

End of Life Care
Health Scrutiny Committee
 19/03/14

End of Life Care

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Purpose of the report:

Overview of Services that support individuals’ choices in end of life care.

End of Life Care Definition

- a) The term ‘end of life care’ can often be interpreted in a variety of ways. Throughout this document the term ‘end of life care’ (EOL) will adhere to the following definition:

‘Care that helps all those with advanced, progressive, incurable illness (malignant and non-malignant alike) 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.’

Introduction

1. Due to the ageing population, the number of deaths per year in England and Wales is expected to rise by 17% between 2012-2030 (Gomes & Higginson 2008), increasing pressure on the quality of End of life care (EoLC) services.
2. In an ageing population, the number of deaths in England is set to rise from 500,000 to 590,000 over the next 20 years increasing pressure on the quality of EoLC services.
3. Nationally 70% of people would prefer to die at home, yet 51% die in hospital.
4. End of life care is one of the 12 national QIPP (Quality, Innovation, Productivity and Prevention) work streams and is a national priority. Combined with the End of life care strategy (2008) the focus is on early identification of patients, integration of services and patient centred care.
5. With increasing age, patients accrue multiple co-morbidities and more complex need. Historically, End of life care has always centred on cancer. Future provision must cater for all other long term conditions (respiratory, cardiac, and neurological including dementia) and we also need to recognise general frailty.

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6. When end of life care is unplanned it makes it more likely that people are admitted to hospital in a crisis and as a consequence die in an unfamiliar and possibly distressing environment
7. In areas using an Electronic Palliative Care Co-ordination System (EPaCCS), 76% of people die in their preferred place & 8% die in hospital, a significant improvement in quality of care. Research shows that (after friends & family) people turn to GPs for information about EOLC- education, training and professional support are key to the EPaCCS.

End of Life Care Pathway

8. Improving end of life care in Surrey is a key priority for the Clinical Commissioning Groups, linked to our growing aging population and ensuring people and their families are able to access the care they need, as well as die with dignity in their preferred setting of care. There is also a growing prevalence of dementia with people in Surrey living longer, which requires commissioning screening, diagnosis and support services to help people maintain independent lifestyles, as well as their carers.
9. Our aim is to commission end of life care pathways that consist of high quality service, embed best practice and support both patients and carers, taking account of their physical, psychological, spiritual, cultural and social needs during the end of life and into bereavement.

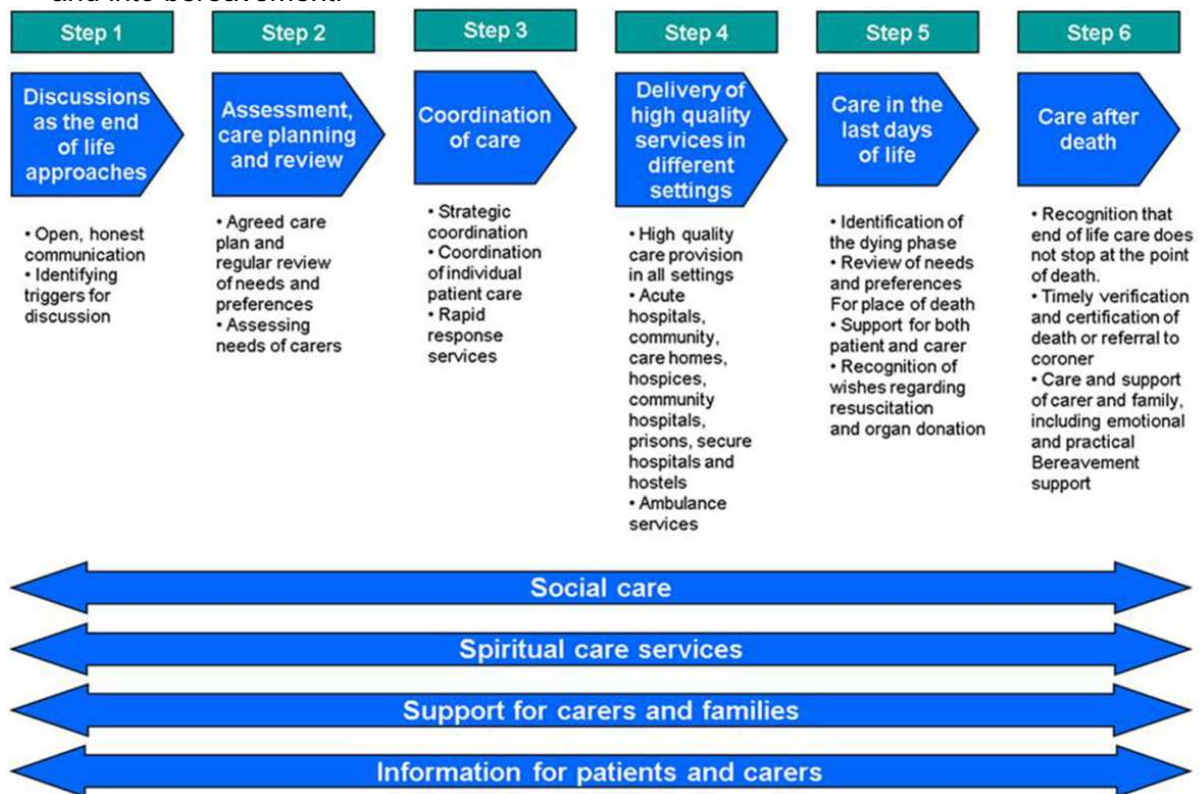


Figure 1: End of Life Care Pathway

10. All the Clinical Commissioning Groups in Surrey have identified end of life care as a local priority for improvement, and are implementing plans that are tailored to local needs as outlined in the sections below.

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East Surrey CCG End of Life Care Strategy

1) Summary

- a) Improving the coordination of end of life care for our population is one of the 3 local ESCCG priorities and straddles many of the work streams related to Long Term Conditions and admissions avoidance. With 70% of people preferring to die at home and yet 51% still dying in hospital a significant transformation in coordination and provision of care is required. Where patients are identified as end-of-life in East Surrey, 92.5% achieve their Preferred Place of Death (First Community Health & Care.)

2) Improvements in End of Life Care Services:

- a) Implementation of an Electronic Palliative Care Co-ordination System is planned from April 2014 (ShareMyCare) to improve identification and communication of patient's wishes, while working with St Catherine's Hospice to provide communications, clinical and education support.
- b) A provider led EoL Programme Board has been established across the local health economy. The aim of the Board is to work towards the development of a cohesive approach to End of Life Care involving key partners across services within the local health economy to benefit the patient and carer experience.
- c) Advanced Care Planning documentation and an EoLC Pathway have been redesigned and are in their final drafts supported by Marie Curie Cancer Care.
- d) EoLC is commissioned from the local community provider First Community Health & Care through the District Nursing service specification.
- e) Commissioning of a Risk Stratification Tool and a Proactive Care Team to improve early identification and support for patients at greatest risk of hospital admission and in need of intensive community support.
- f) Integrated EoLC Services commissioned using the Better Care Fund to ensure whole system working.
- g) The East Surrey Dementia Commissioning Plan has been agreed and Implementation Task & Finish Groups are being established with implementation over the next 12-18 months.
- h) A Clinical Lead for EoLC and a Macmillan GP are in post.
- i) The Surrey-wide CHC review identified the need for a geographical focus and ESCCG plans to support a robust fast track process for those wishing to die at home.
- j) A Nursing Home Demand Management Scheme has been implemented to provide targeted support by GP's to community care homes offering MDT support.
- k) The Long Term Conditions Telehealth project for COPD (Chronic Obstructive Pulmonary Disease) & Heart Failure was implemented in December 2013 to promote better self-management at home.
- l) A community service for pleural effusions & ascites, using vacuum-assisted drainage to support palliative care has been commissioned.
- m) Marie Curie Cancer Care approached Surrey and Sussex Healthcare Trust (SASH) in mid-2013 to discuss the possibility of more collaborative working to improve End of Life care for Surrey and Sussex patients, within the SASH catchment area. They introduced the concept of the supported discharge model, this is a model that Marie Curie has successfully implemented in Acute Trusts in other areas and is having positive results. A decision had been made to analyse and highlight problems with the discharge service for one year, with one or two nurses (Marie Curie funded) working within SASH, to enable solutions to expedite discharge.
- n) A pathway & gap analysis was developed through workshops with a sub-group of the East Surrey, Crawley, Horsham and Mid-Sussex CCGs End of Life Care Programme Board. Each phase identified what people at the End of Life, relatives and carers

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need; what support is available in East Surrey, Crawley, Horsham and Mid Sussex to support these needs and what needs to happen to ensure those needs are met.

North East Hampshire and Farnham CCG End of Life Care Strategy

1) Summary

- a) Our key objective is to increase the percentage of patients dying in their preferred place of care, year-on-year for the next five years. We have identified the following critical success factors to achieving this:
 - i) The timely identification of patients at end of life using appropriate prognostic indicators – such as, but not limited to, those outlined by the Gold Standards Framework (2011).
 - ii) Ensuring discussions take place with patients, and carers where appropriate, about their wishes and future care needs as early as the patient feels comfortable to do so. Recording of this information will need to be populated electronically on the ‘Gold Register’.
 - iii) Ensuring providers of EoL Care have real-time, immediate access to patients’ wishes to enable the effective co-ordination of their care.
 - iv) An agreed clinical model and pathway is developed with providers for the provision of cohesive and co-ordinated EoL Care.
 - v) Ensuring Providers embed the End of Life Care Quality Standards (2011) in all care settings.

2) Our plans to improve end of life care

- a) Improve public perception of death and dying so that our community is not threatened by this topic and feel comfortable enough to discuss these matters free and openly.
- b) Adopt a consistent approach to the early identification of all patients nearing end of life using appropriate prognostic indicators such as, but not limited to, those outlined by the Gold Standards Framework (2011).
- c) Increase the number of discussions taking place between patients and healthcare professionals, and carers where appropriate, about their wishes and future care needs as early as the patient feels comfortable to do so.
- d) Increase the number of patients uploaded onto the Gold Register (EPACCS) in order to ensure providers of EoL Care have real-time, immediate access to patients’ wishes to enable the effective co-ordination of their care.
- e) Ensure there is EoL healthcare support readily available to patients 24 hours a day, 7 days a week to enable quality palliative and supportive care to be delivered within our locality in an efficient manner.
- f) Improve the collaborative working arrangements and communication links between EoL Care providers in order to ensure patients experience a seamless, streamlined and holistic service to cater for the wide range of individual needs and preferences of patients.
- g) Improve the access to EoL training to ensure that all healthcare professionals involved in delivering EoL care have the confidence, support, and appropriate skills and competences in order to deliver high-quality, effective care.
- h) Ensure all providers have the End of Life Care Quality Standards (2011) embedded in all care settings.
- i) Ensure that following the death of a patient any carer/friend/family member wishing to receive bereavement support is offered this in a timely fashion and receives appropriate counselling and/or support.
- j) Ensure all EoL care and support is equitable for all our patients across the CCG.

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Guildford and Waverley CCG End of Life Care Strategy

1) Summary

- a) The CCG has identified a number of organisational requirements and enablers to support the delivery of end of life care. The CCG has appointed a GP for Cancer Care in partnership with MacMillan and we have a governing body GP lead who provides clinical leadership for end of life care.
- b) The CCG is currently in discussion with its current providers and partners, (Royal Surrey County Hospital, Surrey County Council, Phyllis Tuckwell Hospice, Virgin care, Marie Curie and Macmillan) to agree the most effective model of care for people in need of end of life care. The need for home-based care is likely to increase. This will require decision-making about the skill mix required and competencies, roles and responsibilities.
- c) Funding for end of life care is provided through a number of single and multi- agency agreements that include:
 - i) NHS
 - ii) Council
 - iii) Charitable Donation

2) Our plans to improve end of life care

- a) Integrating services to work more effectively and provide a single point of co-ordination for people needing end of life care
- b) Increasing early identification including risk stratification to ensure patients get the support they need
- c) As part of our overall End of Life Care Strategy we will be working towards the implementation of the Gold Standard Framework (including Advanced Care Planning), encouraging appropriate use of DNAR paperwork and ensuring that whenever it is possible all patients including Cancer Patients can die in the location of their choice. This will be supported by a Macmillan GP Facilitator.
- d) Implementing Palliative care beds within hospital to improve the co-ordination of care for those people requiring end of life care.

3) Next Steps

- a) Implement agreed integrated service in Guildford and Waverley – July 2014
- b) Implement Gold Standards Framework plan for Care Homes in Guildford and Waverley – June 2014
- c) Evaluate Palliative Care Bed pilot at Royal Surrey County Hospital – April 2014
- d) Implement Dementia Liaison Service for Dementia Care Homes – April 2014

North West Surrey CCG End of Life Care Strategy

1) Summary

- a) North West Surrey Clinical Commissioning Group (NWS CCG) has identified end of life care as a local priority for improvement. We want people at the end of life and their relatives/carers to:
 - i) Be supported to remain as independent as possible in the best place for me
 - ii) Receive appropriate and effective care, when required and in line with my wishes
 - iii) Have a good experience at end of life and be treated with dignity and respect

2) Our objectives:

- a) To increase identification of people at the end of life stage
- b) To ensure all patients at end of life stage have a care plan in place
- c) To strengthen the commissioning of end of life care services

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3) Our plans include:

- a) Supporting General Practice and care homes (nursing and residential homes) to identify patients at end of life to enable planning of care
 - i) Earlier identification of patients at the end of their life to allow sufficient time for planning and implementation of an advance care plan: "A year of care".
- b) Improve commissioning of end of life care
 - i) Work collaboratively with all community services to ensure earlier assessment and appropriate care planning for people who may be in the last year of life and their carers
 - (1) Increased number of patients with an up to date advance care plan which is accessible and visible to all healthcare providers
 - (2) Regular review and adjustment of the advance care plan in accordance with the patient's needs and wishes
 - ii) Work with all providers to encourage good communication to deliver integrated multi agency services
 - (1) Identification of a senior clinician or healthcare provider to oversee an individual's care throughout the end of life journey.
 - (2) Increased number of patients with an up to date advance care plan which is accessible and visible to all healthcare providers
 - (3) Regular review and adjustment of the advance care plan in accordance with the patient's needs and wishes
 - iii) Use of voluntary sector to deliver support services at an early stage
 - (1) Sign posting to multi agency community services such as the voluntary sector to support people who may be in the last year of life
 - iv) Ensure delivery of 24/7 integrated palliative care services
 - (1) Core provision of specialist palliative care consultants within Ashford and St Peters Hospitals which integrates with other work streams (elderly frail, dementia, unplanned care).
 - v) Increase delivery of 24/7 community services
 - (1) Robust round the clock community nursing services throughout the whole of NWS.
 - (2) Improved community based services to allow patients to die at home. These services need to be cost effective
 - vi) Specify a service to meet the needs of respiratory patients at End of Life
 - (1) There has been little change since 2006/7 in the location of deaths from respiratory disease with about 66% taking place in hospital
 - vii) Ensuring good quality end of life care should be the responsibility of all health and social care professionals. NWS CCG has invited local stakeholders to join an End of Life Steering Group, with the purpose of developing a high-level strategic vision for End of Life Care.
 - viii) The steering group is responsible for the commissioning, development, and implementation of high quality, coordinated, integrated, personalised and cost effective End of Life Care across the NWS CCG.

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Surrey Downs CCG End of Life Care Strategy

1) Summary

- a) The organisational requirements and enablers for supporting the delivery of our end of life care strategy have been identified as a focus on clinical leadership, contracting arrangements, information communication and technology, workforce and funding arrangements.
- b) The CCG is in the process of appointing a clinical lead for EOLC as part of the Clinical Leadership Framework, with an existing lead for dementia in post for the past year.
- c) The implementation of a new Electronic Palliative Care Register - Coordinate My Care, will be integrated with the local rollout of the Single Digit Number (111) rollout. IT systems will have to support a single register and will need to ensure that patients' preferences and treatment plans are available to all relevant parties in the health and social care system. Use of CMC will be underpinned by QoF, QP and CQUINs with all providers.
- d) The need for home-based care is likely to increase. This will require decision-making about the skill mix required and competencies, roles and responsibilities. GPs are being supported by new Link Workers specifically recruited for dementia promoting a new type of workforce model.

2) Our plans to improve end of life care

- a) Implementing an Electronic Palliative Care Co-ordination System
- b) Increasing early identification including risk stratification to ensure patients get the support they need
- c) Integrating care services and enable whole system working
- d) Gold Service Framework Accreditation for end of life care provided in care homes for people with dementia.
- e) Implementation of an Electronic Register (Palliative Care Co-ordination System) will enable us to:
 - i) Identify people who are considered to be in their last year of life and, with appropriate consent, add them to an electronic register
 - ii) Co-ordinate the care of patients on the register to ensure that patients are supported within their last year of life with reduced levels of non-elective admissions
 - iii) Support people to die in the place of their choosing and with their preferred care package
 - iv) Enable all providers, including out of hours and ambulance services to access the inter-operable EPaCCs to prevent avoidable acute admissions
 - v) Educate clinicians in Primary, Community Care and other providers to manage EPaCCs and provide gold standard care.

Surrey Heath CCG End of Life Care Strategy

1) Summary

- a) End of Life Care is a commissioning priority for Surrey Heath CCG and is a key area of work to realise and much can still be done to improve the quality of life for people in the last years of their life. The CCG is working together with North East Hants and Farnham (NEHF) CCG and aims to finalise our end of life strategy for the next 5 years during the summer of 2014, supported by our newly appointed MacMillan GP. This is a joint appointment with NEHF and will support the alignment of our two strategies at a system level. This strategy will give an overview of the strategic direction in which the commissioners aim to take adult EoL Care in the foreseeable

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future and to inspire action from key stakeholders which will lead to improved EoL Care for our patients.

2) Our vision for End of Life Care within Surrey Heath CCG would see

- a) A community that is comfortable discuss the issues and arrangements at this stage their lives freely and openly.
- b) A consistent approach to the early identification of all patients nearing end of life, coupled with a clear intent to initiate conversations with these patients about their EoL care; this would then lead to the electronic recording of patients' wishes and preferences for their care.
- c) EoL healthcare support will be resourced to be readily available to patients 24 hours a day, 7 days a week to enable quality palliative and supportive care to be delivered within our locality in an efficient manner.
- d) EoL care providers would work collaboratively and effectively within our CCG's locality with good, strong communication links and the ability to offer a seamless, streamlined and holistic service to cater for the wide range of individual needs and preferences of patients.
- e) Our vision would ensure that all healthcare professionals involved in delivering EoL care have the confidence, support, and appropriate skills and competences in order to deliver high-quality, effective care. This would result in patients being treated with dignity and respect at the end of their lives resulting in a positive experience of the care they receive.
- f) EoL patients would be in receipt of high-quality, effective care which would result in patients dying in their preferred place of care in accordance with their wishes and preferences.
- g) Following the death of a patient any carer/friend/family member wishing to receive bereavement support would be offered this in a timely fashion and receive appropriate counselling and/or support. All care and support will be equitable for all our patients across the CCG.

Whole System Partnership Fund, End of Life Care Project Evaluation 2014
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1) Introduction and Background

- a) The Clinical Commissioning Groups (CCGs) and Surrey County Council (SCC) have been leading the planned approach for spend against the DH investment for the Whole Systems Partnership Grant. A number of projects were set out in the original plan e.g. pump priming the set-up of virtual wards in each Clinical Consortia Group area. The list of initiatives was expanded in June 2012 to include twelve months partnership funding to localise and expand the existing Community End of Life Care (EOLC) project with the aim of testing the model and enabling CCGs to make informed decisions around future commissioning going forward. A further extension of funds until Dec 2013 was subsequently agreed.
- b) A Business Case requesting further funding to support the continuation of the existing EOLC Partnership Project until end March 2014 – submitted by NWS CCG, G&W CCG, Surrey Heath CCG and Farnham and NW Hampshire CCGs has recently been approved by the Whole Systems Steering Board.
- c) This funding extension is to allow time for CCGs to develop local plans and models of care to support patients approaching the EOL 27/7 within the community.
- d) An evaluation of the quality and effectiveness of the services has been carried out and this paper summarises the key findings.

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2) Service Objectives

- a) Each of the Surrey CCGs received an allocation of funding based on total population for EOLC services via the partnership fund. Further allocations were agreed for the period June –December 2013 and this was then further extended until 31st March 2014.
- b) While the actual delivery models have varied slightly across CCGs they were all required to demonstrate the key objectives below:
 - i) Enhancing patient and carer experience, quality of care, and choice for preferred place of care.
 - ii) To support adult patients (all diagnosis) in the last weeks/days of life and to support their carers
 - iii) To provide high quality, safe, responsive and clinically effective care
 - iv) To develop partnership and coordinated models of care in conjunction with local providers that supports preferred place of care and reduced unplanned admission to hospital in the last days/weeks of life
 - v) To support independence, choice of care and quality of life
 - vi) To maximise efficiency and ensure timeliness of intervention
 - vii) To support rapid discharge from hospital at the end of life in line with preferred place of care

3) The Virgin EOLC Service

a) History

- i) The initial Beacon Care at Home Model (2003-2009) was set up to co-ordinate and respond to EOLC requests from Community Nurses across Guildford & Waverley (G&W), Surrey Heath (SH), Farnham and NW Hampshire. It provided an integrated rota of day/night care provision in conjunction with Marie Curie and was deemed successful in supporting preferred place of care/death.
- ii) A proposal was then submitted to test the replication of the service and outcomes across the whole of Surrey and further funding was awarded via the SHA Innovation fund for 2 years from 2010 until June 2012. This funding supported the development the Coordination hub at the Beacon with bank palliative care staff providing care during the day and overnight (10pm-7am).
- iii) The Whole Systems Partnership agreed in June 13 to provide a further years funding (and subsequently an additional 6 months funding) with the agreement to localise the model within the NWS, G&W, SH and Farnham CCG areas.

b) Overview of Local Virgin Model (June 12 – Dec 13)

- i) Many patients approaching the EOL require complex and multiple care packages.
- ii) The funding has enabled Virgin Care Services to work in an integrated way with Marie Curie and usual District Nursing services to provide increased capacity and a 24 hour a day and 7 day a week community EOLC service – delivering both nursing and personal care. The care has been delivered by staff with experience in palliative care (on bank contracts due to the temporary nature of the funding).
- iii) A Surrey coordination hub enables 24 hour coordination of requests, prioritisation of resource against clinical need, deployment of staff and robust communication. Care after 6pm is led by the Community Twilight and Night Response Service.

4) Evaluation

- a) Evaluation of the effectiveness of the community EOLC service has proved complex for a number of reasons:
 - i) There are different resources across the CCGs – as through the coordination fund they have been allocating partnership funding, Marie Curie funding and some other local charitable funds which are only applicable to some CCGs

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- ii) Although a year's data has been provided by Virgin (Oct 12- Sept 13) the way it was collected changed - whereas the data from Oct 12- June 13 included all spend the data from July 13- Sept 13 only indicated partnership spend
- iii) The ongoing temporary nature of the service has meant reliance on a bank staff model of provision – not only has this cost more but it has proved more difficult to ensure sufficient resource is always available to meet demand.
- iv) It is difficult to determine service costs and return of investment as charges vary according to local circumstances e.g. NWS CCG only pay 30% of tariff for acute care as they are over performing on their acute contract
- v) The current data is only looking at place of death – a further review of unplanned admissions in the last year of life to understand the effect additional EOLC support had on reducing these was to be undertaken – however data and issues with information governance have meant this has not yet been completed

5) Summary Data

- a) The table below compares the % probability of hospital deaths in those with District Nursing only verses District Nursing and additional EOLC services.

Data Oct 12- Sept 13

CCG	Non EOLC - District Nurse (DN) only -% probability hosp death	Total no. Deaths on DN caseload	DN+EOLC support - %probability hosp death	No. Pts receiving additional EOLC support	Partnership allocation per quarter
NWS	23%	292	4%	165	£71,200
G&W	14%	304	6%	162	£41,098
SH	11%	70	0%	23	£18,612
Farnham	8%	61	6%	26	£9,438

- NB: Non EOLC = District Nurse only
- DN + EOLC = additional partnership (additional Marie Curie, coordination, Beacon at Home, additional community out of hours, other resources)
- For a more detailed breakdown of the data for each of the CCGs (Oct 12 –June 13) - see appendix 1

6) Discussion and Findings

- a) The evaluation demonstrates that while it improves quality of care and supports more people to be cared for and die in their preferred place - the cost of the service is high when compared to savings achievable from reduced hospital admissions.
- b) Although the data appears to show an increased probability of hospital death with DN care alone – this needs further investigation and may be due to a combination of reasons including vacant posts, differing levels of support from specialist palliative care services etc.

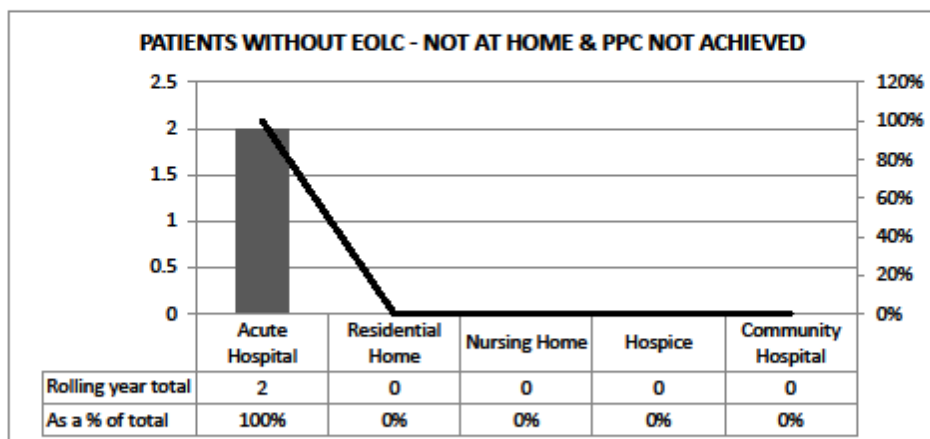
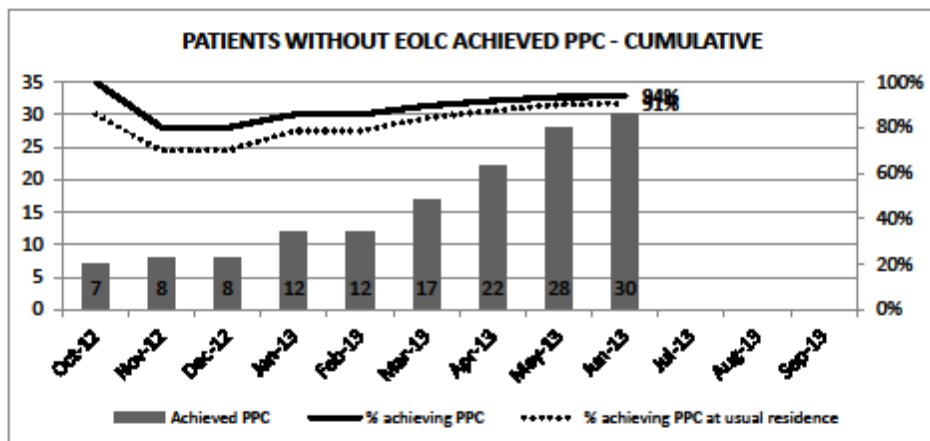
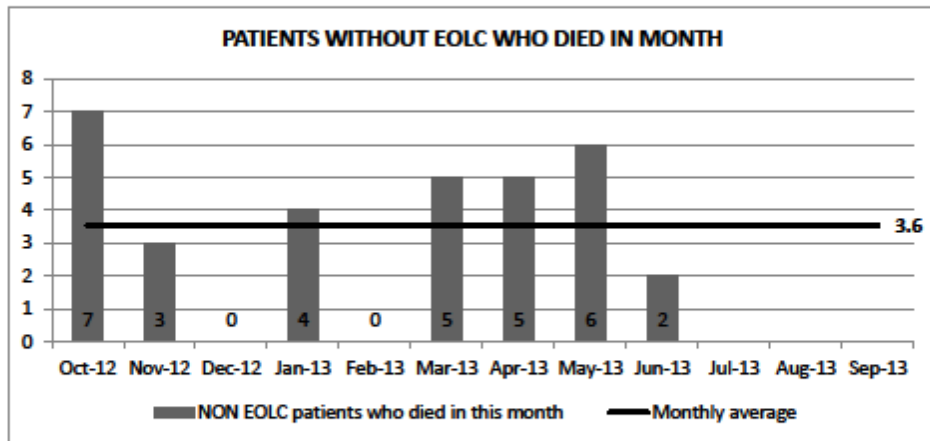
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Appendix 1

EOLC (Jun 2013) Farnham.xlsx

FARNHAM

PATIENTS WITHOUT EOLC



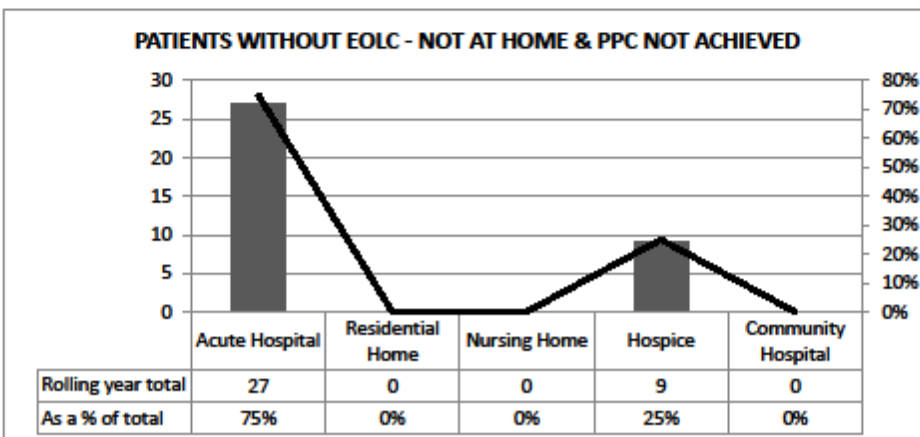
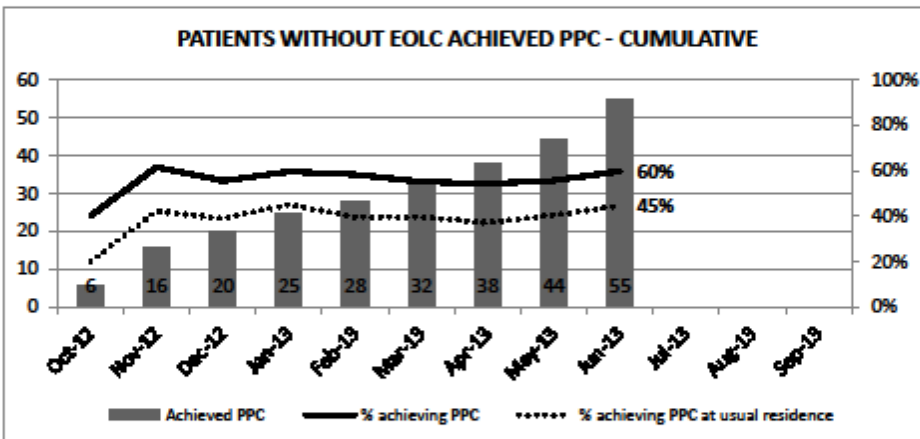
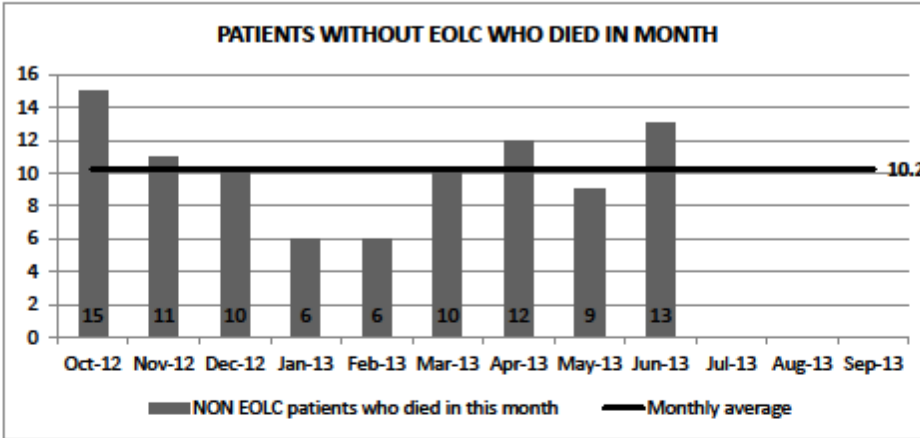
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EOLC (Jun 2013) NWS.xlsx

NORTH WEST SURREY

PATIENTS WITHOUT EOLC



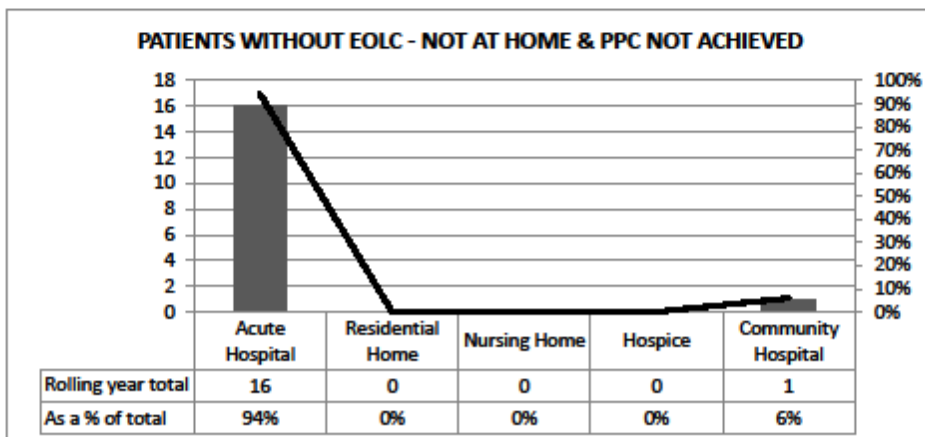
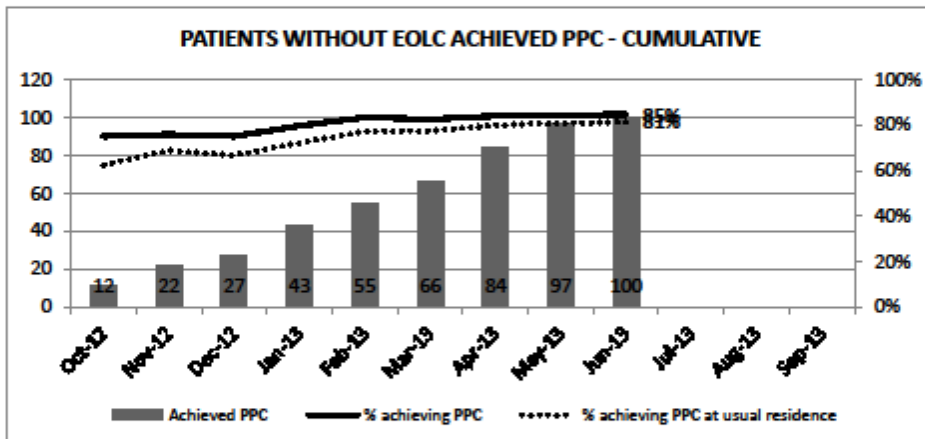
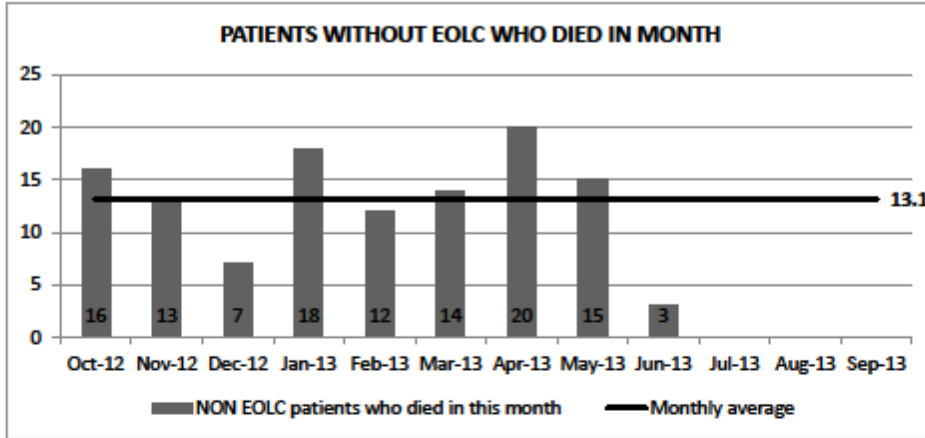
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EOLC (Jun 2013) G&W.xlsx

GUILDFORD AND WAVERLEY

PATIENTS WITHOUT EOLC



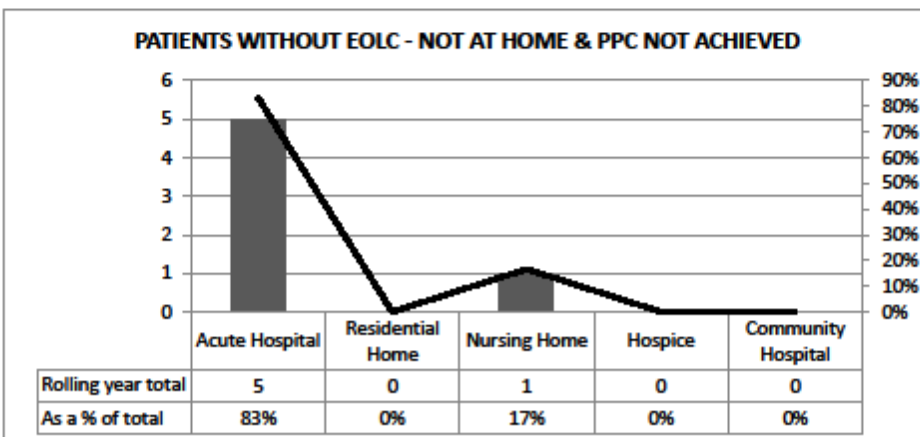
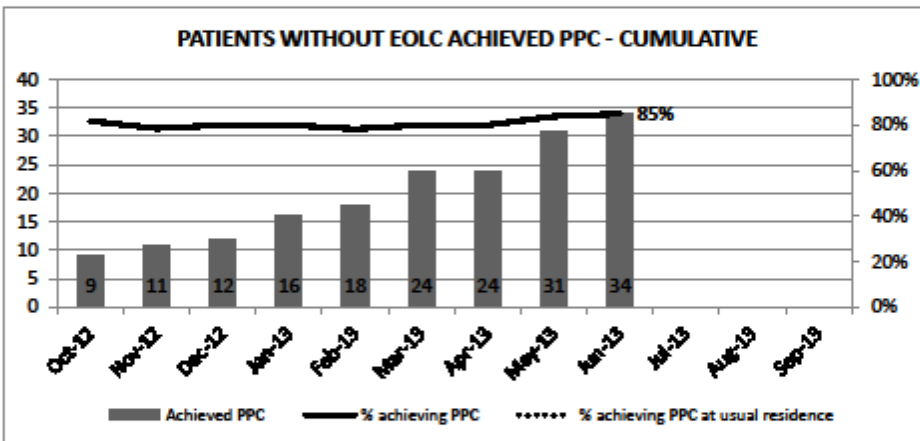
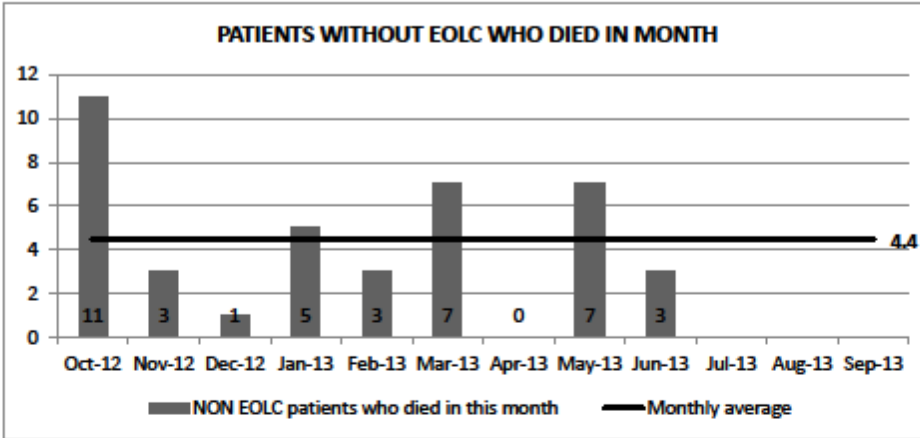
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EOLC (Jun 2013) Surrey Heath.xlsx

SURREY HEATH

PATIENTS WITHOUT EOLC



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Conclusions

1. Improving end of life care in Surrey is a key priority for the Clinical Commissioning Groups and includes the following:
 - a. Integrating services to work more effectively and provide a single point of co-ordination for people needing end of life care.
 - b. Introducing an electronic register: Electronic Palliative Care Co-ordination System (EPaCCS) to improve the co-ordination of care through better communication of people's wishes and preferences for care at the end of life.
 - c. Increasing early identification of patients at end of life including risk stratification to ensure patients get the support they need.
 - d. Increasing the use of Advanced Care Planning to encourage good communication.

Public Health Impacts

1. The End of Life Care Co-ordination (EoLCC) National Information Standard (ISB 1580) aims to improve the co-ordination of care through better communication of people's wishes and preferences for care at the end of life. This is to be implemented across the UK by June 2014 and includes use of the Electronic Palliative Care Co-ordination Systems (EPaCCS).
2. End of Life Care Co-ordination Systems (EPaCCS) enable health and social care professionals to record and share information about people's preferences and there is already evidence that they are having a positive impact.
3. There is evidence that implementation of Electronic Palliative Care Co-ordination Systems (EPaCCS) could save at least £35,910 for a 200,000 population each year based on a conservative estimate of £399 saved for each death supported in the usual place of residence rather than a hospital setting.
4. Having accurate, timely and relevant records about people's preferences for care at the end of life, including information about where they would prefer to die, are key to ensuring more people achieve a 'good' death.

Recommendations

- The Committee are asked to support the approach of East Surrey CCG, North East Hampshire and Farnham CCG, Guildford and Waverley CCG, North West Surrey CCG, Surrey Downs CCG, and Surrey Heath CCG, to End of Life Care across Surrey.

Next steps

- East Surrey CCG, North East Hampshire and Farnham CCG, Guildford and Waverley CCG, North West Surrey CCG, Surrey Downs CCG, and Surrey Heath CCG will provide further updates on progress on their End of Life Care Strategies.
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End of Life Care

Report contacts:

- Jo-Anne Alner, Director Quality & Innovation, North West Surrey CCG
Joanne.alner@nwsurreyccg.nhs.uk
- Karen Parsons, Chief Operating Officer, Surrey Downs CCG
Karen.parsons@surreydownsccg.nhs.uk
- Joe McEvoy, Director of Clinical Commissioning, Guildford & Waverley CCG
joseph.mcevoy@nhs.net
- Samantha Stanbridge, Director of Commissioning and Engagement, East Surrey CCG
Samantha.Stanbridge@eastsurreyccg.nhs.uk
- Nicola Airey, Director of Operations, Surrey Heath CCG Nicola.airey@nhs.net
- Julie Curtis, Executive Director of Delivery, NE Hants & Farnham CCG
julie.curtis@hampshire.nhs.uk
- Pauline Jervis, Assistant Senior Manager – Commissioning, Adult Social Care, Surrey County Council pauline.jervis@surreycc.gov.uk

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