Accounting for Value

A value report for the ‘Die Well’ domain in the North East Essex Health & Wellbeing Alliance

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- North East Essex Health and Wellbeing Alliance End of Life Board
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Foreword

This is the first Accounting for Value report prepared for the North East Essex Health and Wellbeing Alliance, and the first report of its kind to take a methodical look through a value-lens at dying and death from both an individual and system perspective for a defined local population in the UK.

Inspired by the NHS Right Care Atlases of Value, the report seeks to provide a locally focused companion piece to the Atlas of Variation in Palliative and End of Life Care for England published by Public Health England in 2018. Explorations of variation between localities are of interest, but do not tell us much about how successful a given area is at using the resources available to it to achieve what is important to dying people and their families – this report begins to address that.

This is the culmination of several years work in the north east Essex health and care system. Starting with the Marie Curie Delivering Choice Programme in 2011, which led to the introduction of the My Care Choices Register and the SinglePoint palliative care coordination centre in 2013, we have been on a long journey in North East Essex toward a system approach to palliative and end of life care. One that is focused on identifying and addressing unmet need and inequity in access to care and support, and in achieving a shift to out of hospital care being for the norm at the end of people's lives. Whilst there have been some successes there is further to go.

Within the North East Essex Health and Wellbeing Alliance, one of three Alliances in the Suffolk and North East Essex Integrated Care System (ICS), there has been a recognition that to improve end of life care requires an inclusive and collaborative approach across all health and care partners based on engagement and involvement of local people and linked to a wider outcome based framework.

The Accounting for Value report goes a long way to proving our working hypothesis that the single best way to release value for reinvestment in end of life care is to reduce emergency admissions to hospital toward the end of people's lives, and that the main ways to achieve this are through reducing referrals to hospital through better advance care planning (using the My Care Choices Register) and increasing discharges to preferred place of care by building community capacity and capabilities.

The conclusions from this report and proposed next steps will I hope provide a firm foundation for the implementation of a fully realised population approach to end of life care in North East Essex with great potential for shared learning and scalability in the wider ICS and beyond.

Mark Jarman-Howe,

Chair,

North East Essex Health and Wellbeing Alliance

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Commonly used abbreviations

Abbreviation/acronym	*Meaning*
3V	Oxford Centre for Triple Value Healthcare
CCG	Clinical Commissioning Group
COPD	Chronic obstructive pulmonary disease
CQC	Care Quality Commission
CVI	Continuous value improvement
ECHO	Extension of Community Healthcare Outcomes
EoL	End of life
EoLC	End of life care
EPaCCS	Electronic Palliative Care Co-ordination System
GP	General practitioner
GSF	Gold Standard Framework
HES	Hospital episode statistics
ICHP	Imperial College Healthcare Partners
ICP	Integrated care provider
ICS	Integrated care system
IHD	Ischaemic heart disease
IMD	Index of Multiple Deprivation
IRNP	Integrated residential and nursing payment
LA	Local authority
LES	Locally enhanced service
LTLA	Lower-tier local authority
MCCR	My Care Choices Register
MDT	Multidisciplinary team
MVA	Multivariate analysis
NEE	North East Essex
ONS	Office for National Statistics
PCN	Primary care network
PHE	Public Health England
PPC	Preferred place of care
QOF	Quality and Outcomes Framework
SNEE	Suffolk and North East Essex
the Alliance	North East Essex Health and Wellbeing Alliance
UPoR	Usual place of residence

Executive summary

Context

The NHS Long Term Plan outlines the move to integrated care systems (ICSs). In an ICS, NHS organisations, local authority and other partners including third sector organisations, such as hospices, ***take collective responsibility for the management of resources to improve the health of the population they serve***. This report describes how North East Essex Health and Wellbeing Alliance (the Alliance), as part of the Suffolk and North East Essex (SNEE) ICS will take collective responsibility for the management of resources to improve the outcomes that matter for people in the last year of life.

'Die Well' is one of the six priority domains for the Alliance. The End of Life Board in NEE has undertaken important work over recent years to establish and increase the uptake of My Care Choices Register (MCCR), an electronic Palliative Care Coordination system (EPaCCS), and to train staff to improve care for people at the end of life.

Local knowledge and experience of care, however, has highlighted that some people receive higher value care at the end of life, whereas there are people who would benefit from higher value end-of-life care but do not receive it. Thus, ***there are likely to be inequities in the provision of higher value end-of-life care*** for the population in north east Essex, resulting in inequalities of outcomes for people in the last year of life.

Population definition

The population segment of interest was defined as ***people aged 18 years and over identified to be in the last 12 months of life***, and this population includes people with the following 'index' conditions: dementia, severe frailty/high frailty score, cancer, congestive heart failure, chronic obstructive pulmonary disease (COPD), neurological conditions, liver failure, ischaemic heart disease (IHD), stroke and renal failure. The end-of-life population group ***excludes*** people who die suddenly, who do not have one of the index conditions and who are aged under 18 years.

End-of-life population profile

The ***number of deaths in North East Essex (NEE) has been increasing over the last decade***. According to projections up to the year ***2030, the number of deaths will increase by approximately 30% or 1100 people***. The proportion of deaths in people aged over 75 years is higher in NEE than in England. The causes of death in NEE are changing, with large increases in dementia and COPD as a cause, or underlying cause, of death.

People are more likely to die in their usual place of residence and less likely to die in hospital in NEE when compared with England, although there are some demographically similar CCGs in which a greater percentage of people die in their usual place of residence.

For ***people dying of non-cancer conditions, roughly the same number of people die in hospital as at home***. People who live in the ***most deprived areas are more likely to die in hospital*** than not.

Over the last decade, there has been a ***44% increase in people at end of life with three or more emergency admissions to hospital in the last 90 days of life***, a similar level to that in demographically similar CCGs. People registered with ***general practices with a higher deprivation profile are more likely to be have three or more emergency hospital admissions in the last 90 days of life***.

Referrals to the coroner cause distress to families. Of 377 referrals to the coroner in 2018/19, nine required no action, and 308 went no further with the issuance of a certificate. The referral rate to the coroner in NEE is much lower than the average for England and Wales.

End-of-life population budget

Data was available from four sources of funding for the care for people in the last year of life in NEE: expenditure on hospital admissions, St Helena Hospice charitable funds, St Helena Hospice NHS grant-funded expenditure, and the NHS continuing healthcare fast-track pathway. In 2018/19, total expenditure from these four sources was £39,884,297. The majority of expenditure for people in the last year of life was due to ***admissions to hospital amounting to £30 million (19% of the total expenditure on hospital admissions), of which £26.5 million was expenditure on emergency admissions to hospital in the last year of life, comprising 37% of the total expenditure on emergency admissions***.

Expenditure on NHS continuing healthcare fast-track pathway care packages has fluctuated over the last five years. In 2018/19, 250 people received these care packages, 43% of which cost less than the tariff for a single emergency admission to hospital.

St Helena Hospice charitable funding was a major component of funding for hospice-care services in NEE in 2018/19: 65% of funding for hospice care was from this source (£5.1 million), and 35% (£3.1 million) was received from the NHS.

In 2018/19, 1029 people died while receiving social care services. On average, people received care for 196 days, although 496 people (48%) received social care services for 90 days or less, suggesting that many were in receipt of a local authority care package because they were approaching end of life.

Outcomes that matter

In consulting bereaved family members, carers and frontline providers of care, it became clear that avoiding admissions to, and dying in, hospital were good proxies for outcomes that matter to people who are at the end of life, and were also issues that could usefully be explored given data limitations. Therefore, the focus of much of the analysis was the potential for avoiding admissions to hospital and death in hospital and the associated implications for reallocation of resources to higher value activities.

Outputs from the analysis

Preliminary analysis showed there is an ***association between the likelihood of an individual dying out of hospital and a higher rate of MCCR use*** (as a proportion of all deaths) by the general practice with which the individual is registered. In-depth analysis showed that the average expenditure on admissions to hospital per person in the last year of life is influenced considerably by place of death (in hospital or out of hospital).

If all general practices could be supported to achieve the characteristics of high MCCR usage practices, the potential for re-investment is about £422,138 for people with cancer in the last year of life and £1,728,754 for people with non-cancer conditions in the last year of life; the total being £2,150,892.

A local clinical audit of 100 clinical records of people who died in hospital in 2018 showed that ***39% of people could have died out of hospital if there had been the capacity to discharge them with support***. Based on this percentage, ***potentially £401,794 of resources could be freed for re-investment for people with cancer in the last year of life and £2,642,453 for people with non-cancer conditions in the last year of life; the total being £3.044,247***

Both estimates are predicated on the provision of development funds or other support for higher value interventions in end-of-life care. The estimates do not represent savings but will improve outcomes.

The estimate based on all general practices developing to become a high MCCR usage practice is likely to focus on the prevention of admission to hospital, with support being provided to the individual and their family and/or other carers.

The estimate based on the findings of the audit is likely to focus on the capacity to discharge people at the end of life from hospital, which would require considerable re-investment in community resources such as nursing-home placement and home support.

Next steps

Following the publication and dissemination of this report, the main recommendation is to establish an environment in which resources can be disinvested and re-invested for people in the last year of life, that is, to create an environment in which ***continuous value improvement (CVI)*** becomes the norm. For this to happen, it is important to discuss and agree the governance conditions under which the End of Life Board will assume greater authority for the optimisation of resource use to improve outcomes that matter to the people being served, and will be supported and held accountable for doing so, becoming a Population Stewardship Forum.

Introduction

Recent changes in the English NHS

The NHS Long Term Plan outlines the move to integrated care systems (ICSs), such as the Suffolk and North East Essex ICS (SNEE ICS), in which NHS organisations, local authorities and other partners including third sector organisations, such as hospices, take collective responsibility for the management of resources to improve the health of the population they serve.[1]

These recent changes brought into focus in the NHS Long Term Plan are in part a response to an operating context in which health and care systems are under pressure from increasing need and demand due to:

- changes in population demographics, including ageing
- innovations in care that are more expensive
- an increasing intensity and volume of clinical practice
- a mismatch between public demand and need for care, which can be manifest as over-demanding and/or under-demanding depending on various contextual factors

At the same time, budgetary settlements are challenging, and there are widespread workforce shortages, especially among clinical staff.

Evolving paradigms in health and care systems

Two key concepts are the foundations for the development of ICSs:

1. Population health
2. Optimisation of resources

These concepts are also fundamental to value-based healthcare (see Figure 1), in which resource allocation across the population is ascertained and investigated with a view to shifting resources from lower value to higher value care.

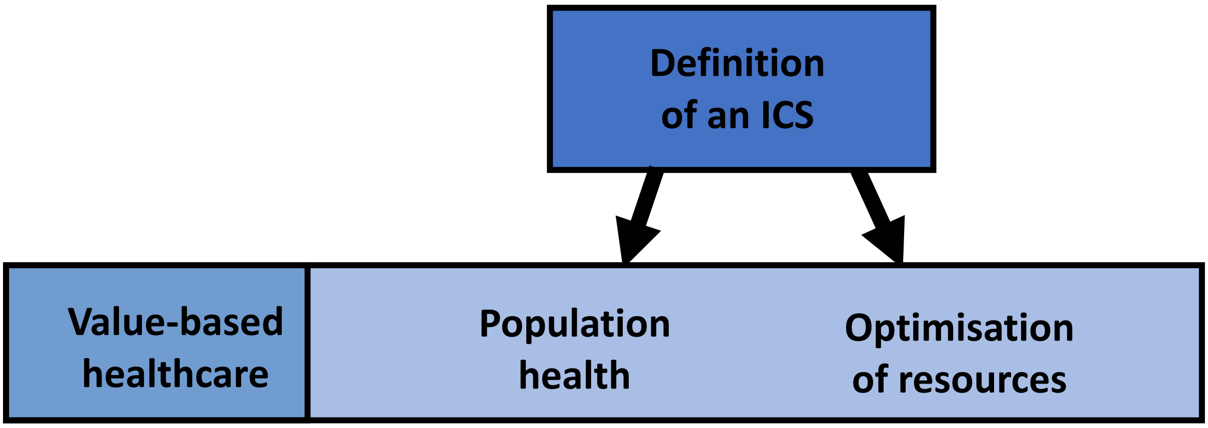

Figure 1: Common foundations for the development of integrated care systems and the introduction and implementation of value-based healthcare. (Source: 3V)

Developments in the NHS at a local level

Suffolk and North East Essex ICS has adopted Friedman's approach of outcomes-based accountability, in which resources are used wisely in the pursuit of better outcomes and service providers are held

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[1] NHS England https://www.england.nhs.uk/integratedcare/integrated-care-systems/

accountable to the population served.[2] Identifying the ‘outcomes that matter’ to the people served is a core component of both value-based healthcare and outcomes-based accountability (see Figure 2).

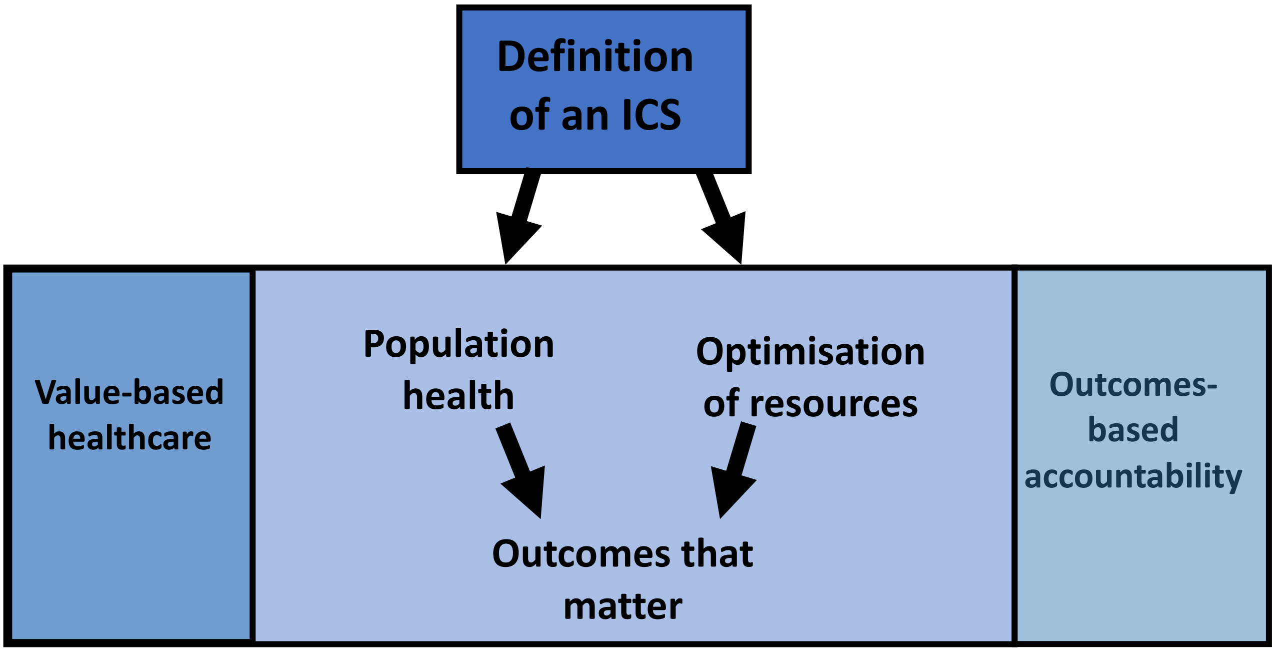

Figure 2: Outcomes that matter: core components of value-based healthcare and outcomes-based accountability. (Source: 3V)

In North East Essex, the Alliance, an integral part of the SNEE ICS, seeks to improve the health of the 351,776 people in NEE through optimising the use of resources to increase the value obtained from those resources in terms of the outcomes that matter to the people being served.

End-of-life care: a local priority

End-of-life care is a priority for both the SNEE ICS and the Alliance; this is encapsulated in the ‘Die Well’ domain, one of six priority domains for the Alliance (see Figure 3).[3] The activity within this domain is concerned with giving individuals nearing end of life choice around their care.

Figure 3: North East Essex Health and Wellbeing Alliance priority domains. (Source: the Alliance)

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[2] Friedman M. 2015. Trying Hard Is Not Good Enough: How to Produce Measurable Improvements for Customers and Communities PARSE - Publishing

[3] Suffolk and North East Essex Integrated Care System (ICS) Operational Plan 2019/2020

The work of the End of Life Board in North East Essex

An overview of the work undertaken from 2013 to 2018 by the End of Life Board in NEE is shown in Figure 4. A major public-facing campaign promoted advance care planning and the local electronic Palliative Care Co-ordination System (EPaCCS), known as the My Care Choices Register (MCCR; see Figure 5). In NEE, registration on MCCR was later expanded to enable the recording of care preferences for people with long-term conditions, dementia and frailty. The purpose of MCCR is to enable the co-ordination of care for people nearing the end of life in accordance with their preferences. MCCR can be accessed by staff working in primary care, secondary care (local hospital), the mental health trust, the ambulance service, the out-of-hours medical service and the hospice.

2013	2016	2017	2018
• Launch of My Care Choices Register • Commencement of a primary care end-of-life care locally enhanced service (ongoing) • Launch of a 24/7 single point of access for people nearing the end of life	My Care Choices Register widened to support the care choices of people with long-term conditions, dementia and frailty not thought to be at the end of life	An integrated end-of-life care system designed for North East Essex	• North East Essex Health and Wellbeing Alliance End of Life Board was constituted • My Care Choices Register moved to a software integrated with primary care systems

Figure 4: Timeline of major activities relating to end-of-life care in North East Essex. (Source: St Helena Hospice)

Figure 5: My Care Choices promotional material. (Source: St Helena Hospice)

Following the promotional campaign, more than 1% of the local population in NEE have recorded their preferences for future care on the MCCR. The effect of this campaign can be seen in Figure 6 where, from 2012/13 to 2014/15, there was a greater increase in the percentage of people on a GP end-of-life register in NEE than in England; by 2017/18, this higher level of registration when compared with England had been maintained.

In addition to the activities shown in Figure 4, a cross-boundary Gold Standard Framework (GSF) programme involving 36 care homes, several domiciliary care agencies and two mental health wards for people with dementia, improved access to palliative care and advance care planning for people nearing the end of life, many of whom had conditions other than cancer.

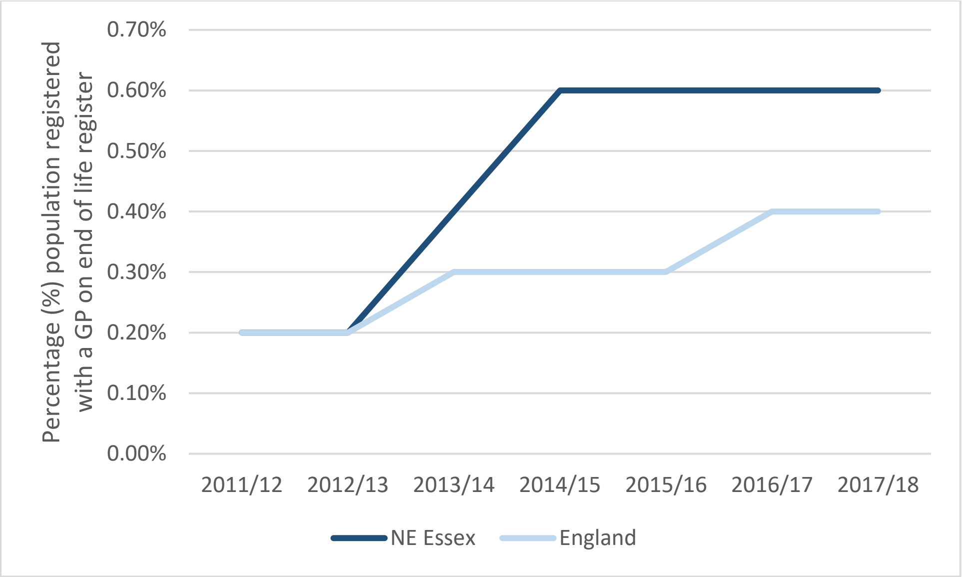

Figure 6: Quality and Outcomes Framework prevalence (whole practice) for end-of-life register in North East Essex (dark-blue line) and England (light-blue line). (Source: PHE Fingertips)

In a project known as ECHO (Extension of Community Healthcare Outcomes), an innovative system utilising technology was used to provide education and training in the workplace to a community of local care home staff to support the GSF programme.

An advance care planning project was undertaken with sheltered housing organisations because residents in sheltered housing were found to have a much higher rate of death in hospital when compared with the locality average. An end-of-life education project was also undertaken with staff at care homes where residents had a high rate of death in hospital.

Three primary-care end-of-life champions, responsible for promoting excellence in end-of-life care in their respective primary care networks (PCNs), were recruited. The establishment of these roles has been associated with an increase in access to the MCCR for their populations.

A primary-care locally enhanced service (LES) was commissioned to promote the identification of people nearing the end of life, which resulted in higher rates of advance care planning and of achievement for people’s preferred place of care (PPC) at the time of death. The number of people in NEE achieving their preferred place of care (PPC) at the time of death is generally increasing, although there are fluctuations from month to month (see Figure 7, showing achievement for the period from September 2018 to January 2020).

As a result of the work of the End of Life Board, since 2011/12, the percentage of people dying at home in NEE is higher than that for the East of England and that for England, although the gap has narrowed since 2016/17 (see Figure 8).

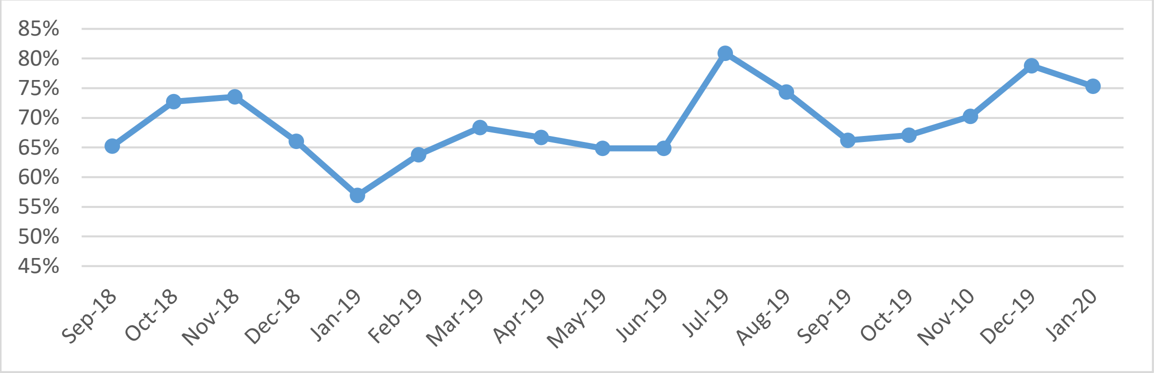

Figure 7: Percentage (%) of people on the My Care Choices Register in North East Essex who achieved their preferred place of care, September 2018-January 2020. (Source: St Helena Hospice)

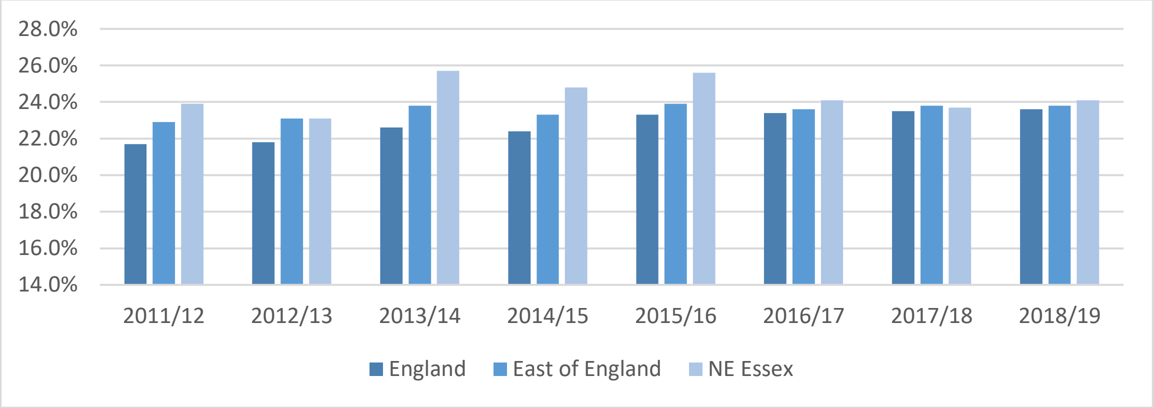

Figure 8: Percentage (%) of deaths at home in England (dark-blue columns), East of England (mid-blue columns) and North East Essex (light-blue columns), 2011/12 to 2018/19. (Source: ONS)

End-of-life care: an exemplar in North East Essex

The End of Life Board has been identified as an exemplar for the introduction and implementation of population health and value-based healthcare on behalf of SNEE ICS and the Alliance, and is charged with the optimal use of resources to ensure that, where possible, providers responsible for people at the end of life in NEE achieve the goals of the 'Die Well' domain.

Value-based healthcare and population health for people at the end of life

Providing the best possible care for people at the end of life is seen as one of the most important duties of the health and social care system in NEE, but what does 'best possible' care mean?

- 'Best' can be defined only by the person who is dying, their family and other carers: what are the outcomes that matter to them?
- 'Possible' means what is achievable within the prevailing science of care at end of life and the resources allocated to the local population deemed to be at the end of life.

To provide the best possible care for people at the end of life means the End of Life Board needs to take greater control of the resources currently allocated to end-of-life care. This innovation in allocative efficiency for end-of-life care was described in an editorial in the *British Journal of General Practice* in 2017,[4] which highlighted that improved recognition of people at the end of life and optimised out-of-hospital services could translate into benefits not only for people nearing the end of

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[4] Thomas, K., & Gray, M. (2018, March 1). Population-based, person-centred end-of-life care: Time for a rethink. British Journal of General Practice. Royal College of General Practitioners.

life but also for the NHS in terms of considerable re-investment opportunities.[5] Earlier identification of people at the end of life can lead to care services that are anticipatory and prevent crises, especially in the last year of life. In a clinical audit of 100 people who died in Colchester Hospital in 2018 (not publicly available), it was found that 39 people could have died at home.

The formal establishment of a local network (Population Stewardship Forums) such as that exemplified by the End of Life Board, which have greater control of resources was described by the King's Fund in a report on placed-based systems of care[6], and echoed in the King's Fund's review of the Canterbury Health Board in New Zealand.[7] The development of such integrated care systems builds on Ostrom's Nobel prize-winning work about the collective management of resources,[8] and capitalises on the beneficial outcomes achieved in healthcare systems such as that developed in Grand Junction, Colorado.[9] Moving to an environment in which the End of Life Board has greater control of the use of resources and:

- Aligns with the purpose of an ICS as defined by NHS England
- Aligns with the overall strategies of SNEE ICS and the Alliance, particularly for outcomes-based accountability and the NEE H&WB Alliance End of Life Strategy
- Delivers on a key priority for the Alliance – 'Die Well'
- Is in line with the new paradigms of population health and value-based healthcare
- Is supported by evidence (case-studies) in the published literature
- Is based in Nobel prize-winning economic theory

In this 'Accounting for Value' report, the work done to identify the opportunities to shift resources from lower value to higher value interventions in end-of-life care is described. It is these opportunities for investment, disinvestment and re-investment over which the End of Life Board in NEE can take greater responsibility for, and authority over, as ICSs develop and evolve, leading to the collective management of resources for the benefit of the whole population at the end of life (population value) and improved outcomes for individuals (personal value), both of which in turn will contribute to better outcomes for the community as a whole (social value; see Figure 9).

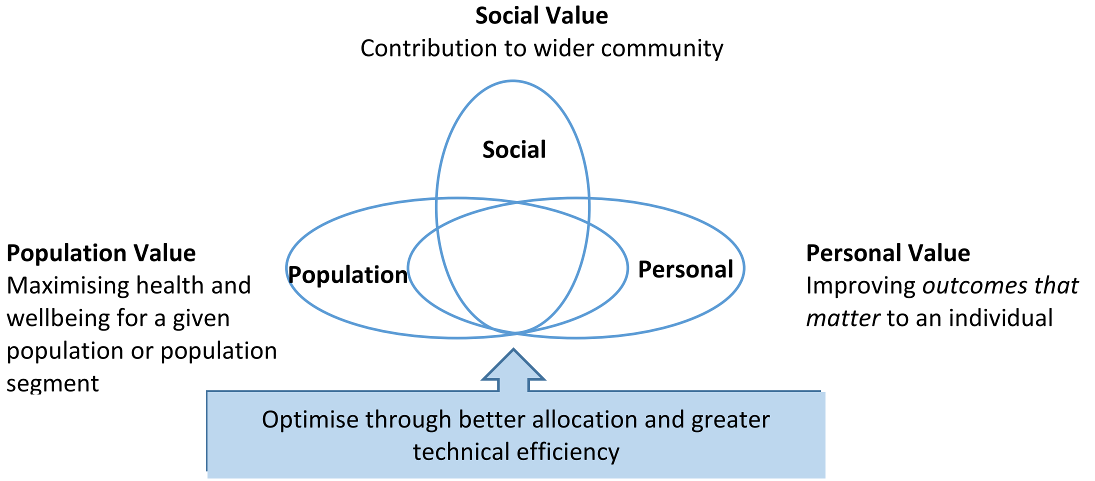

Figure 9: Increasing value for individuals, population groups and the wider community. (Source: 3V)

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[5] Hughes-Hallett T, Craft A, Davies C. Palliative care funding review. Funding the right care and support for everyone. Secretary of State for Health, 2011

[6] Ham, C., Alderwick, H., & King's Fund. London (2015). Place-based systems of care : a way forward for the NHS in England.

[7] Timmins, N., & Ham, C. (2015). The quest for integrated health and social care: A case study in Canterbury, New Zealand. Retrieved from www.kingsfund.org.uk

[8] McGinnis, M. D. (2013). Caring for the Health Commons: What it is and who's responsible for it. SSRN Electronic Journal. https://doi.org/10.2139/ssrn.2221413

[9] Bodenheimer, Thomas and David West. 2010. "Low-Cost Lessons from Grand Junction, Colorado," New England Journal of Medicine Perspective, 363:1391-1393, October 7, 2010.

The mission: increasing value and improving outcomes in end-of-life care

It is estimated that about 1% of the population, 30% of hospital patients and 80% of care-home residents are in the last year of life.[10] These estimates apply to people with cancer[11] [12] and people with non-cancer conditions.[13] [14]

It is clear, however, that although some people receive higher value care at the end of life, there are people who would benefit from higher value end-of-life care but who do not receive it, thus, revealing inequity in the provision of end-of-life care (see Figure 10), which will result in inequalities in outcomes for the population at end of life.

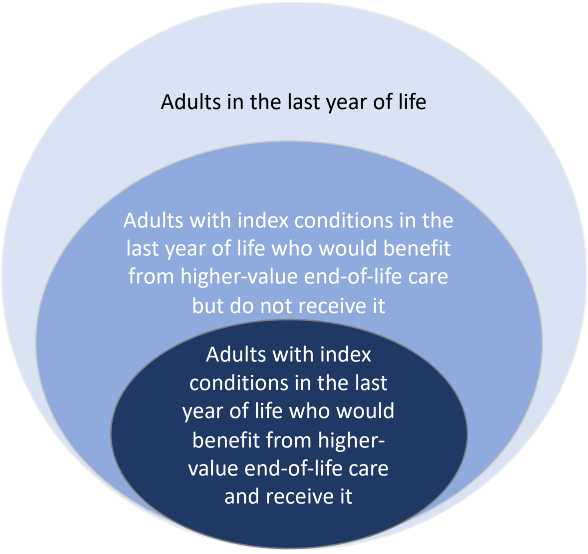

Figure 10: Population groups who are benefitting and would benefit from higher-value end-of life care in North East Essex. (Source: 3V)

It is vital, therefore, to create the conditions in which the End of Life Board can optimise the use of resources to ensure that more people at the end of life benefit from higher value care and improved outcomes (see Figure 11), thereby reducing inequities in the provision of care.

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[10] Clark D, Armstrong A, Allan A, et al. Imminence of death among hospital inpatients: prevalent cohort study. Palliat Med 2014; **28(6)**: 474–479

[11] Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., … Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. New England Journal of Medicine, 363(8), 733–742.

[12] Bowden, J., Fenning, S., Marron, B., Macpherson, C., Boyce, S., Wardrope, V., … Johnston, L. (2018). Best supportive care in advanced lung cancer-more than a label? BMJ (Clinical Research Ed.), 363, k5017.

[13] Warraich, H. J., & Meier, D. E. (2019). Serious-Illness Care 2.0 — Meeting the Needs of Patients with Heart Failure. New England Journal of Medicine, 380(26), 2492–2494.

[14] Higginson, I. J., Bausewein, C., Reilly, C. C., Gao, W., Gysels, M., Dzingina, M., … Moxham, J. (2014). An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial. The Lancet Respiratory Medicine, 2(12), 979–987.

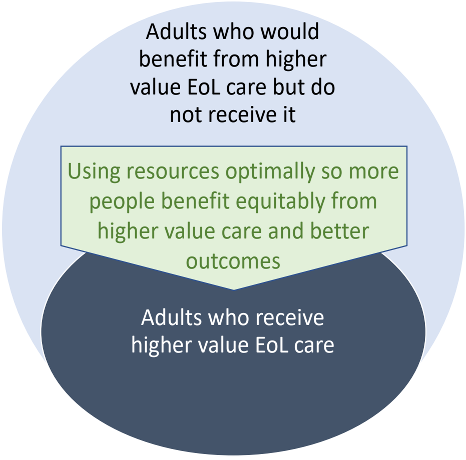

Figure 11: Optimal use of resources to increase the number of people receiving higher value end-of-life care in North East Essex. (Source: 3V)

Creating the conditions for the optimal use of resources will allow the End of Life Board to:

- Test where the disinvestment and re-investment of resources improves outcomes and increases value
- Roll out interventions/models of care of higher value
- Introduce innovations of higher value
- Where possible, increase the value obtained from interventions of lower value
- Stop interventions of lower value where value cannot be increased
- Encourage and develop a culture of continuous value improvement (CVI) supported and informed by a linked dataset and dashboard

Defining value in end-of-life care

The first step in increasing value in end-of-life care is to define what is meant by 'value'. As the nature of value is subjective, based as it is on an assessment of outcomes for the resources used, it is likely that different stakeholders will identify or chose different outcomes that matter.

For instance, a private hospital or insurance company may decide to maintain the health outcomes originally agreed and established while reducing costs, which would result in increased profitability and thereby increased value for shareholders.

By contrast, in universal health systems, there are founding principles that govern the outcomes of importance and therefore the nature of the value the system must achieve. For instance, the seven founding principles in the constitution of the English NHS are:

1. The NHS provides a comprehensive service, available to all
2. Access to NHS services is based on clinical need, not an individual's ability to pay
3. The NHS aspires to the highest standards of excellence and professionalism
4. The patient will be at the heart of everything the NHS does
5. The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population
6. The NHS is committed to providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources
7. The NHS is accountable to the public, communities and patients that it serves[15]

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[15] https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england#principles-that-guide-the-nhs

Using these principles, it is possible to identify the building blocks necessary to achieve value for people at the end of life in SNEE ICS, as follows:

- Improving outcomes that matter for all people at the end of life based on need
- Using resources optimally to improve the outcomes that matter
- Being accountable to the bereaved families, carers and the community served

Furthermore, as reducing health inequalities is a goal for the the Alliance, addressing health and care inequities in the provision of care for people at the end of life is an important part of delivering that goal, a goal mainly within the control of the health and care system. At present, it is likely that although some people in the last year of life in NEE receive and benefit from higher value end-of-life care, there are also people who would benefit from higher value end-of-life care but do not receive it (see Figure 11).

Creating the conditions to increase value for people at the end of life

There are five key tasks to creating the conditions for increasing value for people at the end of life:

1. Defining the population in need: who are the people at end of life (population definition), what is known about them (population profiling) and what resources are currently used to care for them (population budget)?
2. Agreeing a 'value framework': based on the principles of the local health and care system, what are the outcomes of importance and how are they to be measured?
3. Developing networks (Population Stewardship Forums): using collective resources for the good of the whole population, and the development of integrated care, needs to be addressed by Population Stewardship Forums, not by bureaucracies or institutions; it is the role of Population Stewardship Forums to use resources optimally and equitably and to be held accountable for such resource use
4. Increasing personal value: to avoid the utilitarianism that may be an unintended outcome of focusing on a specific population, it is important to improve outcomes that matter to every individual in a population by ensuring that care is personalised
5. Adopting a culture of stewardship: using resources wisely for current and future populations means equipping leaders in the health and care system with the skills to create such a culture

In this 'Accounting for Value' report, the outputs from Tasks 1 and 2 are described, and the opportunities for investment, disinvestment and re-investment by the End of Life Board as a Population Stewardship Forum are analysed and discussed as the foundation for Task 3.

Outputs from Task 1: Defining the population in need

There are three main outputs from Task 1, ‘Defining the population in need’:

1. Population definition
2. Population profiling
3. Population budgeting

Population definition

To define the population at the end of life, information was collated from the following sources:

- A session with the End of Life Board
- A focus group held with family members who had been bereaved, carers and representatives from the third sector
- A focus group held with frontline service providers of end-of-life care
- Local sources of information (routine and non-routine data)
- National datasets, including those from the End of Life Intelligence Network, and HES-ONS

The following elements of population definition were extracted for consideration:

- Whole population at end of life
- Criteria for inclusion in/exclusion from the population group, for example, by identifying ‘index’ conditions
- Ambiguities for inclusion/exclusion

Whole population at end of life

The End of Life Board agreed to address the needs of the following population group:

> *People aged 18 years and over identified to be in the last 12 months of life*

Criteria for inclusion/exclusion

The end-of-life population group includes people with the following ‘index’ conditions:

- dementia
- severe frailty/high frailty score (as determined using the Elixhauser Comorbidity Index[16])
- cancer
- congestive heart failure
- chronic obstructive pulmonary disease (COPD)
- neurological conditions
- liver failure
- ischaemic heart disease (IHD)
- stroke
- renal failure

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[16] Menendez, M. E., Neuhaus, V., Van Dijk, C. N., & Ring, D. (2014). The Elixhauser comorbidity method outperforms the Charlson index in predicting inpatient death after orthopaedic surgery. *Clinical Orthopaedics and Related Research*, *472*(9), 2878–2886. https://doi.org/10.1007/s11999-014-3686-7

The end-of-life population group ***excludes***:

- People who die suddenly
- People who do not have one of the index conditions
- People aged under 18 years

Ambiguities for inclusion/exclusion

For the following groups of people, there are difficulties associated with population definition and consequently with population profiling and different phases of the analysis:

- People with IHD, some of whom may die suddenly, and some may not
- People with stroke, some of whom may die suddenly, and some may not

Population profiling

The following information from local and national data sources was extracted, collated and visualised to develop a profile of the population group at the end of life in NEE during 2018/19:

- Number of people who died
- Projections of the number of people who will die in future
- Cause of death:
  - cancer
  - dementia
  - heart failure
  - COPD
  - stroke
  - liver disease
- Place of death:
  - in hospital
  - out of hospital
- Admissions to hospital:
  - last year of life
  - last 90 days of life
- Factors influencing outcomes:
  - residence in a care home
  - deprivation
- Referrals to coroner

Number of deaths in 2018/19

From 2006 to 2013, the annual number of deaths in NEE was relatively similar with fluctuations; however, from 2014 to 2017, the number of deaths in NEE increased (see Figure 12).

In 2018/2019, 3,490 people died who were registered with NEE CCG practices.

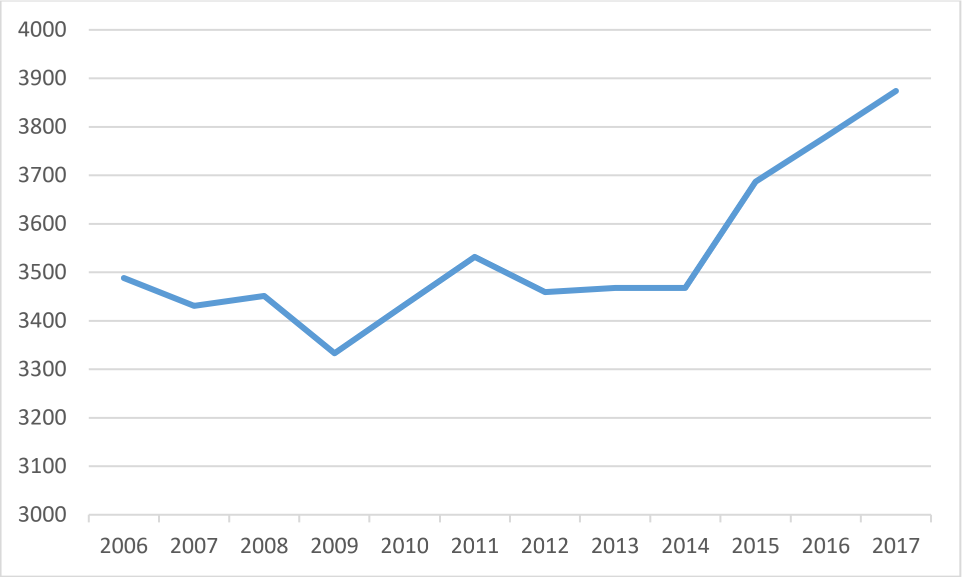

Figure 12: Annual numbers of deaths in North East Essex, 2006-2018. (Source: PHE Online Interactive Tool for End of Life Care)

In 2019, the age profile of people in NEE was older when compared with that in England, with fewer working age adults (see Figure 13).

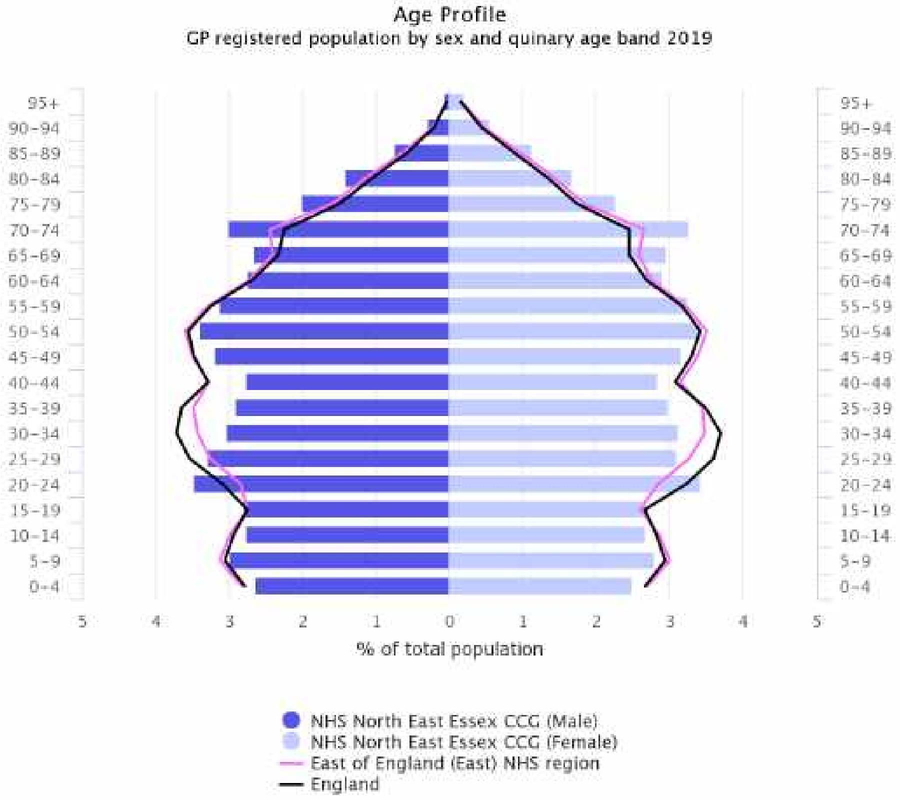

Figure 13: Age-sex profile of the population in North East Essex (light and darker blue horizontal bars) in comparison with that in England (black outline) and the East of England (pink outline). (Source: PHE Fingertips)

From 2006 to 2017, a higher percentage of people over 75 years of age died in NEE when compared with the percentage for England (see Figure 14).

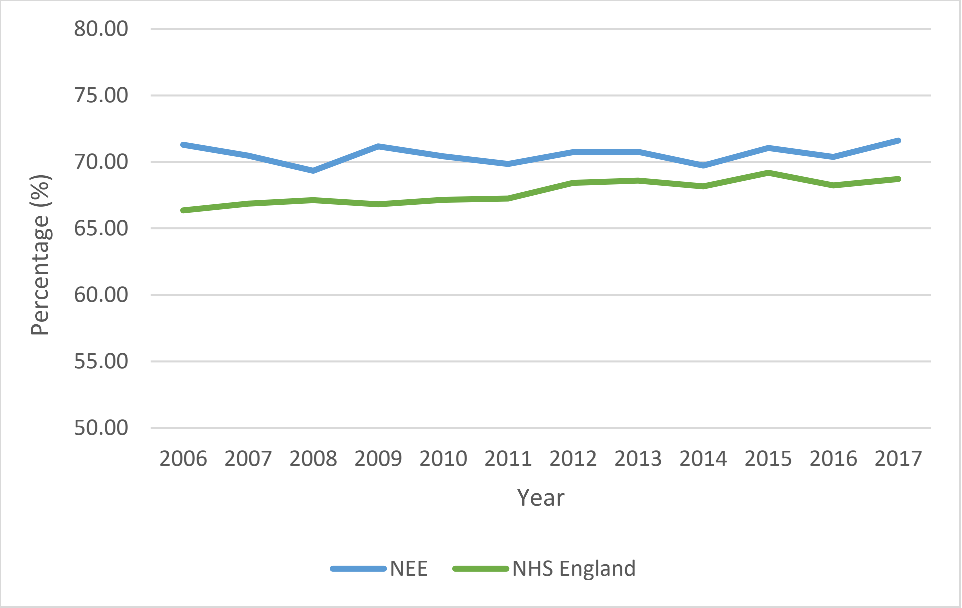

Figure 14: Percentage (%) of people dying aged over 75 years as a proportion of all deaths, 2006-2017. Key: blue = North East Essex, green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

Projected number of deaths

According to projections made by Public Health England (PHE), the number of deaths in England will increase from 2016 to 2040 due to demographic change (see Figure 15). Owing to demographic changes including population growth, the number of deaths in NEE is also likely to increase. When compared with the number of deaths in 2014, by 2030 PHE estimate there will be:

- 29.94% more deaths in Colchester District
- 30.96% more deaths in Tendring District

This increase in the number of deaths, potentially an additional 1,100 people dying in NEE by 2040, means the need to make best use of resources for people at the end of life is pressing.

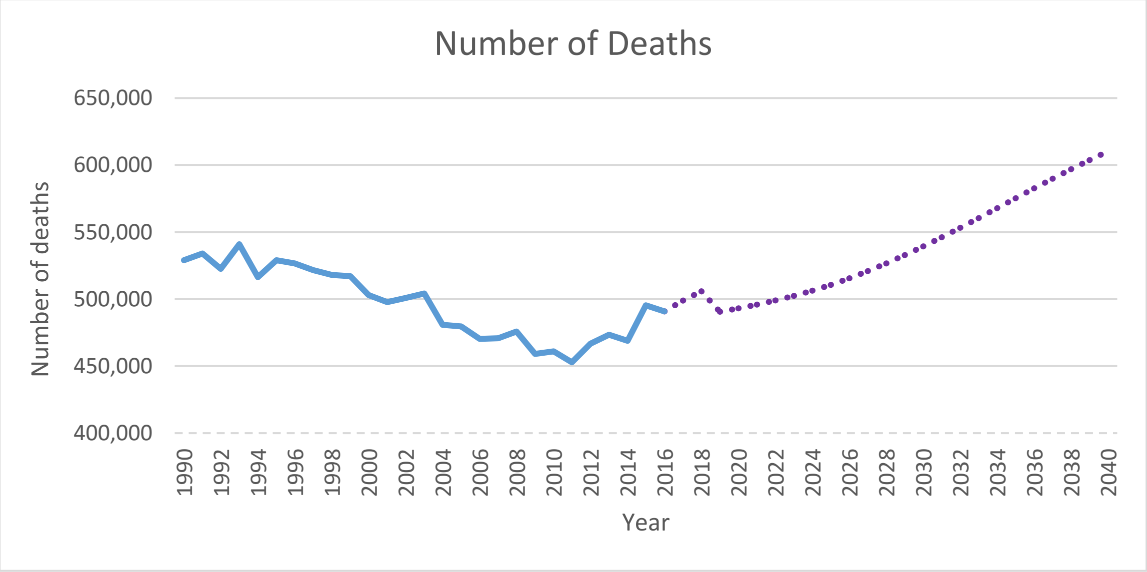

Figure 15: Actual (solid blue line) and predicted (dotted purple line) number of deaths in England, 1995-2030. (Source: PHE End of Life and Palliative Care Atlas)

Place of death

In NEE, the majority of people die out of hospital (see Table 1). In 2018/19:

- 1,565 people died out of hospital – 53% of total deaths
- 1,335people died in hospital – 47% of total deaths[17]

Table 1: Place of death (in hospital; out of hospital) for people in the last year of life in North East Essex with cancer and non-cancer conditions, 2018/19. See footnote and Appendix 2 for information about data suppression.[18] (Source: ICHP analysis)

Cause of death	No. people dying in hospital	No. people dying out of hospital	*Total*
Cancer	285	450	735
Non-cancer	1050	1115	2165
Total	1335	1565	

As can be seen from Table 1 and Figure 16, in 2018/19, almost three-fifths (59%) of people with cancer in NEE died out of hospital (59%) than in (41%), whereas only slightly more than half of people with non-cancer conditions in NEE die out of hospital (51%) than in (49%).

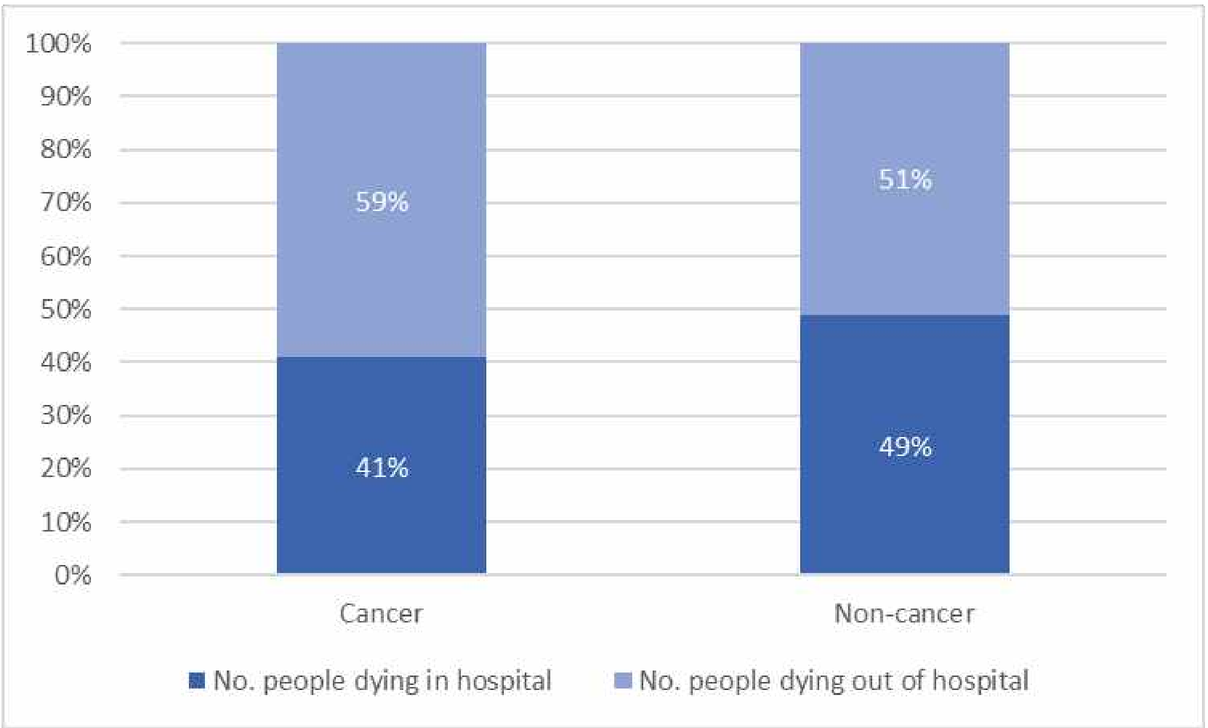

Figure 16: Percentage (%) of people in the last year of life in North East Essex dying from cancer and non-cancer conditions according to place of death (in hospital; out of hospital), 2018/19. (Source: ICHP analysis)

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[17] Analysis in this report is subject to NHS Digital data suppression rules, and analysis derived from practice-level data is subject to rounding at the practice level. This leads to a discrepancy between actual deaths and those presented in this analysis (see Appendix 2)

[18] Analysis in this report is subject to NHS Digital data suppression rules, and analysis derived from practice-level data is subject to rounding at the practice level. This leads to a discrepancy between actual deaths and those presented in this analysis (see Appendix 2)

When compared with the average for England, from 2006 to 2015, a higher percentage of people in NEE died in their usual place of residence (UPoR; see Figure 17). In 2017, for this metric, NEE performed better than the average for England and second best out of a group of ten demographically similar CCGs (see Figure 18).

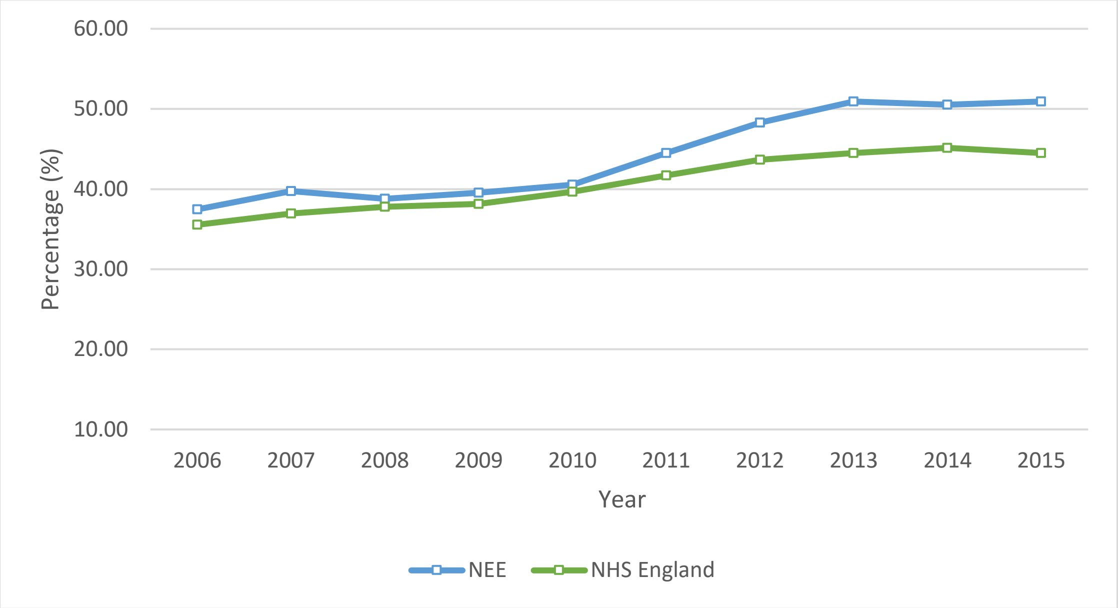


Figure 17: Percentage (%) of people dying in their usual place of residence (UPoR), 2006-2015. Key: blue = North East Essex; red = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

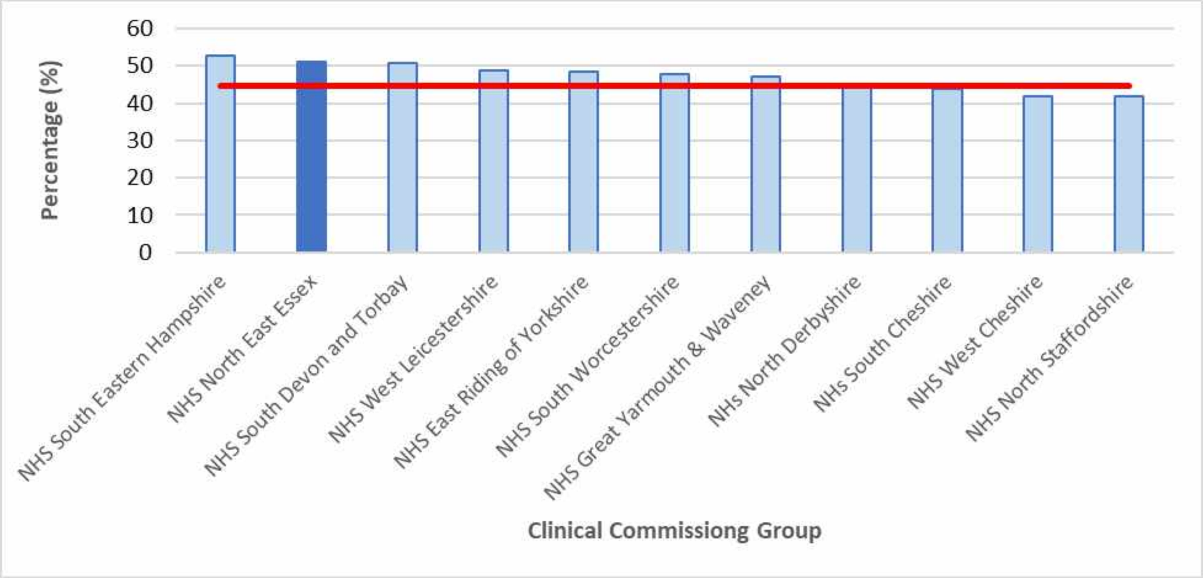


Figure 18: Percentage (%) of people in North East Essex (darker blue column) dying in their usual place of residence (UPoR) compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2017. (Source: PHE Online Tool for End of Life Care)

Since 2006, the percentage of deaths in hospital has decreased in both NEE and England (see Figure 19); in 2015, the percentage of deaths in hospital was slightly lower in NEE than the average for England and for six out of ten CCGs with a similar demography (see Figure 20).

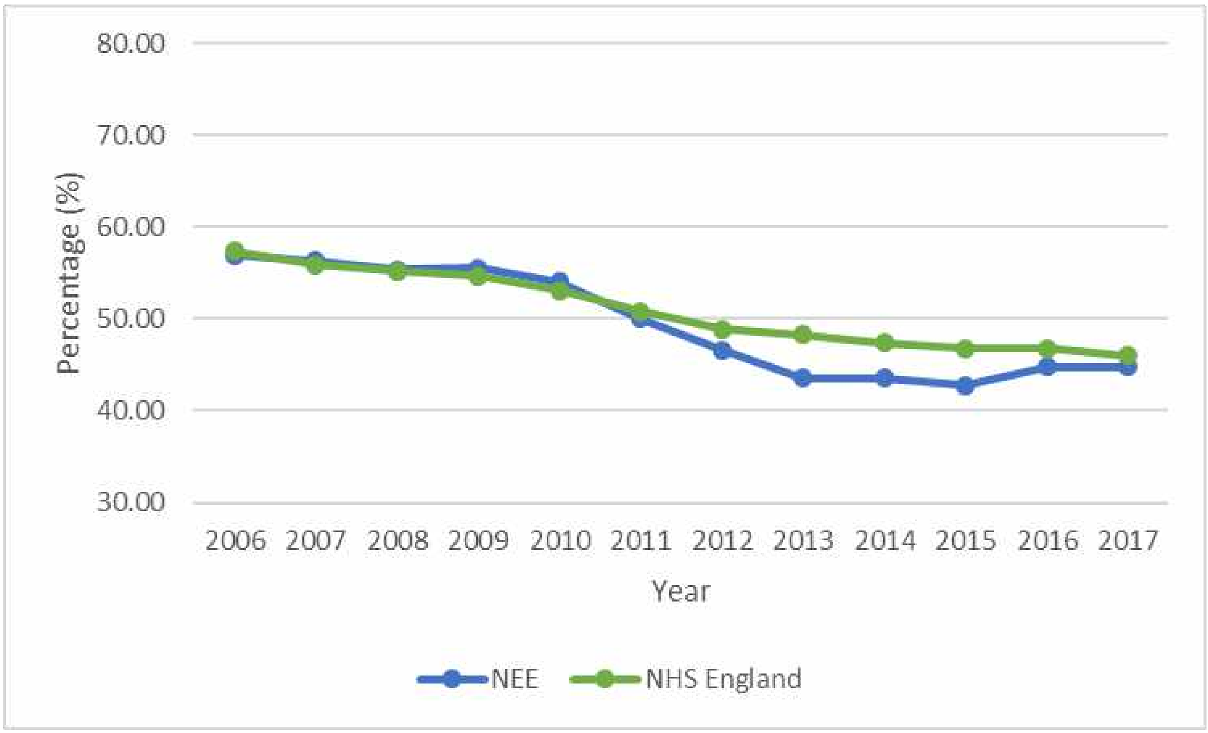


Figure 19: Percentage (%) of people dying in hospital as a proportion of all deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

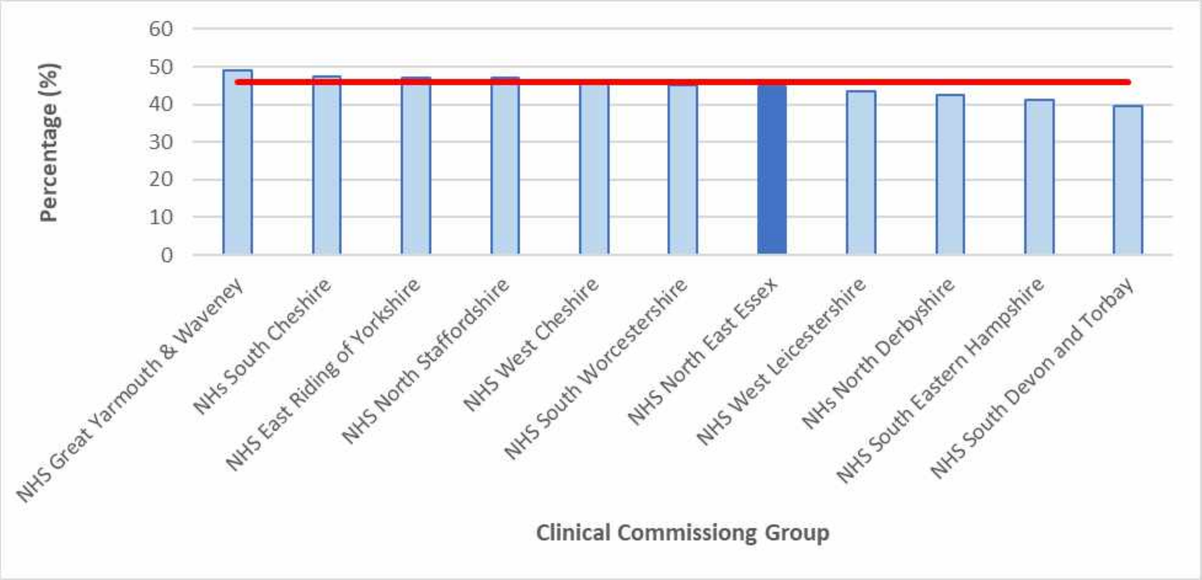
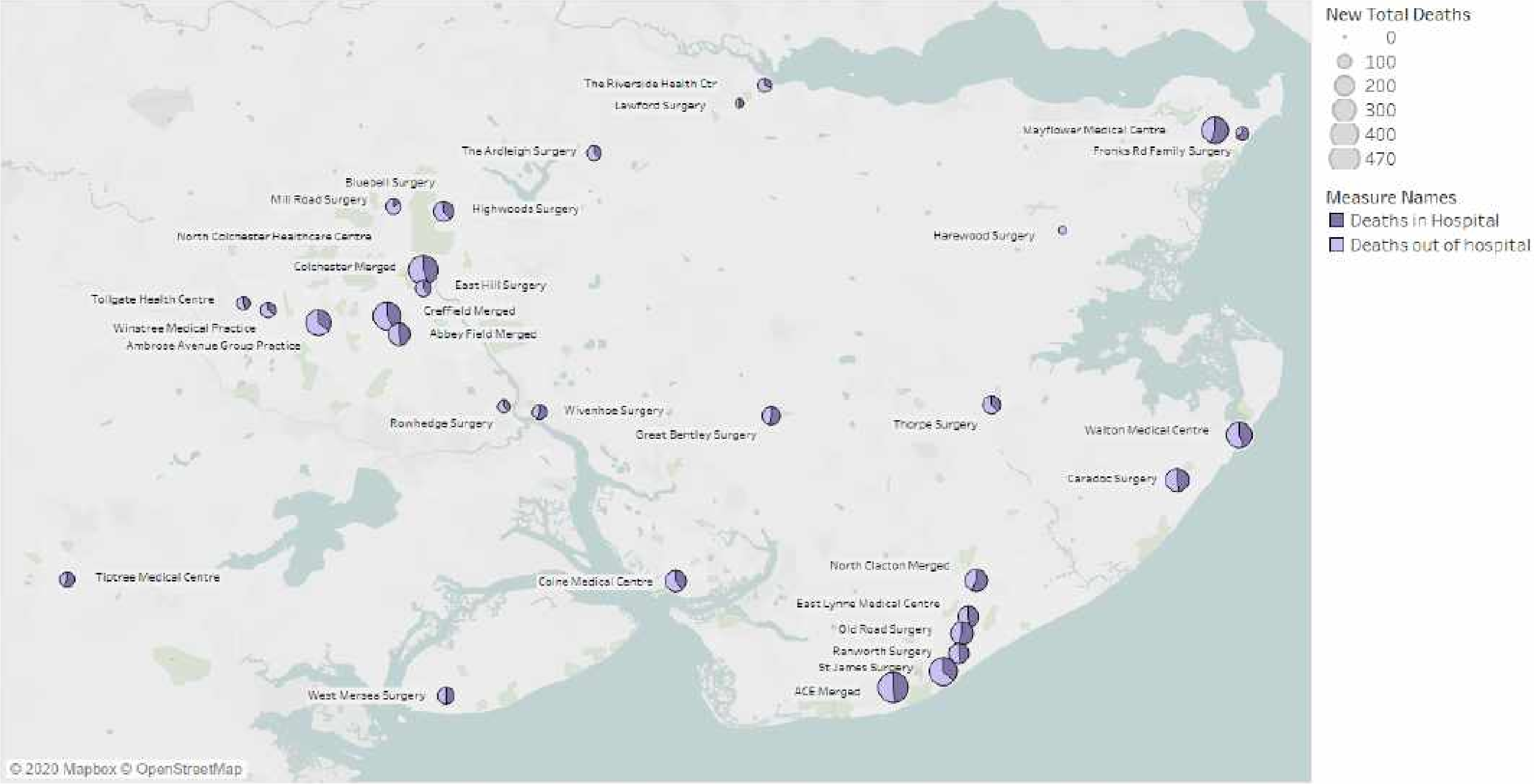


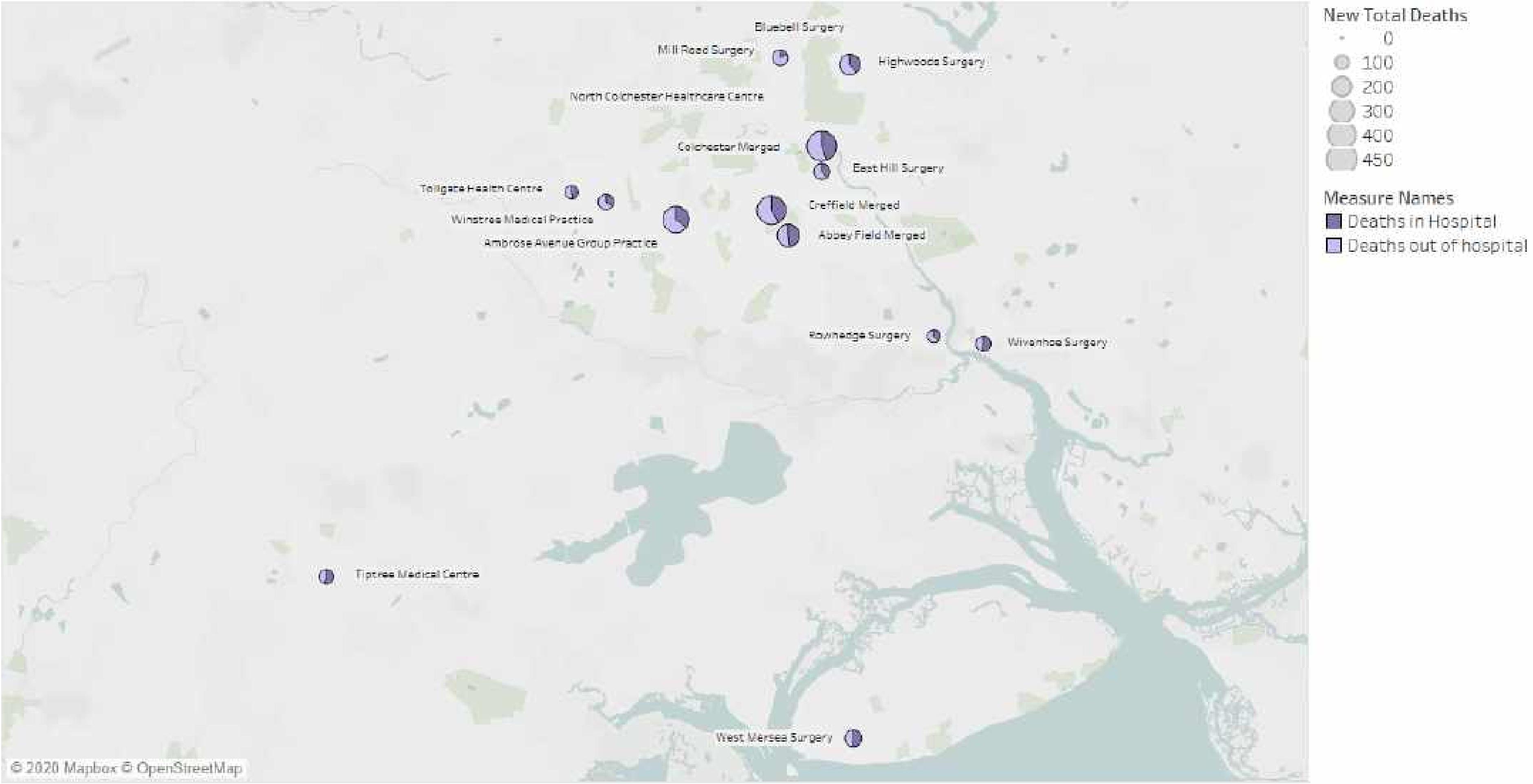
Figure 20: Percentage (%) of people in North East Essex (darker blue column) dying in hospital compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2015. (Source: PHE Online Interactive Tool for End of Life Care)

In Maps 1-3, the number of deaths in NEE has been shown for each general practice. Map 1 shows the number of deaths across NEE, Map 2 shows the number of deaths for Colchester District Council and Map 3 shows the number of deaths for Tendring District Council. For each general practice, the number of deaths in hospital in relation to the number of deaths out of hospital has been visualised as a pie chart (i.e. within each circle); the size of each circle represents the number of deaths recorded.



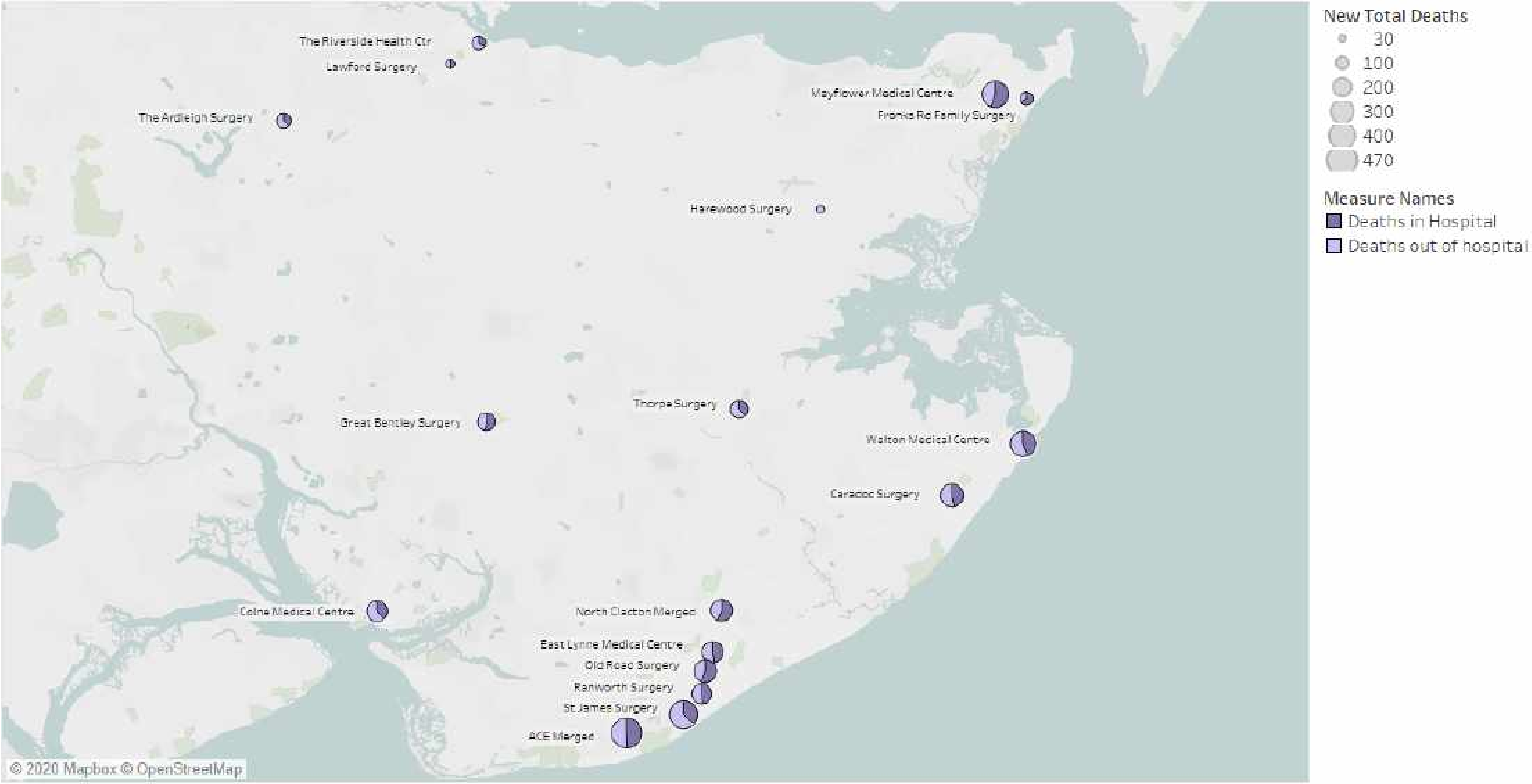
Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows sum of New Total Deaths. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice, which has multiple members selected

Map 1: Number of deaths (in hospital; out of hospital) by general practice in North East Essex, 2018/19. (Source ICHP analysis)



Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows sum of New Total Deaths. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice, which keeps 16 members.

Map 2: Number of deaths (in hospital; out of hospital) by general practice in Colchester District. (Source ICHP analysis)



Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows sum of New Total Deaths. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice, which has multiple members selected.

Map 3: Number of deaths (in hospital; out of hospital) by general practice in Tendring District. (Source ICHP analysis)

Cause of death

In NEE in 2018/19, although cancer was the single commonest cause of death, most people died from causes other than cancer, notably dementia, COPD, heart failure, stroke and liver disease:

- 985 died from cancer (26.2%)
- 2,780 people died from non-cancer conditions (73.8%)

In terms of the burden of mortality, percentage changes in the cause of death from 2006 to 2017 have occurred for:

- dementia (as a cause or underlying cause), which doubled to 16.58% of all deaths (see Figure 21)
- COPD, which almost doubled to 11.3% of all deaths (see Figure 22)
- stroke, which almost halved to 4.53% of all deaths (see Figure 23), and had been falling consistently
- liver disease, which increased to 2.33% of all deaths (see Figure 24), and although this is only a small percentage of the total, it represents an increase of 80% since 2006

The percentage of people dying from cancer was relatively unchanged from 2006, accounting for 27.71% or more than a quarter of all deaths in 2017 (see Figure 25). Similarly, the percentage change in heart failure as a cause of death did not change greatly over the period 2006-2017, dropping as a cause of death from 12.7% to 11.04% (see Figure 26).

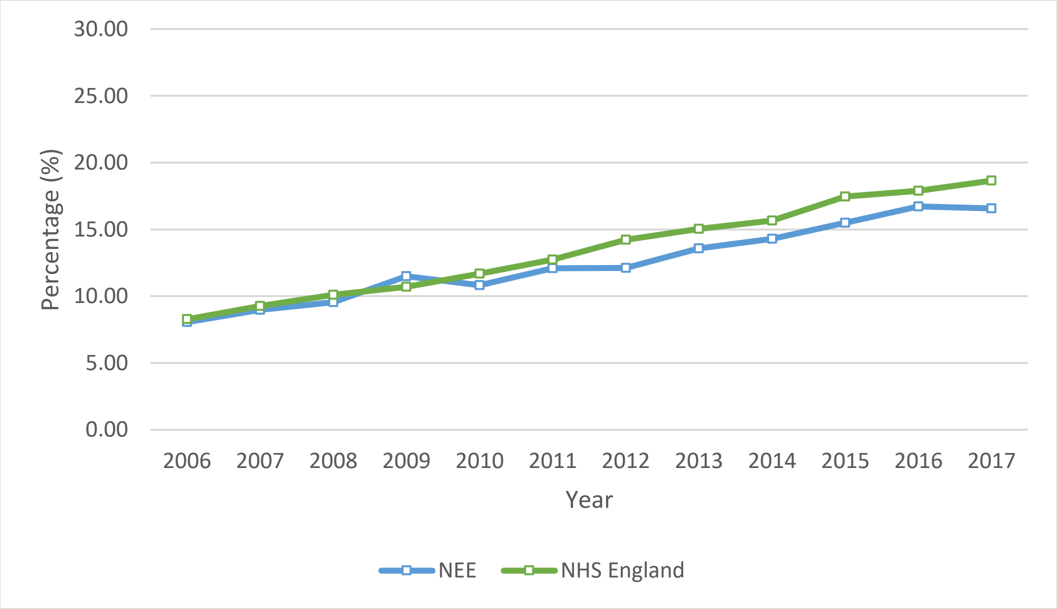


Figure 21: People dying of dementia as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

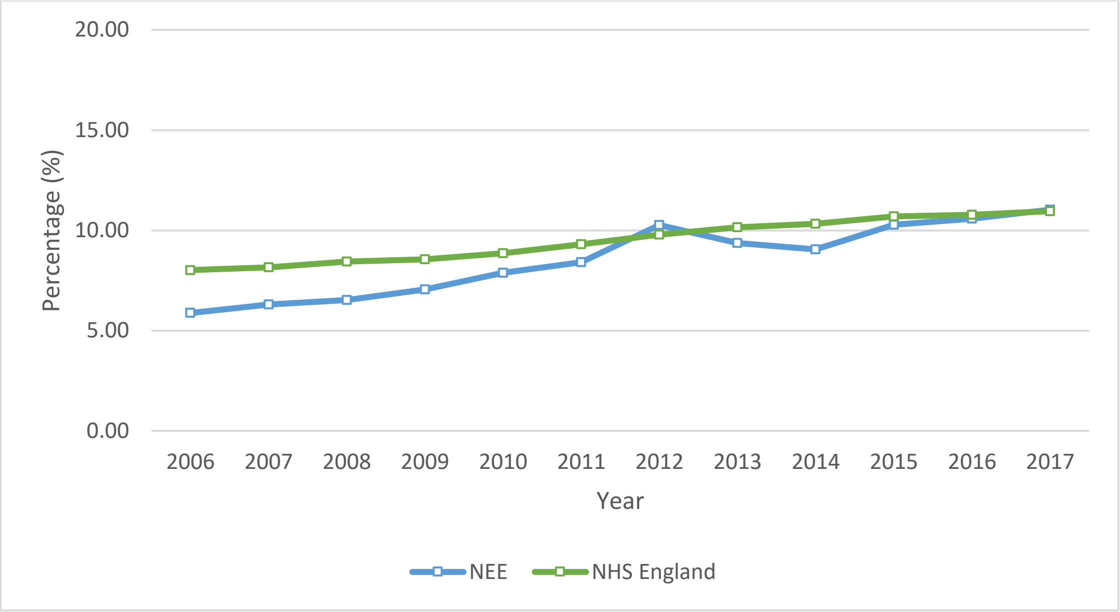


Figure 22: People dying of COPD as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

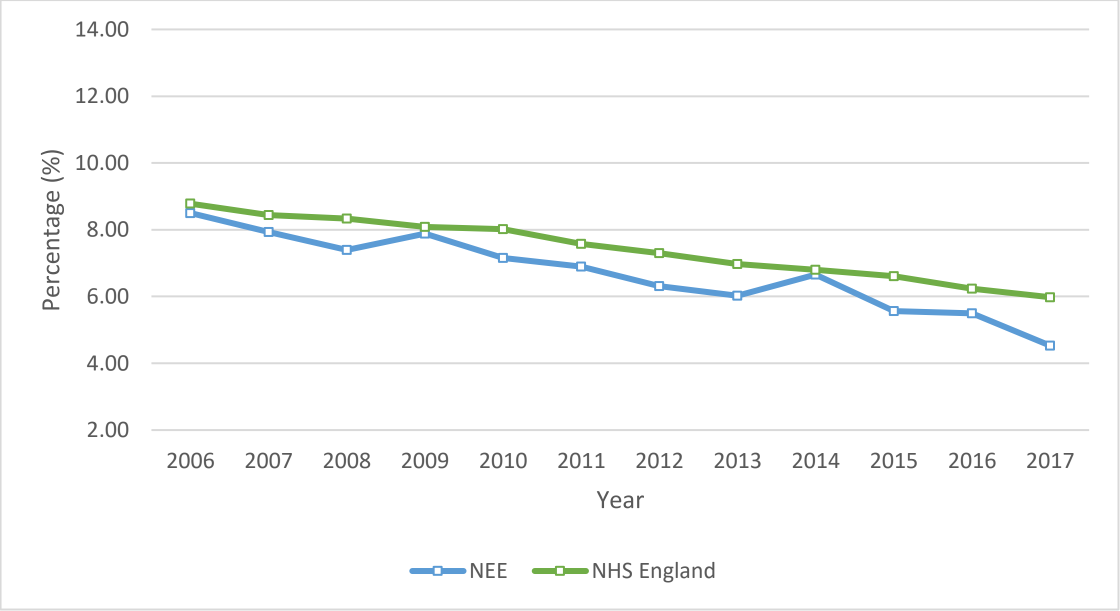


Figure 23: People dying of stroke as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

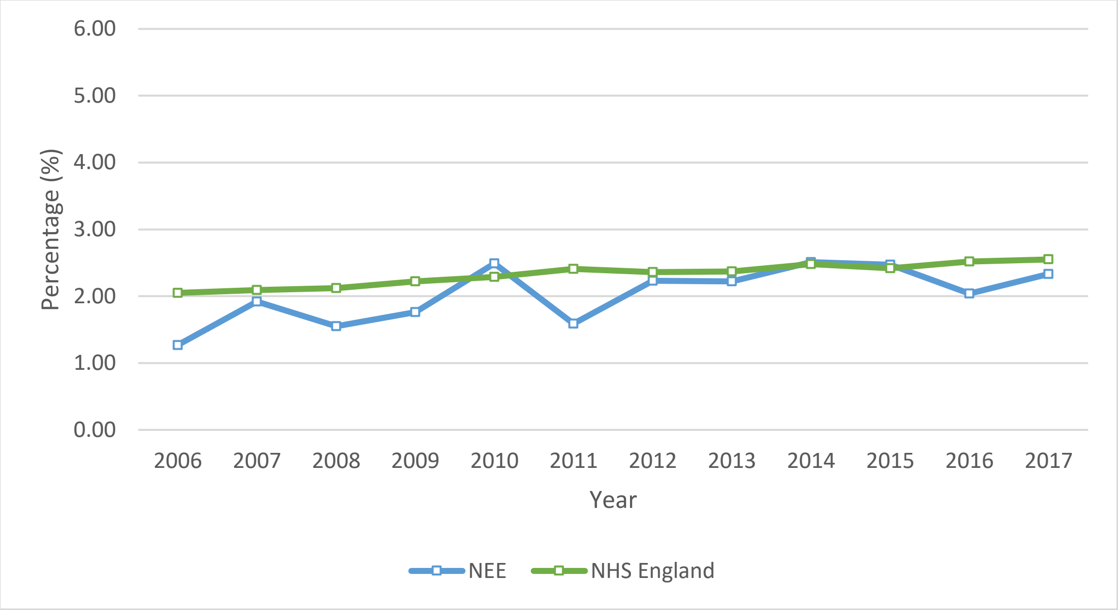


Figure 24: People dying of liver disease as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

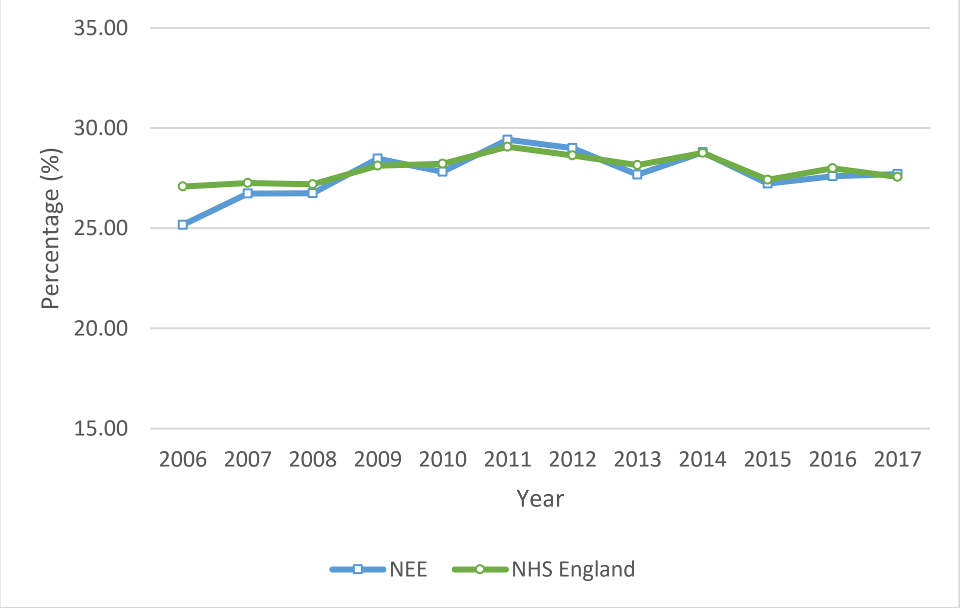


Figure 25: People dying of cancer as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

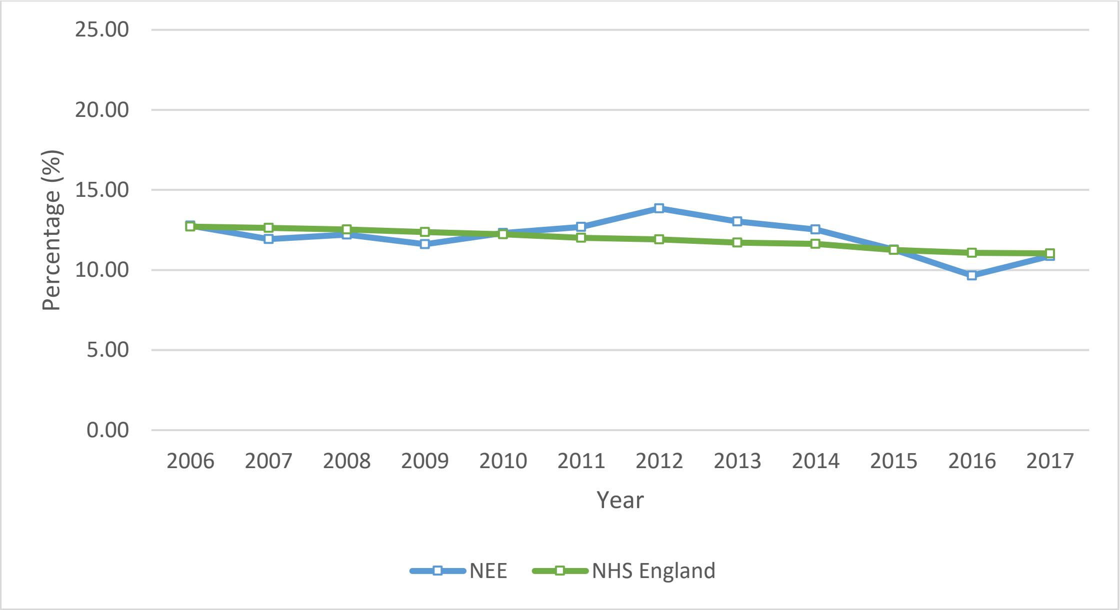


Figure 26: People dying of heart failure as a percentage (%) of total deaths, 2006-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

Admissions to hospital

Despite the decrease in the percentage of people dying in hospital since 2006 (see Figure 19), the percentage of people admitted to hospital in the last 90 days of life has remained at a similar level (approximately 68%), not only in NEE but also across England (see Figure 27).

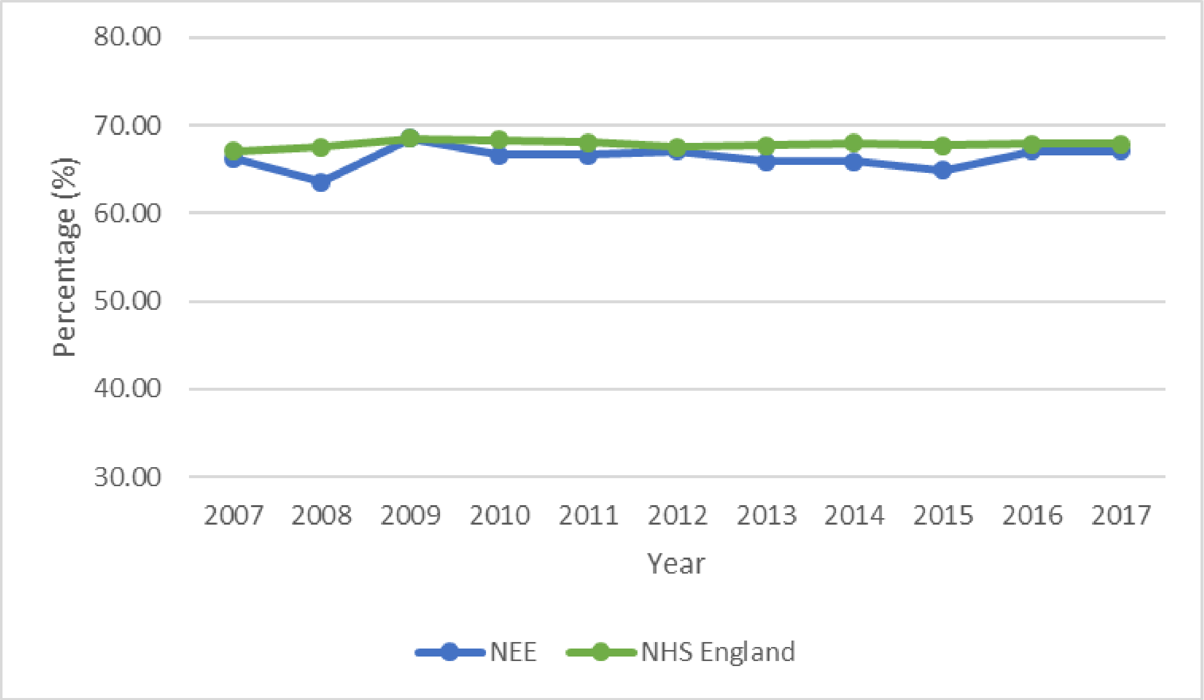


Figure 27: Percentage (%) of people admitted to hospital in the last 90 days of life, 2007-2017. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

In 2017, the percentage of people in NEE admitted to hospital in the last 90 days of life was the same as the England average and at a similar level to that for 10 demographically similar CCGs (see Figure 28).

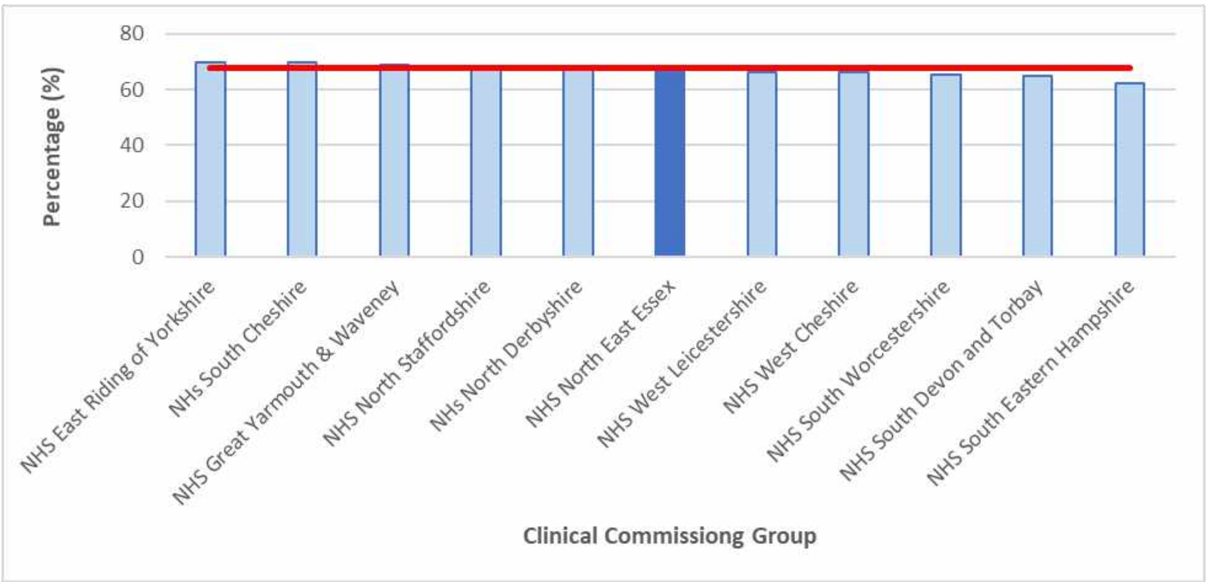


Figure 28: Percentage (%) of people in North East Essex (darker blue column) admitted to hospital in the last 90 days of life compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2017. (Source PHE Online Interactive Tool for End of Life Care)

By contrast, there has been an increase in the percentage of people in the last year of life with three or more emergency admissions in the last 90 days of life both in NEE and in England (see Figure 29). Between 2006 and 2017, there was a 44% increase in NEE.

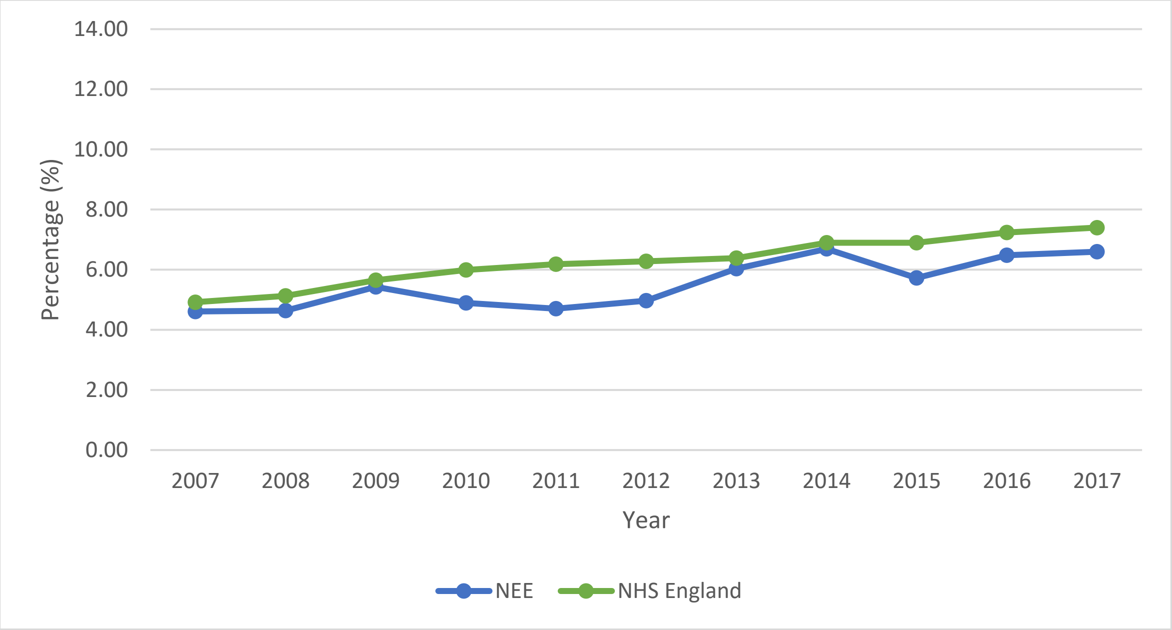


Figure 29: Percentage (%) of people with three or more emergency admissions in the last 90 days of life, 2007-2017 Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)

When compared with 10 demographically similar CCGs in 2017, NEE had a lower percentage of people with three or more emergency admissions in the last 90 days of life than that in six of them (see Figure 30); it was also lower than the England average.

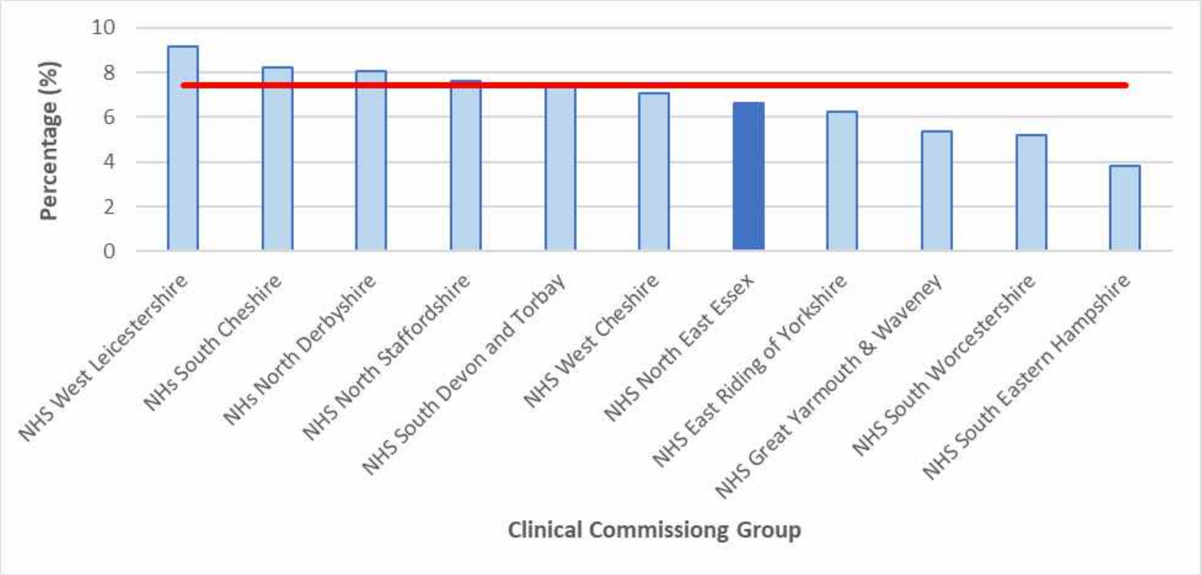


Figure 30: Percentage (%) of people in North East Essex (darker blue column) with three or more emergency admissions in the last 90 days of life compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2017. (Source: PHE Online Interactive Tool for End of Life Care)

Factors influencing outcomes: residence in a care home

There is a concentration of care homes in the coastal areas of NEE, especially Clacton-on-Sea in Tendring District Council (see Map 4). In 2011, the percentage of the population living in a care home in Tendring District Council was higher than the England average, whereas that for Colchester District Council was lower (see Figure 31).

Map 4: Location of care homes in Clacton-on-Sea in relation to general practices. (Source: Care Quality Commission)

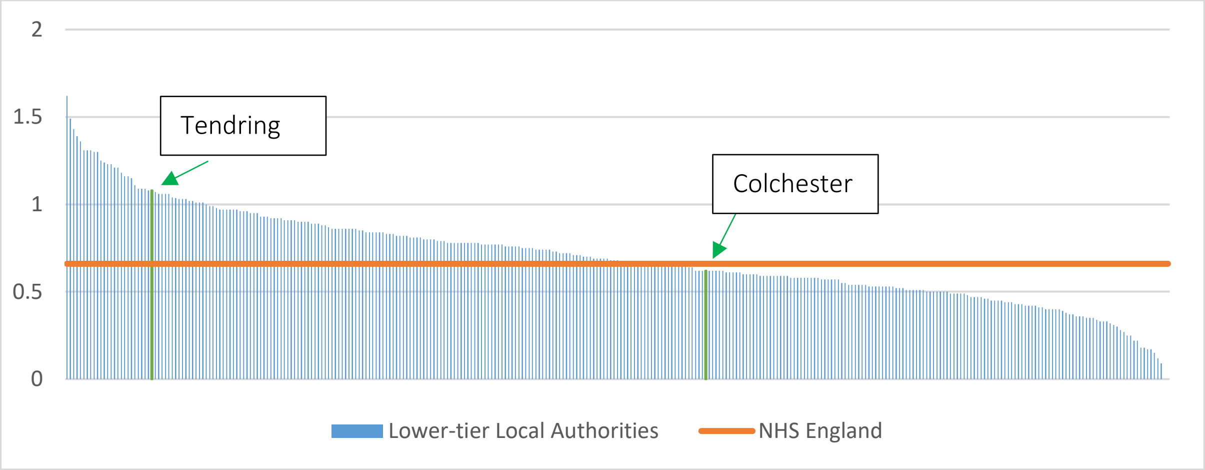


Figure 31: Percentage (%) of the population living in a care home by lower-tier local authority (LTLA) in England, 2011. Key: transverse red line = NHS England average; Tendring and Colchester District Councils = green columns; other LTLAs = blue columns). (Source:: PHE Online Interactive Tool for End of Life Care)

The percentage of care-home residents dying in a care home in both NEE and England increased over the period from 2006 to 2015 (see Figure 32).[19]

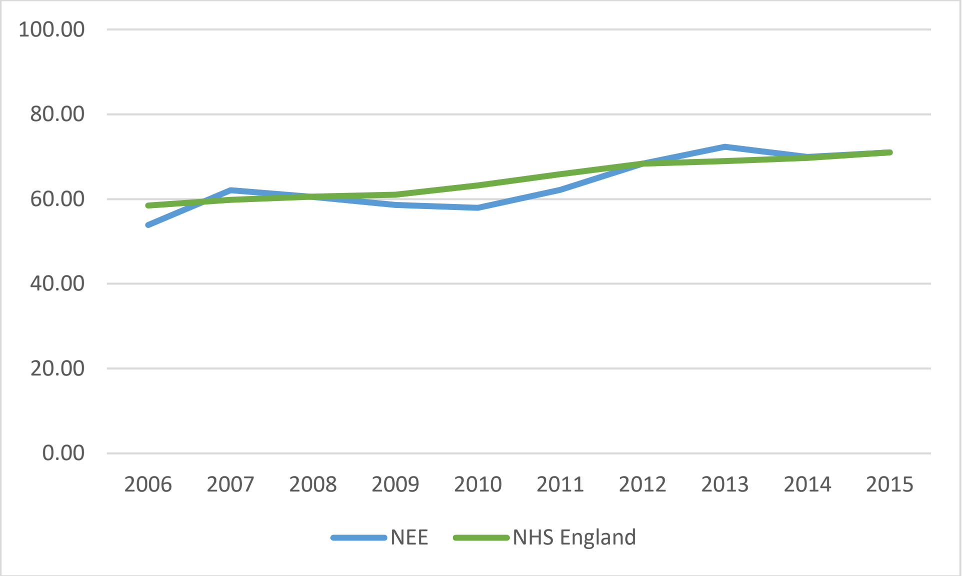


Figure 32: Percentage (%) of care-home residents dying in a care home, 2006-2015. Key: blue = North East Essex; green = NHS England. (Source: PHE Online Interactive Tool for End of Life Care)[19]

When compared with 10 demographically similar CCGs in 2015, however, the percentage of care-home residents dying in residential care homes in NEE was lower than that in seven of them, but at a similar level to the England average (see Figure 33).

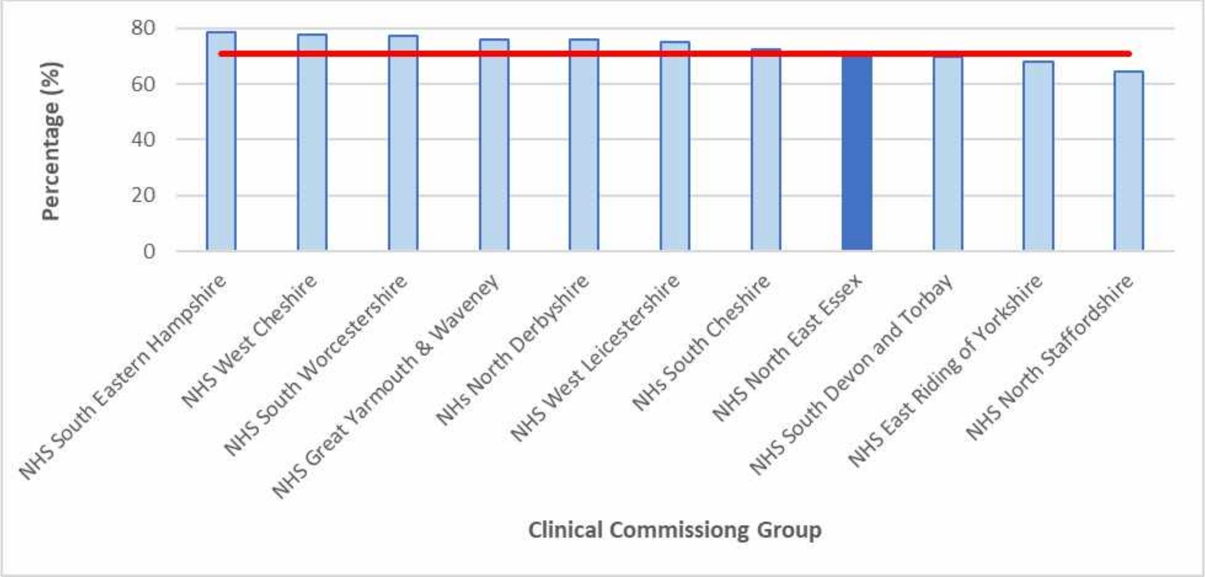


Figure 33: Percentage (%) of care-home residents dying in a care home in North East Essex (darker blue column) compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2015. (Source: PHE Online Interactive Tool for End of Life Care)

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[19] PHE (the data source) does not make it clear whether the term ‘care homes’ refers to both residential and nursing care homes or to only one type of care home.

In 2017, the number of nursing home beds in NEE was lower than the England average and that in seven out of ten demographically similar CCGs (see Figure 34).

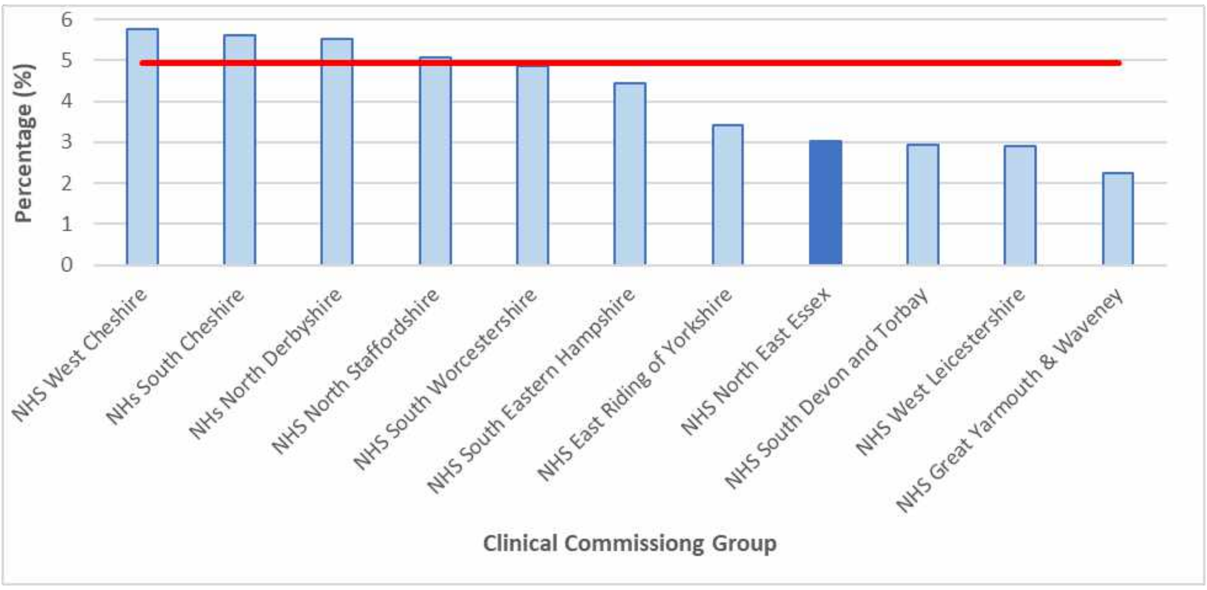
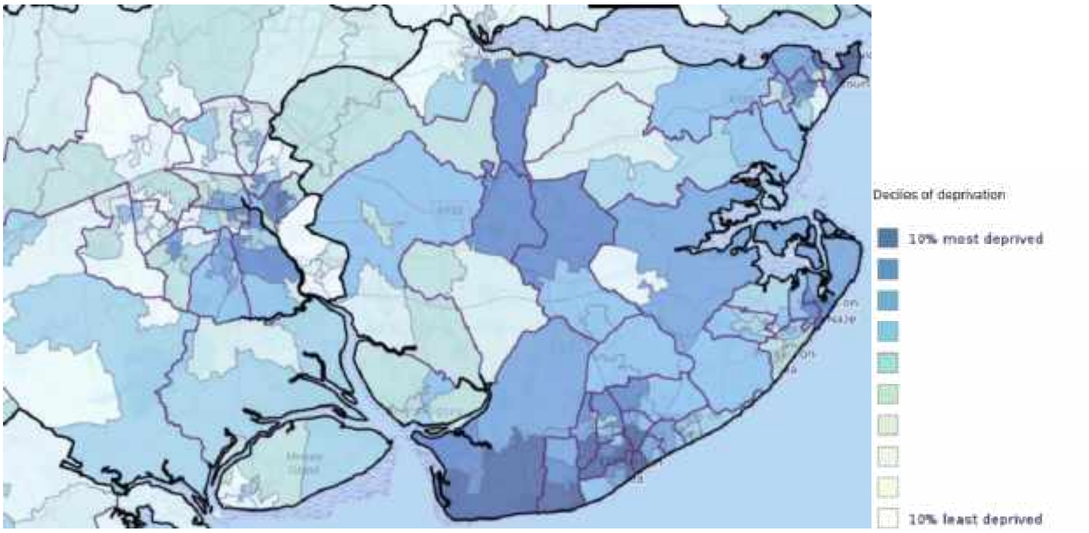


Figure 34: Number of nursing home beds per 100 people aged more than 75 years in North East Essex (darker blue column) compared with the England average (transverse red line) and that in 10 demographically similar CCGs (lighter blue columns), 2017. (Source PHE Online Interactive Tool for End of Life Care)

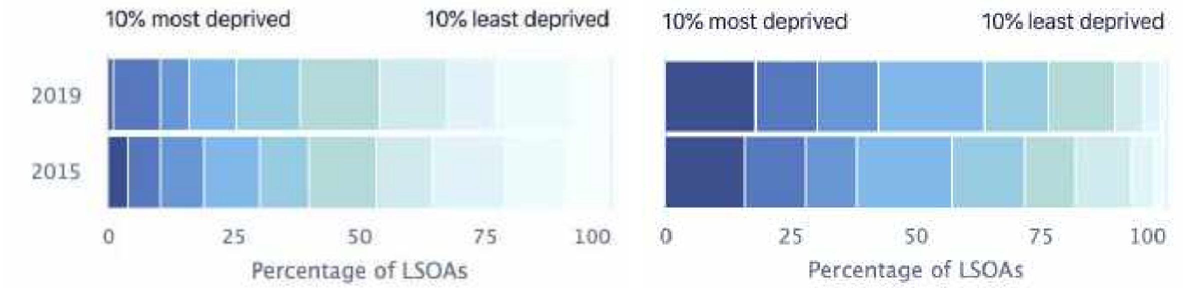
Factors influencing outcomes: deprivation

Across NEE, the level of deprivation is wide ranging (see Map 5).



Map 5: The level of deprivation by lower super output area (LSOA) in North East Essex. (Source: The English Indices of Deprivation 2019 - Statistical Release)

Although the levels of deprivation in Colchester District Council fell between 2015 and 2019, the levels of deprivation increased in Tendring District Council (see Figure 35).



Colchester District

Tendring district

Figure 35: Change in the percentage (%) of LSOAs in Colchester and Tendring District Councils in the decile groups for the Index of Multiple Deprivation (IMD) between 2015 and 2019. (Source: The English Indices of Deprivation 2019 - Statistical Release)

In 2018/19, people who lived the most-deprived quintile of lower super output areas (LSOAs) in NEE were more likely to die in hospital than out of hospital, whereas people who lived in the least-deprived quintile of LSOAs were more likely to die out of hospital than in hospital (see Figure 36).

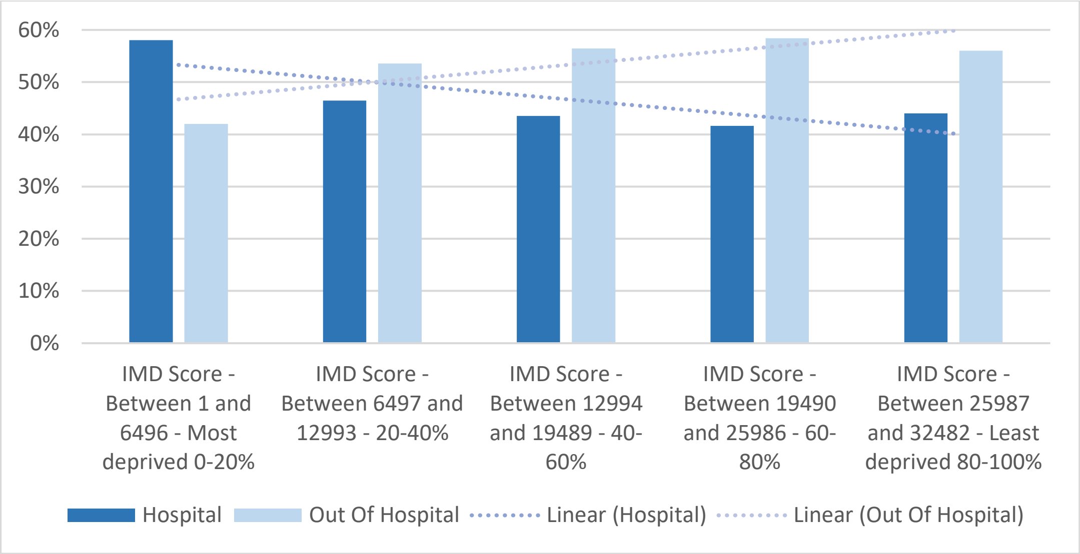


Figure 36: Place of death (in hospital; out of hospital) for people in the last year of life in North East Essex according to quintiles of IMD score by LSOA, 2018/19. (Source: ICHP analysis)

Furthermore, a higher percentage of people registered with general practices which have deprivation scores in the most-deprived quintile of practices are more likely to have three or more emergency admissions in the last 90 days of life when compared with people registered with general practices which have deprivation scores in the least-deprived quintile of practices (see Figure 37).

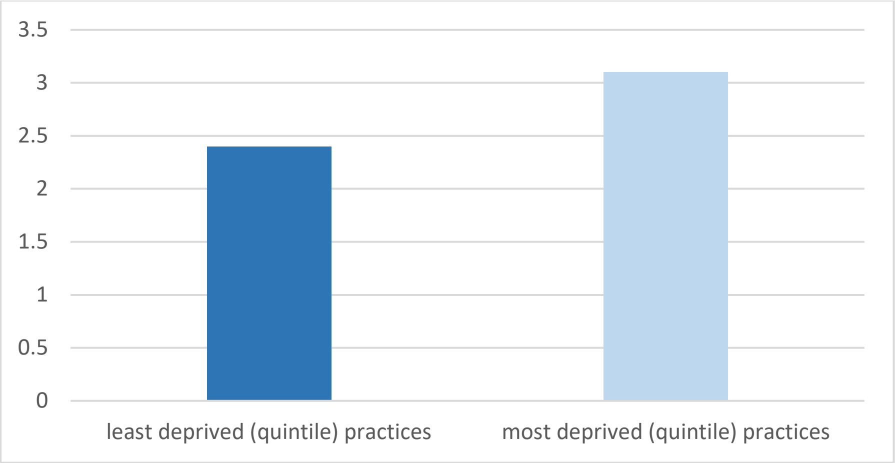


Figure 37: Percentage (%) of people with three of more emergency admissions in the last 90 days of life who were registered with general practices which have deprivation scores in the most-deprived and least-deprived quintiles of practices in North East Essex, 2018/19. (Source: ICHP analysis)

Referrals to the coroner

In the focus group including bereaved family members, it was reported that families find referrals to the coroner distressing. As such, it is important to understand the context for and contributory factors to this process.

In 2018/19, 377 out of 3490 deaths in NEE were referred to the coroner, representing 10.8% of deaths.[20] This percentage is low when compared with that for England and Wales, where in 2018, 220,648 of 541,627 deaths were referred to the coroner, representing 41% of deaths.[21]

Of the 377 deaths in NEE referred to the coroner:

- 9 deaths required no action by the coroner and a death certificate was issued
- 308 (81.6%) deaths were reviewed followed by permission for the issuance of a death certificate
- 42 (11%) deaths led to a post-mortem followed by permission for the issuance of a death certificate (compared with 38% for England and Wales)
- 18 (5%) deaths led to an inquest (compared with 13% for E&W)

One general practice in NEE has a relatively high percentage of all referrals to the coroner, at 5.2%, but only 2.5% of all deaths. This general practice is responsible for residents in a large care home, to which many people are discharged from hospital in the last days or weeks of life. Care provision is by a modern extended general practice team, and people often die before their GP sees them. Most of these referrals are resolved with permission for the issuance of a death certificate. The relatively high number of referrals from this general practice may reflect ambiguities in death certification legislation, which may not have kept pace with modern clinical practice. The practice of discharging people from hospital who are nearing death, however, merits further study using a linked dataset.

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[20] Source: Essex County Council Freedom of Information Team

[21] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/810303/Coroners_Statistics_Annual_2018.pdf

Summary of Population Profile for people in the last year of life in NEE

- The number of deaths in NEE has been increasing over the last decade
- According to population projections by PHE up to the year 2030, the number of deaths will increase by approximately 30% (or an additional 1100 people dying)
- The percentage of deaths in people aged over 75 years is higher in NEE than in England
- Cancer remains the single largest cause of death, however, the cause of death is changing, with large increases in dementia and COPD as a cause, or underlying cause, of death
- More people with cancer die out of hospital than in, whereas almost the same number of people with non-cancer conditions die in hospital as out
- People are more likely to die in their usual place of residence and less likely to die in hospital in NEE when compared with England, although there are some demographically similar CCGs in which a greater percentage of people die in their usual place of residence
- Over the last decade, in NEE there has been a 44% increase in people at end of life with three or more emergency admissions to hospital in the last 90 days of life. The rate is at a similar level to that seen in demographically similar CCGs. The number of people admitted in the last 90 days of life overall has been largely unchanged over the last ten years.
- The levels of deprivation decreased in Colchester between 2015 and 2019, but increased in Tendring over the same time-period
- People living in the most-deprived quintile of LSOAs are more likely to die in hospital, whereas people living in the least-deprived quintile of LSOAs are more likely to die at home
- People registered with general practices located in areas with the highest deprivation scores are more likely to have three or more emergency admissions to hospital in the last 90 days of life than people registered with the general practices located in areas with the lowest deprivation scores
- There is a concentration of care homes in Tendring District Council, particularly in Clacton-on-Sea
- Of 377 referrals to the coroner in 2018/19, nine required no action and 308 went no further with the issuance of a certificate; however, one general practice had a relatively high number of referrals in relation to the number of deaths

Population budgeting

To define a full population budget, it is important to identify all the resources used to provide care for the specific population group, including:

- financial resources
- workforce
- time
- carbon

For the first phase of this work, however, the amount of money spent on providing care for people in the last year of life in NEE has been ascertained using tariff, adjusted for reference costs, from the following sources:

- hospital expenditure
- St Helena Hospice charitable funds
- St Helena Hospice NHS grant-funded
- NHS continuing healthcare fast-track pathway

As described in the section entitled ‘Next steps’, further and additional collection of financial data should be undertaken as continuous value improvement commences. Methods of collecting information on carbon usage and workforce resources also need to be explored.

Limitations of the financial analysis

Financial data it was ***not*** possible to obtain for this analysis includes expenditure relating to:

- attendance at outpatient premises
- general practice
- community care (apart from NHS continuing healthcare fast-track pathway)
- prescribing
- social care (NB: data for social care activity is available, see below).

In addition, it was not possible to obtain information relating to actual costs for admissions to hospital. Therefore, this analysis provides a sense of scale and opportunity rather than of precision.

Expenditure on people in the last year of life in NEE

In 2018/19, expenditure on people in the last year of life in NEE derived from four funding sources is shown in Table 3 and Figure 38. It can be seen that, of the four sources of funding for which data could be obtained, three-quarters of the expenditure on people in the last year of life was for admissions to hospital (75%), followed by hospice-care services from St Helena Hospice charitable funds (13%).

Table 2: Expenditure (£) on various end-of-life care services for people in the last year of life in North East Essex using data from four sources of funding, 2018/19. (Source: ICHP analysis, St Helena Hospice, NEE CCG)

Source of funding for end-of-life care	*Expenditure (£) in NEE in 2018/19*	*Percentage (%) of total*
Hospital expenditure	£30,111,421	75%
St Helena Hospice charitable funds	£5,188,000	13%
St Helena Hospice NHS grant-funded	£3,110,000	8%
NHS continuing healthcare fast-track pathway	£1,474,876	4%
Total	£39,884,297	

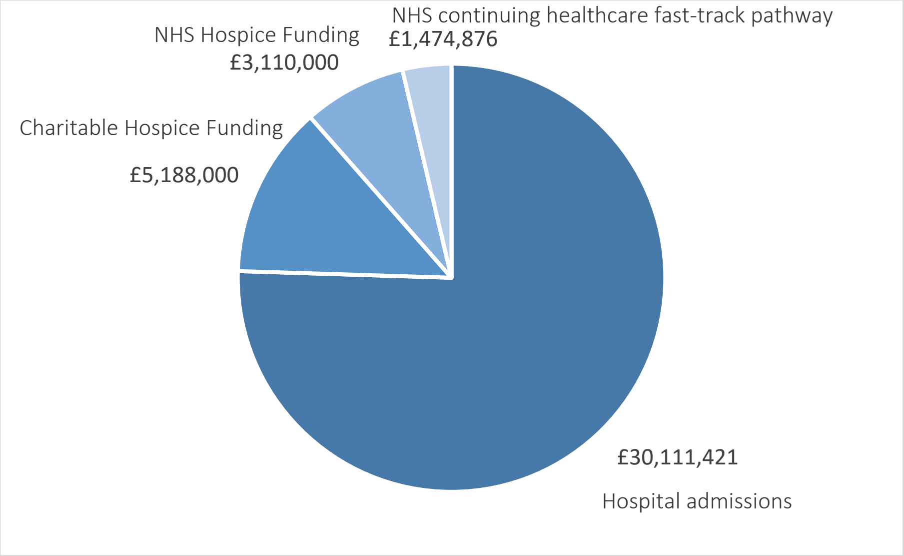

Figure 38: Expenditure (£) on various services for people in the last year of life in North East Essex using data from four sources of funding, 2018/19. (Source ICHP analysis, St Helena Hospice, NEE CCG)

Expenditure on hospital care

In NEE, there is a block contract with NHS East Suffolk and North Essex NHS Foundation Trust, although activity levels are agreed prior to each financial year. Admissions to hospital for people in the last year of life in NEE represent 12.35% all admissions to hospital (see Table 3).

Table 3: Number of admissions to hospital for people in the last year of life and for all residents in North East Essex, 2018/19. (Source: ICHP analysis)

Population group in North East Essex	*Number of hospital admissions*
People in the last year of life	11,884
All residents, including those in the last year of life	96,219

Expenditure on admissions to hospital for all residents in NEE and for people in the last year of life is shown in Table 4 and Figure 39. In 2018/19, 19% of the total expenditure on all admissions to hospital, 6% of the expenditure on planned admissions and 27% of the total expenditure on emergency admissions was spent on people in the last year of life.

Table 4: Expenditure (£) on admissions to hospital for all residents and for people in the last year of life in North East Essex, 2018/19. (Source: ICHP analysis)

	Expenditure (£) for all residents	*Expenditure (£) for people in last year of life*	*Total expenditure (£)*	*Percentage (%) of total expenditure*
All admissions	£ 131,196,650	£ 30,111,421	£ 161,308,071	19%
Planned admissions	£ 60,107,545	£ 3,611,874	£ 63,719,419	6%
Emergency admissions	£ 71,089,105	£ 26,499,547	£ 97,588,652	27%

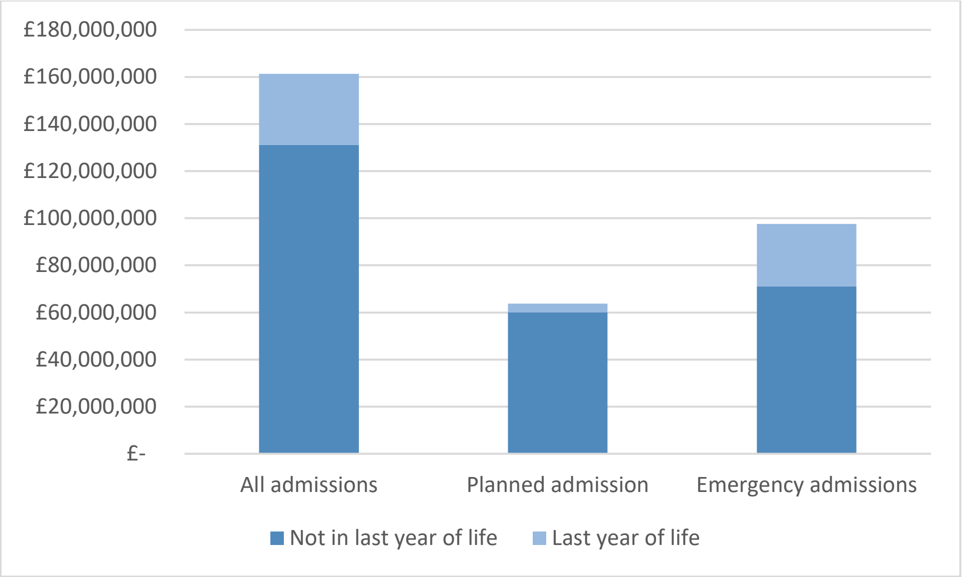

Figure 39: Expenditure (£) on admissions – all, planned and emergency – to hospital for people in the last year of life (lighter blue) and for people not in the last year of life (darker blue) in North East Essex, 2018/19. (Source: ICHP analysis)

In this analysis using data from four funding sources, in terms of expenditure for people in the last year of life, emergency admissions to hospital was the largest draw on resources, and the amount was almost seven times greater than that for planned admissions to hospital. Although more people are dying out of hospital, there has been an increase in emergency admissions to hospital for people in the last 90 days of life: between 2006 and 2017, it was 44%, and between 2017 and 2019 it was 15%. In 2018/19, expenditure on emergency admissions in the last 90 days of life was a high percentage of the total expenditure on planned and emergency admissions to hospital (see Table 5):

- for people who died of cancer, it was 49% of total expenditure on their hospital admissions
- for people who died of non-cancer conditions, it was 56% of total expenditure on their hospital admissions

NHS continuing healthcare fast-track pathway

NHS continuing healthcare is free social care funded solely by the NHS for some people with long-term complex health needs, provided in a variety of settings outside hospital.[22] If a person is deteriorating rapidly and is considered to be at the end of life, they can be considered for the NHS continuing healthcare fast-track pathway, in which an appropriate care and support package is put into place as soon as possible, usually within 48 hours. Although the fast-track pathway is not exclusively used for people at the end of life, it often is.

The budget for the local NHS continuing healthcare fast-track pathway is fixed at the beginning of each fiscal year with an expectation that there will be no overspend. A decision whether someone should receive this type of care package is made by the local commissioner following assessment by a multidisciplinary team.

Expenditure on the NHS continuing healthcare fast-track pathway, the number of people receiving these care packages and median expenditure per person in NEE from 2015/16 to 2018/19 are shown in Table 5. The range of expenditure per person receiving NHS continuing healthcare fast-track pathway care packages in 2018/19 is shown in Figure 40. Of the 250 people receiving the NHS

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[22] NHS continuing healthcare. https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/

continuing healthcare fast-track pathway care packages in 2018/19, 108 had a care package that was lower in cost than the reference cost for one night's emergency admission to hospital.

Table 5: Expenditure (£ million) on NHS continuing healthcare fast-track pathway care packages, the number of people receiving these care packages and median expenditure (£) per person in North East Essex, 2015/16-2018/19. (Source: NEE CCG)

Financial year	*Expenditure (£ million)*	*No. people receiving care packages*	*Median expenditure per person (£)*
2015/16	£1.2	143	£1,609
2016/17	£0.7	151	£1,589
2017/18	£1.3	309	£1,286
2018/19	£1.5	250	£2,028

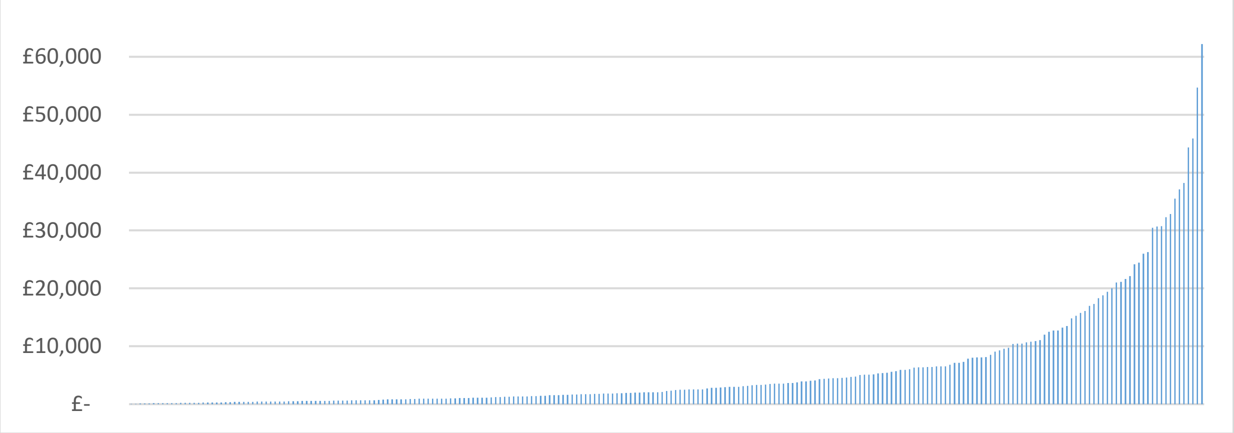

Figure 40: Range of expenditure (£) on the NHS continuing healthcare fast-track pathway care packages for 250 people in North East Essex, 2018/19. (Source: NEE CCG)

Hospice-care services

Hospice-care services are provided in several ways, including:

- at home (visits or 'hospice at home')
- as an 'outpatient'
- in the hospice

More than two-thirds of hospice care (73%) in NEE is paid for from St Helena Hospice charitable funds (see Figure 41 and Table 6).

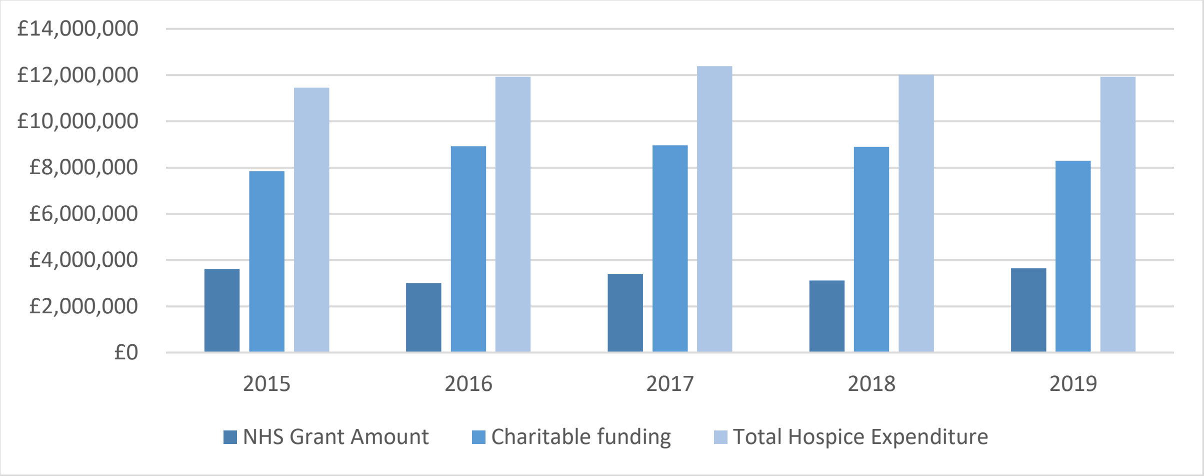

Figure 41: Expenditure (£) on St Helena Hospice care services, 2015-2019. (Source: St Helena Hospice)

Table 6: Expenditure (£) on St Helena Hospice care services, 2015-2019. (Source: St Helena Hospice)

	NHS grant funding	*St Helena Hospice charitable funding*	*Total expenditure on hospice care services*
2015	£ 3,615,012	£ 7,840,473	£ 11,455,485
2016	£ 3,011,097	£ 8,921,165	£ 11,932,262
2017	£ 3,411,698	£ 8,970,863	£ 12,382,561
2018	£ 3,110,190	£ 8,898,796	£ 12,008,986
2019	£ 3,636,417	£ 8,298,332	£ 11,934,749

Activity data for local authority social care services

Many people who are at the end of life are already in receipt of local authority social care support or of local authority social care support as part of a package to help them die in their preferred place of care. It is not possible to differentiate between these two needs for support from the records available. In 2018/19, 1029 people died while receiving local authority social care support (see Table 7). On average, each person received care for 196 days, but 496 people (48%) received support for 90 days or less (see Figure 42), suggesting that many people were in receipt of a local authority social care package because they were nearing the end of life.

Table 7: Types of local authority social care package commonly given to residents in North East Essex, 2018/19. (Source: Essex County Council Social Services)

Type of local authority social care package	*No. people receiving this type of package*
Domiciliary care	168
Live-at-home domiciliary	227
Spot placements	190
Integrated residential and nursing payments	322

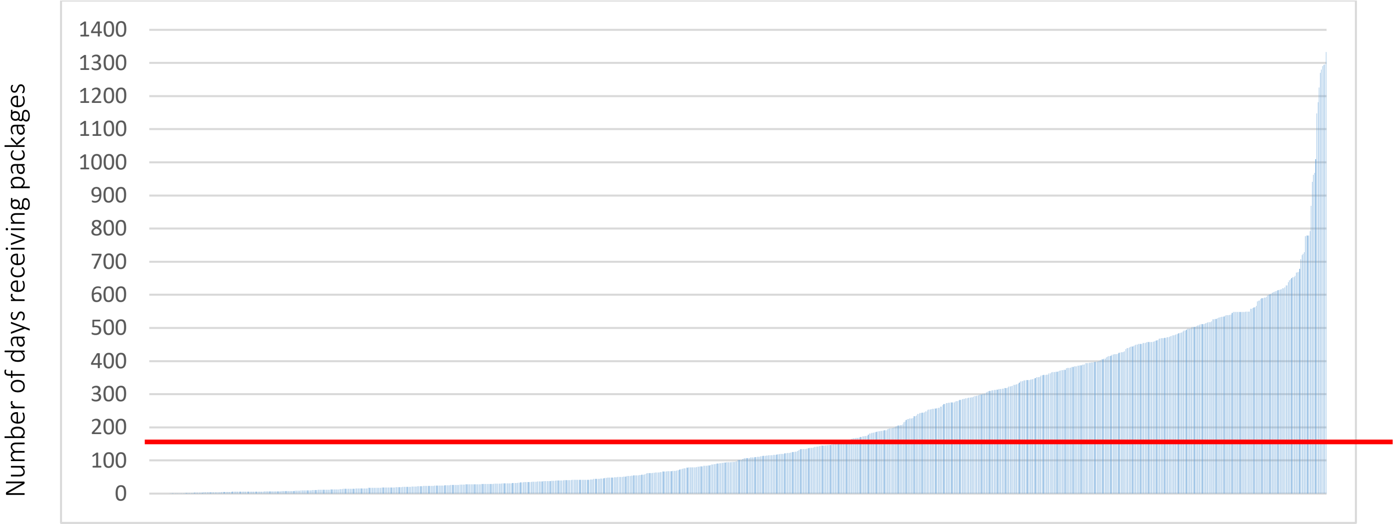

Figure 42: Length (days) of local authority social care packages per person in North East Essex, 2018/19. Key: transverse red line = mean for North East Essex. (Source: Essex County Council Social Services)

Summary of Population Budget for people in the last year of life in NEE, 2018/19

- Data was available from four sources of funding for people in the last year of life in NEE: hospital, St Helena Hospice charitable, St Helena Hospice NHS grant-funded, and NHS continuing healthcare fast-track pathway
- In 2018/19, total expenditure from these four sources was £39,884,297
- Most of the expenditure for people in the last year of life was due to admissions to hospital amounting to £30.1 million, of which £26.5 million was expenditure on emergency admissions to hospital
- Admissions to hospital for people in the last year of life represent 19% of the total expenditure on admissions to hospital and emergency admissions to hospital for people in the last year of life represent 27% of total expenditure on emergency admissions to hospital for NEE residents
- In 2018/19, 250 people received NHS continuing healthcare fast-track care packages, 108 of which cost less than the tariff for a single emergency admission to hospital
- A major component of funding for hospice-care services in NEE in 2018/19 was from St Helena Hospice charitable funds: 65% of funding for hospice care was from this source (£5.8 million), whereas 35% (£3.1 million) was from the NHS
- In 2018/19, 1029 people died while receiving social care services. On average, people received care for 196 days, although 496 people (48%) received social care services for 90 days or less, suggesting that many were in receipt of a local authority social care package because they were nearing end of life

Outputs from Task 2: Agreeing a value framework

Developing a value framework

The main components of a value framework are:

- Aim
- Outcomes that matter
- Supporting Objectives
- Indicators | Criteria for measurement

Although information derived from Task 1 – Population definition – is the initial starting point for the value framework, the aim, outcomes that matter and objectives, are drafted using the results of stakeholder engagement, followed by a round of review and amendment.

Indicators and/or criteria for the measurement of outcomes that matter are developed using not only the results of stakeholder engagement, but also a review of the suitability of existing indicators/criteria through a desk-top appraisal. In general, not many outcome indicators are collected at present, therefore, in the first iteration of a value framework it is important to identify proxy-outcome measures and indicators that can be used for the initial data analysis of opportunities during Task 3.

A value framework for people in the last year of life in NEE

To develop the value framework for people in the last year of life in NEE, the following engagement activities were undertaken:

- A focus group with bereaved family members and carers of people who had recently died and personnel from third sector organisations with a remit/role relating to people at the end of life – this group was convened with the co-operation of the public participation group of the End of Life Board
- A focus group for service providers of end-of-life care in NEE
- A consultation session with the End of Life Board for NEE

The topics for discussion during stakeholder engagement are shown in Figure 43.

- Population to be defined as nearing the end of life and in need of care
- Aim of end-of-life care
- Outcomes that matter to people at the end of life and their families/carers
- End-of-life care that is overused and end-of-life care that is underused
- Inequities in end-of-life care – by geography, by group of people, etc.
- Suggestions about the way in which the outcomes that matter can be measured

Figure 43: Topics for discussion during the engagement activities to develop a value framework for people in the last year of life in North East Essex. (Source: 3V)

The responses from all three engagement activities were collated, and a draft value framework for review was circulated to all participants who had been consulted. Once the draft had been approved by participants, the value framework was discussed, validated and adopted by the End of Life Board. The full value framework can be seen in Appendix 1; in this section, the aim and the ten outcomes that matter are shown below.

Aim

Through improving outcomes that matter with the resources given, to increase the value of care for people aged 18 years and over in the last 12 months of life

Outcomes that matter for people in the last year of life in NEE

Planning

1. To identify and recognise people in the last 12 months of life
2. To inform people thought to be within the last 12 months of life and their families of the likelihood of death within the next 12 months sensitively and honestly
3. To elicit and record people's preferences for care during the last 12 months of life
4. To ensure people's preferences for care are accessible to all parts of the health and social care system/end-of-life-care system

Delivering and caring

5. To respect people's preferences for care during the last 12 months of their life
6. To treat people at end of life as individuals, with dignity, compassion and empathy
7. To control pain and manage symptoms for people during the last 12 months of life
8. To minimise inappropriate, unnecessary and futile medical intervention during the last 12 months of people's life
9. To ensure that people at end of life have equitable access to flexible 24/7 end-of-life care services irrespective of the place of care or the organisation/s providing care
10. To provide support to the families and other carers during and after their loved one's end of life

The ten outcomes that matter originated in NEE are consistent with the outcomes developed by National Voices and the National Council for Palliative Care in partnership with NHS England, including consultation with experts in end-of life care. Five domains were established which were converted into 'I statements', that is, statements expressed as if they had been written by a person at the end of life (see Figure 44).[23] Each domain has between two and seven outcomes associated with it.

- We work for my goals and the quality of my life and death
- I have honest discussions and the chance to plan
- The people who are important to me are at the centre of my support
- My physical, emotional, spiritual and practical needs are met
- I have responsive timely support day and night

Figure 44: Five domains in outcomes for end-of-life care. (Source: National Voices and the National Council for Palliative Care[23])

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[23] National Voices and The National Council for Palliative Care. (2015) Every Moment Counts. A narrative for person centred coordinated care for people near the end of life. Available at https://www.nationalvoices.org.uk/sites/default/files/public/publications/every_moment_counts.pdf

Outputs relevant to Task 3: Identifying opportunities for improving outcomes and increasing value

There are two main groups of activities relevant to identifying opportunities for improving outcomes and increasing value for people towards the end of life:

1. Interrogating the published literature
2. Analysing the best available routine and non-routine data

To help undertake these activities, some of the information derived from Task 1 on population definition, profiling and budgeting and some of that derived from Task 2 on proxy measures and agreed outcomes is used.

The outputs from these activities will then be used to inform the work of the Population Stewardship Forum (network) which will focus on increasing allocative efficiency in the care of people in the last year of life (see section entitled 'Next steps').

Information from the published literature

In terms of key guidance, NICE has recently updated the guidance on interventions to improve outcomes for people at the end of life, including taking account of the recommendations from the Neuberger review of the Liverpool Care Pathway for dying patients[24]. The 12 recommendations made by NICE are shown in Figure 45.[25]

1. Identifying adults who may be approaching the end of their life, their carers and other people important to them
2. Assessing holistic needs
3. Supporting carers
4. Providing information
5. Reviewing current treatment
6. Advance care planning
7. Reviewing needs
8. Communicating and sharing information between services
9. Providing multi-practitioner care
10. Providing end-of-life care coordination
11. Transferring people between care settings
12. Providing out-of-hours care

Figure 45: Interventions to improve outcomes for people at the end of life. (Source: NICE, 2019)

The strength of evidence for the NICE recommendations is variable. In 2016, a Cochrane review of an integrated approach to end-of-life care, including the Liverpool Care Pathway, was inconclusive, chiefly due to the quality of research papers included in the review.[26] Thus, although there are a range of interventions that can be implemented, they need to be continually assessed and reviewed for their relative value in improving outcomes that matter to people at the end of life.

In terms of interventions for people with specific diseases, those to improve outcomes for people with cancer at the end of life are reasonably well established, mainly because people with cancer

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[24] Independent Review of the Liverpool Care Pathway. (2013) More care, less pathway. A Review of the Liverpool Care Pathway. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

[25] End of life care for adults: service delivery NICE guideline. (2019) Available at: www.nice.org.uk/guidance/ng142

[26] Chan, R. J., Webster, J., & Bowers, A. (2016) End-of-life care pathways for improving outcomes in caring for the dying. Cochrane Database of Systematic Reviews. https://doi.org/10.1002/14651858.CD008006.pub4

were the first population group to be a focus for the hospice and end-of-life movement. Interventions include best supportive care, which has been demonstrated to be a high-value intervention (that is, better outcomes for lower costs).[27]

The evidence about specific interventions to improve end-of-life care for people with dementia is weaker. A Lancet commission in 2017 did not identify any specific interventions beyond those applicable to people dying from other conditions, although the commission did emphasise the importance of ascertaining people's preferences for care and undertaking advance care planning before the person with dementia becomes unable to express their preferences.[28] Interventions with the potential to improve outcomes for people dying with dementia are those that reduce hospitalisation from care homes, including developing care home leadership.[29]

People at the end of life with COPD have been found to experience several barriers to accessing higher value end-of-life care, including:

- The difficulty associated with prognosticating the variable disease trajectory
- Clinicians' lack of time to discuss end-of-life care
- Clinicians being fearful of taking away a person's hope by holding a discussion about end-of-life care
- Availability of specialist palliative care from services that are already overburdened[30]

There are, however, specific interventions, such as teaching 'breathless mastery', that can improve survival rates and outcomes and reduce admissions to hospital.[31]

For people dying with heart failure, a fundamental barrier to accessing high-value end-of-life care is poor understanding of heart failure as a life-shortening illness.[32] In a primary care database study of deaths during 2009, it was found that, although half of the people dying from cancer were on a general practice palliative care register, only 7% of people dying from heart failure were. Of those with heart failure on the palliative care register, a third were entered only within one week of death, which is not long enough to support a person to die at home if that is their preference.[33]

Until recently, one of the barriers to accessing palliative care for people with heart failure was the lack of evidence from clinical trials showing a benefit. Between 2014 and 2016, however, three clinical trials designed to compare usual care with multi-professional specialist palliative care were published.

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[27] Bowden, J., Fenning, S., Marron, B., Macpherson, C., Boyce, S., Wardrope, V., … Johnston, L. (2018). Best supportive care in advanced lung cancer-more than a label? BMJ (Clinical Research Ed.), 363, k5017. https://doi.org/10.1136/bmj.k5017

[28] Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., … Mukadam, N. (2017, December 16). Dementia prevention, intervention, and care. The Lancet. Lancet Publishing Group. https://doi.org/10.1016/S0140-6736(17)31363-6

[29] Ouslander, J. G., Lamb, G., Tappen, R., Herndon, L., Diaz, S., Roos, B. A., … Bonner, A. (2011). Interventions to reduce hospitalizations from nursing homes: Evaluation of the INTERACT II collaborative quality improvement project. Journal of the American Geriatrics Society, 59(4), 745–753. https://doi.org/10.1111/j.1532-5415.2011.03333.x

[30] Smallwood, N., Currow, D., Booth, S., Spathis, A., Irving, L., & Philip, J. (2018). Attitudes to specialist palliative care and advance care planning in people with COPD: a multi-national survey of palliative and respiratory medicine specialists. BMC Palliative Care, 17(1), 115. https://doi.org/10.1186/s12904-018-0371-8

[31] Higginson, I. J., Bausewein, C., Reilly, C. C., Gao, W., Gysels, M., Dzingina, M., … Moxham, J. (2014). An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial. The Lancet Respiratory Medicine, 2(12), 979–987. https://doi.org/10.1016/S2213-2600(14)70226-7

[32] Buetow SA, Coster GD. Do general practice patients with heart failure understand its nature and seriousness, and want improved information? Patient Education and Counseling 2001; 45:181-185.

[33] Gadoud A, Kane E, Macleod U, Ansell P, Oliver S, Johnson M. Palliative care among heart failure patients in primary care: a comparison to cancer patients using English family practice data. PLoS One 2014; 9(11):e113188.

Participants receiving specialist palliative care experienced the following benefits with no reduction in survival:

- Improved quality of life
- Capacity to undertake advance care planning
- Improved symptom control
- Fewer re-hospitalisations

In a recent systematic review and meta-analysis of these three trials, it was found that palliative care interventions reduced hospital re-admissions by 42%.[34] [35] [36] [37]

Analysis to support an understanding of lower and higher value end-of-life care

Any analysis to determine the variables that contribute to higher or lower value care is hampered by NHS Digital's restrictions on linking various NHS and social care datasets. Overcoming this barrier is critical to understanding not only how resources can be shifted, but also the effect of shifting those resources on the outcomes that matter; this is addressed in the section entitled 'Next steps'.

In the absence of the data linkage, the focus of the analysis in this report is the relationship between general practice usage of MCCR and hospital activity. The analysis is based on two assumptions:

1. The usage of MCCR by general practices is a proxy for better end-of-life care
2. In the absence of outcome data, admissions to hospital and death in hospital are appropriate proxies for determining outcomes at the end of life

Preliminary analysis: usage of MCCR by general practices in NEE and its relationship to admissions to hospital

The use of the MCCR is linked to an enhanced payment (Locally Enhanced Service) for identifying people at the end of life and enabling the provision of care in their preferred place. Analysis to identify the level of value in end-of-life care focused on whether general practices appear to be 'pro-active' in registering people on MCCR. Pro-activity was initially assessed in two ways.

1. Calculating the percentage of people on MCCR as a proportion of people over 65 years registered with each general practice
2. Calculating, of total deaths in a year for each general practice, the percentage of people who were on MCCR

For the purposes of this analysis, calculating the percentage of people on MCCR as a proportion of people over 65 years of age was found to be a crude assessment of the pro-active use of MCCR, albeit best practice to anticipate the needs of individuals before the terminal phase of an incurable illness or the development of dementia symptoms which make it difficult to ascertain preferences for care or encourage participation in advance care planning.

Among general practices in NEE, the percentage of people over 65 years on MCCR ranged from 2% to 14%. Anecdotally, it is thought that some of the general practices with a higher percentage of people over 65 years on MCCR have made a concerted effort to promote the MCCR, especially with care-home residents.

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[34] Brannstrom M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study. European Journal of Heart Failure 2014; 16(10):1142-1151.

[35] Sidebottom AC, Jorgenson A, Richards H, Kirven J, Sillah A: Inpatient palliative care for patients with acute heart failure: outcomes from a randomised trial. Journal of Palliative Medicine 2015; 18(2):134-142.

[36] Wong FK, Ng AY, Lee PH, Lam PT, Ng JS, Ng NH, Sham MM. Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. Heart 2016.

[37] Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM. Palliative care interventions for patients with heart failure: a systematic review and meta-analysis. Journal of Palliative Medicine 2017; 20(1):84-92.

The percentage of people who die on MCCR versus the percentage of people who die but are not on MCCR for each general practice in NEE is shown in two different visualisations in Figure 46. Map 6 shows both the percentage of peoples who die on MCCR and the proportion who die in an out of hospital.

MCCR usage by general practices, measured as a percentage of total deaths the people who died on MCCR, ranged from 14% to 80%. [38] Maps 7 and 8 show the percentage of people who die on MCCR in relation to the percentage of people who die but are not on MCCR for each general practice in Colchester District and Tendring District, respectively.

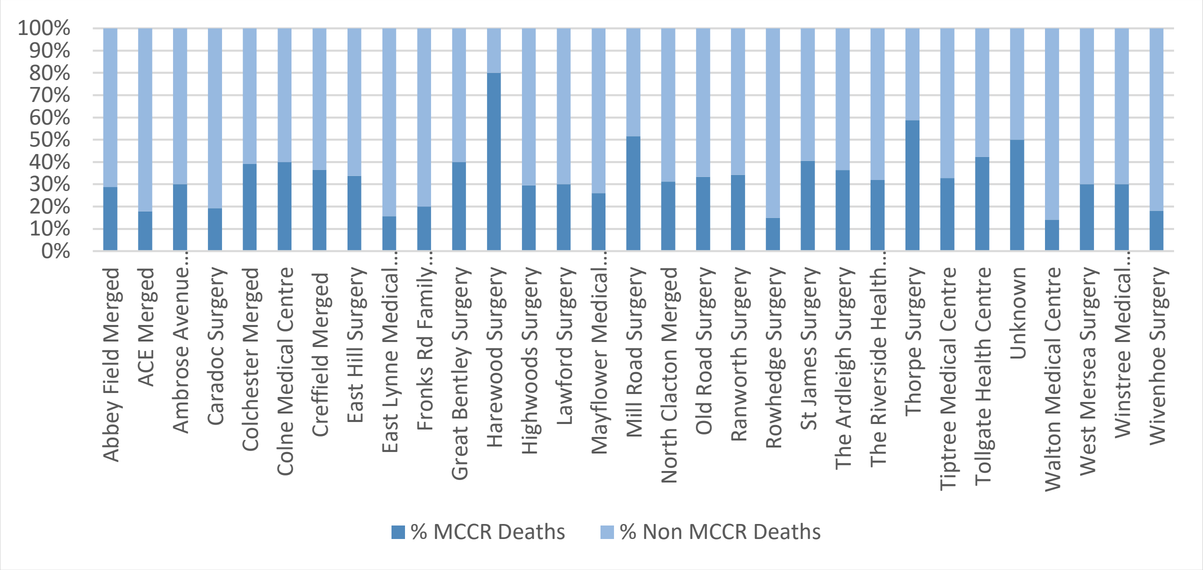

Figure 46: Usage of MCCR by general practices in North East Essex: the percentage (%) of people who die on MCCR ('MCCR deaths' in darker blue) versus the percentage (%) of people who die but are not on MCCR ('Non MCCR deaths' in lighter blue), 2018/19. (Source: ICHP Analysis)

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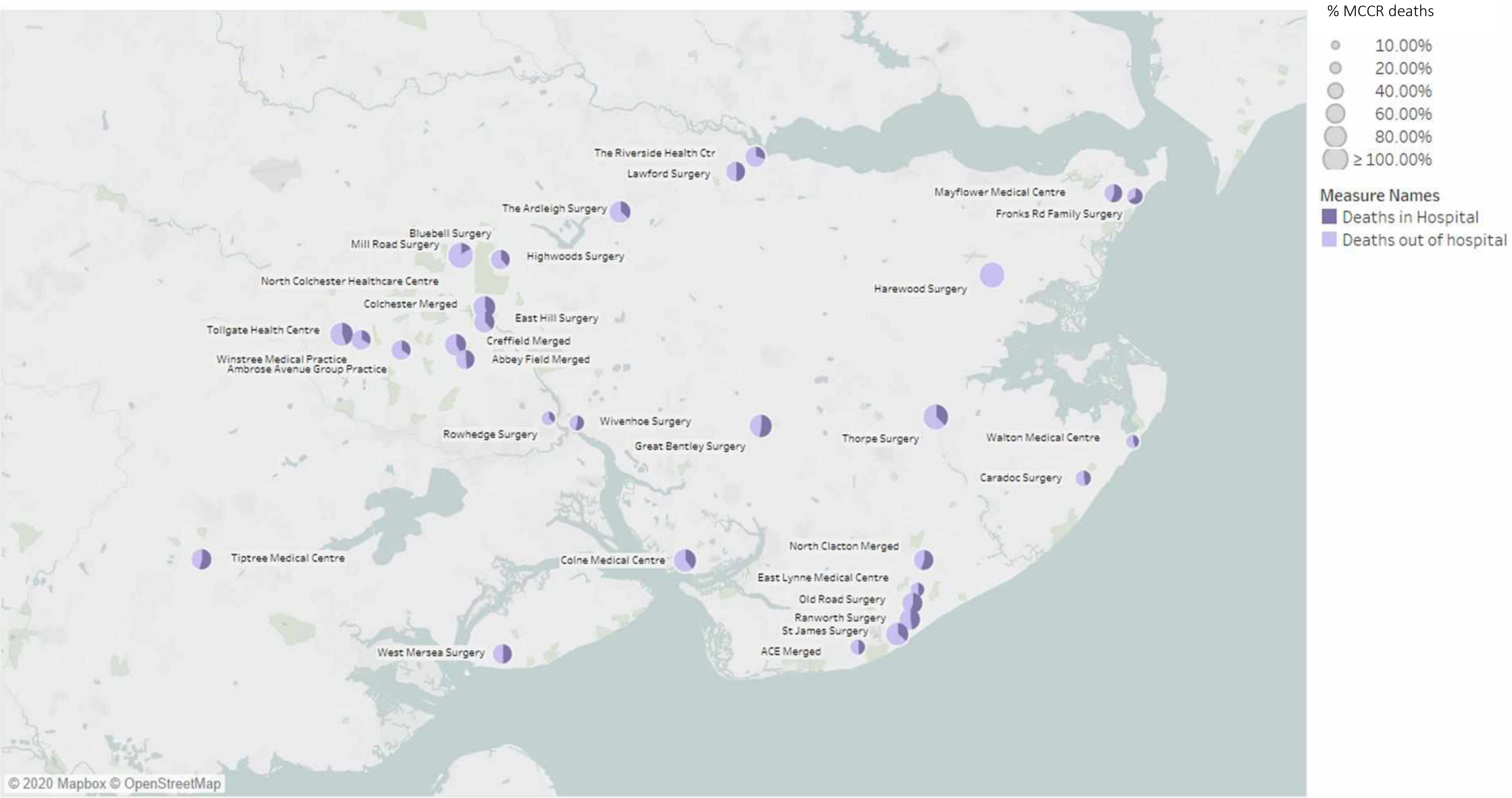
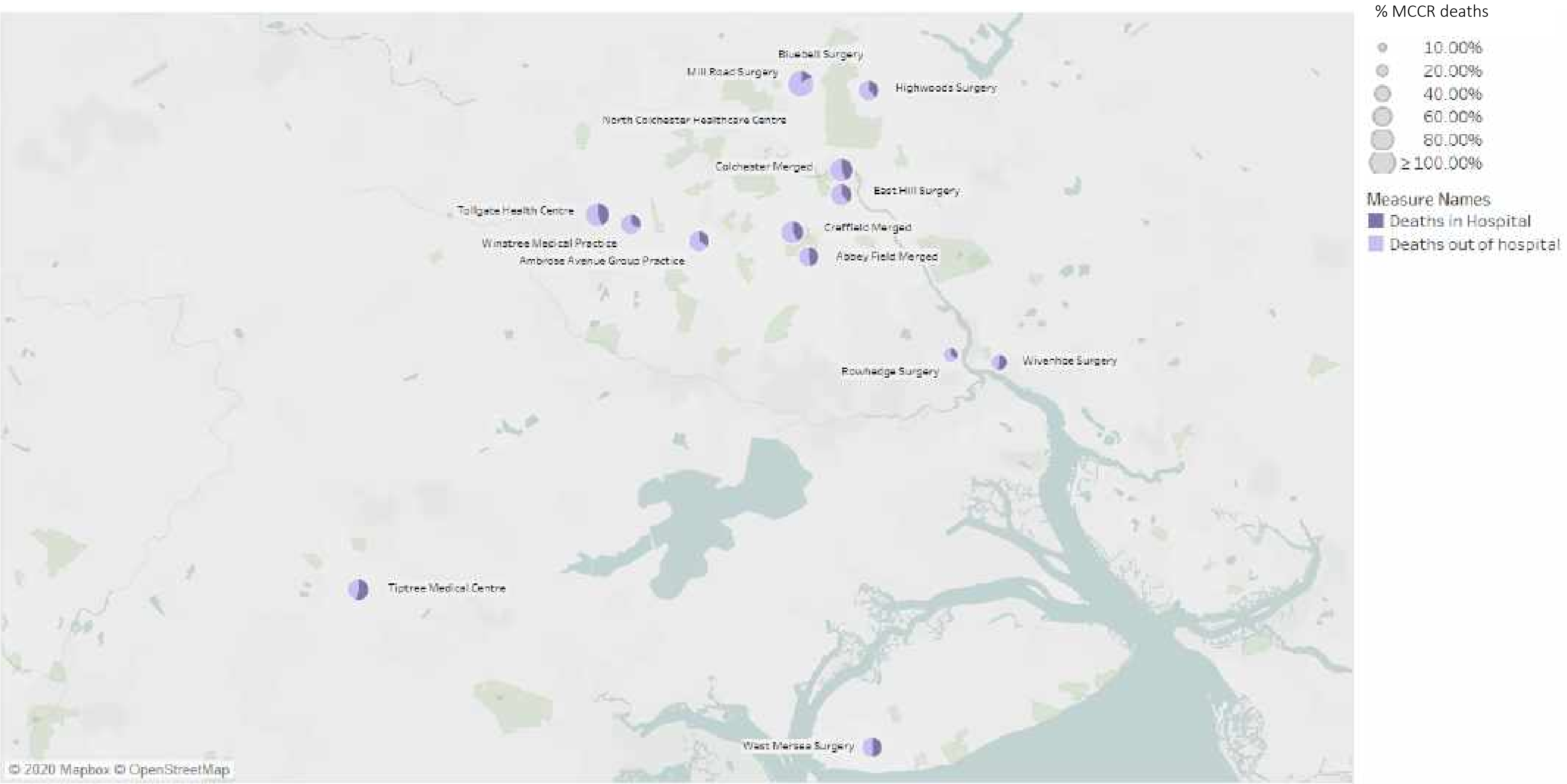
[38] The remainder of the analysis was conducted utilising general practice MCCR usage as a percentage of people who died.



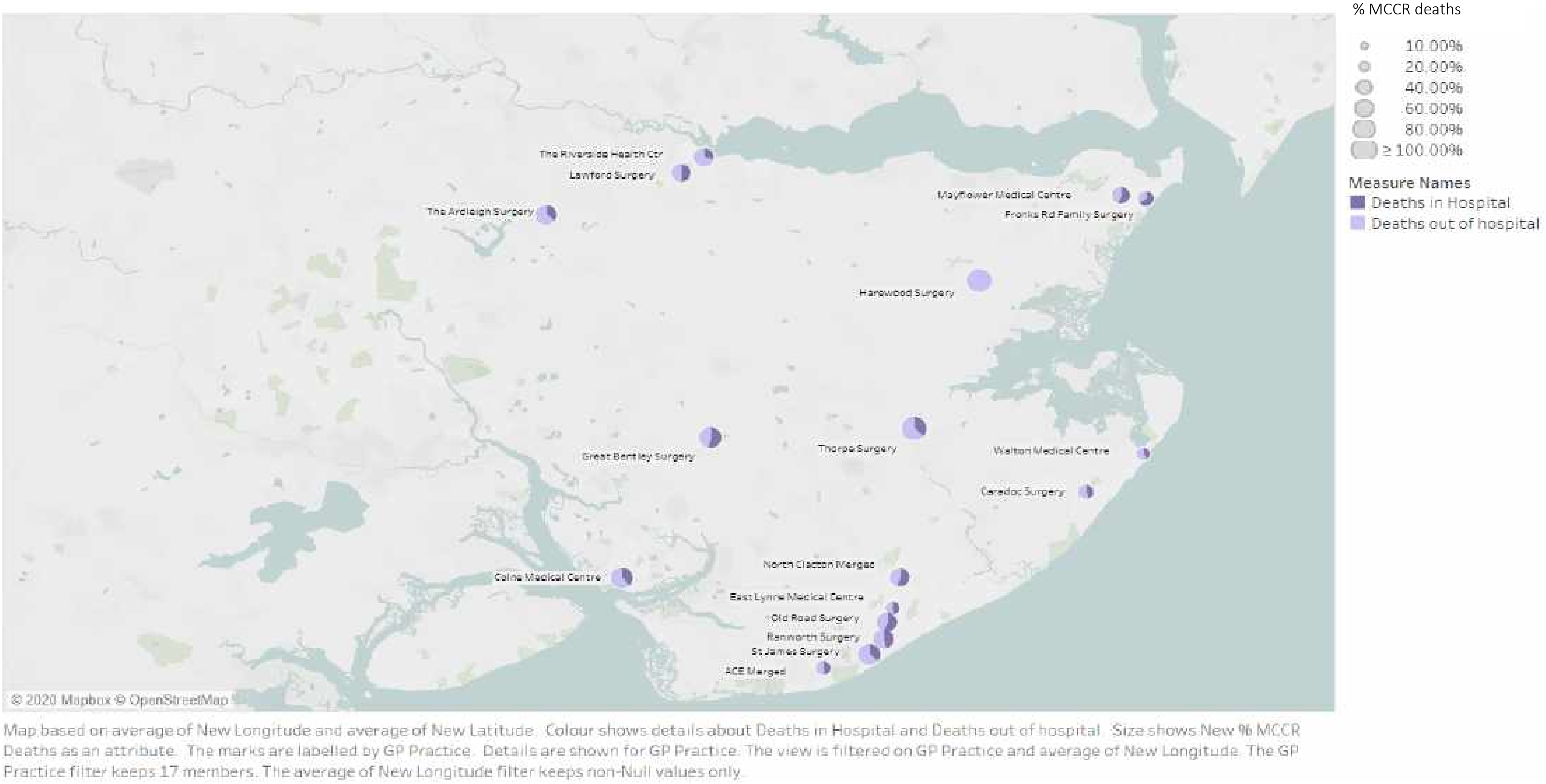
Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows New % MCCR Deaths as an attribute. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice and average of New Longitude. The GP Practice filter has multiple members selected. The average of New Longitude filter keeps non-Null values only.

Map 6: Percentage (%) of people registered with individual general practices in North East Essex who died on MCCR (size of circle); each pie chart shows the relative proportions between deaths in hospital (dark mauve) and deaths out of hospital (light mauve), 2018/19. (Source: ICHP analysis)



Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows New % MCCR Deaths as an attribute. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice and average of New Longitude. The GP Practice filter keeps 15 members. The average of New Longitude filter keeps non-Null values only.

Map 7: Percentage (%) of people registered with individual general practices in Colchester District who died on MCCR (size of circle); each pie chart shows the relative proportions between deaths in hospital (dark mauve) and deaths out of hospital (light mauve), 2018/19. (Source: ICHP analysis)



Map based on average of New Longitude and average of New Latitude. Colour shows details about Deaths in Hospital and Deaths out of hospital. Size shows New % MCCR Deaths as an attribute. The marks are labelled by GP Practice. Details are shown for GP Practice. The view is filtered on GP Practice and average of New Longitude. The GP Practice filter keeps 17 members. The average of New Longitude filter keeps non-Null values only.

Map 8: Percentage (%) of people registered with individual general practices in Tendring District who died on MCCR (size of circle); each pie chart shows the relative proportions between deaths in hospital (dark mauve) and deaths out of hospital (light mauve), 2018/19. (Source: ICHP analysis)

Level of MCCR usage and place of death

A statistically significant ($p<0.01$) correlation was found between higher usage of MCCR by a general practice and a greater likelihood of a person registered with that practice dying out of hospital (see Figure 47).

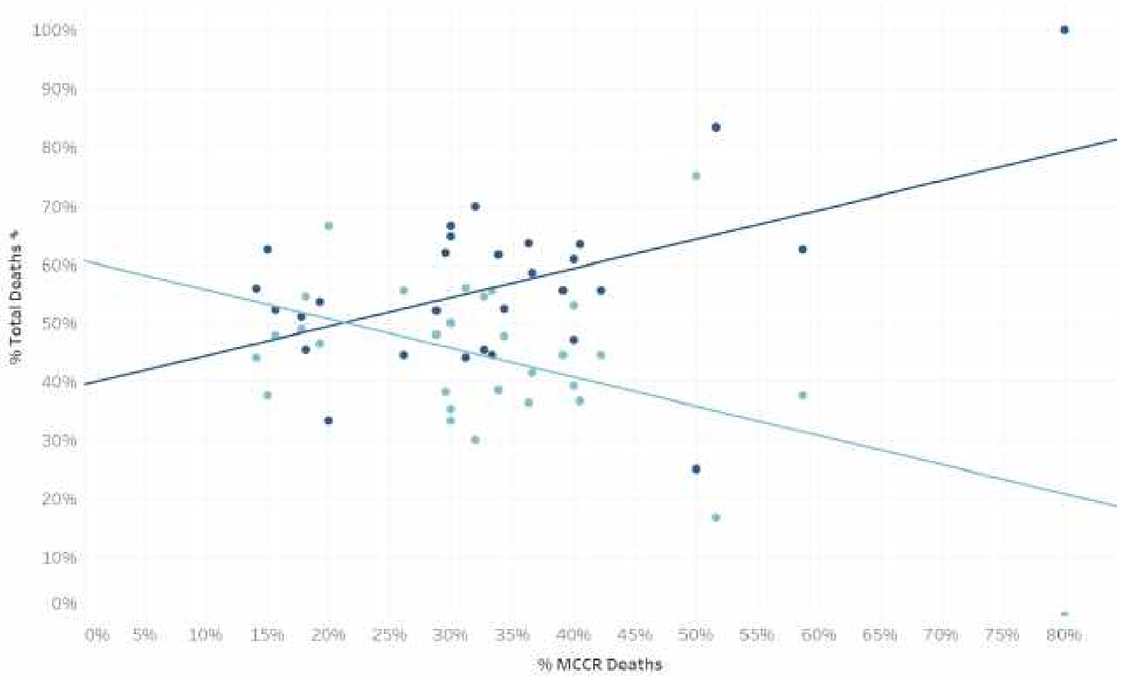


Figure 47: Place of death (in hospital; out of hospital) for people in the last year of life in North East Essex in relation to MCCR usage by the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

General practices in NEE were then categorised into three groups according to the level of usage of MCCR, as shown in Table 8.

Table 8: MCCR usage categories for general practices in North East Essex as a percentage (%) of people who died on MCCR as a percentage of total deaths in a general practice. (Source: ICHP analysis)

MCCR usage category	*Level of MCCR usage (people who died on MCCR as a percentage of total deaths in a general practice)*
High	>6.5%
Medium	3.5-6.4%
Low	<3.5%

Following categorisation of general practices as 'High', 'Medium' or 'Low' users of MCCR, place of death was analysed according to MCCR usage group. Although an association was found between people dying out of hospital and being registered with a general practice in the high MCCR usage group, it was not statistically significant, which might be due to small sample sizes (see Figure 48).

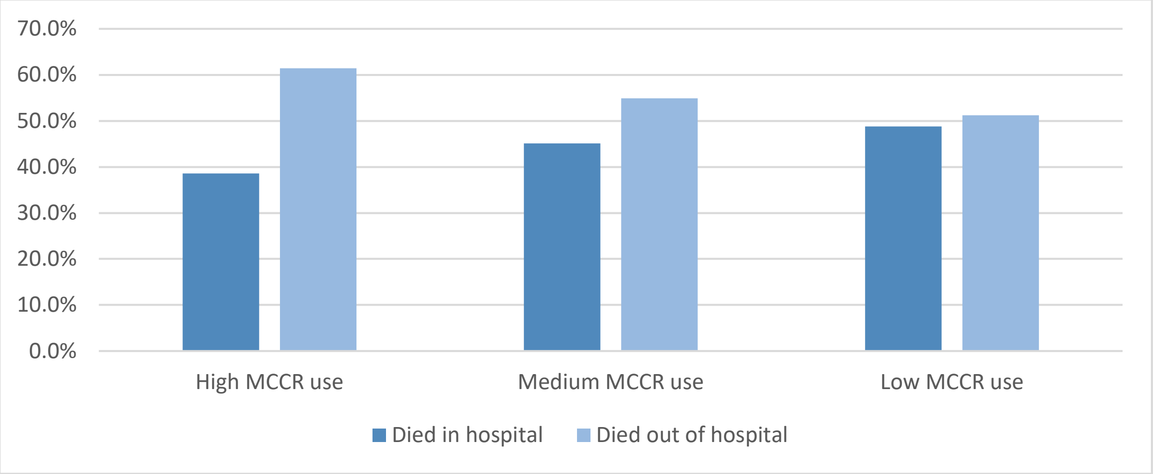


Figure 48: Place of death (in hospital; out of hospital) for people in the last year of life in North East Essex in relation to the MCCR usage group of the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

For patients who were considered frail,[39] there was an association between MCCR usage and place of death, although it was not statistically significant (p=0.07; see Figure 49); thus, there may have been a greater likelihood that people with frailty died out of hospital if they were registered with a general practice in the high MCCR usage group when compared with the other two MCCR usage groups.

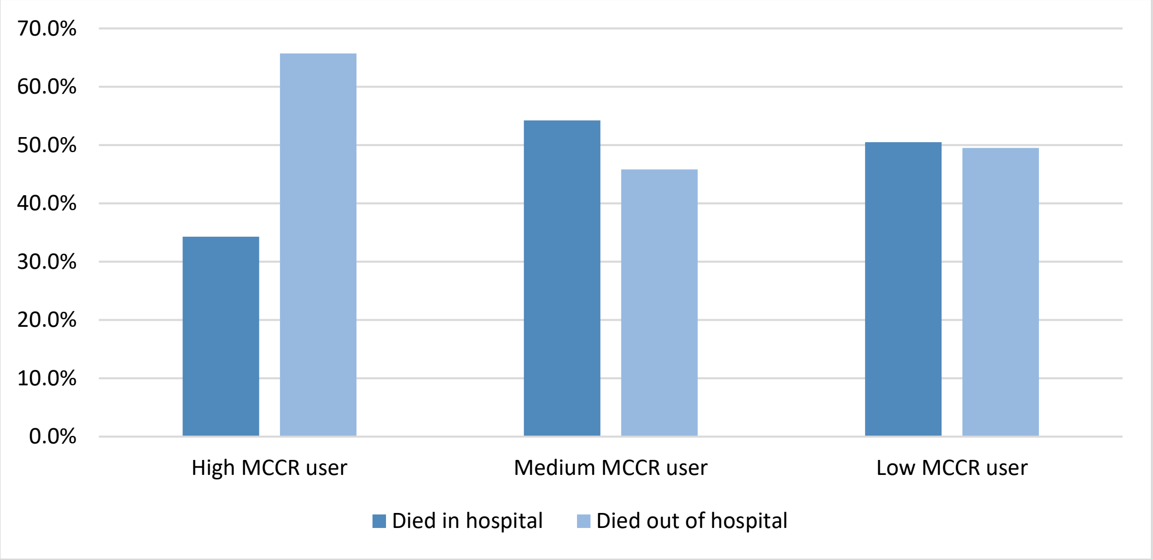


Figure 49: For people considered frail (see footnote) in the last year of life in North East Essex, place of death (in hospital; out of hospital) in relation to the MCCR usage group of the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

For people with a non-cancer condition in NEE, a statistically significant correlation was found between MCCR usage and place of death (p=0.05; see Figure 50): thus, people with a non-cancer condition registered with a general practice with a higher usage of MCCR were more likely to die out of hospital.

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[39] Frailty was determined from HES data using the Elixhauser comorbidity method; see Menendez, M. E., Neuhaus, V., Van Dijk, C. N., & Ring, D. (2014). The Elixhauser comorbidity method outperforms the Charlson index in predicting inpatient death after orthopaedic surgery. *Clinical Orthopaedics and Related Research*, *472*(9), 2878–2886. https://doi.org/10.1007/s11999-014-3686-7

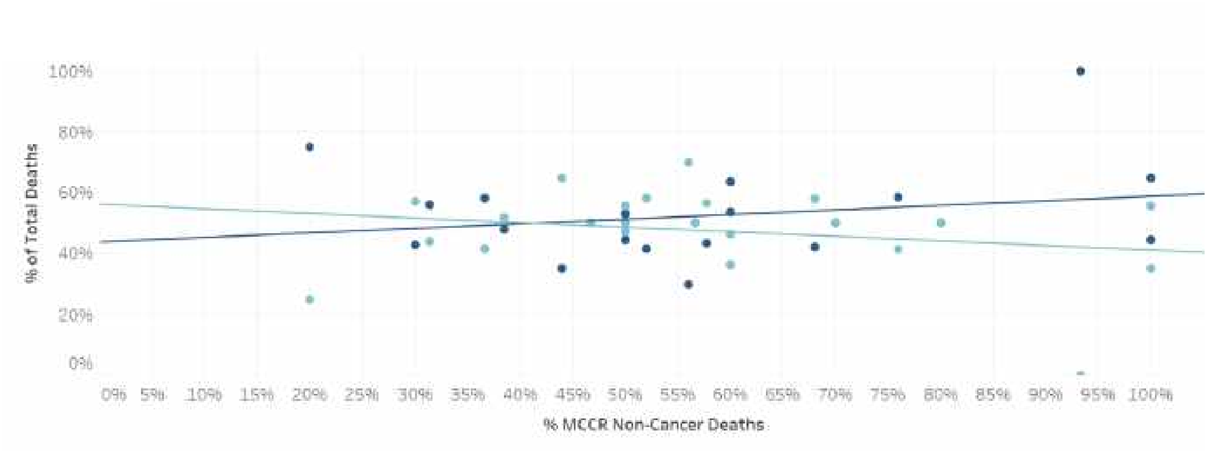

Figure 50: For people with a non-cancer condition in North East Essex, place of death (in hospital; out of hospital) in relation to the level of MCCR usage for the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

For people with a non-cancer condition in NEE, a statistically significant correlation was found between MCCR usage group and place of death ($p<0.05$; see Figure 51); thus, people with a non-cancer condition registered with a general practice in the high MCCR usage group were more likely to die out of hospital when compared with the other two MCCR usage groups.

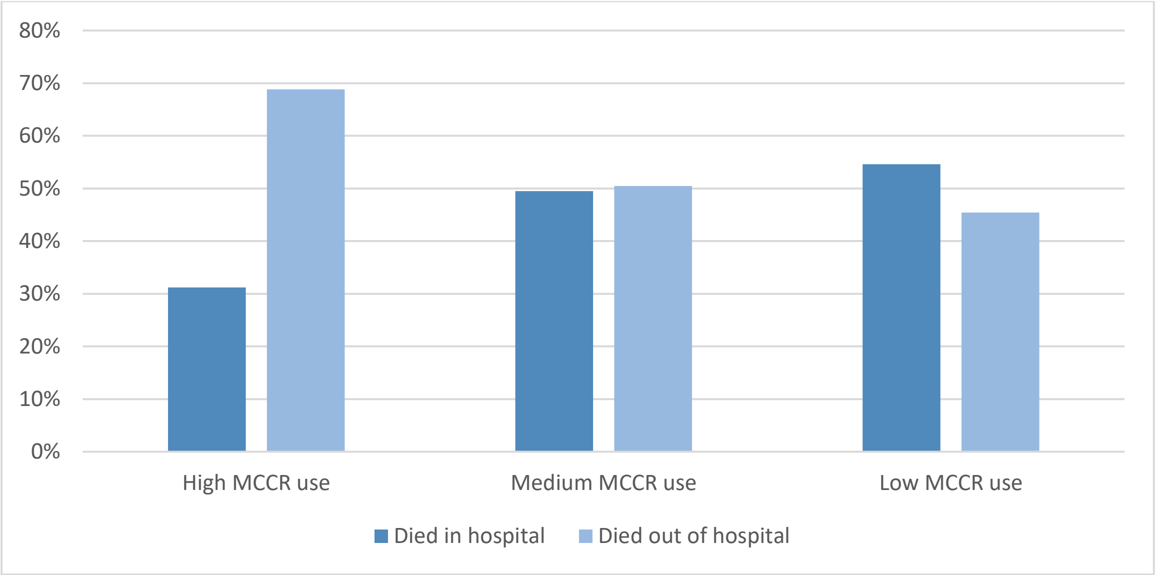

Figure 51: For people with a non-cancer condition in North East Essex, place of death (in hospital; out of hospital) in North East Essex in relation to the MCCR usage group of the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

When analysing general practice MCCR usage in relation to place of death for people with cancer, it was necessary to adjust the MCCR usage categories as shown in Table 9.

Table 9: MCCR usage categories for general practices in North East Essex regarding people with cancer in the last year of life. (Source: ICHP analysis)

MCCR usage category	***Level of general practice MCCR usage*** *(people with cancer who died on MCCR as a percentage of total deaths in a general practice)*
High	>60%
Medium	50-60%
Low	<50%

For people with cancer in NEE, a statistically significant correlation was found between general practice MCCR usage and place of death (p<0.01; see Figure 52); thus, people with cancer registered with a general practice with a higher usage of MCCR were more likely to die out of hospital. The strength of this correlation was influenced by five general practices where all the people who died of cancer died at home.

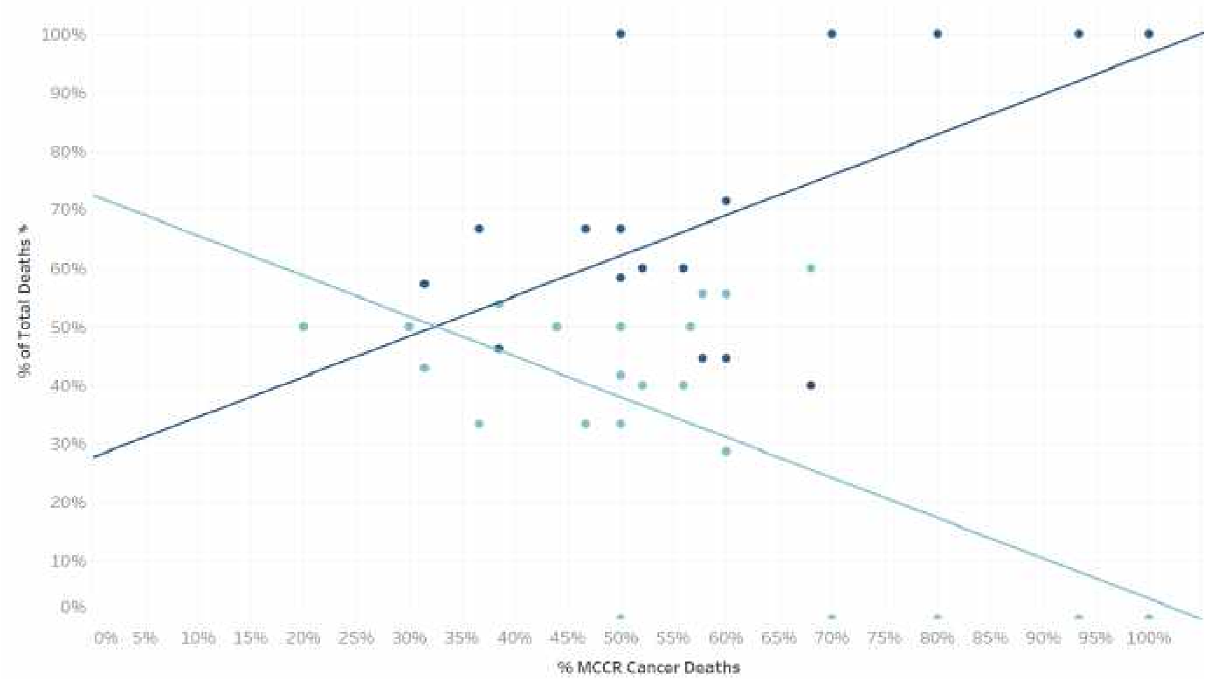

Figure 52: For people with cancer in North East Essex, place of death (in hospital; out of hospital) in relation to the level of MCCR usage of the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

For people with cancer in NEE, a statistically significant correlation was found between MCCR usage group and place of death (p<0.01; see Figure 53); thus, people with cancer registered with a general practice in the high MCCR usage group were more likely to die out of hospital when compared with the other two MCCR usage groups.

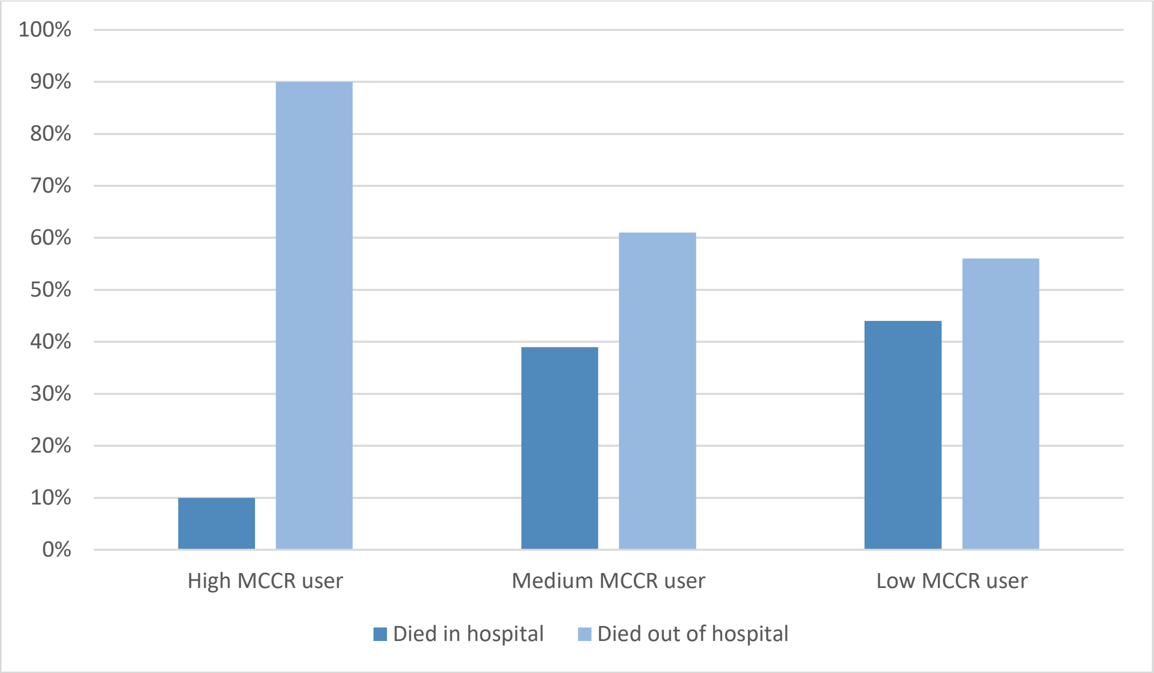

Figure 53: For people with cancer in North East Essex, place of death (in hospital; out of hospital) in relation to the MCCR usage group of the general practice at which they were registered, 2018/19. (Source: ICHP analysis)

Summary of results from the preliminary analysis

- There is an association between the likelihood of an individual dying out of hospital and a higher level of MCCR usage (as a percentage of all deaths) by the general practice with which an individual is registered
- This association between higher general practice MCCR usage and death out of hospital applies to people with cancer, people with a non-cancer condition and for people with frailty

Analysis to identify opportunities for disinvestment and re-investment

As the preliminary analysis showed an association between high MCCR usage by a general practice and a greater likelihood of people in the last year of life registered with that general practice dying out of hospital, the hypothesis for the next round of analysis was if all general practices could be supported to increase their level of MCCR usage to the ‘high’ group, that is, more than 6.5% of people who die in a year are registered on MCCR, what would be the opportunities for disinvestment-re-investment of financial resources?

As the cost of admissions to hospital for people in the last 90 days of life is about 50% of the total expenditure on admissions to hospital in the last year of life (see page 47), this was one of the first financial variables to be investigated. Indeed, a statistically significant correlation (p=0.04) was found between cost of admissions in the last 90 days of life and general practice MCCR usage (see Figure 54); thus, lower levels of MCCR usage were associated with a higher average cost of admissions to hospital for people in the last 90 days of life.

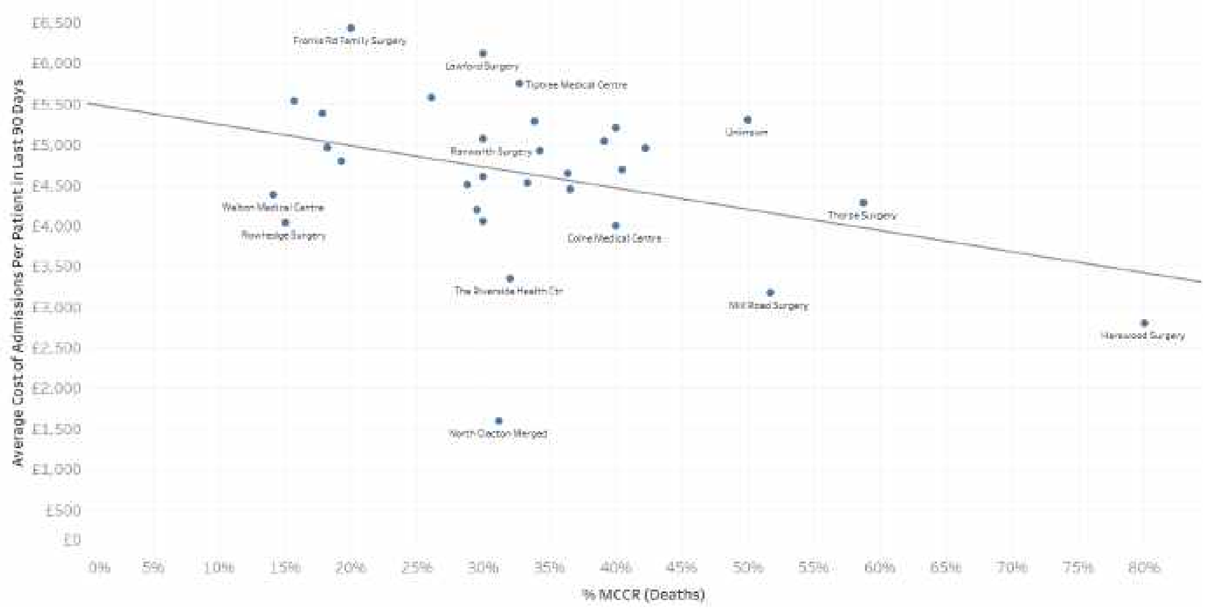

Figure 54: Relationship between the level of MCCR usage by a general practice (as a percentage of total deaths) and the average cost (£) of admissions to hospital for people in the last 90 days of life in North East Essex, 2018/19. (Source: ICHP analysis)

A statistically significant correlation was also found between the average cost of emergency admissions to hospital in the last 90 days of life and the level of MCCR usage (p=0.04; see Figure 55); thus, lower levels of MCCR usage were associated with a higher average cost of emergency admissions to hospital for people in the last 90 days of life.

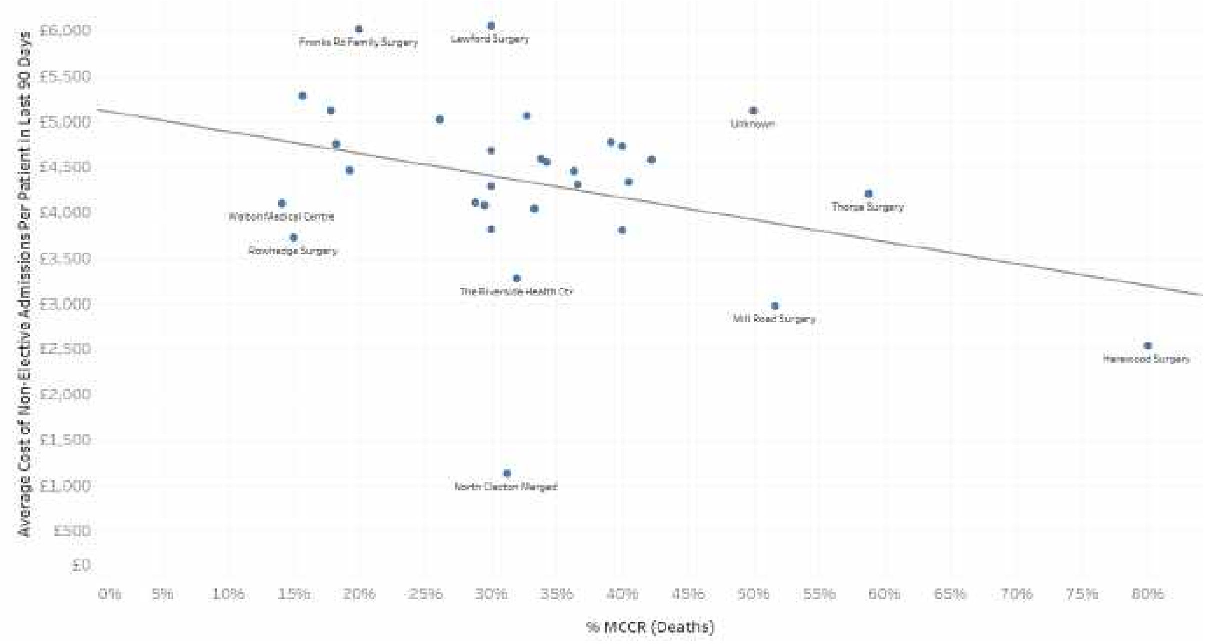

Figure 55: Relationship between the level of MCCR usage by a general practice (as a percentage of total deaths) and the average cost (£) of emergency admissions to hospital for people in the last 90 days of life in North East Essex, 2018/19. (Source: ICHP analysis)

Although a similar association was found between the average cost of planned admissions to hospital and the level of MCCR usage (see Figure 56), it was not statistically significant, which might be due to smaller sample sizes.

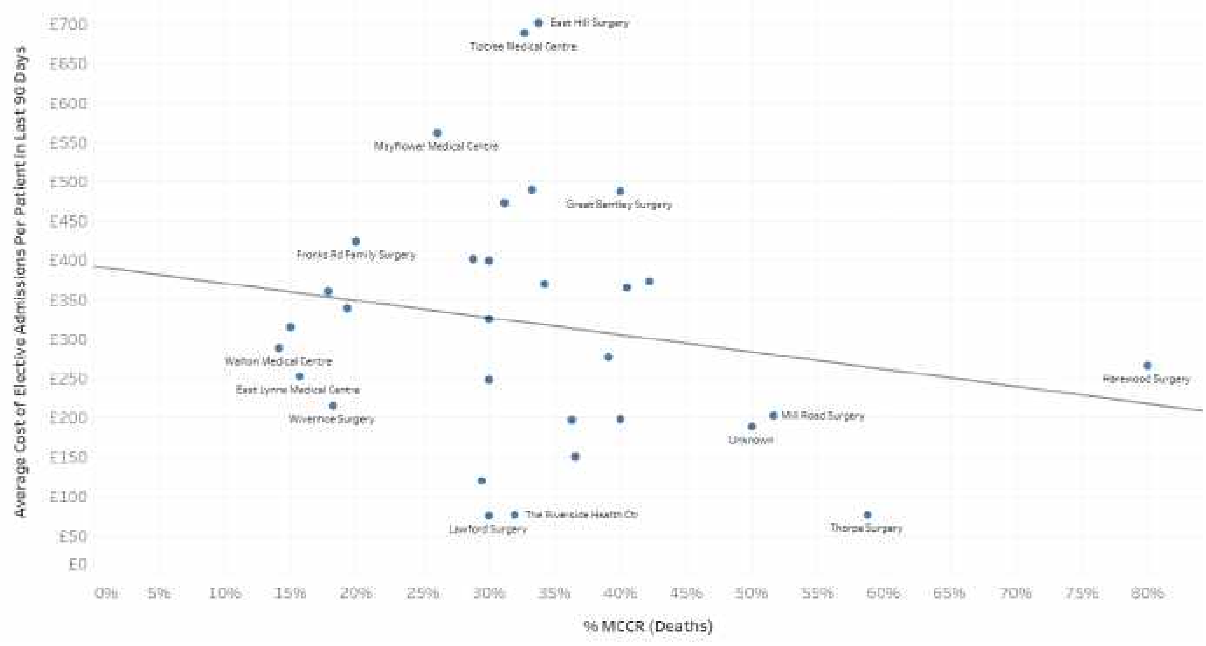

Figure 56: Relationship between the level of MCCR usage by a general practice (as a percentage of total deaths) and the average cost (£) of planned admissions to hospital for people in the last 90 days of life in North East Essex, 2018/19. (Source: ICHP analysis)

The average expenditure on admissions to hospital per person who died in NEE in 2018/19 is shown in Table 10 and Figure 57. The difference in average expenditure per person on admissions to hospital between people who died in hospital and people who died out of hospital is statistically significant ($p<0.01$); thus, the average cost of admissions to hospital per person is greater for people who died in hospital for each type of admission, and irrespective of whether a person had cancer or a non-cancer condition.

Table 10: Average expenditure (£) on all admissions, emergency admissions and planned admissions to hospital per person who died (in hospital; out of hospital) in North East Essex, and average expenditure (£) on admissions to hospital for people who died with cancer and people with a non-cancer condition, 2018/19. (Source: ICHP analysis)

Nature of admission to hospital	*Average expenditure (£) per person dying in hospital*	*Average expenditure (£) per person dying out of hospital*	*Difference in expenditure (£)*
All admissions	£10,260	£6,259	£4,001
Emergency admissions	£9,492	£5,529	£3,963
Planned admissions	£1,096	£738	£358
Admissions for people who died with cancer	£13,379	£10,836	£2,543
Admissions for people who died with non-cancer	£11,538	£6,556	£4,982

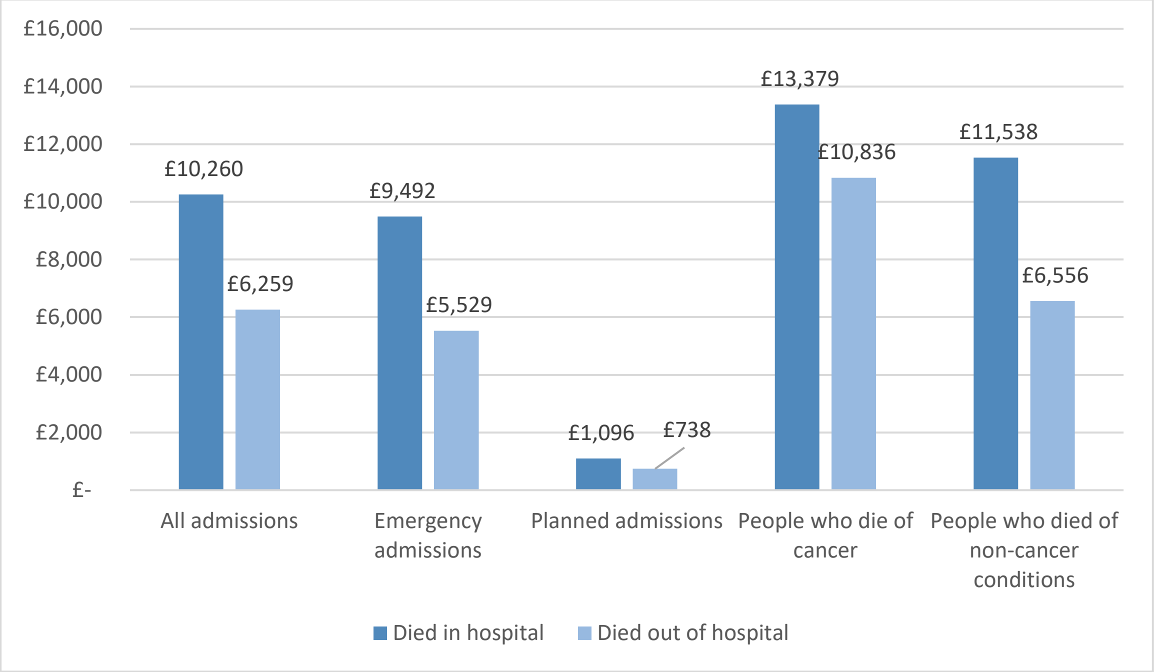

Figure 57: Average expenditure (£) on all admissions, emergency admissions and planned admissions to hospital per person who died (in hospital; out of hospital) in North East Essex, and average expenditure (£) on admissions to hospital for people with cancer and people with a non-cancer condition, 2018/19. (Source: ICHP analysis)

When general practice MCCR usage group (by percentage of general practice total deaths) was analysed in relation to average expenditure on hospital admissions per person in the last year of life, there was little difference in cost per person among MCCR usage groups (see Figure 58). However, high MCCR usage general practices had fewer people who were admitted to hospital (see Table 11).

Table 11: Number and percentage (%) of people who died in and out of hospital categorised by general practice MCCR usage group. (Source: ICHP analysis).

General practice MCCR usage group	*People who died in hospital (number and percentage)*	*People who died out of hospital (number and percentage)*
Low	585 (48.8%)	625 (51.2%)
Medium	390 (45.1%)	465 (54.9%)
High	460 (38.6%)	670 (61.4%)

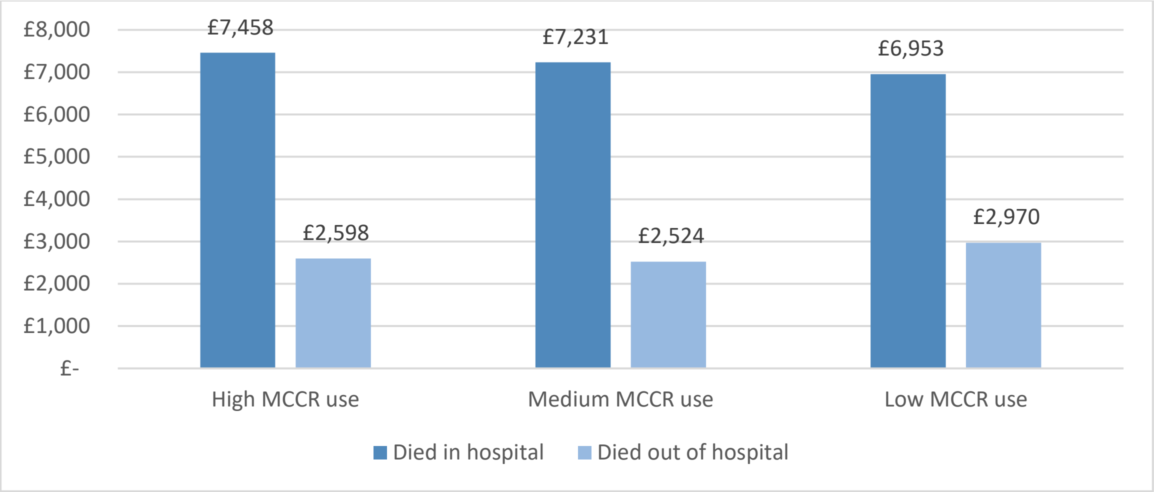

Figure 58: Average expenditure (£) on admissions to hospital per person in the last year of life in North East Essex by place of death (in hospital; out of hospital) in relation to the level of MCCR usage for the general practice at which each individual was registered, 2018/19. (Source: ICHP analysis)

Increasing allocative efficiency

In this section, inferences are drawn about the opportunities for increasing allocative efficiency and the value of care for people in the last year of life. When the relationship between the level of general practice MCCR usage and the place of death is combined with the relationship between expenditure in the last year of life and place of death, it is possible to estimate the potential financial resources that could be re-invested in higher value end-of-life care. The data shown in Table 10 have been used to derive the estimates shown below.

Level of MCCR usage and place of death

For people dying with cancer, the association between higher levels of MCCR usage by general practices and an increased likelihood of people dying out of hospital can be used to identify potential opportunities for disinvesting and re-investing financial resources. For people dying with cancer, the financial re-investment potential is shown in Figure 59.

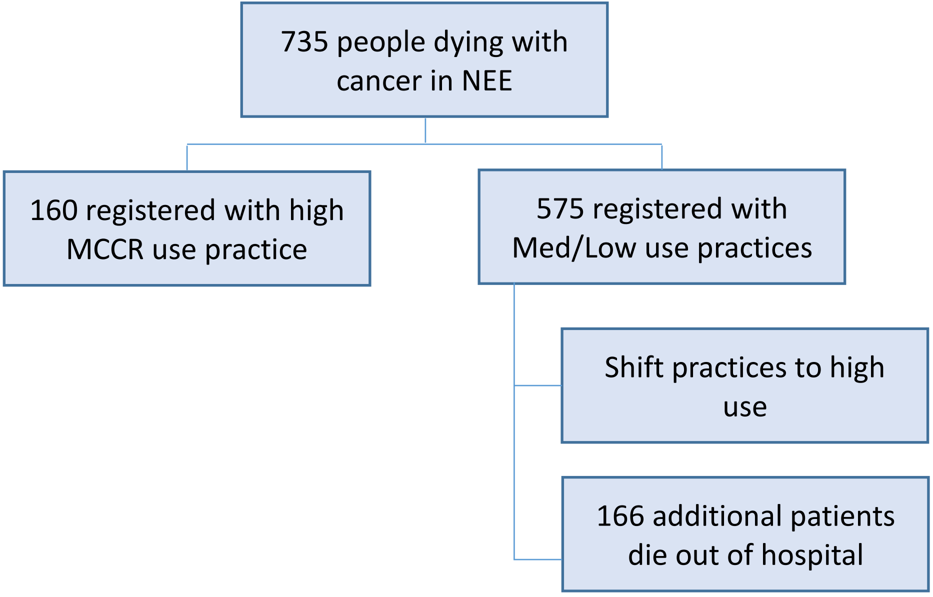

Figure 59: For people with cancer in the last year of life in North East Essex, the opportunities identified from this analysis for the disinvestment and re-investment of financial resources. (Source: ICHP analysis)

One way to increase allocative efficiency and thereby to increase value for people with cancer in the last year of life in NEE would be to work with general practices, via the primary care networks (PCNs), to transfer the learning from general practices in the high MCCR usage group to general practices in the low and medium MCCR usage groups, ensuring that the characteristics of high levels of MCCR usage are actively disseminated throughout SNEE ICS. This potential for the re-investment of financial resources could facilitate more people with cancer in the last year of life dying out of hospital.

Additional 166 people with cancer who would die at home in a year, each with a lower spend of £2543 = **£422,138**

For people dying with non-cancer conditions, the association between higher levels of MCCR usage and an increased likelihood of people dying out of hospital can be used to identify potential opportunities for disinvesting and re-investing financial resources. For people dying of non-cancer conditions, the financial re-investment potential is shown in Figure 60.

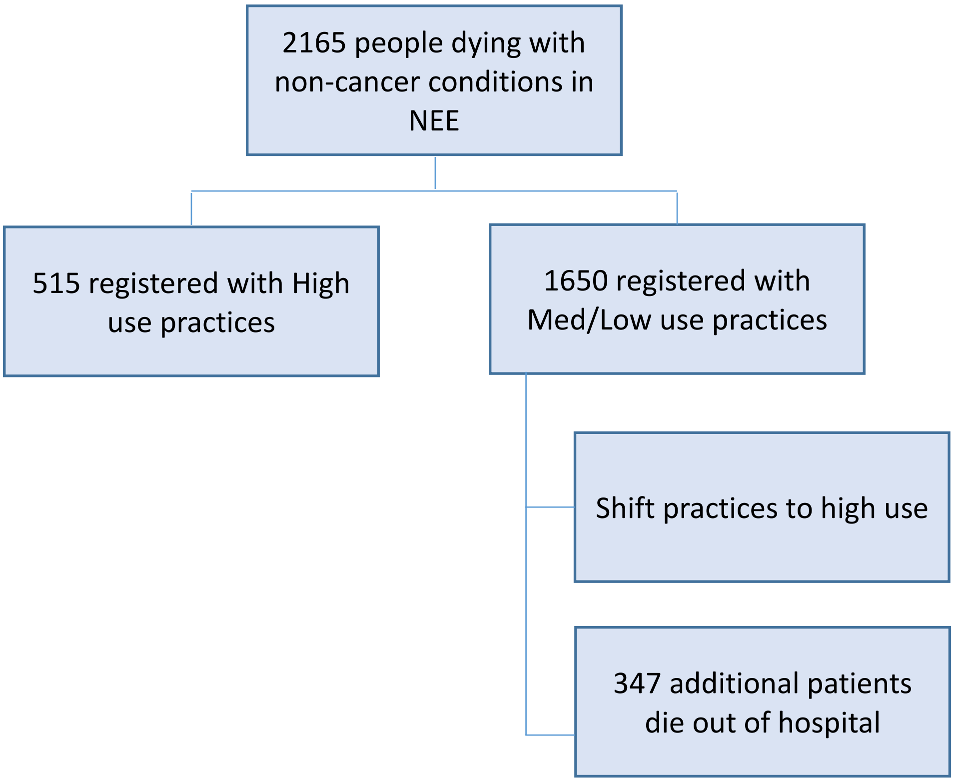

Figure 60: For people with non-cancer in the last year of life in North East Essex, the opportunities identified from this analysis for the disinvestment and re-investment of financial resources. (Source: ICHP analysis)

As for people in the last year of life with cancer, one way to increase allocative efficiency and thereby to increase value for people with non-cancer in the last year of life in NEE would be to work with general practices, via the PCNs, to transfer the learning from general practices in the high MCCR usage group to general practices in the low and medium MCCR usage groups, again ensuring that the characteristics of high levels of MCCR usage are actively disseminated throughout SNEE ICS. This potential for the re-investment of financial resources could facilitate more people with non-cancer in the last year of life dying out of hospital:

Additional 347 people with non-cancer conditions who would die at home in a year, each with a lower spend of £4982 = **£1,728,754**

Local clinical audit of in-hospital deaths

Outwith this project, the Alliance commissioned a clinical audit of the records of people who died in hospital (not publicly available) to ascertain whether these people might have been able to die in another setting. One hundred files of people who died in hospital were randomly selected from the financial year 2017/18 and examined using a proforma. Of the 100 deaths, 61 were considered inevitable hospital deaths; however, 39 of the deaths could have occurred out of hospital.

As there is a lower average expenditure per person with cancer dying out of hospital of £2,543, and if 39% of all deaths in hospital could be avoided, an estimated £401,794 is potentially available for re-investment in higher value end-of-life care (see Figure 61).

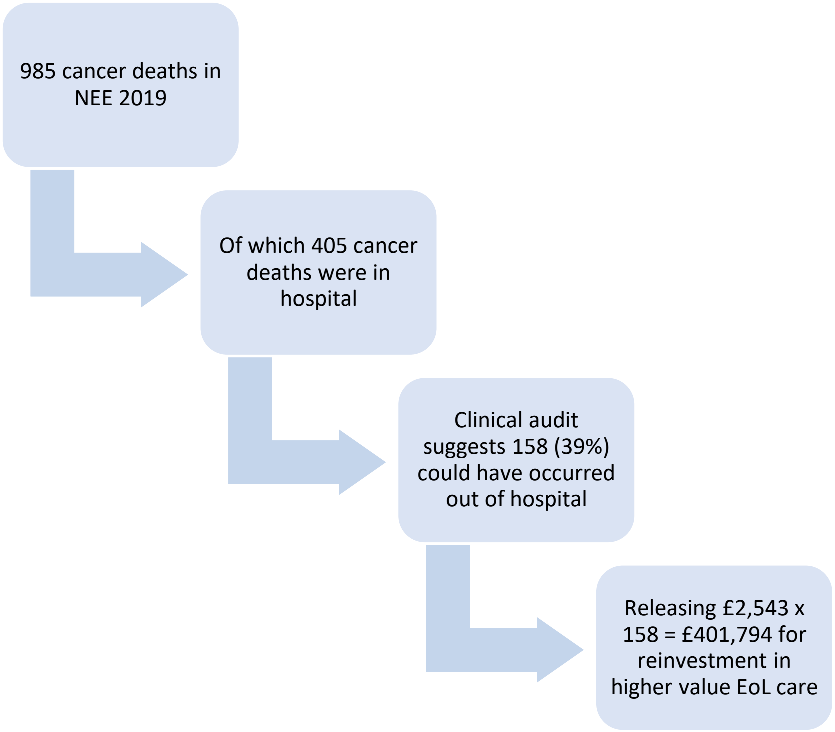

Figure 61: For people with cancer in the last year of life in North East Essex, an estimate of the financial resources potentially available for re-investment in a year if 39% of all deaths in hospital are avoided. (Source: local clinical audit and ICHP analysis)

Similarly, as there is a lower average expenditure per person for people with non-cancer dying out of hospital of £4,982, and if 39% of all deaths in hospital could be avoided, an estimated £2,642,453 is potentially available for re-investment in higher value end-of-life care (see Figure 62).

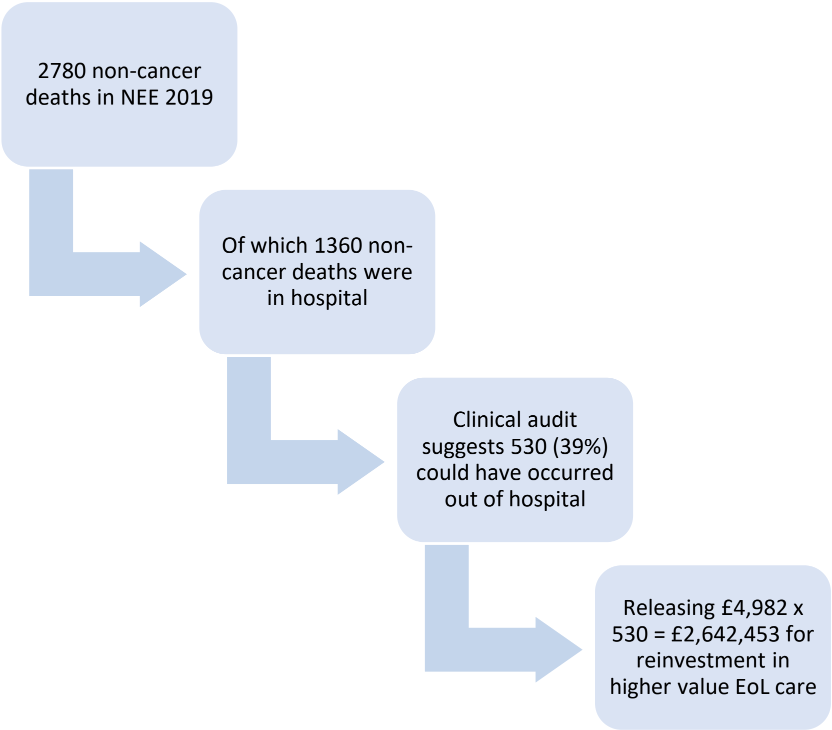

Figure 62: For people with non-cancer conditions in the last year of life in North East Essex, an estimate of the financial resources potentially available for re-investment in a year if 39% of all deaths in hospital are avoided. (Source: local clinical audit and ICHP analysis)

It is important to note that not all deaths in hospital represent low-value care, nor do all deaths in a person's usual place of residence represent high-value care; however, not only in the consultation with bereaved family members and carers of people who had died but also in that with frontline service providers in end-of-life health and social care, dying out of hospital was identified as an outcome that matters.

What can we infer about the value of care for people at the end of life in North East Essex?

Although the two estimates (the former based on registration with a general practice with high levels of MCCR usage and the latter based on the local clinical audit of deaths in hospital) overlap in their implications, there are important differences:

- The implementation strategy to achieve the estimate based all general practices developing to become a high MCCR usage practice is likely to focus on interventions that prevent admission to hospital, and that provide support to the individual in need of end-of-life care and their families and/or other carers
- The implementation strategy to achieve the estimate based on the local clinical audit of deaths in hospital is likely to focus on interventions enhancing the capacity to discharge people in the last year of life from hospital, including considerable re-investment in community resources, such as nursing-home placement and home support

The realisation of both estimates is predicated on the investment of resources in general-practice development and/or other higher value interventions. These estimates do not represent savings, nor do they represent a request for long-term funding; these estimates form the basis for a reallocation of resources from lower value to higher value care that will improve outcomes and increase value not only for individuals but also for the population nearing the end of life. Seed funding may be necessary to initiate this process of resource reallocation.

Summary of opportunities for increasing allocative efficiency

- Place of death (in hospital or out of hospital) has a considerable impact on average expenditure on admissions to hospital per person in the last year of life
- If all general practices could be supported to achieve high levels of MCCR usage, the potential for financial re-investment over one year is about £422,138 for people with cancer in the last year of life and £1,728,754 for people with non-cancer conditions in the last year of life; the total being £2,150,892
- The local clinical audit of 100 records of people who died in hospital in 2017/2018 showed that 39% of people could have died out of hospital if there had been the capacity to discharge them with support. Based on this percentage, over one year, there is potentially £401,794 that could be freed for re-investment for people with cancer in the last year of life and £2,642,453 for people with non-cancer conditions in the last year of life; the total being £3,044,247
- Both sets of estimates are predicated on the provision of development funds or other support for higher value interventions in end-of-life care. The estimates do not represent savings, but will improve outcomes for individuals and the population nearing the end of life
- The implementation strategy to realise the estimate based on all general practices being supported to develop with high levels of MCCR usage is likely to focus on the prevention of admission to hospital through better advance care planning, with support provided to the individual and their family and/or other carers
- The implementation strategy to realise the estimate based on the findings of the local clinical audit is likely to focus on the capacity to discharge people at the end of life from hospital, which would require considerable re-investment in community resources such as nursing-home placement and home support

Next steps relevant to Task 3: Developing a Population Stewardship Forum

A key element in increasing the value of end-of-life care in NEE is to develop a Population Stewardship Forum (network). An important foundation for the development of a stewardship network is to set the rules of operation for the network, which also cover:

- The roles and responsibilities of the network
- The degree of authority the network has over resource allocation
- Governance and accountability, including reporting to the population served

This report is concerned with adults at the end of life. Similar consideration needs to be given to establishing a stewardship network responsible for children and young people at the end of life in NEE.

Future development of the End of Life Board as a stewardship network

The ability to reallocate resources from lower value to higher value interventions is critical to improving the value of care for people nearing the end of life. It requires the establishment of a culture of continuous value improvement (CVI) informed by the outputs from linked datasets and a dashboard (see Figure 63).

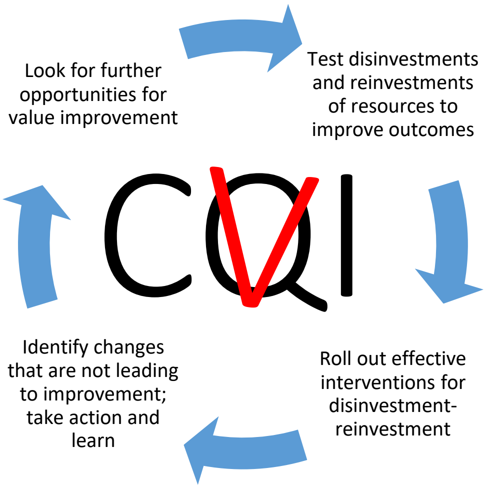

Figure 63: Continuous value improvement (CVI) cycle. (Source: 3V)

It is suggested that there should be a phased transition during which the End of Life Board is given increasing authority that will allow them to exercise collective responsibility for the management of resources for people at the end of life in NEE.

The next steps involve establishing the conditions in which the End of Life Board can optimise resource use to improve outcomes for people in the last year of life in NEE. Five tasks are necessary to create these conditions:

1. Reaching a consensus about the identification of people who belong to the population group of adults at the end of life, and ascertaining and monitoring the resources used for the care of this population
2. Monitoring progress against the value framework
3. Conferring greater authority on the End of Life Board to undertake CVI
4. Further promoting the use of MCCR as a way of increasing value for individuals nearing the end of life

5. Creating a culture of stewardship

Identifying people who belong to the population group of adults at the end of life and ascertaining and monitoring the resources used for their care

Although people in the last year of life are the focus of the analysis in this document, many people can be identified as entering the last phase of life before it is the last year. Therefore, the definition of the population designated to be at end of life needs to be formally agreed.

Agreement also needs to be reached about when people with long-term conditions or states, such as dementia, frailty, COPD, and heart failure, are nearing the end of life. This is important because when people near the end of life, the outcomes that matter to them and their families can change.

In terms of ascertaining the financial resources available for the care of people nearing the end of life, SNEE ICS and the Alliance need to:

- Agree the resource envelope currently being invested in people in the last year of life – in this report, only some aspects of financial resource investment have been analysed, including the largest item of expenditure, admissions to hospital
- Monitor the use of resources and provide this information to the End of Life Board

There are limitations in the financial information available for analysis in this report, because:

- There are gaps in the data
- There is a reliance on tariff rather than actual costs (a common problem)

These limitations mean that the amounts which have been identified in this report for disinvestment and re-investment are not precise; however, the financial analysis is robust enough to recommend progressing with a programme of CVI, especially given the strong face validity. Owing to the limitations outlined, any future work must include financial information from a greater number of funding sources for end-of-life care and information on actual costs rather than tariff. These improvements in data collection are critical, and ultimately must include financial and costing information from all providers of care for people at the end of life.

As the collection of financial and costing information evolves, it will also be important to explore relationships between outcomes that matter, proxy outcomes and variables that might affect outcomes, such as age, condition/s or health status at end of life, residence in a care home, the model of end-of-lifecare at a general practice. Such information should form the basis of a 'dashboard' that will enable reporting at a strategic level and interrogation of the data to an operational level. It is important, however, not to wait until better quality data is available before acting.

For the end-of-life population segment, a scheme outlining the cascading population size in relation to financial resource investment for SNEE ICS, the Alliance and associated PCNs is shown in Figure 64.

Suffolk and North East Essex ICS spent £1.8 billion in 2016 on 953,000 people

- 9900 who died in 2018
- Amount of the ICS budget that should be allocated to end of life care including in NEE

North East Essex Health and Wellbeing Alliance spent £537 million in 2018/19 on 351,776 people

- End of Life Board: 3,490 people who died in 2018/19
- Amount that should be spent on end of life care (£39.9 million identified)
- Amount the End of Life Board should directly manage

Primary care networks (50-70k)

- For example, Clacton PCN: 57,000 population
  - Clacton population at the end of life: 800
  - Resources the End of Life Board provides to Clacton PCN

Figure 64: Schematic of Suffolk and North East Essex integrated care system and its population, showing the cascade through levels of jurisdiction in relation to current patterns of financial resource investment. (Source: 3V)

Monitoring performance against the value framework

Following engagement with bereaved family members, carers, and frontline service providers from the public, private and third sectors in NEE, a set of outcomes that matter were developed. In the detailed value framework (shown in Appendix 1), indicators/criteria have been suggested to monitor whether these outcomes are being achieved. Agreement is needed about the:

- Collection of data and information to support these measures
- Frequency of data/information collection
- Methods of data/information/collection

Conferring greater authority on the End of Life Board

Conferring greater authority on the End of Life Board for the investment, disinvestment and re-investment of resources is a major component of the next phase of development. The intention should be that the Alliance holds the End of Life Board accountable for delivering outcomes that matter within a given allocation of resources but does not undertake close performance management of the process.

Agreement is needed about the:

- Degree of authority and responsibility that will be invested in the End of Life Board
- Way in which authority and responsibility will be handed over to the End of Life Board
- Phasing of the hand-over
- Relationship between the Alliance and End of Life Board

This phase of work needs to outline reasonable and transparent approaches to resource investment, disinvestment and re-investment,[40] rather than focus on managing service-provider conflicts of interest.

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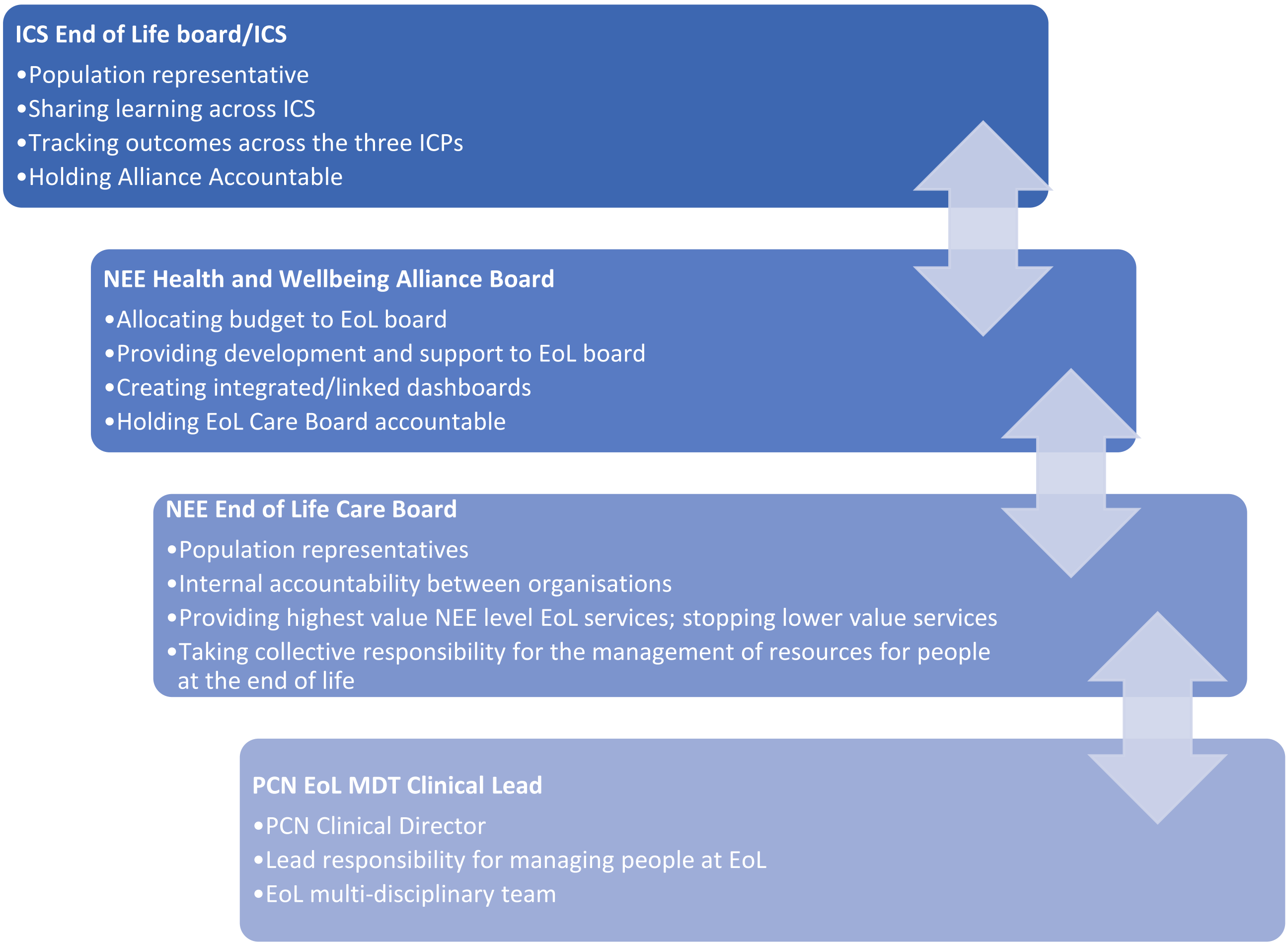
[40] Daniels, N., & Sabin, J. E. (2008). Accountability for reasonableness: an update. BMJ (Clinical Research Ed.), 337, a1850. https://doi.org/10.1136/bmj.a1850

The schematic in Figure 65 shows the governance and accountability lines for end-of-life care from SNEE ICS to local PCNs.



ICS End of Life board/ICS

- Population representative
- Sharing learning across ICS
- Tracking outcomes across the three ICPs
- Holding Alliance Accountable

NEE Health and Wellbeing Alliance Board

- Allocating budget to EoL board
- Providing development and support to EoL board
- Creating integrated/linked dashboards
- Holding EoL Care Board accountable

NEE End of Life Care Board

- Population representatives
- Internal accountability between organisations
- Providing highest value NEE level EoL services; stopping lower value services
- Taking collective responsibility for the management of resources for people at the end of life

PCN EoL MDT Clinical Lead

- PCN Clinical Director
- Lead responsibility for managing people at EoL
- EoL multi-disciplinary team

Figure 65: Roles and responsibilities for different levels of governance and accountability for population health and end-of-life care in Suffolk and North East Essex ICS. (Source: 3V)

A performance dashboard, which monitors outcomes using the measures identified, is needed to support the work of the End of Life Board. The dashboard could also include linked datasets allowing users to explore questions such as:

- How many people's preferred place of care is being fulfilled
- Whether fulfilment of a person's preferred place of care relates to registration on MCC
- Whether anticipatory prescribing affects the number of emergency admissions to hospital

The introduction and use of such a dashboard will allow the End of Life Board to monitor the impact of resource investment and other service improvements as a result of CVI and to identify any problems as they arise. The degree to which the Alliance uses the same dashboard to hold the End of Life Board accountable for the achievement of outcomes that matter needs to be agreed. Over time, the monitoring of resource usage should include financial information, the amount of clinical time dedicated to end-of-life care and carbon emissions resulting from end-of-life care.

Further promoting the use of MCCR as a way of increasing personal value

In end-of-life care, the importance of elucidating, recording and honouring personal preferences for care are well documented. Local preferences for end-of-life care are reflected in the set of outcomes that matter outlined in the value framework (see section entitled 'Outputs from Task 2: Agreeing a Value Framework' and Appendix 1).[41]

An important role for the End of Life Board will be to continue to promote the MCCR. Promotion of the MCCR could include:

- Training and skills development for staff involved in end-of-life care – the NHS England Sponsored Institute for Personalisation, which has a budget for staff training, may be a useful resource in this respect
- Identifying actions specific to individuals in need of end-of-life care, their family and carers, to improve the outcomes that matter to them

Applying CVI to the following challenges is likely to be beneficial in improving outcomes for people nearing the end of life:

- General practices with low levels of MCCR usage
- End-of-life care for residents in care homes
- End-of-life care for people with specific conditions, especially dementia

An end-of-life dashboard should help to identify the variables influencing the outcomes that matter and the aspects of end-of-life care which are most amenable to value improvement.

Creating a culture of stewardship

Transformational change in an organisation or partnership occurs when the culture changes.[42] The creation of a new culture is a leadership role, which in this case will be shared across the organisations comprising the End of Life Board. To begin with, the End of Life Board could focus on three areas, as follows.

1. Identifying, and reaching a consensus about, behaviours that will promote the new culture of stewardship in end-of-life care, and behaviours that will detract from it. This could include developing and establishing processes to reinforce behaviours that promote the new culture, while agreeing to identify and address behaviours that detract from the new culture when they occur
2. Identifying and agreeing a new common language. This could include ensuring people understand the need for a common language and encouraging them to use it. As language shapes the way people think, a change in language leads to neurophysiological re-wiring. As a new culture of stewardship is developed, the End of Life Board need to agree and promote the use of some words, for instance, 'disinvestment' and 're-investment', and to ban the use of others, such as 'savings'
3. Publishing an annual report for the population served and for the families and carers of people at the end of life, describing how resources are being used to improve outcomes for people in the last year of life in NEE

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[41] Gawande A. https://www.newyorker.com/magazine/2010/08/02/letting-go-2

[42] Schwandt, D. (2017). Karl E. Weick: Departing from traditional rational models of organizational change. In *The Palgrave Handbook of Organizational Change Thinkers* (pp. 1415–1431). Springer International Publishing. https://doi.org/10.1007/978-3-319-52878-6_62

The themes in this section of the report will be addressed in more detail in the next phase of work focusing on governance processes, including information requirements, contractual vehicles, accountability and support to the End of Life Board, and on the phasing of budgetary responsibility to match increasing accuracy of the data required for allocative efficiency.

Appendix 1 Value Framework

Value Framework

Aim

Through improving outcomes that matter with the resources given increase the value of care for people aged 18 years and over in the last 12 months of life

Outcomes that matter.

The following ten outcomes are derived from focus groups with patients, families, carers and providers.

Planning

1. To identify and recognise people in the last 12 months of life
2. To inform people thought to be within the last 12 months of life and their families of the likelihood of death within the next 12 months sensitively and honestly
3. To elicit and record people's preferences for care during the last 12 months of life
4. To ensure people's preferences for care are accessible to all parts of the health and social care system/end-of-life-care system

Delivering and caring

5. To respect people's preferences for care during the last 12 months of their life
6. To treat people at end of life as individuals, with dignity, compassion and empathy
7. To control pain and manage symptoms for people during the last 12 months of life
8. To minimise inappropriate, unnecessary and futile medical intervention during the last 12 months of people's life
9. To ensure that people at end of life have equitable access to flexible 24/7 end-of-life care services irrespective of the place of care or the organisation/s providing care
10. To provide support to the families and other carers during and after their loved one's end of life

Outcomes	Suggested metrics
Planning	
1. To identify and recognise people in the last 12 months of life	*Family & other carers* Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey)[43] *Consider a question exploring what point staff involved in end-of-life care (EoLC) recognised and identified the loved one's end of life and whether the family/other carers felt that identification could have been made sooner, plus an open section asking what symptoms and signs did not trigger identification* *System* • Numbers of patients in need of palliative care/support as recorded on GP disease registers per 100 deaths

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[43] Seow, H., Bainbridge, D., Brouwers, M., Pond, G., & Cairney, J. (2017). Validation of a modified VOICES survey to measure end-of-life care quality: the CaregiverVoice survey. *BMC Palliative Care*, *16*(1), 44.

	• Percentage of people who died in the last 12 months who were on the My Care Choices Register (MCCR) • Percentage of people who died in the last 12 months whose death was not amenable to EoLC • Median and mode time between the identification of a person considered to be in the last year or life and their death • Percentage of staff in key organisations proving EoLC services trained in the recognition and identification of end of life
2. To inform people thought to be within the last 12 months of life and their families of the likelihood of death within the next 12 months sensitively and honestly	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether the EoLC staff informed the person at end of life and their family with sensitivity and honesty, plus an open section eliciting the nature of the communication if it was not sensitive and/or honest* ***System*** • Percentage of staff in key organisations providing EoLC services trained in communication skills for EoLC • Number and type of complaints about EoLC
3. To elicit and record people's preferences for care during the last 12 months of life	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey)[1] *Consider question regarding whether the patient's preferences for care were discussed and explained clearly, and whether the patient was encouraged to discuss their options/decisions with (a) family/other carers and (b) their GP* ***System*** • Percentage of people in a GP practice on MCCR • Percentage of people who died in the last 12 months who were on the MCCR • Percentage of people on MCCR whose preferences for place of care at end of life are recorded • Completion of MCCR by place of residence • Numbers of patients in need of palliative care/support as recorded on GP disease registers per 100 deaths

4. To respect people’s preferences for care during the last 12 months of their life	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether the patient’s preferences for care were respected, plus an open section eliciting their experience if the answer is negative* ***System*** • Percentage of people on MCCR who die in their preferred place of care (1st and 2nd choice) at end of life • Distribution of people on MCCR who die in their preferred place of care (1st and 2nd choice) at end of life Percentage of people who die who are not on MCCR and whose condition was amenable to end-of-life care
Delivering and caring	
5. To ensure people’s preferences for care are accessible to all parts of the health and social care system/end-of-life-care system	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether the all staff involved in their loved one’s care were able to access MCCR; need multiple choice section which lists the possible types of staff who might be encountered during the loved one’s end of life* ***System*** • Numbers of patients in need of palliative care/support as recorded on MCCR per 100 deaths • Number of times staff from different organisations involved in EoLC access MCCR Number of reports from staff involved in EoLC who cannot access MCCR
6. To treat people at end of life as individuals, with dignity, compassion and empathy	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider questions regarding whether the family’s/carer’s loved one was treated with dignity, compassion and empathy, plus an open section eliciting their experience if the answer is negative, and a similar question and open section regarding whether the family/other carers felt they were treated with dignity, compassion and empathy* ***System*** Number and type of complaints about EoLC
7. To control pain and manage symptoms for people during the last 12 months of life	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether family/other carers considered their loved one’s pain was controlled and symptoms were managed, plus an open section eliciting their experience if the answer is negative* ***System***

	• Numbers of patients in need of palliative care/support as recorded on GP disease registers per 100 deaths • Percentage of people on MCCR with the anticipatory prescribing section completed • Percentage of people on MCCR in a GP practice with anticipatory prescribing recorded • Percentage of people who died in the last 12 months who received anticipatory prescribing • Percentage of people at end of life admitted to hospital receiving pain relief from a specialist in palliative care within a specified time-frame • Emergency admissions rate and LoS • Ambulance call-outs per population at end of life • Percentage of people admitted to hospital in the last 90/180/365 days of life • Percentage of people who had 3 or more emergency admissions to hospital in the last 90 days of life • Percentage hospital admissions of 8 days or longer ending in death • Percentage of people within the last 12 months of life receiving medicines optimisation • Range and median pain control/relief score at points in last 12 months of life • Number and type of complaints about EoLC • Referrals to hospice care services • Percentage of residential care homes with anticipatory prescribing medicines on site
8. To minimise inappropriate, unnecessary and futile medical intervention during the last 12 months of people's life	***Family & carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether family/other carers considered their loved one received inappropriate, unnecessary and/or futile care, plus an open section eliciting their experience if the answer is negative* ***System*** • DToC rate (number of people who have delayed transfers of care) • Emergency admissions rate • Median and mode length of stay (LoS) following emergency admission to hospital for people in the last 12 months of life • Planned admissions rate • Median and mode length of stay (LoS) following planned admission to hospital for people in the last 12 months of life • Percentage of people admitted to hospital in the last 90/108/365 days of life • Percentage of people with 3 or more emergency admissions in the last 90 days of life

	• Re-admissions rate • Percentage hospital admissions of 8 days or longer ending in death • Percentage of people within the last 12 months of life receiving medicines optimisation • Range and median pain control/relief score • Percentage of people within the last 12 months of life admitted to hospital receiving (a) blood tests and (b) CT/ MRI scans End-of-life treatment intensity score[44]
9. To ensure that people at end of life have equitable access to flexible 24/7 end-of-life care services irrespective of the place of care or the organisation/s providing care	***Family & other carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey) *Consider question regarding whether families'/carers' loved one had access to 24/7 EoLC services, plus an open section eliciting their experience if the answer is negative* *Could consider questions regarding whether families/other carers (a) were aware of the range of services available for people at end of life and (b) felt capable of advocating for their loved one (e.g. requesting a particular service/intervention)* ***System*** • Numbers of patients in need of palliative care/support as recorded on GP disease registers per 100 deaths • Percentage of expenditure on end of life care allocated to: o Primary care o Social care o Community care • Number of out-of-hours call-outs for doctors • Ambulance call-outs • Number of staff from key organisations involved in EoLC providing information about the range of services to people at end of life/their family/other carers • Percentage of people receiving social care package/s • Percentage of people receiving primary care package/s • Percentage of people receiving community care package/s • DToCs Number and type of complaints about EoLC
10. To provide support to the families and other carers during and after their loved one's end of life	***Family & carers*** Family/carer survey (e.g. see survey instrument at the CareGiverVoice survey)

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[44] Barnato, A. E., Farrell, M. H., Chang, C. C. H., Lave, J. R., Roberts, M. S., & Angus, D. C. (2009). Development and validation of hospital end-of-life treatment intensity measures. *Medical Care*, *47*(10), 1098–1105.

	Consider question regarding whether the family/other carers felt support and/or received support (a) during and (b) after the end of life of their loved one, plus an open section asking if they did not receive any or all of the support they required what type of support was missing/needed *Consider question regarding whether the family/other carers felt there were able to spend 'protected' time with their loved one at end of life and/or whether they felt their needs for access to their loved one were met* *Could consider a question regarding whether family/other carers feel they have the capability/capacity to care for their loved one at home* System • Number/median number of visits by primary care staff per person at end of life • Number/median number of people at end of life receiving primary care visits • Number/median number of community care visits per person at end of life • Number/median number of people receiving community care visit • Number/median number of healthcare personal care packages per person at end of life • Number/median number of people receiving healthcare personal care packages • Median length of healthcare personal care packages • Distribution of length of healthcare personal care packages by number of people • Number/median number of social care packages per person at end of life • Number/median number of people at end of life receiving social care package • Median length of social care packages • Distribution of length of social care packages by number of people • DToCs • Number/percentage of families/other carers offered training in basic skills to care for a loved one at home • Number of families/other carers offered respite care • Number of families/other carers receiving respite care • Number of families and other carers offered support: o ***during*** the end of life of their loved one o ***after*** the death of their loved one Referrals to coroner

End of Life Board Population Health and Care Objectives

In all health systems aiming to deliver high value population health and social care there are some further core objectives that need to be addressed:

Objectives	Suggested metrics
Common population health management (PHM) objectives	
1. To make optimal use of resources	Outcomes compared to spend against benchmark geographies
2. To reduce inequity	• Differences in various outcomes between least deprived and most deprived wards, e.g. percentage of people on MCCR • Numbers of patients in need of palliative care/support as recorded on GP disease registers per 100 deaths • Health status/diagnosis of people on MCCR (i.e. the stage of their illness) • Number of referrals to hospice care • Percentage of people on MCCR/not on MCCR referred to hospice care • GPs/other primary care staff per population • Vacancy rates for GPs/other primary care staff • Number of care homes (residential and nursing) per population • Ratio of staff to residents in residential care homes
3. To develop and support staff	• Percentage of staff who have completed a training programme in: o Communication skills for end of life o Symptom management in EoLC o Pain control in EoLC • Range and median level of level of satisfaction for staff involved in EoLC • Number of staff involved in EoLC offered support • Number of staff involved in EoLC requesting support • Number of staff involved in EoLC receiving support
4. To be accountable to the population served	Production of an annual report that describes the value provided to the EoL population subgroup on the above measures Dissemination of annual report to patient groups involved in EoLC, and EoLC service stakeholders Feedback on content of annual report (structured questionnaire) Level of awareness among general public of benefits of registration on MCCR

Factors to be included in monitoring:

Population factors

- Index of multiple deprivation
- Place of care

Personal factors

- Place of residence
- Dominant condition
- Level of frailty
- Comorbidity/ies

Appendix 2: Analytical approach and methods

Terminology

The definition of several terms relating to the analysis in this report are summarised below:

- Registered patients = the total number of patients registered at a general practice
- % MCCR deaths = (people who died on MCCR) ÷ (total patients who died)
- % MCCR patients 65+ = (patients on MCCR) ÷ (registered patients aged 65+)
- % MCCR cancer deaths = (patients who died of cancer on MCCR) ÷ (total patients who died of cancer)
- % MCCR non-cancer deaths = (patients who died of non-cancer conditions on MCCR) ÷ (total patients who died of non-cancer conditions)
- Expenditure when used in relation to admissions to hospital refers to the tariff cost of each hospital admission, that is, CCG expenditure

Approach

There were three parts to the approach used in the analysis:

1. Collation of baseline data to identify the scale of hospital activity during the last 12 months of life for people who died in 2018/19, and comparable activity for all residents in NEE CCG in 2018/19
2. Analysis of the MCCR dataset to determine the level of MCCR usage by general practices in NEE (see the section entitled 'Grouping of general practices' below)
3. Findings from the general practice MCCR usage analysis were then analysed in relation to the HES-ONS dataset. This stage of analysis was undertaken to identify proxy outcomes for people in the last year of life in relation to the level of MCCR usage for the general practice with which they were registered

Data sources

The following data sources were used:

- Via Harvey Nash, data suppliers to ICHP, NHS Digital Hospital Episode Statistics (HES) linked to the ONS database for deaths, which enabled an understanding of hospital activity for people in the last year of life in NEE
- My Care Choices Register (MCCR) data from St Helena Hospice, which enabled an understanding of levels of MCCR use by general practices in NEE

The study period was the financial year 2018/19, and it included all the people who died during this timeframe. If a person died during 2018/19, the hospital activity associated with that person during the previous 12 months was analysed.

Expenditure on hospital activity was derived by ICHP using tariff adjusted for reference costs. Expenditure on NHS continuing healthcare fast-track pathway care packages and St Helena Hospice charitable funds and NHS grant funding was actual expenditure.

Handling of data in relation to mergers/de-mergers of general practices in North East Essex

During recent years, there have been mergers and de-mergers of general practices in NEE. The data on general practices for this analysis was supplied according to clusters of practices identified by the 'parent' general practice. The following clusters of general practices were used to match the pattern of mergers and de-mergers that was current for the timeframe of this analysis:

Abbey Field Merged:

- Abby Field Medical Centre
- Hawthorn Surgery
- Portland Medical Practice

ACE Merged:

- ACE community practice (Green Elms)
- Epping Close
- The Frinton Road Medical Centre

N.B. Caradoc was excluded from ACE in this analysis because data from NEE CCG was reported separately.

Colchester Merged:

- Colchester Medical Practice
- Parsons Heath Medical Centre
- Shrub End Surgery
- Wimpole Road Surgery

Creffield Merged:

- Creffield Medical Centre
- Layer Road Surgery
- North Hill Medical Group

North Clacton Merged:

- Crusader Surgery
- Great Clacton Medical Practice

Methods

A hypothesis matrix was originated by 3V and developed by ICHP to facilitate the testing of possible correlations among variables at the end of life using multivariate analysis (MVA; refer to Figure 69) and identifying whether any of the correlations were statistically significant. Statistical significance is given in the report when relevant; according to accepted convention, a p-value of equal to or less than 0.05 is considered statistically significant.

During the analysis, the hypotheses that seemed to be the most fruitful areas of investigation were the correlations between the level of:

1. MCCR usage by general practices (as a percentage of total deaths in a general practice) *and admissions to hospital*
2. MCCR usage by general practices (as a percentage of total deaths in a general practice) *and place of death*

The analysis of the level of MCCR usage and hospital activity was undertaken by MCCR usage at each general practice and by MCCR usage by MCCR usage group of general practices (see below). This analysis of MCCR usage became the focus of the investigation of the potential to increase the value of end-of-life care in NEE.

Grouping of general practices by level of MCCR usage

For the purpose of analysis, general practices were grouped into high, medium and low levels of MCCR usage.

- For MCCR/death (see ‘Terminology’), general practices were categorised into one of three MCCR usage groups: High ≥35%; Medium = 30-34.9%; and Low <30% groups (see Figure 66).
- For MCCR/registered patient over 65 years, general practices were categorised into one of three MCCR usage groups: High ≥6.5%; Medium = 3.5-6.4%; Low <3.5% (see Figure 67).

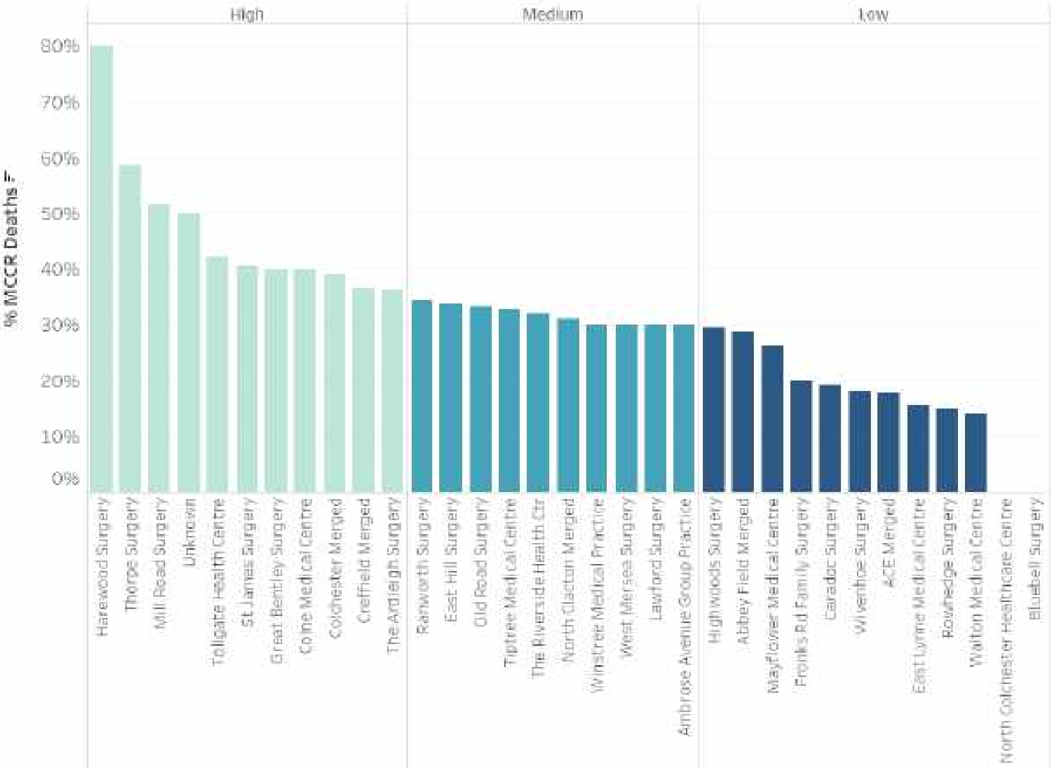

Figure 66: General practice MCCR usage groups for MCCR/deaths (high = light blue; medium = mid blue; low = light blue). (Source: ICHP analysis)

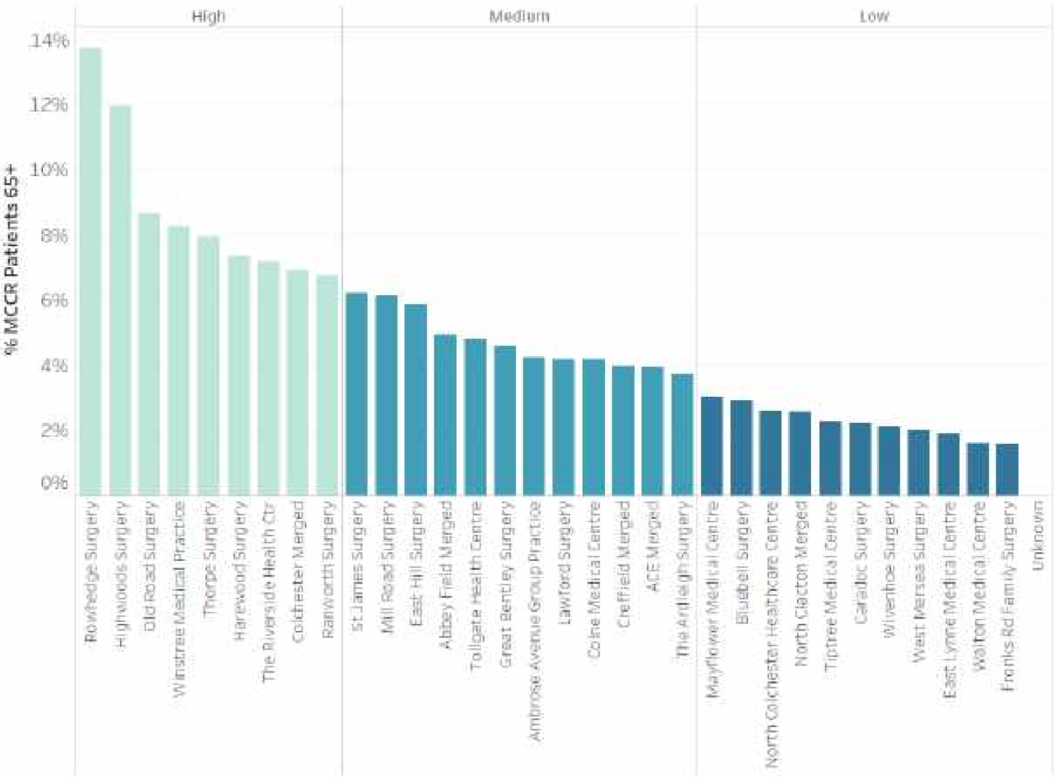

Figure 67: General practice MCCR usage groups for MCCR/65+ registered population (high = light blue; medium = mid blue; low = light blue). (Source: ICHP analysis)

Suppression of data

The approach taken by ICHP to enable analysis was to generate all data points by addition at the general practice level. The total deaths identified for each general practice were split by age-band and death setting which generated four different values for the number of deaths. These four values were summed for each practice to give a total, these totals were then summed to give the total for NEE.

According to NHS Digital rules for data suppression, values lower than 8 were suppressed to a value of 5, and all values were rounded to the nearest 5. The effects of data suppression is illustrated in Figure 68 where the actual number of deaths at a general practice are shown in green and the data received by ICHP, after suppression and rounding, are shown in blue. Data suppression accounts for the difference in totals for the number of deaths in NEE, as noted in this report, and that reported by ONS.

During the timeframe for analysis, several general practices merged. As the data relating to these general practices was manually collated, it increased the likelihood of small number suppression leading to discrepancies.

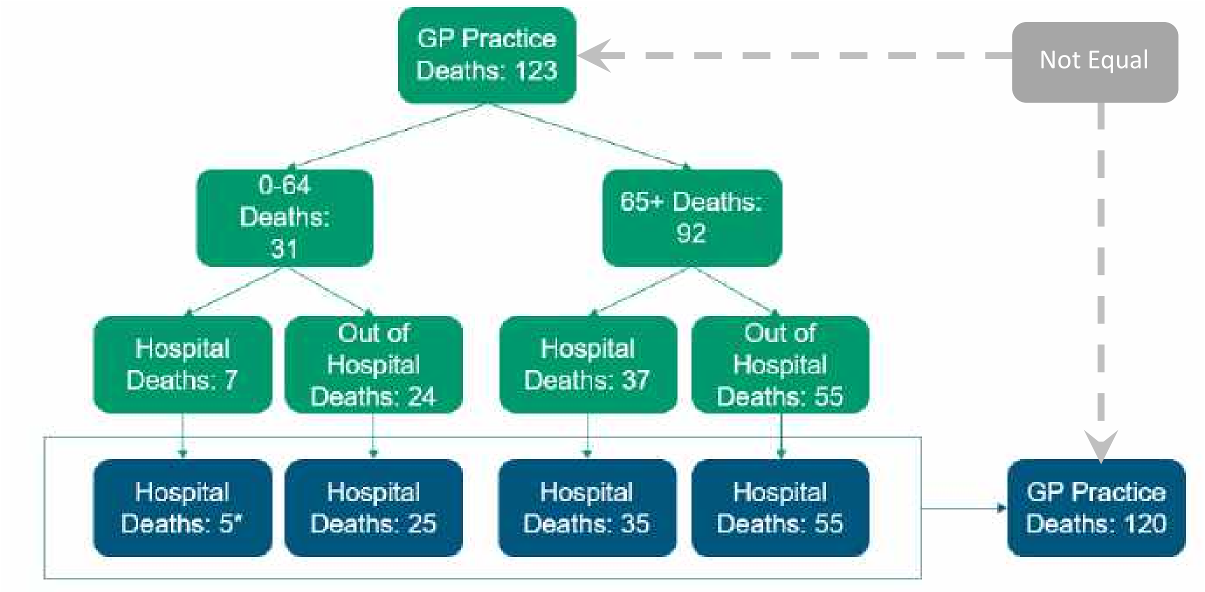

Figure 68: Illustration of the effects of data suppression on the number of deaths at an individual general practice. (Source: ICHP analysis)

Inclusion of children in the analysis- impact

ICHP included children in the analysis of deaths. However, it was not felt by ICHP to be material to the outputs based on the following consideration: For the cohort of 3,490 deaths in NEE only 24 of these were for patients aged 18 and under. As there are over 30 GP practices within this analysis, most will only have had 1 death of a patient aged 18 or under, while others will not have had any. Due to the suppression and rounding of the data as specified previously, the impact of these 24 deaths will likely be negligible in relation to the overall analysis.

Limitations of the analysis

A major challenge during data analysis was the stringent requirements for permission to link various datasets held within NHS organisations and among different providers of end-of-life care. Analysis could be enhanced by linkage between datasets held by the local authority, the NHS and the third sector. This is especially problematic when using the dataset derived from the MCCR, which contains people's preferences for place of care, and in some cases other important information such as anticipatory prescribing.

Another challenge during data analysis was small sample size, which affected capacity to demonstrate statistical significance; in some instances, therefore, it was possible to show only an association, as indicated in the text.

	No. admissions to hospital in last 90 days of life (and medical intensity score)	*% of people with 3 or more emergency admissions in the last 90 days of life*	*Emergency admissions rate*	*Emergency admissions LoS*	*Planned admissions rate*	*Planned admissions LoS*	*No. readmissions to hospital within a specific timeframe*	*No. admissions to hospital per person in last 90 |days of life*	*No. admissions to hospital per person in last 180 days of life*	*No. admissions to hospital per person in last 365 days of life*	*% of hospital admissions that end in death that are 8 days or longer*	*Death Setting*
Vacancy rates [GP]	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely could be higher	If vacancy rates high, likely could be higher	If vacancy rates high, may be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be higher	If vacancy rates high, likely to be lower
GPs/head of population	If GPs/head is low, likely to be higher	🟩 If GPs/head is low, likely to be higher (p=0.015)	If GPs/head is low, likely to be higher	If GPs/head is low, likely to be higher	If GPs/head is low, could be higher	If GPs/head is low, could be higher	If GPs/head is low, may be higher	If GPs/head is low, likely to be higher	If GPs/head is low, likely to be higher	If GPs/head is low, likely to be higher	If GPs/head is low, likely to be higher	If GPs/head is low, likely to be lower
Deprivation by GP practice	🟩 If IMD is higher rank (most deprived), number of admissions likely to be higher (p=0.034).	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be lower
% 65+ in nursing home	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, could be higher	If care home density high, could be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, likely to be higher	If care home density high, could be higher
% people on MCCR by GP practice	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	If % on MCCR high, may be lower	🟥 If % on MCCR high, may be lower (p<0.01)	🟩 If % on MCCR high, likely to be lower (Reattendances within 7 days p=0.02)	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	If % on MCCR high, likely to be lower	🟩 If % on MCCR high, likely to be higher (p<0.01)
No patients on in Hospital palliative care as % deaths	🟥 If no. on register high, likely to be lower (p=0.012)	If no. on register high, likely to be lower	If no. on register high, likely to be lower	If no. on register high, likely to be lower	If no. on register high, may be lower	If no. on register high, may be lower	If no. on register high, likely to be lower	If no. on register high, likely to be lower	If no. on register high, likely to be lower	If no. on register high, likely to be lower	🟥 If no. on register high, likely to be lower (p=0.02)	If no. on register high, likely to be higher
% with LTCs	If comorbidity high, could be higher	If comorbidity high, could be higher	If comorbidity high, could be higher	If comorbidity high, could be higher	If comorbidity high, may be higher?	If comorbidity high, may be higher?	If comorbidity high, could be higher	If comorbidity high, could be higher	If comorbidity high, could be higher	If comorbidity high, could be higher	🟩 If comorbidity high, could be higher (p<0.01)	If comorbidity high, could be higher or lower, more LTC more in hospital deaths
Death Setting	If cared for at home, likely to be lower	If cared for at home, likely to be lower	🟩 If cared for at home, likely to be lower (p<0.01)	🟩 If cared for at home, likely to be lower (p<0.01)	🟩 If cared for at home, could be lower (p<0.01)	🟩 If cared for at home, could be lower (p<0.01)	If cared for at home, may be lower	🟩 If cared for at home, likely to be lower (p<0.01)	🟩 If cared for at home, likely to be lower (p<0.01)	🟩 If cared for at home, likely to be lower (p<0.01)	If cared for at home, likely to be lower	☐ If cared for at home, likely to be higher
Deprivation by residence	🟥 If IMD is higher rank (most deprived), likely to be higher (p=0.025)	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), could be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be higher	If IMD is higher rank (most deprived), likely to be lower
Frailty score	🟩 If severely frail, could be higher (p<0.01)	☐ If severely frail, could be higher	🟩 If severely frail, could be higher (p=0.026)	🟩 If severely frail, could be higher (p=0.03)	🟥 If severely frail, may be higher? (p<0.01)	🟥 If severely frail, may be higher? (p<0.01)	🟩 If severely frail, could be higher (p<0.01)	🟩 If severely frail, could be higher (p<0.01)	🟩 If severely frail, could be higher (p<0.01)	🟩 If severely frail, could be higher (p<0.01)	If severely frail, could be higher	If severely frail, could be higher or lower. More frail lower out of hospital deaths
Condition: cancer/non cancer	🟩 If cancer is dominant diagnosis, likely to be lower (p<0.01) ** Last 365 Days **	☐ If cancer is dominant diagnosis, likely to be lower	🟥 If cancer is dominant diagnosis, likely to be lower (p<0.01)	☐ If cancer is dominant diagnosis, likely to be lower	☐ If cancer is dominant diagnosis, could be lower/may be higher, cancer has higher admission rate	☐ If cancer is dominant diagnosis, could be lower/may be higher if cancer higher LOS	☐ If cancer is dominant diagnosis, likely to be lower	☐ If cancer is dominant diagnosis, could be lower/higher depending on timeliness of diagnosis (if cancer higher admissions)	☐ If cancer is dominant diagnosis, could be lower/higher depending on timeliness of diagnosis (if cancer higher admissions)	🟩 If cancer is dominant diagnosis, could be lower/higher depending on timeliness of diagnosis (if cancer higher admissions higher p<0.01)	☐ If cancer is dominant diagnosis, likely to be lower	If cancer is dominant diagnosis, likely to be higher
Comorbidities	🟩 If comorbidity high, could be higher (p=0.02) ** Last 365 Days **	☐ If comorbidity high, could be higher	🟩 If comorbidity high, could be higher (p<0.01)	☐ If comorbidity high, could be higher	☐ If comorbidity high, may be higher?	☐ If comorbidity high, may be higher?	☐ If comorbidity high, could be higher	☐ If comorbidity high, could be higher	☐ If comorbidity high, could be higher	🟩 If comorbidity high, could be higher (p<0.01)	☐ If comorbidity high, could be higher	If comorbidity high, could be higher or lower

Figure 69: Matrix of hypotheses for investigation during multivariate analysis, summarising the associations found – see key. (Source: ICHP and 3V)

Key

☐ Not tested by ICHP (e.g. data inadequacy)

🟩 P<0.05 supporting hypothetical correlation

🟥 P<0.05 against hypothetical correlation

🟦 P>0.05 for hypothetical correlation