

# Health and Wellbeing Board

## North Yorkshire



### North Yorkshire Scrutiny of Health - In-depth scrutiny of End of Life Care in the county

17 March 2017

**Presented by:** Cllr Jim Clark, Chairman, North Yorkshire Scrutiny of Health Committee  
Daniel Harry, Scrutiny Team Leader, North Yorkshire County Council

#### **Summary:**

The North Yorkshire Scrutiny of Health Committee has undertaken an extended piece of scrutiny looking into the commissioning and provision of end of life care services in the county. This has involved engagement with a broad range of commissioners, service providers, patients and the public.

There are 9 recommendations in the report, many of which flow from the first recommendation to establish a multi-agency forum for commissioners and providers of end of life care in the county.

This extended scrutiny relates directly to the JHWS theme of 'Dying Well'.

#### **Which of the themes and/or enablers in the North Yorkshire Joint Health & Wellbeing Strategy are addressed in this paper?**

[Please tick as appropriate]

Themes	✓
Connected Communities	✓
Start Well	
Live Well	
Age Well	
Dying Well	✓
Enablers	
A new relationship with people using services	✓
Workforce	✓
Technology	✓
Economic Prosperity	

**How does this paper fit with other strategies and plans in place in North Yorkshire?**

The recommendations in the report relate to a number of strategies across health, public health, social care and the community and voluntary sector.

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**What do you want the Health & Wellbeing Board to do as a result of this paper?**

Consider the recommendations and agree a way in which they can be taken forward.

In particular, consider recommendation 1 'to establish a multi-agency forum for commissioners and providers of end of life care in the county'.

Daniel Harry  
Scrutiny Team Leader  
North Yorkshire County Council.

# North Yorkshire County Council

## Scrutiny of Health

### In-depth scrutiny of End of Life Care in the county

#### Executive Summary

The objective of this piece of extended scrutiny work has been to engage with a broad range of commissioners, service providers, patients and the public to better understand the current provision of end of life care in North Yorkshire and identify any areas where recommendations for improvements could be made.

The challenge has been to keep a focus on adding value to the work that has been done to date nationally, regionally and locally and highlighting areas for improvement or further investigation that are realistic and achievable.

Key findings from this piece of extended scrutiny include:

- People are neither used to nor comfortable with talking about death. This is a societal issue that has far reaching consequences for people in the last months of their lives
- The type of patient for whom end of life care services and interventions are provided is changing
- The support that is given to people in the last 12 months of their life is overwhelmingly provided by carers and close family members
- Bereavement counselling and psychological therapies are not widely available or accessible to people in need
- Whilst hospital may be the appropriate place for many people to die, there are significant costs associated with end of life care in hospital and any unplanned or emergency admissions
- There is a strong financial case to support increased funding for multi-agency community-based end of life care packages on the basis of an 'invest to save' argument
- New ways of working may be required to meet the challenges posed by the rural nature of the county
- At present, there is no shared, common vision or strategy for end of life care commissioning and provision throughout the county
- Hospices have over 30 years of specialist knowledge and expertise and could be better involved in the development of a co-ordinated approach across the county
- The planning and co-ordination of care for people in the last 12 months of their life is hampered by the lack of a common electronic system for sharing and updating care plans and patient notes
- The provision of 7 day services and/or out of hours care remains a challenge in health and social care in general and it is also the case for end of life care
- End of life care does not stop at the point in which a patient dies. The way in which family members and carers experience the death of a loved one and how that person is treated after their death will have a lasting impact.

There are 9 recommendations in the report, many of which flow from the first recommendation to establish a multi-agency forum for commissioners and providers of end of life care in the county. It is anticipated that this would enable:

- greater co-ordination of service planning and delivery across health, social care and the voluntary sector
- the agreement of some common standards and principles for equitable end of life care, possibly in the form of a charter or a similar statement of intent
- the identification of a set of outcomes to be achieved with milestones and a mechanism in place for tracking progress against those milestones
- sharing of good and best practice
- the identification of areas for service improvement
- patient and carer representation and involvement and opportunities for co-design
- health and social care strategic planning to be influenced
- inequalities in the access to end of life care services across the county to be addressed.

The recommendations in this report will be presented to the North Yorkshire Health and Wellbeing Board at their meeting of 17 March 2017.

## Section 1 – Background, objectives and methodology

### Background

In July 2015 the North Yorkshire Scrutiny of Health Committee was consulted on the 2015 update of the North Yorkshire Joint Health and Wellbeing Strategy (JHWS) 2015-2020. The Committee concluded that there should be a greater emphasis on improving End of Life Care and supporting friends and relatives deal with bereavement and, in some cases, the longer term problems around isolation and loneliness.

The Committee recommended that End of Life Care should be given greater prominence in the Strategy and that there should be a specific priority of 'Dying Well'. This recommendation was accepted by the Health and Wellbeing Board.

The Joint Health and Wellbeing Strategy 2015–2020 was revised to include the 'Dying well' theme. Under this theme a number of improvements to the quality of end of life care services and interventions are listed that will be progressed by 2020, as below:

- A greater range of support options for people in their last years of life
- More people receiving support for themselves and their families at the end of life
- More people dying at home or in the place that they choose
- Greater numbers of trained staff and carers with deeper understanding about the range of issues in end of life care
- Adoption of new and emerging best practice and principles around end of life care (Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 - [www.endoflifecareambitions.org.uk](http://www.endoflifecareambitions.org.uk))
- End of life care being planned in an effective and sensitively appropriate way, and for staff to be adequately trained.

A copy of the North Yorkshire Joint Health and Wellbeing Strategy 2015–2020 is available here - <http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=21125&p=0>

### The role of the Scrutiny of Health Committee

The role of the Scrutiny of Health Committee is to review any matter relating to the planning, provision and operation of health services in the County.

The aim is to act as a lever to improve the health of local people, ensuring that the needs of the local people are considered as an integral part of the delivery and development of health services.

This includes:

- Focus on action to achieve health improvement
- Examine healthcare in the context of the wider determinants of health

- Examine how health services address the needs of local communities
- Address health inequalities
- Ensure that local health and health related issues are being tackled jointly and in a coordinated way across agencies.

The extended scrutiny of end of life care services and interventions in the county supports the aim to ensure that ‘the needs of local people are considered as an integral part of the delivery and development of health services’.

## **Objective**

The objective of this piece of extended scrutiny work has been to engage with a broad range of commissioners, service providers, patients and the public to better understand the current provision of end of life care in North Yorkshire and identify any areas where improvements could be made.

Recommendations for any improvements will be reviewed at the Scrutiny of Health Committee on 27 January 2017. The intention is then for the final version of the report to be signed off at the committee’s Mid Cycle Briefing on 3 March 2017. Thereafter, the report would be formally submitted to the North Yorkshire Health and Wellbeing Board at their meeting of 17 March 2017.

## **Methodology**

The approach taken has been extended scrutiny over a 6 month period. The project has been overseen by the Committee Chairman in consultation with the group spokespersons.

The project was launched at the Scrutiny of Health Committee meeting on 1 July 2016 and a project plan endorsed at committee on 2 September 2016.

The approach has included:

- Desktop research into national guidance, policy and best practice
- Written reports and presentations to the full committee
- Expert witnesses
- Visits to hospices
- Consultation/focus group discussions with stakeholders, carers and patients.

## **Children and adults**

Whilst the majority of people who die are older people, in North Yorkshire typically 85 years of age or older, children, young people also die and so the end of life care services that are on offer to them and their families have also be considered within the scope of this extended piece of scrutiny.

## Work plan

The following version of the work programme was agreed by the Scrutiny of Health Committee on 2 September 2016:

Date	Action
July 2016	Committee meeting on 1 July - project launch, initial meeting, and engagement with Hospices.
	Mid Cycle Briefing on 29 July - identification of issues (lines of enquiry) to explore at focus group meetings.
August 2016	Further research and contacts, refinement of the project plan and preparation for 2 September committee meeting.
September 2016	<p>Committee meeting on 2 September - update on Joint Strategic Needs Assessment and evidence from 'expert witnesses'.</p> <p>Joint Strategic Needs Assessment (JSNA) report 'Dying Well: an Overview of End of Life Care in North Yorkshire' report and presentation - Victoria Turner, Specialty Registrar in Public Health.</p> <p>Expert witness - Alex Bird, Chief Executive Officer, Age UK North Yorkshire – Health and Wellbeing Sponsor for Health and Wellbeing Strategy priority of 'Dying Well'.</p>
October 2016	Mid Cycle Briefing on 14 October – CCG perspective – overview of the current and planned provision and commissioning of End of life care services by the 5 CCGs in North Yorkshire.
	21 October – North Yorkshire Wider Partnership Conference workshop on End of Life Care.
November 2016	10 November 2016 – site visit to Saint Michael's, Harrogate - convened by Tony Collins.
	16 November 2016 – site visit to St Catherine's Hospice, Scarborough - convened by Mike Wilkerson.
	A joint press release to be issued, by NYCC and NY Healthwatch, inviting people to share their experiences of End of Life Care. Responses to be gathered and analysed by NY Healthwatch.
	Committee meeting on 18 November – update on programme of work, outcome of site visits and evidence from 'expert witnesses'.

Date	Action
	Expert witness – Clair Holdsworth, Deputy Director of Clinical Services, Martin House - Hospice Care for Children and Young People.
December 2016	Mid Cycle Briefing on 16 December – early draft of report for discussion.
	13 December 2016 – site visit to St Leonard’s Hospice, York - convened by Emma Johnson.
	Healthwatch to undertake a survey and analysis of findings to feed into December early draft report.
January 2017	Healthwatch to undertake ‘Enter and View’ visits and feed the analysis of findings into the report in February 2017.
	<p>Early January 2017 - circulate report to partners and contributors for comment, additions and amendments.</p> <p>Committee meeting on 27 January – draft report for review.</p>
February 2017	Finalisation of report.
March 2017	Report to Scrutiny of Health Mid Cycle Briefing for sign off on 3 March 2017
	Report to Health and Wellbeing Board on 17 March.

## Definition of terms

**End of life care** - End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict. End of life care aims to help people live as well as possible and to die with dignity. End of life care continues for as long as it is needed. End of life care includes the palliative management of pain and other symptoms.

**Palliative care** - Palliative care is generally for people living with a terminal illness where a cure is no longer possible. It can also be used by people who have a complex illness and need their symptoms controlled. The goal of palliative care is to help the person and everyone affected by their illness to achieve the best quality of life.

**Own home** – The definition of ‘own home’ is broad as people in the last 12 months of their life may be living in a range of different settings, which they may call home. These could include: a home that they own or rent; the home of a relative or friend; a residential care home; a nursing home; and a hospice. It may be more useful to refer to ‘familiar surroundings’.



**Last 12 months of life** – throughout policy and practice reference is made to the last 12 months of life as the period during which end of life care planning should be undertaken. Medical professionals make an informed judgement as to when a patient is in the last 12 months of their life.

## Section 2 – Literature review

### Introduction

There is a wide range of research, policy, strategy, guidance and best practice on the subject of end of life care. This reflects the position of the UK as an international lead in the provision of end of life care services and interventions. This also reflects the momentum that has been gained since the publication of the 2008 National Strategy for End of Life Care.

The literature review summarises the key issues identified in a range of documents that have been identified as the most significant. It is, by necessity, exclusive.

### National data and needs assessments

#### Office for National Statistics (July 2016) Statistical bulletin: Deaths registered in England and Wales: 2015

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationssummarytables/previousReleases>

The annual data on death registrations highlights:

- There were 529,655 deaths registered in England and Wales in 2015, an increase of 5.6% compared with 2014
- Age-standardised mortality rates (ASMRs) increased in 2015 by 5.1% for females and 3.1% for males; a change to the general decrease in rates in recent years.
- In 2015, mortality rates for respiratory diseases (including flu) increased notably for both males and females.
- Cancer was the most common broad cause of death (28% of all deaths registered) followed by circulatory diseases, such as heart disease and strokes (26%).
- The infant mortality rate remained at 3.9 deaths per 1,000 live births in 2015.

#### Office for National Statistics (2015) National Survey of Bereaved People (VOICES)

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/previousReleases>

This national survey has been run for 5 years. The summary findings from the 2015 survey are as below:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good
- 1 out of 10 (10%) rated care as poor
- Overall quality of care for females was rated significantly higher than males with 44% of respondents rating the care as outstanding or excellent compared with 39% for males
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%)
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%)
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital
- 3 out of 4 bereaved people (75%) agreed that the patient's nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) disagreed that the patient had support to eat or receive nutrition
- More than 3 out of 4 bereaved people (78%) agreed that the patient had support to drink or receive fluid in the last 2 days of life, almost 1 out of 8 (12%) disagreed that the patient had support to drink or receive fluid
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

### **Nuffield Trust (2014) Exploring the cost of End of Life Care**

[http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end\\_of\\_life\\_care.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf)

The Nuffield Trust conducted research into the costs associated with non-hospital care services and how people were using them at the end of their lives. Key findings include:

- Hospital costs were by far the largest cost elements of end-of-life care. These averaged over £4,500 per person for those who died, during the final 90 days of their lives. The bulk of this cost was due to emergency hospital admissions. Hospital costs increased rapidly in the last few weeks of life.
- Approximately two thirds of patients saw their GP at least once during the last three months of life, and there were an average of four to five GP visits per person in this time – costing an average of £147 per patient
- Just over a quarter of patients used local authority funded social care during the last 90 days of their life, but the high costs of nursing and residential care meant this averaged out at £1,010 per person who died.

A health economics report is being written by Public Health England and University of York on the costs of end of life care. At the time of writing, this report had not been published.

## **The Choice in End of Life Care (2015) Programme Board ‘What’s important to me - A Review of Choice in End of Life Care’**

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/407244/CHOICE\\_REVIEW\\_FINAL\\_for\\_web.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf)

The Choice in End of Life Care Programme Board was a multi-agency group tasked by Government to provide advice on improving the quality and experience of care for adults at the end of life and those around them. The programme board agreed the following commitment for the provision of end of life care services.

Each person who may be in need of end of life care is offered choices in their care focused on what is important to them and that this offer is:

- made as soon as is practicable after it is recognised that the person may die in the foreseeable future
- based on honest conversations with health and care staff, which supports the person to make informed choices
- consistently reviewed through conversations with health and care staff.

A total of 30 recommendations were made covering: the individual; family and carers; workforce; health and social care; Government; society and community.

## **Royal College of Physicians (May 2014) National care of the dying audit for hospitals**

<https://www.rcplondon.ac.uk/projects/outputs/national-care-dying-audit-hospitals>

The 2013/14 audit involved a case note review of a sample of all patients dying in hospital. A total of 131 trusts (90% of those eligible) submitted data to the organisational audit. The key findings were:

- Less than a quarter of hospitals had face-to-face palliative care services 7 days per week
- The provision of mandatory training on end of life care for doctors and nursing staff was low
- Documentation of key decisions, assessments and needs in case notes was either inconsistent or key actions were not being taken. For example, there was evidence of only 21% of patients being asked about their spiritual needs
- Local surveys of bereaved relatives showed that 24% did not feel they were involved in decisions about the care and treatment of their family member at all
- Three quarters of bereaved relatives surveyed felt adequately supported during the patient’s last 2 days of life.

## **Local data and needs assessments**

### **North Yorkshire Joint Strategic Needs Assessment**

The North Yorkshire Joint Strategic Needs Assessment (JSNA) provides an overview of the current and future health and wellbeing needs of the people of North Yorkshire. It does not look at the particular needs of individual people but seeks to

identify where needs are not being met as well as they could be. Specifically, it sets out to answer the following:

- What do people need?
- What are we doing already?
- Is it working?
- Are there things we should be doing but are not?
- Are we targeting services properly?

At the Scrutiny of Health Committee meeting on 2 September 2016, Dr Victoria Turner, Public Health Registrar, presented the findings of the JSNA review of end of life care, as summarised below:

### **Headline data**

Place of death in North Yorkshire in 2013:

- In 2013 there were 6,197 deaths in North Yorkshire across all age groups (1.03% of the total population)
- Of these, 22.2% (1,375) deaths occurred at home
- 26.4% (1,636) deaths occurred in a care home
- 5.8% (358) deaths occurred in a hospice
- 43.3% (2,681) deaths occurred in hospital
- 2.4% (147) deaths occurred in other places.

The place of death does not necessarily indicate the range of different settings a person may have received treatment or support in the period leading up to their death.

The top three causes of death in North Yorkshire in 2013:

- Cancer – 27%
- Circulatory disease – 31%
- Respiratory disease – 13%.

### **Unmet need**

Areas of potential unmet need identified:

- Access to preferred place of dying
- Integration of end of life care into all care pathways, particularly for illness pathways other than cancer
- Co-ordinated IT system to enable greater data sharing
- Access to inpatient hospice facilities – there are none in Craven\*, Hambleton, and Richmondshire. Also, there is no children's hospice within North Yorkshire
- Training in palliative care
- Out of hours access
- Holistic care.

\*Craven residents can access Hospice facilities outside of the county.

## Areas for further investigation

It also highlighted areas for further assessment and/or investigation, as below:

- Training, particularly for those people working in more general palliative and end of life care, such as social workers, care home staff and primary care staff. Examples include, e\_ELCA (End of Life Care for All training on line) <http://www.e-lfh.org.uk/programmes/end-of-life-care/learning-paths/>
- Accuracy of recording on the palliative care register
- Information on patient experience at a North Yorkshire level
- Preferred place of death - what proportion of those who express their preference actually die there?
- Assessment of non-health needs, such as social care, spiritual care, legal assistance, general wellbeing advice and emotional support
- Access to services among different socioeconomic groups
- Detailed funding arrangements
- Cost-effectiveness of End of Life Care.

The full report entitled 'Dying Well: an Overview of End of Life Care in North Yorkshire - Joint Strategic Needs Assessment - July 2016' is available on the North Yorkshire County Council website –

<http://hub.datanorthyorkshire.org/dataset/2cb529f6-4715-4c2d-9364-a770deb03472/resource/21e21b0d-54a1-4eb0-9665-bddf2efa24ac/download/eolc-jsna-report-13-07-16.pdf>

## National strategy

### Ambitions for Palliative and End of Life Care - 2015

The key policy document that has been issued by the Government in the past 5 years is the National Palliative and End of Life Care Partnership (2015) 'Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020' - <http://endoflifecareambitions.org.uk/>

This national framework, aimed at local health and social care and community leaders, builds upon the Department of Health's 2008 Strategy for End of Life Care. It has a strong emphasis upon local delivery, partnership, collaboration and co-operation.

The delivery of the national framework is not supported by additional funding. Instead, the emphasis is upon inspiring a wide range of agencies and organisations to drive forward improvements in end of life care.

The national framework has six positive ambitions for palliative and end of life care:

1. Each person is seen as an individual – Honest conversations, Systems for person centred care, Clear expectations, Access to social care, Helping people take control, Integrated care, Good end of life care includes bereavement.
2. Each person gets fair access to care – Using existing data, Community partnerships, Generating new data, Unwavering commitment, Population based needs assessment, Person-centred outcome measurement.

3. Maximising comfort and wellbeing – Recognising distress whatever the cause, Addressing all forms of distress, Skilled assessment and symptom management, Specialist palliative care, Priorities for care of the dying person, Rehabilitative palliative care.
4. Care is co-ordinated - Shared records, Clear roles and responsibilities, A system-wide response, Everyone matters, Continuity in partnership
5. All staff are prepared to care – Professional ethos, Support and resilience, Knowledge based judgement, Using new technology, Awareness of legislation, Executive governance
6. Each community is prepared to help – Compassionate and resilient communities, Public awareness, Practical support, Volunteers.

These ambitions are founded upon:

1. Personalised care planning
2. Education and training
3. Evidence and information
4. Co-design
5. Shared records
6. 24/7 access
7. Those important to the dying person
8. Leadership.

### **Strategy for End of Life Care - 2008**

Department of Health (2008) End of Life Care Strategy - Promoting high quality care for all adults at the end of life

<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>

The intention of the 2008 Strategy was to raise awareness of the importance of end of life care provision and increase access to high quality care for all people approaching the end of life.

Adopting a whole system and care pathway approach, the strategy defined a set of minimum expectations around a 'good death' as being

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

The strategy outlined what its successful implementation would mean for patients and carers, as follows:

- The opportunity to discuss your personal needs and preferences with professionals who can support you, have them recorded in a care plan and acted upon
- Coordinated care and support
- Rapid specialist advice and clinical assessment
- High quality care and support during the last days of your life

- Services which treat you with dignity and respect both before and after death
- Appropriate advice and support for your carers at every stage.

To achieve this, services will be:

- Well planned and coordinated
- Quality assured and delivered to a high standard
- Monitored and assessed to ensure quality
- Informed by the experience of others who have been in a similar situation to you.

The strategy is credited with having managed to reverse the upward trend of people dying in hospital. Also, that it generated momentum and energy, which led to significant improvements in end of life care.

### **One chance to get it right - 2014**

Leadership Alliance for the Care of Dying People (2014) 'One chance to get it right - Improving people's experience of care in the last few days and hours of life'.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)

In 2014 the Leadership Alliance for the Care of Dying People published a report setting out an approach to caring for dying people that should be applied system wide, in all settings. In summary, the Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

- The possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed
- Sensitive communication takes place between staff and the dying person, and those identified as important to them
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The Leadership Alliance, a partnership of 21 organisations from health, social care and the community and voluntary sector, was set up in response to the independent review of the Liverpool care Pathway for the Dying Patient (LcP), which reported in July 2013.

### **Actions for End of Life Care – 2014**

NHS England (2014) Actions for End of Life Care: 2014-16

<https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

This national policy statement set-out a series of commitments for the period 2014-16, based upon a 'House of Care' model, as below:

- People who are living with progressive, life-limiting conditions must be at the centre of any decision, plan or action for their care or treatment
- Health and care professionals build and sustain their commitment to working in partnership with each other, and with the people they care for and those close to them
- Consistent, coordinated care is a crucial component of person-centred care, especially for people with progressive, life-limiting conditions, and those close to them
- Improve the commissioning of palliative and end of life care services so that people living with progressive, life-limiting conditions, and those close to them, can receive the best possible care which matches their level of need and, as far as possible, preference.

It pre-dates the 2015 national framework and represents a restatement of much of the 2008 Strategy.

## **Clinical guidance and best practice**

### **NICE commissioning guidelines - CMG42 (December 2011) 'Guide for commissioners on end of life care for adults'**

<https://www.nice.org.uk/guidance/qs13/resources>

The guidelines identify a number of areas in which clinical practice and quality can be improved:

- Reducing inequalities and improving identification through de-stigmatising death and dying and encouraging healthcare professionals and people with end of life care needs and their families and carers to engage in open conversations
- Improving the quality of care including care after death, through holistic assessments and timely interventions in the right place by a knowledgeable, caring and competent workforce
- Increasing choice and personalisation through care planning and advance care planning, including advance statements and advance decisions to refuse treatment and provision of resources that enable these choices to be achieved.
- Ensuring care is coordinated and integrated across all sectors involved in delivering end of life care
- Improving the psychological, physical and spiritual well-being of people with end of life care needs and their carers through access to an appropriately trained and resourced workforce
- Timely access to information and support to enable people with end of life care needs and their families and carers to make informed decisions
- Timely provision of continuing NHS healthcare funding to support people to die in their place of choice
- Supporting carers and ensuring access to an assessment of need as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004
- Timely access to generalist and specialist palliative care services on the basis of need and not diagnosis. This includes the provision of community based support



and access to specialist advice (which may be via telephone) 24 hours a day, 7 days a week

- Reducing unnecessary hospital admissions and length of stay by developing capacity to deliver expertise to the person's usual place of residence through pathway redesign and workforce development. This includes supporting staff in social care settings such as care homes and domiciliary workers; supporting relatives and friends who are caring for a person with end of life care needs; and providing the necessary clinical expertise, medicines and equipment
- Improving cross-boundary and partnership working, through close working between health and social care services to ensure flexible and integrated services that have the infrastructure to enable this (for example shared IT networks). This should improve care coordination, minimise unnecessary duplication and reduce costs
- Improving knowledge and skills in generalist and specialist palliative care settings, and in social care settings including independent residential and nursing homes and domiciliary workers.

**Care Quality Commission (May 2016) 'A different ending: End of life care review' - Addressing inequalities in end of life care**

<http://www.cqc.org.uk/content/different-ending-our-review-looking-end-life-care-published>

The report found that there were significant variations in end of life care and that a number of groups were under-represented:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and Minority Ethnic (BME) groups
- lesbian, gay, bisexual and transgender people
- people with a learning disability
- people with a mental health condition
- people who are homeless
- people who are in secure or detained setting
- Gypsies and Travellers.

Specific actions that have been identified to enable everyone to access the care that they need:

1. Leaders of local health and care systems to work together to develop a plan for delivering good quality, equitable end of life care for everyone in their community.
2. Commissioners and providers to fulfil their duties under the NHS Constitution, the Health and Social Care Act 2012 and the Equality Act 2010 to reduce inequalities, eliminate discrimination and advance equality when developing, arranging or delivering end of life care.
3. Commissioners and providers to ensure that staff who care for people who may be approaching the end of life, including care home staff, have the knowledge, skills and support they need.

4. Hospices to champion an equality-led approach, engage communities, deliver equitable end of life care, and support others to do the same.
5. GPs to ensure that everyone with a life-limiting progressive condition has the opportunity to have early and on-going conversations about end of life care, and is given a named care coordinator.

## **Non-governmental guidance and best practice**

### **End of Life Care Coalition ‘On the Brink: The Future of End of Life Care’**

<http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf>

The following are identified as making a difference:

- Well-funded high quality care available both inside and outside hospital for all who need it
- Investment in palliative care specialists and generalist health and social care professionals with the knowledge, understanding and time to deliver choice and provide high quality care for people at the end of their lives
- Access to good quality advice and support, including out of hours, to provide families and carers with practical assistance and guidance if the person they are caring for has a change in symptoms or needs additional help
- Fully co-ordinated and integrated care across all teams and services supporting a person at the end of their life, including fair access to social care, using appropriate care plans in a joined-up way
- Training for all health care professionals, so they know how to support someone approaching the end of their life confidently and sensitively
- A higher proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families.

### **Together for short lives ‘Charter’**

‘Together for short lives’ is a UK charity that represents all children and young people who are expected to have short lives.

- Every child and family member should be treated with respect and dignity
- The child and family should be offered an individual care and support package that is built around their unique needs
- A multi-disciplinary team should work together to support the family, and communicate with the child and family in an open and honest manner
- Children and families should always be listened to, and be encouraged to talk through their wishes and care choices
- At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information that they can understand
- Where possible, children should be cared for in the family’s place of choice – in hospital, a hospice, or at home
- Emotional, psychological and spiritual support should be offered to the child, and those close to him or her

- Children and young people should be given the opportunity to access education and employment that is right for them
- The child and family's wishes concerning end of life care should be discussed and planned for well in advance
- Support and care should extend to all family members, friends and all those involved with the child.

Further information is available from the Together for short lives website, as follows <http://www.togetherforshortlives.org.uk/>

## **Summary of key findings from the literature review**

There are a number of themes that have been identified in the literature review, as below:

- The majority of people, about 75%, experience good quality end of life care, whether that is at home, in a care home or in a hospital. However, 25% do not.
- Whilst most people state that the preferred place of death is their own home, most people, 43%, die in hospital. It is recognised, however, that a person's view on where they would like to die depends on the nature and progress of their disease and how their quality of life and ability to exercise personal choice can best be supported. Often, this will mean that a hospital bed is preferred to their own home.
- In 2013/14, less than a quarter of hospitals had face-to-face palliative care services 7 days per week and mandatory training for doctors and nurses on care of the dying was not universally provided or taken up.
- The question that should be posed is not one of 'where would you prefer to die' but 'what would you like to have in place to make your death the best it can be for you and those around you?'
- There remains a reticence to openly discuss death and make plans and decisions about how someone will live out the last 12 months of their life. This reticence is cultural/societal and so inhibits the ability of patients, carers and health and social care staff to plan care packages and make informed choices.
- There are an excessive number of unplanned hospital admissions for people in the last months of their life. Typically, these admissions are via Accident and Emergency Departments. This reactive approach is not in keeping with good quality care and effective symptom management and can generate unnecessary costs to the health system.
- Care is not consistently co-ordinated throughout the health and social care system. The wishes of an individual are not routinely recorded and shared as a personalised care plan, which can be accessed by all relevant health and social care agencies and organisations.

- Not all health and social care staff are trained and in assessment and symptom management.
- There is a shortage of specialist end of life care and palliative care knowledge and experience within health and social care services.
- Family members and carers are not routinely involved in dying people's care planning.
- Out of hours support for patients and their carers, when in their own home, is varied and inconsistent. As a result, many people who could be supported to live in their own home during their last 12 months of life are unable to.
- There is only limited assessment of non-health needs, such as social care, spiritual care, bereavement support, legal assistance, general wellbeing advice and emotional support.
- There is not consistent and fair access to end of life care services and interventions, with variations in access to among different socioeconomic groups.
- There are no inpatient hospice facilities in Craven, Hambleton, and Richmondshire district council areas.
- Over time, end of life care services and interventions have been based around people suffering from terminal cancer. There are a number of other terminal diseases for which end of life care pathways need to be developed and improved.
- There is no new central Government funding and securing additional local funding will depend on whether end of life care is a local priority.

### **Section 3 - Organisations Giving Evidence**

#### **County Council – Health and Adult Services**

Ian Spicer - (Interim) Assistant Director, Care and Support, attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016 and provided an overview of the role that the County Council plays in supporting adults in the last months of their life. In particular, what is currently in place and where there were further opportunities for joint working and/or service improvements.

#### **Existing approach**

- A service specification is in place for independent care Homes and Nursing Homes that sets out some minimum standards for end of life care and for the promotion of dignity.
- There is a commitment to promote choice and for people to be enabled to plan the last 12 months of their life, including where they would prefer to die.

- The key role that carers have to play is recognised, as is the need to provide consistent support to them.
- A new role within Health and Adult Services (HAS) has been created, 'Practice lead', which has responsibility for end of life care, amongst other. The focus here will be upon promoting good practice and high quality assessments of need, under the new model for care and support that HAS adopted.

### **Service improvements**

- There are opportunities for joint training and staff awareness across the health, social care and community sector.
- There could be closer working with hospices in the county, drawing upon their extensive experience of end of live care service development and implementation. The Hospice UK website has a number of examples of joint working across hospices, health and social care - <https://www.hospiceuk.org/policy-advocacy/briefings-consultations>
- Improvements could be made in end of life care planning, particularly following any changes in placement.

## **County Council – Children and Young People’s Services**

Emma Thomas, Children’s Commissioning Manager – Healthy Outcomes, attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016 and provided an overview of the role that the County Council plays in supporting children and young people in the last months of their life.

Children are subject to the ‘continuing care’ process of assessment. A continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

‘Together for short lives’ is a UK charity that represents all children and young people who are expected to have short lives. The aim of the charity is to help children and families make the most of their time together. Together for short lives has produced a summary of how end of life care for children and young people is different to adults, as below:

- The number of children who die is small
- Many of the conditions are extremely rare with diagnoses specific to childhood
- Palliative care may last only a few days, weeks or months, or may be delivered on and off for a number of years.
- Many of the conditions are genetic
- Children’s palliative care embraces the whole family
- Children’s palliative care providers need to be aware of and respond to the continuing physical, emotional and cognitive development throughout childhood
- Provision of education and play when a child is seriously ill is essential.

Further information is available from the Together for short lives website, as follows <http://www.togetherforshortlives.org.uk/>

## **Clinical Commissioning Groups**

Representatives from the five Clinical Commissioning Groups that commission services in North Yorkshire attended a Mid Cycle Briefing of the Scrutiny of Health Committee on 14 October 2016, to discuss end of life care provision in the county. The key issues identified are summarised as below.

### **Key challenges**

- Both a dispersed population and a dispersed system of health and social care resources having an impact on the effective delivery of packages of end of life care in people's homes
- Lack of domiciliary care and difficulties in commissioning Fast Track Continuing Healthcare
- Fragile market of specialist and generalist health and social care providers
- End of life care for people who are frail, have dementia or a number of different conditions
- Delivery of an equitable approach across the county that reflects local needs, infrastructure and services
- Shortages of trained health and social care staff who can support delivery of end of life care
- Need to better understand the 'disease trajectories' and what specific conditions, other than cancer, mean for people's end of life care
- Need to provide support for carers and families, once a package of end of life care has been put in place. Otherwise, the package of care can fail as carers and families struggle in the final days of a loved one's life.

### **Key infrastructure**

- Strong working relationship between the Acute Trust and the CCGs
- Electronic Palliative Care Coordination System (EPaCCS) – question as to whether this will be put in place across North Yorkshire
- Community nurses play a key role in delivering and coordinating community-based end of life care
- Reliance upon the community and voluntary sector
- The 111 directory is helpful but only if kept up to date
- Rapid relief teams as a replacement for fastrack, in some areas.

### **Sustainability Transformation Plans**

- Concerns that end of life care may not be a priority under the new planning regime
- CCGs and need to ensure that, despite the large geographic coverage of the STPs, a local approach to end of life care is implemented
- STPs are focussed upon the centralisation of specialist services but end of life care is best provided locally and in the community
- The STPs may offer some economies of scale and enable the provider market to be strengthened.

## **Engagement**

- Some patients and carers are fiercely independent and do not accept the care or support that they need until it is too late for an end of life care package to be put in place
- Need to ensure that health and social care practitioners are trained in and have confidence in having discussions with people, as they approach the last year of their life, about their choices
- Queries about how you identify someone as being in the last year of their life
- If you get it right for one person, then others will hear of it and it will increase confidence amongst service users and providers.

## **Examples of local good practice**

- Gold line 24/7 service for patients thought to be in their last year of life and their carers. Patients who use Goldline have better outcomes and reduced hospital admissions (14% die in hospital compared to 35% of all deaths in Airedale, Wharfedale and Craven (AWC) CCG area. Covers AWC CCG and 2 Bradford CCGs
- AWC CCG is part of the National Pioneer Programme that is testing out new models of care
- System 1 – shared across GPs, hospitals, community nurses and hospices in AWC CCG area
- Serious Illness Care Programme UK, which looks at improving joint planning of patient care
- Use of step up and step down beds and commissioning of nursing home beds for end of life care – Hambleton, Richmondshire and Whitby (HRW) CCG
- Wrap around care in people's homes and community therapy, intermediate care and community nursing services AWC CCG
- Joint work with pharmacies to ensure access to medication – Harrogate and Rural District (H&RD) CCG
- PalCall Service – nurse led out of hours helpline in Scarborough and Ryedale (S&R) CCG
- Voluntary and Community sector care and support through the Carers' Resource and home from hospital services.

## **Possible next steps**

- Create a forum for commissioners and providers of end of life care to meet and work through shared challenges, share best practice, coordinate activity and tackle gaps in provision
- Retain a strong focus on commissioning community based palliative care in people's homes
- Agree a shared vision for the outcomes that we collectively want to achieve for end of life care in North Yorkshire. The focus is upon outcomes and standards and not processes.
- Join up the health and social care workforce strategies
- Review level of support, information and advice provided to carers of people who are nearing the last 12 months of their life
- Articulate the financial argument in favour of supporting people to die in their own home
- Clarify care home training needs

- Review fast track commissioning arrangements/intentions
- Agree realistic targets to work to for people dying in the place of their choosing
- Strengthen links with Yorkshire Ambulance Service.

## Hospices

### **Tony Collins, Saint Michael's Hospice**

Tony Collins, Chief Executive, Saint Michael's Hospice, Harrogate presented a report to the Scrutiny of Health Committee on 1 July 2016. The key points raised are summarised as below.

A copy of the full report is available on the North Yorkshire County Council website.

<http://democracy.northyorks.gov.uk/committees.aspx?commid=23&meetid=3368>

### **North Yorkshire End of Life Care**

North Yorkshire has a statistically higher than average:

- Older population (those above 65, 75 and 85) for males and females
- Death rate
- Percentage of deaths
- Deaths in care homes
- Deaths from heart disease.

North Yorkshire has a statistically lower than average:

- Deaths in hospital
- Residents in urban localities
- Deaths from respiratory disease
- Deaths from liver disease.

It has been estimated that 3,600 will die within the population each year. It is likely, however, that from the 16,448 people over 85 years of age, some end of life care service will be required and could be required for longer than the last months of life.

### **Value for money**

Taken from a number of sources, including Hospice UK and Marie Curie, evidence suggests that Hospices are value for money. Hospices provide value for money:

- Hospices can support in the reduction of unnecessary admissions
- Hospices can reduce hospital deaths by 20% each year generating a saving of £80m to the NHS
- The palliative care funding review for England found extending 'specialist and core' services could result in net savings.

Bereavement increases the risk of mortality and poor health. In Scotland, this cost was estimated to be £20 million, which when extrapolated to England was between £150 and £190 million.

There is estimated to be between 80,000 and 124,000 people living with Lymphoedema in the UK. Lymphoedema is a swelling that develops as a result of an impaired lymphatic system. This may be as a result of the lymphatic system not



developing properly or through damage or trauma, such as cancer. For every £1 spent on Lymphoedema treatments it is estimated that it would save £100 in reduced hospital admissions due to swelling and infection.

### **Clair Holdsworth, Martin House**

Clair Holdsworth, Deputy Director of Clinical Services, Martin House gave a presentation on end of life care to the Scrutiny of Health Committee on 18 November 2016.

Clair gave an overview of the service provided by Martin House, how palliative and hospice care for children and young people differs from that provided to adults, and some of the issues encountered by children, young people and their families when seriously ill and in need of palliative care. Specifically:

- The need for care and services that is right for their age – from neonates to young adults
- Short breaks, with nursing and medical support when required
- To be able to continue with their education and have the opportunity to participate in social activities and be with their friends
- Specialist support for siblings
- Bereavement support for the family.

Clair Holdsworth stated that a piece of research had been undertaken that suggested that there were 398 children in North Yorkshire that needed specialist palliative and hospice support. It is understood that this is an under-estimate and that the real figure is likely to be around 560.

Clair Holdsworth noted that the main referral routes were via consultants and social care.

A number of challenges were identified, as below:

- Recruitment of qualified/skilled staff – albeit that in-house training schemes are in place to up-skill workers
- Shortages of some specialist staff within the NHS locally, which creates gaps in community-based service provision
- Identifying ‘hard to reach’ children and young people
- A shortage of counselling services for children in the community.

## **Voluntary and Community**

### **Alex Bird, Age UK North Yorkshire**

Alex Bird, the Voluntary Sector Representative on the North Yorkshire Health and Wellbeing Board and the Sponsor for the End of Life Care Theme, gave a presentation on end of life care to the Scrutiny of Health Committee on 2 September 2016. The key issues identified are summarised as below:

The End of Life (EoL) for everyone is a time of significant vulnerability both for the person who is dying, and the family/friends they choose to have around them.

Everyone should have the right to high quality palliative care when they have a terminal illness, regardless of their condition, where they live, or their personal circumstances.

The UK has been ranked as the best country in the world for palliative care on offer but access to care is patchy and one in four people who need palliative care miss out each year.

Whether a dying person is cared for at home/hospital/care home/hospice- right to expect that their pain will be managed actively, treated with respect and compassion, and that they are listened to.

### **National approach**

The “Review of choice in End of Life Care” was published in 2015 and set out the elements of EoL Care that people most care about and where people felt choice should play the greatest role.

In July 2016, the Government unveiled a new national commitment on EoL care setting out its vision for improving care for dying people and their families. The key components of personalised care are set out that everybody should expect to receive.

### **Key partners**

Local ownership and accountability will be critical to help achieve the central government vision. Key partners will be the CCGs and the Health and Wellbeing Board. As well as these named players, other important partners include Care Homes, Hospices, voluntary organisations e.g. Macmillan, Marie Curie, Sue Ryder as well as local community based charities and most of all, individuals and the families and carers.

Some key issues identified by people at the EoL include:

- Discrimination and lack of understanding by care and support services
- Religious and spiritual needs
- Assumptions about sexuality or gender identity and family structures
- Varied support networks
- Unsupported grief and bereavement
- Increased pressure on carers.

### **Recommendations**

Making good EoL care happen is not the responsibility of one persons or organisation. It happens because professionals and organisations work together, share information and focus on the individual’s needs. Some key aspects include:

- Training for staff
- Work with national and local charities e.g. MacMillan, Sue Ryder, Hospices
- Ensure that literature and materials about EoL services reflect all diverse groups
- Share examples of local excellence in EoL care
- Strengthen accountability and transparency (June 2018- new Clinical Priority Area) and leadership

- Equality - understand, acknowledge and action variations in EoL care.

As providers, funders and leaders we all have a role to play in helping to deliver improvements and to use our influences to help more people achieve their wishes and preferences at the end of life.

## **NY Wider Partnership Conference**

A workshop on 'End of Life – Dying Well' was held at the North Yorkshire Wider Partnership Conference on 21 October 2016. The workshop was hosted by Alex Bird, the Voluntary Sector Representative on the North Yorkshire Health and Wellbeing Board. The key issues raised from the group discussions at the workshop are as summarised below:

### **Key questions**

- How do we effect cultural change and encourage people to plan for the last 12 months of their life?
- Processes as an enabler for choice and not a barrier?
- Pain management well covered but what of practical day to day needs of people that ensure a high quality of life in their last months and days?
- Can we agree a common set of performance indicators and targets?
- Do we need a Charter for North Yorkshire that sets out a shared set of principles and goals?
- Is there a role for the private sector in end of life care provision?

**Challenge 1** – about 80% of people want to die in their own home but only about 20% do. How do we close the gap?

**Challenge 2** -for the 20% that opt to die elsewhere, do they get the care that they wanted?

### **Areas for development**

- Training a range of health and social care staff to enable them to have difficult conversations with people about how they want their last 12 months of life to be
- Look at the disease pathways for non-cancer diseases so people are better able to help people plan their last 12 months of life
- Sharing of best practice like 'Goldline'
- Support for carers, including pre-bereavement work
- Documenting, sharing and adhering to an end of life care plan with all those who need it
- End of life care for people who are learning disabled
- Role of GP in having the initial conversation with patients about their end of life care
- Care home and residential nursing home policy and practice
- Awareness of the range of different needs of people at the end of life, including cultural and religious
- Better communication from specialists when a patient is felt to have exhausted all possible active treatment for their long term condition. It is not always clear to a GP when a patient is moving from active care to palliative care phase of illness.

## Other

- A hospice can play a key role in helping to stabilise someone who has deteriorated before then returning them home
- Death cafes enable a broad range of people to work through some of the practicalities around end of life care
- Voluntary and community sector often have a key role to play but can find it difficult to connect with and work with the NHS and other public sector services.

The presentation from the workshop can be accessed here -

<http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=35439&p=0>

## Hospitals

A number of questions, informed by the overview of CQC reports in section 4, were sent by email to the Chief Executives of the three main hospital trusts in the county: Harrogate and District NHS Foundation Trust; York Teaching Hospital NHS Foundation Trust; and Airedale NHS Foundation Trust. The replies that had been received at the time of writing are included below:

### **Dr Ros Tolcher, Chief Executive, Harrogate and District NHS Foundation Trust**

The Specialist Palliative Care (SPC) team take a lead role in delivering and supporting others to provide End of Life Care (EoLC) in both the hospital and community setting. The team ethos within the organisation is to work collaboratively with many agencies across health and social care and would value the opportunity to discuss this further.

#### *Is there a strategy or plan for the delivery of End of Life Care?*

A draft work programme for EoLC has been drawn up and is due to be ratified at the HDFT End of Life Steering Group meeting towards the end of January. This piece of work reflects comments from the most recent CQC report and feedback from clinicians and service users. Its content is structured around and informed by the national framework document 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' which emphasises the need to make decisions and deliver services based on local need.

#### *Are specialist End of Life Care services available 7 days a week?*

Currently there is a SPC service which provides advice and support for patients in the hospital and community Monday to Friday 08:30-17:00. Out of hours there is access to telephone advice for health care professionals from Saint Michael's Hospice. This is provided by hospice nurses, the hospice doctor on call, or the consultant on call as appropriate. This is an informal working arrangement that enables out of hours cover.

The team has compiled an options paper on a 7 day per week service which describes the evidence for delivering such a service and the investment required to meet this. This paper will aid discussions with the Trust and the Clinical Commissioning Group (CCG) about moving towards this in the future.

#### *Are all staff able to identify anyone who might benefit from specialist End of Life Care services?*

For all staff to identify patients who may benefit from EoLC every time requires an appropriate level of education and training and we recognise that more is required. Training in EoLC is not mandatory for community and hospital staff at present. The SPC team does however, plan to appoint a Clinical Nurse Specialist in the near future who will lead on education and will develop a comprehensive education and training strategy for all staff groups in the hospital and community, the aim being that all staff are prepared to care for patients at the end of life.

Health care professionals are able to use the SPC team referral criteria to help guide them in their decision making. The community SPC Clinical Nurse Specialists aim to attend all the Gold Standards Framework / Palliative Register meetings at GP Practices to guide Primary Care teams in whom to include on the register and in managing the patients effectively in a timely and responsive manner.

*To what extent are hospital staff able to access End of Life Care plans that have been developed by GPs and others?*

GPs aim to create care plans for the 2% of patients most likely to have unplanned hospital attendances. This 2% will include some patients who are approaching the end of life. If a care plan is created, a template is completed on SystemOne and the patient is given a paper copy, but the plan is not shared with the hospital (most hospital staff cannot access SystemOne). So the plan will only be accessed if a paper copy comes in to hospital with the patient; this does not often happen.

There is an opportunity to improve communication around end of life decisions and discussions by enabling shared access to patient information by using an Electronic Palliative Care Coordination System (EPaCCS). A business case has been developed by the New Care Models IM&T and the Local Digital Roadmap Group but there is no definite plan currently to take this forward. The introduction and implementation of EPaCCS is a key area for improvement in the End of Life work plan.

*Is there an issue relating to the breakdown of End of Life Care in the community and unplanned hospital admissions?*

We do not currently collect data on unplanned hospital admissions related to a breakdown of care in the community, although a significant issue would be captured via incident reporting. It is therefore difficult to draw clear conclusions.

Fast track services are not currently commissioned through HDFT as they are provided by independent providers which are booked through the Partnership Commissioning Unit on behalf of the CCG. They are frequently unable to source care packages. Care is sometimes picked up by the Community Care Teams wherever they have capacity as an interim.

There are delays in discharging patients in the last weeks of life in a timely manner for the above reasons. Anecdotally, patients are waiting several days to a week or so for discharge home, often due to care packages being unavailable. Again this is a key area of exploration for the EoLC work programme.

*Are there any obvious gaps in services that prevent Hospitals from playing a fuller role in End of Life Care planning and delivery? What more could be done to fill such gaps?*

There are actions that can be taken to enhance care planning and delivery and these have been discussed: for example

- Funding and provision of a 7 day face to face assessment SPC service,
- Implementation of EPaCCS across the locality and consideration of solutions to share information between community and hospital setting,
- Timely rapid discharge home to die (last weeks /days of life) from hospital and further collaboration with social care.

We would welcome the opportunity for a fuller discussion around commissioning of services in the community around End of Life Care. We hope this information is helpful and look forward to further discussions.

## **Local Medical Committee**

The following questions were sent to YORLMC, the Local Medical Committee for North Yorkshire, on 6 January 2017.

In response, a series of telephone interviews were conducted, in the week commencing 16 January 2017, with YORLMC representatives, as summarised below:

*Do GPs routinely discuss End of Life Care with patients in the last 12 months of their life?*

Yes. GPs play a key role in starting a discussion with patients who are in their last 12 months of life, their families and carers about the type of care that can be made available to them. There is a strong focus on symptom control (all symptoms and not just pain), a collaborative approach and providing support to family members and carers.

*Are End of Life Care plans developed with GPs and shared with all relevant partner agencies?*

Yes. End of Life Care Plans are initially developed by GPs, District Nurses and Macmillan Nurses with the patient, family members and carers. These are then shared with partner agencies and organisations. Regular Gold Standards Framework / Palliative Register meetings are convened by GPs and attended by community and hospital based nursing staff.

There can be difficulties associated with sharing the care plans with all those that need to see them, particularly at a point of crisis. There is no common means across all health and social care agencies in the county that has been adopted that allows the sharing electronic versions of care plans in a format that can be updated.

A software system, called the Medical Interoperability Gateway (MIG), is available that can connect health and social care organisations and enable the sharing of patient records (in a read-only format).

NHS Digital is currently reviewing how special patient notes can be made accessible to all health and social care agencies involved in the delivery of a care plan.

*Are there any obvious gaps in services that prevent GPs from playing a fuller role in End of Life Care planning and delivery?*

There are a number of gaps in services and care pathways, as outlined below:

- District Nurses - the District Nurse Service in the county is not 24/7. Service provision ends each day at 10pm. North Yorkshire is one of only 2 areas in the country not to have a 24/7 service.
- Do Not Attempt Resuscitation (DNAR) forms are only applicable to people suffering from a cardiac arrest. For people with other conditions, a Living Will or Advance Directive is needed. If not, then people may well be admitted to hospital contrary to what they have previously requested for their care.
- Palliative Clinical Nurse Specialists – there is a shortage of these specialist nurses.
- Hospice admission – further work could be done to clarify the admissions procedures for hospices, particularly out of hours and for respite care. At present, GPs can admit directly to hospices out of hours.
- Respite care – there is a shortage of respite care.
- Psychological therapies – there are significant gaps in the provision of psychological therapies and support for people who are dying and their carers and family members.
- Palliative care drugs – there are concerns that there is insufficient access to and availability of palliative care drugs from community pharmacies, particularly out of hours. There are also issues of cost (£3,000) and time (6 months of more) around applications for licences to stock Schedule 2 palliative care drugs.
- Patient records - there is no common means across all health and social care agencies in the county that has been adopted that allows the sharing electronic versions of care plans in a format that can be updated.

*Any additional comments?*

Out of hours GP services have a key role to play in the delivery of End of Life Care Plans, particularly at a point of crisis. Links with other health and social care services who operate out of hours are good but more could be done to look at how the out of hours system works and to improve patient outcomes.

GPs regularly conduct reviews of the quality of End of Life Care that has been provided, as part of the Significant Event reporting system. This provides opportunities for lessons to be learned and services to be improved.

## **Local Pharmaceutical Committee**

Jack Davies, attended a meeting of the North Yorkshire Scrutiny of Health Mid Cycle Briefing on 16 December 2016 to discuss Government changes to the funding of community pharmacies. The following possible impacts of reduced funding were highlighted:

- Reduced opening hours and staffing levels

- End free services, such as the home delivery of medicines
- Reduced investment in facilities and services
- Reduced stock held on the premises, with the result that people may not be able to get the medicine they need then and there.

The reduction in stock and the end of free services, such as home delivery of prescriptions could impact upon the availability of and access to palliative care drugs, particularly at a time of crisis.

Jack Davies also suggested that an independent community pharmacy was contacted to further understanding of the role that they play in supporting the delivery of end of life care services in the community.

A telephone interview was conducted with an independent community pharmacy in the county on 6 January 2017. The outcome of the interview is summarised as below:

*What role do community pharmacies play in End of Life Care and supporting people in their own home?*

The key role is one of ensuring that palliative care drugs are available as and when needed. The pharmacy also operates a free delivery scheme, as part of its general business operation, of prescriptions to people in the community. This includes palliative care drugs.

*Are community pharmacies involved in care planning and do they work with the GP and Hospital?*

There is no role for community pharmacies in palliative care planning but the pharmacy works closely with local GPs and District Nurses to ensure that the drugs that are needed are made available promptly and often out of hours.

*Are community pharmacies able to maintain a sufficient stock of palliative care drugs?*

The pharmacy is commissioned under the Palliative Care Drugs Service to maintain a stock of a locally agreed list of palliative care medicines. A small number of community pharmacies will be commissioned to provide this service across any given area, with a view to maintaining sufficient coverage. Individual community pharmacies may also have stocks of various palliative care drugs.

Follow up questions with Jack Davies revealed that a Palliative Care Drugs Service is only commissioned by the Vale of York and Scarborough and Ryedale CCGs. It was noted, however, that a number of community pharmacies elsewhere in the county have volunteered to maintain sufficient stocks of palliative care drugs.



## Summary of key findings

There are a number of themes that have been identified, as below:

- There are opportunities for joint training and awareness raising on end of life care planning across health, social care and the voluntary sector that are not currently being realised.
- Hospices have been providing end of life care in the county for over 30 years and have built up years of specialist knowledge and expertise that could be used to support training and awareness raising.
- Whilst end of life care for people with terminal cancer is well established, it is not for people suffering from other terminal diseases. Further work is needed to better understand the 'disease trajectories' and what this means for end of life care planning.
- Good practice or best practice is not routinely shared across agencies and organisations in the county and there is no place or forum for work to be co-ordinated at a county-level.
- There is no agreed set of principles or standards for the provision of end of life care in the county, against which the performance of organisations and agencies can be judged and for which people can be held accountable.
- The financial arguments supporting co-ordinated end of life care and enabling people to die in their own homes are well known but not used as part of the evidence for service development. Investment in community based end of life care services and interventions will save hospitals significant amounts of money, reducing demand for beds and reducing unplanned admissions through Accident and Emergency.
- The broader welfare and wellbeing needs of people in the last 12 months of their life are not always being met. Whilst medical needs such as symptom control and pain relief are well understood, in many cases basic quality of life issues are not addressed. For example, bathing.
- The lack of one single IT system for the creation, sharing and updating of end of life care plans across key agencies and organisations results in unplanned admissions to hospital through Accident and Emergency. It also results in the Ambulance Service making journeys that could have been avoided.
- A number of Delayed Transfers of Care that are attributed to short falls in community based provision relate to people in the last months or weeks of their life. This can lead to the breakdown in an end of life care plan and significant distress to the patient, their family and carers.
- The business case for an Electronic Palliative Care Coordination System (EPaCCS) has been developed by the Harrogate and Rural District End of Life

Care Locality Steering Group and a number of organisations but it is unclear whether there is the necessary support to implement such a system countywide.

- A seven day a week Specialist Palliative Care Service is not routinely provided in hospital. Out of hours support, information and advice is provided through a number of routes, including hospices. Harrogate and District NHS Foundation Trust are currently reviewing options for a seven day a week Specialist Palliative Care Service.
- Training in end of life care is not mandatory for community and hospital staff at present. There may also be a need to consider how specific end of life care training and awareness raising is provided to locum GPs, particularly those working in the Out of Hours Service.
- It is not clear whether there is sufficient availability of and access to palliative care drugs across the county. A Palliative Care Drugs Service is commissioned by 2 of the 5 CCGs in the county. In the other 3 CCG areas voluntary arrangements are in place for the stocking of palliative care drugs. Service user evidence gathered as part of this extended piece of scrutiny suggests that there are gaps in availability and access, gaps that are often filled by people going to Accident and Emergency.
- In the next 3 to 5 years, changes to Government funding to community pharmacies may result in a reduction in the range and coverage of a number of pharmacy services, including free home delivery. This may, in turn, impact upon the viability of some community based end of life care plans.
- It is not always clear to a GP when a patient is moving from active care to palliative care phase of illness. This could be resolved if there was better communication by specialists when a patient is felt to have exhausted all possible active treatment for their long term condition.
- There are gaps in the provision of community nursing. The District Nurse Service in the county is not 24/7 and at present the service provision ends each day at 10pm. There is also a shortage in Palliative Clinical Nurse Specialist provision.
- There may be a need for some awareness raising about the need for a Living Will, Advance Directive or the ReSPECT form, as opposed to the use of Do Not Attempt Resuscitation (DNAR) forms.
- There are gaps in out of hours provision across agencies and organisations that provide elements of end of life care. There may be value in undertaking a system wide review to better understand the gaps and their impacts.

## Section 4 – Care Quality Commission

### Care Quality Commission inspection reports

The Care Quality Commission (CQC) regularly conducts both announced and unannounced inspections of hospitals. Inspection reports include an assessment of the quality and effectiveness of End of Life Care. The elements relating to End of Life Care are summarised below.

#### Harrogate District Hospital Quality Report 27/07/2016

<http://www.cqc.org.uk/location/RCD01>

This report followed an inspection from 2 to 5 February 2016. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring and well-led. The criteria of responsiveness was rated as 'requires improvement'. The issues that were identified by the CQC are summarised below:

- A strong culture of incident reporting
- Participated in the National Care of the Dying Audit of hospitals
- A care planning process had been developed and was being used based on current national guidance
- Working with the Clinical Commissioning Group and community teams to develop a five year strategic plan for end of life care
- Face to face specialist support for end of life care was not available 7 days and week
- Staff are not able to identify everyone who might benefit from palliative care team support because of work pressures in the hospital and the limited palliative care cover available
- There was no locally agreed service plan in place for end of life care with commissioners.

#### Scarborough Hospital Quality Report 08/10/15

<https://www.cqc.org.uk/location/RCBCA>

This report followed an inspection over the periods 17 to 20 March 2015, 30 to 31 March 2015 and 11 May 2015. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Specialist nurses and medical staff provided specialist support in a timely way that aimed to develop the skills of non-specialist staff
- Staff were caring and compassionate and responsive to patients' needs
- Good use of auditing to identify and improve patient outcomes
- A vision and strategy for end of life care services was in place
- Development of a number of initiatives, such as non-cancer end of life care.

#### The York Hospital Quality Report 08/10/15

<http://www.cqc.org.uk/location/RCB00>

This report followed an inspection over the periods 17 to 20 March 2015, 30 to 31 March 2015 and 11 May 2015. End of Life Care was rated as 'good' overall and for

the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Good use of auditing to identify and improve patient outcomes
- A vision and strategy for end of life care services was in place
- Consistent leadership
- Development of a number of initiatives, such as non-cancer end of life care.

### **Airedale General Hospital Quality Report 10/08/16**

<http://www.cqc.org.uk/location/RCF22>

This report followed an inspection over the periods 15 to 18 March 2016, 31 March and 11 May 2016. End of Life Care was rated as 'good' overall and for the criteria of safe, effective, caring, well-led and responsive. The issues that were identified by the CQC are summarised below:

- Seven day face to face specialist palliative care support available to patients was in place
- Staff were trained and demonstrated a consistently good knowledge of end of life care issues
- Pain was well managed
- The Gold Standards Framework was in use throughout the hospital to support the development of good quality end of life care
- An electronic palliative care coordination system was in use
- Positive multidisciplinary team work and a high standard of collaborative working internally and externally
- There was below the national minimum staffing recommendations for hospital specialist palliative care doctors
- A lack of engagement with Black and Minority Ethnic (BME) communities.

### **Darlington Memorial Hospital Quality Report 29/09/15**

<http://www.cqc.org.uk/provider/RXP>

This report followed an inspection over the period 5 and 6 February 2015. End of Life Care was rated as 'requires improvement' overall and also 'requires improvement' for the criteria of safe, effective and well-led. The issues that were identified by the CQC are summarised below:

- Staff were caring and compassionate
- Monitoring of the safe use of syringe drivers for end of life medication was not being recorded consistently
- Mental capacity assessments were not being recorded
- Development of pastoral and spiritual services were planned
- Specialist palliative care regularly attend wards to support staff to develop skills a round end of life care
- Staffing difficulties had impacted on the ability of the specialist palliative care team to develop the service
- A focus on preferred place of care for patients at the end of life wishing to be at home.

## **James Cook University Hospital Quality Report 28/10/16**

<http://www.cqc.org.uk/location/RTRAT>

This report followed an inspection over the period 8 to 10 June and 21 June 2016. End of Life Care was rated as 'good' overall and for the three criteria of safe, effective and well-led. The issues that were identified by the CQC are summarised below:

- Patients were provided with an end of life care service that was safe and caring
- A culture of incident reporting
- Clear, well documented and individualised care of the dying documents
- Mandatory training in place with 100% compliance
- A clear vision for the service but no overall strategic lead for palliative care
- Poor performance against the 2015 National Care of the Dying Audit criteria, achieving only two of the eight organisational indicators.

## **Hull Royal Infirmary Quality Report 29/07/15**

This report followed an inspection over the period 28 to 29 January 2015. End of Life Care was rated as 'good' overall and for all of the criteria. The issues that were identified by the CQC are summarised below:

- A dedicated palliative care team are in place that consists of palliative care consultants, specialist nurses and an end of life care facilitator. The team was available Monday to Friday with a helpline service during evenings and weekends
- Individual wards had end of life care champions
- Patients received safe and effective end of life care, which involved patients and relatives/carers
- Care was flexible and responsive to individual needs and there were good systems to facilitate preferred place of care.
- There was a retrospective end of life case review group, which met regularly to review care practice and identify areas for learning.

## **St James University Hospital Leeds Quality Report 27/09/2016**

This report followed an inspection over the period 28 to 29 January 2015. End of Life Care was rated as 'good' overall and for all of the criteria. The issues that were identified by the CQC are summarised below:

- Safety incidents were investigated when things went wrong and lessons learned were widely shared
- There was clear guidance for staff to follow within the care of the dying person individual care plan when prescribing medicines at end of life
- There were some very good examples of record keeping in the individual care plans.

## **Summary of key findings**

People living in North Yorkshire access a broad range of hospitals depending upon where they live and what treatment they are undergoing. The CQC reports vary in the breadth and depth of their assessment of end of life care and interventions provided at the hospitals but offer an insight into some of the key issues faced in a busy clinical environment.

- Face to face specialist end of life care is not available 7 days a week across all hospitals.
- Strategies for the delivery of end of life care services and interventions in hospitals are either in place or under development.
- Non-cancer end of life care is either in place or under development.
- Staffing pressures had impacted in some hospitals upon the consistency and quality of end of life care being offered.
- The quality and suitability of mortuary services was highlighted as a concern in a number of cases, in particular the room where the body of someone who has recently died is viewed by bereaved relatives.

Anecdotal evidence gathered as part of this extended piece of scrutiny suggests that there may be a conflict between resource management and end of life care in a hospital setting. Where someone in the last days of their life is admitted to a busy hospital ward, there have been cases where good quality of end of life care has not been provided.

## **Section 5 – site visits to hospices**

Structured visits were undertaken to three hospices in North Yorkshire and York. These hospices were selected on the basis on being the major providers of hospice care to in-patients, day patients and community patients.

The hospices visited were:

- St Michael’s Hospice, Harrogate – 10 November 2016
- St Catherine’s Hospice, Scarborough – 16 November 2016
- St Leonard’s Hospice – 13 December 2016

The visits were undertaken by members of the Scrutiny of Health Committee along with the Chair of the Scrutiny of Health Committee and the Scrutiny Team Leader. The visits tended to have the following format:

- 10.00am – Welcome and introductions
- 10.10am – Meetings with staff
- 11.00am – Meetings with in-patients and day patients (where possible)
- 12.00noon – Informal discussions – to involve a number of people from social work, bereavement support, a carer, community team leaders and fundraising
- 1.00pm – Site tour
- 1.45pm - Reconvene for wrap up questions and discussions.

What follows is a summary of the key issues identified at all three site visits:

## **Funding**

- Savings to the system that the hospices in North Yorkshire make cannot be realised and funding cannot be diverted as it is all taken up by the larger acute trusts
- A large proportion of funding is unpredictable and high risk. This makes service planning difficult year on year. Budget deficits are likely in 2017/18 and beyond, if the funding position is not improved. There will then be a review of services to ascertain a sustainable delivery model for the future
- Do not want 100% public funding as need to retain independence, aim for 35% public funding. Currently around 20%.
- Strong argument for 'invest to save'

## **Service delivery**

- Wide range, including: bereavement counselling; Occupational Therapy; in-reach into residential and nursing homes; hospice at home; neurology nursing; Palliative Clinical Nurse Specialist provision
- Concerns over the long term impacts of reductions in both NHS and social care services and budgets
- A large number of volunteers support the delivery of hospice services both at the Hospice itself and in the wider community
- There are shortages of skilled staff across health and social care, which has a knock on effect to the services provided by the hospice as they take up more of the slack and fill gaps
- Need for more respite care for carers – this makes community based packages of support more robust and less likely to breakdown
- Need to start thinking collectively about the patient of the future, what their needs will be and what options will be available to them. Likely to have dementia and not be a cancer patient
- Community based bereavement services make significant savings for mental health services
- Pain control best managed in a hospital or hospice, less well at home.

## **Out of hours**

- There is very little routine out of hours care in place across health and social care. Hospices and other organisations often fill the gaps, particularly at the weekend, but this is not sustainable in the long term. The lack of out of hours care often results in unplanned admissions to hospital, unnecessary ambulance journeys and increased stress upon the patient and carers
- PALCALL in Scarborough and Ryedale offers 24 hour support for carers of people undergoing community based palliative care (similar to Goldline in Airedale, Wharfedale and Craven).

## **Referrals**

- Most referrals, approximately 50% to 80%, are from GPs and hospitals and are typically people with terminal cancer. More could be done to highlight the hospice services and interventions that are available to people with other terminal diseases.

## **Education and training**

- The hospices deliver a range of formal, accredited training courses, professional development and mentoring and coaching
- Training for nursing and residential care homes helps ensure that more people are able to die in their home, as opposed to a hospital
- Considerable programme of education run by the hospice: communication skills; advanced care planning; symptom management; ceilings of care; palliative care.

## **Coordination**

- Lack of a forum for commissioners and providers of End of Life Care to meet and plan through a system wide approach
- Lack of places for people to be discharged to from hospital.
- There is no single case record management system in place that enables all relevant organisations to access the care plans of patients in their last months of life. This can result in unplanned admissions to hospital, unnecessary ambulance journeys and increased stress upon the patient and carers
- Hospices are part of the solution and can help support the wider health and social care system through establishing good practice norms and educating.

## **Sustainability and Transformation Plans**

- End of life care does not feature in the STP planning process, at present
- STP may present an opportunity for system-wide commissioning.

## **Approach**

- Overly focussed on the place of death and not the quality of the last 12 months of life. Key questions to ask :
  - How do you want to die?
  - Where do you not want to die?
  - What experience do you want of dying?
  - What things will be important to you?

## **Summary of key findings**

There are a number of themes that have emerged, from the visits to the three hospices, relating to the gaps in services and areas for improvement. These include:

- High quality and wide ranging end of life care is provided by hospices on an in-patient basis and in the community at little or no cost to the public sector. The majority of hospice funding, typically 80%, comes from retail, fundraising, donations and legacies.
- Hospice funding is increasingly unpredictable and under stress. A number of hospices are planning to run a budget deficit in 2017/18. This will impact on the range of services that hospices can provide.
- Hospices have responded to gaps in provision and developed services that meet new and emergent needs, such as community based support and nursing for neurology and lymphedema.



- There is uncertainty about what impact increasing demand for health and social care services, shortages of skilled health and social care workers and budgetary pressures in health and social care will have upon the demand for hospice services and interventions.
- The delivery of community-based services in the county is expensive due to the travel costs and times associated with accessing rural areas.
- Informal and formal education and training is provided by hospices to health and social care workers. More education and training could be done with providers of residential care and nursing homes but there are limited resources and providers of residential and nursing care under significant financial stress.
- The type of patient that health and social care organisations is working with is changing. In the longer term, people in the last months of their life are likely to be frail and suffering from a number of long term conditions, including dementia. More needs to be done to plan the countywide response to this changing disease profile and the development of end of life care services and interventions for people with dementia.
- Carers are critical to the effective delivery of any end of life care plan. More could be done to provide support and respite for carers in the community.
- Hospices often serve as a default out of hours service to support end of life care in the community, as most health and social care services are not commissioned on a 7 day basis.
- There is no one single IT system for the creation, sharing and updating of end of life care plans across key agencies and organisations. This creates unnecessary delays and inefficiencies and care lead to breakdowns in continuity of care provided.
- GPs are key to the provision and co-ordination of End of Life Care. They are already stretched and there are emergent shortages of GPs.
- The discussions are end of life care have tended to focus upon the where people want to die, with a working assumption that dying in your own home is the preference. However, the question could better be asked as to what things do people need to have in place to make their death the best it can be for them and those around them?

## **Section 6 – patients, carers and family members**

### **Focus groups**

Convened by Tony Collins, Chief Executive, Saint Michael's, Harrogate -  
Bereavement counselling – 23 November 2016

### **Case study 1 – bereaved wife**

- Key role played by the GP in supporting the family and providing continuity of care in the community
- Concerns raised about the level of care that can be provided on busy hospital wards to people in the last days of life
- Concerns raised about the ability of District Nurses to provide support when and where needed
- Concerns about the ability of the Hospital to provide continuity of care in the community and respond to changes in patient condition
- Difficulties in maintaining an uninterrupted supply of prescribed palliative care drugs
- Multiple visits to A&E.

### **Case study 2 – bereaved teenage son**

- Excellent standard of hospital care
- Stress upon the immediate family leading to family breakdown after the death of the mother
- School not able to provide the necessary support, leading to a disrupted education and unresolved emotional problems associated with grieving and loss
- Key role of the grandmother in providing support.

### **General**

- There are some concerns about the quality of end of life care provided in some cases in hospitals. Concerns that this may not be picked up as part of CQC inspections
- 'Just-B' bereavement service receives no funding from CCGs or local authorities and the service covers Harrogate District only
- Most referrals to 'Just-B' are from GPs
- Most people who attend the 'Just-B' service are grieving for loved ones who did not 'die well'.

The website for 'Just-B' can be found here - <http://justb.org.uk/wordpress/>

### **Summary of key findings**

The openness and willingness of patients, carers and family members to speak with the members of the Scrutiny of Health Committee was much appreciated. Some of the key issues raised are highlighted below:

- There is only limited bereavement support that can be accessed in a timely way in the county. This is provided in part by the NHS and in part by the voluntary and community sector.
- The way in which the death of a close family member is experienced can have a significant impact upon the mental wellbeing of someone who has been bereaved. Where support is not available, it can lead to a disrupted education, job loss and family breakdown.

- It is unclear what systems are in place to identify children and young people in school who have been bereaved and what support is in place or can be accessed by them.
- There is a question as to whether general CQC inspections of a hospital are able to assess the quality of end of life care services.

## Section 7 – Areas for further investigation

It has not been possible to undertake a complete and exhaustive assessment of the state of end of life care in the county. As such, there are a number of areas for further investigation, as below:

### **Schools**

The role that schools have to play in identifying and supporting children and young people through the last months of a parent or sibling's life is unclear. As is the ability of the school to provide or access appropriate bereavement support for a child or young person.

### **Former service personnel**

The Armed Forces Community Covenant for North Yorkshire has as one of its aims to 'encourage local communities to support the armed forces community in their areas, and vice versa'. There is a question as to whether former service personnel in the county have specific needs around end of life care and whether these are currently being met.

### **Equality and diversity**

There is further work to be done to understand and address the barriers that exist to people accessing end of life care services and interventions, specifically for Lesbian Gay Bisexual and Transgender people, Black and Minority Ethnic groups, gypsies and travellers, people who are homeless.

### **Patient and family and carer experience**

There is an opportunity to do further work with Healthwatch North Yorkshire to gather the views of patients, family members and carers on end of life care services and interventions in the county. The results of this could then inform targeted 'Enter and View' visits.

### **Respite care for carers**

The critical role that carers have to play in the delivery of community based end of life care plans is widely acknowledged. What is not clear is the extent to which the needs of carers are identified and opportunities for respite care provided.

### **Befriending**

Befriending and support to patients, carers and family members as part of end of life care has been seen in some cases to be beneficial. Further work could be

undertaken to better understand the benefits of befriending and whether it has a role to play in end of life care provision in North Yorkshire.

### **Private sector**

The role of private sector providers of end of life care services and interventions has not been fully explored. Nor has the potential for markets for private sector providers to be developed.

### **Yorkshire Ambulance Service**

The role of the Ambulance Service in the delivery of end of life care planning and the costs incurred when packages of community-based care breakdown. It is noted that lack of an electronic system to share and update patient notes and end of life care plans means that staff responding through the 999 or 111 services are not aware of what care has been agreed.

## **Section 8 – Recommendations**

### **Recommendations**

The following recommendations are made for consideration by the North Yorkshire Scrutiny of Health Committee:

1. That a multi-agency forum is established for commissioners and providers of end of life care in the county to enable:
  - greater co-ordination of service planning and delivery across health, social care and the voluntary sector
  - the agreement of some common standards and principles for equitable end of life care, possibly in the form of a charter or a similar statement of intent
  - the identification of a set of outcomes to be achieved with milestones and a mechanism in place for tracking progress against those milestones
  - sharing of good and best practice
  - the identification of areas for service improvement
  - patient and carer representation and involvement and opportunities for co-design
  - health and social care strategic planning to be influenced
  - inequalities in the access to end of life care services across the county to be addressed.
2. That a local financial analysis of community-based end of life care and bereavement services be undertaken, with a view to assessing what efficiency gains could be made within the health and social care system. The methodology to be informed by the Public Health England and University of York health economics report on the costs of end of life care.
3. That a multi-agency programme of training in end of life care and care for the dying be developed and implemented, covering as a minimum:
  - Communication skills and honest conversations

- Advanced care planning, including holistic care
- Symptom management
- Palliative care.

Consideration also to be given as to how this training could be targeted at different priority groups of health and social care workers across the county.

4. That existing joint work between the NHS and the County Council on health and social care workforce planning, takes into account the need for skilled, specialist staff to co-ordinate end of life care and palliative care.
5. That a way of enabling the sharing and updating of end of life care plans and patient notes electronically is developed for all health and social care agencies and organisations in the county.
6. That a local analysis of 'the patient of the future' is undertaken that looks at the changing disease profile of people in their last 12 months of life and what this means for the development and delivery of end of life care.
7. That a system-wide analysis is undertaken of the current provision of out of hours, specialist end of life care and palliative care, including access to palliative care medication, to assess where there may be gaps in provision and suggest what could be done to fill any such gaps.
8. That agencies and organisations work together to promote a culture of open and honest discussions about death and planning the last 12 months of someone's life.
9. That the areas for further investigation listed in Section 7 of this report are looked into further.

In making these recommendations, it is recognised that the health and social care system is under increasing financial strain and that there is no new funding available. There are, however, efficiency gains to be made from a change to the way in which end of life care services and interventions are commissioned and provided in the county, which will also improve outcomes for patients, carers and family members.

Daniel Harry  
 Scrutiny Team Leader  
 North Yorkshire County Council  
 28 February 2017

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- Joanne Crewe, Harrogate and Rural District Clinical Commissioning Group
- Dr Sarah Hay, Governing Body Member, Harrogate and Rural District Clinical Commissioning Group
- Colin Renwick, Airedale and Wharfedale Craven Clinical Commissioning Group
- Paul Howatson, Vale of York Clinical Commissioning Group
- John Turner, Scarborough and Ryedale Clinical Commissioning Group
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