AUDIT AND GOVERNANCE COMMITTEE WORKING GROUP

PALLIATIVE / END OF LIFE CARE

AGENDA

Thursday 14 January 2016

at 10.00am

in Council Chamber, Civic Centre, Hartlepool

MEMBERS: Councillors Ainslie, S Akers-Belcher, Belcher, Cook, Lawton and Martin-Wells

Standards Co-opted Members: Mr Norman Rollo and Ms Clare Wilson.
Parish Council Representatives: Parish Councillor J Cambridge (Headland) and Parish Councillor B Walker (Greatham)

1. APOLOGIES FOR ABSENCE

2. DECLARATIONS OF INTEREST

3. INTRODUCTION – COVERING REPORT (SCRUTINY MANAGER)

4. **TIMETABLE FOR SESSION**

10.00am to 12.00noon - SERVICE DELIVERY INFORMATION - (PRESENTATIONS)

12.00noon - LUNCH / BREAK

1.00pm - BREAK OUT SESSIONS - EXPLORING VIEWS ON:

- What works well?
- How services can be made better?
- What are the priorities for the future in the provision of these services?

2.00pm - FEEDBACK FROM TABLE DISCUSSIONS

2.20pm - NEXT STEPS AND CLOSE

AUDIT AND GOVERNANCE COMMITTEE WORKING GROUP

14 January 2016

Report of: Scrutiny Manager

Subject: END OF LIFE / PALLIATIVE CARE SERVICES IN HARTLEPOOL – WORKING GROUP INTRODUCTION

---

1. PURPOSE OF REPORT

1.1 To:

i) A recap on the information / evidence received by the Committee to date; and
ii) Introduce further evidence for consider by the Committee in the formulation of its recommendations in relation to the provision of end of life and palliative care services in Hartlepool.

2. BACKGROUND – INFORMATION / EVIDENCE RECAP

2.1 The Committee, at its meeting on the 20 August 2015, agreed to review end of life / palliative care services provided for patients, and their families / carers in Hartlepool, looking at:

a) National and local policies, plans and strategies in relation to the provision of end of life and palliative care, focusing specifically on the provision of services in community settings.

b) What good end of life / palliative care looks like?

c) Issues around:
  - Patient pathways for accessing end of life / palliative care services;
  - The support offered to users, carers and families;
  - Factors that prevent people from different areas and groups from experiencing good quality, joined up, end of life / palliative care; and
  - How service providers work together.

d) The end of life / palliative care services currently provided by:

  - NHS bodies
  - Local Authority (Adult Services and Public Health Services)
  - Voluntary Sector
  - Private Sector

e) Current level of need in Hartlepool and trends / patterns that will influence future service delivery requirements.

2.2 Given the breadth of issues considered by the Committee in 2015, to assist Members details of the information / evidence so far presented in relation to this investigation is attached. A summary is as follows:-

i) Scoping Report (20 August 2015) – **Appendix A**
ii) Setting the Scene Presentation (CCG) (3 September 2015) – **Appendix B**
iii) HealthWatch Presentation (12 November 2015) – **Appendix C**
iv) Relevant Minute Extracts - **Appendix D**

3. TODAY'S WORKING GROUP

3.1 The Committee will today be holding its final evidence gathering session and will receive additional information in relation to the areas outlined in Section 2.1 of this report. Evidence to be provided to include information in relation to:-

i) Most current Hartlepool specific data (cause of death)?
ii) The Better care for at Risk Patients Scheme?
iii) The Review of Specialist Palliative Care Services (community)?
iv) New End of Life Document used in GP practices?
v) GP Palliative Care Register (numbers – effectiveness)?
vi) The work of the Mcmillan GP's / Nurses / Community Nurses?
vii) The End of Life Pathway and associated services / activities provided in and through the University Hospital of Hartlepool?
viii) Social Care – How do we support the provision of end of life / palliative care services?
ix) How services meet the needs of all sections of the community (inc. Learning Disability and Sensory Loss, minority groups)?

3.2 In drawing in the direct views and experiences of residents and service users, the Committee will be facilitating an interactive breakout session to explore:-

i) What works well?
ii) How can things be made better?
iii) What are the priorities for the future?

3.3 invitations have been extended across the following groups

- Carers / Families
- Voluntary and Community Sector Groups
- The Bereavement Service
- Hartlepool Hospice
- Hospital of God
- Care Homes (residential and nursing)

- Other Groups (representing all aspects of the community inc. Learning disabilities / sensory loss (inc dementia), Minority Groups)

3.4 This information, in addition to informing recommendations for the way forward, will also be fed into the work currently being undertaken in relation to the development of a Local Health and Social Care Plan for Hartlepool.

3.5 In addition to this a questionnaire has been circulated to providers and commissioners to obtain answers to the suggested questions identified as good practice by the Centre for Public Scrutiny (**Appendix E**). The results of this questionnaire are to be compiled and whilst they will not be available for this meeting, will be presented to the Committee in due course.

4. RECOMMENDATIONS

4.1 That Members:

i) Note the report;
ii) Receive the setting the presentations and seek clarification where required; and
iii) Utilise the evidence obtained through the break out session to inform their final report.

5. REASONS FOR RECOMMENDATIONS

5.1 To inform the development of recommendations for inclusion in the Committees End of Life / Palliative Care Final Report.

6. CONTACT OFFICER

Joan Stevens – Scrutiny Manager
Chief Executive’s Department – Legal Services
Hartlepool Borough Council
Tel: 01429 284142
Email: joan.stevens@hartlepool.gov.uk

AUDIT AND GOVERNANCE COMMITTEE

20 August 2015

Report of: Scrutiny Manager

Subject: END OF LIFE / PALLIATIVE CARE IN THE COMMUNITY SCRUTINY INVESTIGATION INTO – SCOPING REPORT

1. PURPOSE OF REPORT

1.1 To make proposals to the Audit and Governance Committee for the conduct of its forthcoming investigation in to the ‘Delivery of End of Life / Palliative Care Services in the Community’.

2. BACKGROUND INFORMATION

2.1 The Audit and Governance Committee on 6 August 2015 agreed its work programme for 2015/16. The Committee scored potential investigations against a PICK scoring matrix, assessing each topic against its interest to the public, its social, economic and environmental impact on wellbeing, Council performance and efficiency and finally its context to prevent duplication in other areas. Against this matrix, the Committee prioritised an investigation in to the delivery of end of Life / palliative care in the community’. Members at this meeting agreed to establish small groups of Members to carry out work relating to specific areas within each chosen topic, as such, suggestions for the group work are outlined in section 9 of the report.

2.3 The terms palliative and end of life care are all used in this area and have considerable overlap, each defined as follows:-

Palliative Care - the active holistic care of patients with advanced progressive illness, with the management of pain / other symptoms and provision of psychological, social and spiritual support. The goal of palliative care is to achievement of the best quality of life for patients and their families and incorporates end of life care, but, as these terms are sometimes used interchangeably.

End of Life Care - helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (‘End of Life Care Strategy’, Department of Health 2008).

2.3 Palliative care is be provided in different places including in domestic homes, hospitals, care homes or hospices, and is provided by two main groups of professionals:-

General Care is provided on a day-to-day basis by GP’s, community nurses, social workers, care workers, spiritual care professionals and Marie Curie Nurses, for people with advanced illness and their family and friends. The aim of general palliative care being to provide:

- information for patients, families or friends, signposting to other services;
- accurate and all-round assessment of meet needs;
- coordination of care teams in and out of hours;
- basic levels of symptom control;
- psychological, social, spiritual and practical support; and
- good communication with patients, families or friends and the professionals.

Specialist care services manage more complex care problems that cannot be dealt with by generalist services. Palliative care specialists usually work in teams to provide joined-up care and patient may see one or more specialists. Specialist teams include doctors, consultants in palliative medicine, clinical nurse specialists, counsellors and specialist allied health professionals, such as physiotherapists, occupational therapists, dieticians and social workers. Specialist palliative care services may be provided by the NHS (local health and social care trust in Northern Ireland), local councils and voluntary organisations. These could include inpatient and outpatient facilities and bereavement support services.

2.4 The Health and Social Care Act 2012 gives commissioning and regulatory organisations in England duties to secure or promote integrated services. The national information standard supports integration of end of life care services across health, social care, voluntary and independent sectors. The standard supports integrated working between professionals and staff working across multiple organisations and sectors including health, social care, voluntary sector, out-of-hours service providers, ambulance services and the private sector. In this way, provision of seamless, person-centred and individualised care for people and their families and carers is supported. The Care Bill 2013-2014 also promotes integration of care and support between health and social care services.

2.5 Data collected by the National End of Life Intelligence Network (part of NHS England)[1] shows that each year in 2013, 473,552[2] people died in England, of whom 84% were aged 65 or older and 39% were aged 85 or older. Almost half of women dying in England and Wales in 2013 (48%) were age 85 or

---

[1] National End of Life Care Intelligence Network - What we know now 2014

[2] Source: Office of National Statistics (ONS)

older.[3] The number is expected to rise by 17% from 2012 to 20305. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030.

2.6 A large majority of these deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths occur in NHS hospitals, with increasing dependence on the care and support of others; friends, relatives, their wider community, health and social services. The duty to care well for those nearing the end of their life, respecting their wishes, treating them at all times with respect and ensuring their dignity is a significant responsibility for society. Projections of the number of deaths in the future suggest that after a period of stability the number of deaths each year will be rising in the early 2020s[4].

2.7 The number of people requiring palliative care each year in England has been estimated as 355,000 (Hughes-Hallett[5]) and 63% of deaths (Murtagh) suggesting 294,000 in 2013. The number of young adults (18 to 40) living with life-limiting conditions (LLC) in England is estimated to be 55,721, the prevalence of LLC in this age group per 10,000 has increased from 26.0 to 34.6 over ten years.

2.8 Hospital remains the most common place of death in England, but the proportion of deaths that are in hospital is falling, and was less than half of all deaths in 2013.

Distribution of place of death in England

	2013	2004
Hospital	48%	57%
Home	22%	18%
Care home	22%	16%
Hospice	6%	5%

2.9 The National Survey of Bereaved People[6] indicate that home is the preferred place for many people, however, only 32% of deceased people expressed a preference of where they would like to die. However, only half of the deceased who wanted to die at home actually did and about one-third who wanted to die at home, died in hospital. Of those who did express a preference in terms of a place of death:

Home 79%	Hospital 3%
Hospice 8%	Other 2%
Care home 8%	

---

[3] ONS Death Registrations Summary Tables, England and Wales, 2013 www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-317522

[4] ONS 2012-based Subnational Population Projections for England www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2012-based-projections/rft-projected-coc.xls

[5] Hughes-Hallett T, et al. Independent Palliative Care Funding Review.

[6] National Survey of Bereaved People (VOICES), 2013. Published July 2014.

2.10 In the past, end of life care within the NHS and social care services had a relatively low profile. Reflecting this, the quality of care has been very variable. Implementation of National End of life Strategy aimed to make a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere.

3. INITIAL HARTLEPOOL DATA[7]

3.1 In 2011, Hartlepool was estimated to have 7,100 residents aged over 75 years and by 2016 this will have risen to 7,900 (an increase of 11%) and by 2021 there will be 8,500, a 20% increase from the 2011 figure. It is likely that this increase in the older population will lead to a corresponding increase in the need for end of life care services.

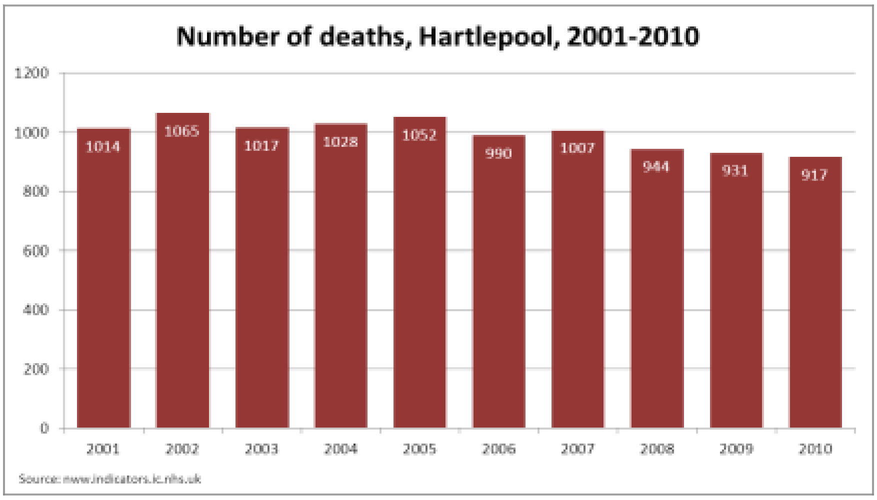
3.2 Good quality end of life care spans all services and conditions and should be a generic skill throughout the workforce. Specialist services including:

- Specialist palliative care nursing
- Specialist palliative care consultants
- Hospice care
- Marie Curie Services
- Bereavement services
- Allied health professionals
- Community and specialist nursing
- Psychologists

3.3 In Hartlepool the numbers of deaths have been falling in recent years, despite increasing population size, with in 2010 nearly 100 fewer deaths than a decade earlier.

---

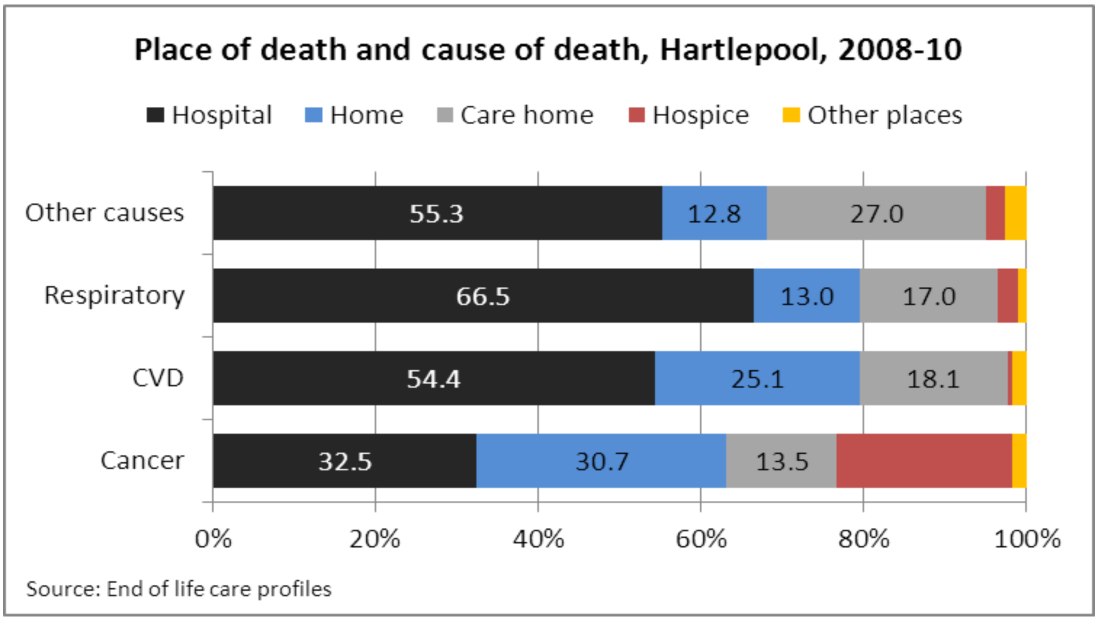
[7] Hartlepool JSNA



Source: www.indicators.ic.nhs.uk

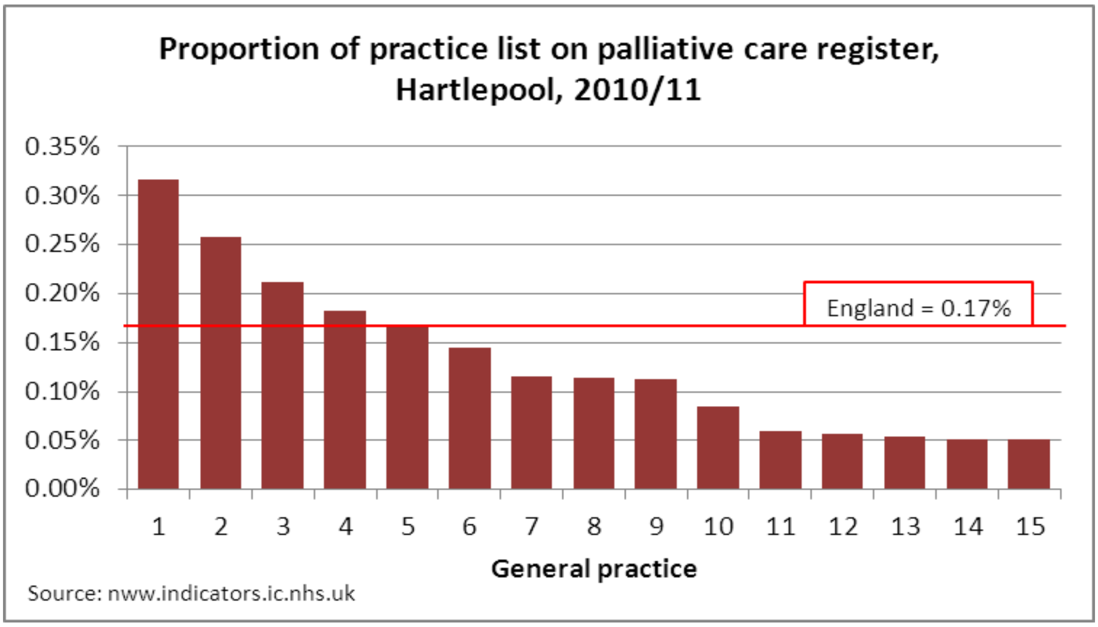
3.4 In Hartlepool, more people die in a hospital than any other setting, but the proportion dying in hospital is lower than other areas in Teesside. The proportion of people who die in hospital is similar in all age groups. Deaths at home are most common for people aged under 65 years. People aged 85+ are the most likely to die in a care home.

3.5 There were 220 deaths in hospices in Hartlepool in the three years 2009-10, of these. 187 (85%) were people with cancer as an underlying cause of death, with 95% in the rest of Teesside. Proportionately, more people die in hospices in Hartlepool than elsewhere in Teesside.



Source: End of life care profiles

3.6 Palliative care registers are maintained by GP's, with a total of 115 people on registers in 2010/11. The proportion of people on palliative care register varies from 0.05% to 0.32% of people registered with the practice.



Source: nww.indicators.ic.nhs.uk

3.7 Improving end of life care involves working in partnership to consider how best to engage with local communities to raise the importance of end of life care, potentially engaging with schools, faith groups, funeral directors, care homes, hospices, independent and voluntary sector providers and employers amongst others. Meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care, however, evidence from the Care Quality Commission has shown that people from particular groups experience end of life care that is of poorer quality and does not always meet their needs. On this basis they are focusing a review on the following priority groups:

- People with a diagnosis other than cancer:
- People aged over 75
- People with dementia
- People from BAME groups; and
- Other groups of people who may have specific needs, such as people with mental health needs, people with learning disabilities, people who identify as LGBT, people who are homeless, prisoners, travellers and gypsies.

4. OVERALL AIM OF THE SCRUTINY INVESTIGATION/ENQUIRY

4.1 To review end of life / palliative care services provided in community settings for patients, and their families / carers in Hartlepool.

5. PROPOSED TERMS OF REFERENCE FOR THE SCRUTINY INVESTIGATION/ENQUIRY

5.1 The Centre for Public Scrutiny, in conjunction with the National Council for Palliative Care, produced a guide to assist overview and scrutiny committees. The questions identified in the guide are summarised in **Appendix 2** and explore the areas of need, strategy, process, resources, co-ordination, training, monitoring, support for carers, and choice, in a multi-disciplinary context. It is suggest that they are utilised to further inform the investigation.

5.2 The following Terms of Reference for the investigation are proposed:-

a) Gain an understanding of national and local policies, plans and strategies in relation to the provision of end of life and palliative care, focusing specifically on the provision of services in community settings.

b) Consider what good end of life / palliative care looks like and explores good practice in other areas.

c) To explore:
   - Patient pathways for accessing end of life / palliative care services;
   - The support offered to users, carers and families;
   - Factors that prevent people from different areas and groups from experiencing good quality, joined up, end of life / palliative care; and
   - How service providers work together.

(d) To gain an understanding of end of life / palliative care services currently provided by:

- NHS bodies
- Local Authority (Adult Services and Public Health Services)
- Voluntary Sector
- Private Sector

(e) To establish the current level of need in Hartlepool and consider trends / patterns that will influence future service delivery requirements.

(f) To explore whether need is being adequately met and whether there is a need for development in current service provision.

(g) Consider how services are provided for the priority groups that experience end of life care that is of poorer quality and does not always meet their needs, as identified by the Care Quality Commission:

- People with a diagnosis other than cancer
- People aged over 75
- People with dementia
- People from BAME groups; and
- Other groups of people who may have specific needs, such as people with mental health needs, people with learning disabilities, people who identify as LGBT, people who are homeless, prisoners, travellers and gypsies.

(h) To take evidence from a wide a range of stakeholders and service users.

6. POTENTIAL AREAS OF ENQUIRY / SOURCES OF EVIDENCE

6.1 Members of the Forum can request a range of evidential and comparative information throughout the Scrutiny review.

6.2 The Forum can invite a variety of people to attend to assist in the forming of a balanced and focused range of recommendations as follows:-

(a) Member of Parliament for Hartlepool;
(b) Chair of Hartlepool’s Health and Wellbeing Board;
(c) Ward Councillors;
(d) Director of Public Health and the Public Health Team;
(e) Hartlepool and Stockton-on-Tees Clinical Commissioning Group;
(f) GP’s / Specialist GP’s;
(g) North Tees and Hartlepool NHS Foundation Trust;
(h) Hartlepool Healthwatch;
(i) Local residents;
(j) Hartlepool Carers and Hartlepool Young Carers;
(k) Caring for the Dying Patient Review Group
(l) Key stakeholders, including:
- Statutory purchasers or commissioners of care

- Statutory providers of care
- Expert advisors
- Charities relevant to providing care at end of life
- Community, voluntary and independent organisations
- Patient or service user representative organisations
- Carer organisations
- nursing home providers
- End of life hospice services: Macmillan Specialist Palliative Care Team
- End of life hospice services: Hartlepool & District Hospice

(m) Voluntary and Community Sector groups;
(n) Representatives of minority communities of interest or heritage

6.3 The Forum may also wish to refer to a variety of documentary / internet sources, key suggestions are as highlighted below:-

(a) Hartlepool's Joint Strategic Needs Assessment – www.teesjsna.org.uk
(b) National End of life Strategy, Department of Health, 2008
(c) Case studies and documents from http://www.endoflifecareforadults.nhs.uk/
(d) Map of Medicine end-of-life pathway
(e) Department of Health (DH), (2008). End of Life Care Strategy - promoting high quality care for all adults at the end of life. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
(f) National End of Life Care Intelligence Network. (2011). End of Life Care Profiles. http://www.endoflifecare-intelligence.org.uk/profiles.aspx
(g) The Marie Curie Palliative Care Institute Liverpool, (2011). National Care of the Dying Audit – Hospitals, 3rd Round. http://www.mcpcil.org.uk/liverpool-care-pathway/national-care-of-dying-audit.htm
(h) The Marie Curie Palliative Care Institute Liverpool, (2010). Liverpool Care Pathway for the Dying Patient. http://www.mcpcil.org.uk/liverpool-care-pathway/
(i) National End of life Care Intelligence Network, (2012). Deprivation and death: Variation in place and cause of death. http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death.aspx
(j) Further details regarding end-of-life data are available at:
(k) http://www.endoflifecare-intelligence.org.uk/profiles.aspx
(l) The National End of Life Care Intelligence Network (NEoLCIN)
(m) *NHS - Actions for End of Life Care: 2014-16* - sets out NHS England's
(n) NICE Quality Standard for End of Life Care (2011)
(o) Every Moment Counts: a narrative for person centred coordinated care for people near the end of life
(p) Hospice UK's website is **www.hospiceuk.org**
(q) www.ncpc.org.uk/dyingmatters
(r) End of Life Care Strategy, 2008
(s) National strategy for children's palliative care – Better Care, Better Lives – was published in February 2008

(t) Carers UK – support and resources for carers
(u) NHS Inform – palliative care zone

7. COMMUNITY ENGAGEMENT / DIVERSITY AND EQUALITY

7.1 Community engagement plays a crucial role in the Scrutiny process and diversity issues have been considered in the background research for this enquiry under the Equality Standards for Local Government. Based upon the research undertaken, paragraph 5.2 includes suggestions as to potential groups which the Forum may wish involve throughout the inquiry (where it is felt appropriate and time allows).

8. REQUEST FOR FUNDING FROM THE DEDICATED OVERVIEW AND SCRUTINY BUDGET

8.1 Consideration has been given, through the background research for this scoping report, to the need to request funding from the dedicated Overview and Scrutiny budget to aid Members in their enquiry. At this stage no additional funding has been identified as being necessary to support Members in their investigation. Members, however, may wish to seek additional funding over the course of the investigation and the pro forma attached at **Appendix 1** outlines the criteria on which a request will be judged.

9. PROPOSED TIMETABLE OF THE SCRUTINY INVESTIGATION

8.1 Detailed below is the proposed timetable for the review to be undertaken, which may be changed at any stage:-

3 September 2015 – 'Setting the Scene' Presentation covering terms of reference (a), (b), (c), (d), (e) and evidence from Healthwatch (subject to their availability).

September 2015 – January 2016 – Working / Task and Finish Group to look at:-

Group 1 - General care services - covering terms of reference (f), (g), (h) with the potential to visit service providers.

Group 2 - Specialist care services - covering terms of reference (f), (g), (h) with the potential to visit service providers.

Group 3 - To seek the views of patients and their families and carers and the Caring for the Dying Patient Review Group (subject to their availability) - covering terms of reference (f), (g), (h) and the

11 February 2016 – Feedback from the group work to the Audit and Governance Committee

3 March 2016 – Draft Final Report

9. RECOMMENDATION

9.1 Members are recommended to agree the Audit and Governance Committee's remit of the investigation outlined in paragraphs 4 and 5 and the proposed timescale outlined in paragraph 8.

Contact Officer: - Joan Stevens
Chief Executives Department – Legal Services
Hartlepool Borough Council
Tel: - 01429 284142
Email:- joan.stevenshartlepool.gov.uk

BACKGROUND PAPERS

The following background paper was used in the preparation of this report:-

(i) Hartlepool's Joint Strategic Needs Assessment – www.teesjsna.org.uk

(ii) British Heart Foundation – bhf.org.uk

Appendix 1

PRO-FORMA TO REQUEST FUNDING TO SUPPORT CURRENT SCRUTINY INVESTIGATION

Title of the Overview and Scrutiny Committee:
Title of the current scrutiny investigation for which funding is requested:
To clearly identify the purpose for which additional support is required:
To outline indicative costs to be incurred as a result of the additional support:
To outline any associated timescale implications:
To outline the 'added value' that may be achieved by utilising the additional support as part of the undertaking of the Scrutiny Investigation:
To outline any requirements / processes to be adhered to in accordance with the Council's Financial Procedure Rules / Standing Orders:
To outline the possible disadvantages of not utilising the additional support during the undertaking of the Scrutiny Investigation:
To outline any possible alternative means of additional support outside of this proposal:

Appendix 2

10 questions to help you review End of Life Care

1. What is the need in your area?

The questions below aim to help you to get a sense of the areas of greatest need in your area.

- How many people die in your locality every year?
- What do they die from?
- What age and social class are they?
- What is their ethnic background?
- Where do they die? E.g. home, acute hospital, community hospital, hospices, sheltered housing, care homes (nursing or personal care).
- Has a baseline review of your population needs been carried out in your area?
- Did this identify any gaps in the available data/information?
- What are the priorities and how are these gaps being addressed to inform end of life care commissioning and planning?

2. Is there a clear strategy, supported by dedicated resources, for meeting end of life care needs in your locality, covering different settings and sectors of care?

Strategy

- Does the strategy clearly arise from the assessment of population need including e.g. ageing population, those with multiple conditions and those with dementia?
- How is population need measured? Is this a part of Joint Strategic Needs Assessment?
- Who do you think the key stakeholders should be in developing this strategy and do you feel that all have been involved? For example: health, social care (including care homes) and housing (see above list of partners).
- How is the strategy reviewed and by whom?
- Does the strategy include all of the elements defined as important within the national End of Life Care Strategy, such as Commissioning, User Involvement, Workforce Planning and Development, Measurement, Care Pathway Across Settings/Sectors of Care, Co-ordination of Care, 24/7 access to services, Rapid Response, Care at Home, Single Point of Contact.
- Does the strategy clearly link with other local strategies such as the NHS Next Stage Review Long Term Conditions and Mental Health Workstreams, Dementia Strategy, Stroke Strategy and Carers Strategy? The National Council for Palliative Care has developed guidance on the way in which different policy agendas can be joined up.

Resources

- What resources are dedicated to end of life care locally?
- Funding for specialist palliative care such as hospices is often provided by voluntary donations. What is the situation in your area?
- How is the use of resources monitored?
- PCT plans for spending the additional funds allocated to end of life care should align with Local Area Agreements – do they in your area?
- Do the PCT plans reflect the strategy (above)? Do the plans and funding include all stakeholders across health and social care?
- Have lead commissioners for end of life care been identified? Who are they?
- Do they have the necessary knowledge to commission end of life care effectively?
- Do they link their work with commissioners of other services such as long term conditions and mental health?

3. Is there a clear structure for workforce development and training across settings and sectors of care?

- Does your locality/region have a clear plan for identifying the staff who deliver end of life care including community and care home staff, and then a strategy for workforce planning and development that includes all key stakeholders?
- Does your locality have an identified lead for end of life care workforce planning and development?
- Does your local workforce development plan include the key skills of communication, symptom control, assessment/care planning and advance care planning?
- Do care homes in your area have a training programme in end of life care in place, for example, NCPC's *Care to Learn* materials?
- Does your local workforce development plan include details for commissioning and meeting their training and educational needs?
- Does your local workforce strategy include details of how workforce planning and development will be monitored and reviewed?
- Don't forget that workforce development and training include staff attitudes. Two key things that patients and carers value is compassion and empathy. How do you foster these in your area?
- Assessment, care planning and advance care planning including end of life care all require a skilled and competent workforce (see below). The leaflet entitled 'Planning for your future care' provides helpful advice for patients and carers.

4. Is there a clear structure for monitoring end of life care?

- Does your locality monitor outcomes?
- How does this inform planning and decision making?
- Do the different provider settings each monitor end of life care at Board level?

Example 1: gathering case studies or personal stories of people dying in your locality.
- How are these captured and by whom?
- How are these used to review and improve services?
- How is the learning disseminated?

Example 2: Examples of good practice
- Are there examples of good practice in your area?
- How are these evaluated?
- How is the learning disseminated to inform others?

5. Practical support for patients, families and carers

Patients, families and carers will all have needs when the patient is nearing the end of life. How are these met? Some important issues are listed below:

- ***Financial assistance***: What fast track financial assistance is available for families who will have a great deal of additional expenditure associated with care of a very sick relative? Is there access to a specialist benefits advisor who can give them timely access to available benefits?
- ***24 hour advice and support:*** Is there a 24 hour telephone number that patients, families and carers can call for advice or support, especially during the final stages of the illness?
- ***Support:*** Are carers adequately supported? Do they receive a formal assessment, time out (respite), access to training and suitable support with employment? Do they have a "life of their own" as well as their caring role? Do

patients and carers have access to peer support such as buddy systems and patient or carer support groups?

- ***Equipment:*** Is equipment readily available? All too often people request a hospital bed and it arrives after the person has died.
- ***Information:*** Is there a one stop shop for information, for example about how to navigate through the "system" signposting people where necessary. Where is this and how can people access it?
- ***Single point of contact:*** Who is the main point of contact for the patient?
- ***Palliative social worker:*** Is there a palliative social worker available to arrange palliative care and provide for support needs, thus taking the strain off the family?
- ***Basic care:*** This includes hydration, nutrition, pain control, and being cared for with dignity amongst many other things. Two examples are:
In hospitals and care homes, how are staff made aware of people who need additional help with eating? Is there a universal sign to indicate this? Is there appropriate mouth care?
Is there easy access to effective pain control for people in the community and is it available 24/7? Do pharmacists and GPs work together to ensure to ensure that they are readily available?
- ***Bereavement care:*** What support is available for bereaved adults and children?

6. Place of care

- If the patient dies on a hospital ward, what privacy and dignity can be expected?
- How many people are transferred from their home (which could include care home) to hospital in the last weeks of life?
- How many people transfer from hospice to home at the end of life?
- How many people's choice in place of care is fulfilled?

7. Is there a clear process in your locality for assessment of needs, care planning and advance care planning for end of life care?

- What process is in place for assessment of needs which includes end of life care? For the patient? For the carer?
- Is it joint across health and social care?
- Is this standardised across (a) settings of care and (b) sectors of care?
- If not, are there plans to place to review this and implement new processes?
- How are these to be monitored/ reviewed?
- Is there a clear process for assessment of need to lead to a review of the care plan including end of life care, both for the individual and for the carer?
- Is there a clear process for discussing advance care planning and end of life care wishes with the individual and their carer? How will patients and carers be reassured that their plans will be met and that all professionals involved will have access to this information?

13

8. Co-ordination of care

Owing to the variety of professionals involved in end of life care, co-ordination is vital.

- Is there a clear process for information sharing about people in the end of life phase across sectors and care settings i.e. a register?
- Who leads a multidisciplinary team, in particular when both health and social care providers are part of it?
- To what degree are settings able to share information?
- How are out of hours services informed of people's end of life care needs?
- To what degree are sectors (for example health, social care, independent and third sectors) able to share information?

- Is this being reviewed?

9. Do you know what local patients and carers want from services?

- Does your locality involve service users and carers in planning, developing, monitoring and evaluating end of life care services?
- Do you have a strategy for this?
- Does your Patient and Public Involvement lead have a remit for end of life care?
- Is your Local Involvement Network doing any work around end of life care?
- Do you have a plan in place to support service users, carers and staff who are carrying out user involvement in this area?
- Do you consistently and routinely provide feedback to service users and carers who are involved?
- Have you mapped out user involvement in other organisations to learn from this?
- What stops you from involving service users and carers?
- Do you log your lessons learned so that you can continually build on user involvement and share these within the organisation and outside?
- Have you accessed NCPC's free guide: A guide to involving patients, carers and the public in end of life care. Available from http://www.ncpc.org.uk/users/index.htmlx

10. Raising public awareness

- Do you have local public awareness plans and any campaigns around the issues of dying, death and bereavement?
- How is your locality linked to Dying Matters, the national coalition on dying, death and bereavement led by the NCPC? Sign up your organisation to get regular updates and resources. Visit www.ncpc.org.uk/dyingmatters to find out more.

Appendix B

NHS
Hartlepool and Stockton-on-Tees
Clinical Commissioning Group

End of Life and Palliative Care

Hartlepool Borough Council
Audit and Governance meeting
3rd September 2015

Paul Whittingham, Commissioning Manager
Dr Hatim El Sheriff, Hartlepool GP Macmillan Lead

National/Local Context

The CCG’s strategic direction to transform End of Life Care (last 12 months of life) has been informed by key policies and reports including;

- Dying without Dignity: investigations by the Parliamentary and Health service ombudsman into complaints about End of Life care (May 2015
- NHS England Actions for End of Life care 2014-16 (November 2014)
- ‘One more chance to get it Right’ Leadership Alliance: Care of Dying People (2014)
- Quality Standard for End of Life Care for Adults (2012)
- National End of life Programme: Routes to Success Guide (2012)
- More Care, Less Pathway: A Review of the Liverpool Care pathway (2013)
- Nice Quality Standards for End of Life Care (2011)
- National End of Life Strategy (2008)
- Call to Action Event Nov (2013 – Feb 2014) – Local Engagement

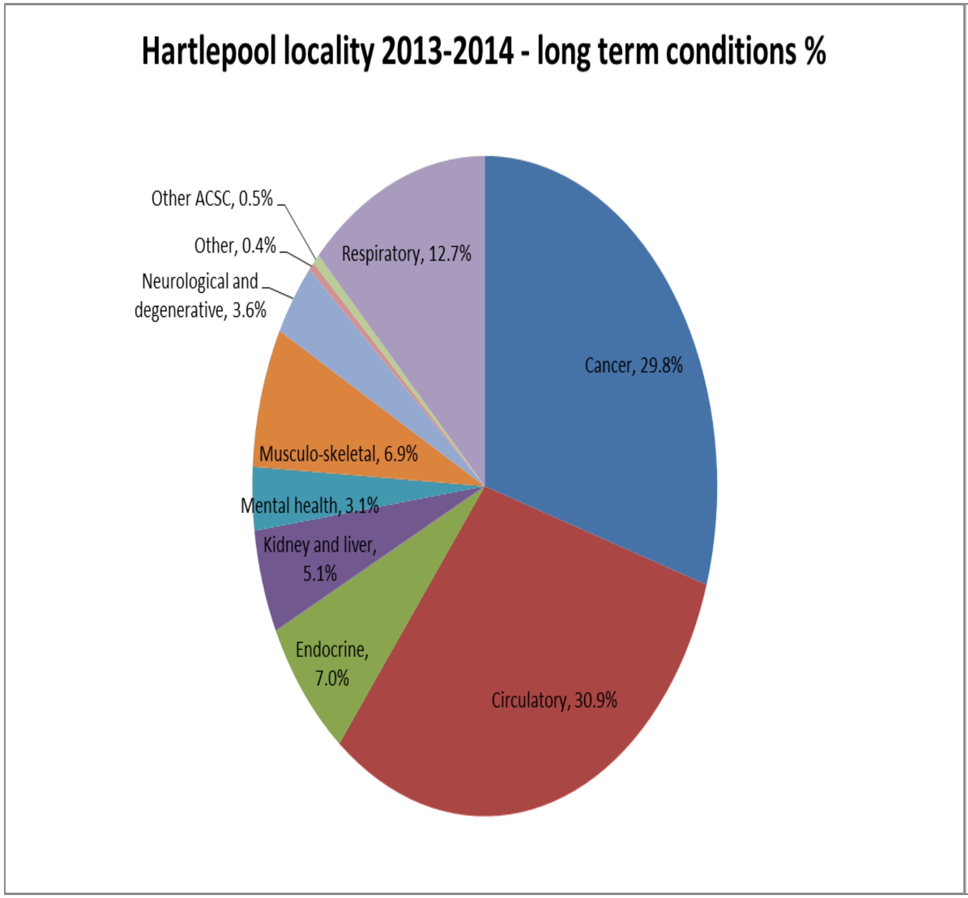
CCG Vision

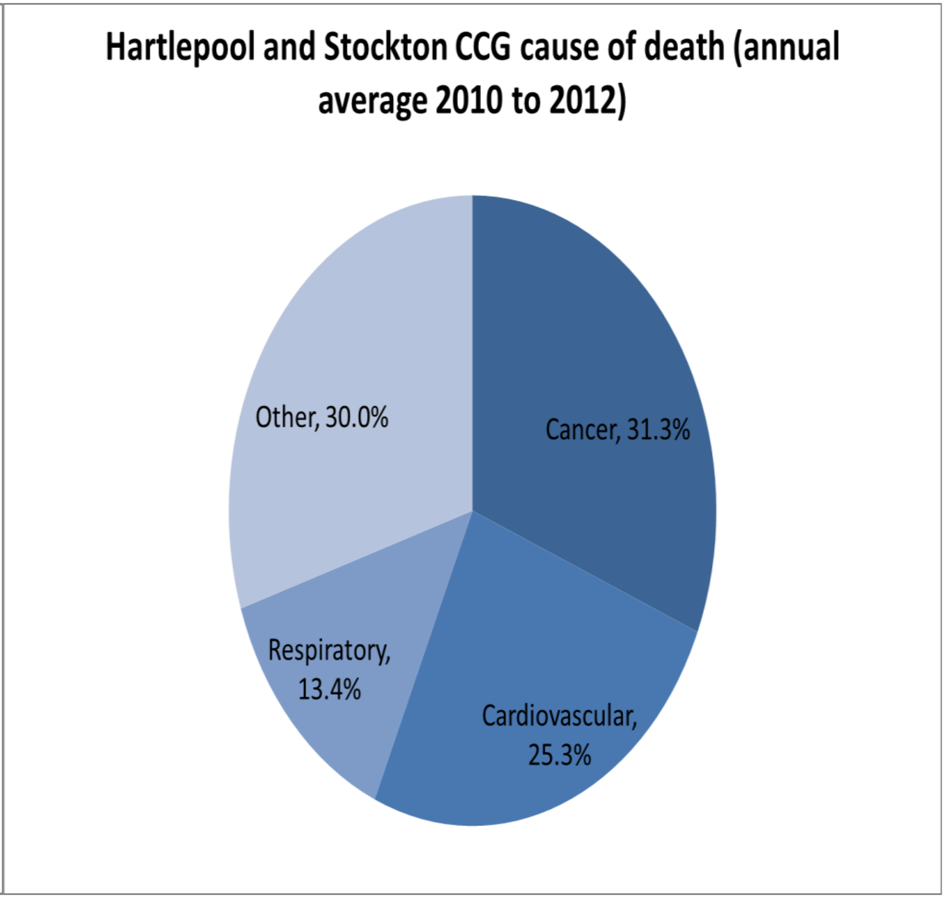
"People who are nearing the end of life should receive timely access to relevant health and social care professionals to help explore the persons understanding of their condition and to assess their physical, mental, social and spiritual needs. End of Life Care services should provide high quality care, support, choice and control, with full involvement of patients and their families', regular communication and the allocation of a nominated senior responsible clinician."

Case for Change

- The national bereavement survey undertaken by VOICES, (2012) showed that of those who expressed a preference, the majority preferred to die at home (81%), but only half of these actually died at home (49%). The most common reported place of death was a hospital (52%)
- 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available
- The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care. (British Social Attitudes Survey 2012)
- On average each patient will have three crisis admissions in the final year of life
- Emergency admissions rise in the final few days of life for patients that die in hospital
- 75% of people that die in hospital following an admission in the last month of life have mention of 13 different conditions
- Older people (85-89 year olds) see their GP on average 14 times a year
- The costs of caring for people at end of their lives are estimated to run into billions of

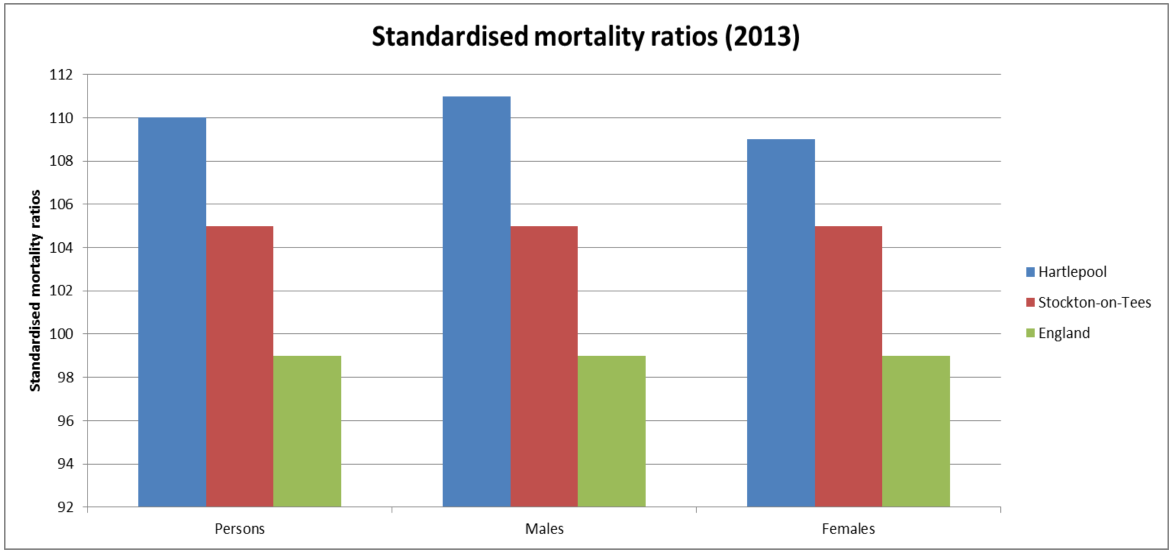
Local Profile



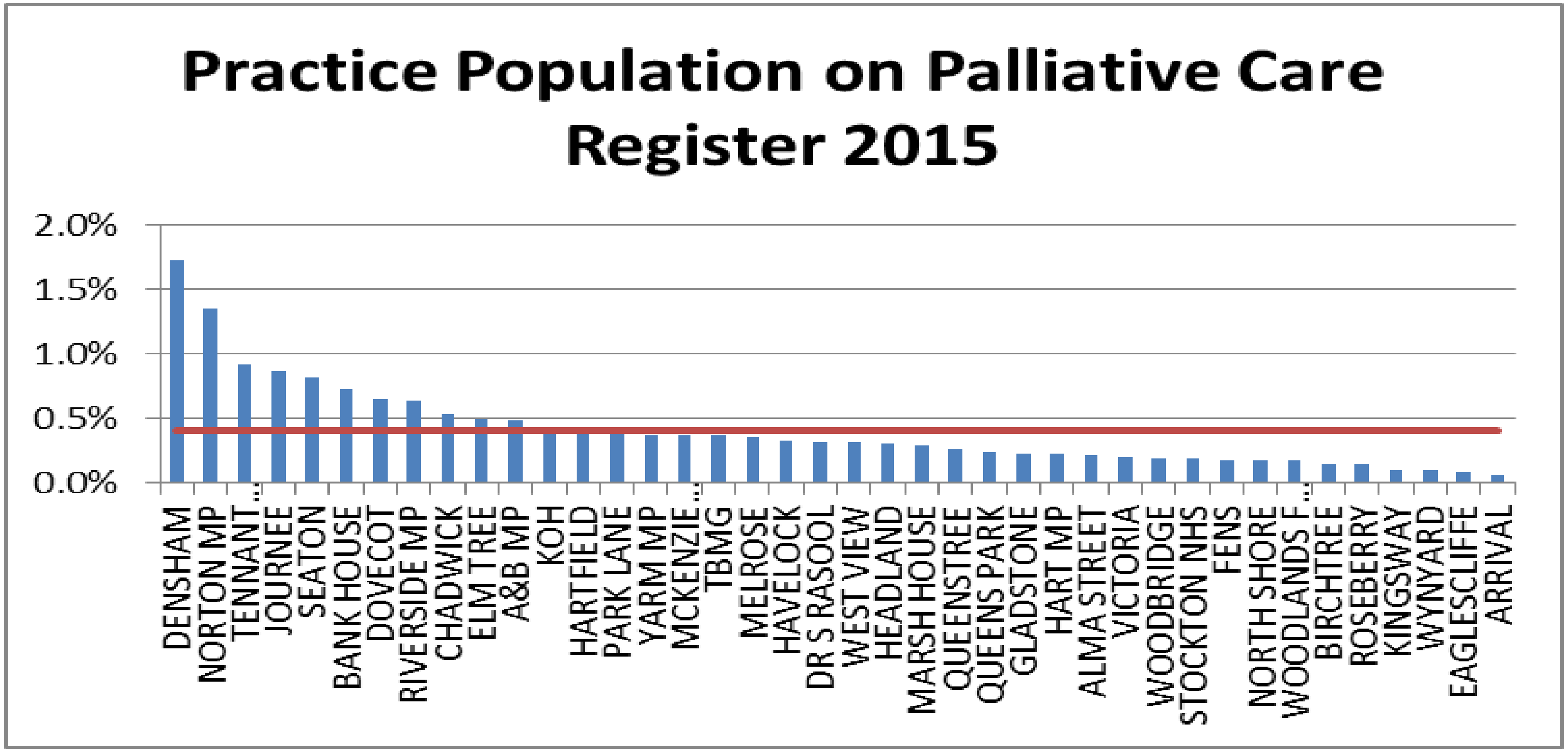


Mortality rates

- The standardised mortality ratios for 2013 taken from the Office of National Statistics, indicate that Stockton and Hartlepool localities have a higher ratio than the England average.



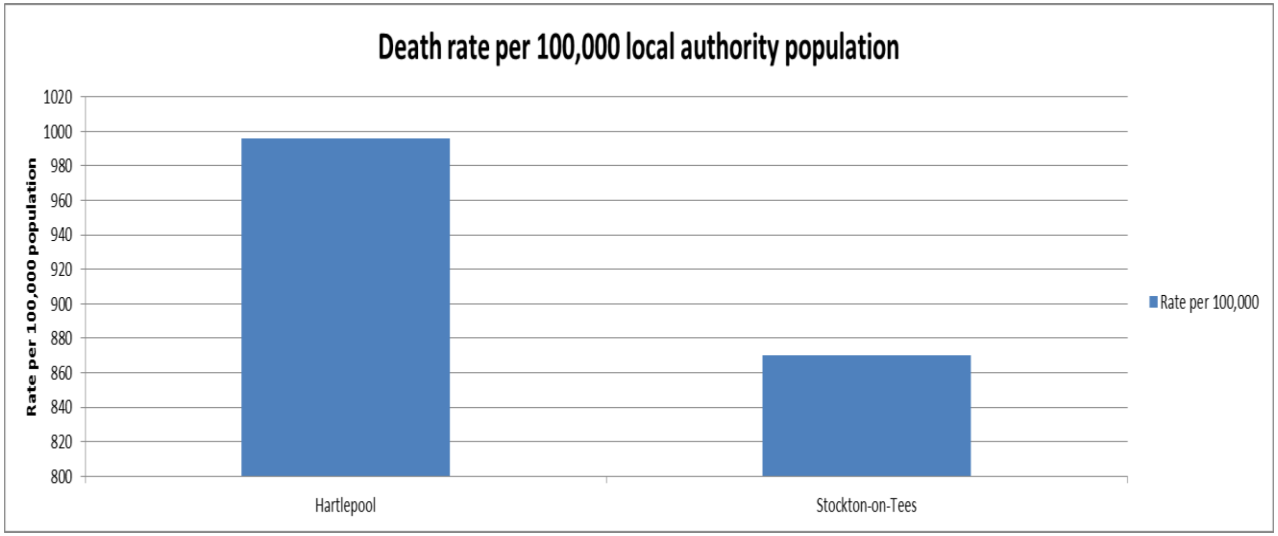
CCG Palliative Care Registers



Good Health
Everybody's business

Deaths across Hartlepool

- The death rate shows that the number of deaths in 2013 per 100,000 population in Hartlepool is 996, whereas the equivalent for Stockton is 870.

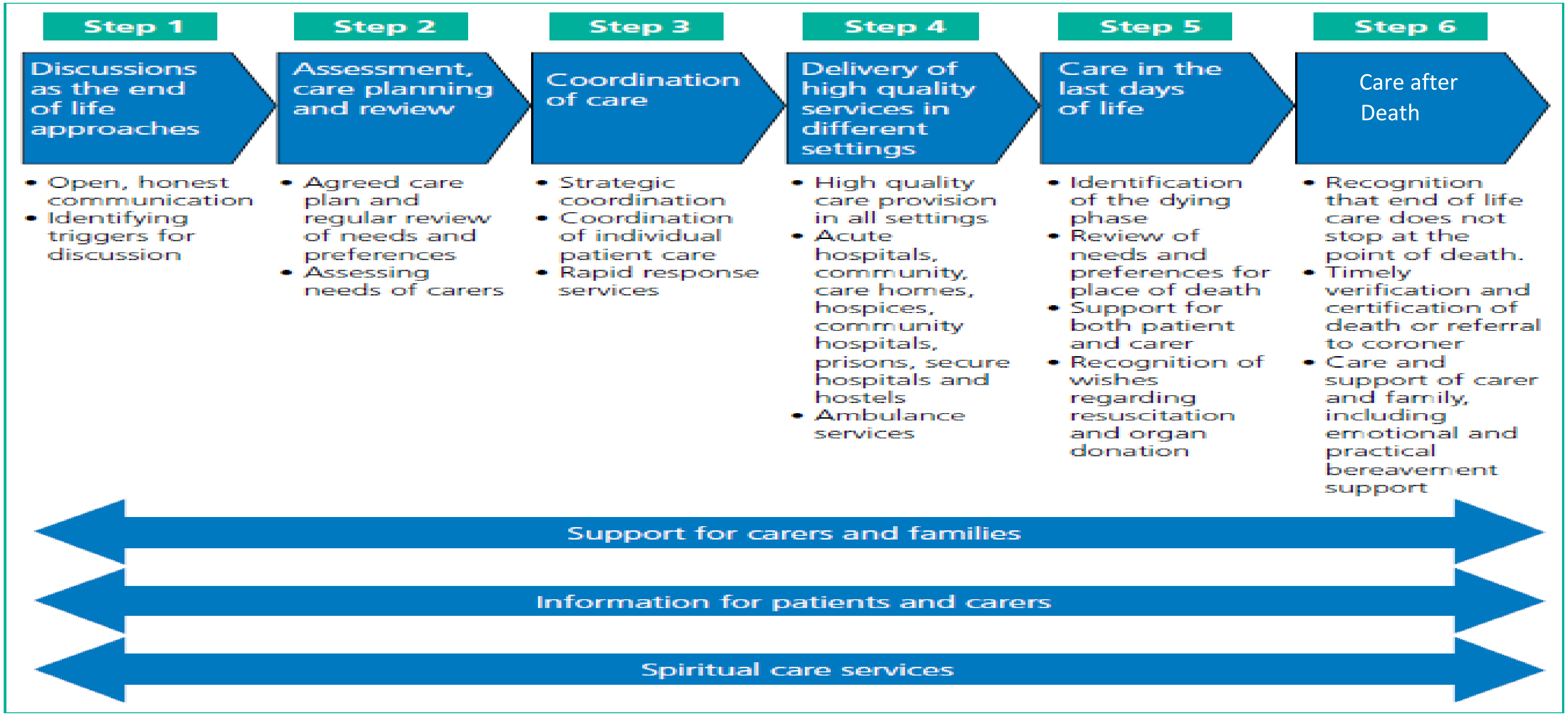


What good End of Life Care look like…

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

Steps to good End of life Care

Our aim is to improve access at each step ensuring that people are seen in the right place, at the right time by the right person



Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	Assessment, care planning and review	Coordination of care	Delivery of high quality services in different settings	Care in the last days of life	Care after Death
• Open, honest communication • Identifying triggers for discussion	• Agreed care plan and regular review of needs and preferences • Assessing needs of carers	• Strategic coordination • Coordination of individual patient care • Rapid response services	• High quality care provision in all settings • Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels • Ambulance services	• Identification of the dying phase • Review of needs and preferences for place of death • Support for both patient and carer • Recognition of wishes regarding resuscitation and organ donation	• Recognition that end of life care does not stop at the point of death. • Timely verification and certification of death or referral to coroner • Care and support of carer and family, including emotional and practical bereavement support

Support for carers and families

Information for patients and carers

Spiritual care services

Current Service Provision

The CCG currently commission a range of services to support patients at the end of life including:

- District Nursing Services 24 hours, 7 days
- Macmillan Specialist Palliative Care Team and Macmillan Lung Specialists
- Macmillan Specialist Nurses and Macmillan Carers Scheme
- Marie Curie Services
- Palliative Care – Hospice
- Palliative Care – Cancer Community Psychology
- Occupational Therapy in Macmillan Services
- Occupational Therapy in Palliative Care
- Palliative Out of Hours
- Physiotherapy in Macmillan Services
- Better Care for at Risk Patients scheme: longer appointments for Frail Older People, regular care home visits and care planning including discussions around End of Life and Do not Attempt Resuscitation documentation (DNAR)

Delivering the Vision

The CCG is committed to involving local people in decisions about the provision of healthcare for our local communities and we have worked and will continue to work with local people to develop the vision, priorities and future plans.

Our primary goal will be to:

- Increase the number of people on practice palliative care registers to support better End of Life Care
- Increase the number of people with advanced care plans
- Increase the number of people who die in their preferred place of choice
- Improve carer involvement and experience at End of Life
- Reduce the number of palliative care emergency admissions

Where we are so far

- Appointed Macmillan GP's for 2 years – (funded by Macmillan evaluation of roles to be undertaken in 2016)
- Developed 5 Year End of Life Commissioning Strategy (April 2015)
- Collaborated with NHS Foundation Trust and Strategic Clinical Network to develop standardised document to support the Dying Patient across both acute, community and primary care settings (Launched 1st Sept)
- Undertaken a 3P engagement event held with representation from a number of organisations/stakeholders to develop a joined up vision for End of Life care (Aug 2015)
- Undertaking a review of Specialist Palliative care Services (Community) (Completed Dec 2105)
- Primary End of Life Education Programme commissioned to start in Nov 2015 – Feb 2016
- Draft Commissioning Intentions in progress for 2016 to support;

  - Increase Palliative Care Patient numbers on GP Registers
  - Review commissioned bereavement services to understand current provision and future need
  - Explore and develop hospice at home services linking in the End of Life work from 3P event.
  - Develop education and training programme In relation to End of Life care around care homes.

APPENDIX C

healthwatch
Hartlepool

End of Life and Palliative Care

Stephen Thomas

HealthWatch Hartlepool - Our Functions:

Established under the Health and Social Care Act 2014, Healthwatch Hartlepool is expected to –

- Obtain views from the wider community about their needs and experiences of using health and social care services and make these known to those involved in commissioning and providing services.
- Promote and support the involvement of a diverse range of people in the monitoring, commissioning and provision of health and social care services.
- Make reports about how services could or should be improved
- Provide information to the public about accessing health and social care services
- Represent the views of the whole community, patients, service users and carers on the Health and Wellbeing Board and clinical Commissioning Group.
- Make the views and experiences of the communities of Hartlepool known to Healthwatch England, helping it carry out its role as national champion.
- Make recommendations to Healthwatch England to advise the CQC to carry out special reviews or investigations into areas of concern.

End of Life/Palliative Care – Our Experience

- One of the most sensitive and controversial issues we come across.
- When things go wrong, impacts lasting and devastating
- Since early days of LINk through to present day as Healthwatch frequently dealt with isues relating to EoL and Palliative Care treatment.
- Highly controversial at local and national level – Liverpool Care Pathway

Priority Area

- National issue –End of Liverpool Care Pathway – National Review
- Locally Care of the Dying Patient Review Group – Dr Jane Bentley
- Review of North Tees and Hartlepool NHS Trust practices and procedures
- Work well under way, positive feedback and reports on work of group from Healthwatch Hartlepool representatives
- Trust priority area for some time – work around "Family Voice"
- Palliative Care Register – G.P's

Some Themes - Communication

- The patient and the family
- Between care providers
- Consultants, G.P’s, District Nurses, Hospice, McMillan Nurses, O.T’s etc
- Effective coordination of care and care planning
- Dementia, learning disability and sensory loss
- Training and sensitivity
- Palliative care register – access to information

A Good Death?

- A difficult concept but –
- Peaceful and without pain
- Dignified
- At the place of choice of the patient
- As far as humanly possible does not leave loved ones emotionally scarred and traumatised.
- The best possible care has been provided in the best possible way at all stages – right people, right time, right place.

Finally

- Any Questions ?

MINUTE EXTRACTS

20 August 2015

37. Scoping Report – End of Life/Palliative Care in the Community Investigation (*Scrutiny Manager*)

The Scrutiny Manager referred to the meeting of the Committee held on 6 August, 2015 when Members had identified End of Life/Palliative Care in the Community as a topic for investigation during this municipal year. The Scrutiny Manager submitted a report making proposals for the conduct of the investigation, setting out the background and the definitions of palliative and end of life care, together with some relevant initial national and Hartlepool specific statistical information. The report also set out the proposed terms of reference for the investigation with some suggested potential areas of enquiry and sources of information for Members to consider. The timetable for the investigation included detailed work to be undertaken by Task and Finish Groups that had been utilised to good effect in previous investigations. The programme indicated that a draft final report would be considered by the Committee in March 2016.

At this point in the meeting Councillor Ainslie declared a personal interest as a trustee of Hartlepool Hospice.

Members expressed some slight concerns that some of the data quoted in the report was several years out of date and the Scrutiny Manager indicated that the aim was to provide more up-to-date data as it became available through the investigation. It was suggested by a Member that the Task and Finish Group should consist of all Members of the Committee. The Chair indicated that he would look to involving all Members in the Task and Finish Groups and would aim to hold meetings around those already scheduled for the Committee. Members also highlighted the wish of Hartlepool HealthWatch to be involved in the investigation.

A Councillor noted that from the statistics quoted in the report there was an increasing elderly population in the town and questioned if this trend was continuing. The Chair stated that this would be one of the issues relevant to the Task and Finish Groups discussions and further data would be considered there.

A Member of the public referred to there only being one registered Nursing Home in the town and questioned if the public was to be included in the investigation. The Chair indicated that the number of nursing home beds in the town would be an issue for the Task and Finish Group to consider through the investigation. The public were always welcome at the meetings of the Committee and there would be ample opportunity for public involvement and comment through the investigation.

The following recommendations were approved unanimously by the Committee.

Recommended

1. That remit of the investigation and the proposed timescale outlined in the report be approved.
2. That the Task and Finish Group meetings include all Members of the Committee.

3 September 2015

47. End of Life / Palliative Care in the Community Scrutiny Investigation – Setting the Scene Presentation (*Scrutiny Manager*)

The Director of Public Health gave a presentation on health status in Hartlepool as part of the end of life / palliative care in the community scrutiny investigation. It showed that Hartlepool was more deprived than the national average and the health of its residents generally worse than the national average. There were health inequalities in Hartlepool but many indicators were improving and life expectancy was increasing. Members had some concerns in regards to smoking, particularly by young people. The Director confirmed that smoking cessation was a priority for the public health department with officers visiting schools to try to get the message across. She would provide statistical information to members on numbers of young people smoking across the town. Members queried how the message was tailored across the age groups as primary age children tended to be keener and more focused than secondary age children.

A member referred to diet and obesity concerns and asked that holiday hunger be looked into as part of the investigation. He noted that his experience suggested that young people were not being fed fruit regularly and something needed to be done to change this state of affairs. He suggested that focus be put on retaining community centres as these could be hubs where young people could be given access to healthy foods. He asked that both holiday hunger and community centres be included as recommendations on the final report.

Paul Whittingham and Dr Hatim El-Sherif from Hartlepool and Stockton-on-Tees CCG gave a presentation on End of Life and Palliative Care. This referred to the last 12 months of life and was informed by a number of key policies and surveys which showed that while the majority of people preferred to die at home the majority died in a hospital. The presence of friends and family was felt to be the most important aspect closely followed by being pain free. Older people see their GP on average 14 times a year and have 3 crisis admissions in the final year of life. Statistics showed that the major cause of death in the Hartlepool and Stockton CCG area was cancer. Good end of life care was about being treated with dignity and respect, without pain in familiar surroundings in the company of close family and/or friends. Details were given of the steps to good end of life care and the range of services commissioned by the CCG to support patients at the end of life. Processes around end of life were being streamlined with an increase in the number of palliative care registers and the launch of new documentation to be forwarded to all GP practices. A full educational programme would be tailored for GPs, nurses and care homes covering aspects such as the mental capacity act, palliative care, oncology and out of hours information. Visits to all GP practices would take place with a view to looking at cancer cases, screening, reviews and referrals.

A member requested information as to the role carried out by MacMillan as opposed to Marie Curie. Doctor El-Sherif advised that Marie Curie were about hands on support out of hours while MacMillan was more focused on the medical side. The member suggested that all patients diagnosed with cancer should receive the services of a MacMillan nurse commissioned through the CCG. Another member queried whether the CCG currently notified MacMillan of any cancer diagnosis or was the onus on the patient and their family. Dr El-Sherif confirmed that upon diagnosis cancer patients were automatically assigned MacMillan services and it was not left to the family to arrange.

Councillor Jim Ainslie declared a personal interest in this item as a trustee of Hartlepool and District Hospice. He was confident that the hospice would be happy to support the proposed initiatives. He queried how cost effective the proposals were and whether the cheapest option was always the way forward. Mr Whittingham advised that most of the cost related to hospital admissions with £5 million per year spent on emergency admissions from care homes. Not all emergency admissions were strictly necessary but the 'blame culture' meant that carers were more inclined to pass patients onto hospitals. Training of staff in nursing and care homes was needed.

A member noted that whereas in the past deaths were attributed to old age this did not happen these days. Dr El-Sherif felt that there was always a cause of death and families would no longer be satisfied with such a broad reason

Members highlighted that the wishes of patients should be key when any end of life diagnosis was made. If patients expressed a wish to die at home this should be respected however there might be a tendency on the part of medical personnel to pressure patients to be admitted to hospital. The Chair referred to a report on specialist palliative care review services which was due in December and asked that it be sent for consideration by the committee as part of their investigation.

Recommended

That the setting the scene information be received and the following be included as part of the investigation and/or final recommendations:

- Holiday Hunger
- The retention of community services as hubs for healthy eating
- Access to MacMillan services for all patients with a cancer diagnosis
- The report on specialist palliative care review services

12 November 2015

77. End of Life/Palliative Care in the Community *(Scrutiny Manager/HealthWatch Manager) – Subject to approval by the Committee*

Representatives from HealthWatch were in attendance and gave a detailed and comprehensive presentation which outlined the functions of HealthWatch and their work around End of Life/Palliative Care in the Community. The presentation outlined HealthWatch's priority areas for consultation on End of Life/Palliative Care in the Community including the Locally Care of the Dying Patient Review Group, Clinical Commissioning Group and North Tees and Hartlepool NHS Foundation Trust. It was noted however, that during the consultation undertaken, it had proven difficult to obtain information from local General Practitioners and this had prevented the finalisation of recommendations in relation to prevention and early detection which should be a priority for all cancer patients. The HealthWatch representatives welcomed the investigation being undertaken by the Audit and Governance Committee and were happy to share the evidence gained during the consultation they had undertaken and to work collaboratively with the Committee on this issue.

A number of areas were highlighted as areas that could be improved upon within End of Life/Palliative Care and the main theme running through all these areas was communication which was key to improving the services offered at what was an emotionally charged and sensitive time for patients and their families.

In response to a question from the Chair, the representative from HealthWatch indicated that the work undertaken by HealthWatch had not featured Out of Hours as a separate service. The Chair confirmed that the Committee would look at service provision after 5pm as part of its investigation. A discussion ensued on the practice of assisted dying and it was noted that this was illegal in this country and any medical practitioner who assisted someone to die would run the risk of being prosecuted and serving a prison sentence. They key issue for patients on the End of Life pathway was controlling their pain management in a safe and effective way. It was suggested that the Committee may wish to examine what happened around the Liverpool Pathway and Liverpool's current provision as well as the practice of the withdrawal of food and fluids and the family's involvement in this practice.

During the discussion that followed, it was highlighted that around two thirds of people wanted to die at home but evidence suggested that only a third were allowed to do so and it was suggested that the Committee may wish to examine current trends in relation to this. However, this was an area where evidence gathering had proved difficult due to lack of information from GP practices.

The HealthWatch representatives were thanked for their informative presentation and for participating in the discussions that followed. The Scrutiny Manager confirmed that the next stage of the investigation into End of Life/Palliative Care in the Community would be a full day Working Group on Thursday 14 January 2016 and will commence at 10.00am in the Civic Centre. Further details will be circulated nearer the date.

Recommended

(i) That the presentation and discussions that followed to be used to inform the Committee's investigation on End of Life/Palliative Care in the Community.

(ii) The next meeting to consider the End of Life/Palliative Care in the Community would be an all day workshop style meeting of the Audit and Governance Working Group on Thursday 14 January 2016 and will commence at 10.00am in the Civic Centre.

Questions - End of Life Care

1. **Is there a clear strategy, supported by dedicated resources, for meeting end of life care needs in your locality, covering different settings and sectors of care?**

Strategy

i) Does the strategy arise from the assessment of population need including e.g. ageing population, those with multiple conditions and those with dementia?

ii) Who do you think the key stakeholders should be in developing this strategy and do you feel that all have been involved? For example: health, social care (including care homes) and housing.

iii) How is the strategy reviewed and by whom?

iv) Does the strategy include all of the elements defined as important within the national End of Life Care Strategy, such as Commissioning, User Involvement, Workforce Planning and Development, Measurement, Care Pathway Across Settings/Sectors of Care, Co-ordination of Care, 24/7 access to services, Rapid Response, Care at Home, Single Point of Contact.

v) Does the strategy clearly link with other local strategies such as the NHS Next Stage Review Long Term Conditions and Mental Health Workstreams, Dementia Strategy, Stroke Strategy and Carers Strategy? The National Council for Palliative Care has developed guidance on the way in which different policy agendas can be joined up.

Resources

i) What resources are dedicated to end of life care locally?

ii) Funding for specialist palliative care such as hospices is often provided by voluntary donations. What is the situation in your area?

iii) How is the use of resources monitored?

iv) PCT plans for spending the additional funds allocated to end of life care should align with Local Area Agreements – do they in your area?

v) Do the PCT plans reflect the strategy (above)? Do the plans and funding include all stakeholders across health and social care?

vi) Have lead commissioners for end of life care been identified? Who are they?

vii) Do they have the necessary knowledge to commission end of life care effectively?

viii) Do they link their work with commissioners of other services such as long term conditions and mental health?

2. **Is there a clear structure for workforce development and training across settings and sectors of care?**

i) Does your locality/region have a clear plan for identifying the staff who deliver end of life care including community and care home staff, and then a strategy for workforce planning and development that includes all key stakeholders?

ii) Does your locality have an identified lead for end of life care workforce planning and development?

iii) Does your local workforce development plan include the key skills of communication, symptom control, assessment/care planning and advance care planning?

iv) Do care homes in your area have a training programme in end of life care in place, for example, NCPC's *Care to Learn* materials?

v) Does your local workforce development plan include details for commissioning and meeting their training and educational needs?

vi) Does your local workforce strategy include details of how workforce planning and development will be monitored and reviewed?

vii) Don't forget that workforce development and training include staff attitudes. Two key things that patients and carers value is compassion and empathy. How do you foster these in your area?

viii) Assessment, care planning and advance care planning including end of life care all require a skilled and competent workforce (see below). The leaflet entitled 'Planning for your future care' provides helpful advice for patients and carers.

3. Is there a clear structure for monitoring end of life care?

i) Does your locality monitor outcomes?

ii) How does this inform planning and decision making?

4. Practical support for patients, families and carers.

Financial assistance: What fast track financial assistance is available for families who will have a great deal of additional expenditure associated with care of a very sick relative? Is there access to a specialist benefits advisor who can give them timely access to available benefits?

24 hour advice and support: Is there a 24 hour telephone number that patients, families and carers can call for advice or support, especially during the final stages of the illness?

Support: Are carers adequately supported? Do they receive a formal assessment, time out (respite), access to training and suitable support with employment? Do they have a "life of their own" as well as their caring role? Do patients and carers have access to peer support such as buddy systems and patient or carer support groups?

Equipment: Is equipment readily available? All too often people request a hospital bed and it arrives after the person has died.

Information: Is there a one stop shop for information, for example about how to navigate through the "system" signposting people where necessary. Where is this and how can people access it?

Single point of contact: Who is the main point of contact for the patient?

Palliative social worker: Is there a palliative social worker available to arrange palliative care and provide for support needs, thus taking the strain off the family?

Basic care: This includes hydration, nutrition, pain control, and being cared for with dignity amongst many other things. Two examples are:

- In hospitals and care homes, how are staff made aware of people who need additional help with eating? Is there a universal sign to indicate this? Is there appropriate mouth care?
- Is there easy access to effective pain control for people in the community and is it available 24/7? Do pharmacists and GPs work together to ensure to ensure that they are readily available?

Bereavement care: What support is available for bereaved adults and children?

5. Place of care

i) If the patient dies on a hospital ward, what privacy and dignity can be expected?

ii) How many people are transferred from their home (which could include care home) to hospital in the last weeks of life?

iii) How many people transfer from hospice to home at the end of life?

iv) How many people's choice in place of care is fulfilled?

6. Is there a clear process in your locality for assessment of needs, care planning and advance care planning for end of life care?

i) What process is in place for assessment of needs which includes end of life care? For the patient? For the carer?

ii) Is it joint across health and social care?

iii) Is this standardised across (a) settings of care and (b) sectors of care?

iv) If not, are there plans to place to review this and implement new processes?

v) How are these to be monitored/ reviewed?

vi) Is there a clear process for assessment of need to lead to a review of the care plan including end of life care, both for the individual and for the carer?

vii) Is there a clear process for discussing advance care planning and end of life care wishes with the individual and their carer? How will patients and carers be reassured that their plans will be met and that all professionals involved will have access to this information?

7. Co-ordination of care

i) Is there a clear process for information sharing about people in the end of life phase across sectors and care settings i.e. a register?

ii) Who leads a multidisciplinary team, in particular when both health and social care providers are part of it?

iii) To what degree are settings able to share information?

iv) How are out of hours services informed of people's end of life care needs? To what degree are sectors (for example health, social care, independent and third sectors) able to share information?

8. Do you know what local patients and carers want from services?

i) Does your locality involve service users and carers in planning, developing, monitoring and evaluating end of life care services?

ii) Does your Patient and Public Involvement lead have a remit for end of life care?

iii) Do you have a plan in place to support service users, carers and staff who are carrying out user involvement in this area?

iv) Do you consistently and routinely provide feedback to service users and carers who are involved?

v) Do you log your lessons learned so that you can continually build on user involvement and share these within the organisation and outside?

9. Raising public awareness

i) Do you have local public awareness plans and any campaigns around the issues of dying, death and bereavement?

ii) How is your locality linked to Dying Matters, the national coalition on dying, death and bereavement led by the NCPC?

In summary:

What is working well?

How can things be made better?

What are the priorities for the future?

End of Life / Palliative Care Scrutiny Investigation: Submission from HBC Adult Services

Role of HBC Adult Services

The Council's Adult Services work closely with partners to support end of life care and employ two part time Social Workers (equating to one full time equivalent role), who specialise in supporting people at the end of life.

The post was originally funded by Macmillan and focused on cancer care, and was referred to as a 'Macmillan Social Worker'. The funding from Macmillan ceased in 2014 but the Council has continued to fund the post in recognition of the value it brings to the service and the benefits for people who access the support, and the role now has a broader remit inn relation to end of life rather than focusing only on cancer.

The role of the Macmillan Social Worker was one of the focus areas in the Local Account 2013/14 with a summary of the role provided along with case studies to demonstrate how the role operates. The relevant section from the Local Account is attached for information as **Appendix A**.

Priorities for Adult Services

Adult Services support the conclusions and recommendations of the House of Commons Health Committee on End of Life Care (published March 2015) which are attached as **Appendix B**.

Particular local priorities for Adult Services are:

- Implementation of the Gold Standards Framework in all care homes. The CCG has a commissioning intention identified to take this forward, and Adult Services are working with the CCG to support this.
- Improved education, training and support for care homes in relation to end of life care. This has previously been supported through CCG System Resilience Funding and will be part of a wider education and training programme for care homes that is being developed as part of the Better Care Fund plan for Hartlepool.
- Development of a more joined up approach to advance care planning.

Jill Harrison
Assistant Director of Adult Services
8 January 2016

Appendix A: Extract from The Local Account of Adult Social Care Services 2013/2014

Focus on: The Macmillan Social Worker

Macmillan Social Workers are qualified and trained social workers who have received specialist cancer support training and Liz was appointed Macmillan Social Worker in Hartlepool Child and Adult Services in May 2012. Liz qualified as a social worker in 2003 and has worked in various roles including in adult social work teams. Whilst she has a great deal of experience in adult social care, Liz was aware that she lacked experience in the cancer support area, so she took advantage of the induction and Cancer Support Course offered by Macmillan.

Cases are referred to Liz from the local Macmillan Team; the First Contact and Support Hub; other social work teams; colleagues and district nurses. Liz has spent time building up relationships, concentrating particularly on developing links with district nurses and the Hospice Social Worker. Liz sees that a key part of her role is to provide each individual with a seamless service, providing links to health and social care, so the working relationships she develops are vital.

When a new case is referred to Liz, she will ring and talk to the person and explain what her role as Macmillan Social Worker is. Sometimes people do not think they want nor need a social worker so Liz will leave her contact details with an open invitation for the person to ring her if they change their mind.

If the person does want to see Liz, then she will visit the person wherever is best for them – this can be at home or elsewhere. Liz will often find that in her first visit she provides the person with a lot of contacts and information but whatever the need is, Liz's approach is to ask the person how she can help and then listen to what they tell her. Liz finds that people will often describe what is happening to them and she can find out who else is involved with the person, what family and friends are around and where the person is on their cancer journey.

After this first visit Liz leaves with a greater understanding of the person's situation and needs and will know if the person wants to receive support from a social worker or indeed another professional.

So what difference does a Macmillan Social Worker make? For Liz, her focus is on making sure that the person feels in more control. Liz has been able to offer people personal budgets which have helped them feel less isolated and more independent. Liz has also provided some practical help around benefit support, and helped individuals get household equipment through a Macmillan grant. What has made her particularly proud however is being able to be alongside someone, supporting their emotional needs on their cancer journey.

As the work goes on, Liz hopes that the role will continue to develop and the links with her health colleagues and public health will develop and strengthen which will help to improve cancer support in the town.

Case Study – Macmillan Social Worker support for Mr C

It was the third time that Mr C had had cancer and he was finding it really hard to cope. He had no energy, was feeling really bad and very tired and couldn't do anything. The next door neighbour's daughter saw Mr C and realised how much he was struggling. She suggested that he phone social services – Mr C was quite sceptical as to whether social services would help him. However, he did ring and after a few phone calls got a visit from Liz, the Macmillan social worker.

The immediate concern was getting MrC some help with his daily living so that he could stop worrying about his house. Liz set up a personal budget for Mr C and a cleaner was found who spends 1.5 hours a week cleaning his house.

Liz continued to visit Mr C and he felt that she really listened to him and together they worked on developing his support plan. In addition to the cleaner, Mr C's personal budget has allowed him to access the pool and gym at Mill House Leisure Centre and put his dog in kennels so that he could have a holiday. Mr C also had a one-off payment towards a workshop. Mr C was a joiner and really enjoyed making things and having a workshop would allow him to do that.

Together Mr C and Liz identified that Mr C was becoming more and more isolated and in a rut – his workshop has really helped him as it has given him something to do and because of the planning and measuring involved in making things, has got his mind working again. Having somewhere to go and something to occupy his mind was seen by Liz as being really important for Mr C's wellbeing.

Mr C said that Liz, in her role as Macmillan social worker, has really made a difference to him and how he feels about himself. She has provided Mr C with a huge amount of information and contacts including links to other Macmillan workers who have helped him with his benefits and in getting a grant to help him with food and bills so that he can eat a healthier diet and keep his home warm.

When Mr C's oven blew up just before Christmas it was Liz who made an application on his behalf to a Macmillan fund to help him replace it – if Liz was not in the role of Macmillan social worker, he would not have got that help.

Most importantly for Mr C, having Liz as the Macmillan social worker has given him the opportunity to talk to someone who listens and really understands what he is going through. Liz has also given Mr C access to a number of other people who have helped really make a difference to his life.

Case Study – Macmillan Social Worker Support for Mrs D

Mrs D was referred by the hospice to social services and was initially given help from a social worker who set up a personal budget that allowed her to attend the hospice every week, have some complementary therapies and receive a one-off payment for a laptop that Mrs D uses to go online and is going to use for shopping when her daughter sets it up for her.

When Liz was appointed Macmillan social worker, Mrs D was one of the people who was identified for her to support.

Whilst Mrs D had been quite happy with her social worker she did feel that Liz offered something a bit different. Liz listened to her and Mrs D felt comfortable with her and felt that Liz understood some of what she was going through.

For Mrs D, being able to attend the hospice is really important to her. Because of the impact of her illness Mrs D feels uncomfortable and self conscious going to some places – at the hospice she feels she can be herself and doesn't have to 'hide'. This is also the case when Mrs D meets her friends every Tuesday. Liz understands the importance of these things to MrsD and knows they are crucial to helping her mental well-being.

Mrs D did not realise what support that social services could offer her and is pleased that the hospice made that link for her. She is really pleased that Liz has the specialist role because she feels listened to and understood. She knows that she can phone Liz if she needs any help.

Being in touch with social services has also meant that her husband has had a carers assessment and they are hoping that he can get some support with a gym membership. Both Mr and Mrs D used to like visiting the gym together and hope to be able to do so again in the future.

Appendix B: House of Commons Health Committee Report on End of Life Care (March 2015).

Conclusions and Recommendations

Beyond the Liverpool Care Pathway

1. Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life. There should be no reason for any health or care organisation not to have introduced an appropriate alternative to the Liverpool Care Pathway. (Paragraph 34)

2. We recommend that a senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation. (Paragraph 35)

3. We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute and community health care providers' move to the new approach in their inspections and as part of their thematic review. (Paragraph 36)

4. Generalist staff in acute settings must be competent in identifying people who are likely to be at the end of life, irrespective of their medical condition, so that they can offer specialist care where it will be beneficial. We recommend that NHS Trusts ensure that generalist staff are provided with opportunities to learn from specialist palliative care teams. (Paragraph 51)

Access to Palliative and End of Life Care

5. Roundtheclock access to specialist palliative care will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the variation in the quality of end of life care within hospital and community settings. We also recognise the value of specialist outreach services. We recommend that the Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses. (Paragraph 52)

6. People with dementia should have equal access to end of life care as those dying as a result of other conditions. Particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis. (Paragraph 53)

7. Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, including children and adolescents, people from ethnic minority backgrounds and those living in isolated or deprived communities and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care. (Paragraph 54)

Competence of the workforce

8. We heard that too often staff lack confidence and training in raising end of life issues with their patients or delivering the right care. Training should be provided for all health and social care staff who are likely to provide care to people at the end of life, including training in communication skills. We recommend that NHS England works with care providers to identify and roll out tailored end of life care training. (Paragraph 75)

Advance Care Planning

9. We believe there is a role for the Government and NHS England to provide clarity and leadership with regards to the policy on advance care planning and its implementation. We recommend that the Government considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment. The Department should provide an update to our successor Committee on the actions it has taken since publication of its response to the House of Lords Select Committee Report. (Paragraph 88)

10. We recommend that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and the legal status of different options. Training should be developed in partnership with the National Council for Palliative Care and other non-government bodies with relevant expertise. (Paragraph 89)

11. We recommend that the Government engage with Age UK to understand the outcome of their awareness raising pilots, learning lessons that can be applied to supporting other groups as well as older people to understand the options, and developing a strategy to promote advance care planning to patients in different settings. (Paragraph 91)

12. We recommend that the Government carry out a review of the cost of making a Lasting Power of Attorney, including the impact on take up by people from different socioeconomic groups, with a view to identifying any financial barriers for those who have been unable to take out LPAs, and what support is available to those who cannot afford to use a legal **route.** (Paragraph 93)

13. At present, should a person completing the LPA application form make any error, they are obliged to complete a new form and start the application process again, including paying a second time. We recommend that the Government review the LPA application process, with a view to making it simpler and cutting costs for applicants. (Paragraph 94)

14. We recommend that the Government encourage and monitor the take up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), to facilitate information sharing between providers, and that they review the best mechanisms to facilitate the understanding and take up of these plans. We also recommend that the Government explore options for a universal system for recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues. (Paragraph 98)

15. The Department of Health has notified the Committee that NHS England is working with Health Education England to develop a single accredited curriculum for paramedic training that will ensure that paramedics have the skills they need to resolve more calls on the phone (hear and treat) and at the scene (see and treat). We expect end of life care to feature in the new curriculum when the details are issued later in 2015. (Paragraph 99)

Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPR)

16. We recommend that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England. (Paragraph 108)

Community resourcing

17. We recommend that Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. The Committee sees this as essential to enabling people to die at home and in other community settings including care homes and nursing homes, where that is their preference rather than in hospital. This should involve their plans for the recruitment and training of district nurses. (Paragraph 113)

Free social care at end of life

18. We recommend that the Government clarify the eligibility criteria for the NHS Continuing Healthcare Fast Track Pathway and phase out the social care means test (financial assessment) for people at the end of life. (Paragraph 134)

19. This Committee strongly recommends that the Government provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support. (Paragraph 135)

20. We recommend that the Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review. (Paragraph 136)

21. We recommend that the Government ensure that their proposals for the future funding of palliative care fully recognises the importance of the voluntary sector. (Paragraph 137)

Bereavement support

22. Bereavement support provision is currently fragmented, with services not consistently provided around the country. Family members and carers are too often left inadequately supported. We recommend that the Government and NHS England raise awareness amongst health and social care staff of the impact of bereavement and provide for universal access to bereavement services in its funding plans for palliative care. (Paragraph 144)

Measuring quality of care

23. We recommend the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life. (Paragraph 150)

Research into Palliative and End of Life Care

24. We recommend that the Government pursue the research priorities that matter most to people with terminal illnesses, their families and carers and the staff providing care professionally to them, and set out what funding will be provided to ensure that future policy on palliative and end of life care is informed by a robust evidence base. (Paragraph 155)

Leadership

25. The Five Year Forward View sets out a direction of travel for the NHS in England, covering all the major statutory bodies. The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally. (Paragraph 159)