North Yorkshire and York
End of Life and Palliative Care Commissioning Strategy
2008 - 2011
September 2008
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The Vision for North Yorkshire and York

That each individual who is approaching the end of their life is offered effective care and support in the best setting possible for their individual needs, in a timely way, and that family members caring for their relative are offered support to enable them to care for the dying person as well as themselves.

1 Introduction

1.1 A vision for North Yorkshire and York

That people who are in need of palliative care, or have reached the end of their lives, receive the best possible care, in the setting of their choice where this is possible, and that when death finally comes, that they are able to die with dignity.
That carers of those who are receiving palliative care, who are dying or have recently died: have their needs met throughout the process of caring for their loved one.

1.2 Purpose of this Commissioning Strategy

The purpose of this North Yorkshire and York Strategy is to plan for services which can be delivered in partnership with statutory and voluntary organisations, and which deliver the best and most appropriate treatment, care and support services for people who need palliative care or are approaching the end of their lives.

This strategy creates a framework on which to develop an accessible and equitable approach to the provision of palliative care and End of Life services in North Yorkshire and York, which ensures: -

- High quality, evidence-based, individualised care responsive to the individuals’ choice, in the most appropriate setting, from identification of palliative need to the end of life.
- An integrated pathway for all, across social, primary and secondary care in need of supportive and palliative care, End of Life care or both, using a multi-disciplinary approach.
• Timely and accurate diagnosis of palliative need, regardless of the patient’s age or medical condition.

1.3 Commissioning for North Yorkshire and York

North Yorkshire and York Primary Care Trust, North Yorkshire County Council and City of York Council work together to commission care in the statutory, private and voluntary sectors to ensure provision of health and social care services delivered into the person's own home, residential, nursing homes and specialist palliative inpatient care.

North Yorkshire and York PCT is embracing the principles of World Class Commissioning and commissions services which provide, ‘Right Care, Right Place, Right Time, Every Time’.

The PCT aims to commission:

- Best possible models of care
- Hospital is there when you need it
- Bring Services Closer to Home, where appropriate
- Build responsive capacity in the community
- Maintain peoples independence and well-being
- Ensure services are safe and sustainable
- Engage clinicians and service users in planning services

North Yorkshire County Council and City of York Council are developing the personalised care agenda for individuals, following the joint strategic needs assessment. Caring for those with Long Term Illness in their own homes, and transforming the way in which individuals can negotiate their own care provision.

1.4 Commissioners and Commissioning Tools

Commissioners are developing service specifications for existing services, in addition to commissioning new services.

NICE guidance and NSFs are tools which commissioners employ to assess current service provision against national standards and requirements.
2  The Population Served

2.1  General Population and Geography of North Yorkshire and York

North Yorkshire is England’s largest county. It includes market towns, coastal resorts, and some of the most remote and sparsely populated rural areas in the country, as well as the City of York within its boundary.

North Yorkshire and York PCT is co-terminus with North Yorkshire County Council. The PCT also includes the City of York Council (CYC) within its area. It is the third largest Primary Care Trust in England with a total population of 765,000 people, 102 GP practices, 11 Community Hospitals, Community based District Nurses, Allied Health Professionals, Care at Home Services and Specialist Palliative Care Teams.

2.2  Incidence of Death Across NYYPCT

Across North Yorkshire and York, deaths are attributable to three main areas of illness, Heart and Circulatory disease (41%), Cancer (26%) and Respiratory disease (12%). Of the remaining 21%, some deaths will be sudden or unexpected, such as road accidents. Other deaths relate to a range of long term illnesses such as Neurological Disease or Renal Disease. Other deaths relate to frailty and very old age, without a specified diagnosis. Each year, there are between 7,500 and 8000 deaths in North Yorkshire and York. Approximately 56% deaths take place in hospital. 19% of deaths take place in peoples own homes, 5% in hospices, 19% nursing and residential homes. (PCT End of Life Review 2008/ Health Ambitions 2008).

2.3  Outcomes of current service provision

The NYYPCT End of Life Care Review, March 2008 (Appendix 1 or available on www.nyypct.nhs.uk), identifies a range of services across the area providing care for those approaching death. Outcomes of services vary across the area due to their development within the 4 precursor PCTs.
Services are subject to differing external and internal monitoring systems. There is variability in the quality, quantity, regularity and outcome focus of performance monitoring activities. Similar variation is experienced with respect to performance management.

There is no single system to record data relating to patients care as they enter palliative and end of life care phases.

3 Current Service Format

3.1 Services across North Yorkshire and York

Current service provision for those with End of Life Care needs, are set out in associated document of NYYPCT End of Life Care Review March 2008.

A review of children and young people’s service is to be completed in 2008.

This strategy aims to cover children and young peoples needs, though it is recognised that children and young people who have life limiting illnesses and conditions have a complex and particular set of needs.

3.2 Current Performance Monitoring and Management Mechanisms

Performance Indicators are tracked through uptake of some aspects of care.

These include spending on care for some patients accessing NHS fully funded “Continuing Care” scheme.

Costs associated with GPs contract in relation to Gold Standards Framework, Liverpool Care Pathway and “Preferred Priorities of Care” documentation.

Data collected relating to deaths in hospital settings, and costs relating to care delivered in hospitals.
3.3 Gap Analysis

Analysis of the services provided across North Yorkshire and York, indicates that there is much good practice on which staff are to be complimented, and provides a good base on which to build. See NYYPCT End of Life Care Review, March 2008 (Appendix 1 or available on www.nyypct.nhs.uk) for full gap analysis.

3.4 Services/organisations

NYCC and CYC commission and provide services to those with care needs living in the community or in residential homes. Social Care personnel are involved with caring for those at end of life who wish to remain in their place of residence, supported by health care personnel.

A range of agencies, hospices and home care services provide care to people in care settings outside of hospitals.

Close working links with statutory agencies are working well in some parts of the area. There is no single system staff work to, supporting co-ordination of health and social care and services.

Projects such as the development of Partnerships for Older People Project (POPPs), where joint agency teams developed a generic set of health and social care skills, could support the aim of cost effective and clinically effective delivery of care to people in their preferred place of care.

4 Current Delivery Mechanisms

4.1 Providers, Activity and Payments

Current services are provided, based upon assessed historical need by precursor PCTs.

NHS treatment and care is commissioned from secondary care through contracts, service level agreements, and increasingly via Payment by Result mechanisms.

Primary care providers (GPs) received payments through achievement of quality indicators within their contract, in particular the Gold Standards Framework.
PCT provider services provide specialist palliative care services, general nursing and Allied Health Professional (eg: Dietician, Occupational Therapist) care services to patients in a range of community settings.

Funding of these services is based on historical patterns of funding.

Activity is recorded in a range of ways, such as written District Nursing records and GP databases. Hospices submit a minimum data set to the National Council for Palliative Care. There is no single data collection system which is accessible by the PCT reflecting activity and its cost.

Across the Independent sector (voluntary and private organisations) there is a wide range of funding mechanisms ranging from grants to payments related to the level of activity undertaken.

4.2 Collaborations and partnerships

The PCT works in partnership with the three Cancer Networks which cover the area of North Yorkshire and York. Each network has a palliative care group which develops strategic aims for the area including North Yorkshire and York.

The PCT works closely with NYCC and CYC at both strategic and provider levels. For example, NYCC in partnership the PCT had 4 Partnership for Older People Projects, piloting differing ways of delivering care to people in their own homes, and promoting independence for individuals.

4.3 Service Reviews, Performance Monitoring and Management

The PCT End of Life Service Review was completed in March 2008.

The current inability of organisations to share relevant information on a single IT system regarding individuals cared for in different care settings, is frustrating for all. Work on the Single Assessment Process and Person Held Records kept in individuals own homes, is moving forward
5 Outcomes to be delivered by the Strategy

5.1 Person Centred Outcomes relating to palliative care

Access to a timely, multi-disciplinary, person focussed assessment, care delivery and service provision for those with any long-term illness, condition or frailty, using a consistent approach to care pathways and care tools. Assessment to be part of Common Assessment Framework facilitating information sharing across services to benefit the person at the centre of care.

Consistent approach to Advance Care Planning across North Yorkshire and York to ensure equity for all in achieving preferred place of care and death

Access to consistent, cost effective and appropriately skilled multi-professional services to support Palliative care

Access to multi-disciplinary specialist palliative care assessments and interventions when needed (NICE)

Access specialist palliative inpatient care when clinically appropriate

Access to specialist palliative medical advice 24 hours/7 days a week

Access to assessment for, and provision of equipment in a responsive and person-centred time frame.

Access to medication including controlled drugs, 24 hours/7 days a week.

Access to consistent information for individuals and carers regarding Palliative and End of Life care.

5.2 Person Centred Outcomes relating the End of Life Care

Access to one point of contact for co-ordinated 24 hour care services for people approaching the end of life.
Establishment of locality wide register of End of Life patients/people.

Access to timely transportation service to move dying people to their preferred place of care

Access to assessment for and provision of equipment 24 hours/7 days a week

Access to medication including controlled drugs 24 hours / 7 days a week.

Access to health, social and spiritual care appropriate to need 24 hours / 7 days a week.

Access to verification of a death in a timely and sensitive manner.

5.3 Outcomes relating to Quality of services

Consistent End of Life care across North Yorkshire and York, with policies to support this.

Support for carers including services such as short breaks or provision of facilities when person cared for as inpatient, to support the carers.

Provision of 24 hour care services for individuals in their own homes in the last days/weeks of life.

Access to bereavement care and services

Evidence of User and Carer involvement and feedback

Education provision for the total workforce across organisations is sufficient to provide staff with the relevant skills to meet the needs of people in their last year of life.

Provision of sufficient independent nurse prescribers to support multi-professional end of life care 24 hours / 7 days a week.
5.4 Outcomes relating to Performance Monitoring/Performance Management

Access to consistent, cost effective and appropriately skilled multi-professional services to support End of Life care

Achieve increase in the numbers of those who are approaching death to be enabled to die in their preferred priorities of care.

Recording of person’s choice and control of their preferred priorities of care, with on-going changes in that choice recorded along the pathway. Honouring of the persons choice where this is clinically safe.

Reduce the numbers of deaths in acute hospital settings.

Where deaths take place in acute hospital settings, that the patient has been identified as approaching death and care setting is appropriate to patient and carers needs.

Increase the numbers of people who die in their own homes, and community care settings

Systematic data collection, that captures individuals preferred priority of care, actual place of care and numbers of people admitted to services in the last days of life.

Data and information systems to be able to collect and collate the quality of palliative and End of Life services as experienced by individuals and their carers (both formal and informal).

Implementation and recording/documentation of Gold Standards Framework, Liverpool Care Pathway and “Preferred Priorities of Care” within all care settings in North Yorkshire and York.

5.5 Outcomes relating to sustainable services/organisations

Raising of awareness of death and dying within society at large

Workforce strategy which incorporates succession planning.
Achieve and strengthen collaborative working partnerships with statutory voluntary and private providers.

Payment mechanism which support the delivery of flexible, responsive services that can meet the needs of individuals whose requirements may vary several times in a day.

Sufficient provision of suitable alternative care settings for those who do not wish to die at home.

Achievement of targets set in NICE “Improving Outcomes Guidance” for Supportive and Palliative care

6 Non Negotiable Drivers

6.1 NHS Strategies 2008

End of Life and Palliative Care Services are one on the main priorities for the NHS which are reported in “Health Ambitions” 2008, “NHS Next Stage Review” 2008 and “End of Life Care Strategy” 2008.

6.2 NHS Cancer plan (DoH 2000)

This was the first national programme aimed at addressing inequalities of cancer incidence and treatment across the whole patient pathway.

6.3 NICE Improving Supportive & Palliative Care for Adults with Cancer (Sept 2004)

This guideline was the first national programme aimed specifically at improving supportive and palliative care.
6.4 **Manual of Cancer Services Standards - Peer Review process (DoH 2004)**

This is an on-going programme to review services against national standards. There are specific standards for generalist and specialist palliative care, which to date has focused on acute care.

6.5 **Gold Standards Framework (GSF) Liverpool End of Life Care Pathway (LCP)**

GPs, District Nurses, and all professionals involved in palliative care are achieving care delivery within GSF and are working toward LCP in the community to proactively manage their patients.

6.6 **NSFs – (eg Renal Services, Older People, Long Term Neurological Conditions)**

All newly produced NSFs acknowledge the importance of providing good palliative care for the particular cohort of patients.

6.7 **Social Care and Joint Strategies**


6.8 **Better Care, Better Lives (2008)**

National guidance for caring for children and Young People who have life limiting conditions.

7 **Negotiable Drivers**

7.1 **Providers**

Services to review and improve how they work together to meet the needs of dying people. There are a range of providers, supplying differing services at different times along the care pathway.
7.2 **Timescales for Implementation**

To be agreed as part of Action Plan, but to be complete by 2011.

7.3 **Care Pathways**

Care pathways to be as close to home as possible, providing a safe and clinically effective service, with a local focus for individuals.

Across the PCT area, care pathways may be highly complex, due to the number of providers working with the PCT to deliver services to patients in a range of settings.

8 **Strategic Direction**

8.1 **Palliative Care**

Universal health and social care services are provided to those with assessed needs, and these are available regardless of where person is on care pathway.

Palliative care to meet the needs of those with general and specialist care needs, as per NSFs, NICE.

Palliative care assessment to be provided for those in the last year of life, regardless of diagnosis, or in some cases in the absence of a diagnosis.

Timely and accurate diagnosis is fundamental to ensuring patients enter the palliative care pathway, enabling them and their carers to be supported and managed by the most appropriate professional in the most appropriate setting.

Models of service to be reviewed to ensure the most cost-effective and efficient, Peer Review and NICE compliant model is adopted for each locality.
8.2 **Better Management of Care**

All individuals and carers benefit from an integrated and seamless journey, across all settings.

Develop and maintain good standards of practice in line with national guidance

Communications strategy, kept as simple as possible, to facilitate effective and well managed care for patients

Use of IT solutions to achieve well managed care pathways

8.3 **Reducing inequalities**

Flexibility of service delivery across North Yorkshire and York, to enable people in need and carers to receive the same outcomes of care and support, regardless of where they live in North Yorkshire and York.

Access to translation services, advocacy services and other services to promote inclusion, where required

8.4 **Delivering care in most appropriate setting**

Documentation and care planning around person’s stated preferred priorities of care.

Work to achieve care provision in individual’s own home, where this is clinically safe.

Work with providers to ensure a range of care settings for people to choose from, within cost and clinical effectiveness parameters.

8.5 **Using information to improve quality and choice**

Improvement in data collection across all services. The data to be informative, accessible, usable and where possible within a single IT system.
Agreement on a data set baseline for PCT commissioning requirements.

Activity data required for payment under the national tariff is not yet known, although collection of data might be more challenging for some providers than others.

8.6 Workforce Development

As more people with non-cancer diagnoses access palliative care services and a commitment to supporting the preferred priorities of care (with the expectation that more people will choose to be cared for and die at home), there will be a commensurate increase in the demand on all providers. This will require an integrated, cross-agency, cross-professional workforce analysis and plan, linked to local and national training and development frameworks to ensure the workforce are equipped to develop and deliver the needs of the local population.

8.7 Research and Development

PCT to support research and development into all aspects of Palliative and End of Life care to promote continuing improvement is this area.

8.8 Stronger commissioning

It is anticipated there will, at some stage in the future, be a tariff for palliative care services. This will support the development of care provision following recommendations set out in by NICE.

World Class Commissioning (2007), which clarifies the role and responsibility of commissioners, aims to achieve working in partnership with organisation, individuals, carers, clinicians and providers. This will promote commissioning of Palliative and End of Life care services which meet the needs of individuals and their carers in a cost and clinically effective manner.

Costing of service provision for the numbers of people who die each year in North Yorkshire and York and projecting costs for
future years. Develop the use of programme budgeting to support costing of care pathways.

8.9 Future Delivery

Services will be locally delivered, but have PCT and local authority wide outcome and quality measures.

There will be a range of providers and commissioners, working collaboratively to meet the needs of individuals and their carers.

Documentation and record keeping will be unified using an IT solution

8.10 Framework

Communications
Effective communication with individuals and family/carers by all clinicians/care providers.
Effective communication between professionals to support continuity of care
Single point of contact for those who are approaching the End of Life

Information Recording and sharing
Effective recording of individual’s preferred priorities of care, and retrieval of this data 24 hours a day.
Effective documentation of care needs of individuals, with alerts for clinicians/care providers following on, where changes in care are anticipated.

Education
Education of the general public to raise awareness of death and dying as part of life
Education of professionals to communicate bad news to patients
Education of workforce caring for those at end of life, to achieve good death in individual’s preferred priorities of care where this is clinical safe and appropriate
**Key Worker role**
Develop key worker role, to act as link and communicator for individuals care and pathway.

**General Medical Care in community**
GPs and Out of Hours services to provide medical care, symptom control and including anticipatory prescribing using Liverpool Care Pathway.
Access to Specialist Palliative care advice 24/7.
Independent Nurse Prescribers to provide assessments and use of anticipatory prescribing

**General Nursing in community**
Nursing services to assess patients and deliver holistic nursing care, which will include physical, emotional, spiritual and psychological care based upon need of patient and the skills of the nurse. Where the nurse is not able to deliver the care, referral to an appropriately skilled person is required

**Access to Equipment**
Access within specified time frame (24 hours) to all equipment requirements, including adjustable beds, mattresses hoists, commodes and disposables to enable safe nursing of patients outside acute hospital settings

**Access to Social Care**
Carers are offered assessment and support
Access to Respite care/short breaks for carers
Provision of meals and adequate nutrition where needed
Access to a wide range of housing and support solutions e.g. nursing homes, residential homes, supported and extra care housing

**Access to Specialist Palliative Care Multi-disciplinary Team**
Patients to have access to assessment and management of care by Specialist Palliative Care team when this is clinically required.
Patients should be moved in and out of Specialist care team caseload dependent upon their needs.
Access to 24/7 Specialist Palliative care advice.
Use of data collected/monitoring
Collection of data regarding measurable aspects of individual’s care pathway
Access to data
Use of data to monitor and manage quality of care delivery

Governance and Quality
Patient journey monitored for quality, cost and clinically effectiveness.

8.11 Locality groups

Commissioning organisations will require the support and engagement of all stakeholders who have an interest and/or responsibility in these service areas.

North Yorkshire and York to have Palliative Care/End of Life Strategy group with locality groups implementing the strategy locally. Communication flow between local and county-wide groups to inform and implement.

8.12 Views of the public

Views of the General public are incorporated into the strategy and reflect the issues, in particular around communications, equipment and access to services which were fed into the strategy through consultation process.
9.0 References

Building the Best DOH 2004

Caring for Carers (1999) DoH

Dementia Strategy (in development 2008) DoH


End of Life Care Strategy (2008) DoH

Health Ambitions (2008)

Macmillan Gold Standards Framework Programme:
www.macmillan.org.uk or www.modern.nhs.uk/cancer

National Council’s Standards for Palliative Care for hospice and special palliative care services 2000,

National Service Framework for Long-term conditions DOH 2005

NICE (March 2004) Improving Supportive and Palliative Care for Adults with Cancer

Our Health, Our Care, Our Say DOH (2006)

Putting People First (2007) DoH

Revised Manual of Cancer Service Standards DOH 2004