



Norfolk and Waveney STP Palliative and End of Life Care Strategy For Adults 2019 - 2024

Date	Version No.	Summary of changes
29/01/19	1.1	Version 7 of the Delivery Plan developed into a strategy by NCCG
06/03/19	1.2	Updates by Programme Lead and Clinical Lead following engagement
23/03/19	1.3	Comments and edits from members of the Collaborative Group incorporated.
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1. Foreword

The Norfolk and Waveney STP Palliative and End of Life Collaborative Group (Collaborative Group) is made up of the following organisations:

- Commissioners: Norwich Clinical Commissioning Group, North Norfolk Clinical Commissioning Group, Great Yarmouth and Waveney Clinical Commissioning Group, South Norfolk Clinical Commissioning Group and West Norfolk Clinical Commissioning Group, Norfolk County Council and Suffolk County Council
- Norfolk Public Health and Suffolk Public Health
- Providers: James Paget University Hospital NHS Foundation Trust, East Coast Community Healthcare CIC, Norfolk Community Health and Care NHS Trust, Norfolk and Norwich University Hospital NHS Foundation Trust, IC24, East of England Ambulance Trust, The Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust, Norfolk and Suffolk NHS Foundation Trust
- Charitable Trusts: Macmillan Cancer Support, Big C, Marie Curie, Priscilla Bacon Centre, Priscilla Bacon Norfolk Hospice Care Ltd, St Nicholas Hospice Care, St Elizabeth Hospice, East Coast Hospice and Norfolk Hospice (Tapping House) and Swaffham and Litcham Hospice
- Education and Research Body: University of East Anglia Research Centre.

The Collaborative Group would like to introduce you to our jointly developed and refreshed Palliative and End of Life Care strategy for adults.

The STP (Sustainability and Transformation Partnership) Norfolk and Waveney Palliative and End of Life Care Strategy sets out the local vision for palliative and end of life care which is fundamentally built upon the National 6 Ambitions for Palliative and End of Life Care¹ and contains details of how we intend to transform services and why. It builds on the work of the Collaborative Group and the Lord Lieutenant's Palliative Care Forum and links to the work first presented to the National Director of Palliative Care, Professor Bee Wee, in May 2017 to understand what the local gaps and opportunities are within the Norfolk and Waveney system.

The number of deaths within England and Wales are projected to rise to unprecedented levels, with an additional 130,000 deaths each year by 2040, more than half of which will be in people aged 85 years or older. Higginson² states that all care settings will be affected by the rise in deaths and for Norfolk and Waveney we need to acknowledge these trends and increasing complexity of care throughout all care settings.

Therefore key principles of this work is to align commissioning and provider activity and promote uniformity of service provision to improve quality of care for patients and their carers from diagnosis through to bereavement.

The overall aim is to ensure that the people of Norfolk and Waveney can say "I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my

¹ Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

² www.thelancet.com Vol 392 September 15, 2018

carer (s)”³. “In the end, what gives a life meaning is not how it is lived but how it draws to a close” (Tessa Jowell 2018)

³ National Voices and The National Council for Palliative Care (NCPC) and NHS England (2015). Every Moment Counts: A narrative for person centred coordinated care for people near the end of life. London: National Voices.

2. Executive Summary

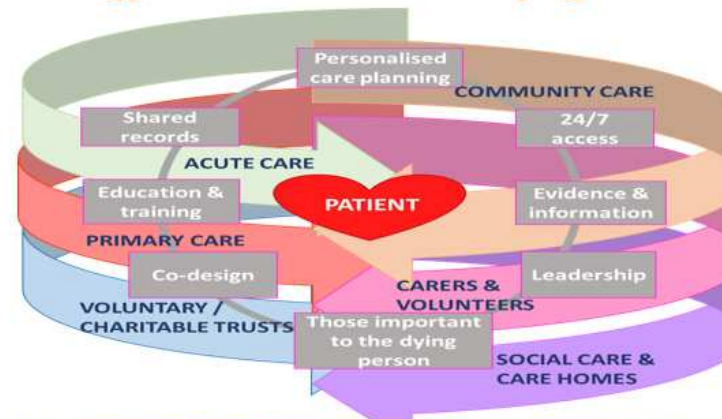
2.1 Strategy on a Page

Norfolk and Waveney STP Palliative and End of Life Strategy 2019 – 2024 – On a page

Vision: Through a new integrated palliative and end of life model of care we will ensure people and their carers/family receive care and support that is coordinated and which meets their individual needs - irrespective of care provider, diagnosis, circumstance or place of residence in Norfolk and Waveney from diagnosis through to bereavement.

Objectives for delivering an integrated model:

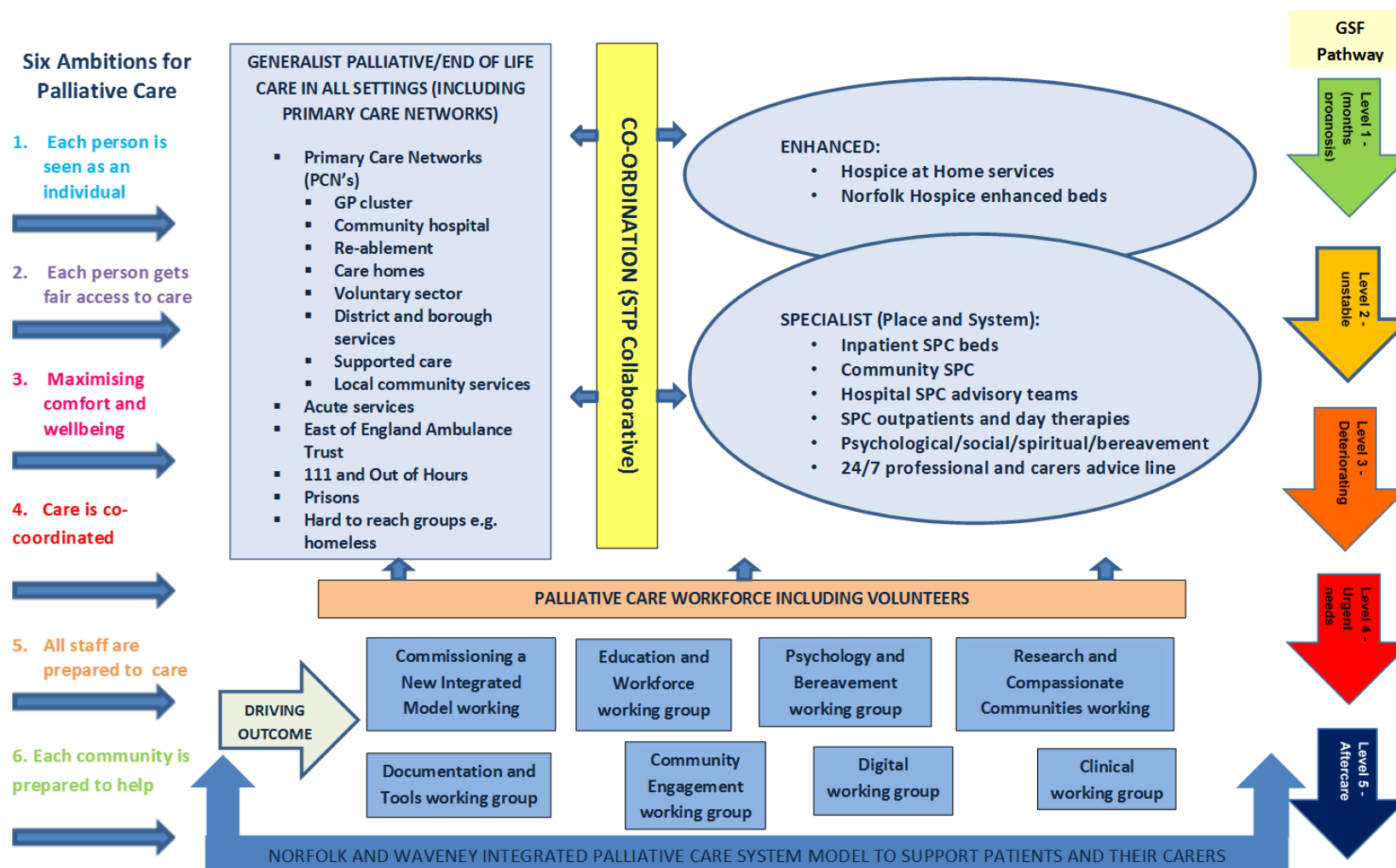
- Consistency across Norfolk and Waveney for palliative care provision e.g. inequity in 24/7 professional advice line, carers advice line, Hospice at Home, Social care Services, dedicated enhanced palliative care beds, psychological and bereavement services
- Capacity to provide palliative and end of life care e.g. develop the workforce across health and social care workforce, Supporting VCSE development, training and developments and assess the need for more specialist beds
- Co-ordinated approach to information/documentation, workforce (including volunteers), education, systems, audit research, performance and complaints and patient engagement
- Compliance in regards to helping people take control such as ability to access personal health budgets for palliative or end of life care
- Partnership working and pathway development with other work streams i.e. Care Homes
- Partnership working with health and social care sector and VCSE
- Social Engagement with community partnerships such as different faiths and culture groups
- Consistent approach to person centred outcome measures e.g. population needs assessment, monitoring and benchmarking
- Financial balance through a decrease in hospital admissions e.g. emergency admissions compared to PPOD



How we plan to achieve our vision & objectives:

- Leadership and coordination via the STP Palliative and End of Life care Collaborative Group
- Commissioners, health and social care providers and voluntary groups working collaboratively to develop and deliver an integrated model for Palliative & End of Life Care through aligning services across Norfolk and Waveney
- Collaborative working with Primary Care Networks, Public Health and the University of East Anglia Research Centre to ensure we are continuously ensuring population health needs are met.
- Increasing system awareness and appropriate utilisation of commissioned palliative care services
- Delivery via the 7 Collaborative working groups.
- Interface with other STP workstreams e.g. Workforce, Care Homes and Dementia

2.2 STP Norfolk and Waveney New Integrated Model of Palliative and End of Life Care



3. Introduction

Palliative and End of Life Care is one of the most challenging aspects of acute and community based care – delivering good care contributes not only to the targets for the health economy but provides support and dignity to patients and their families at the end of their lives. The majority of individuals state their Preferred Place of Death would be outside of a hospital setting (National Survey of Bereaved People (VOICES): England, 2015).

To advance public health and care policies requires the commissioning of high value interventions. A high value intervention is defined as one that achieves high quality as the numerator, and low cost as the denominator. Often, admission to Emergency Departments (ED) is the only alternative for a patient at home living with chronic serious illness and yet, it is widely known hospitals can be harmful to the patient population in need of palliative care. Hospital acquired infections and physical deconditioning can negatively affect quality of life and hasten mortality. In this context, emergency admission hospital can represent a low value intervention.

It is a national priority to support people to die outside hospital, and a core STP principle is “keeping me at home”. There is a strong research base to show that high quality community-based Palliative Care services can:

- Reduce patient symptom burden
- Increase the likelihood that care is well co-ordinated and people are treated with dignity and respect
- Double the chances of people dying at home
- Enable appropriate transfers from acute to intermediate beds
- Reduce inappropriate emergency hospital admissions and length of stay.

As much as 10–12 per cent of total health costs in England are spent on care for people approaching the End of Life. Studies show that people in their last year of life experience an average of 2.28 hospital admissions and spend 30.1 bed days in hospital. This represents a significant economic burden.

When people are not in hospital or specialist care, care takes place either in their own home or in a residential or nursing home setting. There are currently around 570 registered independent care providers across Norfolk and Waveney, with whom we need to engage as partners in end of life care. In addition there is a vigorous voluntary and community sector, providing valuable services in the community across a wide range of needs. All have a contribution to make to end of life care

3.1 Defining Palliative and End of Life Care

Death and dying is inevitable. Palliative and end of life care is a priority for our STP which requires collaboration and co-operation with partners across both health and social care, statutory and voluntary sector organisations, people with personal and professional experience, and with everyone speaking with one voice. More must be done to ensure that high quality, accessible palliative and end of life care is consistently better for all of us. The needs of people of all ages who are living with dying, death and bereavement together with their families, carers and communities must be addressed taking into account their priorities, preferences and wishes.

The definitions need to be clarified as there is still much confusion and incorrect use of terminology around what is classed as 'palliative care', 'end of life care' and 'last days of life'. Definitions are described in full within the document but in summary are:

Palliative Care – refers to an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness,

End of Life Care – this refers to the last 12 months of life

Last Days of Life – this refers to the dying person

This document sets out the vision for Palliative and End of Life care within the Norfolk and Waveney STP and contains the detail of how we intend to transform services.

3.1.1 What is Palliative Care?

The World Health Organisation's definition is:-

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems - physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012⁴, provides a useful breakdown:

General (ist) Palliative Care

Services in all sectors providing day-to-day care to patients with advanced disease and their carers designed to alleviate symptoms and concerns, but not expected to cure the disease. *Adapted from: Improving Supportive and Palliative Care for Adults with Cancer, 2004.*

⁴ <http://www.ncpc.org.uk/publication/commissioning-guidance-specialist-palliative-care-helping-deliver-commissioning-objectiv>

For enhanced palliative care, the definition and delivery within Norfolk and Waveney is based on the *NHS England Enhanced Supportive Care: Integrating supportive care in oncology* model.

Enhanced Palliative Care (Norfolk and Waveney)

There is not a national definition for “enhanced” as Commissioning Guidance allows for local definition. For Norfolk and Waveney ‘enhanced’ is defined as follows:

- Keyworker competencies are exceeded to support generalist care.
- Provides a true holistic approach to End of life care by supporting patients and families when a crisis hits i.e. carer breakdown which would result in the patient being unable to remain in their preferred place for care.
- Acts as a conduit between services to support patients when needed and then refer back to the Keyworker.
- Requires staff within the service to complete extra competencies that will influence their practice i.e. St Christopher’s end of life care competencies.
- Has a more fluid approach to providing care ensure the patient is the focus of all care delivered.

Specialist Palliative Care

Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support. *Source: Tebbit, National Council for Palliative Care, 1999*

It is clear from these definitions that a wide variety of professionals in NHS primary, community, mental health and acute services, as well as social care, independent hospices, the nursing and care home sector, voluntary services and faith groups, district councils and commissioners need to be involved and that commissioning good palliative care services is not necessarily a straightforward matter.

3.1.2 What is End of Life Care?

The General Medical Council (2010)⁵ has defined End of Life in the manner described below, and the National Institute for Health and Care Excellence adopted the same definition in their Quality Standard for End of Life Care for Adults⁶ which was published in 2013.

1. Advanced, progressive, incurable conditions
2. General frailty and co-existing conditions that mean they are expected to die within 12 months
3. Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
4. Life-threatening acute conditions caused by sudden catastrophic events

⁵ The General Medical Council (2010)

⁶ Quality Standard 13

This includes people who are likely to die within 12 months however as a result of the complexities associated with identifying when individuals enter the end of life phase, many patients will require access to End of Life Services for a period of time that is greater than a year. This includes support for families and carers as well as care provided by health, social care and voluntary sector in all settings.

Identifying people who may be in the last year of life allows for assessment and planning on how to support the patient and those important to them. One tool used to identify these patients is the Gold Standards Framework 'surprise' question "Would you be surprised if this patient died within the next 12 months?"

The STP Palliative and End of Life Care programme will build on and improve the use of the Gold Standards Framework (GSF) prognostic indicator (see Fig 1) by improving coding, GSF meetings and end of life care register use and recommending the adoption of the 2018 Gold Standard Framework Quick Practice Guide. This will aid the palliative and end of life care workforce to understand where patients are within their disease trajectory and if this is embedded into the Norfolk and Waveney Palliative Care Model, it will aid co-ordination of care.

Fig 1

Blue All from diagnosis Stable Year plus prognosis	Green Unstable/Advanced disease. Year to Months prognosis	Light Amber Continuing care Weeks to live but stable	Dark Amber Continuing care Weeks to live and deteriorating prognosis. Unstable	Red Final days/ Terminal Care/ Days Prognosis	Navy After Death/ Bereavement Care
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3.1.3 What is defined as last days of life?

[NICE Guidance 31](#) covers the clinical care of adults 18 years and over who are dying during the last 2 to 3 days of life. It is at this time consideration will be given to all patients individualised needs and ensuring that the individual plan of care is implemented to support the provision of dignity, comfort, sensitive communication and palliative care in the patient's last days of life.

4. National Policies

The biggest change in palliative and end of life care came in 2008⁷ when the first end of life strategy was developed. This was followed by 2012-13 changes when the decision based on the outcome of the Neuberger report recommended to abolish the established Liverpool Care Pathway (LCP.) This resulted in the Leadership Alliance for the Care of the Dying (LACDP) published One Chance to Get it Right in June 2014, which set out 5 Priorities of Care for the Dying Person.

1. The possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's wishes, and these are regularly reviewed and decisions revised accordingly
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them

⁷ End of Life Care Strategy 2008, Department of Health

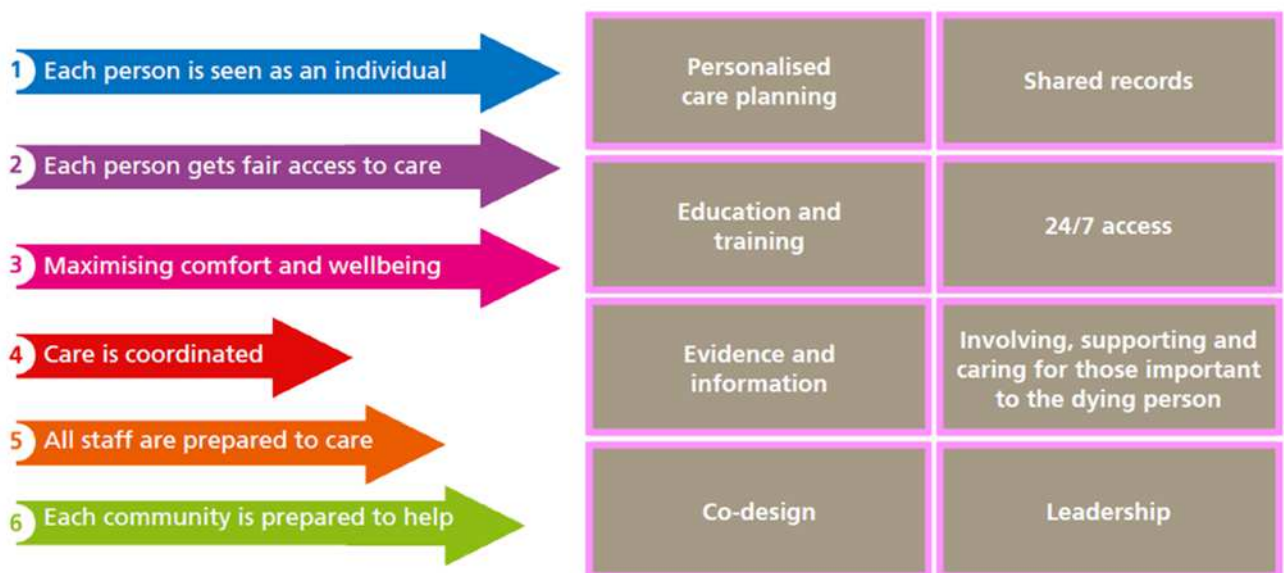
3. The dying person, and those identified as important to them, are involved in decisions about treatment and their care to the extent that the dying person wants
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.

The National Audit of Care at the End of Life (NACEL) was commissioned in October 2017 by the Healthcare improvement partnership (HQIP) on behalf of NHS England and the Welsh Government. The overarching aim of NACEL is to improve the quality of care of people at the end of life in acute, mental health and community hospital. The audit monitors progress against the five priorities of care set out in the One Chance to Get it Right and NICE Quality Standard 144, within the context of NICE Quality Standard 31. NG31 aims to improve end of life care for people in their last days of life by communicating effectively and involving them and the people important to them in decisions and maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

The most current directives guiding both palliative and end of life care is the [Ambitions for Palliative & End of Life Care 'A national framework for local action 2015-2020'](#) and the [NHS Long Term Plan 2019](#).

The 'Ambitions for Palliative Care and End of Life' provides a framework for local action to improve the quality and accessibility of Palliative and End of Life Care. The framework consists of 6 ambitions with eight foundations that need to be in place to support achievement.

Fig. 2. The 6 Ambitions for Palliative & End of Life Care



The **2011 Palliative Care Funding Review** estimated that between 92,000 and 142,500 people each year have an unmet need for palliative care. This number is likely to increase as

the CQC's Report "A Different Ending"⁸ (2016) indicated that people from certain groups in society experience poorer quality care at the end of their lives than others because providers and commissioners do not always understand or fully consider their specific needs.

With early intervention in a person's end of life and reviewing models of care more patients' needs will be met. Constrained resources and increasing demands put all those who use, work in, and lead local organisations under an obligation to create new ways to build more effective systems of care. Currently there are significant shortages (as per the recent Commissioning Guidance for Specialist Palliative Care⁹) therefore we need to put existing resources to more creative and effective use, and if we want to meet guidance, consider extra resource we will need across Norfolk and Waveney. That is why a commitment from local organisations to work together to find new ways of delivering better care has been made a priority for Norfolk and Waveney STP.

The recently published **NHS Long Term Plan** states that *'With patients, families, local authorities and our voluntary sector partners at a local level, including specialist hospices, to ensure we personalise care, to improve end of life care. By rolling out training to help staff identify and support relevant patients, we will introduce proactive and personalised care planning for everyone identified as being in their last year of life. A consequence of better quality care will be a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen'*. This is in line with this Strategy's ambitions.

5. Norfolk and Waveney Picture

5.1.1 Current population and Population Projections

Norfolk and Waveney's population of 1.01 million in 2017 is forecast to increase by about 10% by 2041, to approximately 1.13 million. (Norfolk Insight¹⁰)

Norfolk and Waveney generally have an older population over 65 years (24%) than England (18%) that is projected to increase at a greater rate than the rest of England. By 2041, the population is expected to increase by about 114,000 with most of the increase in the 65 and over age bands.

It is known that the older a person is, the more likely it is that they will have long term conditions.

5.1.2 Life Expectancy

Across Norfolk and Waveney, the life expectancy and the healthy life expectancy has increased over the years. Currently the average life expectancy is approximately 80.2 years for men and 83.6 years for women.

⁸ A Different Ending 2016

⁹ Commissioning Guidance for Specialist Palliative Care

¹⁰ Norfolk Joint Strategic Needs Assessment, Norfolk Insight, <http://www.norfolkinsight.org.uk/>

The healthy life expectancy is 64.5 years for men and 65.4 years for women; i.e. the average number of years a man or a woman can expect to live in good health is about 65, and the years after that lived in poorer health.

5.1.3 Deaths

The actual number of deaths in Norfolk and Waveney were 11,490 in 2017 (last available validated data), and these are forecast to rise to 14,100 by 2041. The largest increase in death is in the 85+ age group for non-cancer where there is likely to be complex needs due to long-term conditions.

Table 1: Number of deaths in different age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041

Deaths	2017	2025	2030	2041
<65	1411	1230	1142	1064
65-74	1824	1361	1310	1006
75-84	3233	3449	3207	2741
85+	5022	5759	6941	9289
All Ages	11,490	11,800	12,600	14,100

Source: Norfolk County Council Intelligence & Analytics Team

Figure 3: Number of deaths in different age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041

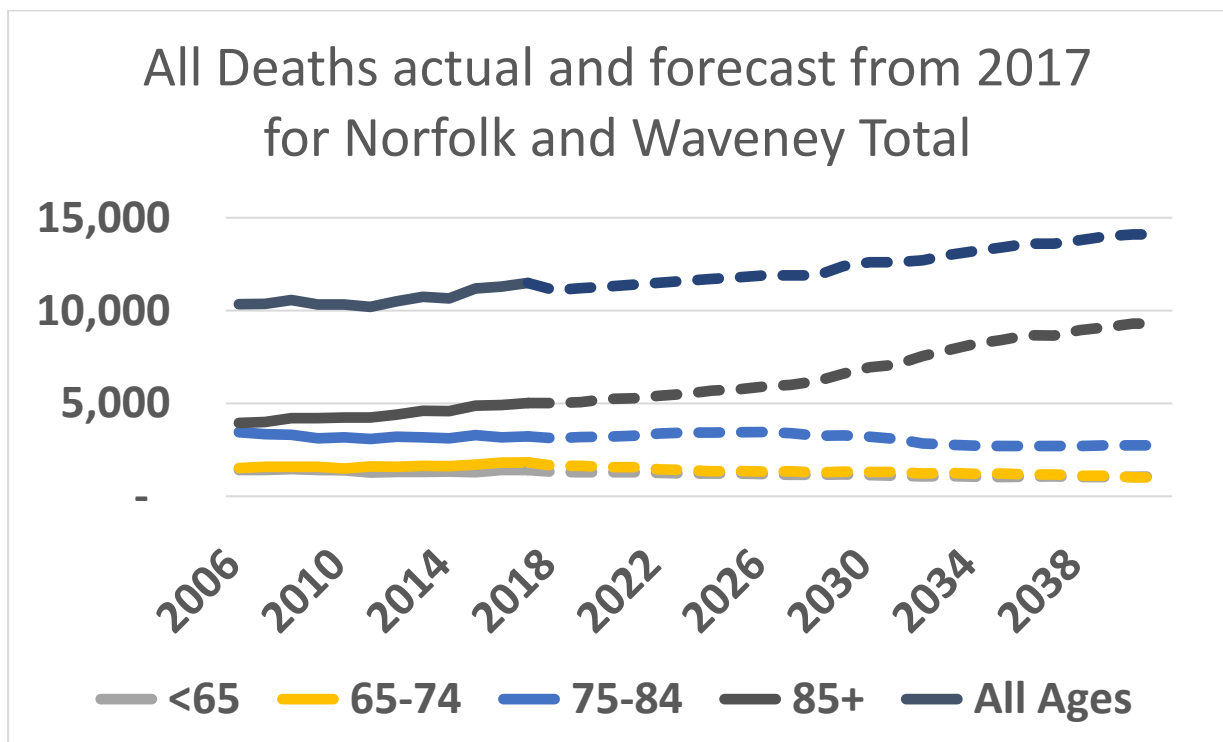


Table 2: Number of deaths in all age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041 – cancers and non-cancers

Deaths	2017	2025	2030	2041
Cancer	3235	3227	3255	3466
Non cancer	8255	8573	9345	10634
All Deaths	11,490	11,800	12,600	14,100

Source: Norfolk County Council Intelligence & Analytics Team

5.1.4 Need for palliative care

The estimated palliative care need is based on: Population-Based Needs Assessment for Palliative Care: A Manual for Cancer Networks. Peter Tebbit. National Council for Hospice and Specialist Palliative Care Services 2004.

The number of people needing palliative care is calculated as all cancer deaths + 67% of all other deaths.

In Norfolk and Waveney, it is expected that palliative care need is going to increase, from an 8766 in 2017 to an estimated 10,590 in 2041.

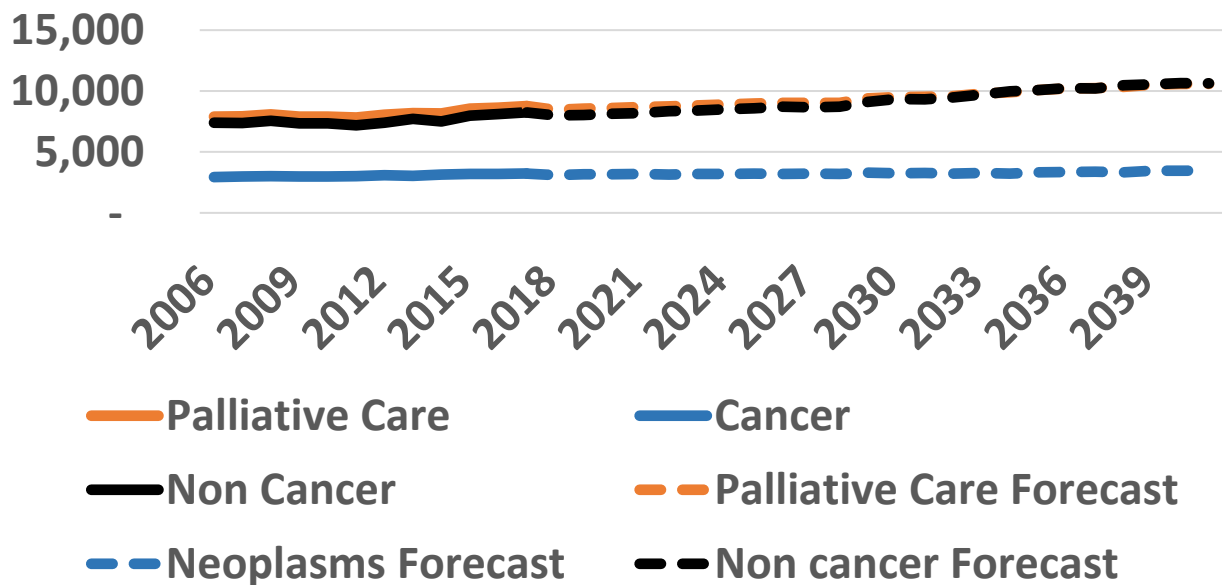
Table 3: Palliative care need in all age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041

Palliative care need	2017	2025	2030	2041
Number of people	8766	8971	9516	10591

Source: Norfolk County Council Intelligence & Analytics Team

Figure 5: Palliative care need in all age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041

All Ages palliative care, cancer and non cancer deaths in Norfolk and Waveney Total



5.1.5 Place of death

The data below shows that compared to England, Norfolk and Waveney have a similar proportion of deaths in hospitals across all age groups but slightly above for deaths in the 65-84 years age group. We are also above the English average for deaths in care homes but significantly below for deaths in hospices (1.8% as compared to 5.7% in England). This could be because we have a large number of care homes where people live and choose to die, but also because we have fewer specialist beds with significantly high delays in transfer of care for palliative patients compared to the national average.

Table 4: Place of Death in 2016 – Persons – % ¹¹

	Lower	Similar	higher
Hospital deaths	England	Norfolk and Waveney	
65-74 years	49.2	51.5	
75-84 years	50.5	51.3	
85 years and over	43.8	43.5	
All ages	46.9	46.9	

¹¹ Fingertips, Public Health England, End of Life Care Profiles, <https://fingertips.phe.org.uk/profile/end-of-life/data>

National VOICES survey 2015 for preferred place of death (PPOD) in hospital	3
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Home deaths	England	Norfolk and Waveney
65-74 years	30.3	33.9
75-84 years	23.8	25.4
85 years and over	16.4	16.3
All ages	23.5	24.6

National VOICES survey 2015 for preferred place of death (PPOD) in home	81
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Care Home deaths	England	Norfolk and Waveney
65-74 years	8.6	9.9
75-84 years	18.7	20.1
85 years and over	36.7	39.2
All ages	21.8	24.7

National VOICES survey 2015 for preferred place of death (PPOD) in care homes	7
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Hospice deaths	England	Norfolk and Waveney
65-74 years	10.0	2.9
75-84 years	5.6	1.8
85 years and over	2.08	0.30
All ages	5.7	1.8

National VOICES survey 2015 for preferred place of death (PPOD) in hospice	8
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Deaths in Other Places	England	Norfolk and Waveney
65-74 years	2.0	1.8
75-84	1.36	1.38
85 years and over	1.01	0.77
All ages	2.2	2.05

National VOICES survey 2015 for preferred place of death (PPOD) in other places	1
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According to 2016 data, about half of all deaths (49.6%) in Norfolk and Waveney occur in “usual place of residence”, the England average was 45.8%. However, according to National Survey of Bereaved People (VOICES): England, 2015, a majority of people are not dying in their preferred place of death.

5.2 Norfolk and Waveney Palliative and End of Life Care Provision

Health and social care services for people living in the Norfolk and Waveney STP area are provided by a large number of organisations and these organisations are generally represented on the Collaborative Group.

Across the STP area there are:

- 5 Clinical Commissioning Groups (CCGs) - West Norfolk CCG, Great Yarmouth and Waveney CCG and a Central group (North Norfolk, Norwich and South Norfolk CCGs).
- 108 primary care general practices
- 3 acute trusts - the James Paget University Hospital (JPUH) based in Great Yarmouth, the Norfolk and Norwich University Hospital Foundation Trust (NNHUFT) located on the outskirts of Norwich and the Queen Elizabeth Hospital (QEH) in King's Lynn
- People living in West and South Norfolk may be geographically closer to and may choose to receive acute care services from hospitals outside of their STP area, including Addenbrookes Hospital in Cambridge, Papworth Hospital in Papworth Everard, Cambridgeshire and the West Suffolk Hospital in Bury St Edmunds.
- Community services are primarily provided by 2 community trusts - the Norfolk Community Health Care & Trust (NCHC) and the East Coastal Community Trust (ECCH)
- The Norfolk and Suffolk Foundation Trust (NSFT) is the largest provider of Mental Health (MH) services across the STP area
- 111 and Out of Hours GP (OOH) is provided by IC24
- Emergency response by the East of England Ambulance Service NHS Trust (EEAST)
- Norfolk County Council and Suffolk County Council fund a proportion of social care which is means tested. Many people fund their own care. Social care across Norfolk & Waveney footprint is provided by around 570 registered independent care providers. This consists of 400 residential care homes, 67 of which provide nursing care, 150 domiciliary care agencies, 22 supported living schemes, 24 Extra Care services and 1 Shared Lives scheme. There is also an increasing number of people who receive Direct Payments and use that to employ their own staff as Personal Assistants. This is a small but growing part of the care workforce that is almost completely overlooked.
- Hospice provision is currently provided by 4 organisations – Priscilla Bacon Centre, St Nicholas Hospice Care, St Elizabeth Hospice and The Norfolk Hospice (Tapping House)
- In addition, there are a number of voluntary sector and charitable trusts, who are key to supporting health and social care services
- Unpaid Carers & Volunteers

- Future Provision: Priscilla Bacon Norfolk Hospice Care Ltd and East Coast Hospice

To develop a model across Norfolk and Waveney the Collaborative Group is recommending that collaboratively the system works towards one model therefore one service description whilst recognising local diversity, historical patterns of working, workforce capacity, gaps within the system and different providers of services.

People who face a progressive life limiting illness require different levels of health and social care at different points in their illness progression. As well as receiving treatment specific to their underlying condition they are likely to have palliative and end of life care needs. Many patients are well cared for by their generalist teams but occasionally will need enhanced and/or specialist care. At times they may require expert assessment, advice and support from professionals who are specialists in palliative care. These professionals should work as part of multidisciplinary teams providing the service direct to patients and those important to them as well as supporting other care teams.

However, only 6% of us nationally will ever benefit from a hospice death, so good joined-up community provision of end of life care is crucial if more people are to benefit from services. That is why we will develop the provision currently being offered across Norfolk and Waveney and progress collaborative methods to delivering a new integrated model of palliative and end of life care.

5.3 Case for Change

5.3.1 National reasons for change

Reports and investigations (VOICES, CQC, and National Audit etc.) too frequently identify poor palliative and end of life care and we need to do better. With a rapidly ageing society and changing patterns of illness many more people will live with long term conditions and each year more of us will die and many more of us will face the challenges of dying, death and bereavement.

For all of us providing palliative and end of life care, this means we face an increase need in provision to manage the rise in demand and the rise in complex issues but do not have the increase in funds and resources. Under the traditional model, this demand is likely to have the biggest impact on hospitals, particularly in a person's last days of life.

Emergency admissions to hospital for people in the last year of life are a substantial and often avoidable burden on the NHS. According to **Marie Curie, Emergency admissions Data briefing** in 2016, there were over 1.6 million emergency admissions for people in the last year of their life, amounting to around 11 million days in hospital, costing the NHS £2.5 billion. While emergency admissions for people in the last year of life are sometimes necessary, they can often be avoided entirely if adequate care in the community is provided. New data shows that in England, the average number of admissions per person is nearly twice as high as in Scotland or Wales, suggesting that A&E services in England are under particularly acute pressure.

Significant action must be taken to improve community services, to meet the needs of our ageing population. Otherwise, by 2041, Marie Curie analysis suggests the cost to the NHS of emergency admissions for people in the last year of life is likely to be as much as double, and up to 8,000 extra hospital beds could be needed. The current cost of emergency admissions

in last year of life is £2,462,265,5061, plus the beds occupied by emergency admission in last year of life of 30,387.

A community-based palliative nursing service, has been found to have lower costs from first contact until death, compared with other models. Cost-savings were achieved through reduced hospital admissions with a potential cost-saving, including community costs, of around £500 per person relative to usual end of life care, evidencing that services closer to home with specialist skills is the most financially sustainable model. This can then be extended by close collaboration with social care providers, voluntary, community and social enterprise (VCSE) sector and families.

The above depicts the avoidable financial burden of specific areas, and does not capture the cost of care that impacts elsewhere i.e. psychological bereavement.

Nor does it capture the quality of care, which again, we know needs much improvement. For example, 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital (VOICES 2015).

People with palliative and end of life care needs are not always able to die in their preferred place of care. All three Acute Trusts within Norfolk and Waveney regularly care for palliative and end of life patients via emergency and out of hours in the last week/days of life, many of these admissions could have been avoided with better community based care. An emergency/out of hour's admission to an acute care setting often does not reflect patient choice and may also lead to poor patient/carer experience and poor quality of care. Studies show that people in their last year of life experience an average of 2.28 hospital admissions and spend 30.1 bed days in hospital. This represents a significant economic burden. As much as 10–12 per cent of total health costs in England are spent on care for people approaching the end of life.

5.3.2 Local reasons for change

As per NHS England's CCG Improvement and Assessment Framework, Norfolk and Waveney Percentage of patients with 3 or more Emergency Admissions 90 days prior, on the whole, is deemed the best quartile in England. In addition, we have higher than average people dying at home which is predominantly the preferred place of death.

However, within Norfolk and Waveney we have a higher than average ageing population, with more people living longer but with more complex illnesses. We have a skilled workforce which is ageing and recruitment is a big challenge.

At present, there are three NHS trusts in Special Measures, an NHS budget deficit and pressure on council budgets.

For Norfolk and Waveney Palliative and End of Life Care Services specifically, a recent gap analysis using the recommended **North West Coast Strategic Clinical network and Cheshire End of Life Partnerships, self-assessment tool**, structured around the Six Ambitions for Palliative & End of Life Care has identified a number of gaps in provision (please see appendix A for further information), but areas that needed our greatest development are (more details can be found in priorities):

- Improvement in consistency across Norfolk and Waveney for palliative care provision e.g. inequity in 24/7 professional advice line, carers advice line, Hospice at Home, dedicated enhanced palliative care beds, psychological and bereavement services
- Improvement in capacity to provide palliative and end of life care

- improved co-ordinated approach to information/documentation, workforce (including social care and VCSE), education, systems, audit research, performance and complaints and patient engagement
- improved compliance in regards to helping people take control such as ability to access personal health budgets for palliative or end of life care
- Further development of partnership working and pathway development with other workstreams i.e. Care Homes
- Further development of partnership working with Social Care, VCSE
- Improvement in engagement with community partnerships such as different faiths and culture groups
- Inconsistent approach to person centred outcome measures.

The results of the gap analysis carried out by the Collaborative Group is also reflected within the findings of Providers recent CQC reports, where need for improvement is highlighted in a number of similar areas (themes will be properly collated and reviewed for Norfolk and Waveney wide improvement). Results from providers National Audit of Care and End of Life also highlights needs for improvement - we need to communicate better with dying families, there is too much variation of care across the system, and general coordination and continuity need to be improved (again, themes will be properly collated and reviewed for Norfolk and Waveney wide improvement).

Generally, there is a lack of benchmarking and consultation with patients across the system to understand if we're delivering care in the best way and if people have identified their preferred place of death (PPOD). This is also true of benchmarking competencies and general evidence base of success – there is a lot of good activity but this needs to be captured and coordinated (and this strategy aims to start to do this).

In addition, due to the lack of population needs assessment we do not understand our focus areas e.g. BAME communities, dementia patients, learning disabilities, non-cancer conditions, older people and other hard to reach groups.

On top of this, one of our biggest issues (both financially and in terms of quality) is a shortage of Specialist Palliative Care in-patient (hospice beds). According to Commissioning Guidance 2012, in Norfolk and Waveney between 77-97 Specialist Palliative Care (SPC) beds are recommended for the population whilst only 30 are available for the system. Therefore there is a 62% shortfall of palliative care beds and when these figures were set they were set for cancer patients only. It is expected that all palliative and end of life patients with all conditions will be treated within these beds. However, it is important to remember that nationally only around 6% of people benefit from Specialist Palliative Care, so we must coordinate care between NHS, social care workforce, VCSE and family support networks if we wish to tackle demand.

Across the system there is also a shortfall of 7.4 specialist palliative care consultants (recent CQC inspections based on Commissioning Guidance for Specialist Palliative Care 2012). This means patients with uncontrolled symptoms are often admitted inappropriately to the acute hospital setting (thus not being supported to die in their preferred place of care) or being cared for at home, in nursing homes or in community hospitals with high levels of unmet need.

Specialist, enhanced and generalist palliative and end of life care services have been predominantly used by cancer patients. The new STP integrated model of care shall ensure that there is equity of access to these services across the footprint. This means that more service users affected by long term conditions (e.g. end stage respiratory, cardiac, renal, neurological conditions, frailty and dementia) will access palliative and EOL care.

To develop any Specialist Palliative and End of Life Care service, the following specialists must be included in leading the service:

- Consultants in Palliative Medicine – who may provide clinical leadership across a number of locality teams.
- Nurses specialising in palliative care – within community settings, hospital palliative care teams or nurse-led outpatient clinics, it is expected that the nurse would be at the level of Clinical Nurse Specialist (CNS) in palliative care or consultant nurse in palliative care.

Table 3 below shows the current resource in provision across Norfolk and Waveney. (The recent CQC inspections have focused on the paucity of provision across the patch and this is an area that requires urgent attention.

Table 3 - identifies the palliative resources required for a population of 250,000 plus a 250 bed hospital. Locally we have documented the population for each area plus the number of hospital beds which equates to the National Palliative Guidance recommendation. The current wte have been added in and any gaps equate to the deficit.

WEST NORFOLK	Population of 250,000 ¹	250 Bed Hospital ¹	Population of 163,000 (West CCG) and 500 Bed Hospital (QEH, NCHC and The Norfolk Hospice (Tapping House))		
			National Palliative Care guidance Recommended WTE	Current	Deficit
Consultants in Palliative Medicine	2	1	3.3	0.7	2.6
Additional supporting doctors	2		1.3	0.3	1.0
SPC Nurses	5	1	5.3	5.25 (including 0.2 education)	-
Inpatient SPC beds (TNTH)	20 - 25		12 – 15	8	7

CENTRAL NORFOLK	Population of 250,000 ¹	Population of 592,600 (Norwich, North and South CCGs)			
		Recommended	Current	Deficit	
Consultants in Palliative Medicine	2	5.6	2.1	3.5	
Additional supporting doctors	2	5.6	3.9	1.7	
Community SPC Nurses	5	11.9	11.5	0.4	
Inpatient SPC beds	20 - 25	47 - 59	16	31 – 43	
NNUH	250 Bed Hospital ¹	1000 Bed Hospital (NNUH)			
		Recommended	Current	Deficit	
Consultants in Palliative Medicine	1	4	4.3		
Hospital SPC Nurses	1	4	6.4 + one nurse for Education	-	
GREAT YARMOUTH AND WAVENEY	Population of 250,000 ¹	250 Bed Hospital ¹	Population of 230,000 (Great Yarmouth and Waveney CCG) and 459 Bed Hospital (ECCH, St Elizabeth Hospice and JPUH)		
			Recommended	Current	Deficit
Consultants in Palliative Medicine	2	1	3.7	2	1.7
Additional supporting doctors	2		1.8	0.6 tbc (due to the recent procurement process)	-
SPC Nurses	5	1	6.4	9 (due to the recent procurement process)	-

Inpatient SPC beds	20 - 25		18 - 23	6 (Beccles Hospital)	17
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Table 3 highlights the deficit in inpatient specialist palliative care beds across the system. However, due to the recent procurement within Great Yarmouth and Waveney, patients will have access to specialist beds within Beccles Hospital and St Elizabeth Hospice. Some South Norfolk patients will have access to St Nicholas' Hospice. Some North Norfolk patients and West Norfolk patients have access to the Norfolk Hospice, Tapping House. Further work needs to be undertaken to describe and map bed provision across the patch and this will also include future plans in regards to the East Coast Hospice and the Priscilla Bacon Hospice. Priscilla Bacon Norfolk Hospice Care Ltd are looking to have 24 beds in the future.

Nationally, Norfolk and Waveney is in a unique position as the specialist palliative care unit within Central Norfolk is 100% funded by the NHS and the other hospices receive differing NHS contributions. This both leads to challenges and opportunities. The current Priscilla Bacon Centre will move to a new provision adjacent to the NNUH site within the next 3 to 5 years. The new site has capacity for 24 specialist palliative care beds therefore the system (including voluntary sector partners) will work together to best optimise this opportunity. These beds will also be known as hospice beds.

In addition, with members of the Collaborative Group willing to develop and deliver key competencies across the system (please see appendix C for Norfolk and Waveney Palliative Education Framework) we may be able to look at our workforce differently such as nurse led beds and support future CQC inspections.

6. Vision, Model and Delivery

The vision included in the Ambitions for Palliative & End of Life Care document states that:

"Death and dying are inevitable. Palliative and end of life care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us."

People living with a palliative prognosis and those approaching the end of their lives, deserve and have a right to appropriate care, compassionately delivered by the health and social care workforce and informal carers. The primary aim is to ensure that all people with palliative and end of life care needs in Norfolk and Waveney can say:

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

6.1 Vision

For the Collaborative Group, our local vision is:

Through a new integrated palliative and end of life model of care we will ensure people and their carers/family receive care and support that is coordinated and which meets their individual needs - irrespective of care provider, diagnosis, circumstance or place of residence in Norfolk and Waveney from diagnosis through to bereavement.

6.2 Model

Our vision and model are underpinned by the six ambitions. The following diagrams (Fig 4 & %) illustrate what, how, and where our integrated model will deliver.

The diagram below (Fig 4) illustrates the way services might provide different types of care as decided by local negotiation. Within Norfolk and Waveney specialist palliative care providers will be involved in providing and leading the provision of some aspects of palliative and end of life care and locally it will be determined which services are enhanced and which are led by specialist and generalist.

Fig 4

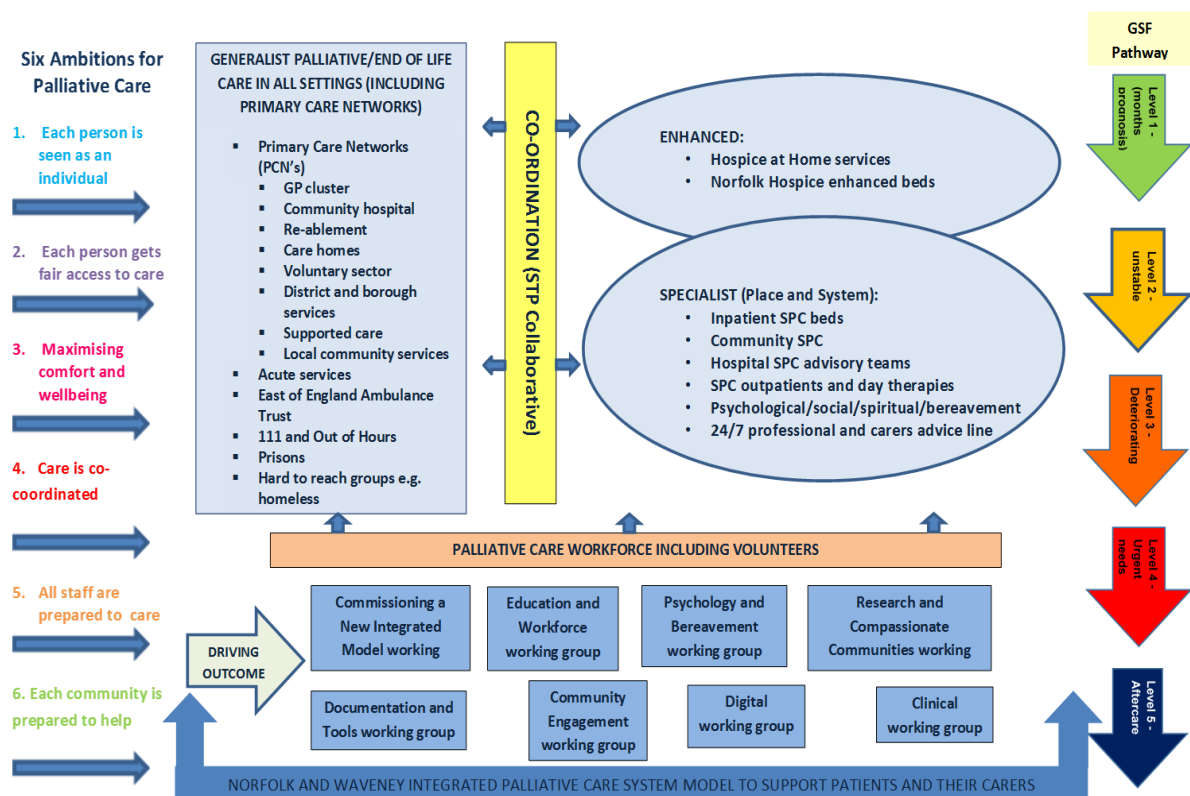
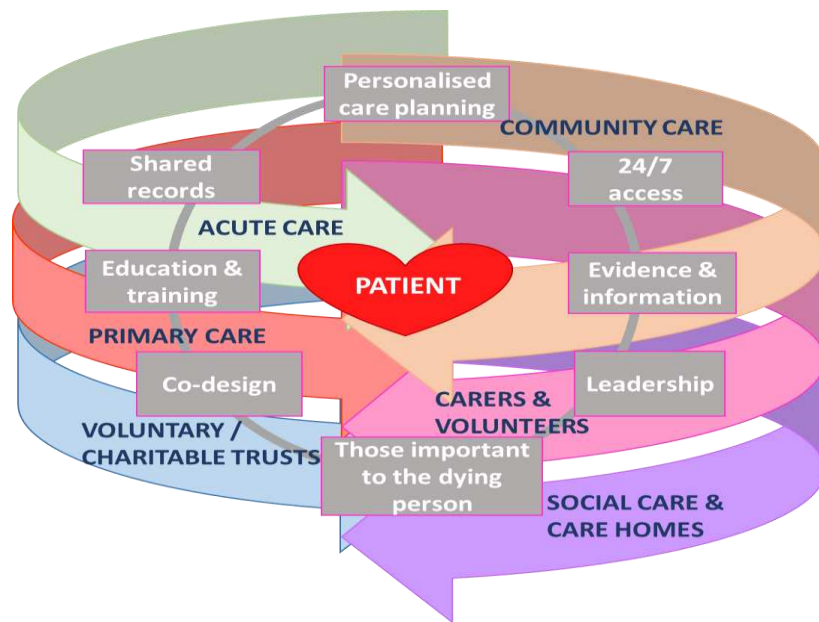


Fig 5. The structure we will use to deliver the new model



To develop a model across Norfolk and Waveney it is essential that collaboratively the system works towards one model therefore one service specification whilst recognising local diversity, historical patterns of working, workforce capacity, gaps within the system and different providers of services. The model should mirror the following:

- The Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, December 2012
- NHS England Specialist Level Palliative Care Information for Commissioners April 2016
- Ambitions for Palliative and End of Life Care
- One Chance to Get It Right 2015 and the 16 Statements related to NICE Quality Standards.
- And align where possible to the core principles of the Daffodil Standards.

People who face progressive life limiting illness require different levels of health and social care at different points in their disease trajectory, including frailty and decline (organ failure, cancer and dementia). As well as receiving treatment specific to their underlying condition they are likely to have palliative and end of life care needs. Many patients are well cared for by their generalist teams but occasionally will need enhanced and/or specialist care. At times they may require expert assessment, advice and support from professionals who are specialists in palliative care. These professionals should work as part of multidisciplinary teams providing the service direct to patients and those important to them as well as supporting other care teams.

Access to these services needs to be equitable across Norfolk and Waveney and core principles and a consistent approach will be essential. For example, all patients should have access to specialist, enhanced and generalist palliative and end of life care, and the staff caring for them will have the skills and knowledge to provide high quality palliative care.

Underpinning the future model new roles should be developed collaboratively as well as the opportunity for further integration amongst services e.g. new volunteer roles within the community to support Hospice at Home services and rotational posts throughout services, as well as better support at the generalist level through collaboration with VSCE and social care.

As the STP evolves into an Integrated Care System ((ICS) - advanced local partnership taking shared responsibility to improve the health and care system for their local population) the Collaborative Group will ensure it works to the agreed key principles and objectives to design the palliative and end of life integrated model.

To translate the overarching system strategies for Norfolk and Waveney into a local solution, five Local Delivery Groups (LDGs) have been established across Norfolk and Waveney. These LDGs will help interpret the local needs of our communities and support delivery via Primary Care Networks (PCNs) - networks of GP practices and staff from community, mental health and social care working together in a more integrated way to specifically address the needs of the local population (typically serving natural communities of around 30,000 to 50,000)

The Collaborative Group, will work with the ICS and LDG's to develop the palliative and end of life care model to ensure service delivery is designed and implemented at all three levels (ICS, LDG and PCN). For PCNs this could include physiotherapists, occupational therapists, social care and spiritual/psychological services with experience and skills in palliative and end of life care with access to VCSE, working as an integrated team to deliver the new model of palliative and end of life care.

6.3 Objectives and Priorities

The Norfolk and Waveney Palliative and End of Life Care Priorities are based on the evidence outlined within 4.3 'Case for Change' which predominantly centres on our recent gap analysis.

Objectives for delivering an integrated model:	
Consistency across Norfolk and Waveney for palliative care provision e.g. inequity in 24/7 professional advice line, carers advice line, Hospice at Home, Social care Services, dedicated enhanced palliative care beds, psychological and bereavement services	
Capacity to provide palliative and end of life care e.g. develop the workforce across health and social care, Supporting VCSE development, training and developments and assess the need for more specialist beds	
Co-ordinated approach to information/documentation, workforce (including volunteers), education, systems, audit research, performance and complaints and patient engagement	
Compliance in regards to helping people take control such as ability to access personal health budgets for palliative or end of life care	
Partnership working and pathway development with other work streams i.e. Care Homes	
Partnership working with health and social care sector and VCSE	
Engagement with community partnerships such as different faiths and culture groups	
Consistent approach to person centred outcome measures e.g. population needs assessment, monitoring and benchmarking	
Financial balance through a decrease in hospital admissions e.g. emergency admissions compared to preferred place of death.	

	National Ambition	Priorities
1.	Each person is seen as an individual	<ul style="list-style-type: none"> • Development of Advance Care Plans with people inc. ReSPECT and IPOC • Explore Personal Budgets with CHC Fast Track to support people taking control of their care
2.	Each person gets fair access to care	<ul style="list-style-type: none"> • Supporting Primary Care to improve GSF and advance care planning through the development of a Primary care offer • Ensuring that Home Based palliative care services are sufficient to meet patient need through Hospice at Home • Develop the current education plan further to include communication skills planning • Collaborative working with Primary Care Networks, Public Health and the University of East Anglia Research Centre to ensure we are continuously ensuring population health needs are met by developing a baseline, recording and regularly evaluating data. • Utilise the newly formed Community Engagement working group to ensure we regularly seek the views, and experiences of people nearing the end of life; including those close to them. • Development of an integrated new model for palliative & End of Life Care, including better recording and monitoring of information.
3.	Maximising comfort and well being	<ul style="list-style-type: none"> • Improved and appropriate pain management through 24/7 anticipatory prescribing • Improved anticipatory care through 24/7 advice line • Improved psychological care • Improved care after death.
4.	Care is coordinated	<ul style="list-style-type: none"> • Develop EPaCCS system wide to ensure records can be shared and updated

		<ul style="list-style-type: none"> • Collaborative working with Primary Care Networks, Public Health and the University of East Anglia Research to ensure we are continuously ensuring population health needs are met by developing a baseline, recording data and regularly evaluating.
5.	All staff are prepared to care	<ul style="list-style-type: none"> • Co-ordinate and develop a framework of professional competencies for training staff • Support and education for Care Homes/Residential and domiciliary staff. • Develop websites, apps etc.
6.	Each community is prepared to help	<ul style="list-style-type: none"> • Work with the voluntary sector to further develop a plan to recruit, train and support volunteers for palliative and end of life care • Increasing system awareness and appropriate utilisation of commissioned palliative care services.

Priorities for 2019/20 can be found in appendix B within each working groups Terms of Reference.

6.4 Delivery and Governance

The Collaborative Group is chaired by an independent subject matter expert within palliative care. It is a multi-disciplinary group with representatives from all three acute hospitals, community providers, CCGs, Public Health, Social Care, VCSE and service users.

Palliative and End of Life Care is one of the priorities of the STP Primary and Community Care work stream. The Primary and Community Care work stream is one of six strategic work streams within the STP infrastructure.

All strategic work streams are accountable to the STP Work Stream Delivery Group which is overseen by the STP Executive.

The Director of Commissioning at Norwich CCG is the commissioning Senior Responsible Officer (SRO) for the Palliative and End of Life Care work programme and attends the STP Primary and Community Care Programme Board to represent the Collaborative Group.

The Collaborative Group reports to the STP Primary and Community Care Board and is led by a Programme Team that includes a Senior Responsible Officer (SRO), an independent clinical advisor, a Clinical Lead, a Programme Manager and a Project Co-ordinator. This Programme Team supports and coordinates work of the Collaborative Group and will be responsible for submitting a monthly highlight report to the Joint Commissioning Committee, Primary and Community Care Programme Board and the STP Delivery Board chaired by the STP Programme Director. Therefore, there is STP Executive oversight and ownership which builds further upon the strong governance, capacity and capability into the system.

The strategic commissioning approach is that there will be one strategic commissioning approach for Palliative and End of Life Care services across Norfolk and Waveney, with a single commissioning group, one leadership team and a single strategic approach for the whole population. The Lead Commissioner is currently Norwich CCG.

Successful delivery of the plan will be supported by robust leadership and strong governance processes. The timeframe for the Palliative and End of Life transformation is divided into five phases:

- Phase 1 - Set Up of Palliative and End of Life Care Transformation Programme – October 2018 – May 2019
- Phase 2 - Design and align commissioning for a new integrated service model across Norfolk and Waveney – April 2019 – March 2020
- Phase 3 – Implementation of the new service model – April 2020 to March 2021
- Phase 4 – Initial evaluation of the new service model – April 2021 to March 2022
- Phase 5 – Further development in line with local and national development - April 2022 – March 2024.

Each phase will include a review of membership, governance, reporting, assurance and co-opting relevant stakeholders as appropriate.

6.4.1 Palliative and End of Life Care working-groups

It is essential that for this strategy and the outlined model to be effective and efficient, all providers including the voluntary and third sector work together in a collaborative manner as defined in the NHS Five Year Forward and the NHS long Term Plan.

Given the number of priorities highlighted, it is vital that there is a collaborative approach across the system that is not solely one organisations responsibility, which is why the working groups made up of experts across the system are key to the delivery of this strategy. Priorities for 2019/20 can be found in appendix B within each working groups Terms of Reference.

There will be 7 working groups, each with their own terms of reference, work plans, subject matter leads and membership made up of the Collaborative Group and wider who will be responsible for reporting progress to the Collaborative Group. These groups which will feed into the Collaborative Group to ensure the programme is coordinated effectively. The working groups are:

1. **Commissioning a New Integrated Model working group** - Develop the new service model (including specialist enhanced and generalist services consistent with the key stages of the nationally defined palliative and end of life pathway). This includes service design with Primary Care Networks, developing multidisciplinary team approaches and planning for specialist beds.
2. **Documentation and tools working group** – Review, design and implement documents and tools that support the whole system in delivering effective and compassionate care. Priorities will include reviewing and refreshing Yellow Folders/Thinking Ahead document to support more advance care planning, rollout of ReSPECT and streamlining current forms and policies e.g. Verification of Death.
3. **Education and workforce working group** - Review and refresh the STP approach to training across all settings including the implementation of the 10 core competencies for palliative and end of life care and developing an education strategy and communications plan to support the workforce.
4. **Clinical working group** - Coordinate themes from CQC visits across provider settings and to improve pain relief and prescribing in community care settings. Symptom

Management Guidelines widely distributed, to support more anticipatory prescribing at EOL

5. **Community Engagement and Compassionate Communities working group** – Looking to service users, carers and the public to promote death and dying (i.e. Dying Matters) within their community and galvanise local community support through the support of a system wide approach to palliative care volunteers. This group will support any redesign of services to ensure patients and carers needs are addressed.
6. **Digital working group** – Develop new and innovative ways of working to coordinate care through digital utilisation.
7. **Psychology and bereavement working group** – Scope the unmet need for psychological and bereavement services across Norfolk and Waveney to understand potential service development.

The Service Providers (three acutes and two community trusts) will use their own in-house Steering Groups to monitor and deliver on palliative and EOL care, and will also share the lead on time limited Task & Finish Groups which will feed back into the above mentioned working groups as and when required.

In addition, following CQC visits for palliative and end of life care; Trusts, Care, residential, nursing homes and other care providers will have their own internal action plans. It is essential that the Collaborative Group reviews these actions plans for thematic learning and to develop a system approach to delivering change and streamlining work.

The Collaborative Group will monitor delivery of the programmes of work, manage risks and mitigation, ensure robust financial planning including expenditure/ savings, review and endorse business cases prior to approval at the appropriate group (e.g. Joint Commissioning and Contracting Executive (JCCE) or STP Executive). The Collaborative Group will also ensure patient choice is central to the transformation program. Where necessary the Collaborative Group will escalate issues to the STP Primary Care & Community Programme Board for resolution.

6.4.2 Interface and dependencies with other STP work streams and forums

The Collaborative Group and its work stream needs to be cognisant of the work of other work streams and seek to collaborate to ensure harmonisation where possible to achieve a new model of palliative and end of life care. For example, patients within care homes, those with dementia and those with complex long term conditions will need to have bespoke support to have a good death.

This also includes enabling STP work streams (Workforce, IT, Estates, Finance and Communications & Engagement) to ensure effective utilisation of resources and skills.

Although this strategy excludes children and young adults, there needs to be a robust transition action plan for Norfolk and Waveney that is developed by a cross work stream Task and Finish group.

6.4.3 Summary of method for achievement

How we plan to achieve our vision & objectives:
1. Leadership and coordination via the STP Palliative and End of Life care Collaborative Group
2. Commissioners, health and social care providers and voluntary groups working collaboratively to develop and deliver an integrated model for Palliative & End of Life Care through aligning services across Norfolk and Waveney
3. Collaborative working with Primary Care Networks, Public Health and the University of East Anglia Research Centre to ensure we are continuously ensuring population health needs are met.
4. Increasing system awareness and appropriate utilisation of commissioned palliative care services
5. Delivery via the 7 Collaborative working groups.
6. Interface with other STP workstreams e.g. Workforce, Care Homes, Dementia etc.
7. Agree one matrix for monitoring performance

6.5 What does success look like?

We will know we are developing our new integrated model effectively if we can address the key gaps identified within the gap analysis and deliver the work assigned to the working groups and meets the following measures.

Objectives	Measure
Consistency across Norfolk and Waveney for palliative care provision e.g. inequity in 24/7 professional advice line, carers advice line, Hospice at Home, dedicated enhanced palliative care beds, psychological and bereavement services	An integrated model of care working to an aligned specifications under a framework that has shared principles.
Capacity to provide palliative and end of life care e.g. develop the workforce, training and developments and assess the need for more specialist beds	An increase in workforce competencies to ensure there is the knowledge and skills to support patients and with the required amount of beds available by following a Norfolk and Waveney Education Framework across the system.
Co-ordinated approach to information/documentation, workforce (including volunteers), education, systems, audit research, performance and complaints and patient engagement	One core suit of strategic policies, procedures, processes, documentation used across the system.
Compliance in regards to helping people take control such as ability to access personal health budgets (PHB) for palliative or end of life care	Advance care Planning guidance in place to support PPOD and Enhanced CHC Fast Track service/access to PHB
Partnership working and pathway development with other workstreams	Palliative and end of life care is addressed in all key STP workstream i.e. Care Homes, Mental health (Dementia) etc.
Partnership working with Social Care, Charitable Trusts and the Voluntary Sector	Agree and implement a Social Care Charter and Civic Charter
Engagement with community partnerships such as different faiths and culture groups	Build our community voice and raise the profile to have 'the difficult conversation' via the Community Engagement and Compassionate Communities Working Group so that a

	community voice is part of everything we do and views are captured and shared across the system i.e. Providers Friends and Families Test, Comments, Compliments and Complaints, Surveys etc.
Consistent approach to person centred outcome measures	We can clearly demonstrate success and areas that need improvement system-wide i.e. e.g. population needs assessment, monitoring and benchmarking
Contribute to the Norfolk and Waveney Finance plan and the Demand and Capacity plan	decrease in hospital admissions e.g. emergency admissions compared to PPOD

7 Achievements and Next Steps

7.1 Achievements to date

The formation of the Collaborative Group has enabled the system to better identify gaps and needs to develop this strategy and drive future work. The Collaborative Group has already driven some change during the creation of this strategy, some of which is reflected below under the 6 Ambitions for Palliative and End of Life Care:

Each person is seen as an individual:

- Review of the yellow folders that identified education need and pathway development which will be reviewed by the newly formed appropriate working groups (Education and Workforce working group and Documentation and tools working group)
- The gap analysis identified the lack of Individualised Plan of Care for Adults (IPoC) and has led to the NNUH developing one for use by the central and West Norfolk system in-patient services. This document was recognised by NHSI as a document of excellent practice and advised cascading to the whole system. This will be further developed and utilised across the system driven by the Documentation and Tools Working Group
- Due to concerns with the consistency of GSF provision within General practice, NCHC undertook an audit and identified some recommendations for improvement. These recommendations will support the development of the Palliative and End of Life Care Primary Care offer.

Each person gets fair access to care:

- Establishing a pilot Hospice at Home service across Central Norfolk which includes 24/7 specialist palliative care advice line and 24/7 carers advice line
- Close relationship developed with the care home STP workstream to ensure patients in care homes receive equitable care, this has led to a revision in the Care Home Coordinators in terms of the education and support they will offer in care homes.

Maximising comfort and well being

- Community drug chart implemented across Central and West Norfolk

Care is co-ordinated

- Task and Finish group set up to plan and deliver ReSPECT which has membership from all key organisations that are involved with a person's clinical care in a future emergency in which they are unable to make or express choices. This group have also secured funding for posts to coordinate and support implementation ReSPECT across Norfolk and Waveney to ensure consistency across the area.

All staff are prepared to care

- The Collaborative Group have developed a draft education plan to support health and social care professionals in delivering palliative and end of life care within Norfolk and Waveney which includes 10 core competencies staff need to meet
- To support the delivery of the Education Plan, Big C and PBL Support Group have funded an educational post for Norfolk and Waveney.

Each community is prepared to help

- Successful compassionate Community workshop to aid community engagement which has led to the development of the Compassionate Communities Working Group

7.2 Next Steps

To underpin and support the development and implementation of the priorities, and thus developing the new integrated model of palliative and end of life care, some other work areas need to be established. These are:

- Formally establish membership of the working groups to ensure fair representation
- Develop work plans for each working group to deliver this strategy
- Population Health Needs Assessment and Gap Analysis (see below)
- Devise a system wide approach to monitoring performance of the changes made and to capture success/required improvements
- Forging strong relationship with organisations outside the NHS i.e. Norfolk and Waveney End of Life Care Charter (see below).

7.2.1 Population Health Needs Assessment and Gap Analysis

The Collaborative Group will assess requirements for carrying out an in-depth population health needs assessment (which is a large piece of work). This work will be driven by the STP wide work on population health needs for the development of the Integrated Care System and Primary Care Networks, which include agreeing a digital tool across Norfolk and Waveney to capture data across the system – for palliative and end of life care EPaCCS will be a great tool in driving this.

The Collaborative Group will support the STP by working with Public Health and relevant partners, including the wider population, people nearing the end of life and their carers to produce a local population-based needs assessment for end of life care. The needs assessment will help the system to design the future palliative and end of life care model and further focus the outcomes of the gap analysis.

7.2.2 Research, Analysis and Evaluation

The Collaborative Group, working with UEA Health and Social Care Partners (UEAHSCP), will monitor the progress of the implementation of the new service model including the tracking onward referrals to other services, transitions in care between inpatient and

community settings, and the functional interface between professional care and voluntary sectors.

In addition, to maintain the quality of its services we will regularly seek the views and experiences of people nearing the end of life and their carers or advocates. Representatives of the Collaborative Group will visit the national pilot sites to learn about good models of care, and use this knowledge to develop options for the development of a future model which will meet the needs of palliative and end of life patients and their carers.

In order to measure the effectiveness of current and future services, audit and research will need to be integral to the Palliative and End of Life Care Programme. One key audit to learn and act upon is the National Audit of Care at the End of Life.

UEAHSCP (in conjunction with the Collaborative Group) has been successful in being awarded funding for two projects. The first project funded by EAHSN focuses on perceived risks and benefits in expanding community involvement in palliative and end of life care. The second project funded by NNUH aims to identify ways of Connecting support pathways to facilitate improved transfers of care to community settings for people approaching the end of life [CONTINUITY].

7.2.3 Monitoring performance

The STP Palliative and End of Life Care Programme is built on a strong safety culture. Palliative and end of life care is a key service and has representation on the three acute hospital and community trust boards. These palliative and end of life care leaders will promote a culture of learning and continuous improvement to maximise quality and outcomes from their services through robust monitoring, ensuring action is taken where required. Data on the quality and patient outcomes will be routinely collated and shared between the three acute units in order to monitor and drive service improvement within Norfolk and Waveney.

Alongside this, the Collaborative Group via the Commissioning a New Integrated Model working group, will develop a palliative and end of life care dashboard which will be used to drive and monitor improvements in care across providers to develop one performance pack of quality/KPIs aligned to the national Ambitions Strategy. For example, we will promote a culture of openness and honesty between professionals and the family, which should be supported by a system of rapid resolution and redress, encouraging learning and ensuring that families quickly receive the help they need. It is envisaged that all end of life complaints across the system should also be reviewed for learning and understanding how system re-design can improve patients and carers experiences.

The Collaborative Group will strengthen governance processes by ensuring that if a serious incident occurs, robust governance processes are in place so that the services can truly understand what went wrong and how the palliative and end of life care services can improve as a consequence. For example, external oversight when a serious incident has occurred will be provided by the Clinical working group (through multi-professional peer review) and CCG Quality Leads, allowing for a robust investigation and the sharing of learning across the organisations. This will also include multi-professional peer review. The process will follow a similar framework to the CQC with palliative and end of life care teams from across the STP assessing the palliative and end of life care services. We will work with our service users and carers to ensure concerns are heard and acted upon. We will ensure that care is personalised around the needs of each patient and their family, with greater continuity of care. Learning from Mortality Reviews will feed into this work.

In addition, The Royal College of General Practitioners and Marie Curie UK have produced 8 core standards (Daffodil Standards) for advanced serious illness and end of life care. The Daffodil Standards offer a structure for general practices. The Collaborative Group will review these standards in conjunction with work programmes already set and ensure priorities are set.

7.2.4 Forging strong relationship with organisations outside the NHS - Norfolk and Waveney End of Life Care Charter

To ensure that any work undertaken also correlates with NHS England's Three End of Life Programmes of Care:

- Enhanced and Physical/Mental Wellbeing
- Transforming Experience of End of Life in the Community and Hospitals
- Commissioning Quality Services that are accessible when needed

The Collaborative Group has prioritised developing a Norfolk and Waveney Dying Well Community Charter. This will set out to outline a visible commitment by individuals, communities and organisations to work together to support the communities we all live in, the people with a life limiting illness, their carers, families and all those who are important to them.

The Charter is a nationally led idea, but the ideas and commitments within it need to be ones that many local organisations will recognise as important and valid for our local community.

A partnership group has been established to understand how we could best create a Norfolk and Waveney Charter as there is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Importantly, that care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility.

8. Appendices

8.1 Appendix A – Gap Analysis

Gap	Ambitions Building Blocks	Where are the current gaps for your locality
Ambition 1: Each person is seen as an individual		
1	The locality have a communication skills training strategy that allows incremental development whilst also responding to the role specific challenges of a diverse workforce	Need to develop a standardised approach and a means of quality monitoring. Will be developed as part of the Education working group
2	The locality can evidence the number of people accessing communication skills training at various levels	Need to develop a standardised approach and a means of quality monitoring which links with the training strategy. A general training audit is to commence shortly
3	The locality is utilising validated tools (e.g. IPOS) to measure patient outcomes against an individual's personally defined goals	will be developed as part of documentation working group
4	The locality is supporting people to take control and to tailor their end of life care through the use of personal budgets	Discuss with CHC and social care as PHB and PB are due to become one
Ambition 2: Each person gets fair access to care		
5	The locality fully understands the current reach of palliative and end of life care services across different diseases, social and ethnic groups and are using this information to plan future services	Need to develop strategy and agree KPIs/metrics with providers to ensure that minority groups can/are able to access services. Link to PH & UEA work
6	The locality has representatives of the population e.g. different faith & cultural groups, as well as those supporting the young and old, feeding into locality specific palliative and end of life care strategy	PH and UEA research have been asked to assist with a population needs assessment to address this
7	The locality routinely collect and report on Palliative and End of Life Care activity to inform ongoing quality improvement work	as part of a new integrated spec, we will request better data is collected across all providers so that a system dashboard can be created
8	The locality have a local population based needs assessment for end of life care	PH and UEA research have been asked to assist with a population needs assessment to address this
9	The locality can demonstrate how end of life care services have been influenced by local population based needs assessments	Could seek co-production approach

10	The locality regularly seek the views, and experiences of people nearing the end of life to inform judgements about the quality and accessibility of its services	to be reviewed as part of the Patient-led Working Group
11	The locality regularly seek the views and experiences of those close to the dying person (including the bereaved) to inform judgements about the quality and accessibility of services	Could seek co-production approach. Patient-led Working Group
12	The locality has a process for independently analysing person centred outcome measures (e.g. IPOS) in order to hold providers to account and ensure fair access to care	Need to develop

Ambition 3: Maximising comfort and wellbeing

13	The locality has robust audit plans in place to monitor the achievement of the 5 priorities for care of the dying person	KPIs need to be developed to capture this across system
14	The locality have 24 hour access to specialist symptom control advice and support for those nearing end of life	business case for Central and West in development for anticipatory prescribing
15	The locality has a 7 day service for Specialist Palliative Care assessments	5 day service in GYW and west
16	Specialist Palliative Care advice is available 24/7 across the locality	5 day service in GYW and west

Ambition 4: Care is coordinated

17	The locality has a dedicated EPaCCS project/steering group with representation from all care settings	Further work needed to agree common approach across N&W
18	EPaCCS information is being shared with the following services:	
18.1	Ambulance Service	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.2	Out of Hours Service	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.3	NHS 111	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.4	Specialist Palliative Care Teams	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey

18.5	Community Teams e.g. District Nurses, Matrons,	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.6	Hospitals	SystmOne Reader available in some hospital departments
18.7	Care Homes	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.8	Hospice	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey
18.9	Social Care	Review data sharing agreements. Need to explore how patient data can be made available across all partners involved in the patient care journey. ICCs offer some information sharing abilities but this is patchy dependent on Practice view to data sharing
19	The locality can evidence the proportion of people dying with an EPaCCS record across both malignant and non-malignant disease groups	digital working group
20	EPaCCS is routinely used to in all Palliative Care Multi-Disciplinary Meetings (MDT)e.g. Gold Standards Framework meetings, to further support the coordination of care	digital working group
21	As part of their EPaCCS system the locality are able to share electronically the personalised care plans of people nearing the end of life e.g. Advance Care Plan	digital working group
22	The locality has mechanisms in place for the person approaching end of life to review and update their wishes and preferences within their electronic record	digital working group
23	The locality have accessible information available for families, carers and individual's on the respective roles and responsibilities of local end of life services, and of education providers	part of education and documentation work group
24	End of Life Care is a core component of new models of care being proposed by the locality under the NHS Forward View	incorporated within strategy which will be presented to LDGs and STP
25	Local end of life strategy is inclusive of approaches to the following groups:	
25.1	Children and young adults	PH and UEA research have been asked to assist with a population needs assessment to address this as part of strategy

25.2	Those of older age and those with frailty	PH and UEA research have been asked to assist with a population needs assessment to address this as part of strategy
25.3	Those with Dementia	PH and UEA research have been asked to assist with a population needs assessment to address this as part of strategy
25.4	Those with Learning Disabilities	PH and UEA research have been asked to assist with a population needs assessment to address this as part of strategy
Ambition 5: All staff are prepared to care		
26	To support those delivering good palliative and end of life care make safe use of new technology to build relationships with those who are approaching death.	digital working group
27	The workforce have access to information pertaining to the diverse approaches to death, dying and bereavement across different communities, to ensure equality of end of life care delivery	Ensuring ACP is imbedded at primary care level and implementation of EPaCCS will support this
Ambition 6: Each community is prepared to help		
28	Practical support, information and training in end of life care is available to local families, neighbours and community organisations	Need to develop an ABCD approach to family and community development
29	The locality recruit and train volunteers to specifically support people approaching the end of life, their families and communities	Some training possibly being delivered through Carers Matter Norfolk. Need to agree an ABCD approach to family and community development

8.2 Appendix B – Working groups terms of reference

Palliative and End of Life (PEoL) – Psychological and Bereavement Working Group

Terms of Reference

1. Aim

1.1. The purpose of the Psychological & Bereavement Working Group is to encourage joint working across health, social care, education and the non-statutory sector, in order to develop a local vision and a plan which will appropriately support patients and their families who are accessing Palliative, End of Life and Bereavement Care.

2. Objectives

The Psychological & Bereavement Working Group are committed to:

- 2.1. working together in order to gather evidence with regards to good practice across psychological and bereavement care for patients and families.
- 2.2. learning from local and National resources to understand the need, as well as to support the development of quality services.
- 2.3. involving individuals, their families, carers and other loved ones, together with wider communities in understanding what is important.
- 2.4. mapping the current scope and quality of service provision including any gaps.
- 2.5. developing and ratifying a co-ordinated, system wide approach to psychological and bereavement care.
- 2.6. ensuring that the local workforce have the appropriate training and education but also the psychological safety, support and resilience needed to work with patients and families facing life crisis.

3. Membership

Lead – Tracey Dryhurst
TBC

4. Remit and Responsibilities 2019/20

- 4.1. The Psychological and Bereavement Working Group has no delegated decision-making powers from CCGs or providers but will work to influence, within their organisation appropriate change.
- 4.2. The remit/work package of the Psychological and Bereavement Working Group is to:
 - Gather evidence in relation to good practice from local and national resources such as Voices, Learning from Deaths, audits, research, CQC.

- Working with key partners such as NSFT and Children's Services, identify the demand for psychological and bereavement care and scope the current local service provision including any gaps.
- Understand local variation and equity.
- Identify and utilise published information for quality assurance.
- Identify current patterns and processes, e.g.: where and how are services provided, how do systems link and what is the experience of care along the pathway.
- Explore the way in which local providers ensure the psychological safety and resilience of their workforce.
- Identify the training and education needs of the workforce to feed into the Education and Workforce Working Group.

4.3. The Psychological & Bereavement Working Group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Working Group will have administrative support supplied by NCHC and commissioning support.

5. Meetings of Working Group

5.1. Meeting arrangements:

- Due to the need to prioritise time to clinic, the psychological and bereavement working group will predominantly work virtually but will meet bi-annually to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

6.1. The Psychological and Bereavement working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved:

Palliative and End of Life (PEoL) – Clinical Working Group

Terms of Reference

1. Aim

- 1.1. The purpose of the Clinical Working Group is to encourage joint working and whole system change, to discuss clinical and pathway issues, provide support and direction to projects discussed and generally ensure Palliative and End of Life Care is clinically led.

2. Objectives

The Clinical Working Group are committed to:

- 2.1. Working together on a single footprint to limit undue variation in care.
- 2.2. Ensuring patients receive the right drugs/equipment/device/care, from the right person at the right time.
- 2.3. Supporting patients to remain in their preferred place of care (PPoC) or preferred place of death (PPoD).
- 2.4. Supporting Primary Care with the Gold Standard Framework (GSF) through anticipatory care advice, guidance and education.
- 2.5. Coordinating a system-wide approach CQC.
- 2.6. Ensuring clinicians across the provider landscape (including pharmacists) are involved with planning for clinical care across Norfolk and Waveney.
- 2.7. Ensuring other working groups are sighted on work delivered by the Clinical Working Group and that work is coordinated as per objectives of the Collaborative

3. Membership

Lead – Dr Sarah Gough
TBC

4. Remit and Responsibilities 2019/20

- 4.1. The Clinical Working Group has no delegated decision-making powers from CCGs or providers but will work to influence, within their organisation appropriate change.
- 4.2. The remit/work package of the Clinical Working Group is to:
- Conduct a pathway review of anticipatory care and prescribing
 - Plan how to align drug usage for pain management across Norfolk and Waveney (currently there are two drug charts in use)
 - Explore accessible training for Primary Care to ensure appropriate pain management dosage is supplied to patients and to support them with GSF

- Recommend to the Commissioning a New Integrated Model working group what should be included within the Primary Care Offer (to support new model)
- Explore the potential for drug hubs so that patients have access to drugs in rural/isolated areas
- Explore how to improve better working with IC24 to ensure they're accessing the appropriate advice/services to ensure appropriate management of avoidable admissions e.g. pain management
- Conduct a thematic review of all providers/services CQC inspections and propose a system-wide plan to support improvements
- Clinical oversight of the Documentation and Tools Working Group in relation to ReSPECT.

4.3. The Clinical Working Group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Clinical Working Group will have administrative support supplied by NCHC and commissioning support.

5. Meetings of Working Group

5.1. Meeting arrangements:

- Due to the need to prioritise time to clinic, the clinical working group will predominantly work virtually but will meet bi-annually to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risk

6. Reporting arrangements

6.1. The clinical working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

Palliative and End of Life (PEoL) – Digital Working Group

Terms of Reference

1. Aim

- 1.1 The purpose of the Digital working group is to encourage joint working and whole system change to limit variation in information, guidance and tools for patients/carers/family members. They will work to develop a digital solution to coordinate care and ensure digital/online solutions (i.e. websites and apps) are fully explored and developed to ensure patients/cares/families and health workers have accessible information, guidance and tools.

2. Objectives

The Digital working group are committed to:

- 2.1. Working together on a single footprint to limit undue variation in information and guidance.
- 2.2. Working in collaboration with the STP Primary Care Digital workstream.
- 2.3. Ensuring patients receive the right care, from the right person at the right time by ensuring digital solutions are explored and developed to better coordinate care.
- 2.4. Ensure there is consistent information across websites.
- 2.5. Ensuring patients/carers/families are involved with the review, design and implementation of any palliative and end of life care app.
- 2.6. Ensuring other working groups are sighted of work delivered by the Digital working group and that work is coordinated as per objectives of the Collaborative.

3. Membership

Lead – (temporary) Natasha Watts (Norwich CCG)

- Andrew Hayward (South Norfolk CCG GP adviser)
- Heike Schaefer (The Queen Elizabeth Hospital Foundation Trust)
- Anne Heath (STP Head of Digital Strategy and Transformation)

4. Remit and Responsibilities 2019/20

- 4.1. The Digital working group has no delegated decision-making powers from CCG's or providers but will work to influence within their organisation/communities appropriate change.
- 4.2. The remit/work package of the Digital working group is to:

- Coordinate the review of Knowledge Anglia and providers/partners website for consistent palliate and end of life information.
- Scope, design, plan and support delivery for a system wide EPaCCS (Electronic Palliative Care Co-ordination Systems) with the Digital Project Manager

4.3. The Digital working group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Digital working group will have commissioning support supplied by Norwich CCG.

5. Meetings of Working Group

5.1. Meeting arrangements:

- The Digital working group will predominantly work virtually but will meet bi-monthly to ensure effective coordination. However, the frequency may need to increase to ensure the delivery of agreed projects.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

6.1. The Digital working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

Palliative and End of Life (PEoL) – Education and Workforce Working Group

Terms of Reference

1. Aim

1.1. The purpose of the Education and Workforce Working Group is to encourage joint working and whole system change in developing a sustainable workforce and ensuring that workforce has the necessary skills, competencies and support for delivering palliative and end of life care – particularly with the development of new care models.

2. Objectives

The Education and Workforce Working Group are committed to:

- 2.1. Working together on a single footprint to limit undue variation in care.
- 2.2. Ensuring patients receive the right care, at the right time in the right place by ensuring all professionals and volunteers involved with providing palliative and end of life care have the right skills, competencies and support.
- 2.3. Ensuring all palliative and end of life care professionals work to national guidance and frameworks where appropriate.
- 2.4. Using the results of CQC inspections as a way of highlighting educational and support need across the footprint.
- 2.5. Ensuring the appropriate training and education is in place when new system wide documents and tools are developed e.g. ReSPECT
- 2.6. Feed into the Workforce Programme in relation to retaining and attracting workforce through better training and education for those working in palliative and end of life care
- 2.7. Ensuring other working groups are sighted on work delivered by the Education and Workforce Working Group and that work is coordinated as per objectives of the Collaborative.

3. Membership

Lead – Sam Glee (Big C)

- Elizabeth Yaxley, Dementia Services Manager, NNUH. Vice Chair
- Rebecca Cooper, Assistant Director for Palliative Care, NCHC
- Anna Farrar, CNS Specialist Palliative Care, NNUH
- Christine Hawkins, Modern Matron Specialist Palliative Care, NCHC
- Dr Viv Lucas, Locum Consultant Palliative Medicine, NCHC
- Julie Noble, Lead Nurse Specialist Palliative Care, NNUH
- Kate Parkin, Lecturer inter-Professional Practise, UEA
- Jane Shuttler, Patient Representative
- Fiona Springall, Acute Learning Disability Liaison Team Nurse, NNUH
- Mavis Thomson, Project Manager for Palliative Care, NCHC
- Racheal Vivian, Macmillan CNS, Integrated Palliative Care Services
- Sandra Winterburn, Senior Lecturer, Consultation Skills Lead, Norwich Medical School UEA

4. Remit and Responsibilities 2019/20

4.1. The Education and Workforce Working Group has no delegated decision-making powers from CCGs or providers but will work to influence, within their organisation appropriate change.

4.2. The remit/work package of the Education and Workforce Working Group is to:

- review palliative and end of life care education provision across all levels within Norfolk and Waveney (variation, addressing any gaps whilst celebrating success) and update the Norfolk & Waveney Palliative End of Life Education Framework i.e. 'Nut and bolts' course.
- ensure the sustainability of current provision and plan new provision to address perceived need through development of an education and workforce matrix.
- roll out the 10 core competencies for palliative and end of life care as defined in the Norfolk & Waveney Palliative End of Life Education Framework.
- develop a communications skills training plan so that all staff are prepared to have the 'difficult conversation' and align this to the work of the Documentation and Tools working group as part of the review of the Education Framework.
- Following the thematic review of all providers/services CQC inspections by the Clinical working group, propose prioritisation of education and support needs across Norfolk and Waveney

4.3. The Education and Workforce Working Group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Education and Workforce Working Group will have administrative support supplied by Big C.

5. Meetings of Working Group

5.1. Meeting arrangements:

- The Education and Workforce working group will predominantly work virtually but will meet bi-monthly to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

- 6.1.** The Education and Workforce working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

Palliative and End of Life (PEoL) – Community Engagement & Compassionate Communities Working Group

Terms of Reference

1. Aim

1.1 The purpose of the Community Engagement working group is to encourage joint working and whole system change to limit variation in care for patients/carers/family members. They will ensure communities have a voice in service development and that they are aware of the services available to and how they can support their communities in better palliative and end of life care.

2. Objectives

The Community Engagement working group are committed to:

- 2.1. working together on a single footprint to limit undue variation in care.
- 2.2. ensuring patients receive the right care, from the right person at the right time by supporting the collaborative in capturing and delivering patient wishes.
- 2.3. Promoting death and dying to ensure communities are suitably planning for death and are prepared to have the 'difficult conversation'.
- 2.4. galvanising local community support through a system wide approach to palliative care volunteers and ensure there is flexibility across the system to allow volunteers to contribute across providers.
- 2.5. supporting any redesign of services by giving scrutiny to other Collaborative working groups to ensure patients are at the heart of everything we do.
- 2.6. Ensuring other working groups are sighted of work delivered by the community engagement working group and that work is coordinated as per objectives of the Collaborative.

3. Membership

Lead – Jane Shuttler (Community Representative) & Guy Peryer (UEA Research)
Laura McCartney Gray (Norwich CCG)

4. Remit and Responsibilities 2019/20

- 4.1. The community engagement working group has no delegated decision-making powers from CCG's or providers but will work to influence within their communities appropriate change.
- 4.2. The remit/work package of the community engagement working group is to:

- Support a campaign plan for death and dying within Norfolk and Waveney, starting with the Dying Matters event to improve 'death literacy'.
- Use the Dying Matters event as a means to consult and promote death and dying services within Norfolk and Waveney.
- Use feedback from the Dying matters as a catalyst to drive the community engagement plan for 2019/20 and develop a Civic Charter
- Lead development of the patient documentation and tools for advance Care Planning i.e. Yellow Folder
- Collate a list of relevant community groups to work with and coordinate the community engagement agenda via them (as and when appropriate).
- Develop and coordinate volunteers across Norfolk and Waveney through the development of a 'volunteer passport'
- Support development and add scrutiny for any palliative and end of life care service developed within Norfolk and Waveney and led by the Collaborative. Including supporting EQIA's.

4.3. The community engagement working group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The community engagement working group will have administrative support and commissioning support supplied by Norwich CCG.

5. Meetings of Working Group

5.1. Meeting arrangements:

- The community engagement working group will predominantly work virtually but will meet quarterly to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

6.1. The community engagement working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

Palliative and End of Life (PEoL) – Documentation and Tool Working Group**Terms of Reference****1. Aim**

- 1.2 The purpose of the Documentation and Tool working group is to encourage joint working and whole system change to limit variation in information and guidance for patients/carers/family members. They will work to ensure documents and tools within palliative and end of life care suitably support education and the coordination of care and that there is a consistent joined up message for delivering care.

2. Objectives

The Documentation and Tool working group are committed to:

- 2.1. Working together on a single footprint to limit undue variation in information and guidance.
- 2.2. Ensuring patients receive the right care, from the right person at the right time by ensuring documents and tools capture and support coordination of the patient and families wishes.
- 2.3. Review, design and implement documents and tools that support the whole system in delivering effective and compassionate care.
- 2.4. Ensuring patients/carers/families are involved with the review, design and implementation of documents and tool. Particularly in relation to documents and tools capturing and coordinating patient wishes.
- 2.5. Ensuring other working groups are sighted of work delivered by the Documentation and Tool working group and that work is coordinated as per objectives of the Collaborative.

3. Membership

Lead – Mavis Thompson (NCHC)

- Chloe O’Grady (Norwich CCG)

4. Remit and Responsibilities 2019/20

- 4.1. The Documentation and Tool working group has no delegated decision-making powers from CCG’s or providers but will work to influence within their organisation/communities appropriate change.
- 4.2. The remit/work package of the Documentation and Tool working group is to develop a spine/library of documents relating to palliative and end of life care for professionals to use in the delivery of care.
This includes documents for patients/carers/families to use in recording their wishes. Specific documents and tools requiring review, development and implementation are:
 - Yellow Folders/Thinking Ahead document to support more advance care planning
 - rollout of ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

- development and roll out of IPoC (Individual plan of care and support for patients at end-of-life)
- streamlining Verification of Death forms and policies e.g.

4.3. The Documentation and Tool working group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Documentation and Tool working group will have administrative support and commissioning support supplied by Norwich CCG.

5. Meetings of Working Group

5.1. Meeting arrangements:

- The Documentation and Tool working group will predominantly work virtually but will meet bi-monthly to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

6.1. The Documentation and Tool working group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

Palliative and End of Life (PEoL) – Commissioning a New Integrated Model Working Group

Terms of Reference

1. Aim

- 1.1. The purpose of the Commissioning a New Integrated Model Working Group is to ensure joint working and whole system change, to discuss commissioning intentions and pathway issues/review, provide strategic support and direction to the Collaborative Group and ensure the appropriate resources are in place to develop a new service model. This includes service design with Primary Care Networks and planning for specialist beds.

2. Objectives

The Commissioning a New Integrated Model Working Group are committed to:

- 2.1. Working together on a single footprint to limit undue variation in care ensuring commissioning is aligned (where appropriate).
- 2.2. Developing commissioning intentions on one footprint but taking into consideration local variation.
- 2.3. Support pathway design.
- 2.4. Support engagement with other workstreams / areas.

3. Membership

Lead – Karin Bryant (NCCG)
TBC

4. Remit and Responsibilities 2019/20

- 4.1. The Commissioning a New Integrated Model Working Group has no delegated decision-making powers from CCGs or providers but will work to influence, within their organisation appropriate change.
- 4.2. The remit/work package of the Commissioning a New Integrated Model Working Group is to:
 - Conduct pathway reviews to understand where service re-design needs to take place
 - Support the development and delivery of the strategy, ensuring it is 'socialised' with all key providers and partners in each CCG area
 - Review service specifications and agree initial alignment
 - Review contracts to ensure consistency in reporting
 - Develop a palliative and end of life care primary care offer, ensuring sufficient MDT approach takes place.

4.3. The Commissioning a New Integrated Model Working Group will update the Collaborative of progress via bi-monthly highlight reports which will be used to inform the status report submitted to the STP.

4.4. The Commissioning a New Integrated Model Working Group will have administrative support supplied by Norwich CCG.

5. Meetings Working Group

5.1. Meeting arrangements:

- The Commissioning a New Integrated Model Working Group will predominantly work virtually but will meet bi-monthly to ensure effective coordination.

5.2. Decision-making:

- It is expected that decisions will be reached by consensus. Should this not be possible then the matter shall be referred to the Collaborative for resolution

5.3. Meeting notes:

- There will be no minutes recorded for this meeting; instead there will be a work package that will capture actions, decision and risks.

6. Reporting arrangements

6.1. The Commissioning a New Integrated Model Working Group is accountable to the Collaborative, and shall provide a bi-monthly report outlining progress and highlighting issues for escalation.

Date Agreed by:

Date Approved by:

8.3 Appendix C - Norfolk and Waveney Palliative Education
Framework



Norfolk and Waveney Palliative Education Framework 2019 – 2024

Delivering on the 10 Core Competencies

Guidance for:

Doctors, Nurses, Allied Health Care Professionals, Social Care Professionals, Paramedics.

Contents:

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Executive Summary

The Norfolk and Waveney Palliative and EOL Collaborative Education Sub-Group Committee was formed to undertake a discrete piece of work to look at the current needs and training gaps for staff working with people affected by a palliative/EOL diagnosis. The work has resulted in the development of this framework which incorporates outcomes for all staff caring for people with a palliative/EOL condition. The framework and outcomes are intended to be used as part of professional, education and workforce developments to support improvements in the delivery of high quality care by focusing on four tiers of workforce groups:¹²

Level 1: Health & Social Carers / Health Care Support Workers
Agency Staff

Level 2: Registered Practitioners
Registered Nurses
Paramedics

Level 3: Senior Registered Practitioners
Senior Registered Nurses
Medical Staff

Level 4: Working within Palliative Care
Medical staff within Palliative Care

The purpose of this document is to:

- 1) Provide a point of reference to identify the knowledge, skills and competence required for those working in palliative and EOL care in Norfolk and Waveney
- 2) Provide a point of reference for the level of education/competence which links to a particular job title
- 3) Provide a framework for career development, training and education for those working in palliative and EOL care in Norfolk and Waveney
- 4) Provide information relevant to employers and commissioners for the development of workforce and subsequent learning/training opportunities.

This framework has been developed and informed by local stakeholders, and national and local policy, guidelines and best practice evidence. This framework advocates that for improvements to be achieved in palliative and EOL care that a co-ordinated approach to education is required across Norfolk and Waveney. In addition, the levels and themes as set out in this document should be used by all to ensure continuity and enable future audit activities to inform service development and associated business planning. The framework may be mapped to local models of care as roles/functions may differ across organisations and settings. By providing a co-ordinated approach to education county wide there is the potential for economy of scale and standardised best practice providing an environment for staff flexibility across patient pathways and organisations as well as a culture for continued learning including research.

¹² St Christopher's End of Life Competency Framework 2012

Introduction

Palliative and End of Life Care is provided in a variety of settings including patients' homes, primary care settings, care homes, hospital wards, outpatient settings, palliative care settings. This framework aims to enhance the delivery of care in these settings – non-specialist and specialist. This framework is aligned to and has been informed by a number of national and local sources (Appendix A).

Context of Palliative and End of Life Care

Palliative and End of Life Care are national and local priorities.¹³

It is recognised that all staff regardless of practice setting will require to have as a minimum, an understanding of palliative care and end of life care, the basic principles of physiological changes that may occur, key interventions, skills in assessing needs of patients and families and communication skills.

Some staff will require a higher level of palliative/end of life knowledge and skills. Advanced education and training is an investment in the multi-professional team to achieve the vision for best care for those being cared for with a palliative or end of life condition. The number of specialist posts has increased and there is a requirement for post holders to undertake professional developments at postgraduate level as well as to achieve professional revalidation.

The provision for palliative and end of life education and training has not developed in a coordinated way across Norfolk and Waveney. A number of learning opportunities are offered (Appendix B – table of current education provision) but a strategic approach county wide would be beneficial.

This work links with the STP with the aim that 'all staff are prepared to care' resulting in reduced fragmentation of services, appropriate care being delivered and peaceful deaths. The success criteria being 'wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care'.¹⁴

Definitions

General Palliative and End of Life Care: is delivered by the usual health and social care workforce of the patient and family integrating palliative and end of life care interventions in settings not specialised in palliative care.

Specialist Palliative and End of Life Care: is provided by multi-professional teams specialising in the provision of palliative and end of life care to patients and their families usually in palliative care settings or via specialist palliative care services in the community.

¹³ *End of Life Care Education Standards*, NHS England, and local NNUH teaching programmes (see Appendix A and B).

¹⁴ *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*.

Principles Underpinning the Framework

The following principles underpin this framework:

- The priorities, needs and experience of people with a palliative or end of life condition are central to the development of palliative and EOL care services
- Palliative and EOL care patients have many, and often complex, needs throughout their care journey. Multidisciplinary/professional and multiagency practice is required for meeting these needs
- Health and social care workers make an important contribution to meeting the needs of palliative and EOL care patients at all stages of the care continuum and across all age groups
- Health and social care personnel working in palliative and EOL care need to continue to develop their knowledge to inform improvements in outcomes for people with palliative or EOL diagnosis.

Whilst this Framework is intended to stand alone it may be used alongside other documents including those referenced in Appendix A (Benchmarking Documents).

By developing this framework this does not attempt to limit or confine education or workplace providers in their delivery of education and services.

Stages of Care Pathway:

The stages of a palliative/end of life care pathway are identified as:

- a) Told of palliative diagnosis
- b) Living with palliative diagnosis
- c) Last year of life
- d) Last weeks of life – rapid health deterioration
- e) Lasts days of life
- f) Last hours of life
- g) Death
- h) Bereavement

Specific Outcomes:

The framework reflects a thematic approach to knowledge and skills outcome:

- i. Communication
- ii. Context – national local
- iii. Science – Disease, treatment, interventions
- iv. Assessment – symptom control, advanced care plan, legal and ethics
- v. Impact – individual, families, HCP
- vi. Leadership, management and Education
- vii. Evidence Base and Research

Ten core competencies:

1. Principles of palliative/EOL care

Describe and discuss the principles of palliative/EOL practice, including the five priorities of care and how health care is organised through the palliative/EOL journey.

2. Communication

Demonstrate the specific communication skills required to explore patient's and carer's understanding of their situation and care options, taking into account their individual views, concerns, values and preferences.

3. Family and friends

Demonstrate the specific skills to provide advice and support that enable family and friends to manage the impact of diagnosis and treatment with those important to them.

4. Changing needs/deterioration

Demonstrate specific skills and knowledge needed to recognise when a patient's condition deteriorates and respond to their needs appropriately.

5. Symptom control

Recognise the common signs and symptoms that may present along the disease trajectory and demonstrate the ability to document, intervene and/or refer appropriately.

6. Psychological distress

Recognise the signs and symptoms of psychological distress and demonstrate the ability to document, intervene and/or refer appropriately.

7. Advanced Care Planning

Demonstrate the required skills to initiate and conduct a sensitive and timely conversation about a patient's advanced care plan.

8. Cultural and spiritual needs

Recognise and respond respectfully to the diverse cultural and spiritual needs of all individual patients.

9. Learning/working together

Demonstrate the specific skills essential to be a collaborative professional that supports communication and the culture of interdisciplinary thinking.

10. Law and ethics

Discuss the importance of legal, ethical and professional issues in relation to the care and management of people with a palliative/EOL diagnosis.

Palliative and End of Life Care Outcomes:

1.0 Principals of Palliative and End of Life care Describe and discuss the principles of palliative/EOL practice, including the five priorities of care and how health care is organised through the palliative/EOL journey.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
1.1 Recognise that palliative/EOL care and support should be centred on the needs and preferences of people, their families and carers.							
1.2 Identify and describe a range of health conditions for which end of life care may be provided.							
1.3 Critically review statistics for palliative/EOL diagnosis and care within Norfolk and Waveney, understanding both demographics and cultural differences.							

2.0 Communication Demonstrate specific communication skills required to explore patient's and carer's understanding of their situation and care options, taking into account their individual views, concerns, values and preferences.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
2.1 Reflect on their own communication skills and apply the principles of effective communication to each individual encounter.							
2.2 Demonstrate skills in active listening and cue based interviewing to: <ul style="list-style-type: none"> - elicit concerns across physical, psychological, social and spiritual domains - establish extent of awareness about illness and prognosis - manage difficult questions and information giving sensitively - facilitate decision making and promotion of the autonomy of the individual patient - facilitate plans for end of life care and bereavement - sensitively break bad news 							
2.4 Recognise the needs of people who cannot communicate easily, either because English is not their first language or because they have a sensory, physical or mental impairment. Locate specialist help, including interpreting services or communication aids if required.							

3.0 Family and friends Demonstrate the specific skills to provide advice and support that enable family and friends to manage the impact of diagnosis and treatment with those important to them.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
3.1 Work sensitively with families and friends to support them as the person decides upon their preferences and wishes during end of life and advanced care planning.							
3.2 Recognise the social, financial and emotional consequences of a palliative/EOL diagnosis for patients and family members and respond appropriately, making suitable referrals.							
3.3 Confidently direct individuals and family members to appropriate services and provide a plan or prescription of information.							

4.0 Changing needs/deterioration Demonstrate specific skills and knowledge needed to recognise when a patient's condition deteriorates and respond to their needs appropriately.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
4.1 Demonstrate a clear understanding of the aetiology, biology and pathophysiology of a disease leading to palliative/EOL diagnosis.							
4.2 Demonstrate an understanding of the complex and changing needs of patients with palliative/EOL diagnosis and respond to it appropriately.							
4.3 Monitor the patient's health status for common signs and symptoms and respond appropriately.							
4.4 Undertake a comprehensive nursing assessment, being aware of relevant physical factors.							
4.5 Identify when a patient has entered the last months/weeks/hours of life and advise, refer or treat appropriately.							

5.0 Symptom control Recognise the common signs and symptoms that may present along the disease trajectory and demonstrate the ability to document, intervene and/or refer appropriately.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
5.1 Recognise the common signs and symptoms that may present along the disease trajectory and demonstrate the ability to document, intervene and/or refer appropriately.							

6.0 Psychological distress Recognise the signs and symptoms of psychological distress and demonstrate the ability to document, intervene and/or refer appropriately.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
6.1 Undertake a comprehensive assessment of psychological distress and demonstrate the ability to document, intervene and/or refer appropriately.							

7.0 Advanced Care Planning Demonstrate the required skills to initiate and conduct a sensitive and timely conversation about a patient's advanced care plan.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
7.1 Implement and record Advanced Care Planning in a sensitive and coherent way at an appropriate time.							
7.2 Demonstrate an understanding of the importance of the seamless transition between the acute and home care, and from active treatment to palliative/EOL care for patients and their family.							
7.3 Engage in appropriate discharge planning and co-ordinate care between different health and social care providers, including voluntary and statutory care agencies.							
7.4 Work sensitively with families and friends to support them as the person decides upon their preferences and wishes during end of life and advanced care planning.							
7.5 Understand the different care needs of patients from disadvantaged or vulnerable groups.							
7.6 Demonstrate and use the principles of holistic assessment in palliative/EOL practice.							
7.7 Demonstrate knowledge of the wider physical, physiological, social and spiritual factors that can affect people living with a palliative/EOL diagnosis.							

8.0 Cultural and spiritual needs Recognise and respond respectfully to the diverse cultural and spiritual needs of all individual patients.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
8.1 Describe how attitudes, values and beliefs in relation to palliative/EOL diagnosis influence the care patients and their families receive.							
8.2 Demonstrate knowledge of main world faith communities, cultures, beliefs and practices relating to illness, death and dying.							
8.3 Identify cultural and spiritual needs and encourage communication, understanding and respect.							

9.0 Learning/working together Demonstrate the specific skills essential to be a collaborative professional that supports communication and the culture of interdisciplinary thinking.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
9.1 Work sensitively with families and friends to support them as the person decides upon their preferences and wishes during end of life and advanced care planning.							
9.2 Understand how multidisciplinary team communication can benefit patient care and improve transitions between acute and home care.							

10.0 Law and ethics Discuss the importance of legal, ethical and professional issues in relation to the care and management of people with a palliative/EOL diagnosis.	Pre-registration practitioners	Support workers	Registrants providing general palliative/EOL care	Registrants providing specialist palliative/EOL care			
Practice-based skills and competences. The practitioner will be able to:	Under supervision			Registered	Senior	Advanced	Consultant
10.1 Be able to challenge poor unethical or discriminatory practice.							
10.2 Inform the strategic direction and lead changes to palliative/EOL service delivery for a population or community.							
10.3 Contribute to the development and delivery of accredited and non-accredited palliative/EOL education.							
10.4 Demonstrate the ability to plan, allocate, coordinate and evaluate the use of health care resources in an appropriate manner when providing care to patients with palliative/EOL diagnosis and their families.							

Success Measures:

The success of any educational framework implementation is difficult to measure. A short, midterm and longitudinal mixed methodology approach is suggested with the following activities of particular use:

- Observational audits
- Patient/carer questionnaires – Service User Questionnaires
- Learning/Educational Programme in place across county
- Complaints register audit
- Staff questionnaires – confidence and competence
- Review case studies – including notes

Benefits of the Framework:

The *Norfolk and Waveney Palliative and End of Life Education Framework* offers the following benefits for health and social care professionals, education providers and commissioners.

- A county-wide standard for pre-registration palliative and EOL care education to prepare new registrants with a minimum level of specific knowledge and skills to deliver care to people affected by a palliative/EOL diagnosis
- Guidance to support workers, registered practitioners, senior practitioners, advanced and consultant level practitioners, who provide care to palliative/EOL care patients in generalist and specialist settings who aspire to a particular career level in this specialist field. The Framework will also identify learning opportunities/outcomes to meet the role requirements
- A county-wide standard for professional development aligned with appropriate learning/academic preparation for those practising at registered, senior, advance and consultant practitioner levels. The Framework will also help with progression to the next level of a career pathway
- Guidance to education providers, including professional organisations and higher education institutions, to develop and deliver learning opportunities, modules and awards at different academic levels for pre-registration students and post-registration health and social care workers which meet the range of learning/education needs of practitioners providing care to people affected by a palliative/EOL diagnosis in general/non-specialist and palliative/EOL specialist services/roles
- Assistance to service providers to develop role descriptors/job plans and to identify professional development requirements for prospective and current roles in palliative/EOL care
- Information to commissioners of palliative/EOL care services and professional education to create a consistent and sustainable approach to learning and education opportunities for practitioners working in palliative/EOL care across Norfolk and Waveney

- Assist commissioners and services to develop minimum standards and key performance indicators for palliative/EOL-specific knowledge and skills of the health and social care workforce.

How to use the Framework:

The Framework and outcomes are intended to have a stand-alone function; they may also be used in conjunction with other frameworks and with local, national and international guidelines.

For practitioners, the Framework and palliative/EOL-specific education outcomes may be a useful tool for:

- Developing and reviewing job/role descriptions
- Assessing clinical competence for different levels of practitioner
- Developing personal goals
- Performance appraisal.

Practitioners may find it helpful to use this Workplace development record template to:

- Identify your current level of practice and role expectations/requirements within your care context (general or specialist palliative/EOL care)
- Identify and develop your knowledge and skills in aspects of palliative/EOL care to realise the potential of your role
- Plan your career pathway by identifying your learning and development needs
- Identify opportunities to influence the development of palliative/EOL care practice
- Discuss the Framework and palliative/EOL-specific education outcomes at your performance review/appraisal meetings to identify learning, development and support needs, and to review your progress to demonstrate achievement of the palliative/EOL-specific learning outcomes
- Develop your action plan and summarise the evidence which demonstrates your achievement of the palliative/EOL-specific education outcomes relevant to your role or career aspirations. Your evidence may include examples of care plans, short reflective accounts of specific cases, copies of care/clinical pathways, analysis of key local policy documents, mentor/peer observation as well as higher education accredited modules and programmes
- Collate evidence relating to the palliative/EOL-specific learning outcomes for NMC revalidation.

The Way Forward:

Each of the different target groups can use this Framework and outcomes in several ways.

The individual health/social care worker

- As a tool for:
 - Determining your professional development needs
 - Developing a professional development plan within the performance development and review (PDR) framework
 - Evaluating different postgraduate modules and programmes in palliative/EOL care.
- To plan your career path
- Use a range of development opportunities to undertake self-directed learning
- To produce evidence for NMS revalidation.

The educator or manager

- As part of professional development planning processes to establish and negotiate practice progression pathways
- To review orientation and annual progress requirements
- To review your organisation's in-service programmes so as to focus their content on guiding health and social care professionals to meet the outcomes relevant to their scope and level of practice
- To develop curricula and in-service programmes, plus identify learning experiences for generalist areas to improve their capability to meet the outcomes for staff in palliative/EOL care
- To evaluate role/job descriptions and person specifications for the support worker, registered, senior, advance and consultant level roles
- To identify opportunities for ongoing quality improvement and audit
- To develop recruitment and retention, and workforce plans.

Higher education institutions

- To map the outcomes to the current pre-registration health and social care workers curriculum and integrate the learning within the curriculum to support practitioners to help meet these outcomes

- Use the outcomes for post-registration health and social care workers at all levels to review your postgraduate palliative/EOL care modules and programmes and integrate the outcomes to support practitioners to meet these
- Use the outcomes for post-registration health and social care workers at all levels to assess prior learning, modules and programmes that might be suitable for accreditation of prior (experiential) learning in postgraduate courses
- Review and develop methods of assessing learning that reflect the level of practice described in the Framework.

Health service commissioners and policy makers

- To define workforce capabilities in different practice settings and areas, according to population needs
- To allocate resources to support preparation of the workforce to match required service expansion capabilities
- To develop new and innovative service models that support the principles inherent in the Framework, including person-centred care, continuity of care, multidisciplinary practice, and partnerships between nurses and other members of the health care team at various levels of practice.

Palliative/EOL care patients and users of palliative/EOL services

- To develop an understanding of the various roles of health and social care workers in the delivery of palliative/EOL care
- To enhance understanding of what palliative/EOL care patients can expect from engaging with palliative/EOL care services
- To identify opportunities to contribute to information and resources that aim to improve the overall experience for palliative/EOL care patients.

The Framework will also provide significant opportunities for individuals and organisations to evaluate improvements in the professional development of the palliative/EOL care workforce. The following examples of key performance indicators can be used to evaluate the extent to which such improvements have been achieved.

Health service performance indicators

- The proportion of practitioners at all levels who can demonstrate meeting the palliative/EOL-specific outcomes
- The proportion of staff development activities that are clearly linked to the palliative/EOL-specific outcomes

- In generalist settings, where people with a palliative/EOL diagnosis receive care, the proportion of workers who have undertaken professional development programmes that help them meet the Framework palliative/EOL-specific learning outcomes
- The proportion of position descriptions for roles that are mapped to the Framework.

Education provider performance indicators

- The proportion of postgraduate theoretical and clinical practice assessments clearly supporting practitioners to meet the palliative/EOL-specific learning outcomes
- The proportion of pre-registration practitioners who have the opportunity to achieve the palliative/EOL-specific learning outcomes through classroom content or practice assessment.

Reference:

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
Care of dying adults in the last days of life. National Institute for Health and Care Excellence (NICE). March 2017.

Taxonomy of educational objectives: The classification of educational goals. Handbook I.
Bloom, B. S.; Engelhart, M. D.; Furst, E. J.; Hill, W. H.; Krathwohl, D. R. (1956). New York: David McKay Company.

Career and Education Framework for Cancer Nursing, Royal College of Nursing, 2017.

Common Core Principles and competences for social care and health workers working with adults at the end of life. Skills for Health and Skills for Care. 2014.

Core competencies for education in Paediatric Palliative Care: Report of the EAPC Children's Palliative Care Education Taskforce. European Association for Palliative Care. November 2013.

End of Life Care Core Skills Education and Training Framework. Skills for Health and Skills for Care. 2017.

End of Life Care Education Standards, NHS England, 2017.

End of Life Care Education Standards. East Midlands Clinic Network's End of Life Group and LOROS Hospice (Leicestershire). August 2017.

End of life care for adults. National Institute for Health and Care Excellence (NICE). November 2011.

Enriching and improving experience: Palliative and End of Life Care, a framework to support the learning and development needs of the health and social service workforce in Scotland. NHS Education for Scotland and Scottish Social Services Council. May 2017.

St Christopher's End of Life Competence Framework 2012

Appendix A

Benchmarking Documents

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
NHS England. End of Life Care Education Standards	National	West	A framework of education standards for all those involved the in care of a person approaching the end of life Published August 2017 Prepared by East Midlands Strategic Clinic Network's End of Life Group jointly with LOROS Hospice, Leicestershire
NHS England PCPLD Network Delivering high quality end of life care for people who have a learning disability	National		Resource and tips for commissioners, service providers and health and social care staff
Care Quality Commission People with a learning disability - A Different Ending	National		
Daffodil Standards for Advanced Serious illness and End of Life Care	National	Primary Care	RCGP and Marie Curie are developing. Currently at the pilot stage
End of Life Care for People with Dementia	Marie Curie	UEA	Online report
Priorities for Car of the Dying Person	National		Hearth Education England. E-learning for Healthcare
One Change to Get It Right. 2014	National		Government. Leadership Alliance for care of the Dying Person
Delivering high quality end of life care for people who have a learning disability	National		PCPLD Network & NHS England Resources and tips for commissioners, service providers and health and social care staff

Appendix B

Education & Training

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
Sage & Thyme Training		NNUH	Licence done by Ipswich, due to run out.
Care to Learn the Introductory End of Life Care Training Programme	National	West	No longer in publication Provided from National Council for Palliative Care
Care to Learn the Introductory End of Life Care Training Programme Mentor's Guidance Book	National	West	No longer in publication Provided from National Council for Palliative Care
Teaching programme planned: Communication skills month in March covering: EOL conversations family discussions dealing with difficult questions assessment skills	Local	NNUH	Open to health care professionals. 4 four one-hour sessions. Also aim for a series of short videos, currently in the process of negotiation with the trust
EOL sessions for HCA in January: As part of the implementation of the individual EOL care plan in the trust	Local	NNUH	Plan to hold open sessions for doctors to come to have teaching on completing the documentation.
Ward based sessions on advanced care planning for AHP and ward nurses	Local	NNUH	
End of Life Care for People with Dementia	UEA		Online health course Provider UEA
Dementia Care short courses	UEA		Online health course Provider UEA

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
GSF End of Life Care for people with Dementia	National	UEA	Distance learning programme
SCiE End of Life Care in Dementia	National	UEA	Online course
End of Life Care	National	UEA	Alzheimer's Society Online document
Foundations of End of Life Care HSC M48E Level 7	UEA	UEA	
Foundations of End of Life Care HSC M48E Level 6	UEA	UEA	
End of Life Care Competency Framework. Band 6/7 District Nurse/ DN Team Leader. Band 6 Active Case Manager, Band 6/7 Specialist Nurse 9 Non-Macmillan) (St Christopher's Level 3)	National		Central & Eastern Cheshire St Christopher's
End of Life Care Competency Framework. Registered Nurses (St Christopher's Level 2)	National		Central & Eastern Cheshire St Christopher's
End of Life Care Competency Framework. Healthcare Assistant/ Auxiliary/ Assistant Practitioner/ Health Care Support Worker in Community (St Christopher's Level 1)	National		Central & Eastern Cheshire St Christopher's

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
End of Life Care Core Skills Education and Training Framework	National		
A guide to using Palliative Care competence Frameworks (March 2007)	National	NNUH	NHS Education for Scotland Scottish Partnership for Palliative Care
Our Commitment to you for end of life care The Government Response to the Review of Choice in End of Life Care (July 2016)	National	NNUH	Department of Health
Standard Operating Procedure (SOP) for the Implementation of Competency for Stairs and Ambulation	NCHC		
Standard Operating Procedure (SOP) for the Implementation of Competency for Stairs and Ambulation	NCHC		
Standard Operating Procedure (SOP) for the Implementation of Competency for the use of the Motomed in Therapy	NCHC		
Standard Operating Procedure (SOP) for the Implementation of Competency for Electrical Muscle Stimulation Therapy	NCHC		

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
Standard Operating Procedure (SOP) for the Implementation of Competency for Practice of Sit to Stand	NCHC		
Standard Operating Procedure (SOP) for the Implementation of Competency for Sitting Balance and Trunk Control	NCHC	NCHC	
Standard Operating Procedure (SOP) for the Implementation of Competency use of Specialist Neuro-Physiotherapy Standing Frames	NCHC	NCHC	
Standard Operating Procedure (SOP) for the Implementation of Competency for Safe Patient Transfers with Devices	NCHC	NCHC	
Standard Operating Procedure (SOP) for the Implementation of Competency for Safe Patient Transfers without Devices	NCHC	NCHC	
Standard Operating Procedure (SOP) for the Implementation of Competency for The Upper Limb	NCHC	NCHC	
The Macmillan Allied Health Professions Competencies Framework	Macmillan	Norfolk Hospice	
Dementia Training courses for Health & Care	National		Social Care Institute for Excellence
The Gold Standards Framework	National		Website Dementia Care training programme
Core competencies for education in Paediatric Palliative Care: Report of the EAPC Children's Palliative Care Education Taskforce	National		European Association for Palliative Care. November 2013

Title	Status (National/ Local) (accredited)	Where used (if known)	Notes
Enriching and improving experience: Palliative and End of Life Care, a framework to support the learning and development needs of the health and social service workforce in Scotland	National		NHS Education for Scotland and Scottish Social Services Council. May 2017
End of Life Care Education Standards.			East Midlands Clinic Network's End of Life Group and LOROS Hospice (Leicestershire). August 2017

Appendix C

Skills for Health Career Framework (2010) Key Elements of the Career Framework¹⁵

9 – Career Framework Level 9

People working at level 9 require knowledge at the most advanced frontier of the field of work and at the interface between fields, They will have responsibility for the

8 – Career Framework Level 8

People at level 8 of the career framework require highly specialised knowledge, some of which is at the forefront of knowledge in a field of work, which they use as the basis for original thinking and/or research. They are leaders with considerable responsibility, and the ability to research and analyse complex processes. They have responsibility for service improvement or development. They may have considerable clinical and/or manage clinical and/or management responsibilities, be accountable for service delivery or have a leader education or commissioning role. **Indicative or Reference title: Consultant**

7 – Career Framework Level 7

People at level 7 of the career framework have a critical awareness of knowledge issues in the field and at the interface between different fields. They are innovative, and have a responsibility for developing and changing practice and/or services in a complex and unpredictable environment. **Indicative or Reference title: Advanced**

6 – Career Framework Level 6

People at level 6 require a critical understanding of detailed theoretical and practical knowledge, are specialist and/or have management and leadership responsibilities. They demonstrate initiative and are creative in finding solutions to problems. They have some responsibility for team performance and service development and they

5 – Career Framework Level 5

People at level 5 will have a comprehensive, specialised, factual and theoretical knowledge within a field of work and an awareness of the boundaries of that knowledge. They are able to use knowledge to solve problems creatively, making judgements which require analysis and interpretation, and actively contribute to service and self-

¹⁵ *Career and Education Framework for Cancer Nursing*, Royal College of Nursing, 2017.

4 – Career Framework Level 4

People at level 4 require factual and theoretical knowledge in broad contexts within a field of work. Work is guided by standard operating procedures, protocols or systems of work, but the worker makes judgements, plans activities, contributes to service development and demonstrates self-development. They may have responsibility for

3 – Career Framework Level 3

People at level 3 require knowledge of facts, principles, processes and general concepts in a field of work. They may carry out a wider range of duties than the person working at level 2, and will have more responsibility, with guidance and supervision available when needed. They will contribute to service development, and are

2 – Career Framework Level 2

People at level 2 require basic factual knowledge of a field of work. They may carry out clinical, technical, scientific or administrative duties according to established protocols or procedures, or systems of work. **Indicative or Reference title: Support Worker**

1 – Career Framework Level 1

People at level 1 are at entry level, and require basic general knowledge. They undertake a limited number of straightforward tasks under direct supervision. They could be any new starter to work in the health sector, and progress rapidly to Level 2. **Indicative or Reference title: Cadet**

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