1. Introduction

This report provides a summary of the current position of palliative and end of life care planning and activity within the Norfolk and Waveney System Transformation Partnership (STP). It also provides information regarding current and planned service delivery activity including workforce and models of care.

Death and dying are inevitable. Palliative and end of life care has been prioritised within our STP. We are one of the only systems to identify and invest proactively for both the planning and delivery of care within the East of England.

Our plans focus on system collaboration and co-operation with partners across health social care, statutory and voluntary bodies, engaging people with personal and professional experience, with an ambition for all to be aligned to a single model of care based on the premise of providing levels of care and where appropriate hospice without walls to enable people to make choices about where they wish to be cared for. Within the last year, much work has been undertaken to promote integration and communication such as integrated end of life care plans. The Hospice at Home Model is now introduced within most of Norfolk excluding Great Yarmouth which is the currently part of a separate procurement process. However, it is recognised that more can 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 principle of the Norfolk and Waveney STP transformation programme is to develop a new holistic person-centred service model that is wrapped around the individual (and their carers/significant others) in partnership with providers and support services across the system.

The local STP transformation programme is based on the delivery of the six National Ambitions for Palliative and End of Life Care (2015). The six ambitions within the national framework for action are principles for how care for those nearing death should be delivered at a local level and eight principles which are the foundations to build and realise the ambitions.

2. Information requested for Norfolk Health Overview and Scrutiny Committee

This section provides the information requested for Norfolk Health Overview and Scrutiny Committee in advance of the meeting.

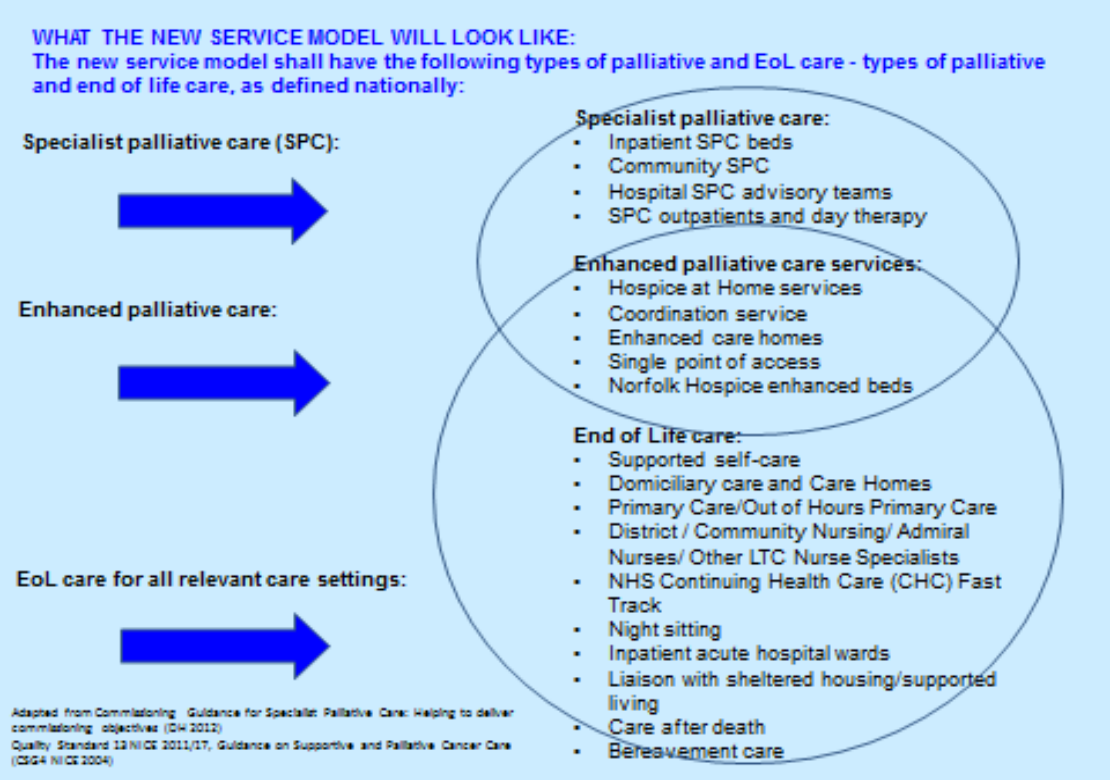
(a) Assessment of the current and future needs for specialist and generalist palliative care services and end of life care in Norfolk:

During the last year the Norfolk and Waveney Collaborative have undertaken an extensive review of gaps across the system. The first review took place in May (2017) when Professor Bee Wee (National Lead for Palliative and End of Life Care) was invited to a workshop with

all providers and commissioners to look at national expectations and review current practice and gaps within the system. The System then reviewed services against the National Ambitions of Palliative Care (2015). This has aided the creation of the work plan for improving palliative care services across Norfolk and Waveney.

Within the last year significant improvements have been made. Central Norfolk have commissioned a hospice at Home Service for North Norfolk, South and Norwich building on the Hospice at Home model in West Norfolk and Great Yarmouth and Waveney are in a procurement process to ensure uniformity across the system.

Following the Collaborative Model of Care Planning workshop all CCGs and providers have agreed to work collaboratively to meet the new model of care principles.



(b) The description of current specialist (including hospice) and generalist palliative services and end of life care in each of the CCG areas covering:-Nature of the specialist services and what they provide. 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)

1. Nature of specialist services and what they provide

Specialist Palliative Care:

- Priscilla Bacon Centre 16 beds and all elements of SPC Care provided
- Specialist Palliative Care within the Acute Trusts; NNUH, JPUH, QEH
- Specialist Palliative Care West Integrated Palliative Care Service supporting community and in-reaching to the QEH
- Specialist Palliative Care 24/7 Advice Line (Central Norfolk and West– out to

Procurement for Great Yarmouth and Waveney)

- Co-ordination Centres West and Central (as above for GY and W)
- Specialist palliative care is provided by:
  - Specialist level in-patient palliative care: this may be delivered in beds in a palliative care unit in hospital or a hospice, or may be delivered by the expert team in the person's usual place of residence in some rural localities. The person's needs are assessed and their care is planned and delivered by medical, nursing and other care staff who specialise in palliative care. Arrangements should be in place for specialist level support to the wider care team at all times (24/7). The service should have access to all essential specialists to constitute a specialist level palliative care team.

  - Specialist level out-patient services: people may have their needs assessed and their care planned by specialists working in out-patient clinics or Day Centres in a variety of settings. Specialist level palliative care out-patient clinics and therapies may be provided by relevant clinicians expert in palliative care from medicine, nursing, Allied Health Professionals, as well as psychology, spiritual advisors or social work that match both the needs of the person and people important to them and their carers. Clinical accountability and responsibility for the coordination and delivery of the person's individualised care plan is shared between the specialist clinician and the person's primary care team in this situation, and clearly agreed arrangements must be in place.

  - Specialist level palliative care liaison work to support the person's care by their usual caring team: this may be undertaken in the hospital or in the community, but both involve the clinical responsibility remaining with the person's key consultant/GP. A specialist assessment can be undertaken leading to recommendations for care that may be provided directly to the person or carried out by the usual caring team who retain clinical responsibility. The person's needs should be reviewed at MDT meetings constituted to consider all specialised level aspects of their care which includes as necessary a palliative care specialist contribution into the meetings held by the usual caring team. Examples may include disease specific multidisciplinary meetings (MDMs) in hospital, Gold Standard Framework of Supportive Care meetings in primary care, and individual review meetings in residential facilities.

<u>Future developments:</u>

Priscilla Bacon Hospice 2 (PBH2)

Discussions are ongoing with East Coast Hospice for the development of a hospice in the Great Yarmouth and Waveney area

<u>Enhanced Palliative Care:</u>

- Norfolk Hospice Tapping House (enhanced beds)
- Care Home Facilitators providing training and advice to staff (North, South, Norwich)
- Hospice at Home multidisciplinary team (North, South, West, Norwich (Out to procurement for Norfolk and Waveney)
- Carers advice line to be commenced (Central, discussion with West and Great Yarmouth and Waveney as part of procurement.

2. Generalist Palliative Care

- Provided by community Nursing and Therapy Teams
- Care Homes (National Six Steps training provided 60 Homes now Accredited) which are seen as the patient's own home
- Out of hours support across the Region
- Access to professional advice line 24/7
- Prisons
- Domiciliary Care
- Community Hospitals
- Acute Hospitals
- Support for Homeless Hostels

Education is provided to support all areas and a collaborative work group have developed core education competencies for palliative care with the aim to implement them within the next year,

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)

Because of the complexity of provision it is difficult to get specific numbers across the patch – the following is the local data mapped against national guidance on compliance of specialist palliative care services

West Norfolk

	Population of 250,000[1]	250 Bed Hospital[1]	Population of 163,000 (West CCG) and 500 Bed Hospital (QEH)		
			Recommended	Current	Variation
Consultants in Palliative Medicine	**2**	**1**	**3.3**	**0.8wte substantive 0.5 wte locum**	**1.3 wte funding and 0.7 wte vacant**
Additional supporting doctors	**2**		**1.3**	**0.6**	**0.7**
SPC Nurses	**5**	**1**	**5.3**	**6.25**	**-**
Inpatient SPC beds	**20 - 25**		**13 - 16**	**0**	**13-16**

Central Norfolk
NCHC community services and SPC inpatient unit

	Population of 250,000[1]	Population of 592,600 (Norwich, North and South CCGs)		
		Recommended	Current	Variation
Consultants in Palliative Medicine	2	5.6	2.1	3.5 in funding
Additional supporting doctors	2	5.6	3.9	1.7
Community SPC Nurses	5	11.9	11.5	0.4
Inpatient SPC beds	20 - 25	47 - 59	16	31 – 43

NNUH

	250 Bed Hospital[1]	1000 Bed Hospital (NNUH)		
		Recommended	Current	Variation
Consultants in Palliative Medicine	1	4	4.2	-
Hospital SPC Nurses	1	4	4.2	-

Great Yarmouth and Waveney

	Population of 250,000[1]	250 Bed Hospital[1]	Population of 230,000 (Great Yarmouth and Waveney CCG) and 459 Bed Hospital (JPH)		
			Recommended	Current	Variation
Consultants in Palliative Medicine	2	1	3.7	1.5 (but posts currently vacant)	2.2 in funding, and 1.5 funded posts currently vacant
Additional supporting doctors	2		1.8	1.0	0.8
SPC Nurses	5	1	6.4	10	-
Inpatient SPC beds	20 - 25		18 - 23	0	18 - 23

4. Geographic location of the services (where applicable)

- Priscilla Bacon Centre for Specialist Palliative Care – Patients access from Norwich, North Norfolk, South Norfolk, Great Yarmouth and Waveney,
- The Norfolk Hospice Tapping House based Hillington West Norfolk Community Health and Care
- St Elizabeth's Hospice Ipswich supports Waveney
- St Nicholas Hospice Bury St Edmunds supports Thetford
- All areas are supported by specialist nurses that outreach to the community.
- Louise Hamilton Centre
- Big C centres
- Future plans/East Coast/PBH2

5. Numbers of in-patient beds, hospice at home 'places', day care 'places', independent hospice and other support services, etc. commissioned

- 16 Specialist Palliative Care Beds Priscilla Bacon Centre
- 4 commissioned beds The Norfolk Hospice Tapping House opening an additional 2 – 3 when needed via spot purchase
- Access to St Nicholas/St Elizabeth Hospices
- Generalist palliative care community hospitals
- Other care settings

Hospice at Home for Central Norfolk
(Enhanced palliative care)

- Norfolk Hospice: Hospice at Home 15 visits allocated per day increases by 5 during winter pressure plus night availability between 1 and 3 patients
- Newly commissioned Hospice at Home 15 Visits a day South, North and Norwich, currently exceeding this
- Great Yarmouth and Waveney – (out to procurement)
- St Nicholas Hospice at Home Service (independent)
- St Elizabeth Hospice at Home service (independent)

6. Who commissions them:
As part of the STP Collaborative there is a Commissioners Sub Group with the aim of working to a single specification with each CCG focusing on specific local need. This includes:

- Norwich, South and North for Central
- West Norfolk, and Great Yarmouth and Waveney

It is expected that Norwich CCG will be the commissioning lead for Palliative and End of Life Care and that all commissioners will work together to have one uniform model acknowledging local diversity. A new specification for Norfolk and Waveney will be written.

7. Who provides them:
NCH&C, NNUH, JPUH, QEH, St Nicholas Hospice, St Elizabeth Hospice and The Norfolk Hospice (Tapping House)

8. Number of patients they serve:
Each service provider has historically collected different data. As part of the Collaborative we will be looking to develop a dashboard where there is uniformity in all data collected and this will provide an overview of all patients and their carers supported by palliative care services.

(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 Palliative Care: Helping to deliver commissioning objectives*[1], December 2012)

A full gap analysis against ambitions was undertaken which has been fed back to the collaborative for palliative care and has formed the work-plan

(d) Analysis of how the capacity of these services compares with the assessment of current and future needs in Norfolk. The previous tables highlight the national position. Work is being undertaken to look at other models of care that are successful elsewhere.

[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

(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)

- Last November we undertook a regional review of services and benchmarked ourselves against other parts of England. This was in alignment with the national lead. We are fortunate that there is a high level of NHS funding compared to other areas. In Scotland hospices receive on average 39% of income from the government. In England on average it is 32% and Wales 27%. Priscilla Bacon Centre and all its elements (inpatients, day therapy, psychological therapies specialist community services), is 100% funded with some posts out of the core specification (complementary therapy) funded by the support group. NHS hospices have reduced significantly over the last few years.

(f) Current 'place of death' statistics for Norfolk, the trend in place of death and how the county compares to the rest of England

Understanding our Population

The table (Appendix 1) highlights the average number of deaths between the years of 2013 and 2015 for both cancer and non-cancer deaths. The average palliative care need has been assumed that 67% the total number of deaths need some form of palliative care. The life expectancy of those living in the most deprived area is lower and the rate of early death from cancer is higher.

Place of death

Norfolk and Waveney has amongst the lowest number of hospice deaths in England and significantly higher numbers of care home deaths. Just over half of all deaths (52%) in Norfolk and Waveney occur in "usual place of residence" (significantly higher than the England average) or 4,865 deaths in 2015. Included in this number are deaths at home that make up about 24% (about the same as the England average), or 2,290 deaths in 2015. Deaths in hospital make up about 44% (significantly less than the England average), or 4,286 deaths in 2015. Most significantly, the proportion of deaths in care homes is well above the national average (27.8% compared with 22.6%).

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 (particularly relevant as Norfolk and Waveney has significantly higher delays in transfers in care for Palliative patients compared to the national average).
- Reduce inappropriate emergency hospital admissions and length of stay.

Place of care/death (Public Health England End of Life Care profiles, 2015 – Place of Death (All Ages) :

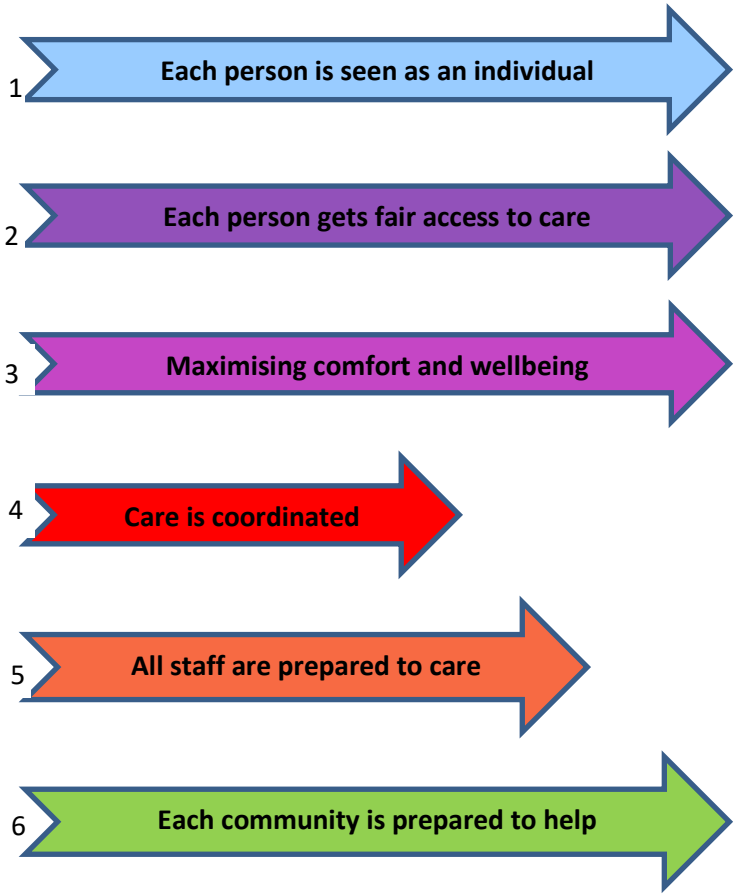
Domain	All ages	England average	Norfolk and Waveney average	Great Yarmouth and Waveney	North Norfolk	Norwich	South Norfolk	West Norfolk
Place of Death	% of deaths in hospital	46.7	44.6	47.2	44.6	47.8	40.5	43.3
	% of deaths in care home	22.6	27.4	25.3	28.1	23.1	29.4	30.6
	% of deaths in own home	22.8	24	25.2	22.6	23.6	24.5	23.6
	Deaths in other places	2.16	2.13	2.17	1.98	2.12	2.23	2.15
	% of deaths in hospice	5.6	1.9	0.2	2.7	3.4	3.2	0.3

Compared with England benchmark:

LOWER	SIMILAR	HIGHER

g) The Norfolk and Waveney Sustainability Transformation Partnership's (STP) ambitions for improvement of palliative and end of life care.

The Ambitions of Palliative and End of Life Care (2015) provides the framework for local action to improve the quality and accessibility of palliative and End of Life Care.



Personalised Care planning	Shared records
Education and training	24/7 access
Evidence and information	Involving, supporting and caring for those important to the dying person
Co-design	Leadership

Key principles of this work are to align commissioning and provider activity and promote uniformity of service provision to improve quality of care for patients and their carers from diagnosis through to Bereavement.

The key initial actions will include:

1) Design and Commission a new service model
2) Review relevant documentation across the STP (Yellow Folders and Respect Documentation)
3) Review and refresh STP approach to workforce planning and training in all relevant care settings
4) Maximise Comfort and Wellbeing

Historically there has been much identification of service need for example through the Marie Curie Delivering Choice Programme therefore this delivery plan focuses on addressing these needs with key stakeholders focusing on integration, communication, coordination and reduction in duplication. 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)".

"In the end, what gives a life meaning is not how it is lived but how it draws to a close" (Tessa Jowell 2018)

Pam Fenner
Clinical Adviser Palliative and End of Life Care
Chair of the Norfolk and Waveney Collaborative

Becky Cooper
Head of Palliative Care Services
Norfolk Community Health and Care

October 2018

Appendix 1 The average number of deaths between the years of 2013 and 2015 for both cancer and non-cancer deaths

Norfolk and Waveney 2013 to 2015 Source: NCC Public Health PCMD data (NHS Digital)	Average Population	Average Cancer Deaths	Average Non Cancer Deaths	Average Total Deaths	Average Palliative Care Need **	Proportion Palliative Care	Male Life Expectancy (Norfolk Data Only)	Female Life Expectancy (Norfolk Data Only)	Age Standardised Rate of early deaths from cancer per 100,000 per year (deaths aged under 75)
Most Deprived Quintile 1	151,721	401	1110	1511	1145	76%	76.3 years	80.7 years	169
Quintile 2	232,644	766	1953	2718	2075	76%	79.8 years	83.7 years	138
Quintile 3	304,417	1022	2628	3650	2783	76%	80.7 years	83.8 years	131
Quintile 4	192,445	553	1455	2009	1528	76%	81.2 years	84.2 years	119
Least Deprived Quintile 5	112,405	296	711	1007	772	77%	83.4 years	86.1 years	96
Norfolk and Waveney	993,632	3038	7857	10895	8302	76%	80.2 years	83.6 years	130