KENT PUBLIC HEALTH OBSERVATORY

End of Life Care

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Produced by

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End of Life Care

Introduction

End of life care (EoLC) is an important public health issue. Awareness and understanding of need as well as service commissioning and provision have been at best driven or promoted only in certain specialist/programme areas. A whole population perspective is required as to how EoLC fits into the wider health and wellbeing agenda and how services can be provided in the context of the emerging national health and social care integration agenda.

There is an increasing percentage of an older population across Kent, many of whom are experiencing multiple long-term conditions and they will require a primary care focus deliverable outside of hospital. Delivering care during a variable end of life time period presents many challenges including prognostic and communication barriers across diverse life-limiting diseases each of which have heterogeneous pathways through many services. It therefore cannot be defined by just one programme area alone.

EoLC is not an add-on service. It is a core and vital part of the existing service structure. The consequences of lack of integrated end of life care provision leads to unplanned and inappropriate admissions and readmissions during this time for the patient and family. This results in disrupted quality of care and more importantly a failure to meet the most common choice which is to die at home with family carers.

Key Issues and Gaps

Finding the one percent

A national campaign that addresses a lot of the EoLC strategy in terms of raising awareness and education, early identification of need, care planning is the Find Your 1% campaign. It is funded by the Quality, Innovation, Productivity, and Prevention End of Life Care work stream (QIPP) and is being hosted by the Dying Matters Coalition. It works with the Royal College of General Practitioners, the National End of Life Care Programme and others to ensure clinicians have the information and resources they need to support a good death. The campaign aims to enhance GPs' ability to:

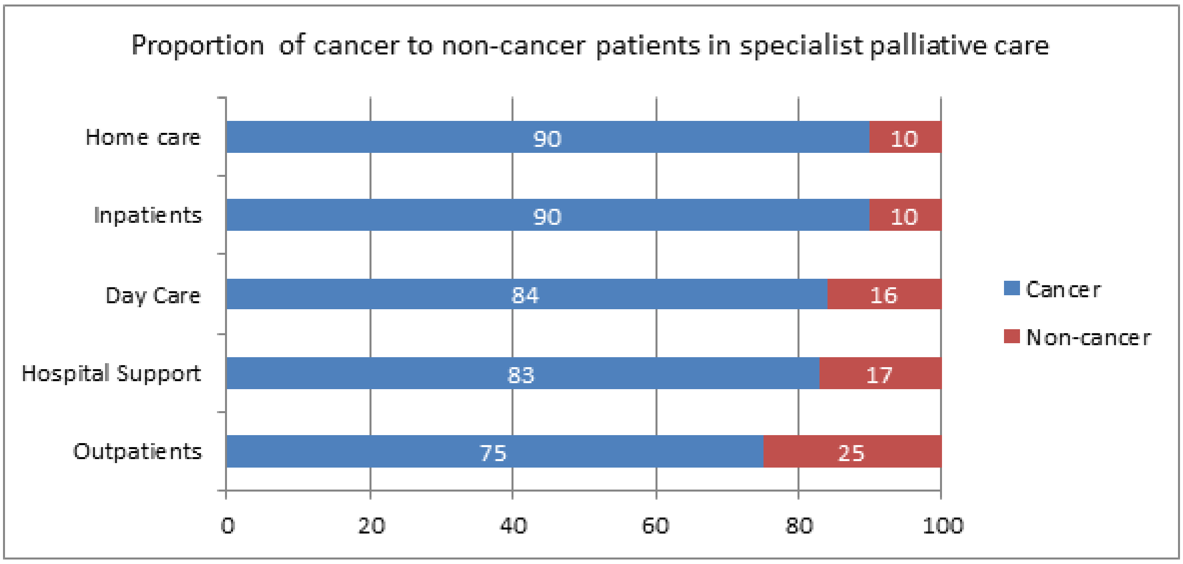
- identify patients with a year or less to live
- initiate conversations about end of life care
- put end of life care plans in place.

Increasing the remit of EoLC: Non-cancer diagnoses

Historically, palliative care services have focused on patients with incurable cancer. However, the current view is that access to palliative care should be based on need rather than diagnosis, and on that criterion many patients with non-malignant diseases qualify as well. The potential requirement for palliative care in other life-limiting illnesses is reflected in the National Service Frameworks.

However, despite the general acknowledgment that palliative care services need to be extended beyond cancer care, this is not yet common practice (see Figure 1 below). Part of the reason is possibly that non-cancer conditions are less predictable and have differing patterns of death, so a unified model of care for non-cancer conditions may not be achievable. However this does not mean that non-cancer conditions do not have specific needs that can be met, but it may require a more flexible EoLC model to meet the differing needs of individuals.

Figure 1: Proportion of cancer to non-cancer patients in specialist palliative care



Source: MDS 2008-11

There has been a national push towards increasing palliative care provision for non-cancer conditions. It may not necessarily mean hospice care but emphasises care based on need rather than diagnosis. This will need to be reflected in commissioning for EoLC services across Kent.

Who's at Risk and Why?

EoLC is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (DH 2008).

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months

- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life threatening acute conditions caused by sudden catastrophic events.(General Medical Council 2010).

End of Life Care Strategy

In 2008, the Department of Health’s End of Life Care Strategy ‘Promoting high quality care for all adults at the end of life’ was published

The EoLC strategy defines a ‘good death’, as:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends.

Some people do die as they would have wished, but many others do not.

The Department of Health’s End of Life Care Strategy ‘Promoting high quality care for all adults at the end of life’ (DH 2008) aims to bring about improvement in access to high quality care for all adults approaching the end of their life and more choice about where they would like to live and die. It encompasses all adults with advanced, progressive illness and care given in all settings. It covers 12 key areas:

- raising the profile of end of life care
- strategic Commissioning
- identifying people nearing end of life Care planning
- coordination of Care
- rapid access to care
- delivery of high quality services
- last days of life and care after death
- involving and supporting carers
- education and training
- measurement and research
- funding.

Key elements of expenditure on end of life care have been identified as: hospital admissions; hospices and specialist palliative care services; community nursing services; and care homes.

NICE (NICE 2011) has produced recent evidence about investment in end of life care services and potential savings to be made.

Since publication of the EoLC Strategy

Since 2008, implementation of the Strategy has been supported by the National End of Life Care Programme (NEoLCP) which has worked collaboratively with a wide range of partners in the statutory, voluntary and private sectors. This programme is also supported by the National End of Life Care Intelligence Network (NEOLCIN).

A fourth annual report on the EoLC strategy was published in 2012 (DH 2012). It charted progress, by showing the national number of deaths in usual place of residence had increased to 42.4%. The 'Dying Matters' programme is increasing discussion of attitudes towards death. A national programme, 'Find Your 1%', which aims to engage GPs in identifying the individuals on their lists who might be in their last year of life, so that they can undertake EoLC planning, has reached its midpoint target of 1,000 GPs signed up by August 2012. Results are also being seen from the Electronic Palliative Care Coordination Systems (EPaCCS), which record people's choice of place of care. The National Survey of Bereaved People – VOICES (Views of Informal Carers – Evaluation of Services) has reported its first results. Hospice care is most highly rated by respondents, followed by care at home. Care in care homes follows closely, but care in hospitals is rated much lower, although hospitals remain the most common place of death. (VOICES survey 2012)

In 2011, NICE produced a Care Quality Standard (NICE 2011a) for the end of life care for adults, covering all settings and services where care is provided by health and social care staff to adults approaching the end of life. The standard sets out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups. The document outlines sixteen quality statements. For each quality statement information is provided on: relevant quality measures, a description of what the quality statement means for each audience (service providers, health and social care workers, commissioners, and people approaching the end of life and their families and carer), data sources, and definitions.

NICE has also produced a NICE (2011) Guide for commissioners of EOLC for adults. This commissioning guide is a resource to assist commissioners, clinicians and managers to commission high quality and evidence based services across England.

In 2011, 'Commissioning End of Life Care: initial actions for new commissioners' was published by the National Council for Palliative Care and the NEoLCP, highlighting best practice (NCPC 2011).

The Level of Need in the Population and Assessment of Future Need

- just over 14,717 people died in Kent in 2016 and mainly of chronic diseases such as cancer, heart disease and respiratory illness

- the acute hospital remains the most frequent place of death (42.9%) though this has declined over the past few years in favour of people's homes, care homes and hospices
- over the past few years there has been renewed focus around improving the quality of End of Life Care nationally and locally as well as addressing the EoLC needs of non-cancer patients in specialist palliative care
- EoLC needs will differ between patients and one of the most important ways of improving EoLC in Kent is the identification of these EoLC needs early in patients and individuals. This will allow sufficient time to plan care, empower the patient and avoid inappropriate admissions to hospital and most of the significant events and negative experiences outlined in the needs assessment.

Practical steps include:

- improving palliative care registers to find the 'one per cent', or using risk stratification to identify relevant patients
- sharing an EoLC register in primary and secondary care to ensure health and social care staff identify these people early
- training of frontline staff to identify and meet the needs of this population group
- in terms of future need, there is an expected increase in the number of cancer and non-cancer deaths due to demographic change. This will have implications on the EoLC service and adequate planning needs to be undertaken to deal with
- an increase in capacity due to increasing cancer deaths
- developing the service to meet the needs of non-cancer patients
- ensuring adequate support is available to meet the EoLC needs of an emerging cohort with dementia.

A major opportunity to address some of the key issues outlined above is through adoption of the new Long Term Conditions Agenda that incorporates the themes of risk-stratification, integrated teams and self-care. The vision is for a unified data hub that integrates activity across all health and social care and a fully functional system will enable early identification for those at risk of death, enable more accurate EoLC planning across a population and ensure health and social care are better coordinated and integrated with each other.

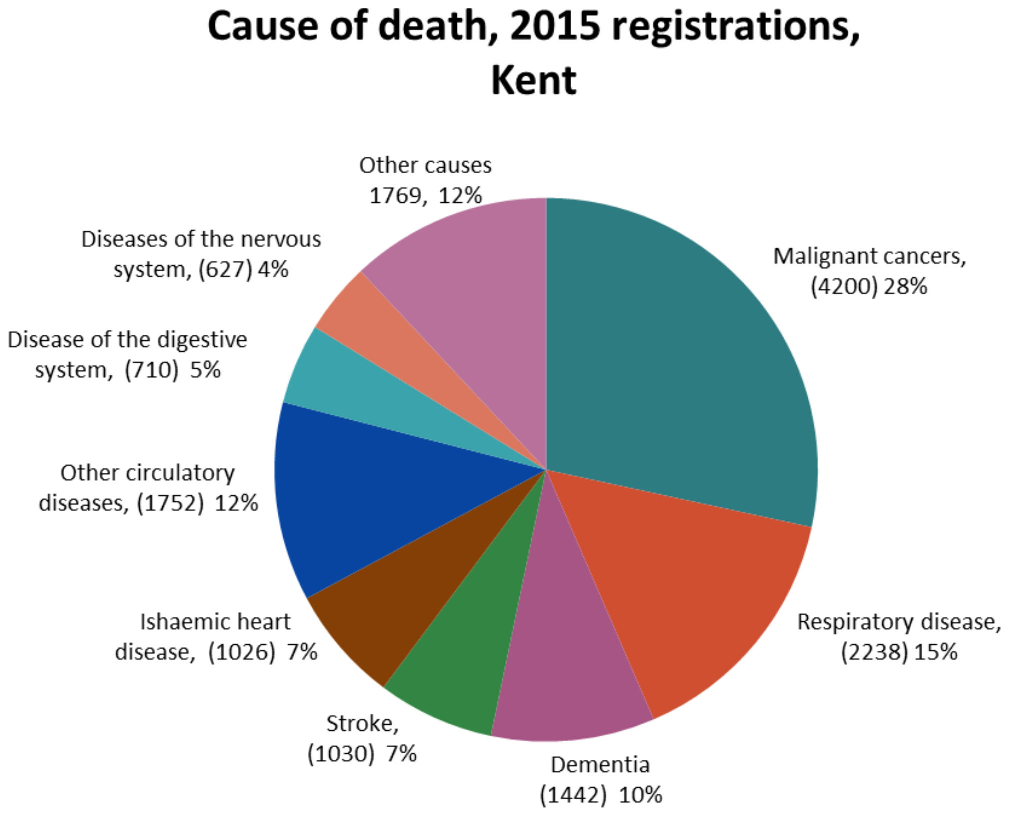
Current Services in Relation to Need and Description of Key Inequity Gradients

The local context

In Kent there has been a renewed emphasis on EoLC across the range of stakeholders.

Estimating Need: Deaths in Kent

Figure 2: Cause of death for Kent registered patients, 2015 registrations

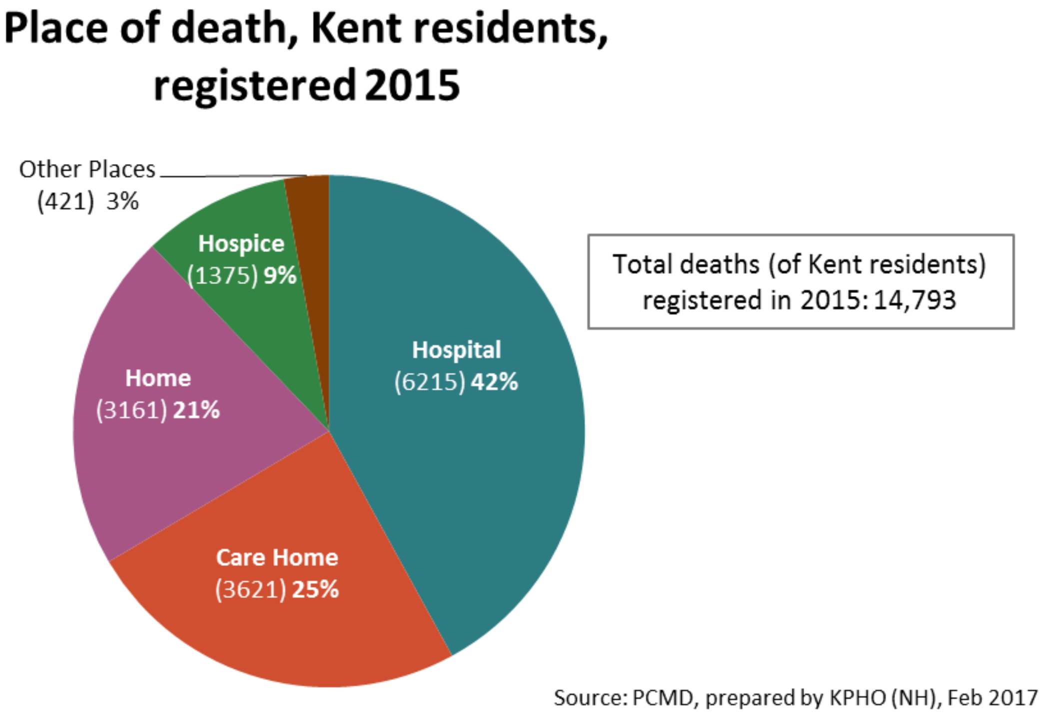


Source: PCMD, prepared by KPHO (NH), Feb 2017

The majority of deaths in Kent were caused by chronic conditions including cancer (28%), respiratory disease (15%), coronary heart disease (7%), stroke (7%) and other circulatory disease (12%). These proportions have changed very little over the past 12 months.

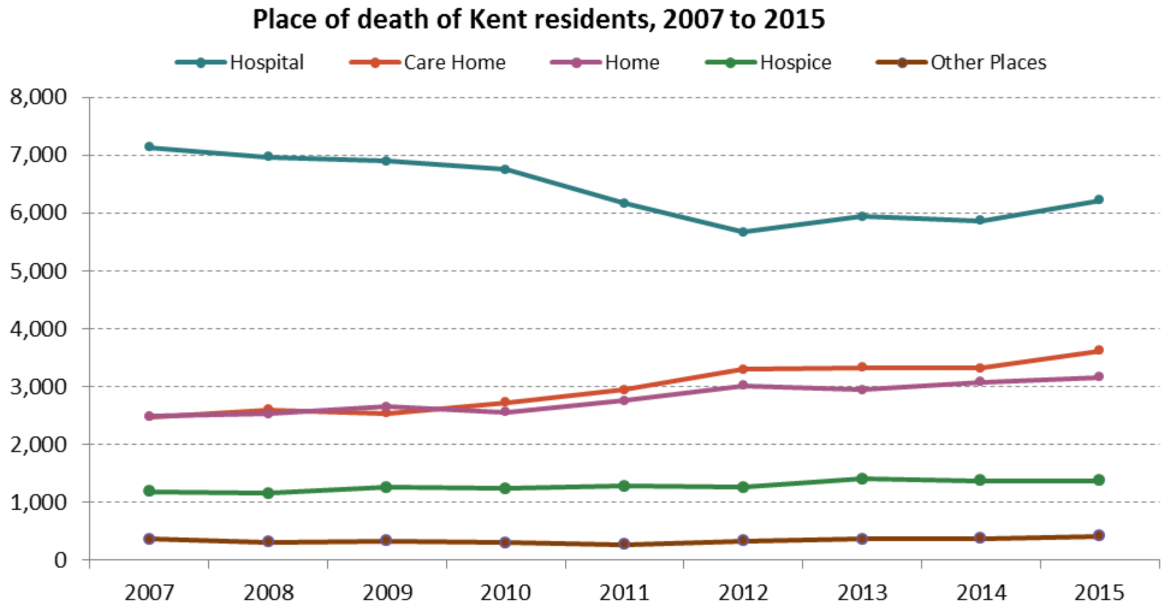
Analysis of deaths nationally suggests that sudden death ranges between 25% and 42%. This suggests that between 3,679 and 6,181 deaths in Kent were unexpected and could not have been identified as requiring some EoLC input in 2015 to 2016. The majority of these deaths may not have required significant EoLC support, however there will also be a proportion of this cohort that would not have been identified in time and not received satisfactory EoLC.

Figure 3: Place of death for Kent registered patients, 2015



Source: PCMD, prepared by KPHO (NH), Feb 2017

Figure 4: Mortality by place of death for Kent registered patients, 2007 to 2015



Source: PCMD, prepared by KPHO (NH), Feb 2017

Home is defined as the deceased's own private residence. Usual place of residence includes home, care homes and religious establishments. Deaths from external causes have been excluded.

Work carried out by the National Cancer Intelligence Network shows preferences for place of death vary between age-groups. Younger people favour home deaths more than their older counterparts and it this is thought to be due to a greater appreciation of the symptoms and challenges of illness and advanced age. The preferences of those aged >75 are important as they account for 67% of all deaths and thus most closely mimic the preferences of those nearing the end of their lives.

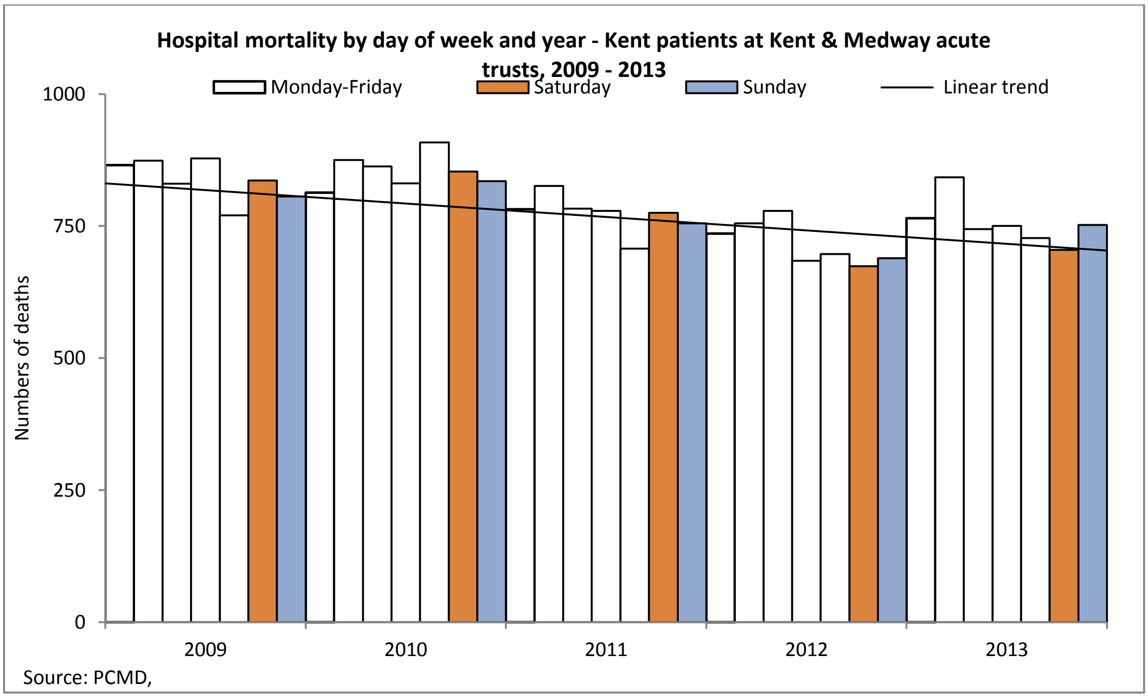
Table 1: Preferred place of death

Place of Death	Preference 16+	Preference 75+	Actual at death
Home	62%	45%	20%
Hospital	2%	6%	46%
Hospice	32%	41%	9%
Care home	1%	5%	24%
Other	3%	3%	1%

Mortality in secondary care

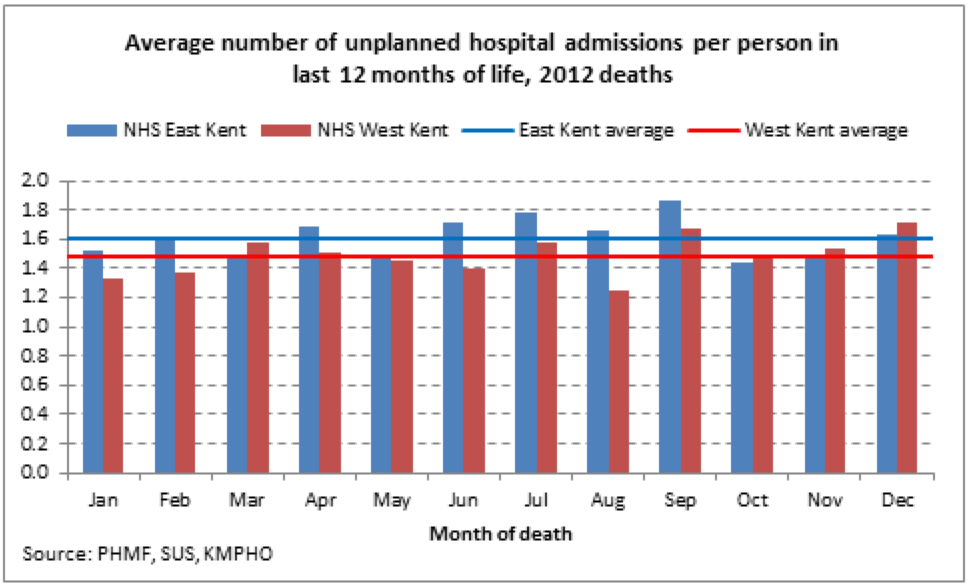
It has been recognised that for the majority of the Kent population, death in hospital is not an ideal outcome for patients, carers or health professionals. Over the past few years there has been varied work locally looking at mortality in secondary care, to better understand the situation and look at potential solutions that can be achieved in partnership with providers and commissioners.

Figure 5: Hospital mortality by day of week and year - Kent patients at Kent and Medway acute trusts, 2009 to 2013



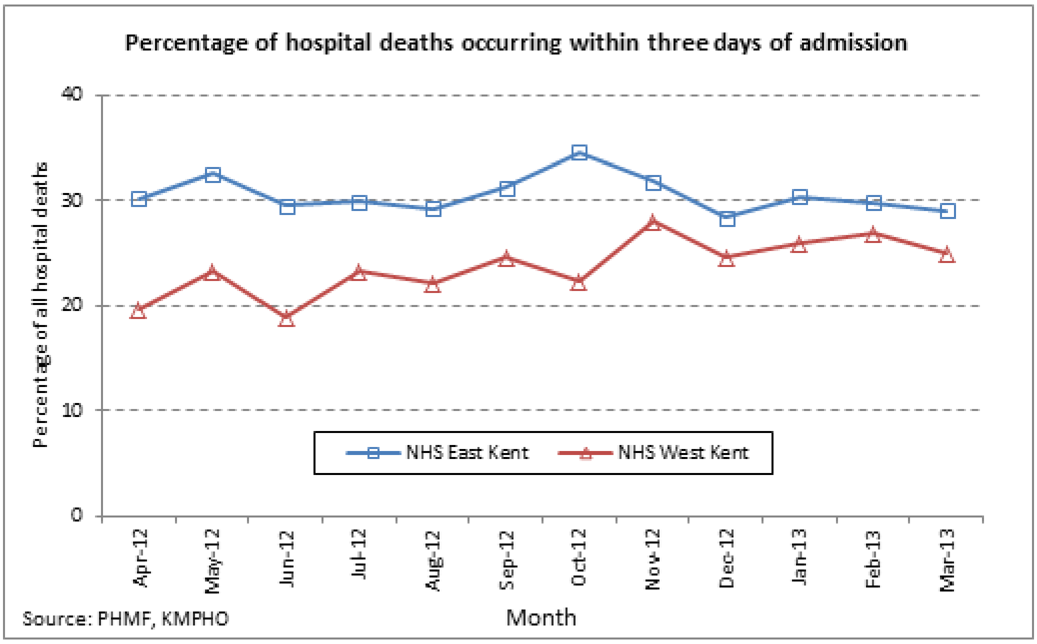
Source: PCMD,

Figure 6: Average number of unplanned hospital admissions per person in last 12 months of life 2012 in Kent



The frequency of admissions decreases almost exponentially from a modal value of zero, the median number of admissions is one. From 2010 to 2011 data just over three-fifths of patients who died in March 2011 had at least one admission between March 2010 and February 2011. Approximately one-fifth had three or more admissions during this time.

Figure 7: Proportion of hospital deaths in Kent occurring within 3 days of admission



EoLC JSNA Figure 8

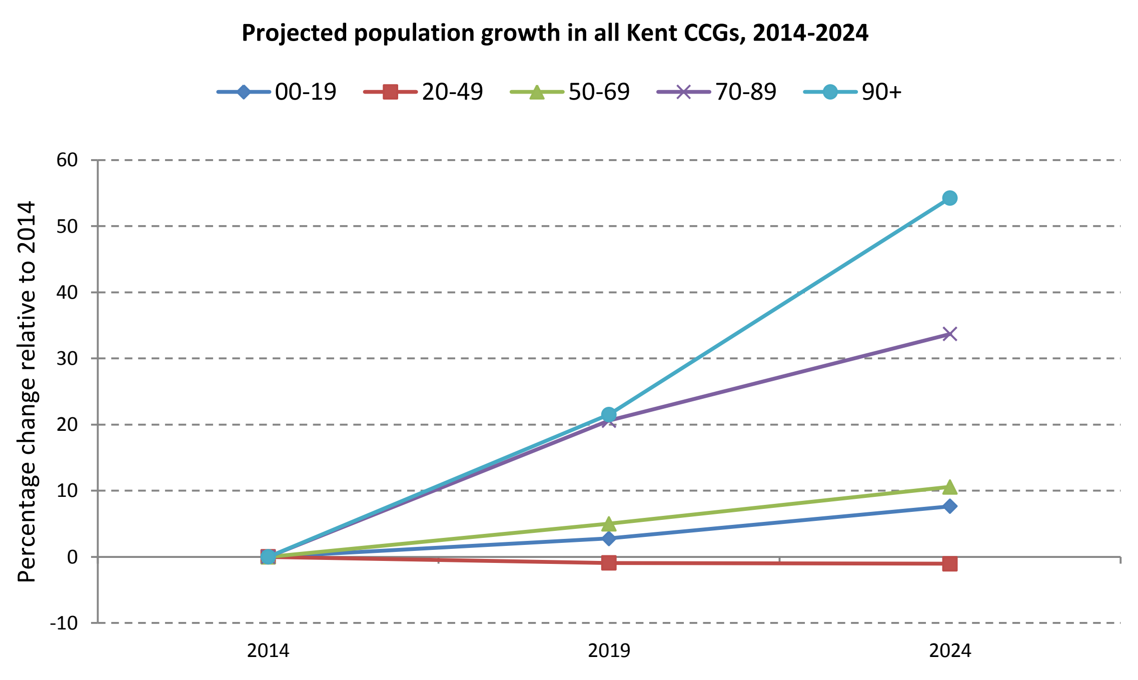
Historic analysis (shown above) reflects all deaths, not just those who were at end of life, and may therefore overstate the gap in preferred place of death against actual place of death. Further work is necessary to repeat this analysis for a range of conditions which could act as proxy for ‘end of life’ patients, and would include COPD, heart failure and angina.

Projected Service Use and Outcomes in Three to Five years and Five to 10 Years

Extent to which these will redress equity differentials/un-met need

Given the projected increase in the proportions of older age groups between 2014 and 2024 (see Figure 8 below) the number of actual deaths will increase (although not necessarily the proportion of deaths). This may present pressures upon provider services both health and social care. CCGs in Kent have and continue to develop and enhance their EoLC strategies and associated commissioning strategies to ensure that there are equitable and suitable services that can be accessed by both patients and carers.

Figure 8: Projected population growth in all Kent CCGs, 2014 to 2024



Source: ONS, KMPHO

Evidence of What Works

Assessment of expected impact (including where possible social care impact assessment)

Department of Health

(2008) End of Life Care Strategy: promoting high quality care for all adults at the end of life. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

(2012) End of Life Care Strategy: 4th annual report. https://www.gov.uk/government/news/end-of-life-care-strategy-fourth-annual-report

(2012a) NHS Outcomes Framework 2013/14. https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014

(2012b) First national Voices survey of bereaved people: key findings report. http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf

NICE Guidance

(2011) QS13: Quality Standard for End of Life Care for Adults. Available at: http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13

(2012) CMG42: End of life care for adults (Commissioning Guide). Available at: http://www.nice.org.uk/guidance/cmg42

Public Health England

(2013) Palliative and End of Life Care for black, Asian and minority ethnic groups in the UK. http://www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf

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

National

National Audit Office (2008) End of Life Care. London: NAO. http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

National Council for Palliative Care (2011) Commissioning End of Life Care: initial actions for new commissioners. http://www.ncpc.org.uk/sites/default/files/AandE.pdf

National End of Life Care Intelligence Network (Public Health England) http://www.endoflifecare-intelligence.org.uk/home

National End of Life Intelligence Network (2012) What do we know now that we didn’t know a year ago? http://www.endoflifecare-intelligence.org.uk/view.aspx?rid=464

NHS The National End of Life Care Programme has now closed (April 2013). Some elements of the programme's work continue within NHS Improving Quality. The continuing work streams are:

- Transforming end of life care in acute hospitals
- Electronic palliative care coordination systems
- Health care facilitators and social care champion's network.

Others

General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making. www.gmc-uk.org/End_of_life.pdf_32486688.pdf

Georghiou T et al (2012) Understanding patterns of health and social care at the end of life: research report. London: Nuffield Trust. http://www.nuffieldtrust.org.uk/sites/files/nuffield/121016_understanding_patterns_of_health_and_social_care_full_report_final.pdf

Hatziandreu E, Archontakis F, Daly Andrew, in conjunction with the National Audit Office/Rand Europe (2008) The potential cost savings of greater use of home- and hospice-based end of life care in England. http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

Healthcare for London (2011) End of life care: good practice guide. http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/EoLC-care-guide.pdf

Information Standards Board for Health and Social Care (2012) National Information Standard. http://www.isb.nhs.uk/library/standard/236

King's Fund (2010) Implementing the end of life care strategy: lessons for good practice. http://www.kingsfund.org.uk/publications/implementing-end-life-care-strategy

Leadbeter, C and Garber, J (2010) Dying for Change. London: Demos. http://www.demos.co.uk/files/Dying_for_change_-_web_-_final_1_.pdf?

User Views

There is currently insufficient evidence from local service user carers apart from the National VOICES source. Steps are currently in place (December 2016) to strengthen this aspect.

Unmet Needs and Service Gaps

Finding the 1%

A national campaign that addresses a lot of the EoLC strategy in terms of raising awareness and education, early identification of need, care planning is the Find Your 1% campaign. It is funded by the Quality, Innovation, Productivity, and Prevention End of Life Care work stream (QIPP) and is being hosted by the Dying Matters Coalition. It works with the Royal

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- identify patients with a year or less to live
- initiate conversations about end of life care
- put end of life care plans in place.

Increasing the remit of EoLC: Non-cancer diagnoses

See Key Issues and Gaps on pages one and two.

Recommendations for Commissioning

With special emphasis on whole systems approach

- link with planning for areas such as long term conditions, care of the elderly, dementia care and carers support
- ensure each GP practice has a means of identifying people approaching end of life, and holds a register of such people (Finding your 1%)
- ensure all people on the register are given a holistic assessment of their care and support needs
- use local population data available form National End of Life Intelligence Network, Hospital Episode Statistics, QOF
- agree quality outcome measures for local organisations – using EoLC Strategy Quality Markers and Measures for EoLC, also NICE quality standard (NICE 2011)
- educate professionals to initiate end of life conversations and advance care planning
- ensure people on EoLC register have access to an identified care co-ordinator, linking all services including voluntary sector and social care
- develop local information sharing systems, particularly for use by out of hours services
- develop pathways for transitions, e.g. from long-term conditions to end of life care
- appoint a clinical commissioning board member to lead on EoLC
- link with partners: local authorities for joint commissioning; voluntary sector organisations; Health and Wellbeing Boards; local care homes; community based supported housing; and user involvement groups
- educate on three levels: public health and population level, individuals to make informed choices, workforce

- work with acute care, so that EoLC is carried out appropriately, e.g. using an appropriate Care Pathway
- realign resources away from unplanned acute care to planned community support.

Locality profiles have been produced to inform service planning and provide comparisons. The profiles present over 40 indicators relating to end of life care and allow easy comparison of a locality's position to England and the current SHA (NEoLCIN website). See Local Authority Profiles 2012 Kent (//www.endoflifecareintelligence.org.uk/end_of_life_care_profiles/la_2012_pdfs)

Recommendations for Needs Assessment Work

There is a need to update current assessments particularly in terms of predicting need and access to palliative care.

Key Contacts

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7. EoLC for people with dementia commissioning guide. 20 June 2012
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National End of Life Care Programme

9. An analysis of the numbers of hospital complaints relating to end-of-life care over a six month period in four hospital trusts. National End of Life Care Programme. November 2010
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