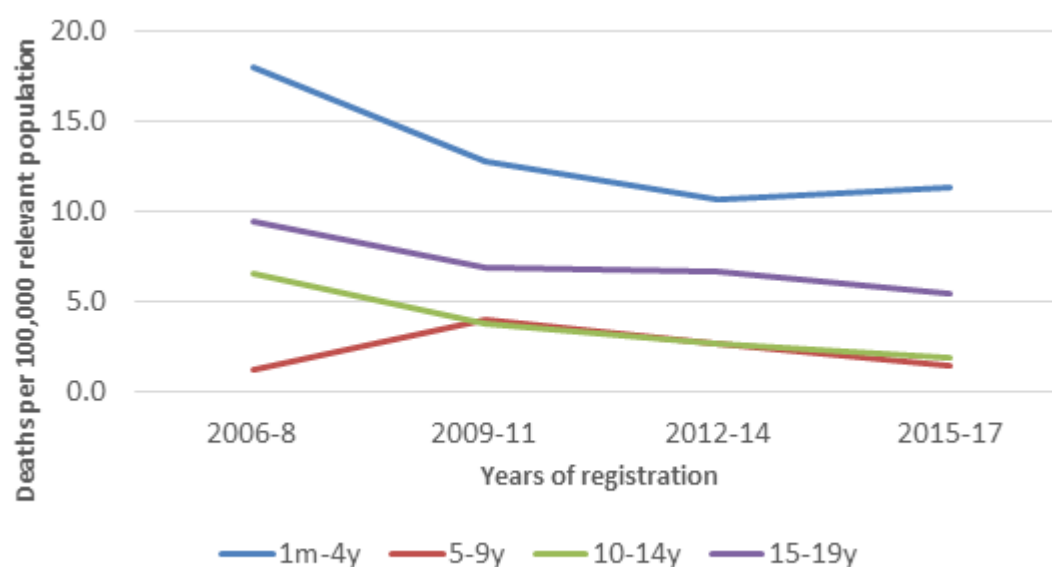
Box 9- key point:

- 279 C&YP died from or with a LLC between 2006 and 2017; 59 died in 2015-17.
- Death rates from LLCs have been decreasing since 2008.

3.4.2 Age and Cause of Death

Fig. 21 Death rates per 100,000 relevant population from a life-limiting or life-threatening condition by age band and calendar year of registration (Table C2).

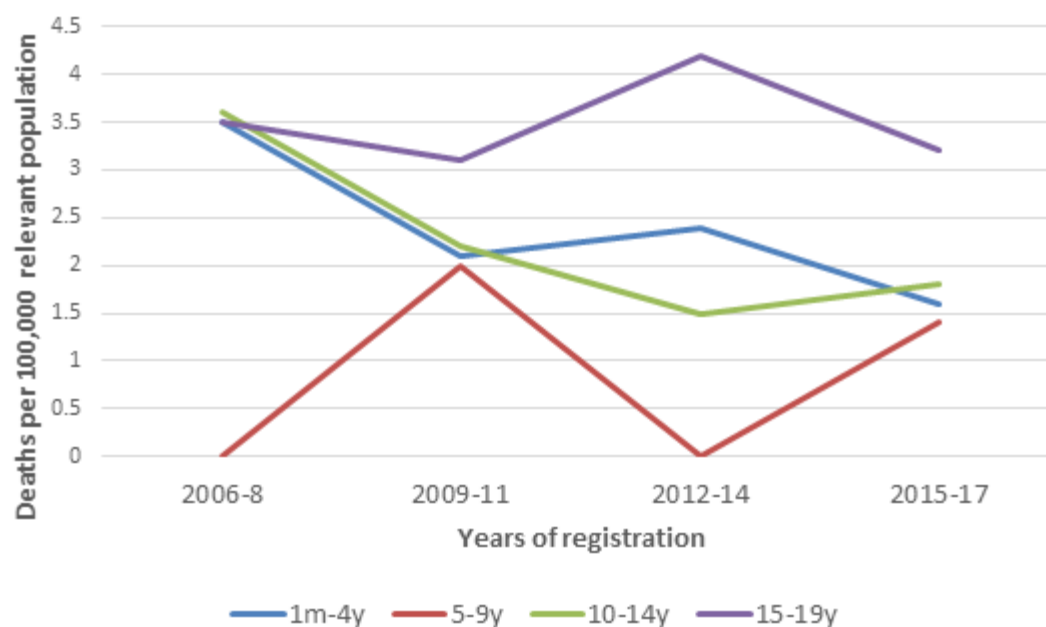
NB. Suppressed data not included



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 22 Death rates from cancer per 100,000 relevant population by age band and calendar year of registration (Table C2).

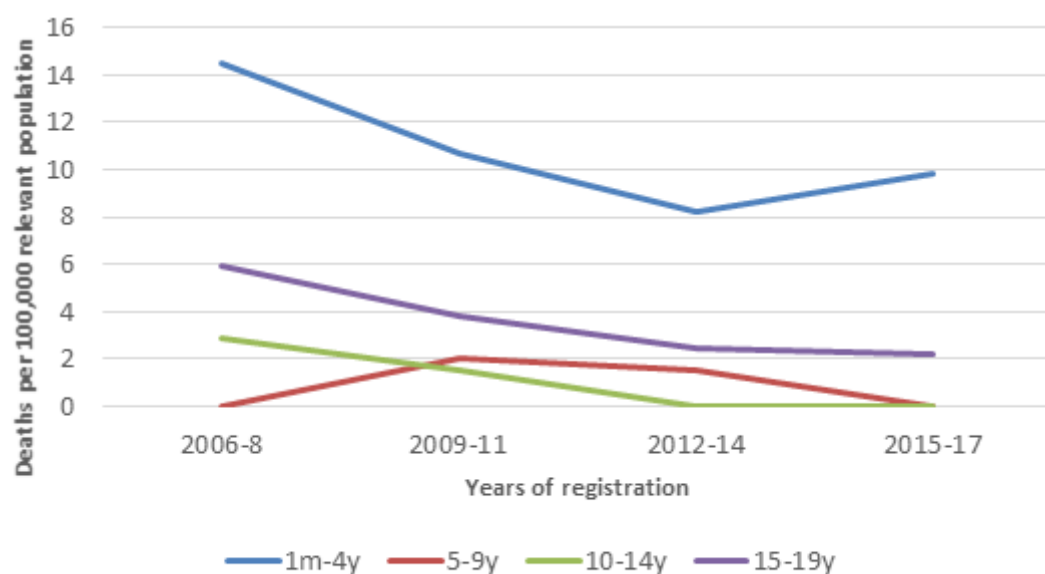
NB. Deaths in the 5-9y age band were <4 and have been suppressed.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

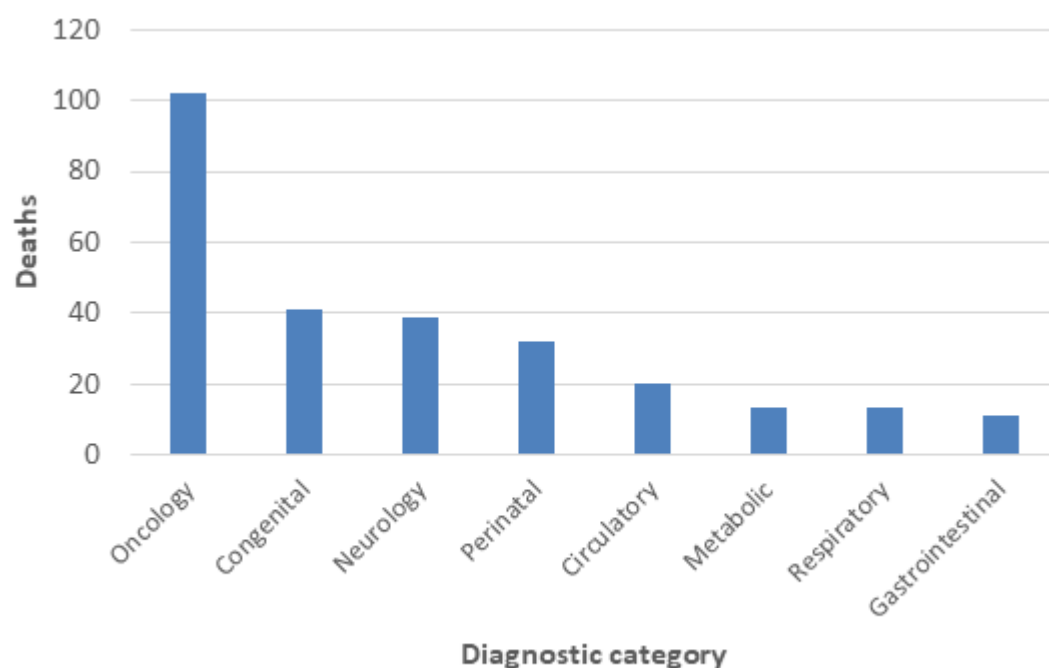
Fig. 23 Death rates from non-cancer per 100,000 relevant population by age band and calendar year of registration (Table C2).

NB. Deaths in the 5-9y and 10-14y age bands were <4 and have been suppressed.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 24 Deaths from a life-limiting or life-threatening condition from 2006-8 to 2015-17 (combined) by diagnostic category (Table C3). *Suppressed data <4



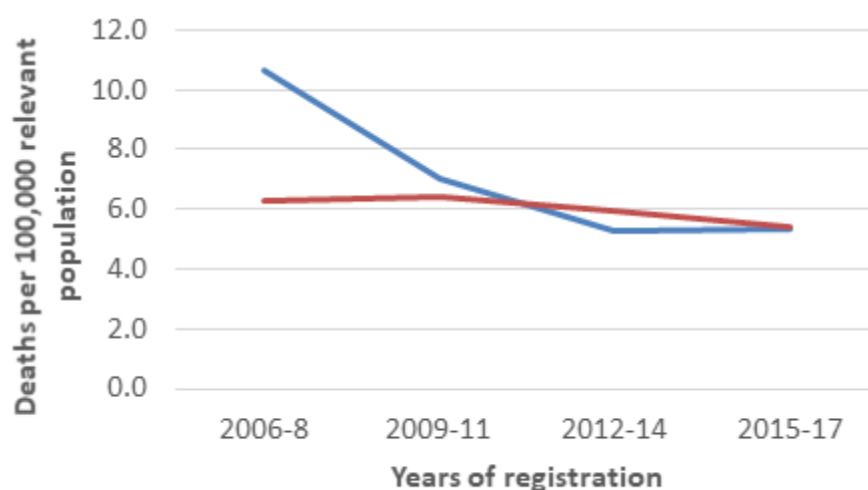
Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 10 - key points:

- Death rates from LLCs have been generally decreasing in all age bands since 2008.
- The highest death rates from LLCs since 2008 are seen in the 1m-4y age band, followed by 15-19y age band.
- The majority of deaths from LLCs from 2006 to 2017 combined were from cancer. Haematological, genitourinary and other conditions caused the fewest number of deaths.
- The highest death rates from cancer since 2011 are seen in the 15-19y age band.
- The highest death rates from non-cancer are seen in the 1m-4y age band across all years.

3.4.3 Gender

Fig. 25 Death rates per 100,000 relevant population from a life-limiting or life-threatening condition by gender and calendar year of registration (Table C4).



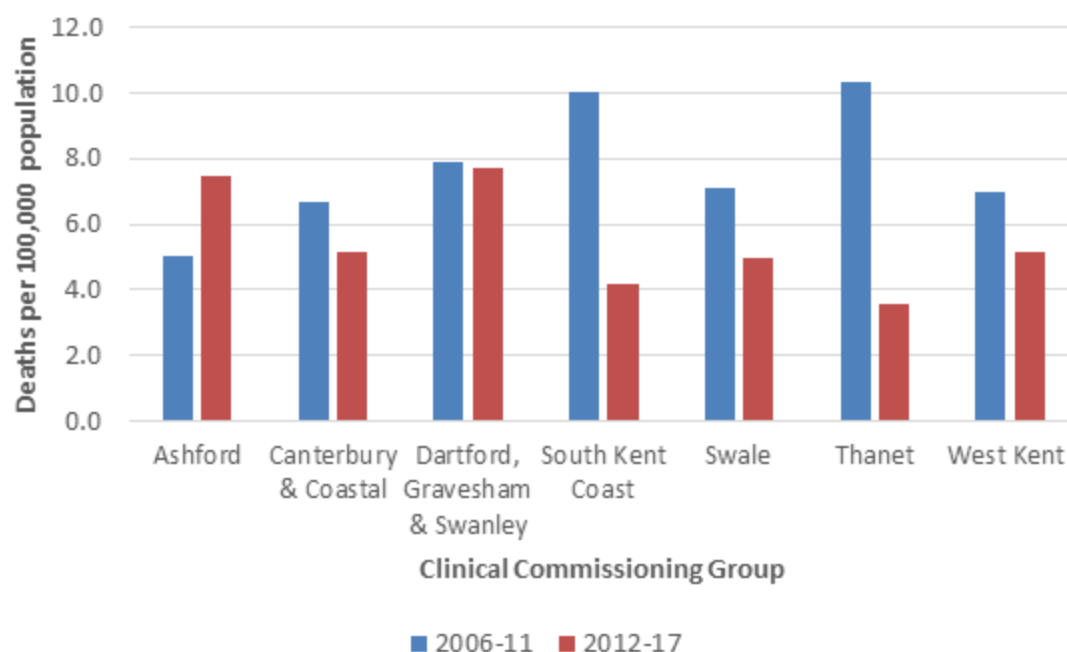
Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 11- key points:

- There were more deaths from LLCs amongst males than females from 2006 to 2017.
- The death rate from LLCs amongst males has steadily decreased since 2008 to approximately equal the death rate of females.

3.4.4 Clinical Commissioning Group

Fig. 26 Death rates per 100,000 relevant population from a life-limiting or life-threatening condition by Clinical Commissioning Group and calendar year of registration (Table C5).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 12 - key points:

- In 2012-17, the highest death rates from LLCs were seen in Ashford and DGS. Rates in both CCGs were higher than that of Kent.
- There was a decline in death rates from LLCs from 2006-11 to 2012-17 in the majority of CCGs. A more significant decline is seen in South Kent Coast and Thanet.
- The only increase in death rates from LLCs from 2006 to 2017 is seen in Ashford.

3.4.5 Deprivation

Fig. 27 Death rates per 100,000 relevant population from a life-limiting or life-threatening condition by deprivation decile and calendar year of registration (Table C6).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

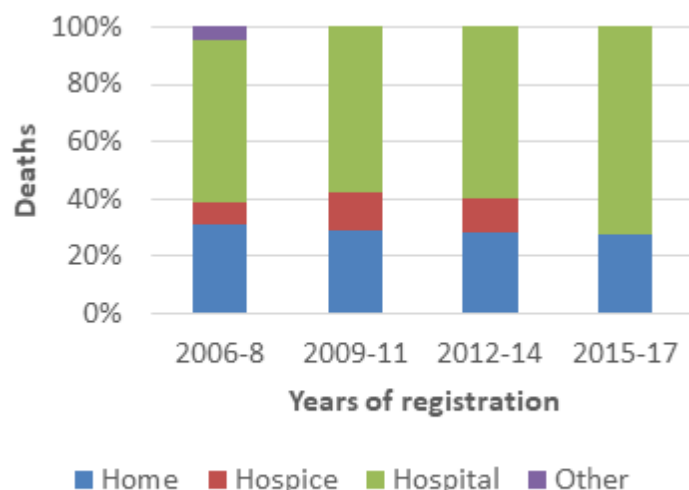
Box 13 - key points:

- In 2006-2017, the deaths rates from LLCs were higher amongst those in the most deprived decile than the least deprived decile.
- Death rates from LLCs have been consistently higher amongst those in the most deprived decile than the least deprived decile since 2008.
- The gap between the most and least deprived deciles narrowed in 2012-14, owing to a decrease in the death rate from LLCs amongst those in the most deprived decile.

3.4.6 Location of Death

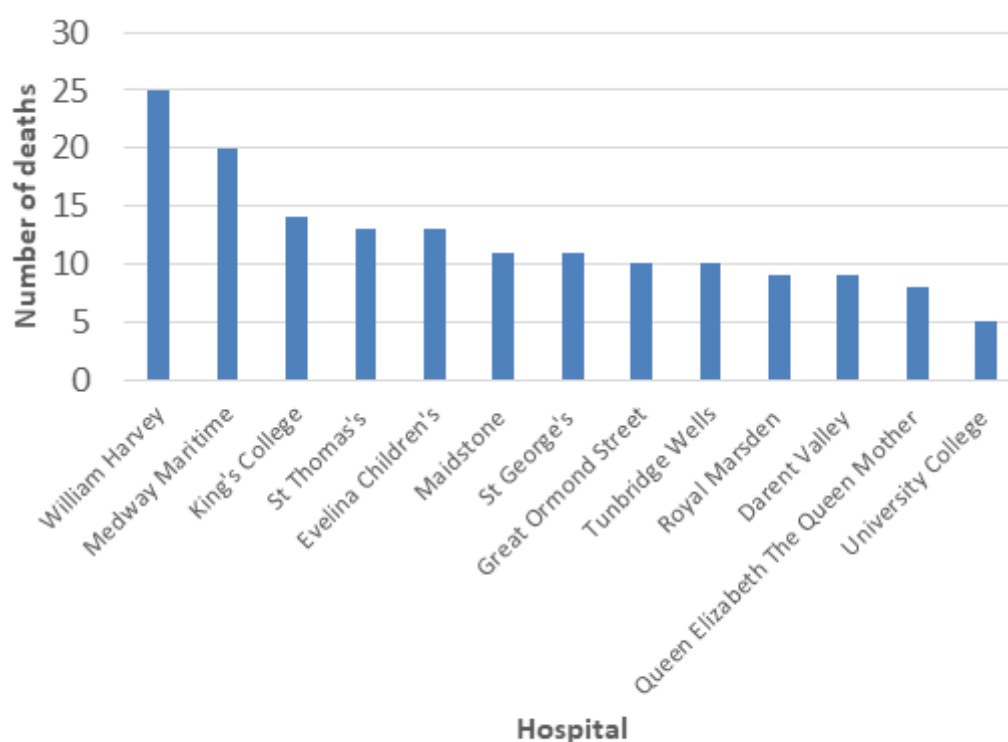
Fig. 28 Deaths from a life-limiting or life-threatening condition by location and calendar year of registration (Table C7).

NB. Hospice deaths in 2015-17 were <4 and have been suppressed.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Fig. 29 London, Kent and Medway hospital deaths from a life-limiting or life-threatening condition by location from 2006-8 to 2015-17 (combined) (Table C8).



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Box 14 - key points:

- There has been a general increase in hospital deaths from LLCs since 2008.
- There has been a general decline in hospice deaths from LLCs since 2011.
- The majority of hospital deaths from LLCs since 2008 have been in K&M hospitals. The majority of these were at William Harvey and Medway Maritime Hospitals.
- The majority of hospital deaths from LLCs since 2008 in London have been at King's College, St. Thomas's and Evelina Children's Hospitals.

4 Projection of Need

From 2014 to 2018 the K&M population of 0-19-year-olds increased by 3.3%²³. This population is projected to grow by 6% over the next five years [Table 5]. If a constant rate of LLCs is assumed from 2017-18 onwards, the projected number of individuals with an LLC in 2023-24 is 622 (Table 5, Fig. 30). Owing to the yearly increase in rate over the four-year period, this is likely to be an underestimate.

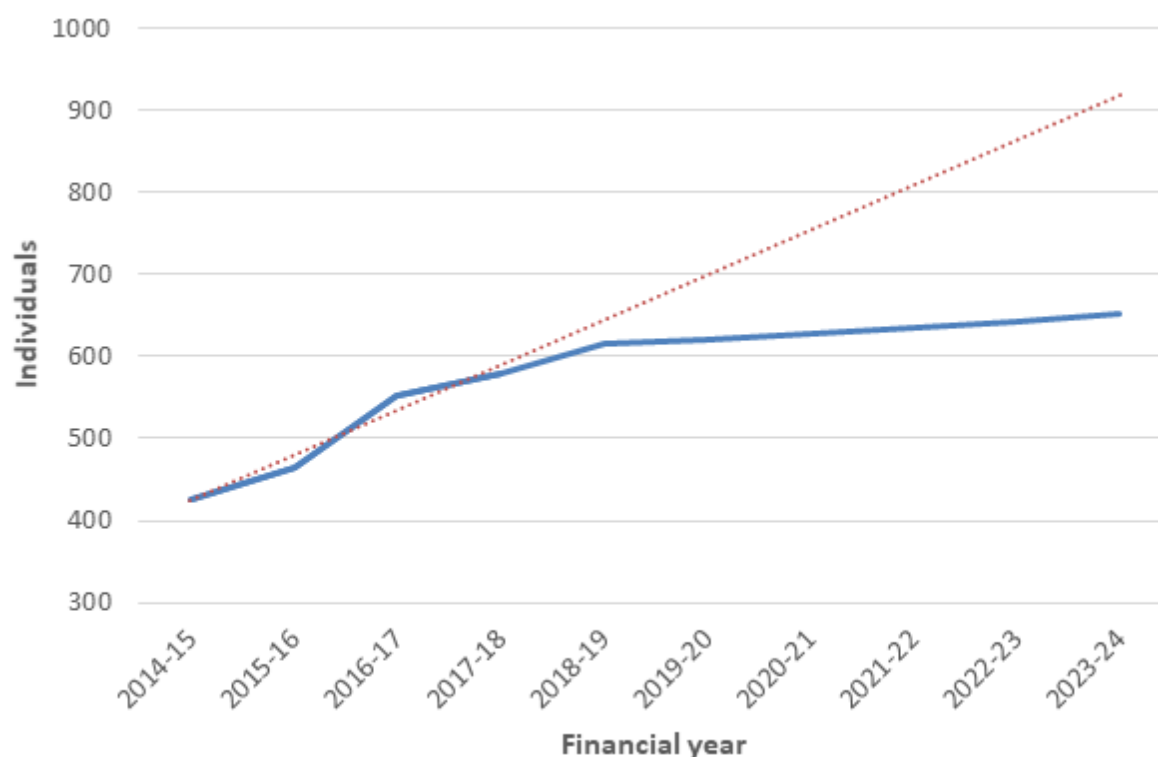
Table 5 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in Kent and Medway by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Population data from the Office for National Statistics²¹. Individuals projections post-2017-18 are 0-19y. Assumes a constant rate post-2017-18. Population projection data from the Kent County Council Housing Led Forecast²³.

Financial year	Individuals per 10,000 relevant population	% change	Population	Individuals
2014-15	9.9		430,303	426
2015-16	10.8	9.1	430,556	465
2016-17	12.6	16.7	438,889	553
2017-18	13.2	4.8	439,394	580
2018-19	13.2	0	445,900	589
2019-20	13.2	0	449,300	593
2020-21	13.2	0	454,400	600
2021-22	13.2	0	460,600	608
2022-23	13.2	0	465,800	615
2023-24	13.2	0	471,500	622

²³ Kent County Council Housing Led Forecasts, Oct 2018, <https://www.kent.gov.uk/about-the-council/information-and-data/Facts-and-figures-about-Kent/population-and-census#tab-3>

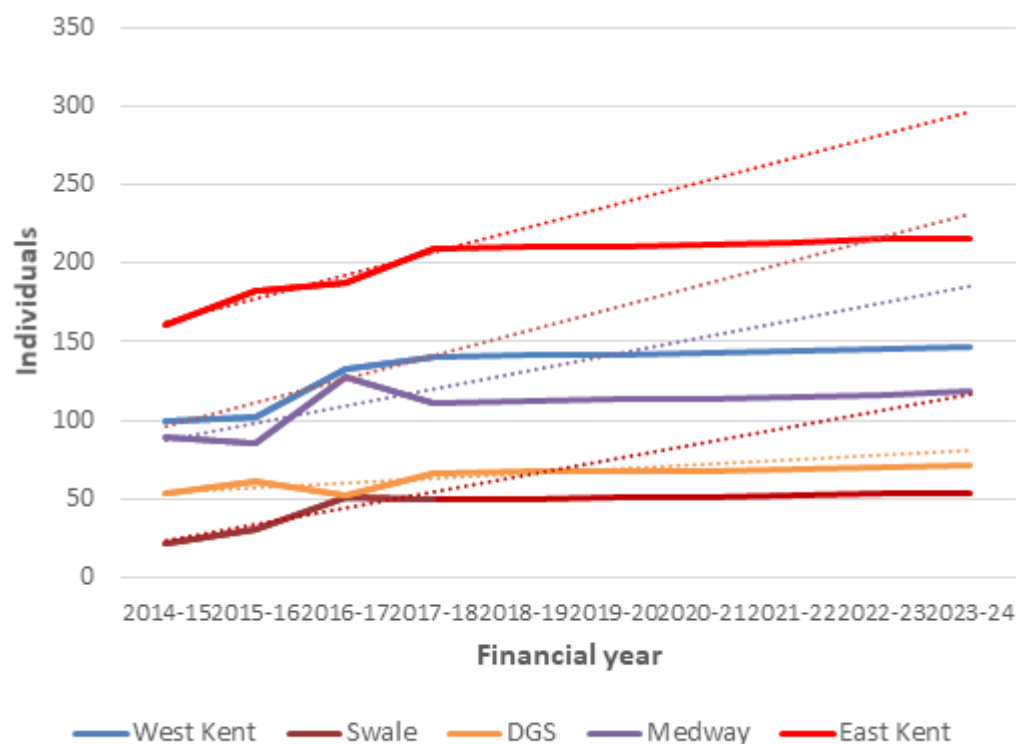
Fig. 30 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in Kent and Medway by financial year if rates in 2017-18 were to remain constant (Table 5). Trendline shows projections if the trend from 2014-15 to 2017-18 were to continue.



Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

Population projections for each commissioning area have been similarly estimated using Office for National Statistics (ONS) data (Fig. 31, Tables D1 to D5). If the rate in 2017-18 were to remain constant, the greatest percentage increase in individuals with a LLC would be seen in DGS and Swale (6%). The number of individuals with a LLC in each area could, however, be much larger if trends were to continue.

Fig. 31 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in each commissioning area by financial year if rates in 2017-18 were to remain constant (Tables D1 to D5). Trendlines show projections if trends between 2014-15 and 2017-18 were to continue.

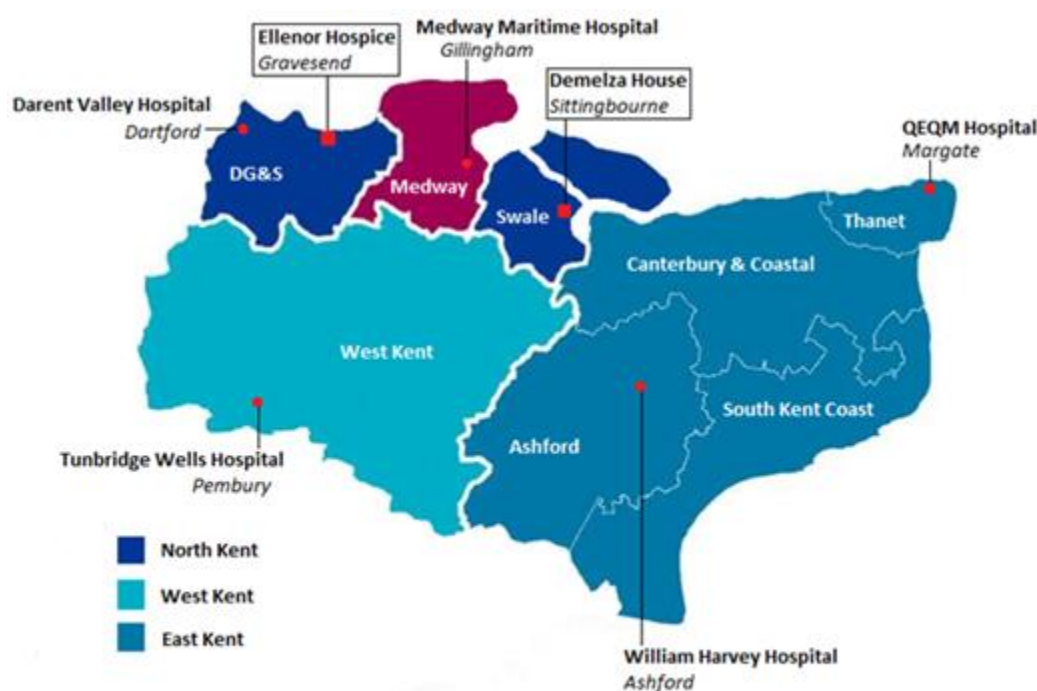


Source: Kent Integrated Dataset, prepared by KPHO (MP), Feb 2019

5 Service Provision

Kent is a large county with seven CCGs and four commissioning areas: North (DGS and Swale), East and West Kent (Fig. 32). Medway is also a standalone CCG. Each of these areas have varying populations and needs with different EOLC providers and commissioning arrangements.

Fig. 32 Map of Kent and Medway Clinical Commissioning Groups, hospices, and hospitals providing inpatient end of life care, adapted from²⁴. *DGS Dartford, Gravesham and Swanley; QEQM Queen Elizabeth Queen Mary



Source: adapted from <https://www.england.nhs.uk/digitaltechnology/wp-content/uploads/sites/31/2016/04/sth-east-map-v2.jpg> December 2018

Within K&M, there are four NHS trusts across five hospital sites, which accept acute admissions for C&YP, listed below:

- Maidstone Tunbridge Wells NHS Trust (Tunbridge Wells Hospital, Pembury)
- Dartford and Gravesham NHS Trust (Darent Valley Hospital, Dartford)
- Medway NHS Foundation Trust (Medway Maritime Hospital, Gillingham)
- East Kent Hospitals University NHS Foundation Trust (William Harvey Hospital, Ashford and Queen Elizabeth Queen Mary Hospital, Margate)

²⁴ <https://www.england.nhs.uk/digitaltechnology/wp-content/uploads/sites/31/2016/04/sth-east-map-v2.jpg>

These hospitals provide varying levels of care on paediatric wards, High-Dependency Units (HDU), Neonatal Intensive Care Units (NICU) and Special Care Baby Units (SCBU). A summary of levels of care is shown below:

- Level 0- for patients whose needs can be met through normal ward care.
- Level 1- for patients at risk of deterioration, or those recently stepped-down from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team.
- Level 2- for patients requiring more detailed observation or intervention, including support for a single failing organ system, post-operative care and those recently stepped-down from higher levels of care.
- Level 3- for patients requiring advanced respiratory support alone, or monitoring and support for two or more organ systems, including multi-organ failure.

Level 1 care for neonates, infants and children is provided on HDU. Level 2 or 3 care for critically ill neonates is provided on NICU. SCBU teams generally provide care for babies who are premature (born at 34 weeks to term) or have a less serious illness. They offer varying levels of critical care and will stabilise a baby's condition before transferring him/her to another unit or provide emergency care, if necessary. Level 2 or 3 care for critically ill children is provided on Paediatric Intensive Care Unit (PICU), however there are no PICUs in K&M and children requiring higher levels of care are transferred to South London trusts as an emergency via the STRS. Significant delays of up to five hours have been reported, during which time a child may receive interim ventilation on the ward. Importantly, a child or young person requiring EOLC may require any level of care during their illness, whether it be level 3 support during an acute deterioration, or comfort care on a ward in his/her last hours or days. Levels of care provided at each hospital in K&M are outlined in more detail below.

There are multiple teams in K&M which provide care in the community to C&YP. When looking at commissioning arrangements, C&YP are broadly divided into three categories: C&YP requiring care at end of life, C&YP with a LLC who require palliative care but have not been formally identified as end of life, and C&YP with complex needs who are not expected to die prematurely in child services. These categories often overlap and C&YP move between categories according to clinical need. For the purposes of this Needs Assessment, we have included the main community providers which have C&YP who die in their care or as part of their caseload. There are two hospices offering inpatient care to C&YP and their families and five nursing teams providing care at home, listed below:

- Demelza Hospice (Sittingbourne)
- Ellenor Hospice (Gravesend) (rarely used by C&YP)
- Ellenor Community Team
- Maidstone and Tunbridge Wells Diana Nursing Team (DNT)
- Kent Community Health NHS Foundation Trust (KCHFT) CCNT
- Medway NHS Foundation Trust Children's Outreach and Specialist Team (COAST)

- Medway Community Healthcare (MCH) CCNT.

These community teams have varying organisational boundaries, and although not all are formally commissioned to provide EOLC, there is a significant overlap in caseloads and collaborative working between teams.

5.1 Acute Trusts

5.1.1 Maidstone and Tunbridge Wells NHS Foundation Trust

Tunbridge Wells Hospital in Pembury provides general and specialist inpatient paediatric care for C&YP aged 0-16 on Hedgehog Ward (23 beds), level 1 care on HDU and level 2 care for neonates on NICU (25 cots).

5.1.2 East Kent Hospitals NHS Foundation Trust

William Harvey Hospital in Ashford provides general inpatient paediatric care for C&YP on Padua Children's Ward, level 3 care for neonates on NICU (25 cots) and higher-level baby care on SCBU. QEQM in Margate provides general inpatient paediatric care for C&YP on Rainbow Ward and higher-level care on SCBU (14 cots, including 2 high-dependency).

5.1.3 Dartford and Gravesham NHS Trust

Darent Valley Hospital in Dartford offers general inpatient paediatric care for C&YP aged 0-16 on Willow Ward (22 beds) and higher-level baby care on SCBU (22 cots including 3 high-dependency). Darent Valley does not provide oncology care and C&YP resident in DGS will usually access oncology care at Medway Maritime Hospital.

5.1.4 Medway NHS Foundation Trust

Medway Maritime Hospital in Gillingham provides general inpatient paediatric care to C&YP aged 0-17 on Dolphin and Penguin Wards (23 beds), level 1 paediatric critical care (with some level 2 work which is not funded by NHSE), level 2 care on NICU and higher-level baby care on Oliver Fisher SCBU (26 cots).

5.1.5 Specialist Paediatric Palliative Care Teams

The majority of C&YP with an LLC in K&M are looked after by a SPPCT at either Evelina London Children's Hospital (Guy's and St. Thomas's NHS Foundation Trust), Great Ormond Street Children's Hospital (GOSH), the Royal Marsden Hospital and the Royal Brompton Hospital. The majority of C&YP with oncological conditions are looked after by the Royal Marsden and GOSH.

5.2 Community Care and Commissioning Arrangements

5.2.1 West Kent

West Kent CCG (WKCCG) is the largest standalone CCG by total population, with 120,000 resident C&YP, 140 of whom were estimated to have an LLC in 2017-18 (Table B4)²¹. WKCCG have commissioning arrangements with the Ellenor Community Team and the DNT and

these teams work in collaboration due to an overlap in caseloads. Their commissioning arrangements are outlined below:

- Ellenor Community Team- receives a grant to deliver the following (as per their service specification):
 - A flexible 9am-5pm Monday to Friday specialist nursing service for C&YP 0-19 years-old with an LLC, involving an MDT approach
 - 24/7 on-call specialist advice service for palliative and end of life care, including practical end of life care, as required
 - high-quality, effective, and equitable care closer to home/at home
 - reduce emergency admissions and facilitate as early a discharge as possible
 - offer high-quality, evidence-based information to support C&YP and families to make informed choices and actively participate in their care
 - offer C&YP and families access to 24/7 specialist support at end of life
 - offer C&YP and families choice about place of death
 - high-quality bereavement support for families and carers
 - training and advice for C&YP and parents and carers on management of their condition(s)
 - high-quality staff education and training programmes
 - an integrated and flexible service which promotes and co-ordinates care
 - support the development of current or new clinical networks for C&YP with LLC.

This grant is used to fund one Whole Time Equivalent (WTE) nurse specialist. Although Ellenor Hospice in Gravesend has capacity to provide inpatient care to C&YP aged 14 and above, including hospice-based Short Breaks, it is rarely used.

- The DNT- receives £190,000 to deliver community children's nursing care. There is no service specification and no formal commissioning of EOLC.

Demelza Hospice in Sittingbourne provides palliative care (including EOLC) to C&YP in West Kent, including residential and day care. Demelza is not formally commissioned to provide EOLC, however receives funding on a case-by-case basis for Individual Placement Agreements, funded via CHC. The first 14 nights of an admission for EOLC is funded by Demelza, followed by a charge of £1180/night to the CCG. The current funding arrangements are subject to change, pending negotiations between CCGs and Demelza.

5.2.2 East Kent

East Kent commissioning body covers the largest geographical area and includes Ashford, Canterbury and Coastal, Thanet and South Kent Coast CCGs. It has the largest population of C&YP, standing at just over 157,000 in mid-2017, 290 of whom are estimated to have had an LLC in 2017-18 (Table B4)²¹. East Kent only has a commissioning arrangement with KCHFT CCNT, outlined below.

- KCHFT CCNT - commissioned as part of a block contract with community paediatrics to provide community children's nursing care and palliative care (including EOLC). The team provides the following in the community (as per their service specification):
 - Continuing Care
 - Palliative care (including EOLC)
 - Respite care
 - Short Breaks (respite care at home if there is an unmet need)
 - Bladder and bowel care
 - Epilepsy care
 - Respiratory care
 - Children's community nursing care.

East Kent also jointly funds an oncology nurse post with the cancer charity CLIC Sargant. Demelza Hospice in Sittingbourne provides palliative care (including EOLC) to C&YP in East Kent, including residential and day care. Demelza is not formally commissioned to provide EOLC and receives funding from East Kent on a case-by-case basis (as above).

5.2.3 North Kent

North Kent includes DGS and Swale CCGs. DGS and Swale have separate commissioning arrangements for EOLC, owing to historical organisational boundaries. They, therefore, cover the smallest geographical areas and smallest populations of C&YP, standing at just over 65,000 and 29,000 in mid-2017, respectively²¹. There were an estimated 66 C&YP with an LLC in DGS and 50 in Swale in 2017-18 (Table B4). We were unable to ascertain specific commissioning arrangements for DGS; however, it is known that DGS have arrangements with at least the Ellenor Community Team and KCHFT CCNT. There may also be an arrangement with the COAST team, as oncology patients from DGS tend to access oncology care at Medway Maritime Hospital where the COAST team provides Outreach care. These teams work in collaboration due to an overlap in caseloads. Swale has a commissioning arrangement with COAST. Commissioning arrangements are outlined below:

- Ellenor Community Team- receives a grant to deliver palliative care (including EOLC) to C&YP and adults (these are not commissioned separately) in DGS. Ellenor provides the same service in DGS as in West Kent (outlined above), as well as community children's nursing care for C&YP with oncological conditions (not end of life). This grant is used to fund one WTE nurse specialist.
- KCHFT CCNT- commissioned to deliver community children's nursing care, but not commissioned to deliver EOLC.
- COAST- commissioned to deliver children's community nursing care. We were unable to ascertain the details of this arrangement, however there is no formal commissioning arrangement for EOLC. Services provided by the team in the community include:
 - CHC packages (spot-purchased by Swale CCG)
 - Oncology care (DGS and Swale)
 - Cystic fibrosis care (DGS and Swale)
 - Diabetes care (Swale)

- Complex care (Swale).

Demelza Hospice in Sittingbourne provides palliative care (including EOLC) to C&YP in North Kent, including residential and day care. Demelza is not formally commissioned to provide EOLC and receives funding from DGS and Swale CCGs on a case-by-case basis (as above).

5.2.4 Medway

Medway is a standalone CCG. There were just over 70,000 resident C&YP in mid-2017, 111 of whom are estimated to have had a LLC in 2017-18 (Table B4). Medway CCG has commissioning arrangements with the MCH CCNT and COAST, outlined below:

- MCH CCNT- commissioned as part of a block contract to provide community children's nursing care and palliative care (including EOLC) in the community, excluding C&YP with cystic fibrosis and oncological conditions. Specialist services provided by the team in the community also include:
 - Continence care
 - Asthma care.
- COAST- commissioned to provide community children's nursing care for C&YP. Services provided by the team in the community include:
 - CHC packages (spot-purchased by Medway CCG)
 - Oncology care
 - Cystic fibrosis care (via tertiary shared care agreement with King's College NHS Foundation Trust)
 - Diabetes care (tariff payments made to the trust under existing contractual arrangements).

Demelza Hospice in Sittingbourne provides palliative care (including EOLC) to C&YP in Medway, including residential and day care. Demelza is not formally commissioned to provide EOLC and receives funding from Medway CCG on a case-by-case basis (as above).

6 Community Provider Engagement and the NICE Quality Standard

The NICE Quality Standard for Palliative Care for Infants, Children and Young People, published in September 2017, describes high-priority areas for quality improvement. Aspects of service provision of each community provider have been mapped against the NICE Quality Statements and outlined below, alongside areas for improvement (Table E1).

6.1 Demelza

Demelza Hospice in Sittingbourne covers the largest geographical area of all the providers, providing palliative care to C&YP aged 0-19 across the whole of K&M. Demelza also has a hospice in Eltham, which covers Southeast London Boroughs, and a community hospice-at-home service in East Sussex.

6.1.1 Service Provision

Demelza Kent provides palliative and EOLC (residential and day care) to C&YP. Admissions to Demelza Kent can be categorised as follows:

- Symptom control (planned or unplanned)
- Emergency admission due to family circumstances or breakdown in package of care
- Short Breaks (respite care at the hospice if there is an unmet need).

Demelza provides support for families and carers primarily via the Family Support Team, which provides advice and support with housing issues and advocacy, charity applications for equipment, benefits, and liaising with health, education and social care providers.

6.1.2 Facilities

Demelza Kent has extensive facilities, including 9 ensuite bedrooms, accommodation for parents and siblings, hydrotherapy pool, wheelchair-accessible playground, soft playroom, music and art therapy rooms, games consoles with eye-tracking technology, interactive games and a cinema room.

6.1.3 Hours of Service

Demelza provides 24-hour residential hospice care. Alongside this, there is a 24-hour on-call service for specialist nursing advice, including one nurse and one senior manager. There is a minimum of two nurses on-site at any one time.

6.1.4 Out-of-Hours Medical Support

Overall medical responsibility lies with the SPPCT. The Demelza Team contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. The Demelza team is proactive in ensuring that all prescription signatures for anticipatory medications are obtained within hours, which is usually done during GP rounds (Demelza have a contract with the local GP surgery). If the SPPCT advises that a prescription needs to be changed, signatures are obtained from the OOH GP.

6.1.5 Caseload

The majority of C&YP who receive EOLC at Demelza have neurological conditions. Approximately 20% of Demelza Kent's caseload overlaps with the Ellenor Community Team. A child or young person may have short breaks and family support at Demelza with short breaks in the home with Ellenor. A child or young person known to Demelza may use Ellenor for care at end of life, however this is limited by Ellenor's capacity. Demelza's caseload also overlaps with the DNT in West Kent, KCHFT CCNT in East Kent and DGS, COAST in Swale, DGS and Medway, and the MCH CCNT in Medway.

6.1.6 Referrals

The main source of referrals to Demelza are tertiary centres (mainly Evelina). The majority of oncology patients are referred from GOSH and the Royal Marsden. Other sources of referrals include anyone in contact with the child or young person e.g. local paediatric teams, CCNTs, social workers, health visitors, schools, CHC teams, local obstetrics/gynaecology teams and families. All referral forms require the signature of the person with parental responsibility.

6.1.7 Clinical Workforce and Training

Demelza Kent has 23 nurses (18.3 WTE, band 5-8) and 29 HCAs (24.5 WTE, band 3). Nursing staff have qualifications in children's and adults' nursing as well as learning disability. Training includes management of tracheostomies, ventilation, central lines, feeding tubes, seizures, behavior, pain and symptoms as well as complex medication regimes and personal care.

6.1.8 Funding

Demelza publicly states that in order to fund all of their services across K&M, Southeast London and East Sussex they need to raise over £10.5 million per year. The majority of funding is sourced from community donations, corporate supporters and charity shops. Less than 20% of funding comes from government and statutory organisations, including CCG funding for symptom admissions and care at end of life, NHSE Children's Hospice Grant and Local Authority funding for Short Breaks.

6.1.9 NICE Quality Statements

- **C&YP with an LLC and their parents or carers are involved in developing an ACP**
100% of admissions.
- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**
100% of C&YP.
- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**

Yes- via Family Support Team and the team signposts to external services. Drop-in support groups, one-to-one support and days out are also available, alongside sibling support and transition support for young people transitioning to adulthood.

- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**

The Demelza team contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Locally, the Demelza team attends joint caseload meetings with Ellenor and the DNT every two months as well as COAST and MCH CCNT. The Demelza team will discuss patients with the KCHFT CCNT as necessary. The Evelina team also holds clinics at Demelza Hospice twice-monthly (not just for children known to Demelza) and the lead nurse from Demelza attends the Evelina MDT meetings in London.

- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**

Yes- via Family Support Team and the team signposts to external services. Bereaved families are able to stay with their child in special rooms in the Hop Garden for up to five days before the funeral. Families also receive invitations to attend remembrance events throughout the year.

- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**

100% of C&YP

6.1.10 Highlighted Areas for Improvement by the Team

- 24-hour EOLC across K&M is patchy and relies heavily on good-will in some areas.
- There is a gap in bereavement support for unexpected deaths and poor individual bereavement support for families not engaging well with services
- There is variability in training for parents e.g. ventilation at home
- Some families accessing the bereavement suite after death are not previously known to Demelza, which could be a reflection of the ongoing stigma around death and hospice care and/or a lack of awareness.
- EOLC is currently funded on a case-by-case basis via CHC. The current funding arrangements are subject to change, pending negotiations between CCGs and Demelza.

6.2 Ellenor

The Ellenor Community Team is the main provider of home-based palliative care (including EOLC) to C&YP aged 0-19 across West Kent and DGS, as well as community children's nursing care for C&YP with oncological conditions in DGS. The team also covers the Bexley area in Southeast London. Ellenor Hospice in Gravesend provides palliative care (residential and day care) to adults. Ellenor Hospice has capacity to provide palliative care (residential and day care, including hospice-based Short Breaks) to two C&YP aged 14 and over, however this is rarely utilised. Ellenor states that approximately one child or young person is referred to their services every week.

6.2.1 Service Provision

The Ellenor Community Team mainly provides home-based palliative and EOLC to C&YP with an LLC across West Kent and DGS, as well as community children's nursing care to C&YP with oncological conditions in DGS. Care provided by the team can be categorised as follows:

- Symptom control (planned or unplanned)
- Emergency respite (mainly at home) due to family circumstances or breakdown in package of care
- Short Breaks (mainly at home) if there is an unmet need
- Inpatient support to paediatric nurses at Tunbridge Wells Hospital for EOLC and discharge facilitation
- Community children's nursing care to C&YP with oncological conditions (DGS).

6.2.2 Hours of Service

The Ellenor community team provides home-based specialist nursing care 8am-6pm 7 days per week. Alongside this, there is a 24-hour on-call service for specialist nursing advice for all end of life C&YP, with home reviews for C&YP with a named SPPC consultant lead. Due to limited capacity, Ellenor nurses rarely stay overnight with a child or young person.

6.2.3 Out-of-Hours Medical Support

The Ellenor Community Team contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Only C&YP with an ACP have a named SPPC consultant lead. The Ellenor team is proactive in ensuring that all prescription signatures for anticipatory medications are obtained within hours. If the SPPCT advises that a prescription needs to be changed, signatures can be obtained from one adult palliative consultant and 2.3 WTE adult palliative specialists who are based at Ellenor Hospice or the OOH GP.

6.2.4 Caseload

Ellenor publicly states that the number of referrals to the Children's Community Team increased by 24% from 2016-17 to 2017-18. Over half of C&YP on the caseload has cancer. Most C&YP on their caseload are at the end of life. The team usually have capacity for 1-3 C&YP at the end of life in the community at one time, depending on their individual needs. Most C&YP on their caseload die at home. Ellenor's caseload overlaps with Demelza in West Kent and DGS (as above), with the COAST team and KCHFT in DGS, and the DNT in West Kent. The KCHFT CCNT in Faversham (East Kent) has also shared part of its caseload with the Ellenor Team in the past, due to inadequate capacity.

6.2.5 Referrals

The main sources of referrals to Ellenor are tertiary centres (mainly the Royal Marsden, GOSH, Evelina, UCLH and Kings). The majority of oncology patients are referred from GOSH

and the Royal Marsden. Other sources of referrals include the paediatric team at Tunbridge Wells Hospital, the DNT and other CCNTs, social workers and families.

6.2.6 Clinical Workforce and Training

The Ellenor Community Team has 4.4 WTE clinical nurse specialists (0.8 WTE band 8 and 3.6 WTE band 7), 3 WTE staff nurses (band 6) and 3.5 WTE HCAs. All nurses in the team are Registered Sick Children's Nurses. Clinical nurse specialists are expected to have significant experience or additional qualifications in working with complex children and palliative/end of life care. Staff nurses have at least 2 years post-qualification experience in a relevant area e.g. community nursing, neurology and complex care.

6.2.7 Funding

Ellenor publicly states that in order to fund all of its services (adults and children) it needs to raise over £6.9 million per year. 70-75% of their funding is sourced from charity fundraising. 25-30% comes from government and statutory organisations, including CCG funded grants and Local Authority funding for Short Breaks. Ellenor also receives funding from Children in Need, put towards a therapist post.

6.2.8 NICE Quality Statements

- **C&YP with an LLC and their parents or carers are involved in developing an ACP**
100% of families offered. Not all families wish to be involved.
- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**
No- only oncology patients and C&YP with an ACP in place have a named medical lead.
- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**
Yes- via the Wellbeing Service and therapy services. Ellenor provides support to families and carers, including family-drop-ins, youth group, transition services, sibling support groups, holiday groups for siblings and under 5's group.
- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**
The Ellenor Community Team contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Locally, the Ellenor team attends joint caseload meetings with Demelza and DNT in West Kent every two months, as well as the COAST team and KCHFT CCNT once per month. A nurse from Ellenor attends the Evelina MDT meetings in London. Ellenor collaborates with COAST in DGS when caring for C&YP with oncological conditions. Ellenor does all community visits and the COAST team co-ordinates outpatient care, doses chemotherapy and liaises with the Primary Treatment Centre.
- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**
Yes- bereavement pathway via Wellbeing Services.
- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**

Yes- children's nursing care is dependent upon capacity.

6.2.9 Highlighted Areas for Improvement by the Team

- There is inadequate funding to provide 24-hour EOLC to all the C&YP who need it. The team also cover a large area and it can be difficult travelling between patients with limited staff. The team have previously had to refuse patients in the community due to inadequate capacity.
- It is difficult to recruit nursing staff in spite of funding arrangements.
- The team is asked to go to the paediatric ward at Tunbridge Wells Hospital to set up McKinley pumps, as nursing staff on the ward are not trained to do this. This is sometimes not possible due to inadequate staffing levels.
- 24-hour EOLC provision across Kent is patchy. Ellenor has previously looked after a patient in Faversham due to inadequate capacity of the KCHFT team, which worked well.
- North Kent does not commission EOLC for adults and C&YP separately, therefore the needs of C&YP and providers of their services are not specifically considered.
- C&YP who are stable do not have a named SPPCT consultant, which limits their options for location of death if they deteriorate without an ACP in place.
- Some long-term ventilated C&YP do not fit the criteria for the Ellenor team and the DNT and fall into a gap in West Kent.
- Ideally, there should be a SPPCT based in K&M.
- Shared caseload meetings between teams are not all regular or frequent. The team would like more shared caseload meetings with other teams, as well as joint home visits.

6.3 Diana Nursing Team

The DNT is a small outreach team based on the paediatric ward at Tunbridge Wells Hospital, part of the MTW NHS Foundation Trust. The team provides home-based specialist paediatric nursing care as well as palliative care (including EOLC) to C&YP in West Kent. They usually care for C&YP aged 0-16, however they care for C&YP with complex needs aged 0-19 and will keep C&YP with oncological conditions on their caseload above 16 if they are receiving treatment. The team are also responsible for ordering community medical consumables. C&YP only requiring consumables but not nursing care from the Diana Team will remain on their caseload until the age of 18 when District Nurses can take over their equipment provision.

6.3.1 Service Provision

The DNT mainly provides home-based specialist nursing care to C&YP. C&YP with oncological conditions tend to remain on the Diana Team caseload and receive palliative care (including EOLC) from the Diana Team. Care provided by the team can be categorised as follows:

- Specialist Nursing care to C&YP under a variety of paediatric sub-specialties, including oncology, diabetes, gastroenterology, respiratory etc. This includes:
 - Phlebotomy for oncology patients

- Administering intravenous medication
- Managing long-term ventilated C&YP etc.
- Palliative care (including EOLC) to C&YP, mainly with oncological conditions. This includes symptom control (planned or unplanned)

The team is also responsible for ordering medical consumables, including equipment for ventilation, gastrostomies, nasogastric tubes etc.

6.3.2 Hours of Service

The DNT provides home-based specialist nursing care and palliative care (including EOLC) 8:30am-4:30pm Monday to Friday. There is no OOH provision.

6.3.3 Out-of-Hours Medical Support

C&YP and their families can call the ward team at Tunbridge Wells Hospital or the tertiary centre (particularly for oncological conditions) for advice.

6.3.4 Caseload

The DNT have approximately 130 C&YP on their caseload at one time. These can be categorised as follows:

- Active caseload: C&YP requiring specialist nursing care and palliative care (including EOLC)- mainly C&YP with oncological conditions, as well as C&YP with LTCs and complex needs
- C&YP under Ellenor for EOLC but require consumables
- C&YP under the Home Enteral Nutrition (HEN) Team but require consumables for gastrostomy care

The majority of their active caseload have LTCs but do not require EOLC. The majority of C&YP who die on the Diana Team caseload have oncological conditions. These C&YP usually die on the ward at Tunbridge Wells Hospital. The DNT's caseload overlaps with Ellenor (for home-based EOLC) and Demelza (for hospice based EOLC).

6.3.5 Referrals

The main sources of referrals to the DNT are tertiary centres. The majority of oncology patients are referred from the Royal Marsden and GOSH. GOSH also tends to refer C&YP with gastrointestinal conditions.

6.3.6 Clinical Workforce

The DNT has 2.2 WTE nurses (one band 7 and three band 6).

6.3.7 Funding

The DNT is funded by MTW NHS Foundation Trust and WKCCG.

6.3.8 NICE Quality Statements

- C&YP with an LLC and their parents or carers are involved in developing an ACP

Unknown

- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**

Unknown

- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**

Yes- by the team.

- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**

The DNT contacts the SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Locally, the DNT attends joint caseload meetings with the Demelza and Ellenor teams in West Kent every two months. The Evelina team also hold joint clinics at Tunbridge Wells and Maidstone Hospitals.

- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**

The team refers to a private counselling service for formal bereavement counselling.

- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**

No- families contact Hedgehog Ward at Tunbridge Wells Hospital for on-call nursing or medical advice or the SPPCT directly.

6.3.9 Highlighted Areas for Improvement by the Team

- The end of life care pathway on the ward for C&YP needs to be smoother, in terms of conversations about death, dying and resuscitation, referral to community teams and their early involvement in a child or young person's care on the ward. Specific issues noted include:
 - Families tend to want the child or young person to remain on active treatment for longer, making it difficult to have meaningful discussions around resuscitation.
 - It can be difficult referring C&YP to community nursing teams for EOLC if they are on active treatment or having bloods taken e.g. oncology patients.
 - It can be difficult referring C&YP to community nursing teams for EOLC if they do not have Do Not Attempt Resuscitation (DNAR) orders.
- At times, teams find it difficult to take responsibility for having conversations about death, dying and resuscitation with a child or young person and his/her family. This is compounded by inadequate training of ward staff to initiate such conversations and not having a SPPCT in K&M to support or lead these conversations. This can affect the quality of clinical care and general awareness of hospice and community team services and support, which can in turn lead to unnecessary deaths in hospital. Discussion around acceptance criteria and earlier involvement in a child or young person's care by community teams on the ward would be beneficial.
- The service is inadequately funded to cover the costs of current staffing, recruitment and equipment.

- The paediatric ward team at Tunbridge Wells Hospital do not have adequate training in end of life care and use of some end of life equipment, including McKinley syringe pumps. The ward team have relied on the Ellenor team in the past to come to the ward to set up end of life equipment and lead the clinical care of a child or young person who is end of life, which is not possible at times when Ellenor is providing EOLC in the community and has limited capacity. The ward team has at times contacted the tertiary centres for equipment advice over the phone.
- Ordering and chasing equipment take important time away from clinical care.
- It is difficult to recruit nursing staff in spite of funding arrangements.
- If the Ellenor team have inadequate capacity, particularly OOH, a child or young person may die on the ward, which may not be the preferred place of death of the child or young person and their family.
- There can be a four to five-hour delay awaiting the STRS if a child or young person needs to be taken up to a tertiary centre in London. C&YP at times have to be put onto a ventilator on the paediatric ward and do not have level 2/3 trained nursing support in the interim period.
- Together for Short Lives offers useful training sessions for nursing staff and delivery of more of these sessions would be beneficial for clinical care.

6.4 Kent Community Health Foundation Trust Children's Community Nursing Team

The KCHFT CCNT is the sole provider of home-based specialist paediatric nursing care as well as palliative care (including EOLC) to C&YP aged 0-19 across East Kent, where the team is divided across four localities. The team also provides home-based specialist paediatric nursing care in DGS (not EOLC).

6.4.1 Service Provision

Care provided by the team can be categorised as follows:

- Children's community nursing care to C&YP with short-term and long-term illnesses and complex needs under a variety of paediatric sub-specialties (East Kent and DGS). This includes:
 - Administering intravenous medication
 - Tracheostomy care
 - Pre-transfusion phlebotomy
- Palliative care (including EOLC) to C&YP (East Kent), including:
 - Symptom control (planned or unplanned)
 - Emergency respite (respite at home due to family circumstances or breakdown in package of care)
 - Short Breaks (respite at home if there is an unmet need)

6.4.2 Hours of Service

The KCHFT CCNT provides home-based specialist nursing care and palliative care (including EOLC) from 9am-5pm Monday to Friday. There is a limited service 8am-9am and 5pm-8pm Monday to Friday and 9-5pm Saturday and Sunday. Alongside this, there is a 24-hour on-call service for specialist nurse EOLC advice, with home reviews, as necessary.

6.4.3 Out-of-Hours Medical Support

Overall medical responsibility lies with the SPPCT. The KCHFT CCNT contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. If advice is needed locally or the SPPCT advises that a prescription needs to be changed, the team has good links with local paediatric oncology consultants at William Harvey and QEQM Hospitals. However, the consultants may not know the child or young person and may not have the expertise to provide advice if he or she does not have an oncological condition. Signatures can also be obtained from the OOH GP; however, they may not have the necessary expertise.

6.4.4 Caseload

The KCHFT CCNT in East Kent have approximately 200 C&YP on their caseload at any one time, which includes C&YP requiring EOLC and community nursing care. The team provides care to C&YP under a variety of different sub-specialities. The majority of C&YP have oncological or congenital conditions. The KCHFT CCNT's caseload overlaps with Demelza in East Kent and COAST and Ellenor in DGS. C&YP would access Demelza for hospice-based palliative care (including Short Breaks and EOLC), sibling support and bereavement support. The KCHFT CCNT in DGS does not provide EOLC but works collaboratively with COAST and Ellenor to provide care for C&YP on shared caseloads.

6.4.5 Referrals

The main sources of referrals to KCHFT CCNT are tertiary centres. Other sources of referrals include anyone in contact with the child or young person e.g. local paediatric teams, CCNTs, social workers, health visitors, schools, CHC teams, local obstetrics/gynaecology teams and families.

6.4.6 Clinical Workforce and Training

The KCHFT CCNT in East Kent has 3.2 WTE band 7, 7.54 WTE band 6, 3.2 WTE band 5, 0.8 WTE band 3. The team includes a CLIC Sargent nurse who specialises in cancer care. There is usually 1 full-time and 1 part-time nurse in each of the four localities across East Kent. Nurses involved in EOLC and symptom management are primarily band 6 and 7. The team receives GOSH training, which is updated yearly, as well as resilience training. The KCHFT CCNT in DGS has 0.6 WTE band 7, 1.5 WTE band 6 and 1 WTE HCA.

6.4.7 Funding

The KCHFT CCNT receives funding from East Kent and DGS CCGs, as well as CLIC Sargent.

6.4.8 NICE Quality Statements

- **C&YP with an LLC and their parents or carers are involved in developing an ACP**
7/8 reviewed ACPs had parent/carer involvement documented. Patient involvement is generally not documented but staff are encouraged to do so.
- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**
100% of C&YP have a SPPCC overseeing their care.
- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**
Yes- via the team, Specialist Nurse Advisor Service and Therapy Service.
- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**
The KCHFT CCNT contacts the SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. In East Kent the team has good links with paediatric oncology consultants at William Harvey and QEQM Hospitals and Demelza. KCHFT CCNT have regular joint caseload meetings with Ellenor and COAST in DGS and will discuss patients with Demelza, as necessary. KCHFT CCNT works collaboratively with the COAST team in DGS. The KCHFT CCNT would do phlebotomy and intravenous line care at home and the COAST team would co-ordinate their outpatient care. In DGS the team sometimes have shared care arrangements with the Ellenor team for C&YP on both caseloads. The team does not usually attend tertiary centre MDTs.
- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**
In East Kent the team offers a bereavement visit to families and then signpost to other bereavement services. There is a pathway in place for joint working with the Children's Therapies Service and Specialist Nurse Advisor Service. Would also refer to Demelza.
- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**
Yes- dependent upon CCNT capacity.

6.4.9 Highlighted Areas for Improvement by the Team

- The service generally works well, however if the need for EOLC increases, they have no reserve capacity. In such circumstances, the caseload is prioritised, with EOLC being a high priority.
- A SPPCT in K&M would be beneficial, as local consultants and GPs sometimes do not have the expertise in the child's condition if a prescription or medical attention is required OOH.

6.5 Medway NHS Foundation Trust Children's Outreach and Specialist Team

The COAST team is an outreach team part of Medway NHS Foundation Trust based at Medway Maritime Hospital. The team provides home-based specialist paediatric nursing care as well as palliative care (including EOLC) to C&YP under a consultant at Medway Maritime Hospital. The team co-ordinates outpatient care, doses chemotherapy and liaises with the Primary Treatment Centre. As a result, the team provides care to C&YP across different areas of K&M, outlined below. The team usually provides care to C&YP aged 0-18.

6.5.1 Service Provision

Community care provided by the team can be categorised as follows:

- Specialist nursing care to C&YP with short-term and long-term illnesses and complex needs under a variety of paediatric sub-specialties.
- Palliative care (including EOLC) to C&YP, including:
 - Symptom control (planned or unplanned)

The COAST team is divided into the following sub-teams:

- Oncology (DGS, Swale and Medway; Darent Valley Hospital does not provide oncology care, therefore patients from DGS access oncology care at Medway Maritime Hospital and are therefore on the COAST team's caseload, but are seen in the community by Ellenor)
- Cystic fibrosis (DGS, Swale and Medway)
- Diabetes (Swale and Medway)
- Complex needs (Swale)
- CHC (Swale and Medway)

6.5.2 Hours of Service

The COAST team provides home-based specialist nursing care and palliative care (including EOLC) from 8am-6pm Monday to Friday. An ad-hoc OOH service for specialist nursing EOLC advice and home reviews is provided, as necessary.

6.5.3 Out-of-Hours Medical Support

Overall medical responsibility lies with the SPPCT. The COAST team contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. If advice is needed locally or the SPPCT advises that a prescription needs to be changed, the medical team on the ward at Medway Maritime Hospital or the general practitioner will usually provide a signature. Families have 24-hour access to the Penguin Assessment Unit at Medway Maritime Hospital, allowing them to bypass A&E if medical attention is required.

6.5.4 Caseload

The COAST team have approximately 440 C&YP on their caseload at any one time. The team's current caseload is outlined below:

- Diabetes - 270
- CF - 18
- Continuing Care - 14
- Oncology - 35
- Complex needs - 103

The majority of C&YP who die on the COAST caseload have oncological conditions. The team has two deaths on average per year. The COAST team's caseload overlaps with Demelza, Ellenor and KCHFT in DGS, Demelza in Swale, and MCH CCNT and Demelza in Medway. C&YP would access Demelza for hospice-based palliative care (including Short Breaks and EOLC), bereavement support and sibling support. Other charities in North Kent also provide Short Breaks.

6.5.5 Referrals

Sources of referrals include tertiary centres, Medway NHS Foundation Trust consultants and local paediatric teams.

6.5.6 Clinical Workforce and Training

The COAST team workforce includes the following:

- Oncology team: 1 WTE band 7 (50% of post funded by CLIC Sargent), 1.2 WTE band 6
- Cystic fibrosis and complex needs teams: 1 WTE band 7, 2.6 WTE band 6
- Diabetes team: 1 WTE band 7, 5.1 WTE band 6
- CHC team: 1 WTE band 7, 1 WTE band 6, 4.9 WTE band 5, 14.5 WTE band 3

If a child or young person requires EOLC, two nurses will usually attend.

6.5.7 Funding

The COAST team receives funding from Medway NHS Foundation Trust, DGS, Swale and Medway CCGs and CLIC Sargent. Funding for cystic fibrosis care comes from King's College Hospital NHS Foundation Trust under a tertiary shared care agreement.

6.5.8 NICE Quality Statements

- **C&YP with an LLC and their parents or carers are involved in developing an ACP**
Unknown
- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**
100% C&YP have a named medical consultant at Medway Maritime Hospital.
- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**
No support within service.

- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**
The MCH CCNT contacts the SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Locally, the team has support from the paediatric team at Medway Maritime Hospital and the GP. The COAST team has joint caseload meetings with Demelza, Ellenor, KCHFT and MCH CCNT. The team rarely attends MDT meetings at the tertiary centres. Ellenor collaborates with COAST in DGS when caring for C&YP with oncological conditions. Ellenor does all community visits and the COAST team co-ordinates outpatient care, doses chemotherapy and liaises with the Primary Treatment Centre.
- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**
No- C&YP also known to Demelza would access bereavement counselling there. North East London NHS Foundation Trust (NELFT) Emotional and Wellbeing Service provides bereavement support to families in Medway, however the team do not usually refer to this service. This service may or may not be appropriate for some families and most families are sign-posted to the charity Holding on Letting Go.
- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**
Intended, but inadequate nursing capacity for ad-hoc OOH EOLC provision.

6.5.9 Highlighted Areas for Improvement by the Team

- A formal commissioning arrangement for EOLC would be beneficial for service provision. The COAST team is in discussion with commissioners and the MCH CCNT regarding collaboration on an OOH on-call rota, owing to inadequate capacity.
- Information from tertiary centres regarding MDTs can be unclear at times. The team does not always know if a patient known to them is being discussed and if they should attend.

6.6 Medway Community Healthcare Community Children's Nursing Team

The MCH CCNT provides home-based specialist paediatric nursing care as well as palliative care (including EOLC) to C&YP aged 0-19 in Medway, excluding C&YP with cystic fibrosis and oncological conditions.

6.6.1 Service Provision

Care provided by the team can be categorised as follows:

- Specialist nursing care to C&YP with short-term and long-term illnesses and complex needs under a variety of paediatric sub-specialties, including renal, cardiology, metabolic, haematology, vascular and respiratory, as well as continence and asthma services. This includes:
 - Administering intravenous medication
 - Managing long-term ventilated C&YP
- Palliative care (including EOLC) to C&YP, including:

- Symptom control (planned or unplanned)

6.6.2 Hours of Service

The MCH CCNT provides home-based specialist nursing care and palliative care (including EOLC) from 8am-6pm Monday to Friday. Since MCH CCNT split from the COAST team in June 2018, an OOH EOLC service has not yet been required in Medway. However, an ad-hoc OOH service for specialist nursing EOLC advice and home reviews can be provided, as necessary.

6.6.3 Out-of-Hours Medical Support

Overall medical responsibility lies with the SPPCT. The MCH CCNT contacts the relevant SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Local medical support is provided by the general practitioner and paediatric teams.

6.6.4 Caseload

The MCH CCNT have approximately 200 C&YP on their caseload at any one time. The team provides care to C&YP under a variety of different sub-specialties. The MCH CCNT's caseload overlaps with Demelza. C&YP would access Demelza for hospice-based palliative care (including Short Breaks and EOLC), bereavement support and sibling support.

6.6.5 Referrals

Sources of referrals include tertiary centres, local paediatric teams, social workers and CHC teams.

6.6.6 Clinical Workforce

The MCH CCNT workforce includes the following:

- Community team: 1.7 WTE band 7 and almost 6 WTE band 6 children's nurses.
- Special schools' team: 3 WTE nurses (one band 6 and two band 5)
- Learning disability team: 2.6 WTE band 6 and 1 WTE band 7

If a child or young person requires EOLC, two nurses will usually attend, including one nurse from the community team and one nurse from any of the three teams.

6.6.7 Funding

The MCH CCNT receives funding from Medway CCG as part of a block contract for specialist community children's health services and local authority for health visiting and school nursing.

6.6.8 NICE Quality Statements

- **C&YP with an LLC and their parents or carers are involved in developing an ACP**
Newly formed service. Unclear what role the CCNT will play in developing ACPs
- **C&YP with an LLC have a named medical specialist who leads and coordinates their care.**

100% of C&YP have a SPPCC overseeing their care.

- **C&YP with an LLC and their parents or carers are given information about emotional and psychological support, including how to access it.**

No support within service.

- **C&YP with an LLC are cared for by an MDT that includes members of the SPPCT**

The MCH CCNT contacts the SPPCT (or the relevant on-call team) in London by telephone if specialist advice is needed at any time. Locally, the team has GP and paediatric team support. MCH CCNT have joint caseload meetings with Demelza and MCH CCNT and attend discharge planning meetings for complex children at tertiary centres (usually GOSH and Evelina). The team does not attend MDT meetings at tertiary centres, however, would attend if a child on the caseload were being discussed and the team were invited.

- **Parents or carers of C&YP approaching end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.**

C&YP also known to Demelza would access bereavement counselling there. NELFT Emotional and Wellbeing Service provides bereavement support to C&YP in Medway, however the team do not usually refer to this service. This service may or may not be appropriate for some families and most families are sign-posted to the charity Holding on Letting Go.

- **C&YP approaching end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care**

Intended, but inadequate nursing capacity for ad-hoc OOH EOLC provision.

6.6.9 Highlighted Areas for Improvement by the Team

- The COAST team is in discussion with commissioners and the MCH CCNT regarding collaboration on an OOH on-call rota, owing to inadequate capacity.

7 Service Activity

Data showing service activity over the last five years was requested from all community providers across K&M. Data was obtained from Demelza and Ellenor and is summarised in Appendix F. Five deceased individuals were known to both Demelza and Ellenor. Barriers to obtaining data from the other community providers included limited or no data collection as part of the teams' practices, limited staff to pull out and prepare the data, and difficulties pulling out relevant data using electronic systems. The majority of data obtained includes very small numbers and has been suppressed or summarised accordingly.

7.1 Demelza

Demelza Kent currently has 317 C&YP on the caseload. Data was provided showing admissions of C&YP (0-19) to Demelza Kent for symptom control and EOLC (referring to care given when the child or young person is thought to be in their last hours or days) over a five-year period from 1st November 2013 to 31st October 2018.

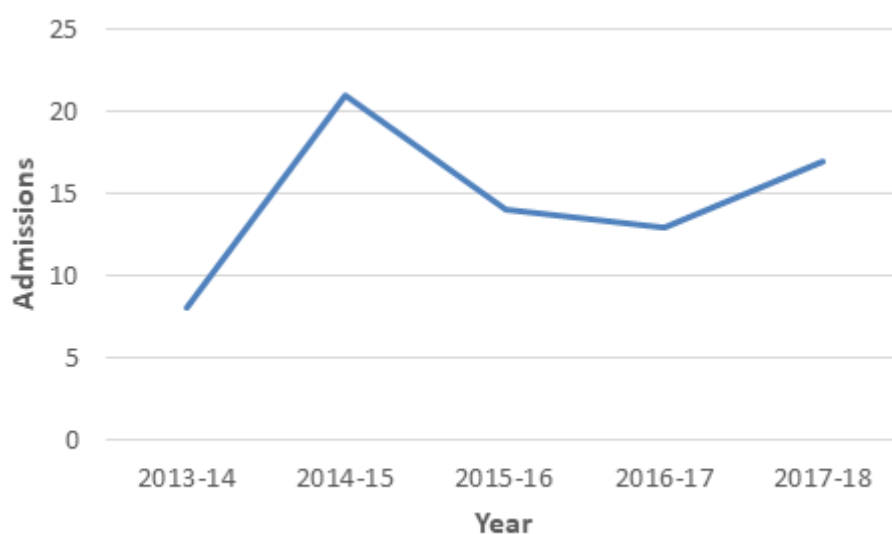
7.1.1 Admissions

- 37 individuals were admitted for symptom control or EOLC.
- 8 individuals died at Demelza.
- As of November 2018, 20 were deceased and 17 were alive.
- There were 20 admissions for EOLC (15 individuals) [Table 6]. The average duration of an admission was 16 days (0-76 days); the majority were under 20 days.
- Of the 20 admissions for EOLC, 7 resulted in deaths at Demelza. Of the remaining 8 individuals, 4 died at home at a later date, 1 died at Demelza at a later date, 1 died in hospital at a later date and 2 were alive as of November 2018.
- There were 53 admissions for symptom control (20 individuals). 1 resulted in death. The average duration of an admission was 6 days (1-27 days) and the majority were under 7 days.

Table 6 Episodes of care provided at Demelza Kent from 1st November 2013 to 31st October 2018. *Suppressed data <4

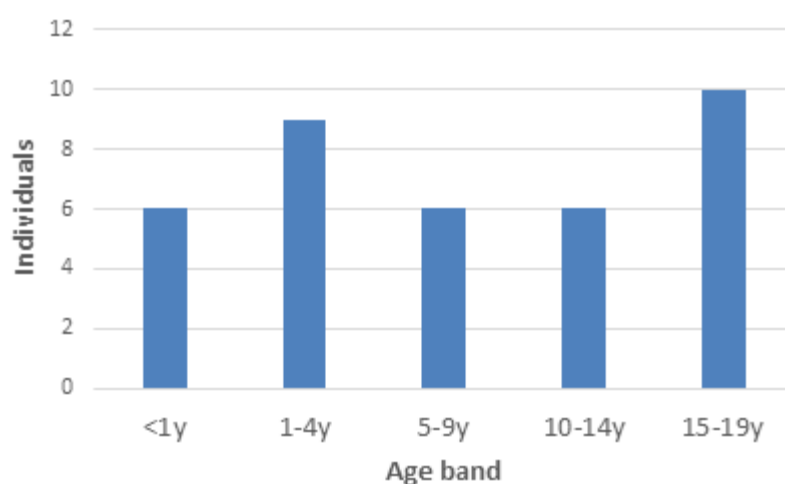
	2013-14	2014-15	2015-16	2016-17	2017-18	Total
End of life care	*	*	*	*	9	20
Symptom control	6	18	11	10	8	53
Total	8	21	14	13	17	73

Fig. 33 Admissions to Demelza for symptom control and end of life care by year (1st November-31st October).



Source: Demelza, March 2019

Fig. 34 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by age band (Table F1).

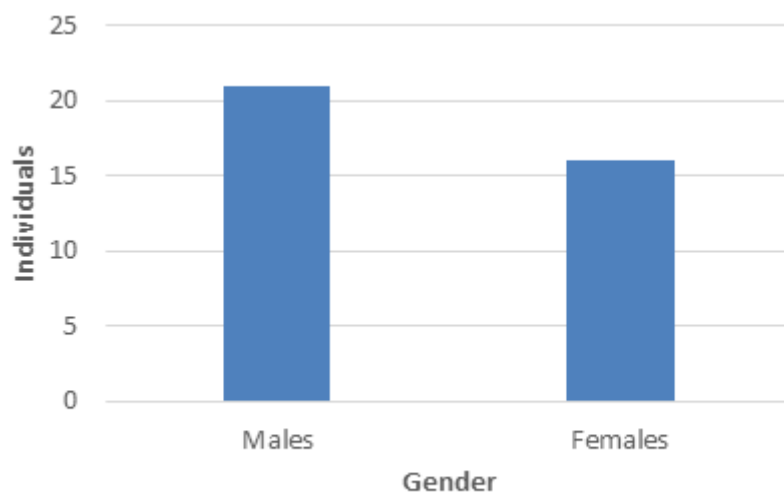


Source: Demelza, March 2019

7.1.2 Individuals

Living and deceased individuals have been amalgamated, owing to low numbers.

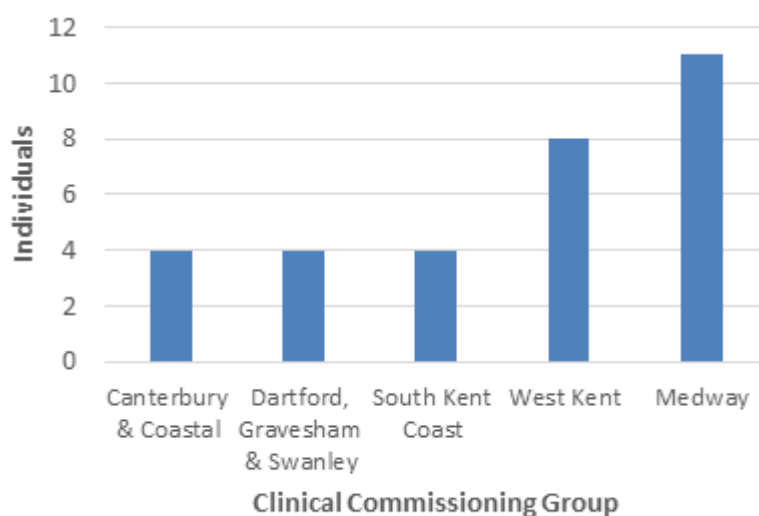
Fig. 35 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by gender (Table F2).



Source: Demelza, March 2019

Fig. 36 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by Clinical Commissioning Group (Table F3).

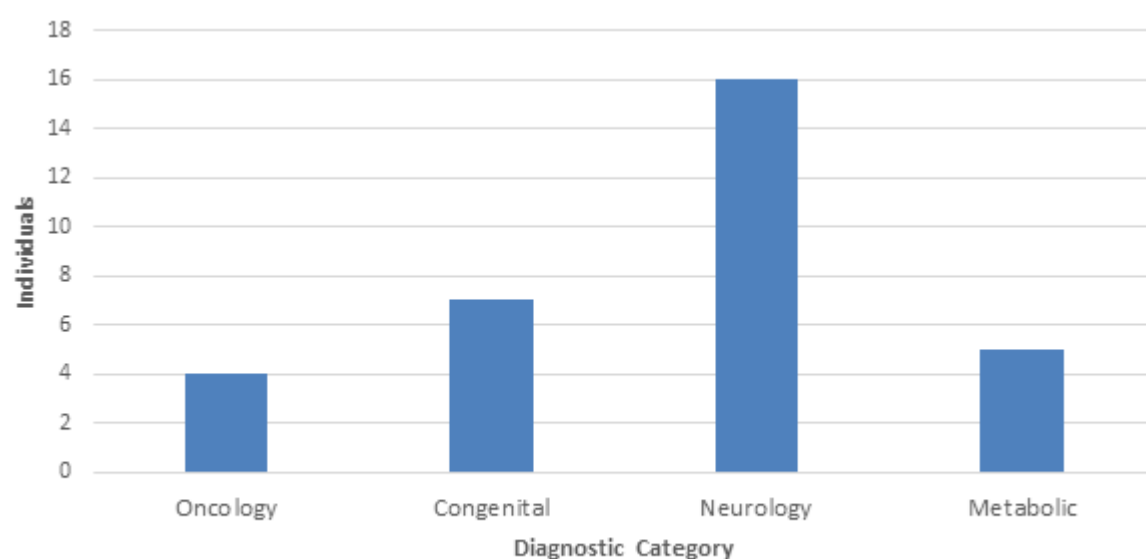
NB. Ashford, Swale and Thanet <4



Source: Demelza, March 2019

Fig. 37 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by diagnostic category (Table F4).

NB. Perinatal, circulatory, respiratory and gastrointestinal <4



Source: Demelza, March 2019

Table 7 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by ethnicity. *Suppressed data <4

Ethnicity	Individuals
White British	30
White other	*
Asian Or Asian British - Indian	*
Black or Black British - African	*

Box 15 - key points:

- 37 C&YP accessed symptom control or EOLC at Demelza Kent over a five-year period.
- The number of C&YP who received EOLC at Demelza significantly increased in 2017-18.
- The majority of C&YP admitted to Demelza for symptom control or EOLC were in the 15-19y and 1-4y age bands.
- More males were admitted to Demelza for symptom control or EOLC than females.
- Medway had the highest number of C&YP admitted to Demelza for symptom control or EOLC, followed by West Kent.
- More C&YP admitted to Demelza for symptom control or EOLC had neurological LLCs than any other condition.
- The majority of C&YP admitted to Demelza for symptom control or EOLC were white British.
- Of the 20 deceased individuals on the caseload, the majority were 0-4 years-old with neurological or congenital conditions and resident in Medway or West Kent. Those with cancer tended to be over 10 years-old and those with other conditions tended to be under 10 years-old.
- Of the 8 individuals who died at Demelza, the majority were 1-4 years-old with neurological conditions.

7.2 Ellenor

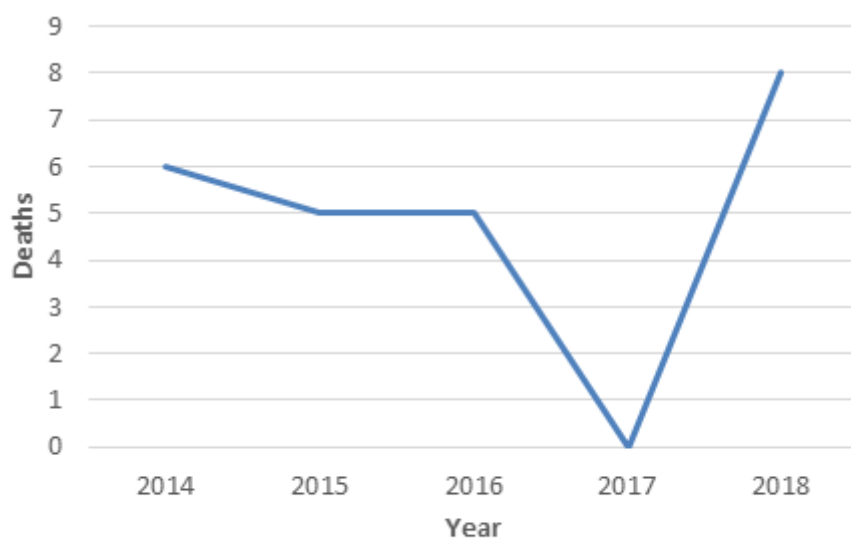
Ellenor currently has 62 C&YP on the caseload (33 in West Kent and 29 in DGS (10 oncology)). Data was provided showing EOLC provided to deceased C&YP (0-19) over a five-year period from 1st January 2014 to 31st December 2018. The data does not include episodes of symptom control and EOLC provided to living C&YP, owing to difficulties pulling the data from the electronic system.

7.2.1 Episodes

- 26 individuals died on Ellenor's caseload.
- The average duration between referral for EOLC and death was 20 months (0-62 months).

Fig. 38 Ellenor deaths by calendar year (Table F5).

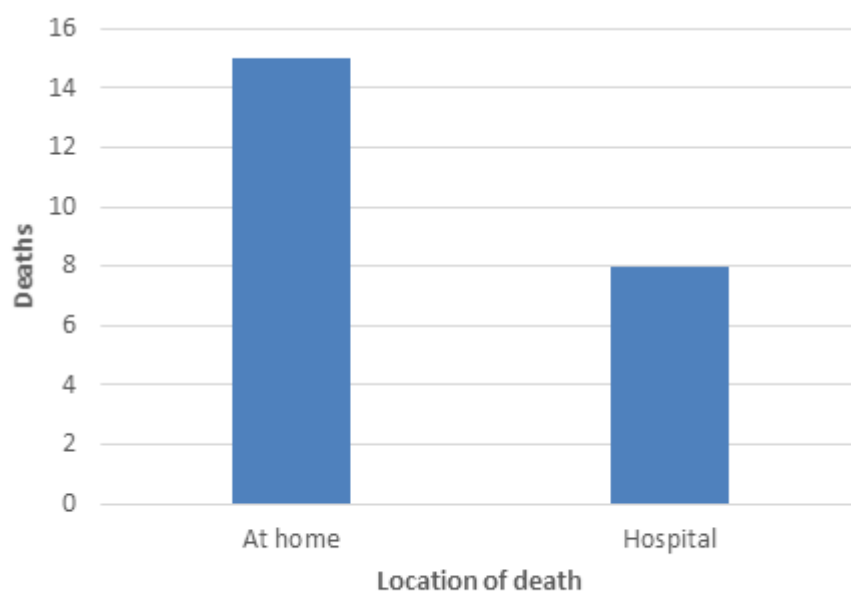
NB. The number of deaths in 2017 was <4 and has been suppressed



Source: Ellenor, March 2019

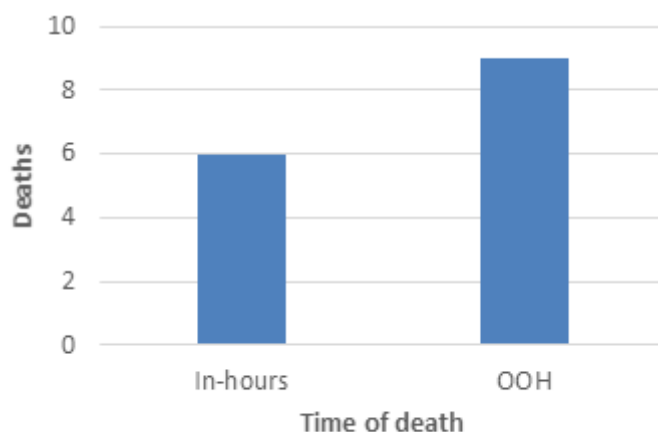
Fig. 39 Ellenor deaths from 1st January 2014 to 31st December 2018 by location (Table F6).

NB. Deaths at Demelza <4



Source: Ellenor, March 2019

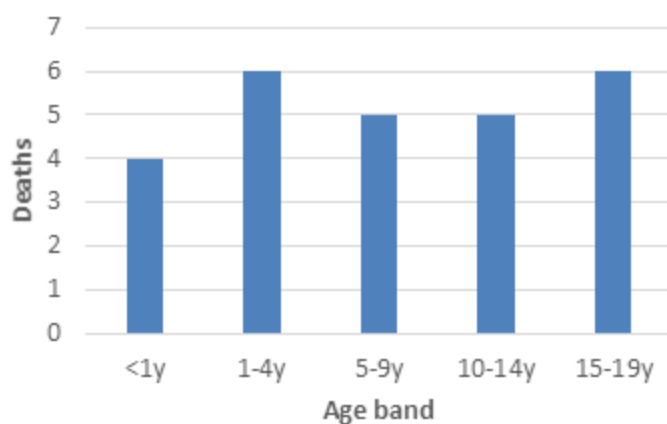
Fig. 40 Ellenor home deaths from 1st January 2014 to 31st December 2018 by time of death (Table F6).



Source: Ellenor, March 2019

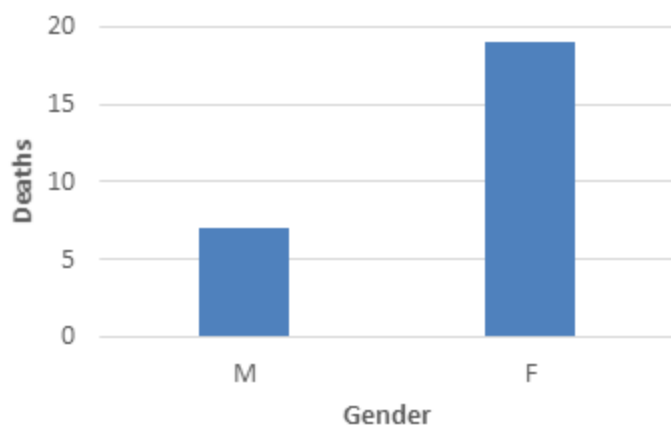
7.2.2 Individuals

Fig. 41 Ellenor deaths from 1st January 2014 to 31st December 2018 by age band (Table F7).



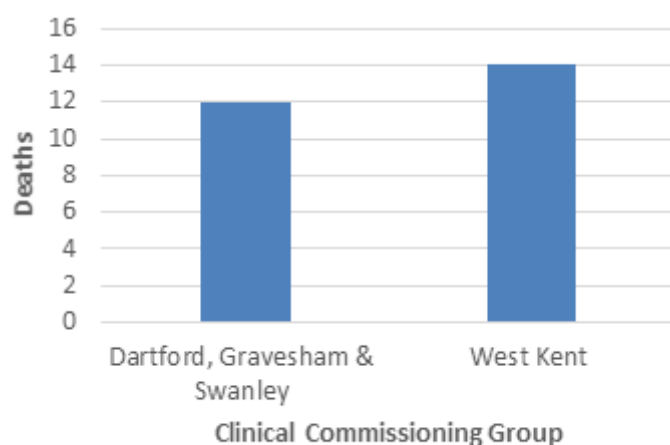
Source: Ellenor, March 2019

Fig. 42 Ellenor deaths from 1st January 2014 to 31st December 2018 by gender (Table F8).



Source: Ellenor, March 2019

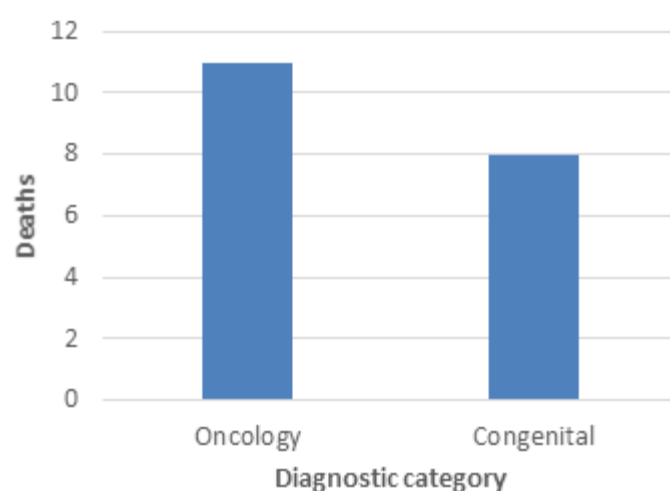
Fig. 43 Ellenor deaths from 1st January 2014 to 31st December 2018 by Clinical Commissioning Group (Table F9).



Source: Ellenor, March 2019

Fig. 44 Ellenor deaths from 1st January 2014 to 31st December 2018 by diagnostic category (Table F10).

NB. Neurology, perinatal and metabolic <4



Source: Ellenor, March 2019

Table 8 Ellenor deaths from 1st January 2014 to 31st December 2018 by diagnostic category.

*Suppressed data <4

Ethnicity	Individuals
White British	21
White other	*
Other ethnic background	4

Box 16 - key points:

- The number of Ellenor deaths was unusually low in 2017 and increased significantly in 2018.
- The majority of Ellenor deaths were at home; the fewest deaths were in hospice. The majority of Ellenor deaths at home took place out of hours.
- There was no significant difference between age bands and CCGs.
- The majority of deaths were amongst females.
- More C&YP died from oncological LLCs than any other condition, followed by congenital.
- The vast majority of C&YP who died on Ellenor's caseload were of white British origin.
- C&YP who died from cancer tended to be over 10 years-old and those with other conditions tended to be under 10 years-old.
- There was no association between diagnostic category and location of death.

8 Conclusions

8.1 The Need for End of Life Care Services for Children and Young People

Within the limitations of the dataset, the following general conclusions can be drawn about the K&M population:

- C&YP who may benefit from EOLC services constitute a small portion of the K&M population. Over a four-year period, there were 1,415 living individuals with a LLC in K&M and over a 12-year period 279 C&YP died from or with a LLC in Kent.
- Despite the cohort being small, the need for EOLC services in hospital and in the community is increasing. Yearly rates of living C&YP with an LLC have significantly increased since 2014-15 and yearly death rates from LLCs have been declining since 2008.
- This cohort creates a large burden on acute trusts and some community services. We estimate that the living C&YP with an LLC had approximately 5,000 hospital admissions over a four-year period. This is an underestimate, as C&YP who died from an LLC are not included.
- Living C&YP with an LLC appear to have some differences in characteristics, and therefore have different needs, to C&YP who have died from an LLC. Similarly, C&YP with cancer appear to have different characteristics to those with other conditions. This is important for strategic planning of EOLC services.

8.1.1 Cohort 1

- The highest rates of LLCs were seen in the 1-4y age band. It should be noted that this needs assessment has underestimated the number of 3-12-month-olds and omitted neonates.
- The lowest rates of LLCs were seen in the 15-19y age band; however, this cohort is growing the most rapidly. In line with national prevalence studies, it is likely that this rapid growth is a result of increased survival time.
- Higher rates of LLCs were seen amongst males. The male cohort is growing more rapidly than the female cohort. There were significantly more males with neurological and oncological LLCs than females.
- Swale, Thanet and Medway had the highest rates of LLCs in more recent years; West Kent had the lowest rate. Rates of LLCs have increased in all CCGs since 2014-15; the rate in Swale is growing most rapidly.
- Higher rates of congenital LLCs were seen than any other diagnostic category. This was seen across all CCGs.
- A higher rate of LLCs was seen in the most deprived decile than the least deprived decile.
- C&YP aged 1-9-years-old had the greatest number of hospital admissions per person.
- C&YP with cancer or a haematological LLC had the greatest number of admissions per person.

- C&YP aged 1-4 years-old with cancer and C&YP aged 15-19 years-old with a haematological LLC had the highest number of admissions per person.
- The number of admissions per person for cancer was highest in Canterbury and Coastal, Swale, South Kent Coast and Medway. The number of admissions per person for haematological LLCs was significantly highest in DGS.

8.1.2 Cohort 2

Statistical significance was difficult to achieve considering the low numbers.

- The highest death rate from an LLC is seen in the 1-4y age band, followed by the 15-19y age band.
- There were more deaths from LLCs amongst males than females. The death rate from LLCs amongst males has steadily decreased since 2008 to approximately equal the death rate of females.
- The highest death rates from LLCs were seen in Ashford and DGS; death rates in these CCGs were higher than Kent.
- There was a decline in death rates from LLCs from 2006-11 to 2012-17 in most CCGs. A more significant decline was seen in South Kent Coast and Thanet. The only increase in death rates from LLCs from 2006-11 to 2012-17 was seen in Ashford.
- The most common cause of death was cancer; the least common causes were haematological, genitourinary and other conditions. The highest death rates from cancer were amongst 15-19-year-olds. The highest death rates from non-cancer were amongst 1-4-year-olds.
- There was a higher rate of LLCs in the most deprived decile than the least deprived decile. The gap between the most and least deprived deciles has narrowed, owing to a decrease in the death rate from LLCs in the most deprived decile.
- There has been a general increase in hospital deaths from LLCs since 2008 and a general decline in hospice deaths from LLCs since 2011.
- Most hospital deaths from LLCs since 2008 have been in K&M hospitals. The majority of these were at William Harvey and Medway Maritime Hospitals.
- Most hospital deaths from LLCs since 2008 in London have been at King's College, St. Thomas's and Evelina Children's Hospitals.

8.1.3 Service Activity

- In the four-year period between 2013-14 and 2017-18, there were approximately 1500 C&YP with an LLC across K&M with access to Demelza Kent. From November 2013 to November 2018, 37 C&YP accessed Demelza for EOLC or symptom control.
- Despite Demelza covering a population almost three times larger than Ellenor, there were twice the number of deaths at home under Ellenor than at Demelza Kent over a five-year period.
- The majority of deaths of C&YP under Ellenor were at home and OOH.
- The number of C&YP who received EOLC at Demelza significantly increased in 2017-18, as did the number of deaths under Ellenor (although numbers remain small).

- The majority of C&YP admitted to Demelza for EOLC or symptom control were in the 15-19y and 1-4y age bands.
- More males were admitted to Demelza for symptom control or EOLC than females. Significantly more females died under Ellenor than males.
- More C&YP admitted to and dying at Demelza had neurological LLCs than any other condition.
- Of the deceased C&YP admitted to Demelza and not known to Ellenor, the majority were 0-4 years-old with congenital or neurological conditions. More C&YP died from cancer under Ellenor than any other condition.
- C&YP who died from cancer under Ellenor tended to be over 10 years-old and those with other conditions tended to be under 10 years-old.
- Medway had the highest number of C&YP admitted to Demelza for EOLC or symptom control, followed by West Kent.
- The majority of C&YP admitted to Demelza for EOLC or symptom control and dying under Ellenor were white British.

8.2 Service Provision

EOLC service provision across K&M is incredibly complex. The number of C&YP requiring EOLC services at any one time is relatively small, however as this number increases, so too does the unpredictability and end of life trajectory of these individuals. In addition, EOLC for C&YP presents greater challenges as a specialty than others, as specific trained skills are needed to have difficult conversations, often with families who are not ready to accept the need for services. Services also need to be more responsive to rapid clinical changes.

The majority of areas for improvement were highlighted in West and North Kent. It is important to note that these areas are covered by multiple providers and service provision is therefore more complex and more likely to have reported issues. The most pressing and stark concern is the inequity of service provision, as some providers struggle to deliver 24-hour EOLC to C&YP and families who need it, increasing the burden on acute services. Community teams do not have the reserve capacity to continue providing the current services as need increases. This is on a background of fundamental issues with the system as whole, in which historical commissioning arrangements and unmapped population needs and service provision have left some areas with overlapping service provision and other areas with gaps. Nursing teams deliver the best quality care they can to as many C&YP and families as they can, within increasing constraints. However, the roles and responsibilities of providers within the system as a whole are not clear, making it difficult for providers to efficiently co-ordinate with each other and to map out clear patient pathways. The main conclusions from provider engagement are outlined below.

8.2.1 Nursing Team Capacity

Financial and workforce constraints and difficulty recruiting specialist nurses are contributing to inadequate capacity and difficulty in delivering equitable, high-quality EOLC

across the whole of K&M. This also includes difficulty in sourcing nursing agencies with adequately trained nurses to provide CHC in some areas. Inadequate capacity not only affects service provision within normal hours, but also has a profound effect on the provision of OOH EOLC services. This can lead to inappropriate hospital admission if a child or young person requires OOH EOLC at home, as well as inappropriate hospital stay if there is no capacity for home care post-discharge. The largest impact of limited capacity was seen in West Kent, where the Ellenor team can usually provide EOLC to 2-3 C&YP at home at one time. Over a four-year period, the Ellenor team covered a population of approximately 550 C&YP with an LLC (Table 9). The knock-on effects of this limited capacity include difficulty in discharging patients to Ellenor from Tunbridge Wells Hospital and difficulty in referring C&YP with cancer to Ellenor from the DNT. Limited capacity was also reported in the COAST and MCH teams, where there is inadequate staffing to provide OOH EOLC nursing support at times, and in the DNT. The KCHFT CCNT reported a limited reserve if demand for EOLC increases at any one time, which is managed by prioritisation of the caseload. Despite widespread limited capacity, teams across K&M show a huge amount of dedication to delivering the best services possible to C&YP and their families. Clinical and executive representatives from community providers, acute trusts and CCG commissioning teams attend quarterly PCN meetings at Demelza Kent with a view to improving service provision across K&M.

Table 9 Community end of life care provider by population coverage and total available nursing workforce (band 5 and above). *NB. Nursing staff delivering end of life care in different teams varied, therefore band 5 has been used as an arbitrary training level.*

Provider	Approximate population coverage in financial years 2014-15 to 2017-18 (children and young people with a life-limiting or life-threatening condition)	Nursing staff (band 5 and above) available to provide end of life care (Whole Time Equivalent)	Children and young people per 1 WTE nurse
Demelza	1500	18.3	82.0
KCHFT CCNT	550	16.04	34.3
Ellenor	550	7.4	74.3
MCH CCNT	220	14.3	15.4
COAST	150	18.8	8.0
DNT	50	2.2	22.7

8.2.2 Commissioning Arrangements

There is a significant resourcing strain on some community teams, making it increasingly difficult to deliver good-quality, equitable care. Alongside this, commissioning arrangements for EOLC in K&M have evolved organically and are incredibly complex, with providers delivering different services across different CCGs, making roles and responsibilities and patient pathways unclear. This can be seen in West Kent and DGS, where the role of the Ellenor team varies, and East Kent and DGS where the role of the KCHFT CCNT varies.

Worryingly, there was significant difficulty in ascertaining commissioning arrangements and service specifications in some areas. This was particularly notable in North Kent, where commissioners responsible for EOLC for C&YP in DGS and Swale could not be identified. Providers also reported a lack of specific consideration for palliative and end of life services for C&YP, as services for adults and children are not commissioned separately in North Kent.

Not all providers delivering EOLC have a formal commissioning arrangement for EOLC or a service specification. Some service specifications are also outdated and no longer reflect the CCG's expectations of what the services should deliver or the current service delivery. This is seen most prominently in West Kent, where the DNT provide EOLC for C&YP with cancer without a service specification and the service is currently based on historical arrangements which have not been updated or formalised. There was confusion around the reason for this, including reported difficulties referring cancer patients still on treatment to Ellenor, as well as commissioning arrangements with WKCCG.

8.2.3 Coordination of Care

There is significant overlap in caseloads between providers, therefore co-ordination between providers is paramount in the delivery of high-quality, clinically effective EOLC. This can be difficult, as not all providers have a formal commissioning arrangement to deliver EOLC or have adequate capacity.

There is significant collaboration between service providers in the form of shared caseload meetings and attendance at MDT or complex discharge meetings at tertiary centres, however not all teams attend these and not all meetings take place on a regular basis. There is some misunderstanding of other teams' role and responsibilities, as well as inconsistencies around the frequency of shared caseload meetings and teams in attendance, with some teams expressing interest in regular and more frequent meetings. Co-ordination between local hospital paediatric teams and community teams is also variable across the area. For example, the Tunbridge Wells Hospital team reported difficulty with involving the Ellenor team early in admissions, owing to inadequate capacity and confusion around referral criteria, including C&YP without a DNAR in place and those still receiving treatment. This particularly affects C&YP with cancer who tend to receive treatment for a longer duration. This impacts greatly on advanced care planning and discharge planning, as ward teams often require community team expertise to have conversations about death, dying,

resuscitation and available community services to combat the persisting stigma towards these topics.

8.2.4 24-Hour End of Life Care

24-hour EOLC is provided in the community by five providers: Ellenor, KCHFT CCNT, COAST, MCH CCNT and Demelza. Services vary across the patch. For example, OOH EOLC is provided on an ad-hoc basis by the COAST team and MCH CCNT, however there is limited capacity within the COAST and MCH teams to deliver this. OOH EOLC is not provided by the DNT, leaving a gap in home-based EOLC provision for C&YP with cancer who are not under Ellenor in West Kent. This not only affects continuity of care but may also result in inappropriate hospital admission.

8.2.5 End of Life Care at Home

Inadequate capacity and reserve capacity of services delivering EOLC at home is noted across K&M. This can lead to inappropriate hospital admission and hospital death, as well as significant stress for family members if the preferred location of care and/or death is the home. Inadequate capacity to provide overnight EOLC at home also means an increasing number of families have overnight packages of care funded by CHC and it is becoming increasingly difficult to source adequately trained agency nurses in some areas of Kent to provide the care needed.

8.2.6 Nursing Team Training and the Patient Pathway

There is variability in training levels of nursing staff within the hospice setting, in CCNTs, and on paediatric wards. There are complexities around the patient pathway at Tunbridge Wells Hospital and inadequate nursing staff training in EOLC. There was reported difficulty in referring patients to Ellenor due to confusion around referral criteria. Ellenor referral criteria for EOLC is in line with other hospices nationally, however some children with long-term health needs do not meet the criteria for Ellenor or the DNT e.g. long-term ventilated C&YP. There was reported difficulty in involving Ellenor during admissions and discharging patients to Ellenor due to inadequate capacity of the Ellenor team. Nursing staff also reported difficulty in having conversations with families around death, dying, resuscitation and hospice service provision with families without the support of the Ellenor team, which has caused increasing delays in putting DNARs and ACPs in place, involving hospice care, prolonged hospital admissions and inappropriate hospital deaths. There was also an expectation of the Ellenor team to deliver EOLC to ward patients due to nursing staff workload and lack of nursing staff training in EOLC and the use of equipment.

8.2.7 Specialist Paediatric Palliative Care Team Advice and Local Medical Support

There is no SPPCT in K&M. There is also a shortage of SPPC consultants nationally, with inadequate consultant support in tertiary centres in London. This has a noticeable impact when OOH support is required and when expertise is required on-site for difficult conversations with families around prognosis and specialist treatment plans. There is also

variable local OOH medical support across the area. Teams do their utmost to ensure anticipatory medications are prescribed and ACPs are completed within hours. If medical advice is needed OOH, some teams rely on local consultants and/or GPs who may lack the expertise in some conditions.

8.2.8 Equipment Ordering

Some providers reported inadequate availability of equipment in the community, as well as a lack of clarity around who is responsible for ordering that equipment, as it is set aside in some budgets and not others. Equipment ordering is expensive and time-consuming for the DNT, with a third of the caseload requiring consumables but not active nursing care from the team. The DNT receives inadequate funding to cover these equipment costs and ordering equipment and chasing orders can take a significant amount of time away from clinical work.

8.2.9 Bereavement Support

There is a lack of knowledge around and provision of locally commissioned bereavement services. The COAST team and MCH CCNT refer C&YP and their families to Demelza and tend to not refer to the commissioned NELFT Emotional and Wellbeing Service, which may or may not be appropriate for some families (most families are sign-posted to the charity Holding on Letting Go). Providers also reported inadequate service-specific bereavement support for families, for example after an unexpected death.

8.2.10 Paediatric Intensive Care Unit

There is no PICU in K&M (level 2 and 3 care). This has a noticeable impact on paediatric ward teams when there is a delay in transfer to London by the STRS as some C&YP require interim ventilation on the ward. This requires adequate nursing team capacity and training for the provision of one-to-one higher-level care, which may not always be available.

8.3 Service Activity Data

Not all providers record service activity and there are complexities with pulling data from some electronic systems. Ellenor, Demelza and KCHFT CCNT record service activity and data was received from Ellenor and Demelza. The DNT has recently begun recording basic service activity data. Where service activity is recorded, some teams lacked the necessary staffing and/or knowledge to pull relevant data out of the systems, causing gaps and significant delays in data collection and analysis.

8.4 Process Engagement

Engaging some providers and the Child Death Review Service for this Needs Assessment was extremely challenging. This included difficulty with identifying individuals and their roles within organisations, as well as variable responses via email and telephone. This led to very

long delays in arranging meetings and obtaining service activity data. Unfortunately, data was not received from the Child Death Review Service and the KCHFT CCNT.

9 Discussion and Recommendations for Service Planning

The landscape of palliative and EOLC for C&YP across the UK is changing. The need for services is escalating year-on-year owing to advancements in diagnosis and management of LLCs. This national picture can also be seen in K&M, where a complex and fragmented system is ill-equipped to cope with this growth in its current form. Likely because of small numbers, the needs of the population and service provision have gone unmapped, allowing services to evolve organically without adequate strategic planning. It is clear that services need to be well-placed with adequate funding and capacity, with special consideration given to cohorts in greatest need, including 15-19-year-olds and those from deprived backgrounds.

With recognition of children's palliative and EOLC as a priority area for the NHS in the Long Term Plan, and the development of the new NHSE service model underway, it is vital that K&M commissioners map out the services needed to meet the needs of their populations, in order to develop an up-to-date and impactful strategy for a new model of care. Co-ordination and collaboration with providers are vital and the PCN is well-placed to aid and drive this process. Specific discussion points and recommendations are outlined below.

9.1 The Need for End of Life Care Services for Children and Young People

In line with national prevalence studies, rates of LLCs amongst living C&YP and death rates from LLCs are consistently higher amongst C&YP in the most deprived decile. This highlights the importance of considering deprived groups when planning EOLC services. Young people aged 15 to 19 years-old also require specific consideration, owing to the rapid increase in prevalence of LLCs in this age band. Services need to be specifically tailored to this age group, whose needs fall somewhere between those met by children's and adults' services. As well as an increasing need for transition services, other conditions will become more prevalent in this age band as C&YP live longer, which need to be considered when planning services. The highest death rates from cancer can also be seen in this age group, highlighting the importance tailored bereavement services for their families.

Careful EOLC service planning in Swale is required in light of the rapid increase in LLCs amongst living C&YP. Particular attention should be paid to oncology, congenital and metabolic conditions, which are highly prevalent in Swale compared to other CCGs. Although of limited statistical significance, Ashford had one of the highest death rates from LLCs and is the only CCG where death rates increased between 2006-11 and 2012-17. This could be explained by the grouping of calendar years, therefore further work looking at yearly trends, location, diagnostic category and demographics of these deaths specifically would be beneficial in order to address this and carefully manage and plan services accordingly, if necessary. Although congenital conditions are the most prevalent LLCs amongst living C&YP, C&YP with haematological conditions have very high admission rates per person but deaths amongst this cohort are low. Secondary care services planning is vital

to cope with the increase in future admissions. This is particularly relevant to DGS, South Kent Coast and Medway, where the rates of haematological LLCs are highest.

The increase in hospital deaths and decline in hospice deaths in K&M may reflect either an increase in hospital admissions if families are unable to access community EOLC, families choosing to continue active treatment for longer, and/or a stigma towards hospice care and conversations about death and dying. The highest number of deaths from LLCs took place at William Harvey and Medway Maritime hospitals, both of which provide EOLC to C&YP with cancer and William Harvey is also likely to keep more unwell infants in the level 3 NICU. Future work should include analysis of CDOP data showing deaths in the preferred location and further analysis of hospital deaths and unplanned admissions.

9.2 Service Provision

It is vital that K&M commissioners are identifiable and map out the services needed to meet the needs of their populations. In order to meet the growing need in the long-term, commissioning arrangements should be revised, requiring intensive involvement of all commissioners and service providers (community and acute) across both K&M and London. The most pressing issue currently is the lack of 24-hour EOLC provision in some areas of K&M. In the immediate term, there needs to be clearly identified commissioners across K&M for EOLC for C&YP. Commissioners need to clarify current roles and responsibilities of each team and consider collaboration between teams to ensure OOH on-call rotas are adequately staffed, currently underway in North Kent and Medway.

In this Needs Assessment West Kent has been highlighted as an area of considerable complexity, with unclear roles and responsibilities between Ellenor and the DNT and an unclear patient pathway. Ellenor has a large population coverage and limited capacity, which is currently impacting on acute services, therefore commissioning arrangements with WKCCG need to be revised and the DNT needs to have a formalised service specification. Particular consideration needs to be given to cancer patients requiring EOLC, as neither the DNT nor Ellenor currently have adequate capacity to provide 24-hour EOLC to this cohort. The KCHFT CCNT currently provides EOLC to cancer patients in East Kent and therefore have the expertise to take on this responsibility in West Kent, however the team has limited reserve capacity. The patient pathway at Tunbridge Wells Hospital (and other hospitals) also needs to be streamlined, to ensure earlier involvement of the community team to provide support for conversations around death and dying, resuscitation and advanced care planning. Referral criteria of community teams needs to be clarified with paediatric ward teams, with consideration given to C&YP without a DNAR and long-term ventilated C&YP.

All acute trusts across K&M and London should be engaged with to provide more frequent training sessions in EOLC. This would help to build nursing team skills and confidence in having difficult conversations with families around death, dying and hospice service provision and streamline the patient pathway. Commissioners should also ensure providers

are aware of local commissioned services, including bereavement support, to ensure the best clinical care and support available is given to C&YP and their families.

Importantly, all providers across K&M should collect service activity data in a consistent way that can be shared easily between providers and commissioners. Potential benefits include wider scope for research and better-quality, cost-effective clinical care by targeting populations in greatest need. The PCN is well-placed to review service activity data collection practices and instigate a community database for data sharing.

9.3 Considerations for Future Work

This needs assessment was limited by lack of service activity data from providers and the Child Death Review Service. This needs assessment should be repeated when service activity data is available, in order to more accurately identify the C&YP not accessing EOLC services. Access to data for detailed analysis for both cohorts could also not be done due to limited death data linked to the KID. Areas for potential focus, as well as alternative methods are outlined below:

- There may be scope to include the PCMD or Hospital Episode Statistics (HES)-ONS-linked mortality data with the KID to allow more detailed analysis of cohort 2 and ensure the wider population in need is identified. This would allow for more detailed analysis of admission rates and hospital deaths, which can be considered alongside service provision. For example, unplanned admissions and hospital deaths could be looked at to identify unstable groups and areas where admissions and hospital deaths are disproportionately high.
- CDOP data showing deaths by preferred place of death and expected/unexpected could be obtained from the CDRS to identify problems accessing out-of-hospital EOLC. Access to child death data may be made easier by the introduction of the new National Child Mortality Database in 2019.
- Neonates could be included in the dataset to reflect the wider system.
- Prevalence by ethnicity should be looked at if data can be identified.
- Acute trusts across London and K&M should be engaged with to explore the patient pathway and the interface between acute and community services.
- Looking into why prevalence is significantly higher in males for cancer and neurological conditions than females is an interesting potential area for future work.
- Patient and family engagement would provide a vital perspective on service provision. This should be sought sensitively and respectfully.

10 Appendices

Appendix A

Life-Limiting and Life-Threatening Conditions

Fig. A1 ICD-10 diagnostic coding framework used to identify children and young people with a life-limiting and life-threatening condition²².

NEUROLOGY	HAEMATOLOGY	ONCOLOGY	METABOLIC	RESPIRATORY	CIRCULATORY	GASTROINTESTINAL	GENITOURINARY	PERINATAL	CONGENITAL		OTHER
A17	B20–B24	C00–C97	E31.0	E84	I21	K55.0	N17	P10.1	Q00.0	Q44.2	H11.1
A81.0	D56.1	D33	E34.8	J84.1	I27.0	K55.9	N18	P11.2	Q01	Q44.7	H49.8
A81.1	D61.0	D43	E70.2	J96	I42	K72	N19	P21.0	Q03.1	Q60.1	H35.5
F84.2	D61.9	D44.4	E71	J98.4	I61.3	K74	N25.8	P28.5	Q03.9	Q60.6	M31.3
G10	D70	D48	E72		I81	K76.5		P29.0	Q04.0	Q61.4	M32.1
G11.1	D76.1		E74			K86.8		P29.3	Q04.2	Q61.9	M89.5
G11.3	D81		E75					P35.0	Q04.3	Q64.2	T86.0
G12	D82.1		E76					P35.1	Q04.4	Q74.3	T86.2
G20	D83		E77					P35.8	Q04.6	Q75.0	Z51.5
G23.0	D89.1		E79.1					P37.1	Q04.9	Q77.2	
G23.8			E83.0					P52.4	Q07.0	Q77.3	
G31.8			E88.0					P52.5	Q20.0	Q77.4	
G31.9			E88.1					P52.9	Q20.3	Q78.0	
G35								P83.2	Q20.4	Q78.5	
G40.4								P91.2	Q20.6	Q79.2	
G40.5								P91.6	Q20.8	Q79.3	
G60.0								P96.0	Q21.3	Q80.4	
G60.1									Q23.2	Q81	
G70.2									Q21.8	Q82.1	
G70.9									Q22.0	Q82.4	
G71.0									Q22.1	Q85.8	
G71.1									Q22.4	Q86.0	
G71.2									Q22.5	Q87.0	
G71.3									Q22.6	Q87.1	
G80.0									Q23.0	Q87.2	
G80.8									Q23.4	Q87.8	
G82.3									Q23.9	Q91	
G82.4									Q25.4	Q92.0	
G82.5									Q25.6	Q92.1	
G93.4									Q26.2	Q92.4	
G93.6									Q26.4	Q92.7	
G93.7									Q26.8	Q92.8	
									Q28.2	Q93.2	
									Q32.1	Q93.3	
									Q33.6	Q93.4	
									Q39.6	Q93.5	
									Q41.0	Q93.8	
									Q41.9	Q95.2	
									Q43.7		

Appendix B

Supplementary Tables: Cohort 1

Table B1 Number and rates of living individuals admitted with a life-limiting or life-threatening condition by financial year.

NB. Individuals with multiple admissions across different financial years are counted once in each financial year and once in the 2014-15 to 2017-18 row.

Financial year	Individuals	Individuals per 10,000 relevant population
2014-15	426	9.9
2015-16	465	10.8
2016-17	553	12.6
2017-18	580	13.2
2014-15 to 2017-18	1415	8.1

Table B2 Living individuals admitted with a life-limiting or life-threatening condition by age band and financial year.

NB. Individuals with multiple admissions across different financial years are counted in each financial year and are counted once in the 2014-15 to 2017-18 row.

Financial year	3-12m		1-4y		5-9y		10-14y		15-19y	
	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population
2014-15	24	14.8	175	20.2	120	11.0	84	8.1	23	2.0
2015-16	20	12.3	170	19.6	124	11.0	99	9.4	52	4.6
2016-17	26	17.9	193	21.6	136	11.8	117	10.9	81	7.3
2017-18	27	18.8	212	24.0	144	12.3	109	9.9	88	8.0
2014-15 to 2017-18	93	15.1	555	15.8	325	7.2	267	6.3	175	3.9

Table B3 Living individuals admitted with a life-limiting or life-threatening condition per 10,000 relevant population by gender and financial year.

NB. Individuals with multiple admissions across different financial years are counted in each financial year and are counted once in the 2014-15 to 2017-18 row.

Financial year	Male		Female	
	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population
2014-15	236	10.7	190	9.1
2015-16	246	11.1	219	10.4
2016-17	319	14.3	233	10.9
2017-18	321	14.2	259	12.1
2014-15 to 2017-18	800	9.4	615	6.9

Table B4 Living individuals admitted with a life-limiting or life-threatening condition by Clinical Commissioning Group and financial year to 2017-18 column. Some individuals moved CCG within the time period and some individuals did not have a coded CCG. This accounts for differing values than previously reported.

Clinical Commissioning Group		2014-15		2015-16		2016-17		2017-18		2014-15 to 2017-18	
		Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population	Individuals	Individuals per 10,000 relevant population
Ashford		30	9.5	27	8.5	30	9.4	34	10.7	89	7.1
Canterbury and Coastal		38	8.2	47	9.9	47	10.1	56	11.8	128	6.8
Dartford, Gravesham and Swanley		53	8.4	61	9.6	52	8.0	66	10.1	159	6.3
South Kent Coast		47	10.3	53	11.7	48	10.6	60	13.3	276	15.6
Swale		22	7.8	31	10.9	51	17.5	50	17.1	138	12.8
Thanet		46	13.9	55	16.6	62	18.7	59	17.8	114	8.7
West Kent		100	8.5	102	8.7	132	11.1	140	11.7	171	3.7
Medway		89	12.8	85	12.1	128	18.1	111	15.6	331	11.3
Kent and Medway		425	9.9	461	10.7	550	12.6	576	13.1	1406	8.1

NB. Individuals with multiple admissions across different financial years are counted in each financial year and are counted once in the 2014-15

Table B5 Living individuals admitted with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and age band. *Suppressed data <6

NB. Individuals with admissions at different ages are counted in each age band. Individuals with more than one LLC are counted in each relevant diagnostic category. This accounts for larger numbers than reported previously.

Age band	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Circulatory	Gastrointestinal	Other	Total
3-12m	6	99	22	7	66	46	*	*	0	*	250
1-4y	131	282	93	21	122	91	10	10	*	*	770
5-9y	135	193	90	26	42	44	17	6	*	*	560
10-14y	87	120	71	23	63	27	19	8	*	*	425
15-19y	32	65	31	11	19	19	43	8	*	*	237
Individuals 3m-19y	195	540	216	58	216	177	86	24	15	14	1,541 (individuals)

Table B6 Kent and Medway hospital admissions of living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and age band. *Suppressed data <6

NB. Admissions at different ages are counted in each age band. Individuals admitted with more than one LLC are counted in each relevant diagnostic category. This accounts for larger numbers than reported previously.

Age band	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Circulatory	Gastrointestinal	Other	Total
3-12m	13	159	38	26	92	74	*	*	0	*	408
1-4y	725	580	207	52	174	156	12	15	*	*	1,935
5-9y	599	369	148	107	56	65	22	6	*	*	1,380
10-14y	393	224	104	101	89	41	22	8	*	*	993
15-19y	112	95	41	108	29	29	76	16	*	*	518
Total	1,842	1,427	538	394	440	365	132*	45*	24	24	5,234

Table B7 Living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and gender.

NB. Individuals with multiple diagnoses are counted in each diagnostic category. This accounts for larger numbers than reported previously.

Gender	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Circulatory	Gastrointestinal	Other	Total
Female	74	248	79	19	97	79	43	11	8	7	665
Male	121	292	137	39	119	98	43	14	7	7	877

Table B8 Living individuals admitted with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and Clinical Commissioning Group (CCG). *Suppressed data <6

NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Individuals with more than one condition are counted in each relevant diagnostic category. Only individuals with a coded CCG are included. Individuals who moved CCG are counted in each CCG area. This accounts for differing numbers than reported previously.

Clinical Commissioning Group	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Total
Ashford	14	27	13	*	16	12	7	89*
Canterbury and Coastal	20	52	19	*	19	16	7	133*
Dartford, Gravesham and Swanley	16	83	28	10	16	21	9	183
South Kent Coast	25	37	19	7	26	12	14	140
Swale	20	45	17	*	14	14	7	117*
Thanet	18	68	25	*	21	12	15	159*
West Kent	49	121	61	12	51	44	13	351
Medway	32	112	34	12	52	45	14	301
Kent and Medway	194	545	216	58	215	176	86	1,490

Table B9 Living individuals admitted with a life-limiting or life-threatening condition per 100,000 relevant population from 2014-15 to 2017-18 (combined), shown by diagnostic category and Clinical Commissioning Group (CCG). *Suppressed data

NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Individuals with more than one condition are counted in each relevant diagnostic category. Only individuals with a coded CCG are included. Individuals who moved CCG are counted in each CCG area.

Clinical Commissioning Group	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Total
Ashford	11.2	21.5	10.4	*	12.8	9.6	5.6	71.0
Canterbury and Coastal	10.6	27.6	10.1	*	10.1	8.5	3.7	70.7
Dartford, Gravesham and Swanley	6.3	32.9	11.1	4.0	6.3	8.3	3.6	72.5
South Kent Coast	14.1	20.9	10.7	4.0	14.7	6.8	7.9	79.1
Swale	18.6	41.7	15.8	*	13.0	13.0	6.5	108.5
Thanet	13.7	51.9	19.1	*	16.0	9.2	11.4	121.3
West Kent	10.6	26.2	13.2	2.6	11.0	9.5	2.8	75.9
Medway	10.9	38.2	11.6	4.1	17.8	15.4	4.8	102.8
Kent and Medway	11.2	31.4	12.4	3.3	12.4	10.1	5.0	85.5

Table B10 Kent and Medway hospital admissions of living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by diagnostic category and Clinical Commissioning Group. *Suppressed data(combined) by diagnostic category and Clinical Commissioning Group. *Suppressed data

NB. Circulatory, gastrointestinal and other categories have been omitted owing to very low numbers. Admissions for more than one condition are counted in each relevant diagnostic category. Only admissions of individuals with a coded CCG are included. Admissions of individuals who moved CCG are counted in each CCG area. This accounts for differing numbers than reported previously.

Clinical Commissioning Group	Oncology	Congenital	Neurology	Haematology	Respiratory	Metabolic	Genitourinary	Total
Ashford	102	49	37	40	31	14	12	285
Canterbury and Coastal	235	148	35	69	37	27	9	560
Dartford, Gravesham and Swanley	80	323	82	113	21	43	13	675
South Kent Coast	275	81	46	24	64	18	15	523
Swale	234	99	36	16	27	33	14	459
Thanet	167	168	83	*	43	20	34	515*
West Kent	406	318	120	30	91	116	17	1,098
Medway	342	240	97	96	122	93	19	1,009
Kent and Medway	1,841	1,426	536	388*	436	364	133	5,124*

Table B11 Living individuals with a life-limiting or life-threatening condition from 2014-15 to 2017-18 (combined) by deprivation decile.

Deprivation Decile	Individuals	Per 10,000 relevant population
1 (most deprived)	203	10.6
2	181	10.8
3	138	8.6
4	153	9.7
5	130	8.2
6	114	7.2
7	135	8.5
8	116	7.8
9	112	7.6
10 (least deprived)	119	7.1

Appendix C

Supplementary Tables: Cohort 2

Table C1 Deaths from a life-limiting or life-threatening condition by calendar year of registration

Calendar Years	Deaths	Deaths per 100,000 relevant population
2006-8	89	8.5
2009-11	71	6.8
2012-14	60	5.6
2015-17	59	5.4
2006-8 to 2015-17	279	6.6

Table C2 Deaths from a likfe-limiting or life-threatening condition by cause of death, age bank and calendar year of registration *Suppressed data <4

Cause of death	Age band	Years of registration								Total deaths 2006-8 to 2015-17	Total deaths per 100,000 relevant population
		2006-8		2009-11		2012-14		2015-17			
		Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population		
Cancer	1m-4y	8	3.5	5	2.1	6	2.4	4	1.6	23	2.3
	5-9y	*	*	5	2.0	*	*	4	1.4	*	*
	10-14y	10	3.6	6	2.2	4	1.5	5	1.8	25	2.3
	15-19y	10	3.5	9	3.1	12	4.2	9	3.2	40	3.5
	Total	28*	2.7*	25	2.4	22*	2.1*	22	2.0	102	2.4
Non-Cancer	1m-4y	33	14.5	26	10.7	21	8.2	25	9.8	105	10.7
	5-9y	*	*	5	2.0	4	1.5	*	*	*	*
	10-14y	8	2.9	4	1.5	*	*	*	*	*	*
	15-19y	17	5.9	11	3.8	7	2.5	6	2.2	41	3.6
	Total	58*	5.6*	46	4.4	32*	3.0*	37	3.4	177	4.2

Table C3 Deaths from a life-limiting or life-threatening condition from 2006-8 to 2015-17 (combined) by diagnostic category. *Suppressed data <4

Diagnostic category	Deaths
Oncology	102
Congenital	41
Neurology	39
Perinatal	32
Circulatory	20
Metabolic	13
Respiratory	13
Gastrointestinal	11
Other	0
Genitourinary	*
Haematology	*

Table C4 Deaths from a life-limiting or life-threatening condition by gender and calendar year of registration.

Year of registration	Male		Female	
	Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population
2006-8	57	10.7	32	6.3
2009-11	38	7.0	33	6.5
2012-14	29	5.3	31	6.0
2015-17	30	5.3	29	5.4
2006-8 to 2015-17	154	7.1	125	6.0

Table C5 Deaths from a life-limiting or life-threatening condition by Clinical Commissioning Group and calendar year of registration.

	Years of registration				Total deaths 2006-11 to 2012-17	Total deaths per 100,000 relevant population
	2006-11		2012-17			
Clinical Commissioning Group	Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population		
Ashford	9	5.0	14	7.4	23	6.3
Canterbury and Coastal	19	6.7	15	5.2	34	5.9
Dartford, Gravesham and Swanley	28	7.9	29	7.7	57	7.8
South Kent Coast	27	10.1	11	4.1	38	7.1
Swale	11	7.1	8	5.0	19	6.0
Thanet	20	10.4	7	3.6	27	6.9
West Kent	46	7.0	35	5.1	81	6.0
Kent	160	7.6	119	5.5	279	6.6

Table C6 Deaths from a life-limiting or life-threatening condition by deprivation decile and calendar year of registration.

Year of registration	Least deprived decile		Most deprived decile	
	Deaths	Deaths per 100,000 relevant population	Deaths	Deaths per 100,000 relevant population
2006-8	6	5.8	14	13.4
2009-11	5	4.8	16	15.2
2012-14	6	5.6	10	9.4
2015-17	6	5.5	11	10.0
2006-8 to 2015-17	23	5.4	51	12

Table C7 Deaths from a life-limiting or life-threatening condition by location of death and calendar year of registration. *Suppressed data <4

Location of death		2006-8	2009-11	2012-14	2015-17	2006-8 to 2015-17
Home		27	20	17	16	80
Hospice		7	9	7	*	*23
Other		4	*	0	0	*4
Hospital	London	20	13	19	19	71
	Kent and Medway	30	25	13	19	87
	Other	0	*	4	4	*8

Table C8 London, Kent and Medway hospital deaths from a life-limiting or life-threatening condition by location from 2006-8 to 2015-17 (combined).

Hospital	Deaths
William Harvey	25
Medway Maritime	20
King's College	14
St. Thomas's	13
Evelina Children's	13
Maidstone	11
St. George's	11
Great Ormond Street	10
Tunbridge Wells	10
Royal Marsden	9
Darent Valley	9
Queen Elizabeth the Queen Mother	8
University College	5

Appendix D

Supplementary Tables: Supplementary Tables: Population Forecasts

Table D1 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in West Kent by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Individuals projections post-2017-18 are 0-19y. Population data from the Office for National Statistics²¹. Assumes a constant rate post-2017-18.

Financial year	Individuals per 10,000 relevant population	Population	Individuals
2014-15	8.5	117,265	100
2015-16	8.7	117,289	102
2016-17	11.1	119,433	132
2017-18	11.7	119,436	140
2018-19	11.7	120,090	141
2019-20	11.7	120,927	141
2020-21	11.7	121,978	143
2021-22	11.7	123,064	144
2022-23	11.7	124,232	145
2023-24	11.7	125,198	146

Table D2 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in Swale by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Individuals projections post-2017-18 are 0-19y. Population data from the Office for National Statistics²¹. Assumes a constant rate post-2017-18.

Financial year	Individuals per 10,000 relevant population	Population	Individuals
2014-15	7.8	28,272	22
2015-16	10.9	28,362	31
2016-17	17.5	29,137	51
2017-18	17.1	29,257	50
2018-19	17.1	29,468	50
2019-20	17.1	29,732	51
2020-21	17.1	30,045	51
2021-22	17.1	30,393	52
2022-23	17.1	30,758	53
2023-24	17.1	31,120	53

Table D3 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in Dartford, Gravesham and Swanley by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Individuals projections post-2017-18 are 0-19y. Population data from the Office for National Statistics²¹. Assumes a constant rate post-2017-18.

Financial year	Individuals per 10,000 relevant population	Population	Individuals
2014-15	8.4	63,373	53
2015-16	9.6	63,689	61
2016-17	8.0	64,679	52
2017-18	10.1	65,235	66
2018-19	10.1	65,971	67
2019-20	10.1	66,807	67
2020-21	10.1	67,698	68
2021-22	10.1	68,594	69
2022-23	10.1	69,515	70
2023-24	10.1	70,370	71

Table D4 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in Medway by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Individuals projections post-2017-18 are 0-19y. Population data from the Office for National Statistics²¹. Assumes a constant rate post-2017-18.

Financial year	Individuals per 10,000 relevant population	Population	Individuals
2014-15	12.8	69,626	89
2015-16	12.1	70,019	85
2016-17	18.1	70,528	128
2017-18	15.6	71,082	111
2018-19	15.6	71,604	112
2019-20	15.6	72,161	113
2020-21	15.6	72,884	114
2021-22	15.6	73,742	115
2022-23	15.6	74,594	116
2023-24	15.6	75,375	118

Table D5 Projection of individuals (0-19 years-old) with a life-limiting or life-threatening condition in East Kent by financial year.

NB. Individuals pre-2018-19 are 3m-19y. Individuals projections post-2017-18 are 0-19y. Population data from the Office for National Statistics²¹. Assumes a constant rate post-2017-18.

Financial year	Individuals per 10,000 relevant population	Population	Individuals
2014-15	10.3	156,483	161
2015-16	11.6	157,408	182
2016-17	11.9	156,986	187
2017-18	13.3	157,503	209
2018-19	13.3	157,931	210
2019-20	13.3	158,394	211
2020-21	13.3	159,191	212
2021-22	13.3	160,166	213
2022-23	13.3	161,352	215
2023-24	13.3	162,487	216

Appendix E

Community Service Provision and NICE Quality Statements

Table E1 End of life care service provision for children and young people in Kent and Medway by provider

	Demelza	Ellenor	DNT	KCHFT CCNT	COAST	MCH CCNT
Areas covered	West Kent, East Kent, North Kent, Medway	West Kent, DGS	West Kent	East Kent, DGS	DGS, Swale, Medway	Medway
Community service provision for C&YP	<ul style="list-style-type: none"> Palliative care (including EOLC) Residential and day care <p>Includes: planned/unplanned symptom admission, emergency admission, Short Breaks, specialist therapies, transition services</p>	<ul style="list-style-type: none"> Palliative care (including EOLC) Oncology nursing care (DGS) Mainly home-based <p>Includes: symptom control, emergency respite (at home), Short Breaks (mainly at home), sibling support, under 5's group, transition services, emergency admission reduction and</p>	<ul style="list-style-type: none"> Specialist nursing care Palliative care (including EOLC) Home-based <p>Includes: blood-taking for oncology patients and ordering of medical consumables</p>	<ul style="list-style-type: none"> Specialist nursing care Palliative care (including EOLC) (East Kent only) Home-based <p>Includes: symptom control, emergency respite, Short Breaks</p>	<ul style="list-style-type: none"> Specialist nursing care Palliative care (including EOLC) Home-based <p>Includes: symptom-control, CHC packages</p>	<ul style="list-style-type: none"> Specialist nursing care (excluding cystic fibrosis and oncology) Palliative care (including EOLC) Home-based <p>Includes: symptom control and ordering of medical consumables</p>

		discharge facilitation				
Age group accepted	0-19	<ul style="list-style-type: none"> 0-19 (community) 14 and over (residential) 	<ul style="list-style-type: none"> Usually 0-16 0-19 complex needs 	0-19	Usually 0-18	0-19
Service provision for families and carers	Family Support Team, sibling support	Family drop-in support, sibling support, commissioned bereavement service	Private counselling service	Nil specific	Nil specific	Nil specific
Hours of operation	<ul style="list-style-type: none"> 24-hour hospice care 24-hour on-call specialist nursing advice (1 nurse and 1 senior manager). <p>Minimum of 2 nurses on-site at any one time</p>	<ul style="list-style-type: none"> 8am-6pm 7 days/week community specialist nursing care 24-hour on-call specialist nursing advice and home review for EOLC, as necessary 	8:30am-4:30pm Monday to Friday	<p>East Kent:</p> <ul style="list-style-type: none"> 9am-5pm Mon-Fri community specialist nursing care 8-9am and 5-8pm Mon-Fri and 9am-5pm Sat-Sun limited service 24-hour on-call specialist nursing advice and home review for EOLC, as necessary 	<ul style="list-style-type: none"> 8am-6pm Monday to Friday <p>Ad-hoc OOH on-call specialist nursing advice and home review for EOLC, as necessary (2 nurses)</p>	<ul style="list-style-type: none"> 8am-6pm Monday to Friday Ad-hoc OOH on-call specialist nursing advice and home review for EOLC, as necessary (2 nurses)

				North Kent: <ul style="list-style-type: none"> 9am-5pm Mon-Fri community specialist nursing care 		
Medical team on-site?	No- GP support	Adult palliative consultant and 2.3 WTE specialists at Ellenor Hospice (no paediatric specialists); GP support	Paediatric team on Hedgehog Ward, Tunbridge Wells Hospital	No- well-supported by local paediatric teams; GP support	Paediatric team on Dolphin and Penguin Wards, Medway Maritime Hospital	No- GP support
Grades and number of staff	<ul style="list-style-type: none"> 18.3 WTE nurses (band 5-8) 24.5 WTE HCAs (band 3) 	<ul style="list-style-type: none"> 0.8 WTE nurses band 8 3.6 WTE nurses band 7 3 WTE nurses band 6 3.5 WTE HCAs 	2.2 WTE clinical nurse specialists (one band 7 and three band 6)	<ul style="list-style-type: none"> 3 WTE nurses band 7 6.7 WTE nurses band 6 2.2 WTE nurses band 5 1.8 WTE nurses band 3 (North Kent: 2.1 WTE nurses, 1 WTE HCA) 	<ul style="list-style-type: none"> Oncology team: 1 WTE nurse band 7, 1.2 WTE nurse band 6 Cystic fibrosis and complex needs teams: 1 WTE nurse band 7, 2.6 WTE nurses band 6 Diabetes team: 1 WTE nurse band 7, 	Community team: <ul style="list-style-type: none"> 1.7 WTE nurses band 7 Approx. 6 WTE nurses band 6 LD team: <ul style="list-style-type: none"> 1 WTE nurse band 7 2.6 WTE nurses band 6 Special schools team: <ul style="list-style-type: none"> 3 WTE nurses (one band 6 and two band

					5.1 WTE nurses band 6 • CHC team: 1 WTE nurse band 7, 1 WTE nurse band 6, 4.9 WTE nurses band 5, 14.5 WTE nurses band 3	5)
Service overlap	<ul style="list-style-type: none"> • 20% overlap with Ellenor • KCHFT CCNT • DNT • COAST • MCH CCNT 	<ul style="list-style-type: none"> • Demelza • DNT • COAST 	<ul style="list-style-type: none"> • Ellenor • Demelza 	<ul style="list-style-type: none"> • Demelza • COAST 	<ul style="list-style-type: none"> • Demelza • Ellenor • MCH CCNT • KCHFT 	<ul style="list-style-type: none"> • Demelza • COAST
NICE Quality Statements						
C&YP and their families or carers are involved in developing an ACP	100% of admissions.	100% of families offered. Not all families wish to be involved.	Unknown	7/8 reviewed ACPs had parent/carers involvement documented. Patient involvement generally not documented.	Unknown	Newly formed service- unclear what role CCNT will play in developing ACPs.
C&YP have a named medical	100% of C&YP have SPPCC overseeing their care.	No- only oncology patients and C&YP with an ACP have	Unknown	100% of C&YP have SPPCC overseeing their	100% of C&YP have a paediatric consultant at	100% of C&YP have SPPCC overseeing their care.

specialist who coordinates and leads their care		named medical lead.		care.	Medway Maritime Hospital.	
Information provided about emotional and psychological support and how to access it	Yes- via Family Support Team and signposted to external services.	Yes- refer to Wellbeing Service and therapy services.	Yes- from team	Yes- via the team, Specialist Nurse Advisor Service and Therapy Service.	No support within service.	No support within service.
Each child or young person is cared for by an MDT that includes members of a SPPCT	Joint caseload meetings with Ellenor and the DNT. Attendance at Evelina MDT meetings and Evelina clinics at Demelza. Patients discussed with KCHFT on a case-by-case basis.	Joint caseload meetings with Demelza, the DNT and COAST. Attendance at Evelina MDT meetings. 15% caseload have SPPCT input.	Joint caseload meetings with Demelza and Ellenor.	Joint caseload meetings with Ellenor and COAST. Patients discussed with Demelza on a case-by-case basis.	Joint caseload meetings with Demelza, Ellenor, MCH CCNT and KCHFT CCNT.	Joint caseload meetings with Demelza and COAST. Do not attend tertiary MDT meetings.
Bereavement support for families or carers before and after death	Yes- via Family Support Team. Would also sign-post to other organisations for bereavement counselling.	Yes- bereavement pathway via Wellbeing Services.	Yes- from team and would also refer to private counselling service.	Yes- via the team and would also refer to Demelza for support.	No- would refer to Demelza.	No- can access Demelza services.

24-hour access to children's nursing care and advice from a SPPC consultant for C&YP approaching end of life	Yes	Yes- dependent upon capacity.	No- families contact Hedgehog Ward or SPPCT directly.	Yes- dependent upon CCNT capacity.	Intended, but inadequate nursing capacity. Families can also attend Penguin Assessment Unit.	Intended, but inadequate nursing capacity.
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Appendix F

Supplementary Tables: Service Activity

Table F1 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by age band.

Age band	Individuals
<1y	6
1-4y	9
5-9y	6
10-14y	6
15-19y	10

Table F2 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by gender.

Gender	Individuals
Male	21
Female	16

Table F3 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by Clinical Commissioning Group. *Suppressed data <4

Clinical Commissioning Group	Individuals
Ashford	*
Canterbury & Coastal	4
Dartford, Gravesham & Swanley	4
South Kent Coast	4
Swale	*
Thanet	*
West Kent	8
Medway	11

Table F4 Individuals admitted to Demelza for symptom control or end of life care from 1st November 2013 to 31st October 2018 by diagnostic category. *Suppressed data <4

Diagnostic category	Individuals
Oncology	4
Congenital	7
Neurology	16
Perinatal	*
Circulatory	*
Metabolic	5
Respiratory	*
Gastrointestinal	*
Genitourinary	0
Haematology	0
Other	0

Table F5 Ellenor deaths by calendar year. *Suppressed data <4

Calendar year	Deaths
2014	6
2015	5
2016	5
2017	*
2018	8

Table F6 Ellenor deaths by location. *Suppressed data <4

Location of death		Deaths
At home	In hours	6
	Out-of-hours	9
Hospital		8
Demelza		*

Table F7 Ellenor deaths from 1st January 2014 to 31st December 2018 by age band.

Age band	Deaths
<1y	4
1-4y	6
5-9y	5
10-14y	5
15-19y	6

Table F8 Ellenor deaths from 1st January 2014 to 31st December 2018 by gender.

Gender	Deaths
Male	7
Female	19

Table F9 Ellenor deaths from 1st January 2014 to 31st December 2018 by Clinical Commissioning Group.

Clinical Commissioning Group	Deaths
Dartford, Gravesham & Swanley	12
West Kent	14

Table F10 Ellenor deaths from 1st January 2014 to 31st December 2018 by diagnostic category. *Suppressed data <4

Diagnostic category	Deaths
Oncology	11
Congenital	8
Neurology	*
Perinatal	*
Circulatory	0
Metabolic	*
Respiratory	0
Gastrointestinal	0
Genitourinary	0
Haematology	0
Other	0