



# Norfolk and Waveney STP Palliative and End of Life Care Strategy 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. |
| 01/04/19 | 1.4         | Edits by Public Health   |
| 04/04/19 | 1.5         | Edits by Commissioners across CCGs                                       |
| 16/04/19 | 1.6         | Comments and edits following meeting with working group                  |
| 22/04/19 | 1.7         | Comments and edits by STP Clinical lead                                  |
| 29/04/19 | 1.8         | Comments and edits by Communications and Engagement leads                |
| 02/05/19 | 1.9         | Final comments from members of the Collaborative and SRO                 |

| Governance Route – For Approval              | Date approved | Version number |
|--|---------------|----------------|
| Palliative & EOL Care Collaborative Group    |               |                |
| Joint Strategic Commissioning Committee      |               |                |
| STP Primary & Community Care Programme Board |               |                |
| STP Executive                                |               |                |

## Contents

|   |    |
|---|----|
| 1. Foreword.....  | 5  |
| 2. Executive Summary.....   | 7  |
| 2.1 Strategy on a Page.....   | 7  |
| 2.2 STP Norfolk and Waveney New Integrated Model of Palliative and End of Life Care.... | 8  |
| 3. Introduction.....  | 9  |
| 3.1 Defining Palliative and End of Life Care.....                                       | 9  |
| 3.1.1 What is Palliative Care? .....  | 10 |
| General(ist) Palliative Care.....   | 10 |
| Enhanced Palliative Care (Norfolk and Waveney).....                                     | 10 |
| Specialist Palliative Care.....   | 11 |
| 3.1.2 What is End of Life Care? .....   | 11 |
| 3.1.3 What is defined as last days of life? .....                                       | 12 |
| 4. National Policies.....   | 12 |
| 5. Norfolk and Waveney Picture.....   | 14 |
| 5.1.1 Current population and Population Projections .....                               | 14 |
| 5.1.2 Life Expectancy .....   | 14 |
| 5.1.3 Deaths.....   | 14 |
| 5.1.4 Need for palliative care.....   | 16 |
| 5.1.5 Place of death.....   | 17 |
| 5.2 Norfolk and Waveney Palliative and End of Life Care Provision .....                 | 18 |
| 5.3 Case for Change .....   | 19 |
| 5.3.1 National reasons for change.....  | 19 |
| 5.3.2 Local reasons for change.....   | 20 |
| 6. Vision, Model and Delivery.....  | 24 |
| 6.1 Vision.....   | 25 |
| 6.2 Model.....  | 25 |
| 6.3 Objectives and Priorities.....  | 29 |
| 6.4 Delivery and Governance.....  | 30 |
| 6.4.1 Palliative and End of Life Care working-groups.....                               | 31 |
| 6.4.2 Interface and dependencies with other STP workstreams and forum .....             | 32 |

6.4.3 Summary of method for achievement ..... 33

6.5 What does success look like? ..... 33

7 Achievements and Next Steps ..... 34

7.1 Achievements to date ..... 34

7.2 Next Steps ..... 35

7.2.1 Population Health Needs Assessment and Gap Analysis ..... 36

7.2.2 Research, Analysis and Evaluation ..... 36

7.2.3 Monitoring performance ..... 36

7.2.4 Forging strong relationship with organisations outside the NHS - Norfolk and Waveney End of Life Care Charter..... 37

8. Appendices ..... 38

8.1 Appendix A – Gap Analysis ..... 38

8.2 Appendix B – Working groups terms of reference..... 38

8.3 Appendix C - Norfolk and Waveney Palliative Education..... 38

Framework..... 38

## 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 Care<sup>1</sup> 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. Higginson<sup>2</sup> 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.

---

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

<sup>2</sup> www.thelancet.com Vol 392 September 15, 2018

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

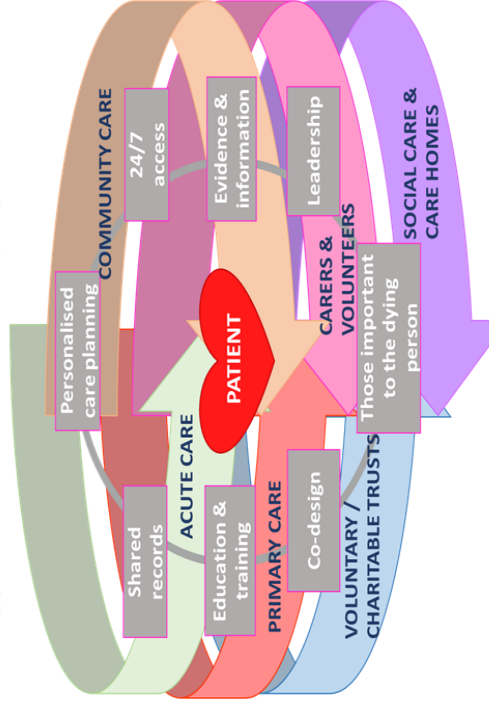
---

<sup>3</sup> 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 patients 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.

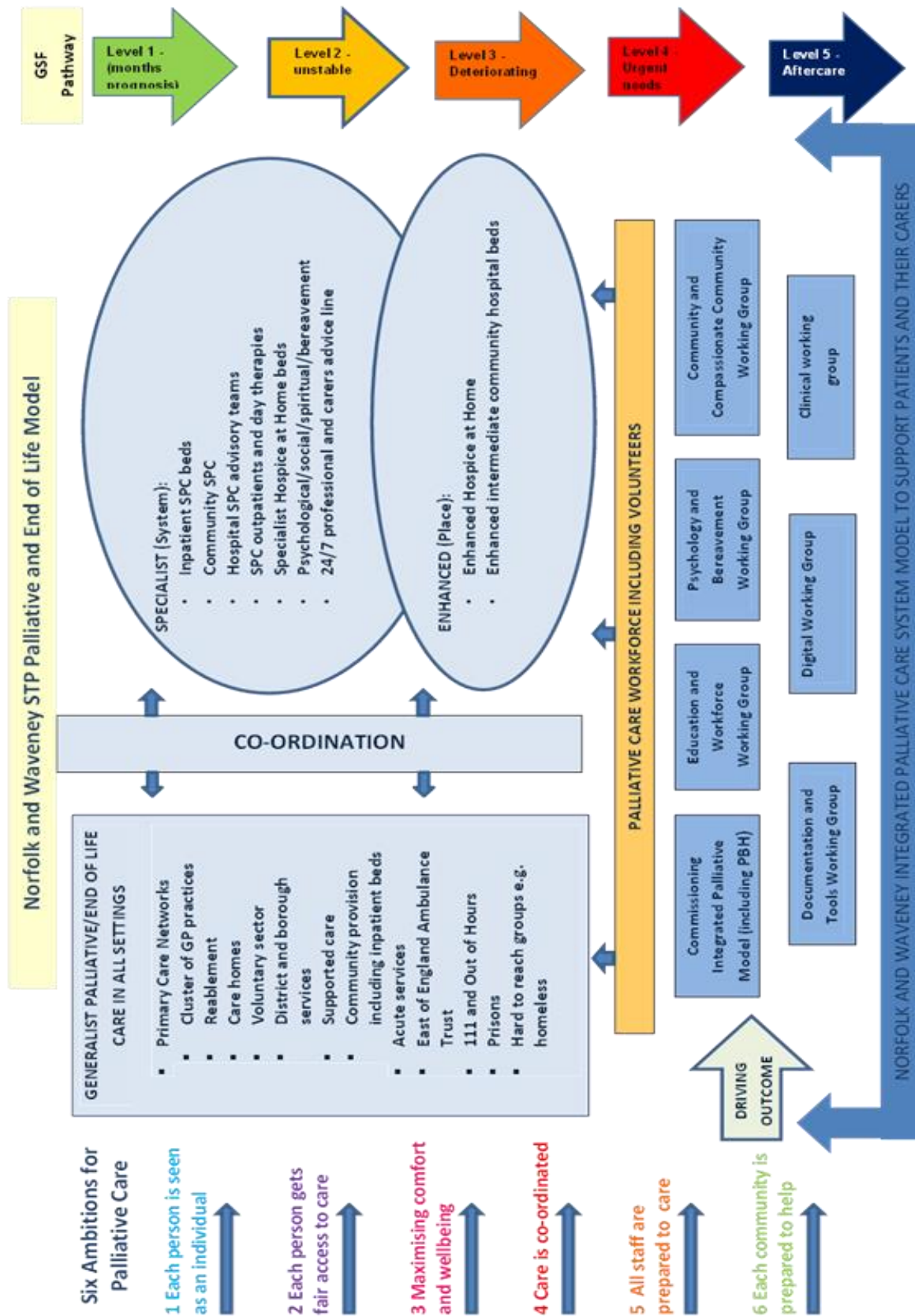
#### **Objectives for delivering an integrated model:**

- Consistency across Norfolk and Waveney for palliative care provision e.g. inequity in 24/7 professional advice line, carers advice line, Hospice at Home, dedicated enhanced palliative care beds, psychological and bereavement services
- 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
- 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 workstreams i.e. Care Homes
- Partnership working with Social Care, Charitable Trusts and the Voluntary Sector
- 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, 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. Care Homes, Dementia etc
- Agree one matrix for monitoring performance

## 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 patients are treated with dignity and respect
- Double the chances of patients 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.

#### 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 patient

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 2012<sup>4</sup>, 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.*

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.

---

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

- 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)<sup>5</sup> 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 Adults<sup>6</sup> 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

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 patients 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

---

<sup>5</sup> The General Medical Council (2010)

<sup>6</sup> Quality Standard 13

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) coding by all GP practice GSF meetings and end of life care registers and will recommend 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  | Green  | Light Amber                                 | Dark Amber  | Red  | Navy                                |
|---|--|---|---|--|-------------------------------------|
| All from diagnosis<br>Stable<br><br>Year plus prognosis | Unstable/Advanced disease.<br>Year to Months prognosis | Continuing care<br>Weeks to live but stable | Continuing care<br>Weeks to live and deteriorating prognosis.<br>Unstable | Final days/<br>Terminal Care/<br>Days<br>Prognosis | After Death/<br>Bereavement<br>Care |

### 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 2008<sup>7</sup> when the first end of life strategy was developed followed by 2012-13 when the decision based on the outcome of the Neuberger report, was to abolish the established Liverpool Care Pathway (LCP.) 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
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.

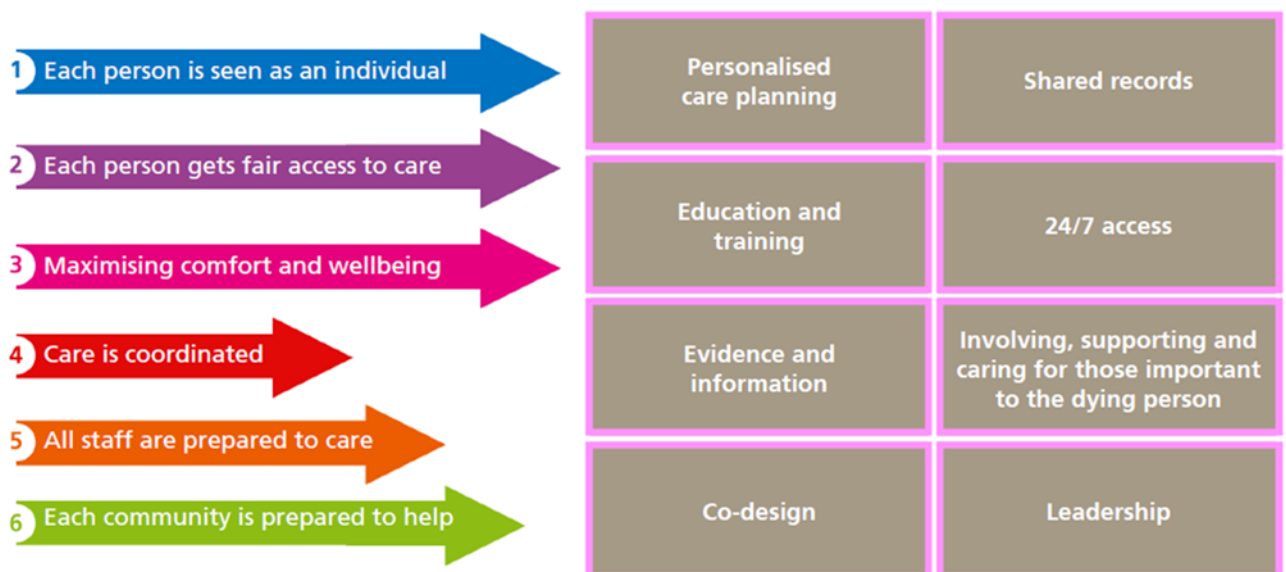
<sup>7</sup> End of Life Care Strategy 2008, Department of Health

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”<sup>8</sup> (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 patient’s disease trajectory and reviewing models of care more patients needs will be met. Constrained resources and increasing demands put all those who

<sup>8</sup> A Different Ending 2016

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 Care<sup>9</sup>) 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 Insight<sup>10</sup>)

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.

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

---

<sup>9</sup> Commissioning Guidance for Specialist Palliative Care

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

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          |
| <b>All Ages</b> | <b>11,490</b> | <b>11,800</b> | <b>12,600</b> | <b>14,100</b> |

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

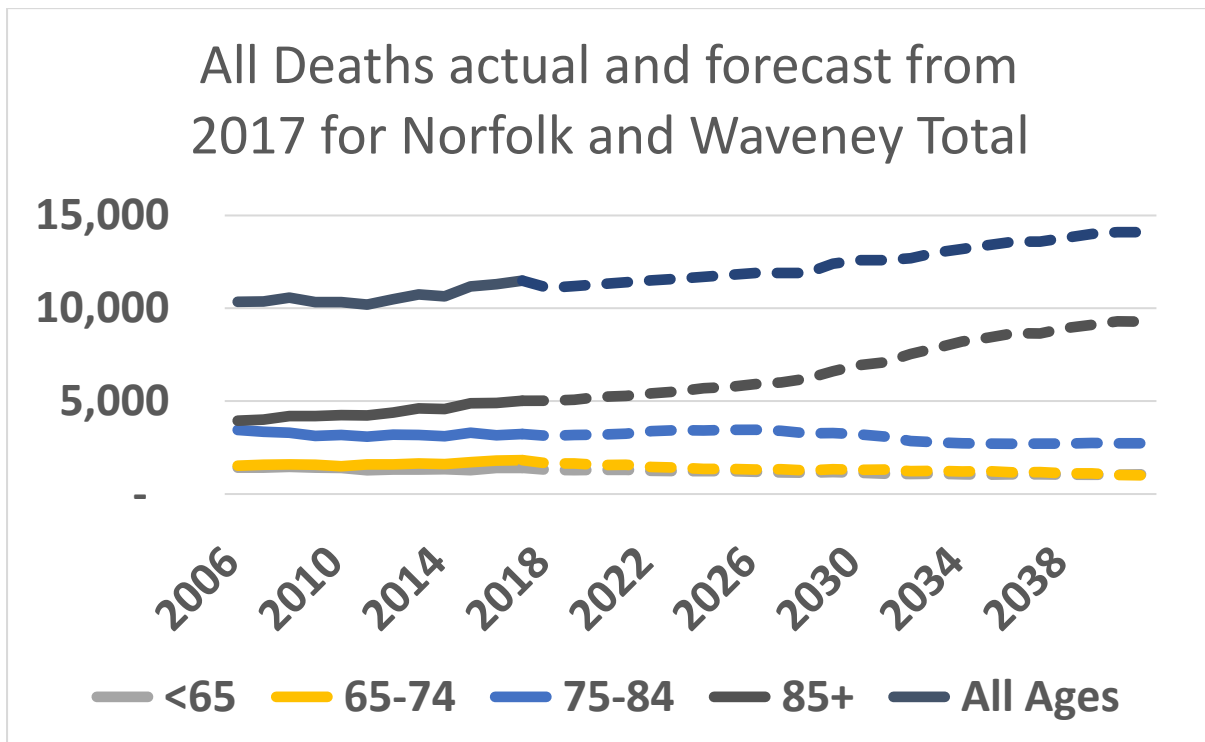


Table 2: Number of deaths in all age groups in Norfolk and Waveney – 2017 (actual) and forecasts to 2041 – cancers and non-cancers

| 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.

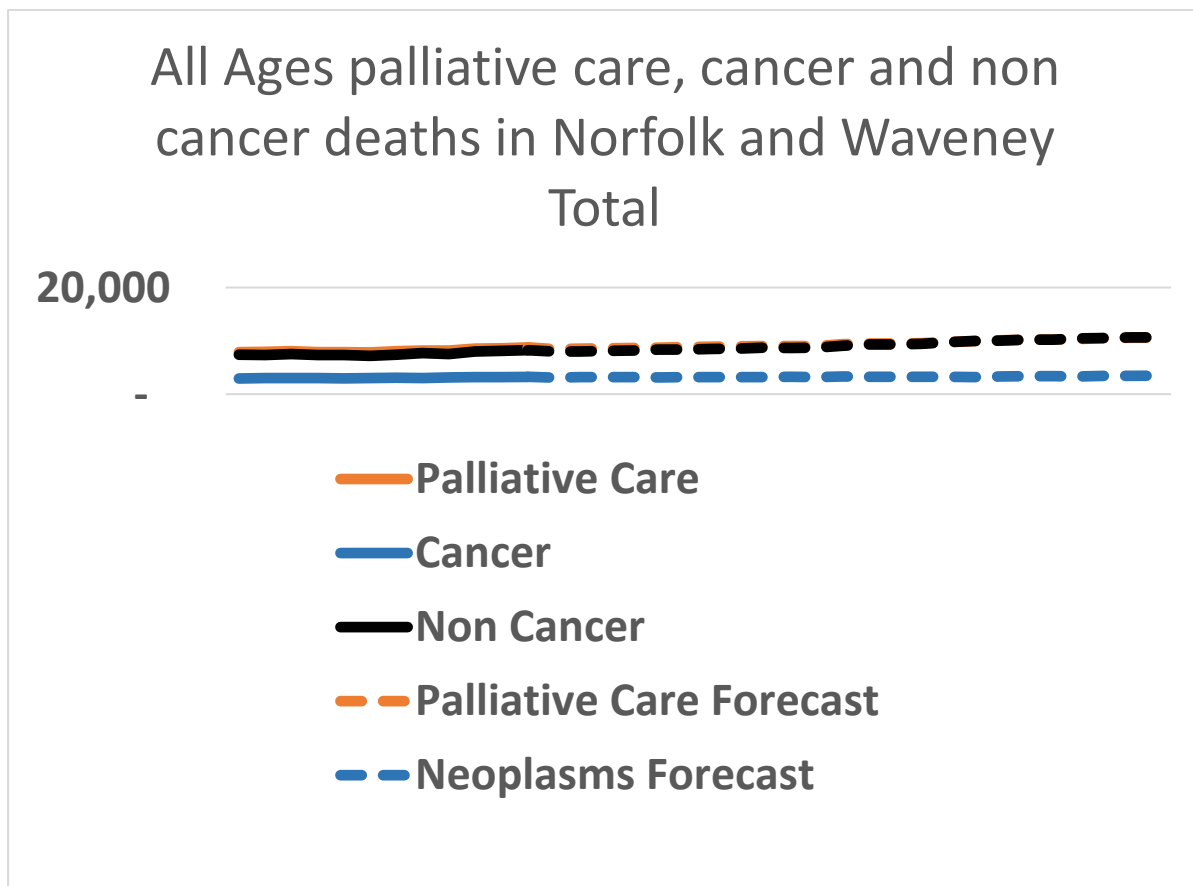
In Norfolk and Waveney, it is expected that palliative care need is going to increase, from an 8766 in 2017 to an estimated 10,590 in 2041.

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





### 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 in the area but 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 – %** <sup>11</sup>

| 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                |

|   |   |
|---|---|
| National VOICES survey 2015 for preferred place of death (PPOD) in hospital | 3 |
|---|---|

| 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 |
|---|----|

| 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 |
|---|---|

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

| 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 |
|--|---|

| 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 |
|---|---|

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)
- Social care services are provided by Norfolk County Council and Suffolk County Council. There are a large number of care homes across the STP footprint as this is a popular retirement area, and significant domiciliary care provision
- 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
- 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.

That is why we will develop the provision currently being offered across Norfolk and Waveney need to 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.

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 hours 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 were (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 volunteers), 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, Charitable Trusts and the Voluntary Sector
- 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.

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 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 <sup>1</sup> | 250 Bed Hospital <sup>1</sup> | 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<br>(including 0.2 education) | -   |
| Inpatient SPC beds (TNTH)          | 20 - 25 |   | 12 – 15 | 8                                 | 7   |

|                        |  |  |  |  |  |
|------------------------|--|--|--|--|--|
| <b>CENTRAL NORFOLK</b> | <b>Population of 250,000<sup>1</sup></b> | <b>Population of 592,600 (Norwich, North and South CCGs)</b> |  |  |  |
|------------------------|--|--|--|--|--|

|                                    |         | 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 |

|             |                                     |                                 |  |  |  |
|-------------|-------------------------------------|---------------------------------|--|--|--|
| <b>NNUH</b> | <b>250 Bed Hospital<sup>1</sup></b> | <b>1000 Bed Hospital (NNUH)</b> |  |  |  |
|-------------|-------------------------------------|---------------------------------|--|--|--|

|                                    |   | Recommended | Current                       | Deficit |
|------------------------------------|---|-------------|-------------------------------|---------|
| Consultants in Palliative Medicine | 1 | 4           | 4.3                           |         |
| Hospital SPC Nurses                | 1 | 4           | 6.4 + one nurse for Education | -       |

|                                   |  |                                     |  |  |  |
|-----------------------------------|--|-------------------------------------|--|--|--|
| <b>GREAT YARMOUTH AND WAVENEY</b> | <b>Population of 250,000<sup>1</sup></b> | <b>250 Bed Hospital<sup>1</sup></b> | <b>Population of 230,000 (Great Yarmouth and Waveney CCG) and 459 Bed Hospital (ECCH, St Elizabeth Hospice and JPUH)</b> |  |  |
|-----------------------------------|--|-------------------------------------|--|--|--|

|  |  |  | Recommended | Current | Deficit |
|--|--|--|-------------|---------|---------|
|--|--|--|-------------|---------|---------|

|                                    |         |   |         |  |     |
|------------------------------------|---------|---|---------|--|-----|
| Consultants in Palliative Medicine | 2       | 1 | 3.7     | 2  | 1.7 |
| Additional supporting doctors      | 2       |   | 1.8     | 0.6 tbc<br>(due to the recent procurement process) | -   |
| SPC Nurses                         | 5       | 1 | 6.4     | 9<br>(due to the recent procurement process)       | -   |
| Inpatient SPC beds                 | 20 - 25 |   | 18 - 23 | 6<br>(Beccles Hospital)                            | 17  |

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 received 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 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).”<sup>1</sup>

## 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 patients 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

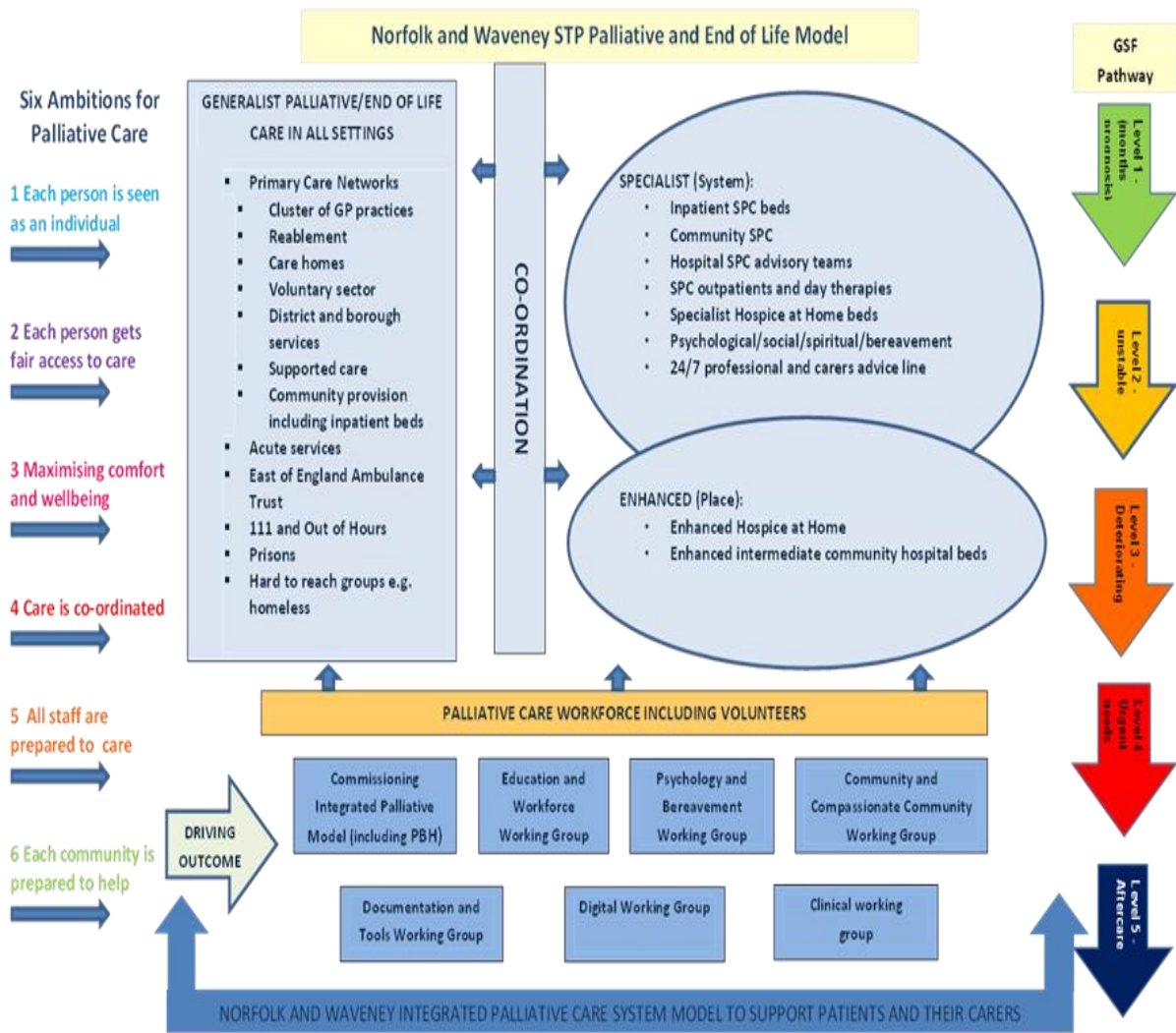
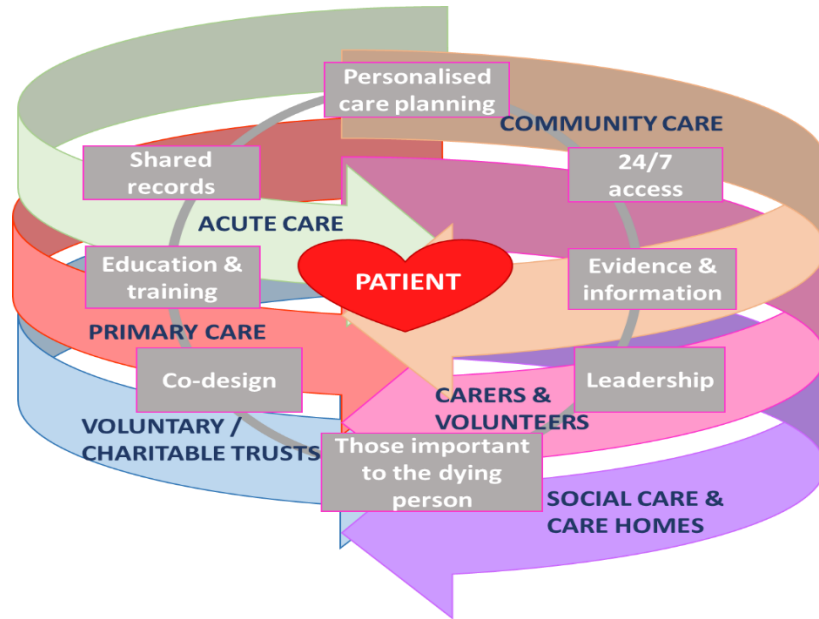


Fig 5. The structure we will use to deliver the new model



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 (organ failure, cancer and dementia, frailty and decline). 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 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 PCN's this could include physiotherapists, occupational therapists, social workers and spiritual/psychological services with experience and skills in palliative and end of life care 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.

| <b>Objectives for delivering an integrated model:</b>   |
|---|
| 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 |
| 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  |
| 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 workstreams i.e. Care Homes  |
| Partnership working with Social Care, Charitable Trusts and the Voluntary Sector  |
| 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.   |

|    | <b>National Ambition</b>             | <b>Priorities</b>   |
|----|--------------------------------------|---|
| 1. | Each person is seen as an individual | <ul style="list-style-type: none"> <li>• Development of Advance Care Plans with patients inc. ReSPECT and IPOC</li> <li>• Explore Personal Budgets with CHC Fast Track to support people taking control of their care</li> </ul>  |
| 2. | Each person gets fair access to care | <ul style="list-style-type: none"> <li>• Supporting Primary Care to improve GSF and advance care planning through the development of a Primary care offer</li> <li>• Ensuring that Home Based palliative care services are sufficient to meet patient need through Hospice at Home</li> <li>• Develop the current education plan further to include communication skills planning</li> <li>• 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.</li> <li>• 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.</li> </ul> |

|    |                                    |  |
|----|------------------------------------|--|
|    |                                    | <ul style="list-style-type: none"> <li>• Development of an integrated new model for palliative &amp; End of Life Care, including better recording and monitoring of information.</li> </ul>  |
| 3. | Maximising comfort and well being  | <ul style="list-style-type: none"> <li>• Improved and appropriate pain management through 24/7 anticipatory prescribing</li> <li>• Improved anticipatory care through 24/7 advice line</li> <li>• Improved psychological care</li> <li>• Improved care after death.</li> </ul>   |
| 4. | Care is coordinated                | <ul style="list-style-type: none"> <li>• Develop EPaCCS system wide to ensure records can be shared and updated</li> <li>• 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.</li> </ul> |
| 5. | All staff are prepared to care     | <ul style="list-style-type: none"> <li>• Co-ordinate and develop a framework of professional competencies for training staff</li> <li>• Support and education for Care Homes and domiciliary staff.</li> <li>• Develop websites, apps etc.</li> </ul>  |
| 6. | Each community is prepared to help | <ul style="list-style-type: none"> <li>• Work with the voluntary sector to further develop a plan to recruit, train and support volunteers for palliative and end of life care</li> <li>• Increasing system awareness and appropriate utilisation of commissioned palliative care services.</li> </ul>   |

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, voluntary groups, community groups and service users.

Palliative and End of Life Care is one of the priorities of the STP Primary and Community Care workstream. The Primary and Community Care workstream is one of six strategic workstreams within the STP infrastructure.

All strategic workstreams are accountable to the STP Workstream 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 Owner (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 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 & 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 workstreams and forum

The Collaborative Group and its workstream needs to be cognoscenti of the work of other workstreams 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 workstreams (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 workstream 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, 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. 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. 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 3 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



Summary of Norfolk and Waveney Comm

### 8.2 Appendix B – Working groups terms of reference



Psychological Bereavement Workin



Clinical working group - Terms of Re



Commissioning working group - Ter



Digital working group - Terms of Re



education and workforce working (



community engagement workin



documentation and tool working group

### 8.3 Appendix C - Norfolk and Waveney Palliative Education Framework



NW Palliative and End of Life Educatio