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Leeds End of Life Care Commissioning Strategy for Adults 2014-2019

Development led by WSYBCSU in conjunction with
Leeds partnerships

West and South Yorkshire and Bassetlaw
Commissioning Support Unit **NHS**

Improving the health and
wellbeing of our
communities

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Executive Summary

The further development of End of Life Care services for the people of Leeds is a major programme of work for the Leeds Health and Social Care Transformation Board and continues to be a key area of focus for the NHS. Investing in End of Life Care services can deliver cost savings and increase patient choice through ensuring that patients have access to and receive care in the right place at the right time. This can be achieved by having responsive primary and community service provision which will prevent unnecessary hospital admission for patients at a time which can be distressing and also place more pressure on the acute hospitals.

The Health Needs Assessment (HNA) for End of Life Care for Adults in Leeds (2013) gives clear indications both on areas of excellent practice within Leeds and on areas where gaps in service provision exist. A summary of the HNA can be found in Appendix 1 on page 27. This is the basis on which this commissioning strategy has been developed on behalf of the three Leeds CCGs.

Key Messages from the HNA

- The number of people needing EoLC in Leeds will increase substantially over the next 20 years.
- Professionals and the public show a reluctance to talk about the end of life approaching, leading to a lack of planning for the type and place of care. This is more apparent for conditions other than cancer.
- One strength of EoLC services in Leeds is its staff. They are committed, resourceful and patient-focussed.
- More people would like to be cared for and die in their own homes, which requires investment in out-of-hospital care, both generalist and specialist 24/7.
- Services could be more co-ordinated, streamlined, accessible and responsive both in and out of hours. This requires a “whole systems approach” to commissioning and service redesign.
- Leeds has two excellent hospices with uneven provision of specialist beds. More people would choose hospice-type inpatient care than can access it in Leeds. Inequalities in access to beds should be addressed.
- Many people will continue to require or choose hospital inpatient care towards the end of their lives
- Performance and outcome measures should be developed and implemented to assess the success of the strategy

The **aims** are:

- To improve end of life care for people in Leeds with advanced, progressive and incurable illness
- To improve access to end of life care services, improve choice and reduce inequalities across the city
- To increase the percentage of patients who are cared for and die in their preferred place of care

The **outcomes** will be:

- Pain and other symptoms should be controlled effectively
- The individual, carers and family should feel well supported and appropriately involved in their care planning

- The individual, carers and family should feel confident in the skills and knowledge of their health and social care professionals
- The individual, carers and family should know who to contact in an emergency and
- The individual should be able to die in their place of choice

The commissioning strategy includes a **Work Programme** (Appendix 2, page 51) with leads and timescales which will ensure that all 66 recommendations from the HNA will be addressed over the next 5 years. The work has been prioritised and grouped under the following sections:

- Service redesign
- Review of selected specialist services
- Ongoing commissioning of key work streams
- Provider organisations to implement
- Work to discuss with other commissioning bodies

The immediate *commissioning priorities for 2014/16* are as follows:

Hospital Discharge

To provide a 7 day Specialist Discharge Service for Palliative Care patients which has the flexibility to respond to the changing needs and preferences of patients transferring from in-patient settings to the community for end of life care

Co-ordination of care

To develop a single point of access for patients 24/7 for advice and signposting

Develop seven day services

To develop a model where Specialist Palliative Care Clinical Nurse Specialists provide care 7 days a week in acute hospitals and community settings

Provide more choice of place of care in the last days of life

To develop nurse-led beds for hospice type care in the last days of life as an option for patients who do not require a specialist service and cannot be cared for at home

Ensure rapid access to care outside of hospital 24/7

To develop an enhanced district nursing service that is able to meet the requirements of the Service Delivery Framework for Palliative and End of Life Care (Leeds) with an increased number of nurses who are able to prescribe and verify expected death. Review hospice admissions system to optimise choice and efficiency for patients

Improve access to medicines

To develop an improved system for co-ordination and delivery of EoLC medication in the community including access to super holding pharmacies

Continue to provide and improve education

The current education strategy will be reviewed and refreshed in order to inform the future commissioning of education provision

Palliative Care Funding Review

Consider the implications of the Palliative Care Funding Review and develop recommendations around the way that end of life care services are commissioned

Support to Care Homes 24/7

Develop a system which provides 24/7 nursing support to Care Homes for patients in the last days of life

Improving carer support and provision of bereavement services

To develop an improved system of carer support to reduce the incidence of carer breakdown. Review bereavement services and re orientate to meet the needs of bereaved people.

Improve medical support to community staff Out of Hours

Link with 111 to develop a system whereby calls from community staff requesting GP support Out of Hours are prioritised

These commissioning priorities will be reviewed after 2 years and further work allocated for completion during 2016-2019

It is proposed that in order to provide a consistent and evidence-based approach towards implementation across all services providing palliative and end of life care, that a framework is introduced following a formal options appraisal. This may include an ***End of Life Joint Protocol for the Transfer of Care*** between services, and a ***Managed Clinical Network*** to provide the structure and accountability to drive real change in the system across these multiple providers. A new performance management system will be developed to effectively monitor the outcomes of this commissioning strategy, and a health economics approach will be used to evaluate service change. This will enable commissioners to have greater control over the services provided by obtaining robust data on service performance which will inform future understanding and commissioning decisions.

1. Setting the scene

1.1. Introduction

This strategy sets out the Leeds CCG's vision and commissioning priorities for 2014-19 to meet the national end of life care standards and address local priorities for improving end of life care for adults in Leeds. It builds upon and replaces the earlier document entitled *Implementing the Leeds Strategic Framework for Adult Palliative and End of Life Care 2010-2015* and is informed by the recent *Health Needs Assessment End of Life Care Services for Adults in Leeds* (2013) (HNA). The strategy aims to address the key issues and improvement priorities reported in the HNA by providers, commissioners, service users, carers and the bereaved and has been written with reference to the following strategies and improvement programmes:

- *End of Life Care Strategy: Promoting high quality care for all adults at the end of life* (DH, 2008), which sets out a vision for giving people approaching the end of life choice about where they would like to live and die.
- NHS Improving Quality (NHSIQ) End of Life Care Programme - *Transforming End of Life Care in acute hospitals*, which aims to improve the quality of end of life care within acute hospitals across England.
- Leeds Integrated Health and Social Care programme.
- *Living well with dementia in Leeds – Our local strategy 2013-16* (Leeds City Council/NHS Leeds North CCG, 2013), which gives an overview of local services and states the local priorities for the next three years.

In the last five years, many achievements have been made in improving End of Life Care services across Leeds, including establishing nurse prescribers in the community, developing outpatient services in new locations and nationally recognised clinics for patients with non-malignant diseases, implementing the Electronic Palliative Care Coordination System (EPaCCS) across Leeds Community Health Care Trust (LCHCT), Leeds hospices and GP practices to improve communication, patient choice for place of care and to reduce the number of people who die in an acute hospital, and a programme of service improvement within LTHT.

2. This strategy should be read in conjunction with the HNA which lays the foundations for the commissioning of high quality end of life care services based on the needs of the local population identified now, with estimates of the growth in the Leeds population likely to require palliative and end of life care services over the next five to ten years. Public sector finances are under increasing pressure and it is imperative that we review our services and priorities in order to maximise value for money across the city.

2.1. Definition

End of life care (EoLC) is defined as care that:

“helps all those with advanced, progressive and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met through the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support” (DH, 2008).

Palliative care is defined as:

“The active holistic care of patients with advanced progressive illness. It is the management of their pain and other symptoms together with the provision of psychological, social and spiritual support” (National Council for Palliative care)

The NICE commissioning guide on end of life care for adults (NICE, 2011) uses the General Medical Council (GMC)’s definition which suggests that *“patients are ‘approaching the end of life’ when they are likely to die within the next 12 months”* (GMC 2010). The GMC guidance specifies that this includes patients whose death is imminent (expected within a few hours or days) and those with:

- a. advanced, progressive, incurable conditions
- b. general frailty and co-existing conditions that mean they are expected to die within 12 months
- c. existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- d. life-threatening acute conditions caused by sudden catastrophic events

1.3 Vision 2014-2019

The aspiration for Leeds is to increase the proportion of patients who are cared for and die in their preferred place of care. This will mean reducing the number of deaths in hospital, and increasing the number of people cared for at home or in a community setting (for example, hospice or residential care home). The vision for adult palliative and end of life care in Leeds is described as follows:

“People approaching the end of life, and their families feel supported to live as well as possible until they die”

1.4 Key principles

End of life care services in Leeds will:

- meet the current and projected needs of the local population
- involve service users in service development and evaluation
- be delivered in a variety of settings so that people can use the service of their choice
- be easy to access 24 hours a day, 7 days a week
- have low, or no, waiting times and no unnecessary waiting
- be developed in line with patient need, including locations and timings of services
- encourage and empower service users to be actively involved in planning their own end of life care and support them to make choices
- treat all service users and carers with dignity and respect
- offer treatment and care that is evidence based and consistent across services
- be cost effective

1.5.Aims and objectives

The overarching aims of the end of life care commissioning strategy 2014-2019 are:

- To improve end of life care for people in Leeds with advanced, progressive and incurable illness
- To improve access to end of life care services, improve choice of type and place of care and reduce inequalities across the city

- To increase the proportion of patients who are cared for and die in their preferred place of care

We will achieve our aims by:

- Increasing early identification of patients within the last 12 months of their life who would benefit from a supportive and palliative care approach
- Improving communication and person centred care with individual patients
- Ensuring that information/plan of care is shared between professionals according to patients wishes
- Improving integration of services and coordination of patient care
- Improving the efficiency of hospital discharge for patients receiving end of life care
- Improving out of hospital care
- Providing services seven days a week
- Improving access to medicines and equipment
- Developing the model and provision of hospice care to ensure optimum and efficient use of resources now and in the future
- Developing provision for patients near the end of life with non-cancer illnesses
- Ensuring equitable access to end of life care services (including specialist palliative care)
- Considering how volunteers could be further used to support end of life care
- Improving support available for carers and the bereaved
- Working to change culture around discussing death and dying
- Continuing to provide high quality end of life care training and education opportunities
- Ensuring that the workforce can deliver modern, integrated end of life care services
- Improving performance management systems
- Improving links to other relevant strategies, for example, the dementia strategy

1.6.Outcomes

We expect to deliver the following outcomes:

- Pain and other symptoms should be controlled effectively
- The individual, carers and family should feel well supported, and appropriately involved in their care planning
- The individual, carers and family should feel confident in the skills and knowledge of their health and social care professionals
- The individual, carers and family should know who to contact in an emergency and
- The individual should be able to die in their place of choice

1.7.Scope

This strategy covers palliative and end of life care needs of Leeds' adult population (18+ years).

The strategy covers the next five years (2014-2019) and will be reviewed by the commissioning partners after two years, to ensure that it remains appropriate and is delivered upon. The scope and focus of the strategy may require revision in response to changing national policy.

This strategy covers the following areas:

- Specialist palliative care
- Generalist palliative care
- Primary care

Whilst this strategy focuses on adult palliative and end of life care services, we will link with relevant children and young people's services strategies to ensure that the needs of young people in transition from children's services to adult services are appropriately addressed.

1.8. Governance

Leeds CCGs are responsible for commissioning palliative and end of life care to meet the needs of the local population. A broad range of public, private and third sector organisations are engaged in the provision of services. The end of life commissioning lead for Leeds sits within the Leeds South and East CCG. The commissioning and adult social care teams work very closely together to ensure that the commissioning process is informed by social care knowledge.

Leeds has a well-established Palliative Care Strategic Group, made up of both commissioners and providers of end of life care services. Members of this group come from specialist end of life care services, statutory agencies and third sector agencies. The inclusive nature of the group, and the joint work that it allows between commissioners and providers, gives members the opportunity to share information and makes it invaluable in identifying areas where further service development is required.

End of life care is a Leeds Transformation Board priority. The Palliative Care Strategy Group reports to the Transformation Board. It is proposed that a Managed Clinical Network (MCN) be developed in order to oversee implementation of the strategy in a co-ordinated way across service providers in Leeds. A proposed diagram of accountability is attached in Appendix 3 (page 58).

2. National context

The national context for End of Life Care comes under the broader health and social care agendas of personalisation and integration against a background of financial austerity and the need to find efficiency savings. There are three main strategic drivers nationally shaping end of life care: the Department of Health End of Life Care Strategy, the Palliative Care Funding review and the NICE and DH quality standards around end of life care. More recently the Liverpool Care Pathway review has been published and any resulting recommendations will be incorporated in the strategy. The HNA describes in detail the relevance of these key national drivers to end of life care work in Leeds.

2.1 End of Life Care Strategy: Promoting high quality care for all adults at the end of life

The guiding policy for EoLC nationally is the *End of Life Care Strategy: Promoting high quality care for all adults at the end of life* (DH, 2008). This strategy describes a "good death" as where a dying person is treated as an individual, with dignity and respect; without pain and other symptoms; in familiar surroundings and in the company of close family or friends.

The strategy aims to raise the profile of EoLC amongst commissioners and change attitudes to death and dying in society. It draws attention to the importance of strategic commissioning across organisations in order to deliver complex services; and that integrated

planning and commissioning is required across sectors and settings to achieve a “whole systems approach”. The strategy recommends six key elements of an EoLC pathway:

- Discussions as the end of life approaches
- Assessment, care planning and review
- Coordination of care for individual patients
- Delivery of high quality services in different settings
- Care in the last days of life
- Care after death

2.2 Palliative Care Funding Review

In 2010 the Department of Health commissioned a review of how palliative care is funded. The review was asked to develop a per-patient funding mechanism for palliative care. The review recommends creating a palliative care tariff, built around a “needs classification system”, so funding “follows patients in a fair and transparent way based on their need”. The report states that there is a need for a clear statement from the Government to describe the support and services patients, families and carers can receive, a per-patient funding model, integrated care packages, removing the need for social care so “*patients on an EoLC locality register*” can be enabled to have a “*prompt discharge from hospital and the creation of an appropriate health and social care package.*”

The report also recommends outside of the tariff commissioners provide support for families and carers including bereavement services, respite care, short breaks, carer support and spiritual care in order to maintain their health and the ability to be supportive to the patient. The report concluded that there is a “*stunning lack of good data surrounding costs for palliative care in England*”. Since the report was published a number of pilots have been set up to collect data and refine its proposals due to the lack of good quality data available.

2.3 Quality standards

The National Institute for Clinical Excellence has published Standards for EoLC for Adults (QS13 NICE, 2011). In addition, a paper published by DH (2009) outlines quality markers and measures for EoLC. This paper also suggests Patient Reported Outcome Measures (PROMs) as a useful method to measure quality.

3. Local context

A number of other health and social care developments locally provide the context for this strategy, in particular the health and social care integration agenda, the development of the *Leeds Care Record* and the personalisation agenda. These developments are described in detail in the HNA.

4. Financial context and cost effectiveness

Given the present economic climate and current and potential pressures on public service finances, it is imperative that services providing end of life care provide high quality care but are also cost effective and deliver measurable outcomes. Some of this can be achieved by staff working differently, but some will require pump-priming (invest to save).

Investing in end of life care services may deliver cost savings through ensuring that patients have access to and receive care in the right place at the right time. This can be achieved by having responsive primary and community service provision which will prevent unnecessary hospital admission for patients at a time which can be distressing and also place more pressure on the acute hospitals.

5. Service provision in Leeds

The majority of specialist palliative care in Leeds is provided by the Leeds Teaching Hospitals (NHS) Trust (LTHT) Specialist Palliative Care team, St. Gemma's Hospice and Sue Ryder Wheatfields Hospice with a smaller input from Martin House (teenage and young adult unit), Marie Curie (in terms of providing nursing staff) and Macmillan (in terms of providing information services). Not all patients require specialist services. Providers of generalist palliative care include hospital ward staff, district nursing teams, specialist community nurses (e.g. heart failure and COPD), community matrons, care home staff, the mental health trust, the intermediate care service, adult social care, independent sector domiciliary care and sheltered housing. Primary care also provides generalist palliative care services but is unique in that it can be the first port of call and access into the system for patients.

6. Commissioning priorities:

The three Leeds CCGs intend to work with partners to find the best way of commissioning and delivering palliative and end of life care services to meet the needs of the people of Leeds, avoiding duplication whilst achieving value for money. Leeds South and East CCG is the lead commissioner and will lead decision making on behalf of Leeds North and Leeds West CCGs through the established governance structures. Agreement on funding flows across hospital and community services needs to be agreed. Priorities will be reviewed, ensuring that interventions are at least cost effective and based on clinical evidence.

Services are currently commissioned from a number of end of life care service providers including LTHT, Leeds Community Health Care Trust, Wheatfields and St. Gemma's Hospices. However, palliative care in Leeds is provided by a broader range of carers and providers than those funded by the CCG. These include friends and family, non-NHS funded hospice provision, GPs, Marie Curie nurses, Macmillan, care home staff and Adult Social Care. It is proposed that in order to provide a consistent and evidence-based approach towards implementation across all services providing palliative and end of life care, that a framework is introduced following a formal options appraisal. This may include an **End of Life Joint Protocol for the Transfer of Care** between services, and a **Managed Clinical Network** to provide the structure and accountability to drive real change in the system across these multiple providers.

The Health Needs Assessment for End of Life Care for Adults in Leeds makes 66 suggestions to support the ongoing improvement of end of life care delivery in Leeds as well as underpinning recommendations to support the end of life care agenda. These suggestions are grouped under the following sections:

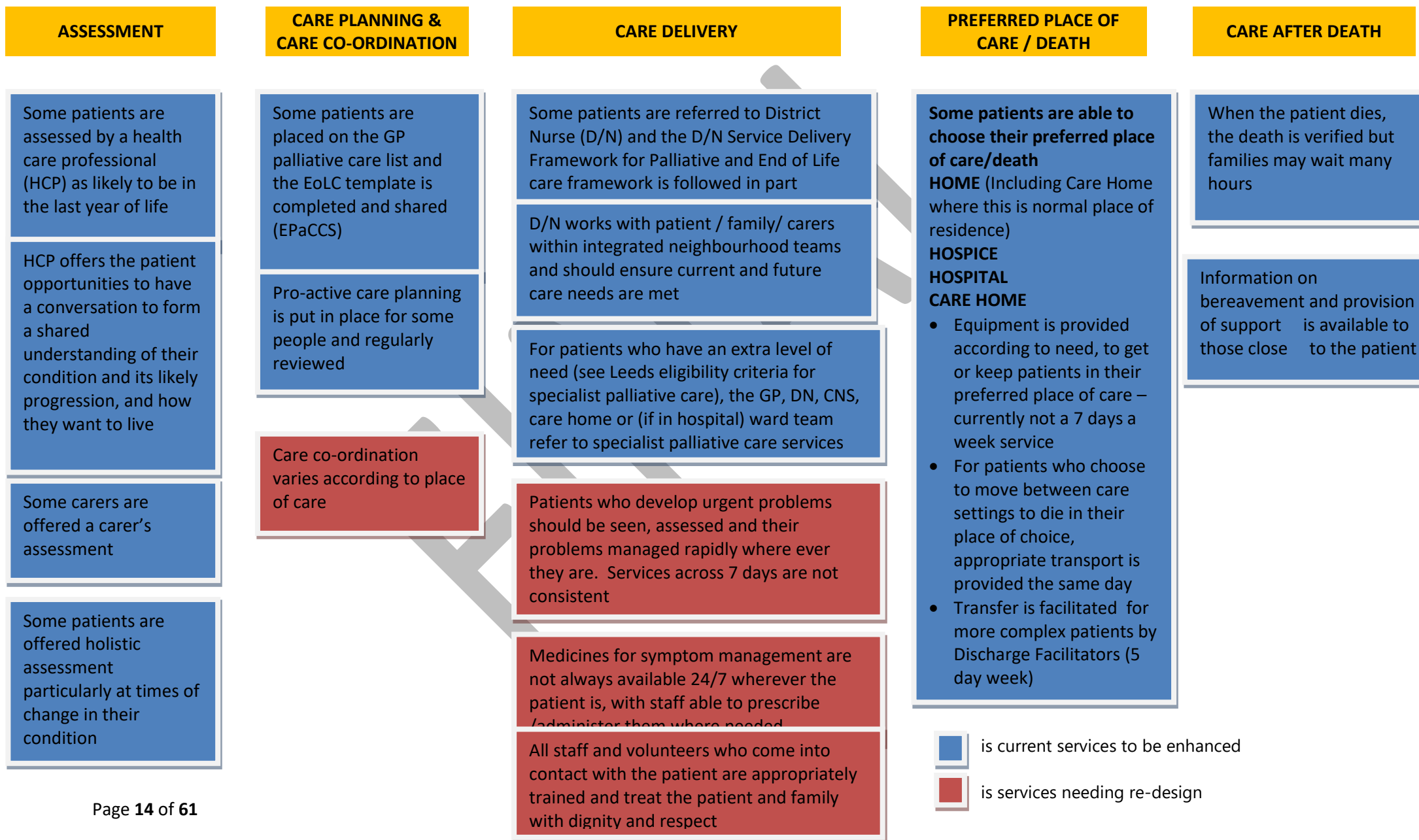
- Service redesign
- Review of selected specialist services
- Ongoing commissioning of key work streams
- Provider organisations to implement
- Work to discuss with other commissioning bodies

The current model for delivering palliative and end of life care in Leeds is in line with national policy drivers and encompasses the following elements: *assessment, care planning and care co-ordination, care delivery, preferred place of care/death and care after death* and is outlined on page 14. It is proposed that this model continues to be followed, with enhancements in service delivery commissioned and developed in line with national policy developments. This future model is outlined on page 15. Whilst the focus of this commissioning strategy is on those areas requiring service redesign and investment; a supporting Work Programme is included at Appendix 2 on page 49. This Work Programme captures all the 66 recommendations from the HNA, with plans/signposting to address their implementation.

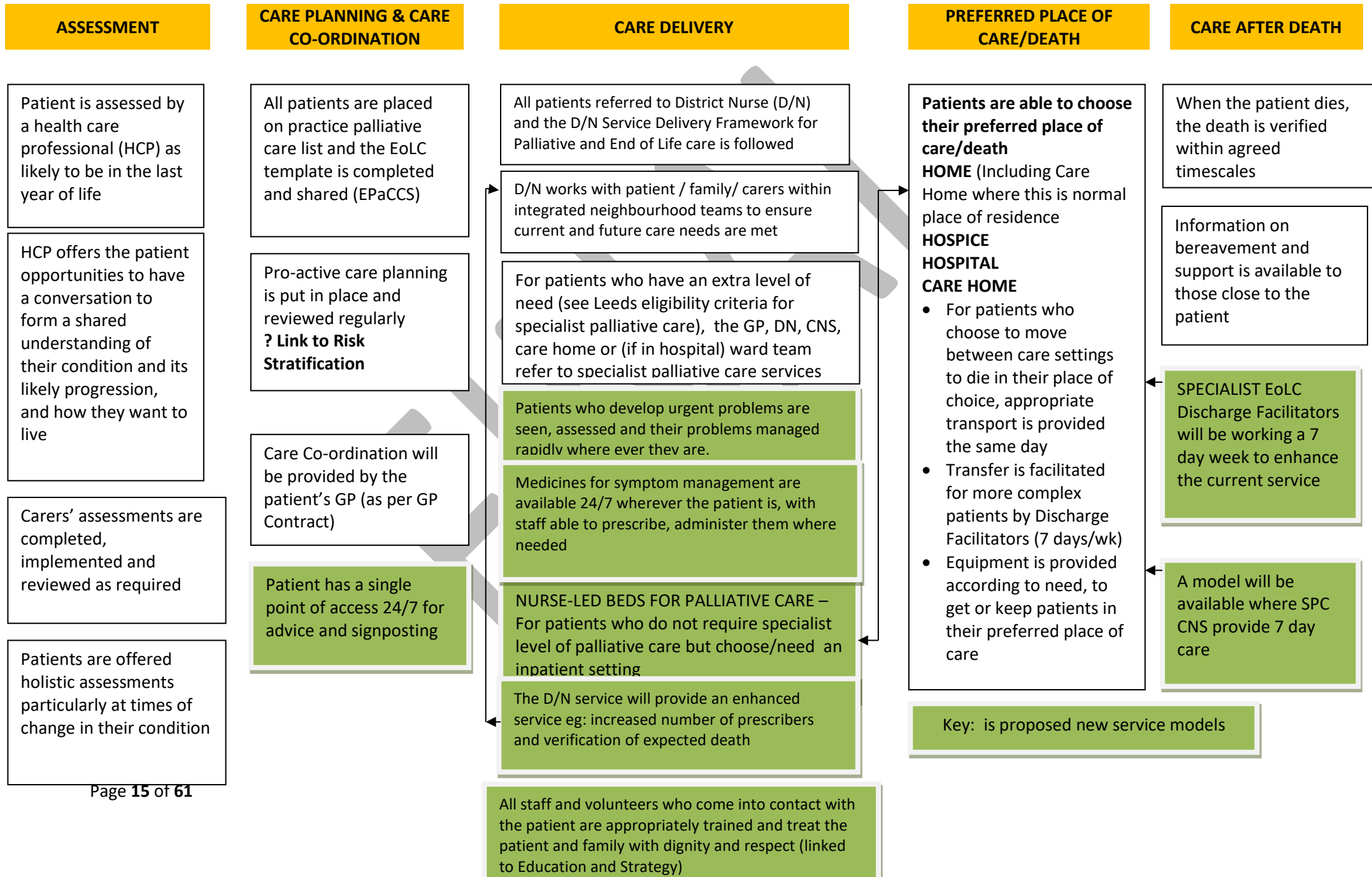
A new performance management system will be developed to effectively monitor the outcomes of this commissioning strategy, and a health economics approach will be used to evaluate service change. This will enable commissioners to have greater control over the services provided by obtaining robust data on service performance which will inform future understanding and commissioning decisions.

FINAL

LEEDS MODEL FOR DELIVERY OF HIGH QUALITY PALLIATIVE & END OF LIFE CARE - (CURRENT)



LEEDS MODEL FOR DELIVERY OF HIGH QUALITY PALLIATIVE & END OF LIFE CARE (FUTURE)



6.1 Hospital Discharge

Discharging a dying patient from hospital involves negotiating with a number of people and can be an incredibly complex process, the responsibility resting with hospital ward staff. Given the imperative to support people to die in their Preferred Place of Care (PPC) and the likely reduced cost of caring for someone outside of hospital, priority should be given to ensuring discharges are completed in a timely manner and as efficiently as possible.

Commissioning intention:

To provide a 7 day specialist Discharge Service for Palliative Care patients which has the flexibility to respond to the changing needs and preferences of patients transferring from in-patient settings to the community for end of life care

6.2 Co-ordination of care

Patients nearing the end of life need rapid access to help and advice 24/7, with a named key worker provided by their GP who will work with them to co-ordinate care across organisational boundaries

Commissioning intention:

To develop a single point of access for patients 24/7 for advice and signposting

6.3 Seven day services

Patients who develop urgent problems should be seen, assessed and their problems managed rapidly wherever they are. NICE Guidance (2004) and NICE Quality Standards for palliative care (2011) recommend the availability of Clinical Nurse Specialist face to face assessments 7 days a week in order to be available to those people who have complex issues arising at weekends or extending into weekends despite plans in place during the week.

Commissioning intention:

To develop a model where Specialist Palliative Care Clinical Nurse Specialists provide care 7 days a week in acute hospitals and community settings and are able to provide a rapid response

6.4 Choice of place of care in the last days of life

The implications of offering hospice care as a true choice to patients needs to be considered. This will involve providing hospice-type care for those people who do not have a specialist level of need in Leeds, but need or prefer care in an inpatient setting. The true level of demand for this type of service is yet to be established. There is an opportunity to run a pilot service within the 14/15 financial year which will enable commissioners to:

- quantify current and future demand for nurse-led palliative care beds
- ensure that more patients achieve their Preferred Place of Care in the most appropriate environment
- reduce unnecessary hospital admissions
- reduce length of stay in hospital by expediting discharges

Commissioning intention:

To develop nurse-led beds for hospice type care in the last days of life as an option for patients who do not require a specialist service

6.5 Rapid access to care outside of hospital 24/7

The availability of 24/7 services can help avoid unnecessary admissions to hospital and support hospital discharge, enabling more people at the end of life to die in the place of their choice. In order to achieve this, consideration needs to be given to how funding can be moved from hospital to community, or investing more in community end of life care, particularly by enhancing both the skills and capacity of district nursing.

Commissioning intention:

To develop an enhanced district nursing service that is able to meet the requirements of the Service Delivery Framework for Palliative and End of Life Care with an increased number of nurses who are able to prescribe and verify expected death. Review hospice admissions system to optimise choice and efficiency for patients.

6.6 Access to medicines

Medicines for symptom management at the end of life are not always available 24/7 in community settings. This can be due to issues such as access and availability of drugs particularly out of hours, lack of anticipatory prescribing or availability of prescribers or staff to administer drugs.

Commissioning intention:

To develop an improved system for co-ordination and delivery of EoLCare medication in the community including access to super holding pharmacies

6.7 Education and training

All staff and volunteers working with patients at the end of life need updating/education as new developments and ways of working occur, in order to demonstrate competence to work in this specialty. All staff and volunteers who come into contact with patients must treat the patient and family with dignity and respect. A Palliative Care Education strategy is in existence and advocates ongoing provision of quality education and training in all relevant organisations across Leeds. This needs reviewing to ensure that it is fit for purpose and aligns with this commissioning strategy.

Commissioning intention:

The current education strategy will be reviewed and refreshed in order to inform the future commissioning of education provision

6.8 Palliative Care Funding System

The independent Palliative Care Funding Review is seeking to create a fair and transparent funding system which incentivises good quality outcomes for patients, and which may be achieved by developing an NHS palliative care tariff based on patient need. It is expected that the final data analysis report will be available in the autumn 2014 with a view to developing the new system from April 2015.

Commissioning intention:

Consider the implications of the Palliative Care Funding Review and develop recommendations around the way that end of life care services are commissioned

6.9 Support to Care Homes 24/7

Some people are sent to hospital from care homes unnecessarily at the very end of life causing avoidable distress. A combination of factors may lead to this, including lack of knowledge/skills or confidence among care home staff, especially out of hours.

Commissioning intention:

Develop a system which provides 24/7 nursing support to Care Homes for patients in the last days of life

6.10 Improving carer support and provision of bereavement services

Although there are services for carers in Leeds it is unclear what specific support is available. It is also unclear exactly what bereavement services are available, how they are accessed and what they offer. Bereavement services require better co-ordination.

Commissioning intention:

To develop an improved system of carer support, in order to reduce the incidence of carer breakdown. Review bereavement services to meet the needs of bereaved people.

6.11 Improve medical support to community staff Out of Hours

In order to support patient choice in achieving their preferred place of death, and to prevent unnecessary hospital admission, it is imperative that clinical staff are able to access medical advice Out of Hours in a timely manner.

Commissioning intention:

Link with 111 to develop a system whereby calls from community staff requesting GP support Out of Hours are prioritised

6.12 Managed Clinical Network

The complex web of palliative and EoLC provision in Leeds is confusing for patients/families and staff, risking duplication and gaps in services. A system-wide approach will be introduced to address this, for example:

- Care co-ordination at individual patient and family level with a key worker and a single point of access for care
- Co-ordination (and where feasible) integration of provision at a service level, ensuring efficient and effective use of resources across a range of providers
- Supporting workforce development and extension of professional roles where appropriate
- Making greater use of technology

Using the Managed Clinical Network or alternative framework we want to enable clinical leadership for service change to be used effectively, supported by management with an understanding of service re-design, development and performance management. This will provide the structure and accountability to drive real change in the system across multiple providers in health, social care and the third sector. The aims are:

- To deliver the palliative and end of life care strategy for Leeds.
- To actively encourage creativity, collaboration, innovation and sharing of best practice in the provision of palliative and EoLC services and the development of new services.
- To enable continuous service improvements and make recommendations to commissioners about the need for any change
- To provide governance for services provided across and between organisations
- To be engaged with research so that practice is evidence based
- To work with other groups in Leeds to ensure that EoLC is integrated with their plans and commissioned separately only where there is a clear need
- To support the development of health and social care professionals to be able to consistently identify and manage patients with palliative care needs to a high standard.
- To ensure that services are provided to all, regardless of race, gender, sexual orientation, religion and belief, disability, age, income and other factors.
- To ensure that the needs of carers are assessed and met.
- To release time to maximize the use of the clinical leadership potential in the city

Core principles are:

- Purpose - to improve patient care
- Need clear structures, lines of accountability and clear roles and responsibilities
- Balances between all three elements – “managed” “clinical” and “network”
- Use of documented evidence base
- Clinically led
- Clinical governance and assurance programme
- Multi- disciplinary, multi- professional involvement and multi-organisational
- Utilise education and training potential
- Patient participation
- Needs appropriate administrative support and appropriate resource to support the network
- Needs to focus on “doing”

7. End of Life Care Commissioning Strategy: Work Programme

The Work Plan at Appendix 2 (page 51) captures all the 66 recommendations from the HNA, with actions/signposting to address their implementation over the next 5 years.

The Work Plan is intended to be used as a high level reference document. The plan's actions are matched to the NICE End of Life Quality Standards, which is used to monitor implementation of city-wide end of life care work through the Palliative Care Operations and Strategy Groups.

FINAL

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Appendices

Appendix 1: Health Needs Assessment End of Life Care Services for Adults in Leeds – Summary

Appendix 2: End of Life Care Commissioning Strategy 2014-19: draft work programme

Appendix 3: Managed Clinical Network -proposed diagram of accountability

FINAL

Health Needs Assessment End of Life Care Services for Adults in Leeds

Summary

DRAFT



NHS Leeds South and East Clinical Commissioning Group



Office of the Director of Public Health, Leeds City Council

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1 Summary

1.1 Introduction

This health needs assessment (HNA) aims to lay the foundations for the Leeds Clinical Commissioning Groups (CCGs) to commission services which meet these needs and contribute to people in Leeds experiencing good end of life care (EoLC). The HNA aims to answer the question “are we providing the best EoLC services possible with the resources available?” The HNA will inform the Leeds CCG EoLC commissioning strategy due to be published in March 2014.

1.2 Background and scope

The HNA was commissioned by the Leeds CCG collaborative and is a Transformation Board priority. It has been overseen by an EoLC working group, chaired by Dr Fiona Hicks and reports to the Transformation Board via the Palliative Care Strategy Group. The HNA has been undertaken by the Leeds City Council Office of the Director of Public Health. The HNA covers adults in Leeds and includes data gathered by three approaches: epidemiological, corporate and comparative. A workshop was held in March 2013 to secure commitment from representatives of staff who currently deliver EoLC in Leeds.

1.3 National and local context

The national policy context for EoLC comes under the broader health and social care agendas of personalisation and integration against a background of financial austerity and the need to find efficiency savings. The three main strategic drivers nationally shaping the EoLC agenda are the Department of Health EoLC Strategy (2008), the Palliative Care Funding review (2011) and the NICE and DH quality standards around EoLC (2011, 2009). More recently the Liverpool Care Pathway review (2013) has been published.

Locally, EoLC needs should be considered within the context of the integration agenda and development of “The Gateway”, the impending Leeds Care Record and the personalisation agenda including individual health budgets.

1.4 Evidence

There is evidence that patients who receive early palliative care have less aggressive care at the end of their life but survive longer with better quality of life and fewer depressive symptoms (Temel et al 2012, Currow et al, 2012). If a patient is within the last 12 months of their life they should be on a palliative care register (PCR) as a gateway to receiving coordinated EoLC services. Research suggests 75% of deaths will require palliative care (Murtagh, 2013).

There is evidence to show that people living in more affluent areas are more likely to die at home when compared to people living in more deprived areas, that people living in the most deprived areas are more likely to die in hospital and that it costs more to treat people who live in deprived areas (Higginson et al, 1999; Grande et al, 1998, NEoLCIN, 2012). The headline target of death in place of usual residence (DiUPR) or preferred place of death (PPD) is narrow and there are other quality issues that need consideration when planning EoLC services.

A recent national survey of over 2,000 members of public showed that 78% of people wanted to be free from pain and discomfort, 71% wanted to be supported by loved ones, 53% wanted privacy and dignity, 45% wanted to be in familiar surroundings and 63% of people wanted to die at home. Only 27% felt that home was a place where they would be free from pain during their final days (Wood

and Salter, 2013). PPD changes as people get closer to death (NEoLCIN, 2012) and discussing death remains taboo for most people in Britain. The Wood and Salter survey found that only 27% of respondents had asked a family member about their EoLC wishes. It is accepted that a lack of open conversations about dying and death make it harder to plan for a “good death” (Leadbeater and Garber, 2010).

84% of people using hospice services in Leeds have a cancer diagnosis. In Leeds in 2011 28% of people aged 65 and over died of cancer (ONS, 2013). National data show that the proportion of deaths that occur in hospital is higher for non-cancer diseases (NEoLCIN, 2012). There is a lack of data around EoLC costs. There is evidence that people from black, Asian and ethnic minority groups are under-represented in the use of EoLC services.

1.5 Epidemiological HNA

In Leeds 20% of the population live in areas which fall within the 10% most deprived nationally. The 2011 census records the population of Leeds as 751,485. The number of people registered with a Leeds GP is 813,684. 81.1% is white British and 18.9% is made up of other ethnic groups. 68,413 people live alone and 38,312 of these are aged 65 and over.

In 2011 48% of people over 18 years in Leeds died in hospital (ONS 2011). If deaths of people aged under 18 are included this figure rises to 48.1%. The most common causes of death in Leeds for adults over 65 are circulatory disease (30%), cancer (28%), respiratory disease (15%) and dementia (9%) (ONS, 2011). Cancer deaths for people aged 65 and over are projected to rise from 1,836 in 2011 to 2,132 in 2031; compared with non-cancer deaths expected to rise from 4,523 to 5,249.

In Leeds a higher proportion of people living in more deprived communities die in hospital compared with people living in affluent communities. More people from affluent communities die in care homes and hospices. There was no pattern relating to deprivation in the proportion of people dying at home. In Leeds 0.14% of people are on the PCR compared to 0.17% nationally. In Leeds the death rate is 0.8% and 75% of people have EoLC needs. The ONS data is accurate but not timely. Analysis of Primary Care data can inform metrics which are timely and paint a fuller picture.

One purpose of understanding the epidemiology of dying in Leeds is to be able to project need, converting population projections into service requirements. However the research evidence published around projecting needs for EoLC services generally focuses on needs based on health service usage and therefore measures comparative demand as opposed to need (Franks et al, 2000, Tebbit, 2004, Chapman and Lennon, 2010). Provision of EoLC services in Leeds is in line with levels these studies recommend, however results from the corporate element of the HNA which takes in to account views of service users, carers, the bereaved and staff delivering EoLC services would suggest there is a lack of capacity in some areas of the system. The studies which take an epidemiological approach (Murtagh, 2013, Higginson, 1997, Rosenwax, 2005, Gomez-Baptiste, 2012) suggest that on average approximately 75% of deaths will require some form of EoLC.

The trajectory towards death is experienced differently depending on diagnosis. Cancer patients are stable and have a rapid decline close to death. Patients with organ failure and physical and cognitive frailty generally experience a number of dips and improvements in their health (Murray and Sheik, 2008) which makes identifying the final EoL stage more challenging. However in terms of symptoms experiences are similar (Solano et al 2006).

1.6 Corporate HNA

The majority of specialist palliative care (SPC) in Leeds is provided by the LTHT SPC team, St. Gemma's and Sue Ryder Wheatfield's hospices. A small number of patients registered with a Leeds GP use the three hospices bordering Leeds. EoLC is also provided by district nursing, specialist community nurses, community matrons, care homes, the mental health trust, adult social care, out of hospital care, continuing health care, Yorkshire Ambulance Service, sheltered housing, GPs, pharmacists, Local Care Direct, bereavement services, Leeds Equipment Service and independent sector domiciliary care providers.

Fifty-seven staff who deliver EoLC in Leeds were interviewed between May and July 2013. GPs, District Nurses, Care Home Managers and Sheltered Housing Wardens were surveyed. A thematic analysis of the interview and survey data is included along with a description of current services in Leeds. Services not commissioned by the Leeds CCGs are included. The themes that emerged most powerfully were: a high level of personal motivation and skill amongst most staff; concerns around the capacity of services in terms of staff numbers and facilities in both the hospital and community, and increasing pressure on out of hospital care; patchy out of hours care, and high workload; problems arising at physical and electronic interfaces between services; concerns around hospital discharge and need for earlier recognition and acknowledgement of the EoL stage and concerns around the PPD target and meaningful patient choice.

Perspectives of service users, carers and the bereaved have been documented using the national VOICES survey findings and the findings of local research conducted by the Commissioning Support Unit. The VOICES survey (2012) benchmarked Leeds in the top 20% for dignity and respect shown by nurses all the time in the last two days and pain management. Leeds was benchmarked in the bottom 20% for patients involved in decisions about care and PPD. The CSU interviewed 51 patients, carers or family members. Key themes that emerged were: the importance of communication, coordination and continuity of care. The importance of full patient and carer involvement in care planning; honesty and support for the bereaved. The need for an advocate for patients and families, the need for accessible information; improved urgent care, integrated team working, pain relief management and maintaining dignity and respect.

1.7 Comparative HNA

Leeds was compared to core cities: Birmingham, Liverpool, Newcastle and Sheffield and two of the best performing areas in terms of home deaths: Torbay and North Somerset. North Somerset and Torbay have a much larger proportion of patients who die in care homes to the other comparators. Comparing Leeds to all comparators apart from Torbay and North Somerset, Leeds performs well and has less hospital deaths and more hospice deaths than other areas however Leeds also has the second lowest proportion of deaths at home. Leeds delivers a range of programmes that other areas don't.

Issues raised by comparators around EoLC are in the main similar to those raised by Leeds staff: lack of interoperability between EPaCCS and Emis; building advance care planning into working culture is a challenge; service planning has relied on the passion, knowledge and commitment of one individual where processes haven't been embedded and formalised; there is a gap around psychological services, bereavement and pastoral support; EoLC needs to be integrated with all programmes e.g. integrated care, LTC, Liver services; CCGs work slowly; the need for more specialist EoLC DNs; no financial backing to pump-prime invest to save projects; getting home care support right; continuing to work with the hospital trust to make sure if a person chooses to die in hospital it is a good experience; that the focus on integration will take focus away from EoLC work; concerns about 111 –

where do the “do not attempt cardio-pulmonary resuscitation” (DNACPR) forms sit; there is no incentive for GPs to deliver EoLC unless they want to. It takes about an hour per patient and the GPs don’t have the time; DN do a good job, beyond their roles but they don’t have to; there is variability in service; the LCP controversy has stirred up issues and the DH strategy is focused on care outside of hospital but there has not been enough consideration about increasing the capacity of community staff including GPs.

Programmes of work other areas have in place that Leeds doesn’t include: NHS commissioned palliative care beds in care homes (in addition to those funded through CHC); commissioning local hospices using the NHS contract; a nurse led hospice; hospice at home service; greater voluntary sector provision e.g. personal and social care for the last 3 months of life including carer breaks and Marie Curie helpers which includes companionship and emotional support; a division of care between the DN team and CNS allocated by GSF code; 2 hour rapid response team which provides support in the event of carer breakdown; “just in case” boxes, including anticipatory medication inpatients’ homes; the same IT system across the patch and a local Public Health Observatory providing performance management data.

2. Discussion

2.1 Introduction

This HNA has provided an opportunity to map EoLC services in Leeds and understand what is working well and what could be improved from the perspectives of staff delivering the services, service users, carers and the bereaved who use them. These findings have been triangulated with epidemiological data and comparisons with other PCT areas. This triangulation has been useful in order to quantify and validate facts from a range of sources, for example some of the comments recorded through staff surveys were negative, but they need to be considered within a context where a vast majority rated as excellent the area they were commenting about.

2.2 Breadth of provision

The HNA shows that Leeds is performing well. Deaths in hospital are at 48%. Staff who were interviewed are committed, skilled and resourceful. The hospices provide excellent care and a larger proportion of people compared to the England average are supported to die there. The Leeds hospices work well together and between them have ensured that every Leeds patient requiring hospice care according to the SPC eligibility criteria is admitted to one of the hospices. The SPC providers in Leeds; the hospices and the LTHT SPC team; provide excellent leadership and support to generalist staff who deliver EoLC in Leeds. They are a resource to be valued.

EoLC is often perceived as synonymous with hospice care. The hospice movement can be pinpointed as the origins of excellent palliative care, however in Leeds, as other areas, EoLC is delivered in a range of settings by a range of providers. 63% of the general public want to die at home and 47% of people on EPaCCS expressed a preference to die at home. We know that 75% of people who die require EoLC however not everyone will need SPC, and in Leeds 9% of people who died did so in a hospice. This is also illustrated by figure 34 below which shows the relationship between SPC and EoLC. Therefore a broad range of services are required in order for this to be achieved. Future EoLC planning should consider the broad range of staff who are likely to have a role to play supporting people who are nearing EoL.

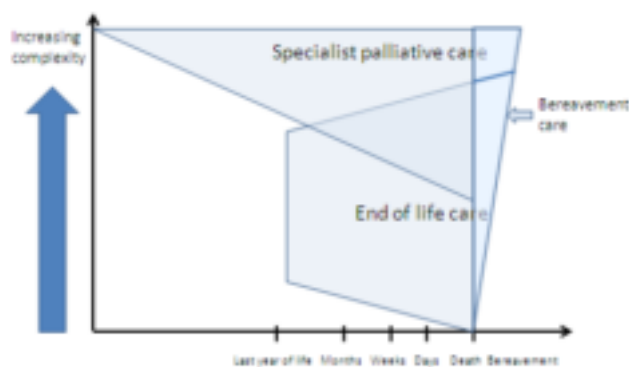


Figure 34: The relationship between SPC and EoLC (from the Association for Palliative Medicine of Great Britain and Ireland et al 2012)

2.3 Areas for improvement

The HNA has identified areas that need improving. In terms of need, according to the research evidence which uses comparative data to suggest service levels for different populations, Leeds has enough SPC provision. However these studies are comparative as opposed to epidemiological and are based on outdated models of care. The number of people who will die is increasing, health needs at the end of life are becoming more complex, more people living in single or all pensioner households will be dying and the preference to die at home coupled with the agenda of care outside hospital combine to make planning excellent EoLC services in the community imperative. Many sources have suggested that the DN teams are excellent but too stretched to deliver all levels of EoLC as stated in the LCH EoLC service delivery framework and that GPs would like to spend more time delivering EoLC but don't have the time to. More people express a preference to die in a hospice than have SPC needs; there is a gap for hospice type care for the "simply dying". The VOICES data show Leeds is poor in terms of discussing EoLC decisions and preferences with patients. There are lessons to be learnt from the interviews undertaken as part of this HNA with patients using EoLC services, their carers and the bereaved around communication, coordination, bereavement support, improving urgent care and pain relief management. There is scope to dramatically increase the number of patients identified as being in the last 12 months of life and ensuring they are on the PCR.

2.4 Commissioning

In terms of funding, good palliative care delivers better clinical care and saves money. EPaCCS has also been shown to save money. The move of care from hospital to community appears to save money, but the estimated costs used to make this conclusion are not robust and any funding saved in the acute sector is rarely released and reinvested in community care as there are always demands that use up any spare capacity created. Care provided in the community appears to be under-resourced and require more investment. The recent Nuffield report examining patterns of use of health and social care services by people nearing the end of their life states that if money is saved in the NHS, the costs are pushed to social care. The Palliative Care Funding Review recommends NHS funds social care of all patients on the PCR are funded by the NHS. This will be more expensive than services currently commissioned. It is logical to pool health and social care budgets. This would accelerate the integration agenda around EoLC and also make tailored EoLC "journeys" easier to plan and manage. The CCGs need to plan for personal health budgets, "however, personal budgets are likely to be more appropriate for people who have prior experience of them, and EoLC may not be

the time to introduce them.” (Addicott and Hiley, 2011) The recent Social Value Act impacts on how commissioners consider the services they commission. It calls on people who commission public services to consider the “social value” of the services they are securing e.g. wider concern for wellbeing, rather than solely the immediate medical problem; deriving social value by involving service users and volunteers; and organising fundraising activities which bring communities together and also raise awareness about health issues.

This chapter reflects on the strengths and weaknesses of the HNA, and discusses key issues identified by the HNA in turn. The issues can be separated into direct improvements required to deliver better EoLC and underpinning actions required to support this to happen.

2.5 Strengths and weaknesses

The strengths of the HNA are that it is embedded strategically, has clear dissemination plans and has a clear purpose which is informing the Leeds CCGs commissioning strategy. The question the HNA was asking was clear; are we providing the best possible EoLC services within the resources available? It was undertaken in a short timescale and includes information from data, views of staff, service users and carers as well as information from other areas Leeds has been compared to. This enables conclusions to be triangulated and quantified. The HNA had a clear plan which was agreed by key stakeholders but also developed iteratively, e.g. the surveys of GPs, DNs, care home managers and sheltered housing wardens weren't initially planned but it became clear these data would be useful so the surveys were undertaken.

The HNA is comprehensive and pragmatic. All epidemiological data has been thoroughly checked. All interview data has been checked at least once with interviewees. The HNA is timely in terms of the Palliative Care Funding review and the Neuberger review of the LCP.

There are also weaknesses, which have been accepted in order to meet the publication deadline which in turn enables the service modelling and commissioning strategy to be developed for March 2014. Ideally social workers and the public would have been included in surveys. The section on evidence has been compiled in a pragmatic way, if there was more resource each sub- category of EoL care relevant to the HNA could have been explored in much greater depth. Interview questions were general, people weren't probed and there are some areas that are a known need that are not explored in the depth they could have been, e.g. carers and bereaved. It was not possible to interview one of the comparator sites (Torbay) despite repeated attempts at making contact. The scope of the HNA does not include young adults or explore the interface between children's and adults EoLC services (beyond describing the work of Martin House Children's Hospice). It has been reported via a lead cancer nurse that feedback from CNSs who work with 16 – 18 year olds that provision for this group was particularly poor. Unfortunately 16 – 18 year olds fall out of the scope of the HNA and this concern has been passed to the children's team. The HNA did not measure uptake of services by minority groups e.g. lesbian, gay, bisexual or transgendered patients, asylum seekers, homeless people, people with learning difficulties etc. The HNA has not gathered independent data measuring patient perspectives and experiences of the hospices specifically. The HNA has not fully assessed the need for bereavement services. The report documents the processes different organisations have in place, but does not share understanding of what these services offer, quantify unmet need, or comment on their quality.

2.6 Direct improvements required to deliver better EoLC

2.6.1 Early identification

Early identification is key to good EoLC. This is even more important for patients who have been diagnosed with dementia. Given that 75% of deaths require EoLC and that only 0.14% of people in Leeds are on the PCR and Leeds is in the bottom 20% in terms of patients expressing their PPD, more work is required in this area. One opportunity would be to run a “Find your 1% campaign” with primary care. This would need sensitive implementation as the death rate in Leeds is lower (0.8%) and will be different for each practice. A blanket approach won’t work. Some surgeries would have more than 1% dying (with older populations) some won’t e.g. the Student Medical Practice. It may be possible to work in partnership with public health colleagues to develop targets for each GP practice. CCGs could have a locally enhanced service agreement in place to incentivise GPs to find their 1%. The work rolling out EPaCCS is excellent and should be continued. There may be benefits to link with the Leeds Older Peoples HNA and work happening under the integration agenda around predictive modelling and risk stratification of patients likely to need EoLC services.

2.6.2 Communication between staff and patients and the importance of person centred care

Good communication with patients and their carers is crucial in EoLC. The Neuberger review highlighted the public’s dislike of the work pathway and the perception that patients were being put on a pathway to death. Some commissioners like the term pathway as it makes clear what services and quality standards a patient should accept. However EoLC does not easily fit into a linear pathway. Commissioners need to be flexible to facilitate EoLC tailored to individual need. Paget and Wood (2013) use the phrase “service journeys”. There is an agenda around individual health budgets, however it has been suggested it may not be appropriate to introduce them for EoLC if the patient and their carers have no previous experience of using them.

Although staff interviewed as part of the HNA welcomed the LCP and have experience of how it has improved patient care, concerns were raised by patients, carers and the bereaved which showed fear and misunderstanding of the LCP. Concrete examples were given, for example people who had been bereaved who were upset that their relative had food and drink withdrawn. If this is necessary it needs to be communicated incredibly clearly and sensitively with relatives and carers.

The VOICES survey showed that Leeds falls in the bottom 20% of PCTs in terms of patients being involved in decisions about their care as much as they wanted and being supported to express their preferred place of death. This echoes with comments made by GPs, hospital consultants, SPC consultants, social workers based in hospital and the anonymous ward sister. It is an area that requires improvement as is key to providing quality EoLC. A Kings Fund report focusing on issues facing commissioners of EoLC stresses that:

“Good communication and person centred care reduces the pain of bereaved people. EoLC needs to be developed as an integrated health and social care service drawing on many different sectors, including SPC, psychiatric services for patients with dementia, community matrons and social support for patients with LTCs as well as GPs. Without assessment of need at an individual or population level, the reality is that many patients in need rarely receive any health and social care support.” (Addicott and Hiley, 2011)

The HNA found examples where doctors were unwilling or unable to have conversations about dying with patients nearing EoL. The HNA also found examples of why having conversations about dying, earlier on, are crucial and make a difference in terms of planning and achieving a “good death”.

Education around skills and attitudes of doctors is required to support these conversations to happen. In addition doctors need to have the time to be able to hold these sensitive conversations and start the process of developing ACPs.

2.6.3 Integration of services and coordination of patient care

There is a need to continue to link EoLC into the integration agenda. Improving IT interfaces across organisations is crucial. EPaCCS needs to be accessed across all IT systems in Leeds. Advance Care Plans written by patients with their social worker in Leeds are currently not shared with the NHS or included on the EPaCCS system or inpatient's notes. Closer links should be made between generalist social workers, DNs and GPs. The integration agenda will support and underpin this change. There are many resources available for social workers around EoLC (NEoLCIN, 2012 and Social Care Institute for

Excellence, 2013) and these should be used in Leeds. Social workers should be included in the education strategy and strategic links should be made between NHS and ASC planning and IT systems. All staff involved in a person's care should be informed. Professions outside of SPC and health professionals that support patients approaching EoL, are not always included in information sharing protocols, e.g. the survey of sheltered housing wardens showed 63.3% of wardens were not informed if an ACP is in place. When planning integrated EoLC, a broad range of professionals should be included; SPC, GPs, DNs and care home managers and also sheltered housing managers and relevant voluntary sector organisations e.g. Leeds Neighbourhood Network Schemes.

The literature talks about a single point of access, in reality there will be many points of access but the analysis of patient and carer interviews suggests it would be helpful to have a single lead contact coordinating a patient's EoLC, this may be a GP, CNS or social worker. Currently the DN is the named lead for community care.

A minority of GPs and DNs do not complete OOH handover forms, it is imperative that all relevant information is shared with LCD OOH to increase the chances of patients receiving

care they have stated a preference for. It is recognised that the process has been made more complex by the introduction of the 111 service in April 2013.

As mentioned in the introduction, funding decisions should be taken jointly between ASC and the NHS and the implications of the Palliative Care Funding Review need to be considered when they are published.

Currently they recommend the NHS meets all care costs of individuals who are put on a PCR. If this was made policy, it has significant implications for any "find your 1% campaign" and there would need to be a link between how GPs decide which patients should be on the PCR and how costs are met, similar to the CHC assessments of eligibility.

The Leeds Care Record answers most problems raised around issues of interoperability and data sharing across organisations. The LCP review recommended that patients notes are kept in "shared care folders", that patients and family can write in. In London a "Coordinate My Care Record" system has been rolled out, it involves using a "mobile app", which aims to give patients access to their records. The service has been

"designed to ensure that people receiving EoLC get appropriate treatment from any health and social care professional they encounter – including respect for any wishes they make about resuscitation or preferences for dying at home rather than hospital." (Cross, 2013)

The “app” went live across London’s entire NHS in April 2013, including an ambulance trust, 34 acute and special trusts and 14 inpatient hospice units.

2.6.4 Discharge from LTHT

Discharging a dying patient from hospital involves negotiating with a number of people and can be an incredibly complex process. Interviews showed there is a debate between training all generalist staff to undertake EoLC discharges; and employing specialist staff to undertake EoLC tasks in a generalist setting. Given the imperative to support people to die in their PPC and the reduced cost of caring for someone outside of hospital, priority should be given to ensuring discharges are completed as efficiently as possible. There has been a suggestion that there is a need for 7 discharge coordinators (one per speciality) to work as a team to make this happen. They could potentially be employed using pump primed funding and an invest-to-save model.

In the community the LCH discharge coordinators are a valued resource and have had an impact on making discharge from hospital to the community a smoother and more efficient experience. St. Gemma’s and Wheatfields both employ discharge facilitators.

40.6% of care home managers don’t think discharges from hospital go smoothly. There is work underway and a CCG member of staff working on this with a hospital discharge group of LTHT managers.

2.6.5 OOH care

Care OOH was raised as an issue by many staff and patients. There are two different issues, care 7 days a week and care 24 hours a day. The DH 2008 strategy states the need for rapid access to care. As a person’s condition may deteriorate rapidly they should have access to support services without delay 24/7. The availability of 24/7 services can avoid unnecessary admissions to hospital and can enable more people at EoL to die in the place of their choice. The DN teams, and hospices provide EoLC 24/7 and SPC consultants are on-call 24/7.

However many interviewees or survey respondents raised concerns that care OOH was poor. Specifically DNs who need input from a GP OOH as often the GP lacks knowledge or confidence to deal effectively with EoLC issues; and there can be long delays waiting for a call back from a GP OOH. Patients who have not accessed LCD via the palliative care telephone number have been lost in the system or taken through the call handlers standard algorithm of questions inappropriately. As previously mentioned not all staff complete the OOH forms and some OOH staff are not well trained in accessing EPaCCS. 64% of GPs think palliative care OOH is adequate. In terms of 7 day a week working, the SPC community team leaders from each hospice, and the LTHT SPC team would like to have one CNS from each base working at the weekend.

Their role would be to proactively contact patients who need specialist input and to support any new referrals with immediate needs. They would take calls from patients, carers and healthcare professionals. This would still be a reduced service, so community visits from the hospice would only be undertaken if there were complex needs.

There are a range of services that may have a positive impact if run 7 days a week. These include: community discharge facilitators; the Leeds Equipment Service; specialised pain services; LTHT EoLC discharge facilitators; EoLC care homes facilitator and oncology social workers based at LTHT.

Staff and patients raised issues around accessing EoLC medicines OOH. There is only one pharmacy which stocks EoLC medication (in Moortown). Patients are not well informed of how to access

medicines. LCD has a good system and can get EoLC medication to patients. Some GPs and hospital doctors are reluctant to prescribe anticipatory medicines. Leeds does not have “just in case” boxes of medications in the home which are in place in other cities. The hospice pharmacists have a good idea about what is needed but are not currently commissioned to lead these changes.

2.6.6 Community services

The agenda welcomed by the majority of patients, and commissioners is to deliver care outside of hospital. DH strategy states that additional costs of providing improved care in the community and care homes will be offset by reductions in hospital admissions and length of stay. In reality this funding has not flowed. Consideration of how to fund EoLC in the community at a higher level is needed. 71.2% of GPs, 44.9% of DNs and 40.6% of care home managers have witnessed an inappropriate admission to hospital. 53.1% of GPs feel they don't have enough time to deliver good care.

The DN service is not always able to deliver all levels of the LCH EoLC service delivery framework; they deliver excellent care in the last days and hours of life but struggle to deliver care weeks and months before someone dies. 47.1% of GPs think the DN services are not adequate. DN staffing levels have reduced by 10% between Feb 2010 and May 2013 when demand is rising. There is a debate within the profession as to whether there should be specialist EoLC DNs, or maintain EoLC skills which all DNs are currently trained to have. More DN should be trained to verify deaths.

There are issues around medication at home as previously discussed. Some community nurses are trained as nurse prescribers, this is to be encouraged. GPs need more training around the importance of anticipatory prescribing. Although not raised as an issue specifically for Leeds, the VOICES survey showed that nationally pain control for home deaths was considered poor. Some staff and patients raised issues about pain control in deaths at home. This is unacceptably poor and is avoidable with a good system of medicines management.

At times there is duplication between DN, GPs and CNS. An agreed key worker should be identified to avoid duplication and confusion.

The QoF target for EoLC delivered in primary care is not ideal. To get the QoF points a GP practice has to identify patients likely to die in the next 12 months, (this is often done using READ codes), ensure the patient is placed on the PCR and discuss all patients on the register quarterly. The target is unsophisticated, as not all patients will need to be discussed, and quarterly discussions may not be frequent enough to provide good care for people who are imminently dying. Consideration should be given to implementing a Gold Standard type of Framework in primary care that considers more than the basic level of care. The GSF sets out higher levels of care which include offering to develop an ACP, recording PPC/PPD, symptom management, continuity with OOHs, LCP use, carer and bereavement support, clinical audit and reflection. This is not currently incentivised in Leeds but is something to be considered.

2.6.7 Access to medicines

The interview and survey findings stressed the importance of good medicines management particularly in terms of timely access to medicines. As previously mentioned there needs to be more anticipatory prescribing and more community nursing staff trained up as nurse prescribers.

The ability to have the prescription fulfilled is also an issue, not all pharmacies stock specialist EoLC drugs or the quantities required. Pharmacists working in the Leeds hospices have developed a proposal for two super holding pharmacies. This needs to be considered by the CCGs.

A complete review of how EoLC medication is accessed in the community is required at a strategic

citywide level. Staff on the ground have devised ways for patients to access the medication they require, but there appears to be no overview and management of this. In addition the HNA notes there is only a small input from a single pain management consultant for patients with complex cancer pain and no cover when she is unavailable. This has recently been raised by a clinical pharmacy team leader and highlights the need for a plan of how to commission and deliver more complex EoLC in the community.

Both St. Gemma's and Wheatfields hospices request additional pharmacy input. They currently receive 13 and 7 sessions respectively.

2.6.8 Hospice care

The national VOICES survey shows that bereaved carers rate hospice care most highly in terms of quality of care, dignity and respect and pain management.

In Leeds both hospices appear to deliver a high quality service. The Leeds figures that show there is a relatively low proportion deaths in hospital is partly a result of the relatively high proportion of deaths in Leeds hospices. In our region only Scarborough has a higher proportion of deaths in hospices. The NHS only partly funds the EoLC the hospices deliver. Good will and cooperation can't be commissioned easily, this is a key strength of St. Gemma's and Wheatfields and should be highly valued and protected. No patients from Leeds use the inpatient services provided by the hospices in Bradford and Harrogate. 34 patients last year were inpatients in Wakefield. This is likely to be due to the location of the 2 Leeds hospices.

The difference in admission between hospices has raised questions. Is this as a result of capacity, patient choice or other factors? Is there a "best" model of hospice care delivered by either hospice? The data collected through the HNA is unable to definitively answer these questions. Neither hospice runs to full capacity. Some GPs have reported they have been unable to have patients admitted when they are ill. There is an impression from some LTHT staff that the eligibility criteria are interpreted differently between the hospices so there may be different referral patterns; however the hospices report that most admissions to hospice come through community referrals. A recent PPD audit undertaken by Wheatfields showed that instead of more people dying in hospital that had stated it as a PPD; more people died in the hospice than had stated a hospice as a PPD, i.e. having a lower admission rate has not resulted in increased hospital deaths. Wheatfields deliver more outpatient appointments. The hospices CNSs deliver their services in slightly different ways. The death in hospital rate for each hospice footprint is similar.

The hospice work developing the non-cancer agenda should be continued and the percentage of patients with non-cancer diagnosis using the hospices should increase. The hospices role as joint leaders with the LTHT SPC team should be highlighted and encouraged. Equality monitoring systems should be improved and a health equity profile should be undertaken including recommendations to increase service usage by any communities found not to be taking up hospice care services.

The CCGs should commission services from hospices using contracts that encourage cooperation and the benefits of maintaining excellent working relationships.

The CCGs should be extremely cautious of taking any action which creates anxiety or competition which will destabilise the citywide delivery of hospice care across the two organisations.

The benefits highlighted by the Social Value Act should also be considered.

Three of the 5 comparator areas interviewed commission their local hospices using the NHS contract. The PPD target includes hospices; however people can only access hospice care if they have eligible

needs. Therefore hospice provision for the “simply dying” should be considered. This is provided in other areas in England. This may take the form of nurse led hospices, hospice wards in hospital, hospice wards in care homes or another format.

Wakefield is accepting patients from Leeds with no funding and has raised this as an issue. They appear to be willing to provide subsidised hospice care and this should be negotiated directly.

2.6.9 Support for carers and the bereaved

The NCPC point out, there are unique issues facing carers of those approaching the end of life. There are difficulties coping as

“the person’s physical, emotional, social and spiritual needs become more complex and or demanding; having to coordinate care and professionals on a 24/7 basis; having conversations about resuscitation, artificial feeding and stopping treatment, organ donation and funeral wishes; dealing with feelings of loss and grief; bereavement” (NCPC, 2013)

DN and GPs gave examples of “carer breakdown” they have experienced in Leeds. Neither Leeds Carers Centre or any other carers organisation were interviewed as part of the HNA so there may be support available. However the interview and survey results suggest it is unclear what support is available for carers. There appear to be more services in place in comparator PCT areas where there are specific EoLC carer support projects that have been developed e.g. the Discharge and Care Management project, the Care Programme and the Helper Service, which are described in chapter 11.

Again, bereavement service staff were not specifically interviewed as part of the HNA but from the general interview and survey data gathered it appears unclear exactly which services are available, how they are accessed and what they offer. In addition, bereavement services appear uncoordinated across Leeds.

2.7 Underpinning actions required to support EoLC service delivery

2.7.1 Culture around death and dying

Survey data show the general public do not openly talk about death and dying. Being open to the fact that dying is inevitable enables planning for EoLC easier. Leeds has not delivered a citywide Dying Matters public education campaign. This is something to be considered and it could be negotiated for the Public Health Resource Centre to lead. Information around death and dying should be included on the Leeds Palliative Care website.

2.7.2 The non-cancer agenda

The results from the epidemiological HNA show that in 2011, more people aged 65 and over in Leeds died of circulatory disease than cancer and a significant number died from respiratory disease or dementia. Only 28% are cancer deaths. In addition, national research evidence shows you are more likely to die in hospital if you have a non-cancer diagnosis. Both Leeds hospices are proactively developing the “non-cancer agenda” however 84% of people using their services have a cancer diagnosis. Data were not requested as part of the HNA from the EPaCCS system to calculate what proportion of patients on the PCR have a non-cancer diagnosis, but some GPs have reported discussing EoLC as more challenging with patients with non-cancer diagnosis because of patient perceptions and the uncertainty of disease trajectories. The LTHT SPC team has started the clinical champions’ network; EoLC training for consultants from non-cancer specialities, this should be evaluated and rolled out more widely if successful. EoLC should be included in all care pathways for

other diseases that could end in death.

It may be helpful to disseminate the Supportive and Palliative Care Indicators (SPICT) tool developed by NHS Lothian and adapted for use in Leeds. The SPICT tool includes information about general clinical deterioration and specific clinical indicators pertinent to patients with advanced heart, vascular, kidney, respiratory, liver, cancer, neurological, dementia and frailty diseases; to try and assess whether a patient is entering their last year of life. The tool may be helpful to generalist staff, especially GPs, who deliver EoLC.

2.7.3 Inequity of access to services

It is essential that people representing all communities in Leeds have equal access to good EoLC. Inequality can be measured in a number of ways including socioeconomic status and ethnicity.

More people in the poorest areas of Leeds die in hospital than those living in more affluent areas. More people from affluent areas die in care homes and hospices than in the poorest areas. There is no difference in the proportions of people dying at home in relation to socioeconomic status. If a decision is taken to use primary care data, PPD and APD data should be analysed by deprivation quintile, to further understand the patterns and reasons why more people living in areas of socioeconomic deprivation die in hospital and less in hospices and take action to counter this. The super holding pharmacy is currently in Moortown. Both hospices are based in the north of the city. Commissioners need to pay attention to the "Inverse Care Law" as described by Julian Tudor-Hart:

"The availability of good medical care tends to vary inversely with the need for it in the population served. This ... operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced."

(Tudor-Hart, 1971)

The data provided by hospices suggest that people from black, Asian and ethnic minority (BAME) communities do not access their services equitably. Data collection should be improved, for both hospices 22% of patients did not have their ethnicity recorded. Between 10 and 14% of people using hospice services last financial year were from BAME communities. The census data show that 19% of the Leeds population come from BAME communities. The hospices used the interpreting service 8 times in the year 2012 – 13. This reflects a national trend reported in the literature. The HNA did not collect data on the ethnicity of people using other EoLC services in Leeds. More work needs to be done to ensure all EoLC services are delivered in a way which meets the needs of BAME communities using the evidence available. This work should build on the work undertaken as part of the Marie Curie Delivering Choice Project in 2008 which focused on improving BAME communities access to palliative care services, and the work undertaken in 2010 by Macmillan Cancer Support and the Black Health Initiative around cancer awareness in BAME communities.

The HNA did not measure uptake of services by other minority groups including lesbian, gay, bisexual or transgendered patients, asylum seekers, homeless people and people with learning difficulties. Access of minority groups to SPC services should be monitored through improved equality monitoring systems which will provide data for future health equity profiles to be created.

2.7.4 The use of volunteers

Both Leeds hospices support and use volunteers. The HNA did not find other examples where volunteers are used to enhance EoLC. There may be a place for volunteers to support people reaching the end of their life in LTH and the community. The anonymous ward sister interviewed suggested peer befrienders on wards to support people with new diagnoses would have a positive impact.

There are lessons to be learnt from comparator areas where volunteers are supported and coordinated to provide companionship and emotional support to patients reaching the end of their lives.

2.7.5 Education

There is a broad range of EoLC education underway in Leeds, coordinated in a strategy. The strategy implementation has stalled and needs refreshing and reviving. Professionals traditionally not included, who may play a role in delivering EoLC should be considered, specifically social workers and sheltered housing managers e.g. 45.5% of sheltered housing wardens felt untrained to care for a tenant nearing end of life. As previously stated, work is required to continue to improve communication between patients and doctors.

“Communication is the cornerstone of good EoLC. Junior doctors are understandably often concerned about communicating with dying patients and their relatives, and should develop their communication skills through observation, simulation, practice, feedback and reflection.” (Sleeman and Collis, 2013)

The public should be included in the education strategy in terms of changing attitudes towards discussing death. Doctors need support around attitudes as well as skills to initiate EoLC discussions as well as flexible appointment times. The education strategy should be updated to include these aspects and also consider specific training needs for different target groups e.g. dementia specialists training on the importance of early ACP. Consider including cultural sensitivity training.

2.7.8 Performance management

Currently the latest data routinely available citywide on performance regarding EoLC is from 2011 ONS data. The only published data which has been analysed nationally is provided by the NEoLCIN. It is recommended that a new performance management system is developed. There is a full discussion on metrics contained in section 7.9 of the report which concludes that actions should be taken to access primary care data to effectively monitor the outcomes of the 2014 CCG EoLC commissioning strategy. It would be useful for the Palliative Care Strategy and Operational Groups to be informed by primary care data, ONS data, PROMS data and VOICES data.

The VOICES data will be published annually and this should be considered by commissioners. It would be useful to supplement the VOICES data with a local dataset measuring patient reported outcome measures (PROMs), in order to triangulate outcome data with patient experience data.

The ONS data has been analysed in this HNA for 2011. There is potential for this to be an annual task commissioned from the Leeds City Council Public Health Intelligence Team. Although there is a time lag, it is a complete and accurate data set. There is potential for ONS data to be considered alongside primary care data. Primary care data are updated daily and measure a wide range of outcomes. Currently the CCGs commission the CSU to audit GP data; this is done quarterly by the Public Health Intelligence Team based at Leeds City Council as part of their current Memorandum of Understanding of Public Health offer to CCGs. What data is extracted is negotiated annually, around April, with GPs (between Nicola Stephens in LCC; Alistair Cartwright from the CCGs; and Martel Henry at the CSU). It may be possible to negotiate the collection of EoLC data, specifically:

- % of patients on the palliative care register
- Time on PCR
- % of patients on the PCR who have been offered an ACP
- % of patients on the PCR who have an ACP in place
- Number of patients on the PCR with PPC recorded
- PPC

Actual place of death
% of people who died in hospital
% of people who died at home (including people whose homes are care homes)
% of GP practices using GSF
% of practices using the LCP (or equivalent)
Numbers of patients on the PCR with an OOH form completed

Data can also be pulled off to understand if PPD is not achieved, why: symptom control, carer breakdown, crisis intervention or unsafe to be left alone. It may be possible to negotiate for the Public Health Intelligence Team to analyse this data and provide quarterly reports to the chair of the Leeds Palliative Care Strategic Group.

It would be possible for this audit to be run alongside a data improvement plan, which could focus on improving coding and validating numbers of death by the age profile of the practice. The percentage of patients on the PCR could inform a “Find your 1%” campaign, the 1% of patients on the GP list who are likely to die within the next twelve months, although in Leeds this is 0.8% and would be different for each individual practice. The standardised mortality rate of the population the GP serves could be superimposed on the actual numbers of patients who are on the PCR, and these data can be used to identify GPs with low numbers of EoLC patients on their PCR. This would need to be handled sensitively post LCP review.

2.8 Conclusion

End of Life Care is unique. It cannot be plotted or considered as a “pathway” but more a “service journey”. There is a vast amount to coordinate in terms of service commissioning, planning and delivery. Reflecting on the experiences from the comparative areas, it may be that there is need for the SPC team in Leeds from LTHT, St. Gemma’s and Wheatfields to take more of an explicit role in the leadership of EoLC in Leeds across a very broad range of organisations and the public. The HNA recommendations should be considered within the context of the Palliative Care Funding Review and the CCG commissioning strategy should be robustly performance managed. The biggest strength across all organisations delivering EoLCare the staff. Cooperation and whole systems planning is essential to ensure that everyone has access to the care and support that is right for them at the end of life.

3 Areas for consideration

The HNA findings highlighted a broad and detailed range of areas of consideration. These 66 ideas are listed below in their entirety, collated underneath themes which aim to mirror the patient service journey and underpinning supporting actions. Ten actions which would lead to high impact in improving EoLC, and some “quick wins” have been pulled out and are included in section 4.

Increase early identification

1 Continue the roll out of EPaCCS.

2 Consider commissioning enhanced services from GPs. Audit % of patients on individual GP practices PCR, share comparative practice level data with GPs and consider ways to increase this percentage. Negotiate to set ambitions with individual GP practices.

3 Continue to work to ensure EoLC is included in care pathways for all diagnoses which could end in death.

4 Prioritise rolling out ACPs with people diagnosed with dementia. Given the nature of dementia, this should happen before a person enters the last 12 months of life.

5 Consider the potential for using predictive modelling in identifying EoLC needs using the Leeds risk stratification tool.

Improve communication and person centred care with individual patients

6 Consider how longer appointments can be made with hospital based doctors and GPs to ensure there is enough time to be able to hold conversations with patients who have been identified as reaching the end of life in a sensitive manner.

7 Ensure the workforce is trained to continue to be incredibly careful when discussing plans for EoLC in the last 24 – 48 hours of life with patients, carers and families.

8 Careful attention should be given to explaining why a patient is no longer receiving food or artificial hydration if this course of action is taken. The word “pathway” should not be used.

9 Patients interviewed requested clear information about EoLC, the LCP and organ donation. Ensure this information is available on the Leeds Palliative Care Website.

10 The LCP review states that generic protocols such as the LCP are the wrong approach, and recommends a series of guides and alerts supplemented by technical guidance specific to certain disease groups. These should be implemented in Leeds when available.

Improve integration of services and coordination of patient care

11 Ensure any advance care plans written by patients with their social worker are shared with permission with the NHS and included on the EPaCCS system or inpatient’s notes. Pay particular attention to ensure all staff including non-health staff involved with a person’s care are aware if an ACP is in place (e.g. sheltered housing warden).

12 Develop a system so there is a single lead contact coordinating a patient’s EoLC, this may be a DN, GP, CNS, social worker.

13 Support the development of the Leeds Care Record and continue to ensure EoLC and EPaCCS are embedded.

14 Audit the delivery of EoLC delivered by GP practices against all “GSF” levels. Ensure this includes patients who are resident in care homes.

15 Ensure all staff, especially GPs and DNs complete OOH handover forms.

16 Consider changing how patient records are managed; consider patient held records, or electronic records that patients can access. Implement the Neuberger recommendation of encouraging patients and carers to write in their own notes.

17 Consider the implications of the Palliative Care Funding Review and consider pooling health and social care funding into a single budget to provide EoLC to a defined cohort of EoLC patients.

Improve the efficiency of discharges from LTHT for patients receiving EoLC

18 Develop a model of specialist EoLC discharge facilitators in LTHT. An invest-to-save model could be used with the aim that the posts could become self-funded with savings that are made.

Improve OOH care and provide services seven days a week

19 Ensure all patients on the PCR are aware of the Palliative Care OOH telephone number.
20 Link with 111 to develop a system where community staff requesting GP support OOH are prioritised.

21 Support St. Gemma's and Wheatfields and LTHT SPC team to develop a 7 day CNS service.

22 Consider the feasibility of providing a broader range of services seven days a week including: community discharge facilitators; the Leeds Equipment Service; AHPs, specialised pain services; LTHT EoLC discharge facilitators; EoLC care homes facilitator; oncology social workers based at LTHT.

23 Improve access to SPC drugs OOH.

Invest further in community services to support increasing care outside of hospital

24 Consider how funding can be moved from hospital to community or investing more in community EoLC.

25 Increase DN capacity. Consider whether there should be specialist EoLC DN or continue to train all DN in EoLC skills. Increase the number of DN Independent Nurse Prescribers and the number of DNs competent to verify death.

26 Ensure an effective medicines management strategy is in place for EoLC medication in the community.

27 Ensure all patients who are nearing EoLC have a named key worker that coordinates care across organisational boundaries.

28 Patients value continuity of care, continue to work towards this happening.

Improve access to medicines

29 Improve anticipatory prescribing practice by GPs and hospital doctors on discharge.

30 Increase the number of Independent Nurse Prescribers.

31 CCGs to develop a strategy to improve coordination and delivery of complex EoLC medication in the community. This should include access to super holding pharmacies.

32 Improve access to pharmacy services to have prescriptions fulfilled.

33 Ensure information about accessing medicines is included on the Leeds Palliative Care website.

34 Review SPC pharmacist provision to hospice and potential for increasing capacity to enable greater support to be provided to community and outpatient staff around EoLC medication.

Specific recommendations for hospice care

35 Ensure future commissioning and contract arrangements support cooperation not competition between St. Gemma's and Wheatfields hospices. They are separate organisations but work flexibly as a single unit to ensure inpatient hospice care is available to all people in Leeds who meet the eligibility criteria.

36 Undertake further research using the quarterly data from primary care to build a deeper understanding of the impact of both hospice models. Complement this by undertaking patient satisfaction research at both hospices. Work towards delivering a single standardised model of hospice care based on evidence of best performance and ensure equity of access to hospice beds across the city.

37 Secure agreement on the geographical footprint each hospice serves.

38 Support both hospices to continue to develop the non-cancer EoLC agenda.

39 Consider the implication of offering hospice care as a true choice to patients. This will involve providing hospice care for the “simply dying” in Leeds. This may mean commissioning additional palliative care beds in care homes, hospital wards or building additional nurse led hospices.

40 Both Leeds hospices are based in the north of the city; consider additional provision in the south of Leeds; or formally commissioning Wakefield hospice.

41 Audit both hospices waiting lists.

Improve support available for carers and the bereaved

42 Consider introducing schemes to improve carer support and reduce the incidence of “carer breakdown”.

43 Services available for bereaved families and carers should be mapped, audited against an agreed standard and reoriented to meet need.

Work to change culture around discussing death and dying

44 Negotiate with Leeds City Council Public Health Team to deliver projects and campaigns aimed at breaking down the taboo around discussing death and dying e.g. the Dying Matters campaign. Open a debate around death, dying, bereavement and making plans.

45 Continue to develop the Leeds Palliative Care website and ensure it links to the Dying Matters material.

Develop the non-cancer agenda

46 Ensure EoLC is embedded in all care pathways that could end in death.

47 Evaluate the clinical champions for end of life care in specialities other than cancer. If effective industrialise this programme.

48 Continue to implement SPICT tool in primary care and consider broadening this to include non-cancer specialities in LTHT.

49 Linked to recommendation 38, hospices to continue to develop the non-cancer agenda, evaluate the impact of initiatives and implement good practice across both hospices.

Ensure EoLC services in Leeds are equitable

50 Improve equality monitoring to quantify known and identify unknown inequities in use of EoLC services in Leeds.

51 Put robust plans in place to reverse inequities in accessing EoLC in the city.

52 Consider undertaking health equity profiles of key services delivering EoLC.

53 Ensure the commissioning strategy explicitly works to reduce the Inverse Care Law.

13.1.2.3 Volunteers

54 Consider how volunteers could be used more in the community and hospital setting to support EoLC and bereavement support.

13.1.2.5 Continue to provide education

55 Refresh and revive the Leeds EoLC education strategy.

56 Ensure the broadest workforce is considered for inclusion e.g. Sheltered Housing Wardens and Social Workers.

57 Work also needs to be done around medic's attitudes towards palliative care and confidence around discussions with patients who are nearing EoL.

58 Include plans to raise awareness amongst the public.

59 Include cultural sensitivity training.

60 Continue to provide education and training around care of the dying.

13.1.2.6 Improve performance management systems

61 Develop a new performance management system for EoLC in Leeds.

62 Continue to use the ONS mortality data, negotiate for this to be analysed annually.

63 Continue to use the annual VOICES data.

64 Consider developing PROMs and other quality measures to use across all organisations delivering EoLC in Leeds.

65 Work with the Leeds City Council Public Health Intelligence Team to set up a system to access, analyse and use primary care data around EoLC quarterly.

66 Synchronise the Leeds Palliative Care Strategic and Operational Groups so they are informed by the quarterly reports.

4 High impact actions and quick wins

The list above is lengthy and represents the complexity and interconnectedness of actions suggested to improve EoLC in Leeds. However the actions below have been pulled out as being either high impact or a quick win.

4.1 Ten high impact actions

4.1.1 Improve EoL discharges from LTHT

Develop a model of specialist EoLC discharge facilitators in LTHT. An invest-to-save model could be used with the aim that the posts could become self-funded with savings that are made.

4.1.2 Deliver a seven day service

Support St. Gemma's and Wheatfields and LTHT SPC team to develop a 7 day CNS service and consider the feasibility of providing a broader range of services seven days a week including: community discharge facilitators; the Leeds Equipment Service; specialised pain services; LTHT EoLC discharge facilitators; EoLC care homes facilitator; oncology social workers based at LTHT.

4.1.3 Improve access to medicines

Improve access to SPC drugs OOH. Improve anticipatory prescribing practice by GPs and hospital doctors on discharge. Increase the number of nurse prescribers.

4.1.4 Increase district nursing capacity

Increase DN capacity. Consider how funding can be moved from hospital to community or investing more in community EoLC.

4.1.5 Improve coordination of care

Ensure all patients who are nearing EoLC have a named key worker that coordinates care across organisational boundaries.

4.1.6 Ensure meaningful patient choice

Consider the implication of offering hospice care as a true choice to patients. This will involve providing hospice care for the "simply dying" in Leeds.

4.1.7 Improve support for carers

Consider introducing schemes to improve carer support and reduce the incidence of "carer breakdown".

4.1.8 Change culture around discussing death and dying

Negotiate with Leeds City Council Public Health Team to deliver projects and campaigns aimed at breaking down the taboo around discussing death and dying e.g. the Dying Matters campaign. Open a debate around death, dying, bereavement and making plans.

4.1.9 Improve performance management of the impact of EoLC services

Develop a new performance management system for EoLC in Leeds based on auditing primary care data.

4.1.10 Ensure equity of access across the city to hospice care

Work towards delivering a single standardised model of hospice care based on evidence of best performance and ensure equity of access to hospice beds across the city.

4.2 Quick wins

4.2.1 Ensure any advance care plans written by patients with their social worker are shared with permission with the NHS and included on the EPaCCS system or inpatient's notes. Pay particular attention to ensure all staff including non-health staff involved with a person's care are aware if an ACP is in place (e.g. sheltered housing wardens).

4.2.2 Prioritise rolling out ACPs with people diagnosed with dementia. Given the nature of dementia, this should happen before a person enters the last 12 months of life.

4.2.3 Ensure information about accessing medicines and organ donation is included on the Leeds Palliative Care website.

4.2.4 Ensure all staff, especially GPs and DNs complete OOH handover forms.

4.2.5 Ensure all patients on the PCR are aware of the Palliative Care OOH telephone number.

5 Glossary

Term Meaning

ACP Advance Care Plan

ADRT Advance Decision to Refuse Treatment

AHP Allied Health Professional

ANP Advanced Nurse Practitioner

ASC Adult Social Care

BAME Black Asian and Minority Ethnic

CCGs Clinical Commissioning Groups

CE Chief Executive

CHC Continuing health care

CNS Clinical Nurse Specialist

COPD Chronic Obstructive Pulmonary Disease

CPD Continuing professional development

CSU Commissioning Support Unit

DiUPR Death in usual place of residence

DH Department of Health

DN District Nurse

DNACPR Do Not Attempt Cardio Pulmonary Resuscitation

DST Decision Support Tool

eDID Electronic Discharge Document

EoL End of Life. People are classed as reaching the end of life when they are likely to die within the next 12 months

EoLC End of Life Care

EPaCCS Electronic Palliative Care Coordination Systems

FT Fast track

Fast track A patient becomes eligible to place a “fast track” funding application for continuing health care if they have a rapidly deteriorating condition with a likely terminal prognosis.

GMC General Medical Council

GP General Practitioner

GSF Gold Standard Framework

HCA Health Care Assistant

HNA Health Needs Assessment

ICD10 codes World Health Organisation system of classifying diseases using standardised codes

Intrathecal Giving medications directly into the spinal fluid

IT Information Technology

JCM Joint Care Managers
JCMT Joint Care Management Team
LCC Leeds City Council
LCH Leeds Community Health
LCP Liverpool Care Pathway for the Dying Patient
LTC Long term conditions
LTHT Leeds Teaching Hospitals Trust
LSE CCG Leeds South and East Clinical Commissioning Group
LYPFT Leeds and York Partnership NHS Foundation Trust
MD Multi-Disciplinary
MDT Multi-Disciplinary Team
NCPC National Council for Palliative Care
NEoICIN National End of Life Care Intelligence Network
NMC Nursing and Midwifery Council
OOH Out of hours
PCR Palliative Care Register
PCT Primary Care Trust
PII Patient Identifiable Information
PPC Preferred Place of Care
PPC Preferred Place of Care
PPD Preferred Place of Death
PPM Patient Pathway Manager
PPI Patient and Public Involvement
PRN As required (medication)
PROMS Patient Reported Outcome Measures
QIPP NHS cost saving agenda; Quality Innovation Productivity
Prevention
QoF Quality and outcomes framework
RDP Rapid Discharge Pathway
Rapid discharge pathway is designed for people within the last days and hours of life,
who need to be discharged within 24 – 48 hours
Simply dying People who are dying but do not need specialist palliative care
input
SPC Specialist Palliative Care
SPCT Specialist Palliative Care Team
SPICT Supportive and Palliative Care Indicators Tool
Statistical artefact Error in data caused by collection or recording methods
VOICES Views of informal carers for the evaluation of services
WTE Whole Time Equivalent
YAS Yorkshire Ambulance Service
YCN Yorkshire Cancer Network

Appendix 2

End of Life Care Commissioning Strategy: Work programme

Key Actions 2014/15 – to be agreed

- 1.
- 2.
- 3.
- 4.
- 5.

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|---|---|---|--|-------------------------------------|--|
| 1 | Service re-design | | | | | |
| 1a | <p>Co-ordination of care</p> <ul style="list-style-type: none"> • Ensure all patients who are nearing EoLC have a named key worker that works with them to coordinate care across organisational boundaries. • Ensure patients have simple, rapid access to help and advice at any time of the day or night. • Risk Stratification/GSF/EPaCCS | <p>13.1.1.3 13.1.1.6 13.1.1.5 13.1.1.2 13.1.1.1</p> | <p>Audit using primary care dataset to obtain a baseline and then take any necessary actions</p> <p>Signposting through a single number for advice.</p> <p>Review best practice models eg Lincolnshire, Bradford and develop options</p> <p>Link through Integrated Health and Social Care agenda</p> | <p>14/15</p> <p>14/15</p> <p>14/16</p> | <p>8</p> <p>9</p> | <p>Naomi Penn, Prakash Babu, Pablo Martin Sarah Follon supported by Joan Kennedy</p> |
| 1b | <p>Hospital discharge</p> <ul style="list-style-type: none"> • Develop a model of specialist EoLC discharge co-ordinators in LTHT working 7 days/week. | <p>13.1.1.4 13.1.1.5</p> | <p>Develop best practice options for service delivery and conduct options appraisal to identify preferred option.</p> | <p>14/15</p> | <p>8</p> | <p>Joan Kennedy</p> |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|--|--|--|---------------------------------|-------------------------------------|---|
| | <ul style="list-style-type: none"> Consider commissioning Leeds Equipment Service for extended hours at weekends. | 13.1.1.6 13.1.1.5 | Financial modelling | 14/15 | 8 | |
| 1c | <p>Develop seven day services</p> <ul style="list-style-type: none"> Support St. Gemma's, Wheatfields and LTHT SPC teams to develop a 7 day CNS service with a rapid response and appropriate medical cover. Consider how support can be delivered to care homes across 7 days (eg extend hours of care home facilitator, commission LCH to support care homes for patients in the last days of life). | 13.1.1.5 13.1.1.6 13.1.1.5 13.1.1.6 | <p>Develop best practice options for service delivery and conduct options appraisal to identify preferred option</p> <p>Link to Integrated Health and Social Care Programme</p> | 14/15 15/16 | 8 | Joan Kennedy/Fiona Hicks Eileen Burns/Fiona Hicks/Joan Kennedy |
| 1d | <p>Ensure rapid access to care 24/7</p> <ul style="list-style-type: none"> Consider how funding can be moved from hospital to community or investing more in community EoLC. Increase DN capacity. Consider whether there should be specialist EoLC DN or continue to train all DN in EoLC skills. Increase the number of DN nurse prescribers and the number of DN trained to verify death. Consider commissioning LCH to provide community clinical support to care homes for patients in the last days of life. | 13.1.1.6 13.1.1.6 13.1.1.7 13.1.1.6 | <p>Need to understand more about current D/N delivery framework, how this is delivered and what KPIs exist to monitor performance and then identify gaps</p> <p>Need to understand more about the current service and compare with best practice in other areas</p> <p>Link to Care Homes work at 1c above</p> | 14/16 14/15 15/16 | 16 16 | Joan Kennedy/Veronica Lovatt Joan Kennedy/Angela Gregson |
| 1e | <p>Provide more choice of place of care in the last days of life</p> <ul style="list-style-type: none"> Consider the implication of offering hospice care | 13.1.1.8 13.1.2.2 | New Service Specification for hospices. | 14/15 | 16 | Veronica Lovatt |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|----|---|---|---|---|-------------------------------------|--|
| | <p>as a true choice to patients. This will involve providing hospice-type care for those people who do not have a specialist level of need in Leeds. This may mean commissioning additional palliative care beds in care homes, hospital wards or building additional nurse-led hospices.</p> <ul style="list-style-type: none"> Hospices to continue to develop the non-cancer agenda, evaluate the impact of initiatives and implement good practice across both hospices | 13.1.2.2 | <p>Pilot of nurse-led hospice type beds managed by the 2 hospices – minimum 5 each side of the city</p> <p>Evaluation of above to be agreed in order to inform future commissioning decisions</p> | <p>14/16</p> <p>14/15</p> <p>14/15</p> | 1 | <p>Kerry Jackson</p> <p>Helen Ankrett</p> <p>Joan Kennedy</p> <p>Veronica Lovatt</p> <p>Kerry Jackson</p> <p>Helen Ankrett</p> |
| 1f | <p>Enable patient choice for type and/or provider of specialist palliative care (home vs hospice, inpatient unit)</p> <ul style="list-style-type: none"> Review systems for admission of patients to Leeds hospices to improve choice and efficiency and reduce waiting times Hospices to collect data on people waiting for admission to inform future modelling of specialist palliative care beds Undertake further research using the quarterly data from primary care to build a deeper understanding of the impact of both Leeds hospice models. Complement this by undertaking patient satisfaction research at both hospices. Work towards delivering a single standardised model of hospice care based on evidence of best performance and Ensure future commissioning and contract | <p>13.1.1.8</p> <p>13.1.1.8</p> <p>13.1.1.8</p> <p>13.1.1.6</p> <p>13.1.1.8</p> | <p>Hospices to develop audit system to provide this information as part of the nurse-led beds pilot - links to 1e</p> <p>For consideration as to whether this is a priority??? Is this something for a health economics expert?</p> <p>Develop Transfer of Care protocol</p> <p>Review of funding flows</p> | <p>14/15</p> <p>14/15</p> <p>15/16</p> <p>14/15</p> | <p>1 and 8</p> | <p>?Managed Clinical Network</p> <p>Helen Ankrett/Kerry Jackson</p> <p>?Managed Clinical network</p> |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|--|---|--|--|-------------------------------------|---|
| | <p>arrangements support co-operation not competition between hospices and ensure equity of access to hospice beds across the city.</p> <ul style="list-style-type: none"> Both Leeds hospices are based in the north of the city; consider additional provision in the south of Leeds; or formally commissioning Wakefield hospice. | | <p>Maximise use of current SPC beds, increase occupancy and reduce waiting times. Consider electronic, shared bed states, criteria for prioritisation if they are full, waiting lists etc to improve patient information, choice and flows. Nurse-led beds could be included to give a full picture This should be informed by the nurse-led hospice type beds pilot</p> | | | ?Managed Clinical Network |
| 1g | <p>Improve carer support and provision of bereavement services</p> <ul style="list-style-type: none"> Consider introducing schemes to improve carer support and reduce the incidence of “carer breakdown”. Services available for bereaved families and carers should be mapped, audited against an agreed standard and reoriented to meet need. Consider how volunteers could be used in the community and hospital setting to support EoLC and bereavement support.(see above) | <p>13.1.1.9</p> <p>13.1.1.9</p> <p>13.1.2.3</p> | <p>Prioritise for 15/16</p> <p>Identify work previously done at former NHS Leeds (Angela Mkandla and Veronica Lovatt 13/14)</p> | <p>15/16</p> <p>15/16</p> <p>15/16</p> | | |
| 1h | <p>Review selected specialist services</p> <ul style="list-style-type: none"> Specialist pharmacy services Specialist interventionalist cancer pain services Psycho-oncology services | <p>13.1.1.7</p> | <p>All large pieces of work - prioritise for later. Liaise with relevant CCGs as to appropriate person to lead this work</p> | <p>15/16 onwards</p> | | Joan Kennedy to liaise with Leeds West/Leeds North CCGs |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|--|---|---|---------------|-------------------------------------|---|
| 2 | Continue to commission key work-streams | | | | | |
| 2a | <p>Continue the implementation of EPaCCS so that it is available in all GP practices, it links with the Leeds Care Record and associated education and including:</p> <ul style="list-style-type: none"> • Ensure any advance care plans written by patients with their social worker are shared with permission with the NHS and included on the EPaCCS system or inpatient's notes. • Prioritise rolling out ACPs with people diagnosed with dementia. Given the nature of dementia this should happen before a person enters the last 12 months of life • Pay particular attention to ensure all staff including non-health staff involved with a person's care are aware if an ACP is in place (e.g. sheltered housing wardens). • Consider changing how patient records are managed; consider patient held records, or electronic records that patients can access. • Ensure all patients on the PCR are aware of who to call in an emergency both in and out of hours | <p>13.1.1.1 13.1.1.3 13.1.1.5</p> | <p>Continue with project management arrangements to oversee the work Develop PID for 2014/2015</p> <p>Links to the citywide dementia strategy. Identify citywide lead</p> | 14/15 | 1 and 8 | <p>Joan Kennedy/Ann Wood J Kennedy/A Wood with EPaCCS gp</p> <p>Tim Sanders</p> |
| 2b | Continue to support the palliative care website information for patients, carers and professionals | <p>13.1.1.7 13.1.1.2 13.1.2.1</p> | <p>Needs governance for the website as several organisations information is held Needs content to be updated regularly</p> | 14/15 onwards | 2 | Possibly a future Managed Clinical Network or the Palliative |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|----|--|--|---|-----------|-------------------------------------|---|
| | | | | | | Care Strategy Group |
| 2c | <p>Refresh and revive the Leeds EoLC education strategy and evaluate education programmes currently being delivered. Ensure the broadest workforce is considered for inclusion e.g. Sheltered Housing Wardens and Social Workers. The strategy should address the following elements:</p> <ul style="list-style-type: none"> • Ensure that GPs receive appropriate training in order to be able to communicate effectively and sensitively with patients at end of life, and with their families/carers including cultural sensitivity training • Careful attention should be given to explaining why a patient is no longer receiving food or artificial hydration if this course of action is taken. The word “pathway” should not be used. • The LCP review states that generic protocols such as the LCP are the wrong approach, and recommends a series of guides and alerts supplemented by technical guidance specific to certain disease groups. These should be implemented in Leeds when available. • Ensure all staff, especially GPs and DNs complete OOH handover forms. • Continue to implement SPICT tool in primary care and consider broadening this to include non-cancer specialities in LTHT. • Improve anticipatory prescribing practice by GPs, trainees and hospital doctors on discharge | <p>13.1.2.5 13.1.1.3 13.1.1.2 13.1.1.5</p> | <p>Set up project management structure and governance arrangements to review and renew education strategy</p> | 14/15 | 15 | Joan Kennedy/Fiona Hicks ?Managed Clinical Network |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|---|----------------------|---|-----------|-------------------------------------|-------------------------------------|
| | <ul style="list-style-type: none"> Implement the Neuberger recommendation of encouraging patients and carers to write in their own notes. Evaluate the clinical champions for end of life care in specialties other than cancer. If effective industrialise the programme. | | | | | |
| 3 | Commissioners to implement | | | | | |
| 3a | <p>Develop a new performance management system for EoLC in Leeds (outlined in HNA) Continue to use the ONS mortality data, negotiate for this to be analysed annually Work with the Leeds City Council Public Health Intelligence Team to set up a system to access, analyse and use primary care data around EoLC quarterly.</p> | 13.1.1.1 13.1.2.6 | Develop a Primary Care Data Sharing Agreement and subsequent quarterly reporting arrangements | 14/15 | 17 | Veronica Lovatt and Sarah McDermott |
| 3b | Consider the implications of the Palliative Care Funding Review and consider pooling health and social care funding into a single budget to provide EoLCare to a defined cohort of EoLCare patients | 13.1.1.3 | Final report on data analysis from Palliative Care Funding Review will be available Autumn 2014 | 14/16 | | Diane Boyne? |
| 3c | Synchronise the Leeds Palliative Care Strategic and Operational Groups so they are informed by the quarterly reports | 13.1.2.6 | | 14/15 | | Veronica Lovatt |
| 4 | Provider organisations to implement | | | | | |
| 4a | All providers to ensure that they provide equitable services to patients in relation to their diagnosis, gender, ethnicity, socio-economic status | 13.1.2.3 | | 14/15 | 3 | ?Managed Clinical Network |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|----|--|--|--|--------------|-------------------------------------|--------------------------------|
| 4b | Ensure EoLCare is embedded in all care pathways that could end in death | 13.1.2.2 | Identify where this can be signposted within the wider health system | To be agreed | | ?Managed Clinical Network |
| 4c | Audit the delivery of EoLC delivered by GP practices against all GSF levels. Ensure this includes patients who are resident in care homes. | 13.1.1.3 | | To Be agreed | | |
| 4d | Providers to evaluate service changes (eg non-cancer work-streams and hospices) | 13.1.1.3 13.1.1.4 13.1.1.5 13.1.1.6 13.1.1.7 13.1.1.8 13.1.1.9 13.1.2.2 | | To be agreed | | ?Managed Clinical Network |
| 4e | Providers to work together to develop and implement appropriate PROMs | 13.1.2.6 | | To be agreed | | ?Managed Clinical Network |
| 5 | Discuss with other commissioning bodies | | | | | |
| 5a | Link with 111 to develop a system where community staff requesting GP support OOH are prioritised | 13.1.1.5 | Identify a lead at North CCG and link to work on the SPA | 14/15 | | |
| 5b | Ensure an effective medicines management strategy is in place for EoLC medication in the community including co-ordination and delivery of <i>complex</i> EoLCare medication. This should include access to super holding pharmacies and improved access to drugs out of hours | 13.1.1.5 | | 14/16 | 4 | Helen Liddell |
| 5c | Include plans to raise awareness amongst the public (see below re culture change) | 13.1.2.5 | | 15/16 | | Public Health England ?who |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|-----------|---|---------------|--|-----------|-------------------------------------|---|
| 6 | Consider the structures needed to support delivery of the commissioning strategy | | | | | |
| 6a | Ensure that all patient outcomes identified in the strategy can be measured | | Identify and agree a set of measures | 14/16 | | Fiona Hicks/Joan Kennedy/Veronica Lovatt |
| 6b | Consider the merits of a Managed Clinical Network or alternative framework | | Conduct a formal options appraisal on the different frameworks for delivery - Managed Clinical Network, lead provider organisation or formal alliance agreement. | 14/15 | | Fiona Hicks/Joan Kennedy |
| 6c | Ensure robust communication with all stakeholders relating to the delivery of the End of Life Care Strategy | 13.1.2.6 | Develop a communications strategy Review the ToR of the operational and strategic groups | 14/15 | | Veronica Lovatt Joan Kennedy Comms Team |
| 6d | Ensure that the general public understand the role of palliative care services and how and when they should access these, ensuring that communities who are hard to reach are included+ | | Develop a communication strategy | 14/16 | | Comms Team |
| 7 | Other | | | | | |
| 7a | <i>Work to change culture around discussing death and dying</i> Negotiate with Leeds City Council Public health team to deliver projects and campaigns aimed at breaking down the taboo around discussing death and dying eg the | | To be agreed | 15/16 | | |

| | Objectives | HNA reference | Action(s) required ** | Timescale | Nice EoL Quality Standard reference | Responsible Lead/ Stakeholders |
|--|---|---------------|-----------------------|-----------|-------------------------------------|--------------------------------|
| | <p>Dying Matters campaign. Open a debate around death, dying, bereavement and making plans This links to PHE above</p> <p><i>Ensure EoLCare services in Leeds are equitable</i></p> <ul style="list-style-type: none"> • Put robust plans in place to reverse inequities in accessing EoLCare in the city • Consider undertaking health equity profiles of key services delivering EoLCare • Ensure the commissioning strategy explicitly works to reduce the Inverse Care Law | | | | | |

Outline for the development of a Managed Clinical Network for Palliative and End of Life Care in Leeds

