Norfolk Health Overview and Scrutiny Committee
18 October 2018
Item no 6

Access to palliative and end of life care

Suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager

Examination of the levels of specialist and generalist palliative and end of life care commissioned and provided for adults in Norfolk in comparison with guidance on levels required.

1.0 Purpose of today's meeting

1.1 To receive a report from NHS commissioner and provider partners within Norfolk and Waveney Sustainability Transformation Partnership (STP) on:-

(a) The level of palliative and end of life care currently commissioned and provided for adults in Norfolk
(b) How this compares with guidance on levels required
(c) Plans for improvement of specialist and generalist palliative and end of life care across the county.

Work to transform specialist and generalist palliative and end of life care is within the primary and community workstream of the STP.

1.2 The NHS partners were asked to provide a report covering:-

(a) Assessment of the current and future needs for specialist and generalist palliative care services and end of life care in Norfolk
(b) Description of current specialist (including hospice) and generalist palliative services and end of life care in each of the CCG areas covering:-
    1. Nature of the specialist services and what they provide
    2. Description of generalist services and details of the ones that are particularly necessary for enabling choice in location of palliative care (e.g. community / district nursing in-hours and out-of-hours)
    3. The kind of staff involved and the numbers of staff (including information about staff vacancies in the services), including specialist and generalist services (i.e. the generalist services that are particularly necessary for enabling choice of location).
    4. Geographic location of the services (where applicable)
    5. Numbers of in-patient beds, hospice at home 'places', day care 'places', independent hospice and other support services, etc. commissioned

        6. Who commissions them
        7. Who provides them
        8. The numbers of patients they serve
    (c) Gap analysis of how these services compare with current standards and guidelines for commissioners and providers (i.e. the requirements of *Ambitions for Palliative and End of Life Care: a national framework for local action 2015 -2020* and *Commissioning Guidance for Specialist Palliaitve Care: Helping to deliver commissioning objectives*[1], December 2012)
    (d) Analysis of how the capacity of these services compares with the assessment of current and future needs in Norfolk
    (e) Benchmarking of the level of services in Norfolk compared to other parts of England (including investment in generalist and specialist palliative care services; investment in hospice in-patient and out-patient services; investment in family / carer support)
    (f) Current 'place of death' statistics for Norfolk, the trend in place of death and how the county compares to the rest of England
    (g) The Norfolk and Waveney Sustainability Transformation Partnership's (STP) ambitions for improvement of palliative and end of life care.

1.3 The STP partners' report is attached at **Appendix A**. NHS commissioner and provider representatives will attend the meeting to give a presentation, attached **Appendix B**, and to answer Members' questions.

The partners are currently working on a *Norfolk and Waveney STP Ambitions for Palliative and End of Life Care Delivery Plan 2017 – 2020*, which was not available for today's meeting but will circulated with the next Norfolk Health Overview and Scrutiny Committee (NHOSC) Briefing.

Members should note that the STP partners' report does not include a full gap analysis of how current palliative and end of life services, generalist & specialised, compare with the requirements of *Ambitions for Palliative and End of Life Care: a national framework for local action 2015 -2020* (as requested at paragraph 1.2 (c) above). It gives assurance that a gap analysis has been done and that the findings are being taken into account in the service planning (Appendix A, page 7, paragraph (c)). The report does, however, include a gap analysis between the current specialist provision in each CCG area and the minimum requirements set out in the *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*, December 2012 (Appendix A (page 4-7)).

The numbers of patients served by the specialist and generalist palliative care services (as requested at paragraph 1.2 (b)8 above) are not provided in the

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[1] 2012 commissioning guidance developed in collaboration with: Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, Palliative Care Section of the Royal Society of Medicine
Available on the NICE website:-
https://www.evidence.nhs.uk/document?id=1619155&returnUrl=Search%3Fpa%3D1%26ps%3D50%26q%3DQIPP&q=QIPP

STP partners' report because service providers have historically collected different data. The STP Collaboration Group will be looking to establish uniformity in future data collection (Appendix A, page 7, paragraph 8).

2.0 Background

2.1 What is palliative and end of life care?

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 problems associated with life-threatening illness. It prevents and relieves suffering through early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or 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[2], provides a useful breakdown:-

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[2] http://www.ncpc.org.uk/publication/commissioning-guidance-specialist-palliative-care-helping-deliver-commissioning-objectiv

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*

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 spiritual / religious leaders need to be involved and that commissioning good palliative care services is not necessarily a straightforward matter.

End of life care

The General Medical Council's definition is that people are 'approaching the end of life' when they are likely to die within the next 12 months[3].

The National Institute of Health and Care Excellence (NICE) uses this definition and recognises that any palliative care within the last 12 months of life is regarded as end of life care.

2.2 Guidance on levels and standards of care

2.2.1 NICE has set out extensive quality standards for palliative and end of life care in the following key documents:-

- Quality Standard for End of Life Care for adults
  QS13, published November 2011
  https://www.nice.org.uk/guidance/qs13

- Care of dying adults in the last days of life
  NICE Guideline NG31, published December 2015
  https://www.nice.org.uk/guidance/ng31

- Improving supportive and palliative care for adults with cancer

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[3] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life

Cancer service guideline CSG4, published March 2004
https://www.nice.org.uk/guidance/csg4

2.2.2 The NICE quality standards for end of life care for adults are set out below. Beneath each one sits a raft of measures to help commissioners and providers put a service in place that meets the standard. The measures come mainly from the *End of Life Care Strategy – Quality Markers and measures for end of life care*, Department of Health, June 2009 and can be viewed via the links at paragraph 2.2.1.

NICE Quality standards

1. **Identification**
   People approaching the end of life are identified in a timely way
2. **Communication and information**
   People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3. **Assessment, care planning and review**
   People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. **Holistic support – physical and psychological**
   People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. **Holistic support – social, practical and emotional**
   People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6. **Holistic support – spiritual and religious**
   People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. **Holistic support – families and carers**
   Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8. **Coordinated care**
   People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. **Urgent care**
   People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10. **Specialist palliative care**

People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

11. **Care in the last days of life**
    The original quality standard was withdrawn following the phasing out of the Liverpool Care Pathway. A new guideline, Care of dying adults in the last days of life NG31, was published in December 2015. Recommendations to help healthcare professionals recognise when a person is entering the last days of life or may have stabilised or may be improving even temporarily; to communicate and share decisions respectfully with the dying person and people important to them; and to manage hydration and commonly experienced symptoms to maintain the person's comfort and dignity without causing unacceptable side effects.
12. **Care after death – care of the body**
    The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. **Care after death – verification and certification**
    Families and carers of people who have died receive timely verification and certification of the death.
14. **Care after death – bereavement support**
    People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
15. **Workforce – training**
    Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16. **Workforce planning**
    Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

2.2.3 From amongst the numerous measures included in the *End of Life Care Strategy: Quality Markers and Measures for End of Life Care* June 2009, upon which the NICE guidance draws, there is a 'top ten' set of markers:-

Top ten Quality Markers for providers

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.

4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (the Liverpool Care Pathway[4] or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

2.2.4 *Commissioning Guidance for* ***Specialist Palliative Care****: Helping to deliver commissioning objectives* was published in December 2012. http://www.ncpc.org.uk/publication/commissioning-guidance-specialist-palliative-care-helping-deliver-commissioning-objectiv

This Guidance document was published collaboratively with the Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK.

The 2012 commissioning guidance included the most recent national and international recommendations on minimum requirements for specialist palliative care provision per population of 250,000 (albeit with numerous caveats about variations in local requirements, etc.).

The STP NHS partners' report at **Appendix A** (page 4-7) provides analysis of Norfolk and Waveney's current position against the **minimum** requirements. It should also be noted that for inpatient specialist palliative care beds the guidance specified a 1:2 nurse:bed ratio.

2.2.5 There is no equivalent analysis of numbers required to deliver generalist palliative care because this service is necessarily provided by generalists right across the health and care system. However, NICE gives comprehensive guidance on the quality of care, training and systems that should be in place. The *Commissioning Guidance for Specialist Palliative Care* (December 2012) also points out that the less end of life care provision there is (or the more fragmented it is) in any setting, the more specialised palliative care will be required).

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[4] The Liverpool Care Pathway was subsequently phased out in 2013-14

2.2.6 In addition, numerous reports and papers have been published, providing a framework for improvement. *Ambitions for Palliative and End of Life Care; a national framework for local action 2015-20*[5] and the *Review of Choice in End of Life Care*[6] both published in 2015, are the most recent examples, re-iterating and building on previous work.

2.2.7 The Norfolk Joint Strategic Needs Assessment (JSNA)[7] notes that;

'Norfolk generally has an older population and that is projected to increase at a greater rate than the rest of England. Almost all of the population increase over the last 5 years has been in those aged 65 and over. Between 2014 and 2025 the population is expected to increase by 66,000 with most of the increase in the 65 and over age bands.'

'The area of Norfolk with the highest numbers of older people is North Norfolk. The population aged 85+ is estimated to grow by more than 40% between now and 2025 to about 42,000 people….The increasing numbers of older people also mean that it is likely to increase the need for palliative care for about 7,700 by 2025.'
(Norfolk JSNA – Older people's health and wellbeing).

2.3 Choice

2.3.1 The *End of Life Care Strategy* published by the Department of Health in July 2008 recognised that,

'From surveys of the general public we know that, given the opportunity and right support, most people would prefer to die at home'.

The *Review of Choice in End of Life Care* published by The Choice in End of Life Care Programme Board in February 2015, quoted the following evidence on preferred place of care and death (page 16):-

'Over 75% of studies from the UK and other countries show the majority of people stating that they would prefer to die at home. This preference is often conditional on the right care being available at home; research has shown that around a fifth of people and family caregivers may change their minds if this is not possible.'

'The National Survey of Bereaved People (VOICES – SF) 2013 provides valuable insight into place of death preferences. According to relatives, 79% of people who had expressed a preference said that they preferred to die at home. Only 3% of people who expressed a preference said they wanted to

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[5] *Ambition for Palliative and End of Life Care: A national framework for local action 2015 – 2020* https://www.england.nhs.uk/ourwork/ltc-op-eolc/improving-eolc/ambitions-for-palliative-and-end-of-life-care-framework/

[6] *What's important to me – A review of choice in end of life care* published by The Choice in End of Life Care Programme Board in February 2015 https://www.gov.uk/government/publications/choice-in-end-of-life-care

[7] Norfolk Joint Strategic Needs Assessment http://www.norfolkinsight.org.uk/jsna/people

die in hospital. 85% of bereaved relatives of people who had died in hospital said that their family member had wanted to die at home.'

As well as choice over their place of care and death people told the Review that they wanted choices over other aspects, such as pain control and involvement of family and those close to them.

It should be noted that a systematic literature review by a research team at the University of Cambridge in 2015[8] concluded that we should be cautious about stating that most patients want to die at home. It identified significant missing data because in many cases patients' wishes were not recorded. When this was included in analyses it was not known where most patients wanted to die. The research team has proposed a research network to identify more accurate information.

Nevertheless, in current national policy and practice the proportion of deaths in hospital is used as a proxy measure for the availability / quality of specialist palliative and end of life care services (i.e. a high level of deaths in hospital indicates a deficit of good quality local specialist palliative and end of life care services).

2.3.2 Without good planning and adequate capacity in the community to manage patients' symptoms and support their families / carers, people's preferences will often not be met. These local services are a prerequisite for making 'choice' in place of death a reality.

2.3.3 The Government's response to the *Review of Choice in End of Life Care* reiterated its commitment to achieving the *Ambitions for Palliative and End of Life Care* by 2020, with improved end of life care services enabling real choice for patients and families.

2.3.4 The STP partners' report at Appendix A (page 8 & 9) provides place of death information from Public Health England (PHE) End of Life Care Profiles[9] 2013-15. The following graphs, extracted from the PHE website, show trends in place of death in Norfolk (county) compared to the English averages from 2004 to 2016 (2016 is the most recent available data).

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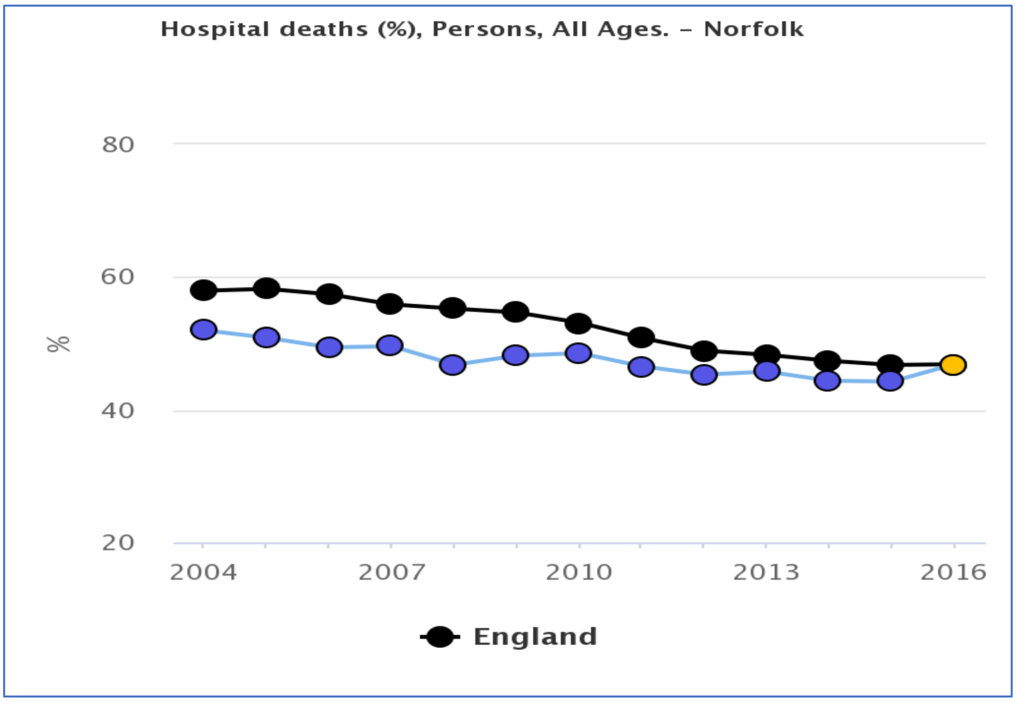
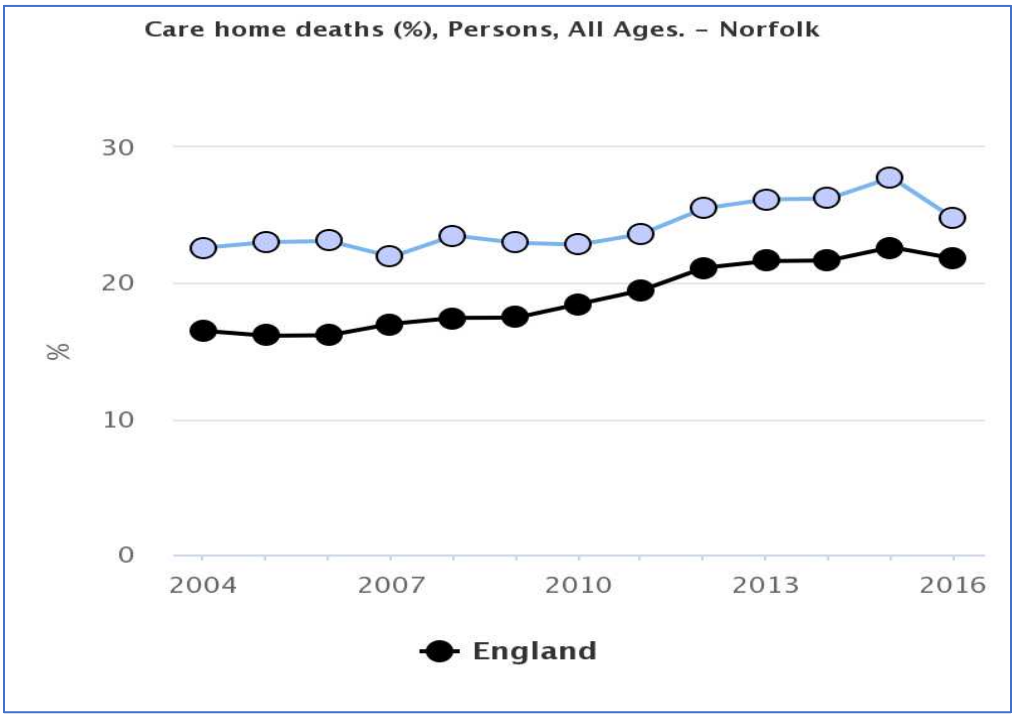
[8] Hoare, S., Morris, Z. S., Kelly, M. P., Kuhn, I., & Barclay, S. (2015). Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. PloS One, 10(11), e0142723. doi:10.1371/journal.pone.0142723

[9] Public Health England End of Life Care Profiles https://fingertips.phe.org.uk/profile/end-of-life/data#page/0

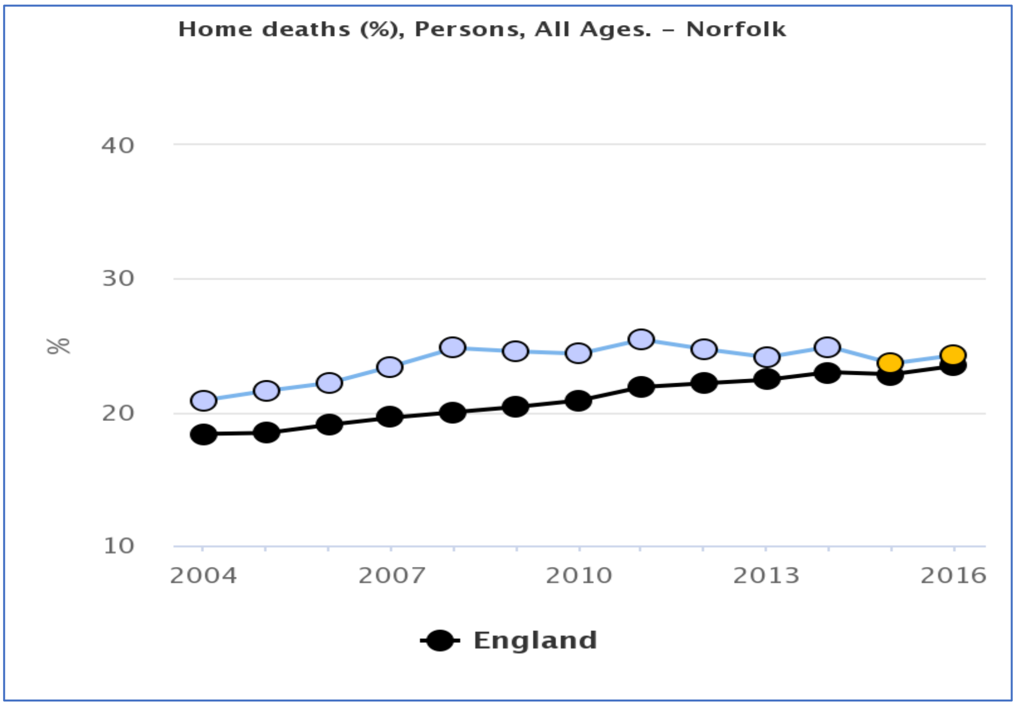
Graph 1



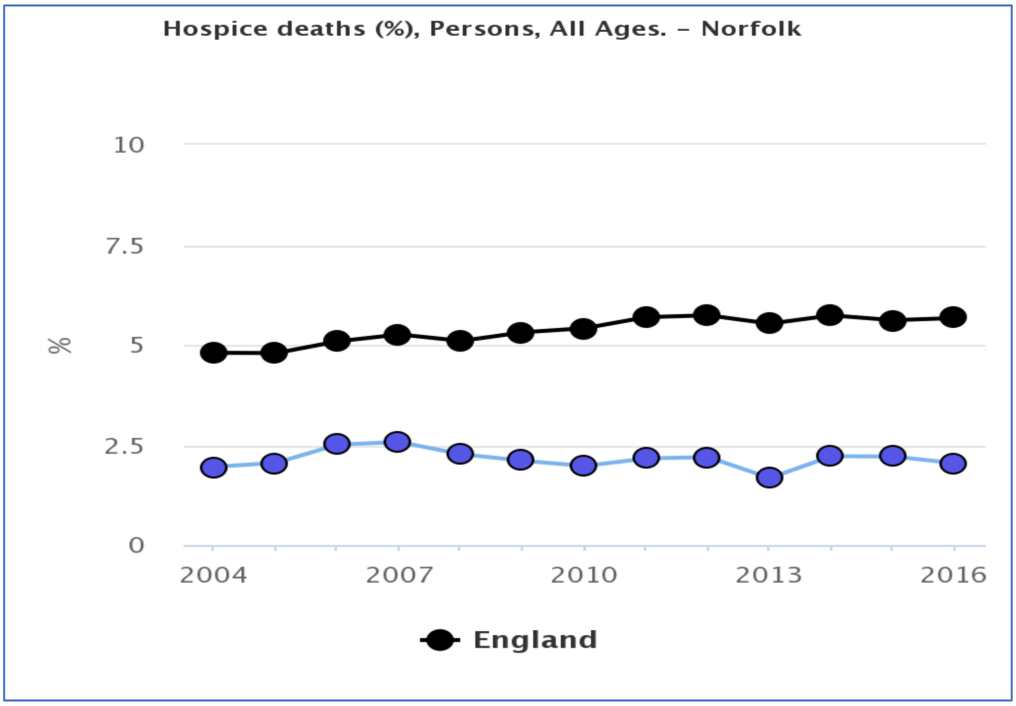
Graph 2



Graph 3



Graph 4



For context, the total numbers of deaths in each setting in each of the five CCG areas is shown below in Table 1 below (PHE End of Life Profiles 2016 data):-

Table 1 – Norfolk and Waveney CCG areas -numbers and places of deaths 2016

Place of death	Numbers of deaths in Norfolk and Waveney 2016 (all ages)					
	GY&W CCG	NN CCG	N CCG	SN CCG	WN CCG	Total
Hospital	1,276	987	960	1,103	993	5,319
Care home	597	612	406	644	593	2,852
Home	698	510	478	564	533	2,783
Other places	53	39	51	44	45	232
Hospice	-	49	77	69	7	202
Total	2624	2197	1972	2,424	2171	11,388

2.3.5 As can be seen from Graph 1 above, in 2016 Norfolk was at the English average for the percentage of deaths that took place in hospital when measured across all deaths in all age groups.

Hospital deaths across England steadily reduced each year from 2005 when 57% of all deaths took place in hospital to 2016 when the percentage was 46.9%.

Hospital deaths in Norfolk have also reduced overall but not as quickly as the English average. In each year from 2004 to 2015 Norfolk was below English average for percentage of deaths in hospital but in 2016 it coincided with English average. Norfolk’s 2016 number of deaths in hospital as a percentage of all deaths in the county was just 2.1% lower than its 2004 percentage (the actual numbers were 4,709 in hospital in 2004 and 4,633 in 2016).

As a proxy measure for quality in end of life care the numbers of deaths in hospitals show that progress towards providing the necessary level of care in the community has been fairly slow in England and slower in Norfolk.

2.3.6 Full details of place of death trends for different age groups, with breakdowns by county, district and CCG area are available on the PHE website (see link at footnote 9 above). The age groupings used by PHE in the End of Life Care Profiles are:-

0 – 64 years
65 – 74 years
75 – 84 years
85 years and over

Average life expectancy in Norfolk is about 80 years for men and about 84 years for women.

2.3.7 The following are the significant variations from English average highlighted by PHE End of Life Care Profiles (2016 data) for the five Norfolk and Waveney CCG areas:-

Great Yarmouth and Waveney CCG

- 26.6% of all deaths were at home (English average 23.5%; Norfolk county average 24.3%). The area is above the English average for home deaths in the 0 – 64 years and 65 – 74 age groups and similar to the English average in the 75 years and above age groups.
- Figures for 2016 deaths in hospice are not available on the PHE website but between 2004 and 2015 the percentage of all age deaths in hospice ranged from 0 to just 0.3% per annum compared to the current English average of 5.7% and Norfolk county average of 2.0%.

North Norfolk CCG

- 27.9% of all deaths were in care homes (English average 21.8%; Norfolk county average 24.8%)
- 35.7% of deaths in the 65 – 74 age group were at home (English average 30.3%; Norfolk county average 33.5%).
- 2.2% of deaths were in hospices (English average 5.7%; Norfolk average 2.0%). Hospice deaths in the area were similar to the English average in the 0 - 64 age group but significantly below the average in all other age groups.

Norwich CCG

- 49.6% of deaths in the 85 years and over age group were in hospital (English average of 43.8%; Norfolk county average 43.5%)
- 44.5% of deaths in the 0 – 64 age group were at home (English average 33.9%; Norfolk county average 39%).
- 3.9% of deaths were in hospices (English average 5.7%; Norfolk average 2.0%). Hospice deaths in the area were similar to the English average in the 65 – 74 and 75 – 84 age groups but significantly below the average in the 0 – 64 and 85 years and over age groups.

South Norfolk CCG

- 38.4% of deaths in the 0 – 64 age group were in hospital (English average of 45.6%; Norfolk county average 42.7%)
- 26.6% of all deaths were in care homes (English average 21.8%; Norfolk average 24.8%). It was the 0 – 64 and 85 years and over age groups where the percentage was significantly above the English average. The 65 – 74 years and 75 – 84 age groups were similar to the English average.
- 2.8% of deaths were in hospices (English average 5.7%; Norfolk average 2.0%). Hospice deaths in the area were significantly below the English average in all age groups, except the 0 – 64 age group which was similar to the average.

West Norfolk CCG

- 25.5% of all deaths were in care homes (English average 21.8%; Norfolk average 24.8%). It was the 65 – 74 age group that was above the English average. Other age groups were similar to the English average.

- 27.5% of deaths in the 75 – 84 years age group were at home (English average 23.8%; Norfolk county average 25.3%).
- 0.3% of deaths were in hospices (English average 5.7%; Norfolk county average 2.0%). Hospice deaths in the area were significantly below the English average in all age groups.

All other measures within the Profiles for the 5 CCGs are similar to English average.

2.3.8 It should be noted that people are not offered the option of an acute hospital as a preferred place of death during planning for end-of-life care. Acute hospitals discharge expectations usually apply right up to the last 24 hours of life expectancy. In practice patients die in the acute hospitals because their condition is such that they cannot be moved or because it has not been possible to arrange a transfer to another setting where the necessary care can be provided.

It should also be noted that a care home may or may not have been a person's usual place of residence before the time of their death.

2.4 Hospice care

2.4.1 As can be seen from Graph 4 in paragraph 2.3.4 above, the proportion of deaths in Norfolk taking place in hospices is low and significantly below the English average, which reflects the lack of access to hospice provision in the county.

2.4.2 The *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*, December 2012, noted that the first national VOICES[10] survey, undertaken by the Office for National Statistics on behalf of the Department of Health showed that quality of care, being treated with dignity and respect, and pain relief, were all best achieved in hospices'[11].

For many requiring specialised palliative care towards the end of life, hospice care would be a desirable alternative option to admission to hospital.

The *Commissioning Guidance for Specialist Palliative Care* defined hospice care as:-

'A hospice is not just a building; it is a way of caring for people. Hospice care aims to improve the lives of people who have a life-limiting or terminal illness, helping them to live well before they die. Hospice care not only takes care of people's physical needs, but looks after their emotional, spiritual and social needs as well. It also supports carers, family members and close friends, both during a person's illness and during bereavement.'

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[10] VOICES is the national bereavement survey

[11] http://www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-bereaved-people-key-findings-report-final.pdf

(adapted from http://www.helpthehospices.org.uk/about-hospice-care/what-is-hospice-care/)

As can be seen from paragraphs 2.4.4 – 2.4.11 below the term ‘hospice’ is identified with a variety of different organisations and services in Norfolk and Waveney.

2.4.3 It should be noted that 90% of the hours of care provided by charitable hospices each year is provided through day care and at home services[12]. Hospices also usually act as a hub for the range of interdisciplinary support services.

2.4.4 Hospice care is rooted in the charitable sector but most hospices in England also receive a proportion of their funding from statutory sources; NHS Clinical Commissioning Groups (CCGs), NHS England and local authorities.

In *Commissioning and statutory funding arrangements for hospices in England – Survey results 2015,* Hospice UK and Together for Short Lives reported that statutory funding of hospices in 2014-15 ranged from 0% (no statutory funding) to more than 50% of care costs being met through CCG funding. It also noted that statutory funding had come under increasing pressure over the past three years, which was beginning to impact on services.

The report also highlighted that demand would continue to rise steeply. In England the number of people dying each year[13] was expected to increase by over 4,000 a year between 2021 and 2025 and by over 8,000 a year between 2031 and 2035.

The report’s recommendations for local commissioners were:-

- To explicitly set out how they commission hospice and palliative care services across their locality, including trends in funding.
- To seek to engage with partner organisations, including other health and social care commissioners to collaborate (for example through lead commissioner arrangements), to help improve efficiency and better support strategic planning of hospice and palliative care services.
- To use contracting arrangements with hospices which are proportionate to the contribution they are making towards hospice care costs; consistent with NHS England Guidance, this should include grant agreements.

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[12] Source: *Commissioning and statutory funding arrangements for hospices in England, Survey results 2015,* Hospice UK & Together for Short Lives, quoting Help the Hospices. *Strength in numbers [Facts card].* London: Help the Hospices 2011

[13] Figures based on 2010 population projections and discussed in Calanzani N. et al *Current and future needs for hospice care: an evidence based report, 2013.* http://www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care/commission-resources

2.4.6 The STP partners' report at Appendix A (page 6-7) provides some information about local hospice services but the following paragraphs include more background information.

2.4.7 There is currently one independent adult hospice facility in Norfolk:-

- The Norfolk Hospice, Tapping House, Hillington, King's Lynn - a charitable company limited by guarantee. The independent inpatient hospice opened in June 2017. It was established to meet the growing demand in palliative and end of life care services across Norfolk with the aim to:
  - Develop end of life and palliative care for Norfolk.
  - Enhance and integrate existing end of life service
  - Supporting care of the highest quality for Norfolk patients and their families

  It provides Consultant Nurse led inpatient beds. Patients are admitted for end of life care and symptom management. The hospice is also supported by GPs (2 visits per week) and has Consultant support from the West Norfolk Palliative Care Centre, which is separate from The Norfolk Hospice inpatient unit but located on the same site.

  West Norfolk CCG has commissioned 4 beds at the hospice on a block basis, i.e. making guaranteed payments so that those beds are always available for local patients, and spot purchases an additional 2 or sometimes 3 beds as and when needed. The CCG does not pay the full cost of care in either block or spot purchased beds but around 30% of the cost, with the charity covering the remaining cost from its own funds. An informal agreement is in place with North Norfolk CCG to also spot purchase the hospice beds on occasion. Norwich CCG has also spot purchased a bed on one occasion. There is potential for the hospice to grow up to 12 beds if required.

  Separately from the inpatient unit, Norfolk Hospice also works with Norfolk Community Health and Care NHS Trust and others in the West Norfolk Integrated Palliative Care Service to provide a Hospice at Home service caring for patients with end of life care needs in their own homes.

  The Hospice also provides an in-house social worker, rehabilitation therapies at home and at the hospice, Specialist Nurse clinics, pre and post bereavement counselling, chaplaincy, home sit services, complimentary therapies, dementia care groups and other social care support groups.

2.4.8 There is also one adult specialist palliative care unit in Norfolk:-

- Priscilla Bacon Lodge - provided by Norfolk Community Health and Care NHS Trust (NCH&C) with Priscilla Bacon Lodge Support Group augmenting core services by providing additional funding through local fundraising from its volunteers, with 16 in-patient beds providing specialist palliative care for patients who the acute hospitals cannot symptom manage. NCH&C also provides approximately 15 palliative health beds within its other facilities across the county.

There are plans for Priscilla Bacon Lodge to expand to 24 beds. A new charity 'Priscilla Bacon Hospice' has been set up and is fundraising for the project.

However, Priscilla Bacon Lodge is not a hospice which terminally ill people can choose in advance as their preferred place of death as the entry criteria are very specialised.

2.4.9 East Coast Hospice, a charitable company limited by guarantee, is currently raising funds to build an independent hospice in the east of the county and has purchased land at Hopton, near Great Yarmouth. The plan is for a 10 bed in-patient unit and a day care and outpatient unit.

2.4.10 The Louise Hamilton Trust had been fundraising for a 10 bed hospice on the James Paget Hospital site but in 2018 Great Yarmouth and Waveney CCG and James Paget University Hospital NHS Foundation Trust said that they could not support the plan. The Louise Hamilton Centre continues to operate in the grounds of the hospital, providing information and support for patients with progressive or life limiting conditions and their carers / families. NHOSC Members visited the centre in 2013.

2.4.11 There are two independent hospices in Suffolk, both charities with in-patient beds, which are available (or have been at times) to some people resident in Norfolk and Waveney:-

- St Nicholas Hospice Care (West Suffolk, Thetford and surrounding area) – day, community and in-patient care (12 beds)
- St Elizabeth's Hospice (Ipswich) – day, community and in-patient care (18 beds)

2.5 Systemic issues

2.5.1 Provision of good palliative and end of life care involves numerous agencies and requires robust cross-agency planning. Norfolk has a complex landscape of agencies with five clinical commissioning groups, two main NHS community care providers (Norfolk Community Health and Care NHS Trust and East Coast Community Healthcare Community Interest Company (CIC)), three acute hospitals, the mental health trust, County Council social care, seven district councils who have a role to play in housing adaptations and community support, plus numerous independent care providers and voluntary agencies. The whole system is under financial pressure.

Some of the systemic challenges in Norfolk around planning, budgets and information sharing are particularly apparent in end of life care.

For instance:-

a) Acute hospital wards do not arrange the discharge planning for patients, including palliative patients. They issue notice to other agencies that a patient is 'medically fit for discharge' (i.e. not needing an acute bed) and a transfer of care is required. When the other agencies have arranged for people to be moved the hospital and ward re-engages in the handover of care in terms of medications, GP letters, etc.

b) The agencies involved are multiple, entitlement to funding tends to be poorly understood and families may have expectations of funding for discharge that cannot be met.

c) For patients coming towards the end of life, discharge services may be the statutory responsibility of the NHS, which provides services free at the point of use; they may require funding via means tested and chargeable social care; or if they have savings above £23.5k they may need to self-fund their care on discharge.

d) The *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*[14] says that '*Individuals with a rapidly deteriorating condition that may be entering a terminal phase may require 'fast tracking' for immediate provision of NHS continuing healthcare'* (page 63, paragraph 217*)*. However, the terms 'rapidly deteriorating' and 'terminal phase' are open to interpretation. A patient with a prognosis of six weeks to live, but who is currently stable and not presently 'rapidly deteriorating' may be considered ineligible for a fast-track decision on NHS continuing healthcare. Such a patient may be discharged to a nursing home on a social care or self-funded basis with the understanding that a fast track assessment for NHS continuing healthcare can happen when the patient is 'rapidly deteriorating' and 'entering a terminal phase'. In practice such assessments rarely happen.

e) As patients may have entitlement to funding / service from various sources (e.g. NHS continuing healthcare; NHS community health care trust provision; CCG spot purchased provision in care or nursing homes; social care funded provision) the multiple budgets for end of life discharge cause a sequential 'application' process which takes time and resources. The information from the multiple assessing agencies is not shared between them, so each one starts from scratch.

f) Each of the separate agencies which may fund a patient's end of life care have their own criteria for which patients their service can accept. This can lead to patients with less complex needs receiving free (at the point of use) NHS care while those with more complex needs are told they need to self-fund. For instance, a palliative care patient with dementia / complex mental health needs may be considered unsuitable for management in an NHS community hospital bed, but also unsuitable for management in a mental health

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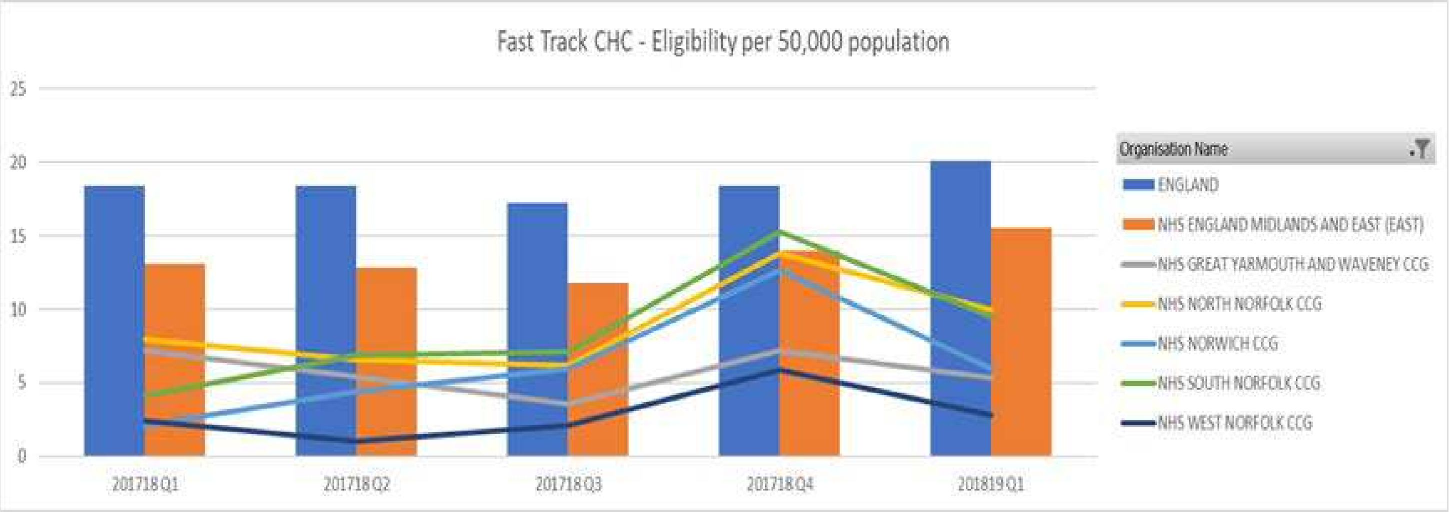
[14] *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. October 2018 (Revised),* https://www.events.england.nhs.uk/upload/entity/30215/national-framework-for-chc-and-fnc-october-2018-revised.pdf

trust bed because of their complex physical health needs for pain relief, etc.

g) The information systems in which patients' treatment and care plans are stored (acute hospital, NHS community services, NHS continuing care and local authority social care) are also diverse, causing challenges as patients move in and out of hospital towards the end of their life. For example, plans made with GPs may not be accessible to the acute hospital or social services and the ambulance service may not know that a patient should not be brought back via A&E if they collapse.

2.5.2 In relation to paragraph 2.5.1 (d) above, Graph 5[15] below shows that significantly fewer people per 50,000 population are assessed as eligible for fast track continuing healthcare in Norfolk than is the case in England as a whole, or in the NHS England Midlands and East (East) region.

Graph 5



2.5.3 The Care Quality Commission 'Beyond Barriers'[16] report published in July 2018, whilst focusing on how older people move between health and care in England and not specifically on palliative or end of life care, usefully summarises the problems that can also affect end of life.

The CQC found:-

- Organisations intended to work together but mostly focused on their own goals

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[15] Graph 5 is based on data extracted from NHS England's *NHS Continuing Healthcare and NHS-Funded Nursing Care* statistics https://www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/2018-19/

[16] Care Quality Commission 'Beyond Barriers', July 2018. https://www.cqc.org.uk/publications/themed-work/beyond-barriers-how-older-people-move-between-health-care-england

- Although there was good planning between services, the way services were funded did not support them to work together
- Organisations ;-
    - were prioritising their own goals over shared responsibility to provide person centred care
    - did not always share information with each other which meant they weren't able to make informed decisions about people's care
    - were not prioritising services which keep people well at home
    - planned their workforce in isolation to other services
- The regulatory framework focuses only on individual organisations.

The CQC recommended:-

1. Reform of planning and commissioning of services. An agreed joint plan, funded in the right way, should support older people in their own homes, help them in an emergency, and then to return home safely.

2. A new approach to system performance management. This would measure how organisations collectively deliver improved outcomes for older people.

3. Joint workforce planning. This would allow flexible and collaborative approaches to staff skills and career paths.

4. Better oversight of local system performance. New legislation so CQC could regulate how people and organisations work together to support people to stay well.

2.5.4 NHS policy nationally and locally is for more people to be cared for at home, or close to home, rather than in hospitals. In line with this policy CCGs and NHS providers have been providing more services that enable people to be cared for at home and have been closing community hospital beds in recent years.

Although many people welcome this direction of travel, there may need to be more focus on how the particular needs of end of life patients, their families and carers are met within the new model, e.g. the availability of district nurses; the speed of provision of essential equipment, such as syringe drivers for pain relief, in the patient's usual place of residence.

2.5.5 There is also the issue of a gap between families' expectations and the reality of current provision. Previously family members may have gone to NHS community hospitals at the end of their life and, at an already very distressing time, families are surprised to find these beds are not available for end-of-life patients.

2.5.6 Providers in Norfolk currently have the following CQC ratings specifically for end of life care:-

Provider	**Rating** (& date published)
Norfolk & Norwich University Hospitals NHS Foundation Trust	Requires improvement (19 June 2018)
James Paget University Hospitals NHS Foundation Trust	Good (20 Dec 2016)
The Queen Elizabeth Hospital NHS Trust	Requires improvement (13 Sept 2018)
Norfolk Community Health and Care NHS Trust	Good (19 Dec 2014)
East Coast Community Healthcare CIC	No overall rating for end of life care
The Norfolk Hospice, Tapping House, King's Lynn	Good (5 July 2017)

The CQC does not necessarily inspect all services each time it visits an organisation; the NCH&C rating is from a previous inspection visit, not the most recent.

2.6 Previous reports to Health Scrutiny

2.6.1 In 2004 Norfolk Health Overview and Scrutiny Committee (NHOSC) commissioned research into local experiences of death and dying in Norfolk, which led to the 'How We Manage Death and Dying in Norfolk and Waveney' report to the committee in September 2005. The report made 45 recommendations covering integrated delivery of services, provision, communication and information, specific issues and operational issues that needed to be addressed. NHOSC monitored progress in committee until April 2010, receiving a final update via the NHOSC Briefing in April 2011.

In the progress report presented to NHOSC on 27 November 2008, Norfolk Primary Care Trust (PCT) told the committee it anticipated that by 2013 100% of patients would have real choice as to where they wanted to spend the end of their lives.

2.6.2 In 2008 NHS East of England (the former Strategic Health Authority) consulted health scrutiny about its vision for the next ten years, including for palliative and end of life care. An East of England Joint Health Scrutiny Committee, in which Norfolk participated, recommended that:-

- That the Strategic Health Authority (SHA) and Primary Care Trusts ensure that 24/7 services, including access to out-of-hours drug services, are made available, together with the necessary funding streams, to secure the ambitions of the End of Life Care Strategy
- That the SHA and PCTs give further consideration to the balance between institutional hospice services and hospice at home services and in doing so ensure and secure the funding of this, and associated voluntary services.

- That the SHA and PCTs in collaboration with national bodies and partners in other regions develop a suite of success measures and desired outcomes which can be developed into mechanisms that demonstrate measurable improvements in services.

The SHA's 10-year vision, *Towards the Best, Together*, March 2009, recognised that the majority of people have a preference to die at home and committed to meeting people's choice of where they want to die. It committed to providing generalist palliative medical and nursing care in all settings 24/7 and meeting NICE criteria for multi-professional team composition, providing face to face assessments 9am – 5pm, seven days a week as a minimum with specialist advice available 24/7.

2.6.3 In April 2013 the NHOSC received a report specifically about use of the Liverpool Care Pathway (LCP) in Norfolk's hospitals and monitored local organisations' progress to phase out use of the LCP until May 2014.

Following publication of NICE Guideline NG31 Care of dying adults in the last days of life published in December 2015 and the Care Quality Commission's A Different Ending report in May 2016 NHOSC returned to the subject on 8 September 2016 to examine local health and care providers' response. The report is available on the County Council website:-
http://norfolkcc.cmis.uk.com/norfolkcc/Meetings/tabid/128/ctl/ViewMeetingPublic/mid/496/Meeting/517/Committee/22/Default.aspx
(agenda item 8)

2.6.4 Most recently, Great Yarmouth and Waveney Joint Health Scrutiny Committee received an information bulletin on 'Palliative and End of Life Care' from Great Yarmouth and Waveney CCG on 13 July 2018:-
http://norfolkcc.cmis.uk.com/norfolkcc/Meetings/tabid/128/ctl/ViewMeetingPublic/mid/496/Meeting/1506/Committee/25/Default.aspx (page 38-40)

2.7 Previous needs assessments and ambitions

2.7.1 In 2004 Norfolk and Waveney Cancer Network completed a comprehensive population based needs assessment for palliative care and concluded that Norfolk and Waveney needed:-

(a) A health and social care workforce that is knowledgeable and skilled in general palliative care
(b) The Gold Standards Framework or equivalent mechanism, which is operational in primary care across the Network
(c) The Liverpool Care Pathway for Care of Dying Patient, or equivalent mechanism, which is operational across the Network in all care settings.
(d) 40 specialist palliative care beds for people with cancer
(e) 20 specialist palliative care beds for people with other diagnoses
(f) 205 day care places a week (this includes about 6% for people with non-cancer)
(g) 25.3 community based clinical nurse specialists

(h) 5.8 consultants for all core services together with 6.5 junior medical staff
(i) 7 clinical nurse specialists for hospital based teams (5 in a Cancer Centre and 2 in a Cancer Unit), plus the community team component)
(j) A full range of other professional staff for each team for each core service as detailed in the NICE Guidance
(k) Access to the specialist beds, day care and community services reflects the differential palliative care needs of the 6 PCT populations[17]

2.7.2 In 2008 both Norfolk and Great Yarmouth and Waveney Primary Care Trusts had independently adopted the methodology of the Marie Curie Delivering Choice Programme. The Programme is essentially a tool to help local organisations to come together to examine needs before designing, piloting and evaluating service improvements to support real choice in where and how people are cared for. It requires multi-agency involvement in whole system redesign and long-term commitment from all involved.

3. Rate of progress

3.1 Local

3.1.1 As can be seen from the gap analysis in Appendix A (page 4-6) Norfolk & Waveney is 62 - 82 beds short of the numbers of specialist palliative care beds that the 2012 commissioning guidance suggested it needs. There are also shortfalls in suitably qualified staff to deliver specialist palliative and end of life care (i.e. Norfolk and Waveney has 9.2 fte fewer consultants in palliative medicine and 3.2 fte fewer additional supporting doctors than the commissioning guidance suggests it needs).

There is unequal provision of hospice and specialist palliative care in-patient facilities across the county with no beds available in the Great Yarmouth and Waveney area.

In addition, ‘hospice at home’ services appear variable across the county. West Norfolk has a well-established service and the three central Norfolk CCGs have very recently introduced a service on a pilot basis, but Great Yarmouth and Waveney CCG stopped its ‘hospice at home’ service in December 2017. Palliative and end of life care is a major component of the NHS community services contract for the Great Yarmouth and Waveney area, which is currently out to re-procurement for implementation from April 2019. Great Yarmouth and Waveney CCG aims to commission improved palliative and end of life care services for its local population and to ensure and integrated, community based service that is compliant with all relevant standards.

In terms of the preference to die at home, the PHE End of Life Care Profiles 2016 show that 46.9% of people who died in Norfolk died in hospital, and the downward trend in proportion of deaths in hospital is slower in Norfolk than

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[17] The 6 Primary Care Trusts (PCTs) were later replaced by 2 PCTs and then by 5 CCGs

the English average (see paragraph 2.3.4). As a proxy measure for the quality of specialist palliative and end of life care in the community, this suggests that the rate of improvement is slow.

The ambitions of *Towards the best, together* (2009) were not fully delivered, and Norfolk appears to be behind schedule for delivering *Ambitions for Palliative and End of Life Care: a national framework for local action* by 2020. One year into the timespan for the *Norfolk and Waveney STP Ambitions for Palliative and End of Life Care Delivery Plan 2017-2020,* the Delivery Plan has not been published, which means it is not possible to fully examine progress. However, it is clear that the Electronic Palliative Care Coordination System is not yet in use and a 24/7 telephone helpline for professionals and carers is not yet available everywhere.

3.1.2 There is an impression of uncertain funding for elements of the service and unequal provision across the county. The CCG areas appear to have been working at different paces with development of 'hospice at home' services and provision of telephone helplines in some areas but not in others. There is piloting and short-term funding arrangements for what appear to be vital services. The provision of MacMillan palliative social workers at the Norfolk and Norwich hospital is a case in point:-

> MacMillan Cancer Support (a charity) proposed and fully funded two palliative social work posts (one qualified, one assistant) at the Norfolk and Norwich (N&N) hospital for two years from 2016. The purpose was to ensure that patients were enabled to be discharged from the N&N to their preferred place of care in a timely and effective manner. At the end of the two years neither the Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH) nor Norfolk County Council were able to allocate ongoing funding for the service and it stopped. Ultimately the NNUH agreed that it would provide for one palliative social work post but the post has not yet been advertised (as at 25 September 2018).

3.1.3 On the positive side:-

- Advance care planning - considerable work has been done to encourage and enable people to think in advance and communicate their wishes about end of life care. As reported to NHOSC by Healthwatch Norfolk in September 2016 (see link to report at paragraph 2.6.3 above (agenda item 8, appendix G)), work has gone into communication with the public on Advance Care Planning for patients. Its 'Thinking Ahead' research fed into the launch of the Thinking Ahead yellow folders to help people record their wishes.

  Healthwatch Norfolk also hosted 'The Big Conversation', a Dying Matters[18] event, at the Forum in Norwich on 12 May 2016. At this

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[18] Dying Matters is a coalition set up in 2009 and led by the National Council for Palliative Care, which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

event, working with Norfolk and Suffolk Palliative Care Academy, Healthwatch drew on the findings of its ‘Thinking Ahead’ research report into the barriers to advanced care planning for end of life. It highlighted the importance of people being able to talk about the issues and concerns they may have about the end of life.

In May 2017 and 2018 the Lord-Lieutenant of Norfolk’s Palliative Care Forum held summits on palliative care as part of ‘Dying Matters – What can you do’. These were attended by health and social care professionals, volunteers, charity and third sector representatives.

Palliative care patients could be considered as a hard-to-reach group in terms of feedback about their direct experience of services during the last year of life because they and their families may not have the energy, time to spare or inclination to engage with surveys. However, local families may wish to engage at a later stage. The initiatives taken in recent years are important in helping people to engage.

- Priscilla Bacon Lodge –it is unusual for specialist palliative care beds to be 100% funded by the NHS but this is the case for the 16 in-patient beds and other core services at Priscilla Bacon Lodge in Norwich. Expansion to 24 in-patient beds is expected within the next five years.

- Hospice at home services in central Norfolk – introduced in the three central Norfolk CCG areas in 2018.

- The Norfolk and Waveney STP Collaboration Group – the formation of this group is a positive development as it appears to include all of the organisations and agencies whose cooperation is required for sustained improvement of palliative and end of life care in Norfolk.

3.2 National

3.2.1 Concerns about the quality of palliative and end of life care have clearly persisted at national level. The Parliamentary and Health Service Ombudsman published ‘Dying without dignity’ in May 2015, which documented commonly experienced themes:-

- not recognising that people are dying and not responding to their needs
- poor symptom control
- poor communication
- inadequate out-of-hours services
- poor care planning
- delays in diagnosis and referrals for treatment.

The Care Quality Commission’s ‘A Different Ending’ report published in May 2016[19] also highlighted that:-

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[19] http://www.cqc.org.uk/content/different-ending-end-life-care-review

- People from certain groups in society were experiencing poorer quality care at the end of their lives than others because providers and commissioners did not always understand or fully consider their specific needs;
- Some commissioners and providers might not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work.
- Health and care staff were not always having conversations with people early enough about their end of life care. This means they didn't have the opportunity to make plans and choices with their loved-ones about how and where they would prefer to die.
- Action was needed to make sure everyone has the same access to high quality, personalised care at the end of their lives, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

3.2.2 On 6 July 2017 City University of London and the Economic and Social Research Institute published the results of a research study[20] funded by Macmillan Cancer Support which found that patients with the four most common cancers (breast, bowel, prostate and lung cancer) living in the most deprived areas of England are more likely to be admitted to hospital as an emergency in the last six months of their lives compared to those living in the least deprived areas, and to spend more days in hospital following an admission.

This suggests that access to good end of life care is least available in the most deprived areas, leading to distressing and costly emergency admissions to hospital. The study estimated that end of life care in hospitals for patients in the poorest areas of England with these four types of cancer alone was costing the NHS an extra £4.6 million year.

3.2.3 The All Party Parliamentary Group on Hospice and Palliative Care launched an inquiry into improving access to hospice and palliative care in March 2018[21]. They are due to report in early 2019. The terms of reference refer to an estimate that over 100,000 people have an unmet palliative care need each year and an increase in demand for palliative care of over 40 per cent in the next 25 years.

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[20] Research by City University of London and the Economic and Social Research Institute published in the *Health Affairs* journal 6 July 2017 and reported on City University of London website:- https://www.city.ac.uk/news/2017/july/improving-end-of-life-care-for-poorest-cancer-patients-could-save-nhs-4.6-million-a-year

[21] All-Party Parliamentary Group on Hospice and Palliative Care, *Improving access to hospice and palliative care;* Inquiry terms of reference March 2018 https://www.hospiceuk.org/policy-advocacy/advocacy/appg-on-hospice-and-palliative-care

4.0 Suggested approach

4.1 After the STP partners have presented their report you may wish to explore the following areas:-

Strategic and systemic issues

(a) Progress with improvement of palliative and end of life care in Norfolk appears to be behind schedule with the *Ambitions for Palliative and End of Life Care: a national framework for local action 2015 – 2020.*

Why is this the case and what can be done to speed it up?

(b) What are the main barriers to providing palliative and end of life care in line with NICE and commissioning guidance?

(c) Like most services, palliative and end of life care is commissioned by the five separate CCGs in the county, each working with social care, and each working within their own tight budget. They have made different decisions about what can be funded at different times. To what extent is there scope for improved county / STP-wide provision now that the Strategic Transformation Partnership and the CCGs' Joint Strategic Commissioning Committee exist?

(d) The Marie Curie Delivering Choice Programme was also a whole system, multi-agency initiative to deliver improved and sustainable end of life care across the Norfolk and Waveney but the change promised in 2008 has not been fully delivered. What makes the STP Palliative and End of Life Care Collaboration Group different?

(e) Bearing in mind that social care is means tested and NHS care is not, do the STP representatives think there would be scope for pooling the multiple health and social care funding streams for palliative patients into integrated funding across health and social care for those in the last few months of life? (To resolve some of the issues set out in paragraph 2.5.1)

(f) In Norfolk, who in the system is responsible for taking the lead for end of life planning for those identified as being in the last year of life? (GP/ NHS community matron / community social worker / hospice staff?)

(g) Is it possible to promote a culture where the community GP / community matron / hospice staff / social worker can reach into the hospital to retrieve their end of life patients home, or as close to home as can be achieved?

(h) When will the Electronic Palliative Care Co-ordination System (EPaCCS) be introduced in Norfolk to enable multiple agencies to build pooled assessment and knowledge of patients' needs?

(i) Provision of a 24/7 helpline has been included in NICE guidance for many years. When will such a service be available across all of Norfolk?

Specialist palliative care (SPC)

(a) The gap analysis between current SPC capacity and the 2012 SPC Commissioning Guidance (Appendix A, page 4 -6), shows that Norfolk and Waveney has 9.2 full time equivalent (fte) fewer Consultants in Palliative Medicine and 3.2 fte fewer Additional Supporting Doctors than the guidance suggests it needs. The STP partners' report alludes to the national shortage of consultants and doctors and mentions work being undertaken to look at other models of care that are successful elsewhere (Appendix A, page 8, paragraph (d)).

Is it possible to provide good quality specialist palliative care with lower levels of highly qualified staff than the current national commissioning guidance requires?

(b) Commissioning Guidance for Specialist Palliative Care (December 2012) says that an SPC team should be a multi-professional team of whose members should have had training and experience in SPC some of whom should be accredited specialists (e.g. consultants). The defined staff requirements are for physicians and nurses as core specialists, with physiotherapists, occupational therapists and social workers as part of the core team. Pharmacists, dieticians, lymphoedema specialists, psychologists, administrative support, chaplains or spiritual care professionals are required as part of the team, possibly as part-time or extended team members.

To what extent do SPC multi-disciplinary team services in Norfolk meet the staffing guidelines in terms of core team physiotherapists, occupational therapists and social workers, and in terms of the allied professionals (pharmacists, dieticians, etc)?

(c) The commissioning guidance for SPC does not use the term 'enhanced palliative care' but the STP's new model of care (Appendix A, page 2) has it overlapping with both specialist palliative care and end of life care in all relevant care settings (i.e. generalist palliative care). What is the difference between 'specialist' and 'enhanced' palliative care?

(d) The STP partners' report says that specialist level <u>in-patient</u> palliative care may be delivered by the expert team in a person's usual place of residence in some rural localities (Appendix A, page 3). How does this work in terms of the equipment that may be needed to ensure that the patient is comfortable? What is the difference between this service and 'hospice at home' or 'enhanced palliative care'?

Hospice provision

(e) Hospice services have historically been provided in the charitable sector but support from and close working with statutory agencies (NHS and social care) is important to them.

To what extent do the STP partners support and engage with the three independent hospice charities (for adult end of life care) in Norfolk?

(f) Norfolk is far below the numbers of specialist palliative care in-patient beds that the 2012 Commissioning Guidance would suggest it needs. There are no in-patient beds within the Great Yarmouth and Waveney area, which would be expected to be an area of high need for palliative care in terms of indices of deprivation and incidence of cancer.

What can be done to increase provision of hospice beds?

(g) How does ‘Hospice at Home’ compare to a hospice in-patient service and how many patients can the central and west Norfolk services support at home at any one time?

(h) It appears the five CCGs across Norfolk have taken different approaches to introducing ‘Hospice at Home’, with some running it as a pilot and Great Yarmouth and Waveney not having it at all at present. What are the reasons for the disparate approach?

Generalist palliative care and end of life care

(i) Care homes are the place of death for an increasing percentage of people who die in Norfolk. The figures are significantly above the English average. Can health and care commissioners be sure that this is a good option for end of life patients in terms of facilities, equipment and staff who are properly trained to support the needs of the individual (particularly with pain and other symptom relief) and their family?

(j) To what extent is palliative care support in the community available at night?

(k) The Gold Standards Framework (GSF) requires GPs to identify palliative care patients potentially entering the last 12 months of life and plan care with the patient / family and a multidisciplinary team (e.g. district nursing, hospital specialists etc.). General practice is under pressure with recruitment difficulties and rising demand. Are commissioners aware to what extent individual practices across the county meet the requirements of the GSF?

(l) The ‘Thinking Ahead’ Yellow Folders, designed to help people with advance care planning for end of life, have been criticised as containing minimal information, some of which is out-of-date and inaccurate (at Great Yarmouth and Waveney Joint Health Scrutiny

Committee 13 July 2018).

Have these criticisms been addressed?

Equity of service

(m)To what extent have the commissioners / STP mapped the inequities in end of life provision across Norfolk in terms of availability / waiting times for specific services, e.g. district nurses for care at home, provision of syringe drivers for pain relief, waiting times for nursing home beds?

(n) How far will the STP's plans for palliative and end of life care improve equity of provision proportionate to needs across the county (including hospice care)?

(o) Do the commissioners / STP partners know how many palliative / end of life patients do not receive NHS funded care because their combination of needs are too complex for any one of the NHS services on offer? (e.g. an NHS community bed / service; an NHS mental health bed / service).

Learning from families

(p) To what extent do the commissioners engage with the families of palliative / end of life patients who do not receive NHS funded end of life care (e.g. too mentally complex for NHS community care; too physically complex for NHS mental health care) to receive their feedback about their experience?

5.0 Action

5.1 Depending on discussions at today's meeting, NHOSC may wish to consider:-

(a) Whether there are specific issues to raise with commissioners or providers of end of life services at a future meeting.

(b) Whether there is further information or updates that Members wish to receive via the NHOSC Briefing.

(c) Whether there are any comments or recommendations that committee wishes to make arising from today's report and discussions that may help to shape STP partners' thinking for the future.

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