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

NHS Leeds South and East Clinical Commissioning Group

Office of the Director of Public Health, Leeds City Council

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Foreword

“Like birth, death is part of life – something no one can avoid.” (Hughes-Hallet, 2011)

My vision is a world where everyone has access to the care and support that is right for them at the end-of-life. We need to respond to surveys which suggest the majority of people express a preference to die at home. However it is important to look behind headline targets and be guided by what people value: to be free from pain and other symptoms, be surrounded by loved ones, to be treated as an individual and die with privacy and dignity. This health needs assessment clearly sets out what is required for Leeds population around end of life care. It is the first step in a process which aims to ensure end of life care provided in Leeds is high quality, equitable, coordinated, integrated, and enabling people to achieve a “good death”. The needs assessment won’t sit on a shelf; it will inform the Leeds CCG’s commissioning strategy and service improvements. We need to start a conversation with the public, break taboos around discussing death and encourage and support people to express their preferences. End of Life Care is provided by a wide range of organisations and individuals alongside the CCGs, this is recognised and highly valued. The strength of end of life care services in Leeds are its staff, who are skilled and committed to delivering good end of life care; and work well in cooperation across organisational boundaries in the interests of patients.

Dr Andrew Harris, Clinical Chief Officer, Leeds South and East CCG
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1. Executive summary

1.1 Introduction
1.1.1 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
1.2.1 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
1.3.1 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.

1.3.2 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
1.4.1 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).

1.4.2 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.

1.4.3 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).

1.4.4 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
1.5.1 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.

1.5.2 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.

1.5.3 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.

1.5.4 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.

1.5.5 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
1.6.1 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.

1.6.2 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.

1.6.3 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

1.7.1 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.

1.7.2 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 choses 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.

1.7.3 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.

1.8 Recommendations
Chapter 13 includes recommendations around performance management systems, changing culture around discussing death and dying, education, ensuring EoLC services are equitable, communication with and patient centred care for individuals, support available for carers, early identification, discharge from LTHT, invest further in community services to support increasing care outside of hospital, integration and coordination of care, bereavement services, access to medicines, provide services seven days a week, develop the non-cancer agenda, provide EoLC support to residential care homes and specific recommendations for hospice care.
2. Introduction

As a result of the UK’s ageing population, the number of deaths per year is expected to rise by 17% between 2013 and 2030. In addition many more people will be dying at an older age, with more complex needs and multiple morbidities as they near the end of their lives (Gomes and Higginson, 2008). Leeds demographics are in line with this national trend and are explored further in chapter 7. The report is timely given the recent review of the Liverpool Care Pathway (Neuberger, 2013), The Keogh Review (2013) and imminent publication of the Palliative Care Funding Review (Hughes Hallet et al, 2011).

This health needs assessment aims to lay the foundations for the Leeds Clinical Commissioning Groups to commission services which meet these needs and contribute to people in Leeds experiencing good end of life care. It is also intended to be an information resource for broader partners in Leeds including the Palliative Care Strategy Group members, to ensure services are planned are coordinated based on evidence of need, and good practice. This introduction explains the background to the health needs assessment and what the report will include.

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).

The NICE commissioning guide uses the GMC definition of end of life; people are approaching the end of life when they are likely to die within the next twelve months. Responsibility for commissioning EoLC services transferred to the Leeds CCGs in April 2013, with Leeds South and East as the lead commissioner.

End of Life care in Leeds is delivered by a broad range of partners including families and friends in the community, primary, secondary and specialist care. The Leeds Strategic Framework for Palliative and End of Life care’s vision is that

“People who have palliative care needs and who die in Leeds have what for them and their carer’s constitutes a positive quality experience”.

The HNA aims to answer the question

“Are we providing the best End of Live Care services possible with the resources available?”

The health needs assessment will provide evidence to inform the development of the Leeds CCG commissioning strategy. The working group will use these data to develop a range of service models with options appraisals, and ultimately the Leeds CCG EoLC Commissioning strategy will be published in March 2014.
3. Methodology

3.1 Introduction
This chapter explains what a health needs assessment is, describes the scope of this HNA, the methods used, which partners were involved and what is included in this HNA report.

3.2 What is a HNA?
Health needs assessment (HNA) has been described by Bindra (2008) as an essential tool to inform commissioning and service planning. HNA can be defined as a systematic method of identifying the unmet health and healthcare needs of a population, and making changes to meet those unmet needs. Stevens and Raftery (1997) define need in the context of health care as “the ability to benefit from health care.” HNA allows for appropriate targeting of resources. HNA involves gathering information to inform service planning with the aim of improving health. Services may need to change for a number of reasons, including: inequalities in outcomes; local sensitivities; changing demographic patterns or disease trends; availability of new treatments and changing expectations.

Stevens et al (2007) describe three approaches to HNA: epidemiological which considers the epidemiology of the condition and current service provision; comparative which compares service provision between different populations and corporate which is based on eliciting the views of stakeholders; these may include professionals, patients and service-users, the public and politicians; on what services are needed.

3.3 The scope of the Leeds HNA into EoLC Needs
A review of previous HNA of EoLC was conducted. Six published HNAs were found, covering populations in Devon, Glasgow and Clyde, Leicester, Cambridgeshire, Lancashire and South Cumbria and Leeds; ranging from 2012 - 2006 (Lang 2012, Chapman and Lennon 2010, Dellar 2010, De Zoete 2009, Tebbit 2009, and Nixon et al 2006). These were reviewed to learn from their approaches and findings. All HNAs included information on demographics of their local population and the epidemiology of dying (number of deaths, cause of deaths, place of death etc). The HNAs tried to either project future need or draw attention to unmet need. Some HNAs included views of professionals, service users and carers. Useful elements from the HNAs have been drawn upon and incorporated into the Leeds HNA.

The Leeds HNA scope is for adults only and includes:
- A summary of the national and local policy contexts.
- An epidemiological analysis of EoLC in the past, present and future projections.
- An epidemiological assessment (as opposed to comparative assessment) of projected need based on the epidemiology described.
- A description of existing EoLC services, including generalist services that contribute to the EoLC provided in Leeds.
- Views of staff working in these services gathered through interview and survey methods.
- Views of patients who have used these services and their carers.
- A comparative analysis benchmarking Leeds against other areas.

3.4 How this HNA was undertaken
3.4.1 Strategic commitment and scoping
An initial data pack including describing key facts around EoLC in Leeds was presented to the Leeds Clinical Commissioning Group Collaborative in August 2012 with a proposal outlining actions required to gather more in depth information. Commitment was secured to deliver a full HNA. The collaborative agreed the HNA would become a priority for the
Palliative Care work stream of the Leeds Transformation Board. In September 2012 the data-pack and recommendations were presented and accepted at the Leeds Palliative Care Strategy Group. In January 2013 a working group was convened and a work plan to deliver the HNA was developed and agreed at the Palliative Care Strategy Group.

3.4.2 Commitment from key stakeholders
Members of the Leeds Palliative Care Strategic and Operational Groups were invited to attend a workshop to launch the HNA process. Participants were informed of the principles, strategic links, purpose, scope, process, methods and next steps of the HNA and discussions were held around their commitment to the HNA, links to 2006 Leeds HNA, service user, carer and bereaved people’s involvement, existing services (what works well and what doesn’t) and who else to involve. All participants committed to the process of the HNA. A full workshop report was collated (Ingold, 2013) and a summary of issues raised is included in appendix 1.

3.4.3 Epidemiological HNA
An epidemiological HNA was undertaken to gather, analyse and present data describing the epidemiology of dying in Leeds in the past, present and future. It contains information about metrics that could be used to performance manage EoLC post March 2014.

3.4.4 Comparative HNA
The comparative HNA compares Leeds EoLC services and outcomes with four similar cities and an area which is the highest performing. Demography, key data sets and views of lead commissioners are compared.

3.4.5 Corporate HNA
The corporate HNA includes a description of current service provision. Mapping these services against quality standards is outside the scope of the HNA and is being done through the ELQuA process led by the Leeds Strategic Palliative Care group. Cost effectiveness is outside the scope of this HNA and will be considered by commissioners whilst developing a service models, options appraisal and commissioning strategy.

The corporate HNA includes the views of professionals delivering EoLC services in Leeds as well as the views of service users, carers and the bereaved. Professionals shared their views at the workshop, through survey questionnaires and interviews. All suggestions made of who to involve at the March workshop were followed up.

The Patient and Public Involvement team at the NHS West and South Yorkshire and Bassetlaw Commissioning Support Unit undertook a piece of work to gather input from service users, carers and the bereaved. This work was guided by the suggestions made for successful involvement at the March workshop.

3.5 Partners involved
The HNA was undertaken by the Leeds City Council Office of the Director of Public Health, at the request of the Leeds South and East CCG on behalf of the three Leeds CCGs. The work was overseen by a Palliative Medicine Consultant at LTHT.

The project was supported by a huge range of partners who have been listed in the acknowledgements section.

The views of staff from a large number of teams were included, these are:
- LTHT SPC team,
- LCC social work team,
- LCC social work team based at LTHT,
• An anonymous ward sister from LTHT,
• A range of consultants from LTHT,
• CCG Pharmacists, Community Pharmacists,
• CCG Business Analyst,
• An independent data support officer,
• LCC housing team,
• LTHT interpreting team,
• Staff from St. Gemma’s, Wheatfields, Wakefield, Bradford and Harrogate hospices,
• Macmillan staff,
• Marie Curie staff,
• The CCG Out of Hospital Care team,
• The CCG Continuing Health Care Team,
• The LCC/NHS dementia lead, CCG commissioners,
• The DN team
• LCH General Manager for District Nursing
• LCH EoLC Lead and EoLC Facilitator
• LCH Discharge Facilitator,
• GPs,
• Sheltered Housing Wardens,
• Care Home Managers,
• End of Life Care facilitators for LTHT and care homes,
• LCH Community Matron team
• Independent sector domiciliary care agency.
• LCH Community Nurse Specialists, and
• Consultants from LYPFT.

3.6 What the report includes
This report includes: a summary of national policy and local context; evidence of good practice in EoLC; a description of existing services in Leeds; a section on the epidemiology of dying in the past, present and future; projections of need; perspectives of staff in Leeds who deliver EoLC; perspectives of service users, carers and the bereaved; a comparison of Leeds against other cities and localities and ideas of how to measure progress in a meaningful and timely way. These findings have been synthesized in a discussion which answers the ten questions posed by the National Council for Palliative Care to assess if an area is ensuring good EoLC (NCPC 2013). The report concludes with specific recommendations for the future.
4. National context

4.1 Introduction
The national 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. There are three main strategic drivers nationally shaping EoLC: the Department of Health EoLC strategy, the Palliative Care Funding review and the NICE and DH quality standards around EoLC. More recently the LCP review has been published. This chapter describes the relevance of these key national drivers to EoLC work in Leeds and describes key EoLC tools.

4.2 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”, published by the Department of Health in 2008. The End of Life Care 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 and or friends. The strategy acknowledges there is variation in the quality of care experienced by patients at the end of their lives and that the profile of EoLC within the NHS and social care services has been low.

The DH state the strategy has been built on evidence, research and experience from voluntary hospices and the NHS EoLC programme (2004 – 2007) which rolled out programmes such as the Gold Standards Framework, Liverpool Care Pathway, Preferred Priorities for Care, the Marie Curie Delivering Choice programme and other examples of innovative practice.

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

In practical terms, the strategy states a list of actions required which are summarised in appendix 2.

The strategy listed a number of outcomes that would be used to measure progress against:

- Results from the Views of Informal Carers – Evaluation of Services (VOICES) survey
- % of patients achieving PPC
- Number of hospital admissions avoided
- Number of deaths in the community
- Results of LCP audits
- Policies in place recording DNACPR (local measure to be decided)
In April 2013 the responsibility for the EoLC Strategy moved from the DH to the NHS England. It is the responsibility of the boards Medical Directorate, forming part of Domain 2 – Long Term Conditions (DH, 2012).

4.3 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, as

“Palliative care has evolved and as such there is a lack of transparency about how the state will fund a good death.”

The review has a broader remit than EoLC, covering all palliative care. Tom Hughes-Hallett, Chief Executive of Marie Curie Cancer Care, chaired the review and produced the final report “Funding the Right Care and Support for Everyone” (2011). The rationale for creating a per-patient funding mechanism is that incentivising the provision of palliative care, leads to better outcomes for patients, supports choice and is cost effective. 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 palliative care tariff would be a top up in addition to any other tariffs which may cover non-palliative care needs.

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 EoL locality register” can be enabled to have a “prompt discharge from hospital and the creation of an appropriate health and social care package.”

Hughes-Hallett recommends the NHS tariff should fund:

- An assessment, on a regular basis, of the needs of the patient
- All the clinically assessed palliative care needs of a patient, irrespective of setting as in any other branch of clinical care
- A coordinator for the patient who will guide them through their journey, signposting patients and families to the full range of service including those provided by society and not funded by the state
- At the end of life, as an addition to the tariff, the social care needs of a patient after they are added to an end of life locality register

In NHS funding terms this would mean anyone on the palliative care register would receive health and social care services via the NHS, triggered at a much lower level of need than is currently the case through the current continuing care system. Although, Hughes-Hallett considers the review’s recommendations will be cost neutral to the state as it is expected the recommendations

“could reduce deaths in hospital by up to 60,000 a year by 2021, using the QIPP estimate of £3,000 per hospital death this would translate as a potential reduction in hospital costs of £180 million per year”.

The review acknowledges it does not provide detail about additional costs incurred by community services to support this shift. Given that in 2006/7 the reported cost of a death ranged from £186 - £6,213 per PCT with 61% of all PCTs spending less than £1,000 a death (DH 2008), this may be an overestimated projection of saving.
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.

Hughes-Hallet’s key conclusion was that there is a “stunning lack of good data surrounding costs for palliative care in England”. The report recommended that pilots be set up to collect data and refine its proposals due to the lack of good quality data currently available. These pilots are currently underway and due to report in March 2014. Leeds is not a pilot site. It is envisaged that between April 2014 and March 2016 shadow currencies and tariffs will be in place and the system will be implemented in April 2016.

### 4.4 Quality Standards

The National Institute for Clinical Excellence has published Standards for EoLC for Adults (Ref: QS13, 2011). They are included as a series of “quality statements” listed in appendix 3.

In addition the DH published a useful paper which outlines quality markers and measures for EoLC (2009) and gives suggested quality standards for different partners delivering EoLC (e.g. commissioners, hospices etc.) In this document the DH sets the top ten quality markers for providers, which are listed in appendix 4.

The paper also suggests PROMs as a useful method to measure quality. PROMs are further described in chapter 7.

### 4.5 QIPP indicators for EoLC

There are three QIPP indicators for EoLC:

- **KPI1**: To increase deaths in usual place of residence (DiUPR)
- **Pilot KPI 2**: To reduce the number of hospital admissions of eight days or more, which end in death (this is based on clinical need, quality of care and individuals’ preferences)
- **Supporting KPI Dashboard**: Reduction in the number of unplanned admissions in the last year of life

*(NEoLCIN, 2012)*

### 4.6 End of Life Care Tools

There are a number of tools to support good practice in EoLC. The main tools are:

- The Gold Standard Framework (GSF)
- Electronic Palliative Care Coordination System (EPaCCS)
- AMBER care bundle
- Advance Care Planning
- Find your 1% campaign
- DNACPR
- Rapid discharge pathway
- Liverpool Care Pathway

These tools, and how they are being applied in Leeds are described fully in appendix 5. It is worth focusing on the LCP in the main body of the HNA report.

#### 4.6.1 Liverpool Care Pathway

The Liverpool Care Pathway for the Dying Patient (LCP) is a model of care which enables healthcare professionals to focus on care in the last hours or days of life when a death is expected. It is tailored to the person’s individual needs and includes consideration of their needs from physical, social, spiritual and psychological perspectives. It was developed by the Royal Liverpool and Broadgreen University Hospitals NHS Trust and the Marie Curie
Palliative Care Institute Liverpool (MCPCIL), which is supported by Marie Curie Cancer Care. It requires senior clinical decision making, communication, a management plan and regular reassessment. It is not a treatment in itself but a framework for managing treatment. It aims to support, but does not replace, clinical judgment. Communication, care and compassion must come from all the healthcare workers caring for an individual and their family. There have been concerns raised recently in the press about the LCP, stating that it has been used to withhold food and water from patients. A broad range of organisations involved in palliative care (including the NHS) signed a consensus statement to try to clarify what the LCP is.

Since then an Independent Review of the LCP has been undertaken led by Baroness Julia Neuberger which was published in July 2013. The review of the LCP was undertaken in response to negative media stories. The review concluded that when the LCP is used properly, patients die a peaceful and dignified death and that those reading the conclusions of the review should not respond by defaulting back to treating dying patients as if they are always curable. The review recommends:

- Change the terminology from “pathway” to “plan”
- Doctors and nurses must communicate with patients and relatives more honestly about clinical uncertainties
- Decisions to place patients on the LCP by staff who are not trained or competent should end
- Relatives and carers should be involved in discussions around the use of the LCP
- Patients should be supported with hydration and nutrition unless there is a strong reason not to do so and refusing food and drink is a decision for the patient, not clinical staff, to make.
- The use of syringe drivers should be discussed with relatives before it is commenced.
- Having a DNACPR arrangement in place is not a proxy for agreement to start the LCP
- Any attempt to shorten a person’s life is illegal
- Facilities and support for the bereaved, including rooms to hold private conversations in, should be in place
- Dying patients must have a named consultant or GP taking overall responsibility for their care
- Caring with compassion for people at the end of their lives should be the aim of all doctors, nurses and health care staff
- Involving patients and their families or carers in discussions about the care plan is an important way of restoring a sense of control
- Shared care folders in hospitals and the community, where relatives and carers can contribute would be helpful
- There should be no discrimination on the basis of age
- The review was concerned about poor care over the weekends and out of hours and the impact this had on quality of care and ability to come home to die
- There should be access to palliative care teams OOH and at weekends, this should be funded
- The public, press, clinical, public figures should be prepared to talk openly and honestly about dying, death and bereavement
- Communication between staff and relatives is key
- Clinicians should be required to demonstrate proficiency in care for the dying as part of their revalidation
- There is no Nursing and Midwifery Council (NMC) guidance for nurses caring for patients at EoL who are dying, this should be provided urgently
• Generic protocols such as the LCP are the wrong approach; the review recommends a series of guides and alerts supplemented by technical guidance specific to certain disease groups.
• The use of the LCP should be replaced over the next 6 – 12 months by an EoLC plan for each patient backed up by a condition-specific good practice guide.

Apart from phasing out the use of the LCP, these recommendations are entirely reasonable. In areas where the LCP has been implemented well, these recommendations are already adhered to. The diagnosis specific information needs to be developed.

In Leeds, the LTHT SPC team recommends the continued use of the LCP approach, as an individualised care plan, instituted by senior medical and nursing staff, fully discussed with patients, where possible, and carers; supported by on-going training and education for staff. If patients or their carers would prefer that the document isn’t used, care will be delivered according to the framework that supports good terminal care but without using the LCP itself. This is the advice until a national alternative is forthcoming.

In the community, all registered nurses can commence the LCP provided they have the knowledge and skills to make that clinical judgement. Multidisciplinary decision making is strongly encouraged and good communication with family and carers is essential.
5. Local context

5.1 Introduction
The recommendations resulting from this report need to be written within the context of other health and social care developments locally. Three linked areas are key: the integration agenda, the Leeds Care Record and the personalisation agenda. They are described in turn below.

5.2 The Integration agenda and gateway
In terms of adult care, Leeds is in the process of integrating a range of community services. It is planned that in time, GPs, hospitals, health workers and social care staff will be increasingly working side by side; sharing information and taking a more coordinated approach to the way services are delivered. It is planned that integrated working will help to eliminate duplicated processes across health and social care; reduce waste and bureaucracy by working as a combined unit, enable people in different parts of the city to have equal access to care and support, minimise delays in care, reduce the need to go into hospital and enable people to better manage their condition and live as independently as possible and improve the sense that services are “fragmented” by reducing the number of professionals that need to be involved in one person’s care.

The Transformation Board is delivering the Integrated Adult Health and Social Care work stream, overseen by a consultant geriatrician. There are now 12 integrated health and social care neighbourhood teams across Leeds that coordinate care and support around the needs of older people and those with long term conditions. They are focused on clusters of GP practices and their registered populations. The teams work closely with primary care using outputs from risk stratification to provide an opportunity for proactive input to prevent ill health and deteriorating health. It is planned that health and social care practitioners will become more generic with the aim that they will take a holistic assessment of the whole person, drawing on specialist support when required. The neighbourhoods are considered “building blocks” of the integrated care delivery model.

There is a plan to develop a “Gateway to services” which has been described as a single “way-in” for professionals who need to refer people for health or social care. Referrals would be assessed then directed to the right place. Staff can also use it when someone is about to be discharged from hospital to make sure any on-going services patients need are arranged before they go home.

5.3 The Leeds Care Record
Lack of interoperability of IT systems across organisations hinders integrated working. In Leeds, the “Leeds Care Record” is being developed. The Leeds Care Record is an IT project, being developed by informatics specialists in the city, funded by the Leeds CCGs. The aim of the Leeds Care Record is to ensure staff across Leeds have timely access to key information about patients across organisational boundaries, and is particularly intended to support the 12 integrated health and social care teams across the city. Currently patient / service user information remains within each organisation and each local system only holds information relevant to the service or treatment provided by that organisation. This leads to delays obtaining information when a patient accesses another service. The purpose of the Leeds Care Record is to ensure health and social care staff have the information they need at the point of care. This will be in the form of a single consolidated read only view of the patient / service users records that health and social care professional can access when the patient or service user is present. At the time of writing, the Leeds Care Record is in its initial phase, working with a few GPs, and LTHT. Longer term, more organisations will be involved. Local Care Direct out of hours services is not involved at this stage. Leeds Care Record complements rather than supersedes the EPaCCs system. One of the work streams is around EoLC to ensure the Leeds Care Record dovetails with EPaCCS. The Leeds Care
Record is one of the first to be developed nationally. The project is in phase one and hopes to be rolled out in two to three years.

5.4 The personalisation agenda

Personalisation is a social care approach described by the Department of Health as meaning that every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings. It is often associated with direct payments and personal budgets. It is also intended to describe the change services need to make to ensure they are tailored to the needs of individual service users, rather than delivering services in a “one-size-fits-all” way.

In Leeds, 18% of people who are eligible for social care support are in receipt of direct payments as part of their individual care budget. A pilot of individual health budgets is being run with 10 continuing health care patients currently with the whole system due to go live in April 2014.
6. Evidence

6.1 Introduction
This section includes evidence relating to good EoLC provision. Evidence has been collected both formally and informally. Leeds Community Healthcare Library Service conducted a formal literature review. A second more focused literature review was conducted by a Public Health Registrar looking at early identification, inequalities and preferred place of death. Evidence has also been collected informally, using twitter, professional networks and keeping up to date with relevant journals and publications. EoLC has been high on the agenda in the medical and popular press due to the LCP review and the questions this has raised. The EoLC agenda is vast and therefore this section focuses on key areas. This chapter also contains evidence on public perception of death and dying, cancer versus other causes of death, costs, patterns of use of health and social care, the concept of “circles of care”, EoLC services and BME communities.

6.2 Early identification
If a patient is within the last 12 months of their life, they should be on a palliative care register as a gateway to receiving coordinated EoLC services. The Murtagh (2013) research stated that 75% of deaths will require generalist palliative care.

There is some 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 2010).

It has been recognised that delivering good quality end of life care has benefits for patients in terms of better symptom control and adjustment to the disease process; to carers in terms of better support whilst caring and better adjustment once the role is relinquished; to the health service in terms of reduced admissions and shorter admissions; and to health practitioners in terms of providing them with better support (Currow et al. 2012).

Findings from 9 EPaCCS sites illustrated by the National EoLC Programme figure 1 below, shows the actual place of death for individuals who were identified as nearing EoL and cared for through the mechanism of a register died more often at home and less often at hospital than the national average.

Figure 1: Place of death, comparing EPaCCS sites with the England average

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Results: Place of death

- Sites with EPaCCS vs England average

![Chart showing place of death comparison](chart.png)
In 2010/11, in Leeds, 0.14% of the population were on an EoLC register. This compares with 0.17% in England. It is expected that prevalence rates for people on EoLC registers should be higher given that 1% of a GP practice population is likely to die on average each year as 75% of deaths require palliative care. In Leeds the death rate is 0.8%.

6.3 Inequalities

A study published in the Journal of Public Health Medicine (Higginson et al 1999) provided evidence that social factors are inversely correlated with home cancer deaths. The study examined data from all deaths registered from cancer between 1985 and 1994 (1.3 million deaths). The authors concluded there are wide variations in the percentage of cancer deaths at home in different electoral wards. Social factors are inversely correlated with home cancer death, and may explain part of this variation. Home care in deprived areas may be especially difficult to achieve. It is acknowledged that it costs more to treat people who live in deprived areas.

The London Regional Strategy Group for Palliative Care tried to quantify the difference in need and calculated that to achieve similar levels of home death rates between affluent and deprived areas, twice the resources are needed for deprived communities. Given that Leeds has a significantly higher proportion of the population living within the most deprived quintile this should be reflected in commissioning plans.

Grande et al 1998 undertook a review of the literature to investigate the factors that influence an individuals' place of death. They identified that higher socioeconomic groups were more likely to experience a home death compared to those individuals in lower socioeconomic groups. They attributed this to better support networks and access to support, the financial means to pay for additional private care services and greater effectiveness at accessing services available to cancer patients due to additional skills such as those afforded by greater educational achievement (Grande et al. 1998).

A retrospective study was undertaken looking for socioeconomic differences in health and care in the year before death (Cartwright 1992) and identified that a greater proportion of middle class individuals died in a residential or nursing home and were reported as having a better quality of life than their working class counterparts. However this research was published in 1991 based on data obtained in 1987, since which time the NHS, primary care and palliative care services have all evolved.

The National EoLC Intelligence Network (2012) has published facts around deprivation and death, gathered using ONS mortality data for all deaths between 2007 and 2009 and the Index of Multiple Deprivation (IMD 2007) by Lower Super Output area. The authors found that:

- Socioeconomic deprivation is a major determinant of where, when and how people die.
- People living in the most deprived quintile are more likely to die in hospital than people living in other quintiles.
- Death in care or nursing homes was less common among people living in the most deprived quintile.
- There are more deaths caused by smoking related cancer in people living in the most deprived quintile that the least quintile.
- There are fewer deaths from malignant melanoma, breast and prostate cancer in the most deprived quintile than any of the other quintiles.
- 27% of deaths in the most deprived quintile were people aged 85 and over compared with 35 – 40% in each of the other quintiles.
- There were twice as many deaths of people aged under 65 in the most deprived quintile as the least deprived quintile.
6.4 Preferred Place of Death

The headline target around EoLC is death in place of usual residence, or preferred place of death. It is important to step back and remember this is just one target. There are other indicators which measure what people value at the end of life. This has been described by Wood and Salter as "separating the where from the want". A recent report (Wood and Salter, 2013) based on a survey of 2,028 members of the public found that 78% of people interviewed wanted to be free from pain and discomfort, 71% wanted to be surrounded by loved ones, 53% wanted privacy and dignity and 45% wanted to be in familiar surroundings. 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, which may have a direct influence on their choices.

The study also found the PPD changed as people neared deaths, in the last year of life 85% of people stated a preference to die at home, this reduced to 67% in the last weeks if life and 44% in the last days of life. In the last year of life 11% of people stated a preference to die in a hospice, this rose to 30% in the last weeks of life and 55% in the last days of life.

Another study asked the general population (aged 16 and over) where they want to die, 63% want to die at home, 29% want to die in a hospice, 3% want to die in hospital, 1.5% want to die in a care home, 1% want to die in a friend’s home and 2.5% want to die elsewhere (PRISMA, 2010). These preferences change as people become aware they are nearing EoL. As reported by those approaching the end of life for people with an EPaCCS record, 47% of people chose to die at home, 29% chose to die in a care home, 33% chose to die in a hospice and 1% chose to die in hospital (National EoLC Intelligence Network 2012).

There is a difference in PPD between patients and carers. Gomes et al 2013 undertook a systematic review of the literature considering both malignant and non-malignant disease with the aim of exploring the preferences of patients, their caregivers and the general public in terms of place of care and place of death. The researchers also explored whether preference changed as the disease progressed. The preference for dying at home in the patient group ranged from 31%-87%, whereas in the caregiver group it ranged from 25%-64% (Gomes et al. 2013).

The most recent study undertaken in Adelaide, Australia suggested that patient preference for a home death dropped from 41% to 35% as the disease progressed (Gomes et al. 2013). They also undertook qualitative analysis where possible and identified that care givers often agree to provide the required care and support to a terminally ill individual without fully understanding the implications of this decision (Gomes et al. 2013).

6.5 Public perception of death and dying

An online survey commissioned by Dying Matters and led by the National Council for Palliative Care, surveyed 2,028 adults and 1,000 GPs. The survey found that discussing EoLC plans remains a taboo subject for most people in Britain with only 27% of respondents having asked a family member about their EoL wishes. Just 19% of the public have written a will, 31% have registered to become an organ donor and only 8% have written down their EoLC wishes. The survey also found that 35% of GPs have not initiated a discussion with a patient around their EoL wishes and that 71% of the public and 70% of GPs agree that people in Britain are uncomfortable discussing dying, death and bereavement. Most people surveyed could see the benefits of being more open to discussions about dying.

It is accepted that the lack of open conversations about dying and death make it harder to plan for a “good death”. Leadbeater and Garber (2010) state:
“Unless we can devise ways to get people to talk about how they want to live while they are dying, our efforts to improve services will be like groping in the dark”.

There is movement led by the Dying Matters Coalition. Their aim is

“to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make ‘living and dying well’ the norm”.

They state this will involve a fundamental change in society in which dying, death and bereavement will be seen and accepted as the natural part of everybody's life cycle. They state changes in the way society views dying and death has impacted on the experience of people who are dying and bereaved. Our lack of openness has affected the quality and range of support and care services available to patients and families. It has also affected our ability to die where or how we would wish.

Literature on the Dying Matters website recognises that

“it's not always easy to know how to talk about dying. Awkwardness, embarrassment and fear means people tend to shy away from connecting with those who are dying or those who are grieving. But when we don't talk about what matters it can increase feelings of isolation, loneliness and distress.”

A Palliative Medicine Consultant interviewed as part of the comparative HNA challenged this view, his personal experience is that patients do want to talk about death and dying and that Medics don’t.

6.6 Health promoting palliative care

There is discussion in the literature around “health promoting palliative care”. Health promoting palliative care was first developed by Alan Kelleher in Australia in the 1990s who argued that EoLC is being professionalised and communities are becoming disempowered to the point where there is an expectation that people who are terminally ill need professionals to deliver their care. Health promoting palliative care is focuses firstly on engaging communities in discussions around death and dying and secondly increasing capacity of communities to look after people who are dying themselves.

Abel et al (2013) argue that specialist palliative care, within hospices in particular, has historically led and set the standard for caring for patients at end of life. The focus of this care has been mostly for patients with cancer. More recently, health and social care services have been developing equality of care for all patients approaching end of life. This has mostly been done in the context of a service delivery approach to care whereby services have become increasingly expert in identifying health and social care need and meeting this need with professional services. The authors propose that instead care should be planned using a model of care which identifies a person with an illness at the centre of a network which includes inner and outer networks, communities and service delivery organisations. All of these are underpinned by policy development, supporting the overall structure. Adoption of this model would allow individuals, communities, service delivery organisations and policy makers to work together to provide end of life care that enhances value and meaning for people at end of life, both patients and communities alike.

A recent study has been published which looked at “public health approaches” to palliative care (Paul and Sallnow, 2013). The authors developed an online survey which was sent to 220 palliative care providers across the UK. They define a public health approach as engaging communities in their own care and discussing approaches that work to promote public openness about death, dying and loss and approaches that focus on empowering people, families and communities to draw on their own networks and community support to
adapt and cope with death. The survey found the most common project was working with schools, followed by engaging with local media. Other examples include public education and awareness events, attending community events, supporting community dialogue about EoL issues and working with faith groups around loss, death, dying and hospice care.

6.7 Cancer v deaths from other causes
We know that in Leeds 84% of patients using hospice services have a cancer diagnosis and that in Leeds in 2011 28% of people aged 65 and over died of cancer. National data show that the proportion of deaths that occur in hospital varies by disease group. In 2010:

- 73% of liver disease deaths
- 65% of respiratory disease deaths
- 57% of cardiovascular deaths
- 50% of renal disease deaths
- 50% of deaths from external causes
- 42% of neurodegenerative disease deaths
- 41% of cancer deaths and
- 25% of deaths from Alzheimer’s disease, dementia or senility occurred in hospital. (NEoLCIN, 2012)

6.8 Costs
The palliative care funding review said there is a “stunning lack of data” around EoLC costs. The NEoLIN published PCT spend per death and these vary wildly with no formula given for how they were calculated.

Marie Curie report the cost of inpatient palliative care for adults per day as £425 and for palliative care in the community per day as £145 based on research conducted by the University of Kent (2010). Marie Curie (2012) has published other costs, listed in table 1 below, although they acknowledge the palliative care funding review will strengthen the evidence base around these costs.

Table 1: Marie Curie estimates of EoLC costs

<table>
<thead>
<tr>
<th>Service</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>District nursing (per contact)</td>
<td>£39</td>
</tr>
<tr>
<td>Community nursing (8 hours)</td>
<td>£246</td>
</tr>
<tr>
<td>Social care (per day)</td>
<td>£27</td>
</tr>
<tr>
<td>Community Nurse Specialist (per hour)</td>
<td>£77</td>
</tr>
<tr>
<td>Outpatient attendance</td>
<td>£194</td>
</tr>
<tr>
<td>Hospital inpatient SPC (per day)</td>
<td>£425</td>
</tr>
<tr>
<td>GP visit (per hour)</td>
<td>£60</td>
</tr>
<tr>
<td>Other health and social care professionals (per hour)</td>
<td>£30</td>
</tr>
<tr>
<td>Marie Curie Nurse (per hour)</td>
<td>£20</td>
</tr>
<tr>
<td>Drugs and equipment loans (per week)</td>
<td>£120</td>
</tr>
</tbody>
</table>

Source: Marie Curie, 2012

A recent literature review looked at international evidence available on the costs and cost effectiveness of palliative care interventions in any setting, between 2002 and 2011 and found that palliative care is most frequently found to be less costly relative to comparator groups (usual care at home or in hospitals) and in most cases the difference in cost is statistically significant (Smith et al 2013).

An economic evaluation of EPaCCS found that EPaCCS was enabling an extra 90 people “per locality” a year to die in their usual place of residence amounting to a saving of nearly £36,000 per 200,000 population, or £133,200 when taking into account reduced hospital
admissions. If EPaCCS was embedded in all Leeds GP practices this would equate to a saving of approximately half a million pounds.

6.9 Patterns of use of health and social care at EoL
The Nuffield Trust recently created and analysed a large health and social care dataset to describe the uptake of key health and social care services for people in the last 12 months of life. They looked at 16,000 patients who died in three English local authority areas, linking their hospital and social care records. They found:

- In England, social care is a significant part of care for people in the last 12 months of life with local authority funded care being awarded to 27.8% of people who died.
- 14.9% of all people who died had some residential or nursing care service in the last year of life.
- There was considerable variation in the use of social care between local authorities.
- More people used hospital care than social care in the last year of life (86.6% compared to 27.87%).
- Where people did use social services, the average local authority social care costs exceeded hospital costs per patient (£12,559 v £7,415).
- Individuals in the last 12 months if life were significantly more likely to use social care than similar individuals in the general population.
- Social care needs were apparent well before the EoL. Hospital costs show a sharp increase in the final few months, social care costs rose gradually up until death.
- Individuals with the highest social care costs had relatively low average hospital costs, the use of social care may prevent the need for hospital care.
- There were significant differences in usage between individuals with different diagnoses. Usage levels were highest for people with dementia, falls and cerebrovascular disease and lowest for people with cancer.
- The least deprived groups within the population used less local authority funded care, which would be expected because of means testing. (Georghiou et al 2012)

6.10 EoLC services uptake by black, Asian and ethnic minority (BAME) communities
There is evidence that individuals from minority ethnic groups are underrepresented in the use of EoLC services. A recent literature review (Evans et al, 2011) was undertaken. The authors concluded that there are complex and interrelated factors which lead to low service use by BAME communities.

Calanzani et al (2013) recently published a report, looking at palliative and EoLC for black, Asian and minority ethnic groups in the UK. They stated that inequalities still exist in the care that different groups of people receive at the end of life. The authors identified 45 literature reviews describing unmet needs and disparities in palliative and EoLC for BAME groups. The authors summarised unmet needs which included:

- Lower uptake compared to majority groups
- Lack of referrals
- Lack of knowledge of services (patients and professionals)
- Lack of knowledge about what hospice care involved
- Information not available in different languages / formats
- Lack of cultural equivalents for words such as hospice
- Religious and family issues; hospice care conflicting with religion (giving up faith in God’s power)
- Avoidance of open disclosure due to religious / family values
- Assumptions from patients (care not accessible)
- Assumptions from care providers (family will provide care)
- Previous negative care experiences; racism, insensitivity, lack of cultural awareness
- Geographical location of hospices
- Socioeconomic factors
- BAME groups currently younger than white majority population
- Lower prevalence of certain types of cancer and higher prevalence of chronic conditions
- Poor communication; lack of translation resources and advocates, problems with using family and friends as translators, low number of minority doctors
- Less likely to complete ACP, more likely to desire life-sustaining / aggressive treatments
- Mistrust from patients
- Influence of religion (God will decide)
- Western values of autonomy not applicable to everyone and contrast with family / community decision-making
- Worse pain outcomes
- Insufficient availability of opioid medication
- Pain severity underestimated
- Less likely to die at home
- Less satisfied with care
7. Epidemiology: past, present and future

7.1 Introduction
This chapter includes information about the demographics of Leeds, data from the National EoLC Intelligence Network comparing key datasets between Leeds and the English average, the latest data describing deaths in Leeds, projected deaths in Leeds, information about past performance and concludes with a discussion on the options to measure performance around EoLC services in Leeds.

7.2 Leeds demographics
Figure 2 below shows a map of Leeds. The black line is the boundary of the city. The areas shaded orange highlight the 20% of Leeds that falls within the 10% most deprived areas nationally.

Figure 2: Map of Leeds showing the areas which fall into the 10% most deprived nationally

The 2011 census (second release) records the population of Leeds as 751,485. This figure has been disputed and the number of people in Leeds registered with a Leeds GP is 813,654. Throughout the HNA it is clear which population count has been used as this effects calculations made.

The 2011 census shows that:
- 49% of the population are male and 51% are female
- 14.6% are aged 65 years and over
- 81.1% of the population is White British and 18.9% is made up of other ethnic groups.
- 4.5% of people live in households where no one has English as a main language.
- 4.2% of people self-report that they have bad health, 1.2% report they have very bad health.
- 6.1% of people provide between 0 and 19 hours of unpaid care a week, 1.4% provide between 20 and 49 hours and 2.2% provide 50 hours or more.
- 21.3% of households are people who live alone (68,413 people), 12% of households are made up of people who live alone are aged 65 years plus (38,312 people).

### 7.3 Comparing Leeds with England

The National End of Life Intelligence Network (NEoLCIN) produces key data sets around EoLC. Table 2 below shows key facts for Leeds, compared to the English average. The data used was ONS data 2008 – 2011 averaged. Cause of death does not add up to 100% because mortality records contain contributory causes of death as well, and the National EoLC Intelligence Network also included data where there were mentions of liver disease, renal disease and dementia.

Table 2: Key EoLC facts comparing Leeds with the England average

<table>
<thead>
<tr>
<th>Domain</th>
<th>Indicator</th>
<th>Number</th>
<th>Leeds PCT</th>
<th>England average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths</td>
<td>Crude death rate</td>
<td>6,452</td>
<td>0.8%</td>
<td>0.9%</td>
</tr>
<tr>
<td></td>
<td>Deaths aged 75+</td>
<td>4,206</td>
<td>65.2%</td>
<td>66.7%</td>
</tr>
<tr>
<td></td>
<td>Deaths aged 85+</td>
<td>2,150</td>
<td>33.3%</td>
<td>36.2%</td>
</tr>
<tr>
<td>Place of death</td>
<td>Hospital</td>
<td>3,440</td>
<td>53.3%</td>
<td>54.5%</td>
</tr>
<tr>
<td></td>
<td>Own home</td>
<td>1,268</td>
<td>19.7%</td>
<td>20.3%</td>
</tr>
<tr>
<td></td>
<td>Hospice</td>
<td>582</td>
<td>9.0%</td>
<td>5.2%</td>
</tr>
<tr>
<td></td>
<td>Care home</td>
<td>1,044</td>
<td>16.2%</td>
<td>17.8%</td>
</tr>
<tr>
<td>Cause of death</td>
<td>Respiratory deaths (underlying cause)</td>
<td>883</td>
<td>13.7%</td>
<td>13.8%</td>
</tr>
<tr>
<td></td>
<td>Respiratory deaths (mentions)</td>
<td>2,148</td>
<td>33.3%</td>
<td>34.2%</td>
</tr>
<tr>
<td></td>
<td>Cancer (underlying cause)</td>
<td>1,820</td>
<td>28.2%</td>
<td>27.7%</td>
</tr>
<tr>
<td></td>
<td>CVD (underlying cause)</td>
<td>1,892</td>
<td>29.3%</td>
<td>29.6%</td>
</tr>
<tr>
<td></td>
<td>Liver disease (mentions)</td>
<td>260</td>
<td>4.0%</td>
<td>3.8%</td>
</tr>
<tr>
<td></td>
<td>Renal disease (mentions)</td>
<td>361</td>
<td>5.6%</td>
<td>5.8%</td>
</tr>
<tr>
<td></td>
<td>Alzheimer’s, dementia, senility (mentions)</td>
<td>1,012</td>
<td>15.7%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Death in hospital</td>
<td>Terminal admissions that are emergencies</td>
<td>2,757</td>
<td>92.2%</td>
<td>89.7%</td>
</tr>
<tr>
<td></td>
<td>Terminal admissions aged 85+</td>
<td>1,085</td>
<td>36.3%</td>
<td>37.8%</td>
</tr>
<tr>
<td></td>
<td>Terminal admissions that are 8 days or longer</td>
<td>1,449</td>
<td>48.5%</td>
<td>48.6%</td>
</tr>
<tr>
<td></td>
<td>Average number of bed days per admission ending in death</td>
<td>39,685</td>
<td>13.3%</td>
<td>12.9%</td>
</tr>
<tr>
<td>EoLC care spend</td>
<td>Total spend on hospice services per death (£)</td>
<td>4,423,000</td>
<td>£686</td>
<td>£525</td>
</tr>
<tr>
<td></td>
<td>Total spend on EoLC care per death (£)</td>
<td>11,469,000</td>
<td>£1,841</td>
<td>£1,096</td>
</tr>
</tbody>
</table>

The NEoLCIN data above show that in Leeds the populations aged 75+ and 85+ are statistically significantly lower than the national average. This would suggest the age structure of Leeds is younger. Significantly more people live in urban settlements and the most deprived quintile. The crude death rate for Leeds is lower than the national average. An explanation for this could be that Leeds has a younger age structure than average. Death rates for people aged 75+ and 85+ are also significantly lower than average. A significantly higher proportion of people die in hospices than the national average.
Significantly lower proportion of people die in care homes. The differences between Leeds and the national average are insignificant for deaths at home and in hospital, however, the percentages of people who are terminally ill and admitted as an emergency is significantly higher. The causes of deaths are not significantly different between Leeds and the national average, apart from deaths which mention Alzheimer’s, dementia or senility, which are significantly lower in Leeds.

7.4 Deaths in Leeds: current, past and projected

In order to gain a more accurate and up to date understanding of deaths in Leeds, the 2011 Office for National Statistics (ONS) data for Leeds were analysed. Place of death and cause of death were analysed, looking at 2011 and back to 2007. The data source is the ONS, which is the most complete data source available around deaths as it is collated from death certificates which are a legal requirement for all deaths. However, information about cause of death can be unreliable as the person verifying death and completing the death certificate may not have access to the patient’s complete medical records, for example, if people die in an acute hospital they don’t have access to mental health trust notes so may never know someone had dementia. Prevalence of dementia of people in their 80s is 27% and in their 90s is 40%; this is likely to be underrepresented in death data (Crowther, 2013).

7.4.1 Current and past

Figure 3 below shows the percentage of people in Leeds who have died in hospital each year from 2007 – 2011. The denominator is all residents aged over 18 years in Leeds, registered with a Leeds GP. The numerator is deaths in any hospital of Leeds residents registered with a Leeds GP. This includes all LTHT hospitals (St. James, LGI, Seacroft, Cookridge, and Wharfedale) as well as hospitals in neighbouring areas that Leeds residents use; this includes Pinderfields, Harrogate District, Bradford Royal Infirmary and other general hospitals. Deaths outside of LTHT hospitals account for approximately 10% of hospital deaths. Therefore this is the most conservative calculation possible for measuring deaths in hospital. This was checked rigorously as the percentage of deaths in hospital for 2011 was low compared with the usually quoted percentage of 53% from the National EoL Intelligence Network data (derived from the 2008 – 10 ONS data). In Leeds, in 2011, only 48% of people aged 18 and over died in hospital, reducing from 50.2% in 2007 (see figure 3 below). Discussions have been held between the Leeds Public Health Intelligence Manager and the Principal Cancer Analyst and End of Life Care Intelligence Lead who prepares the national data set to understand the different percentages calculated. The national lead explained that community establishment codes can change over time in the ONS data and this may cause differences which can be attributed to statistical artifact. In addition, the Leeds data is for people aged over 18, the national data includes all deaths. Using the Leeds ONS data including all deaths (that is deaths of people aged 18 years and younger as well) the percentage of deaths in hospital between 2007 and 2011 are: 50.5, 50.9, 50.6, 50.2 and 48.1. Therefore that does not fully explain the differences, however in Leeds we are certain our data sources and calculations are accurate and have recorded in full how these percentages have been calculated and are confident the analysis is robust and results are valid. The national data is still included in this report as it is useful to compare Leeds to the national average, and to other comparator areas. However, the timeliness of measuring deaths in hospital can be further improved and this is discussed later in this chapter.
Further detail on place of death is provided in the stacked bar chart illustrated in figure 4 below which shows the proportion of people who died at home, elsewhere, other communal establishment, care home, hospice or hospital. “Other communal establishments” includes boarding schools, hostels, prisons and psychiatric units. There is no formal definition provided for “Elsewhere”, however this can include deaths in the street, in ambulances etc. These data show that in Leeds, between 2007 – 11: deaths in hospital have reduced from 50 to 48%, deaths at home have increased from 19 to 21%, care home has increased 15 to 17% and hospice has fallen from 10 – 9%.

Turning to cause of death, the ONS data 2007 – 11 was analysed to explore cause of death. This was done using ICD10 codes. The most common causes of deaths were included in the three chapters, malignant neoplasms (cancer), circulatory disease and respiratory disease. The next largest folder was “mental and behavioral disorders”; the majority of deaths in this folder were coded as dementia. All remaining folders were searched and a large number of dementia codes were found in the folder “diseases of the nervous system”. Advice was taken from George Crowther, a Speciality Registrar with an interest in palliative care and dementia. Dr. Crowther agreed which ICD10 codes could be considered deaths from dementia. The dementia deaths from the “mental and behavioral disorder” and “diseases of the nervous system” chapters together showed that dementia was the fourth most common cause of death for people in Leeds aged 65 and above.
Figures 5 and 6 below show cause of death, from ONS data 2007 – 11 grouped by people who died 18 – 64 years and 65 years plus, presented by percentages of all deaths and crude numbers of deaths.

These data show the three leading causes of death for adults under 65 years of age have been cancer, circulatory disease and respiratory disease. Deaths from dementia are included separately to “other” deaths, to enable comparison with deaths over 65. The data below show that for people aged 65+ the leading cause of death has been circulatory disease, followed by cancer, respiratory disease, dementia then other causes.

When these data are presented as percentages, it is possible to calculate trends. Figure 7 below plots the same data using percentages in place of numbers. It is interesting to note that between 2007 – 2011 deaths for cancer, respiratory and other diseases remain relatively stable, but deaths from dementia have risen 5% and deaths from CVD have reduced by 4%. This may be a recording issue or a true representation of change in cause of death.
7.4.2 Projections

Projections have been made by age group and by illness for deaths in Leeds. These are crude projections and aren’t adjusted to take into account likely changes in the proportions of disease burden (i.e. as smoking rates drop, lung cancer rates are likely to be lower in the future). Figure 8 below shows projected deaths for all people aged 18 plus in Leeds until 2031. This is calculated using ONS projections.

Figure 9 below shows projected deaths in Leeds for the diseases which are currently the most common cause of death. These projections are derived by applying 2011 mortality rates by age band to ONS population projections by age band. As such they account for the increase in proportion of people in oldest age bands, but as previously explained assume mortality rates in each age band will remain unchanged.
Figure 10 below shows projected changes in Leeds population deaths by underlying cause for people aged 65 and over.

![Projected changes in Leeds population deaths by underlying cause, all ages](chart1)

<table>
<thead>
<tr>
<th>Year</th>
<th>Cancer</th>
<th>Circulatory</th>
<th>Respiratory</th>
<th>Dementia</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>1,836</td>
<td>1,798</td>
<td>874</td>
<td>492</td>
<td>1,359</td>
</tr>
<tr>
<td>2021</td>
<td>1,989</td>
<td>1,948</td>
<td>947</td>
<td>534</td>
<td>1,473</td>
</tr>
<tr>
<td>2031</td>
<td>2,132</td>
<td>2,086</td>
<td>1,015</td>
<td>572</td>
<td>1,576</td>
</tr>
</tbody>
</table>

Figure 11 below projects the number of cancer and non-cancer deaths in Leeds expected for people aged 65+ over the next 20 years.

![Projected changes in Leeds population deaths by underlying cause cancer/non-cancer, all ages](chart2)

<table>
<thead>
<tr>
<th>Year</th>
<th>Cancer</th>
<th>Non-Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>1,836</td>
<td>4,523</td>
</tr>
<tr>
<td>2021</td>
<td>1,989</td>
<td>4,902</td>
</tr>
<tr>
<td>2031</td>
<td>2,132</td>
<td>5,249</td>
</tr>
</tbody>
</table>
7.7 Inequality
Data is available for Leeds from the National End of Life Care Intelligence Network which can be used to compare place of death with deprivation. Figure 12 below shows place of death (hospital, home, care home or hospice) against deprivation deciles. The data appear to show that:

- A higher proportion of people living in the poorest areas of Leeds (deciles 1 – 6) die in hospital than those living in the more affluent areas of Leeds (deciles 7 – 10).
- More people from affluent areas (deciles 5 – 10) appear to die in care homes than in less affluent areas (deciles 1 – 4).
- More people from affluent areas appear to die in hospices (deciles 8 – 10) than the majority of other deciles.
- There does not appear to be a gradient or pattern to percentages of people dying at home across the deprivation deciles.

![Percentage of deaths by place of death and Leeds deprivation deciles](image)

In addition people who live in the most deprived areas of Leeds die earlier than those in less deprived areas.

Life expectancy and healthy life expectancy vary according to socioeconomic status. In Leeds a man aged 65 living in the most deprived fifth of the population could expect to live another 15.7 years (until they are 80.7 years old) compared with a man aged 65 living in the most affluent fifth of the population who could expect to live another 19.9 years (until they are 84.9 years old).

People living in the most deprived areas will live a greater proportion of these years in poor health. ONS statistics show that nationally a man aged 65 living in the most affluent fifth of the population would live a further 19.6 years, with 12.6 of these in good health, meaning they will live until they are 84.6 years, and until they are 77.6 years old they will be in good health. A man aged 65 living in the poorest fifth of the population will live an additional 15.5 years, 7.2 of these in good death. This means they will live until they are 77.6 but will have been in poor health from age 72.2.
7.8 Palliative Care Registers
Early identification of a patient who is reaching the end of their life is important. The Yorkshire and Humber Quality Observatory has recently published an End of Life Supporting Benchmarking Tool (Wood, 2012). As previously mentioned, in 2010/11, Leeds, 0.14% of patients are on an End of Life Care register.

7.9 Metrics
There are a number of metrics that can be used to performance manage EoLC. They can be simple to conceive and complex to administer, due to the limitations of various data sources. All data sources measure different footprints, over different time spans, and are calculated slightly differently.

ONS is the best source in terms of completeness but there is a long time lag and so its usefulness in terms of performance managing the impact of EoLC commissioning decisions is limited. There is a Primary Care Mortality Database, which has a time lag of only two months. This includes everyone who has died. There are issues with data quality as there are duplicate records, and there are issues with confidentiality and access as it includes patient identifiable information. This database is held by the Health and Social Care Information Centre. Currently commissioners and the Public Health Intelligence team are unable to access this data due to confidentiality issues. There is Secondary User Service data, which has a 10 week time lag and includes hospital activity data from inpatients, outpatients and Accident and Emergency Units. It is used for contracting purposes by the CCGs. It includes deaths, but only of people who died in hospital. The two other data sets are primary care data, and Leeds Community Healthcare data. LCH data is only held for patients who use LCH services. GP data is held for all patients who have accessed primary care. This data is live.

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 (LCC), Alistair Cartwright (CCGs), and Martel Henry (CSU)).

The primary care data is live and includes data such as:

- % 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.

Deaths in Usual Place of Residence (DiUPR) is considered the main marker of success for the DH EoLC strategy as well as the first Key Performance Indicator for the EoLC QIPP work stream (DH, 2011).

All metrics would need to be triangulated by qualitative data measuring patient experience.

The results from the annual VOICES survey are a valid and useful data source and should be incorporated into local performance management structures. The DH (2009) paper “Quality Markers and Measures for EoLC” also recommends the development of local Patient Reported Outcome Measures (PROMs) for EoLC. The PROM should measure that:

- Pain and other symptoms should be controlled effectively
- The individual, carers and family should feel well supported
- 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
8. Projected need for services

8.1 Introduction
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 is contradictory and most is out of date and based on models of cancer care. Some academics base need on epidemiology, however the majority describe needs based on health service usage. This is not entirely helpful as it will miss unmet need and may include demand (as opposed to need). This chapter describes needs in relation to EoLC and applies different methods of calculating population need to the Leeds data.

8.2 What is need?
Need has been defined in health care terms as the ability to benefit from a service or intervention. People with different diagnoses experience similarities and differences in how they die. People with different diseases have different trajectories towards death. Murray and Sheik (2008) have described how people with different diagnosis die. Figure 13 below illustrates that people with cancer have high function until they are close to death. People with organ failure or physical and cognitive frailty have a gentler decline, with a number of dips in frailty which makes identifying the dying stage more complex for health and social care professionals.

Figure 13: Function nearing death for patients with cancer, organ failure and physical and cognitive frailty (reproduced with permission from the BMJ).

Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

However, in terms of symptoms, their experiences can be more similar. Solano et al (2006) compared symptom prevalence in people dying from cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. Their purpose was to explore symptom management needs of patients with life threatening diseases other than cancer. The
authors undertook a systematic review and identified 11 symptoms commonly experienced by patients reaching the end of their lives. These are: pain, depression, anxiety, confusion, fatigue, breathlessness, insomnia, nausea, constipation, diarrhoea and anorexia. Three symptoms were experienced amongst at least 50% of all patients – pain, breathlessness and fatigue. Authors concluded there appears to be a common pathway toward death for malignant and non-malignant diseases and therefore palliative care is relevant for people with all 5 conditions they examined.

8.3 Headlines
Turning to headline needs, a recent study (Murtagh et al 2013) compared methods for population based estimates. The study found differences in need based on different methods of assessing need. Using a cause of death / symptom method, Higginson (1997) estimates that 60.28% of all deaths need palliative care. Using the International Statistical Classification of Diseases and Related Health Problems, Rosenwax (2005) estimated 37.01 – 96.61% of deaths require palliative care. Using % of deaths plus chronic disease data, Gomez-Baptise (2012) estimates that 75% of deaths need palliative care. Murtagh et al concluded that death registration data using both underlying and contributory cases can give reliable estimates of population based need to palliative care without needing symptom or hospital activity data, and in high income countries 69 – 82% of those who die need palliative care. In Leeds there were 6,302 deaths in people aged 18 plus in 2011 (ONS), which means 4,348 – 5,168 of these deaths would require palliative care. Based on the above, a sensible estimate for Leeds is that 75% of deaths will require palliative care.

8.4 Specifics
In terms of need for specific services, the research is less clear. This HNA draws on 3 research papers and applies their findings to Leeds. These are:

- Franks et al 2000. Franks et al undertook a systematic review of the literature around the need for palliative care and made conclusions based on reviewing 78 articles between 1978 and 1999, a period where different service models were used.
- Tebbit, 2004. Need identified by Tebbit was relational, based on comparing services provided in different areas to the national average.
- Champan and Lennon, 2010 models day care for patients dying of cancer only based on service usage. Day care could include social activities, medical assessment, outpatient clinics, physiotherapy, occupational therapy, focused symptom management interventions, a range of complementary therapies, lymphedema services, art therapy or activities, music therapy, carer support and bereavement support.

8.4.1 Specialist palliative care beds
Franks et al (2000) proposed 40 – 50 specialist palliative care beds are needed per million population. Tebbit (2004) recommended 78 beds per million population, 52 for cancer and 26 for non-cancer. Given the high percentage of deaths from non-malignant causes, this figure could be questioned from an epidemiological perspective. However if we use the figure of 813,654 (number of people registered with a Leeds GP) this calculates the needs for palliative care beds as between 32.6 and 40.7 (Franks et al) and 63.5 (Tebbit). Combining these estimates, average number of beds needed is estimated at 48.5 beds. Leeds compares favourably as there are currently 50 hospice based specialist palliative care beds.

However the issue of hospice beds for “the simply dying” has been raised by professionals in this HNA in order to meet preferred place of care wishes. This would also meet the need of the increasing number of people who live alone. Calanzani et al (2013) published a report exploring future needs for hospice care. They note that the profile of death and dying has changed since the hospice movement started. People are more likely to die older and with
co-morbidities. Calazani et al point out that people with non-malignant conditions and those aged 85 and above are less likely to die at home or in an inpatient hospice bed. They recommend that to meet demand, increasing the availability of hospice beds and diversifying hospice care provision is required.

8.4.2 Specialist palliative community care
Tebbit gives figures for staffing levels required for community palliative care provision. He suggests per million population, 2 Consultants in palliative medicine, 23 community nurse specialists and 0.8 social workers are required. In Leeds this translates to 1.6 consultants in palliative medicine, 18.8 community nurse specialists and 0.7 social workers. In Leeds there are 4.5 hospice based palliative care consultants, 2 of whom work predominately in the community. The definition of community nurse specialists and social worker are unclear. In Leeds there are 18.4 hospice based community nurse specialists. There are 9 local authority social workers who are specialists in Oncologe based in the Bexley Wing at LTHT.

8.4.3 Specialist palliative care in the hospital setting
No literature was found quantifying need for hospital based SPC. In LTHT 25% of SPC work is for residents outside Leeds as it is a tertiary centre. It can be anticipated that patients will continue to be admitted in the last year of life, needing SPC and many will die in hospital.

8.4.4 Specialist palliative care day services
Chapman and Lennon (2010) state that in England in 1999 there were on average 13,000 day care places for cancer patients available per million population per year, equivalent to 300 places per week per million population. This calculates as 245 places per week for cancer patients in Leeds. It is unclear how to quantify day care available in Leeds. St. Gemma’s provided 1,393 days day care last year and Wheatfields provided 1,106. This equates to 48 places a week which suggest Leeds is underprovided. However both St. Gemma's and Wheatfields report they are managing demand and waiting lists for day care services well and do not report any issues with need.

8.5 Conclusion
The research on specific need provides an interesting benchmark, but that is all it is.

One paper suggests the need is far higher for cancer patients, one only considers cancer patients. Deaths in Leeds of people aged 65 and over from cancer are predicted to rise from 1,448 (2011) to 1,615. Deaths of people age 65 and over from non-cancer causes are predicted to rise from 3,815 – 4,435 in the same timescale.

No papers discuss the impact of providing services for patients living in areas of high deprivation. The London Regional Strategy Group estimates it takes twice the resources to support people living in the most deprived communities to die at home (Higginson, 2001). In Leeds 20% of the population live in areas which rank as the 10% most deprived nationally.

The Murtagh et al paper (2013) is based on epidemiology rather than service usage and therefore is the only reliable source to be able to predict need. Murtagh et al estimates that on average 75% of deaths require palliative care, this equates to 4,763 adult deaths in Leeds 2011 and a crude estimate of 5,325 adult deaths in Leeds in 2021 (based on the ONS prediction of an 11.8% increase in population). The paper does not break down what types of care are needed. The quantity of need can be predicted by applying the Murtagh figure of 75% to the predicted number of deaths. The type of need will have to be ascertained using data included in the comparative and corporate sections of this HNA.
9. Existing services in Leeds and perspectives of staff

9.1 Introduction
End of Life Care services in Leeds are provided by a range of organisations and individuals. These can be grouped into three overlapping categories, specialist palliative care, palliative care provided by generalists or specialists in other areas and primary care (see figure 14 below). These services are underpinned by support provided by family, friends and the broader community.

Figure 14: Categories of EoLC provision

The majority of specialist palliative care in Leeds is provided by LTHT SPC team, St. Gemma’s Hospice, Sue Ryder Wheatfields Hospice and Martin House (teenage and young adult unit), with a smaller input from 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 district nursing teams, specialist community nurses (e.g. heart failure and COPD), community matrons, care home staff, the mental health trust, the intermediate care team, adult social care, domiciliary care provided by the independent sector, sheltered housing and ward staff in LTHT. 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. Primary care has been defined as GPs, pharmacists and Local Care Direct.

9.2 Methods
Participants at the stakeholder workshop in March suggested a list of people who should be contacted to gather views to inform the HNA. This list was worked through and between May – July fifty-seven people were interviewed (full list in appendix 6), four consultants provided written responses to the workshop report and four surveys were conducted (sent to GPs, Care Home Managers, Sheltered Housing Wardens and District Nurses). Colleagues were interviewed based on a flexible semi-structured interview schedule which contained questions asking what service they provide, its strengths and weaknesses; any issues or concerns they are aware of and what they are developing currently. Notes were made during the interviews, and were emailed to interviewees for amendments and additions.

LTHT employees were invited via the staff newsletter to input, however only one response was received. Time slots were made for ward sisters to telephone to be interviewed anonymously; one member of staff took this offer up. Service usage data were collected from St. Gemma’s and Wheatfields hospices and plotted on maps of Leeds. Data were gathered from surrounding hospices (Marie Curie Bradford, Wakefield and Saint Michael’s
Harrogate) and were also plotted on a map of Leeds. Interview findings were evidenced where possible with additional data sources e.g. incident reporting and external surveys.

The interview notes and qualitative aspects of survey responses were analysed using thematic analysis. Two researchers separately looked for emerging themes, compared themes and developed a coding framework. Responses were allocated to these codes. Closer systematic analysis of the interview and survey data against these codes enabled them to be refined and ranked in order of importance in terms of frequency of comments.

This chapter describes specialist, generalist and primary care palliative care services in Leeds and includes results from research conducted to gather the views of colleagues working to deliver these services.

9.3 Services
In 2011 – 12, NHS Leeds commissioned services from:
- LCH: early supported discharge service, care home facilitator and “GSF” facilitator, Complex and Palliative Continuing Care Services
- LTHT: specialist palliative care, discharge facilitator post and EPaCCS
- St. Gemma’s and Wheatfields hospices
- An education strategy
- Pharmacy services: from LTHT, Lloyds and Air Products
- LYPFT services: liaison psychiatrist
- YAS: one palliative care ambulances (two from April 2013)
- Independent sector care homes and domiciliary care

This budget and responsibility for commissioning effective EoLC services now lies with the three Leeds CCGs. However, as previously stated, palliative care in Leeds is provided by a broader range of carers and providers than those funded by the CCG EoLC monies; ranging from friends and family, non-NHS funded hospice provision, generalist GP and district and ward nursing care, Marie Curie nurses, Macmillan information and support staff, Specialist Community Nurses, Community Matrons, Adult Social Care, Sheltered Housing Wardens, Care Home staff and Local Care Direct.

Adult SPC services in Leeds are provided by Wheatfields, St. Gemma’s and LTHT SPC team. All three services work to the same eligibility criteria (in appendix 7) and operate a combined consultant rota for OOH medical cover. This provides 24/7 senior medical advice to hospital, hospices and community. Collaborative working over many years has led to nationally recognised service developments and research.

9.3.1 LTHT
Leeds Teaching Hospitals is one of the biggest NHS trusts in the country and offers a range of specialist and general hospital services. There are approximately 3,000 deaths in LTHT per year. LTHT is spread over a number of sites including: Leeds General Infirmary, St. James’s Hospital, Chapel Allerton Hospital and Wharfedale. Patients registered with a Leeds GP also use Mid Yorks, Bradford, Harrogate, York and Airedale hospitals. LTHT includes the St. James’s Institute of Oncology in the Bexley Wing, which is a regional specialist centre serving the Yorkshire and Humber region.

Within LTHT there is a Specialist Palliative Care (SPC) team based in the Robert Ogden Macmillan Centre. The team works from 8am to 4.30 pm Monday - Friday and the SPC consultants staff the citywide on-call rota. The team is made up of:
- 7.6 whole time equivalent clinical nurse specialists (including an education lead)
- 2 EoLC facilitators
- 1 social worker
- 1 part time pharmacist (0.4)
- 1 discharge facilitator
- Registrars on rotation
- 1.2 WTE specialty grade doctors
- 2.7 WTE consultants

The service is advisory and takes referrals from anywhere in the trust who meet the Leeds eligibility criteria for access to adult specialist palliative care (see appendix 7). The team can provide advice about symptom management, psychological support and assess suitability for hospice and discharge planning. There are approximately forty patients on the caseload at any time. Approximately 15% are people with a non-cancer diagnosis. Patients are discussed at MDTs (which include liaison psychiatrist, consultant chronic pain management expert and chaplaincy) twice weekly. Patients are seen depending on need, which ranges from daily to twice a week. The team conducts all assessments for hospice admission for patients in LTHT.

The team is one of 25 acute hospitals in England working to deliver the National End of Life Care Programme “Transforming EoLC in acute hospitals” programme. At the time of interview the team uses the LCP, ACP, rapid discharge and the AMBER care bundle.

The LTHT SPC team delivers a significant amount of education and training to all grades of doctors, nurses and AHPs. This includes leading the Ethics and Law theme that runs throughout the Leeds Undergraduate Medical Curriculum and the Senior Clinicians Development Programme. The team has been involved in recruiting patients to clinical trials and more recently has one consultant with a designated academic session.

LTHT employs a discharge facilitator. This role has a strategic remit with the aim of improving the process of discharging a patient who is nearing the end of their life and wishes to die at home. This post dovetails with the two discharge facilitators employed within the district nursing team.

LTHT also employs two EoLC facilitators, who have a broader and more hands-on role supporting ward sisters to implement and manage the AMBER care bundle, LCP, rapid discharge pathway, advance care planning and EPaCCS. The facilitators deliver training, develop supporting materials, maintain a link nurse network, monitor and audit. They also deliver pieces of work as required e.g. the LTHT bereavement survey and the Dying Matters campaign. Where wards need additional support they will provide this to patients directly.

The SPC team have access to a Consultant Anaesthetist for Pain Management for two sessions per week.

LTHT also host the Interpreting Service. The service has 160 interpreters in their network supporting around 80 languages. The funding for the service is top sliced to enable LTHT ward staff to access it without paying, but other organisations pay a fee per hour to use the service. The mental health trust, district nurses, hospices and LTHT use the services. GPs usually use language line as their consultations are much shorter. Between 1/4/12 and 31/3/13, around the service was used around 26,000 times. It is not possible to extract data describing what the service was used for, however in this time span 8 patients using services at Wheatfields and St. Gemma’s used the Interpreting Service.
9.3.2 Leeds Hospices

There are three hospices in Leeds: St. Gemma’s, Sue Ryder Wheatfields and Martin House. Martin House is a children and young people’s hospice but does provide a service to young people over 18 years in certain circumstances.

Figure 15 below illustrates the hospice footprints. The area shaded blue shows the patch that Wheatfields covers. The area shaded yellow is the patch St. Gemma’s covers. The strong black line around the map is the boundary of Leeds. The finer black lines show the postcode areas. This footprint and population was agreed between both hospices and NHS Leeds, set out in a paper in April 2012. Individuals in Leeds are allocated to each hospice depending on the GP they are registered with. If the GP is situated in the postcode area a hospice serves, all of those patients are allocated to the local hospice, even if they live in a postcode allocated to the other hospice.

Figure 15: Postcode districts allocated to Wheat fields and St Gemma’s hospices

In practice, each hospice will accept day patients and inpatients from outside their own catchment area if a patient makes a particular request for a referral to a particular hospice, or if there are capacity issues at the other hospice. However the existing arrangement is that each hospice is responsible for a geographical footprint therefore patients are not usually offered a choice of provider at the outset. Community referrals outside the defined boundaries are sometimes accepted although this is discouraged due to the established relationships between hospice community teams and primary care providers.

Figure 16 below includes information about deprivation in Leeds. Areas (lower super output areas) are shaded according to which deprivation quintile they fall into. The darkest blue shows the areas in Leeds (approximately 20% of Leeds) that fall into the most deprived 10% areas nationally.
Table 3 below provides information about the number of people who fall into the St. Gemma’s and Wheatfields footprints using the postcode data agreed between both hospices and NHS Leeds. Where a practice has more than one branch, the location for this practice and all of its patients is determined by the location of their main site. These data are a count of patients on Leeds GP lists in January 2012. They are divided by age group. The WF3 postcode area is shared. There is also a category of “other”; these count patients where the practice code is incorrectly recorded, patients attend specialist practices or they attend a practice which provided primary care to the homeless. Both “other” and WF3 patients have been split 50/50 and added to each hospice footprint.

Of the patients who live in the 20% of Leeds which fall into the 10% most deprived, 65% of patients live in the area St. Gemma’s serves and 35% live in the area Wheatfields serves. 39% of the total population and 28% of people aged 65 and above in the St. Gemma’s footprint live in the most deprived 20% of Leeds. This compares with 23% of the total population and 18% over 65s resident in the Wheatfields footprint.

Table 3: Population broken down by age, served by St. Gemma’s and Wheatfields hospices

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>0 - 17</th>
<th>18 - 64</th>
<th>65 - 74</th>
<th>75 - 84</th>
<th>85+</th>
<th>Total aged 65+</th>
<th>Total pop. served</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St. Gemma’s</td>
<td>80,634</td>
<td>229,337</td>
<td>30,135</td>
<td>19,761</td>
<td>7,613</td>
<td>57,509</td>
<td>356,239</td>
</tr>
<tr>
<td>Wheatfields</td>
<td>80,098</td>
<td>314,864</td>
<td>30,508</td>
<td>20,827</td>
<td>8,212</td>
<td>59,547</td>
<td>443,268</td>
</tr>
<tr>
<td>Total</td>
<td>160,732</td>
<td>543,876</td>
<td>60,642</td>
<td>40,587</td>
<td>15,825</td>
<td>117,056</td>
<td>821,662</td>
</tr>
</tbody>
</table>
Both Hospices and the LTHT SPC team contribute to the wider developmental work around EoLC delivery in Leeds. For example

- Education and training e.g. The Senior Clinicians Development programme, 4th year medical undergraduates, graduate certificate in palliative care for nurses, allied health professionals and social workers, GP training including TARGET, DN and YAS training and Quality End of Life Care for All (QELCA) programme.
- Service developments e.g. renal, MND, dementia, heart failure and Parkinson’s disease.
- Partnership work e.g. each specialist service is part of the Palliative Care Operational Group and Strategic Group and also the Sub Regional group supporting the End of Life Care Work programme.

9.3.2.1 St. Gemma’s Hospice

St. Gemma’s Hospice provides specialist palliative care in the hospice and community. The hospice has 32 inpatient beds based on two wards, a day hospice and outpatients department, a community team and an adult and children’s bereavement service.

9.3.2.1.1 Inpatient unit

The inpatient unit is supported by senior medical staff, nursing and health care assistants, in addition to a range of allied health professionals, social workers, bereavement workers, chaplaincy / spiritual care workers, complementary therapists, physiotherapists, OTs, a dietician and a discharge worker. The unit operates 24/7 and takes planned and acute admissions from across Leeds.

9.3.2.1.2 Day hospice

The day hospice provides care to a broad range of patients with advanced life limiting illnesses e.g. MND, heart failure, Parkinson’s disease, cancer and respiratory disease. The service provides supportive therapies including blood transfusion and bisphosphonate infusions, medication reviews and a range of complementary and rehabilitation therapy services.

9.3.2.1.3 Outpatient clinics

St. Gemma’s provide senior medical outpatient clinics on weekdays. In addition there is a weekly consultant clinic in Wetherby. A clinic has recently been set up in Oulton in south Leeds. Between 1/4/12 and 31/3/13 St. Gemma’s delivered 472 medical outpatient appointments.

9.3.2.1.4 Community service

The community service is supported by 0.8 WTE medical consultant, 9 WTE CNSs, and 2 ANPs. The ANPs are nonmedical prescribers, three of the CNSs have completed their non-medical prescribing training and await NMC verification. Two more CNSs are shortly to commence non-medical prescribing training. The team manages complex case loads working in partnership with primary care teams to support patients and families to achieve their preferred place of care. The team supports GSF meetings and has an active role in promoting EPaCCS. To support patients in their own homes, community visits are made by complementary therapy, physiotherapy, OT, bereavement services and social workers. An audit between February 2012 and August 2013 undertaken for the quality account showed the St. Gemma’s CNS’s attended 96% of GP gold standards meetings happening in the St. Gemma’s footprint.
9.3.2.1.5 OOH
The hospice provides OOH advice to patients and families in their homes (including care homes) and to a range of health care professionals.

9.3.2.1.6 Non-cancer patients
St. Gemma’s is developing an EoLC pathway for patients who have heart failure and those who have Parkinson’s disease. This is a city wide project. St. Gemma’s also contributes to the dementia programme, specifically on pain assessment.

9.3.2.1.7 Academic and teaching work
The Academic Unit of Palliative Care has been established at the University of Leeds in partnership with St. Gemma’s Hospice and is physically located on two sites; Leeds Institute of Health Sciences and St. Gemma’s Hospice. The Academic Unit is focused on research, teaching and evidence-based service development and delivery. The programme of research focuses on improving the management of pain for patients in the community, and evaluating clinical decision making and interventions during end of life care. Research is underpinned by £3m in research grant income which supports a large team of 7 NIHR funded researchers, 1 NIHR Clinical Lecturer and 3 Academic Clinical Fellows. St. Gemma’s oversees the palliative care education of 300 medical students per year and provides placements to approximately 30 nursing students per year from the University of Leeds. St. Gemma’s delivers in-service training from clinical and non-clinical staff and manages a graduate certificate in palliative care which is accessed by approximately 60 professionals across Yorkshire each year.

9.3.2.1.8 Activity
Figure 17 below shows initial contact with St. Gemma’s for patients using the inpatient unit, day hospice and community nursing service. The data shown in all maps created for hospice activity has come from the hospices themselves.

Figure 17: St. Gemma’s initial contact for inpatient, day hospice and CNS care

Figure 18 below uses the same template, but this time shows all activity delivered within the three categories in the last financial year.
9.3.2.2 Sue Ryder Wheatfields Hospice
Wheatfields hospice is one of seven Sue Ryder hospices. Wheatfields hospice provides specialist palliative care to patients in the hospice and community. It has 18 inpatient beds, a community team, on site day hospice and outpatients and outpatient clinics in the community and acute hospital trust. There is also a bereavement service.

9.3.2.2.1 Inpatient unit
The inpatient unit is supported by senior medical staff, nursing and health care assistants, social workers, bereavement workers, spiritual care workers, complementary therapists, physiotherapists, occupational therapists, a dietician and a discharge worker. The unit operates 24/7 and takes planned and acute admissions from across Leeds.

9.3.2.2.2 Day hospice
The day hospice runs Monday to Friday and provides access to specialist medical, nursing, physiotherapy, occupational therapy, complementary therapy, spiritual care, social worker, bereavement support and support for carers. Blood transfusions and bisphosphonate infusions are also available.

9.3.2.2.3 Outpatient clinics
Wheatfields provides a Consultant outpatient service for both cancer and non-cancer patients. This includes;
• Sunnyview House, Beeston, South Leeds: Weekly clinic with 5 appointments available. This runs alongside outpatient complementary therapy and access to CNS review.
• Wharfedale Hospital, Otley: Weekly clinic with 4 appointments available.

The following clinics are delivered at LTHT and are open to all EoLC patients across the city.
• Haematology clinic, Bexley wing St. James’s hospital: weekly clinic runs parallel to myeloma clinic with 6 appointments available. Includes patients from both the East and West of Leeds.
• Motor Neurone Disease clinic, Seacroft hospital: monthly clinic with 7 available appointments. Includes patients from both the East and West of Leeds.
• Renal clinic, St. James’s hospital: Weekly clinic with 6 available appointments. Includes social work review and patients from both the East and West of Leeds.

Between 1/4/12 – 31/3/13, 916 medical outpatient consultations occurred at these clinics, the appointments were with doctors, usually a consultant. These numbers do not include any nursing or AHP assessments or any medical assessments occurring during day hospice visits.

The myeloma, MND and renal patients are from both the Wheatfields and St. Gemma’s catchment areas, equally distributed and are not included in any other data including total referrals and non-cancer percentages.

9.3.2.2.4 Community service
Wheatfields community service is provided by a medical consultant, a speciality doctor and 9.4 WTE clinical nurse specialists. Dedicated domiciliary medical consultant cover can be accessed for patients with more complex medical problems and includes face to face assessment and or reviews and an advisory service to GPs. The CNS are allocated to GPs, offering individual and joint visits and regularly attend GSF meetings and support the development of the EPaCCS palliative care register. 5 CNSs are non-medical prescribers and are actively prescribing to support their primary care teams.

The wider community multidisciplinary team includes, OT, physiotherapy, complementary therapy, spiritual care, social workers and bereavement care staff who regularly visit patients in their own homes to help them achieve their preferred place of care.

9.3.2.2.5 OOH
The hospice provides OOH support to patients, families and other professionals in all settings. Admissions are accepted to the inpatient unit 24/7 and the consultants take part in the city-wide on-call rota.

9.3.2.2.6 Non-cancer agenda
Wheatfields hospice is proactively addressing the non-cancer agenda. The community consultant is now a co-director of Leeds MND care centre, is working with Parkinson’s disease clinicians and developing a pathway for people with dementia. Links have been established with the heart failure service and a monthly clinic is held at Wheatfields. The renal clinic has been running for 6 years and is recognised nationally as an innovative model of care, decreasing hospital admissions. As a result the regional renal network has adopted this model of care.

9.3.2.2.7 Academic and teaching work
The CNS team and medical staff have delivered a teaching programme for community matrons, district nurses and specialist community staff. 93 staff were trained in the last year, to establish competence at discussing and signing preferred priorities of care and DNACPR
documentation. Wheatfields is involved with training medical students, nursing students, social work students, AHPs and bereavement volunteers. Dr Edwards has jointly led the Senior Clinicians Development Programme with Dr Hicks, with one aim being to improve the interface between hospice and hospital and patient experience where care is being delivered by clinicians from both LTHT and hospices.

Wheatfields has an active research and development programme both within the national Sue Ryder organisation and through work alongside their Trust partnerships. A paper illustrating the outcomes of the renal clinic has recently been published as a leading article in a peer reviewed journal and presented nationally. More recently Wheatfields has worked locally with Professor Mike Bennett and Dr Hilary Bekker at Leeds University. This year a research nurse has been appointed with community research funding to specifically recruit from Wheatfields hospice to the clinical trials led by Professor Mike Bennett.

9.3.2.2.8 Activity
Figure 19 below shows a map of initial contact for patients using the inpatient unit, day hospice and community nursing service.

Figure 19: Wheatfields initial contact for inpatient, day hospice and CNS care

Figure 20 below uses the same template, but this time shows all activity delivered within the three categories in the last financial year.
9.3.2.3 Comparisons and conclusions

9.3.2.3.1 Funding
All hospices generate most of their income from charitable sources and are organisations which determine their own rates of pay. One of the Leeds hospices is part of a national charity and works within the organisational pay structure although pay is determined by local market forces and local funding. Staff recruitment and retention was a particular issue in 2012 – 13 which resulted in the hospice inpatient unit capacity decreasing for a short time. Decisions about rates of pay are outside the scope of this HNA but recruitment and retention of staff is relevant.

9.3.2.3.2 Bed base and community activity
Wheatfields has a smaller bed base and like St. Gemma’s, places emphasis on relationships between CNS and GPs. Each CNS has a list of GP surgeries allocated to them and two or three care homes that they link in with, and Wheatfields CNSs deliver 32% more community visits than St. Gemma’s. This figure measures CNS home visits only and does not measure attendance at GSF meetings, education and training and telephone contacts. In terms of numbers of patients, between 1/4/12 – 31/3/13, Wheatfields CNSs served 141 more patients (16.4% more) than St. Gemma’s CNSs.

St. Gemma’s has more beds allocated to the East. St. Gemma’s accept referrals from across the city and do not charge for patients from the West of Leeds. St. Gemma’s inpatient unit admitted 45 patients from the Wheatfields area last year. In terms of numbers of patients, between 1/4/12 – 31/3/13, St. Gemma’s inpatient unit served 211 more patients (74.3% more) than the inpatient unit than Wheatfields. St. Gemma’s report that there are no issues managing discharges into the West of the city. Wheatfields took 11 admissions from the St. Gemma’s area last year. This year, the difference was particularly high, compared to previous years where the admissions for out of area have been more similar e.g. in 2011/12 St. Gemma’s admitted 9 patients from the Wheatfields area and Wheatfields admitted 7 from...
the St. Gemma’s area (data from the St. Gemma’s and Wheatfields quarterly reporting for NHS Leeds / the Leeds CCGs).

9.3.2.3.3 Admission rate
The admission rate for St. Gemma’s is 172 admissions per 100,000 population and for Wheatfields is 80 admissions per 100,000 population. This is calculated using 2012 – 13 activity data as a numerator and the total population served data from table 3 above. The admission rate for St. Gemma’s includes admissions from the Wheatfields patch, which accounted for 7% of admissions in 2012 – 13. Conversely the admission rate for Wheatfields includes admissions from the St. Gemma’s patch which accounted for 4% of their admissions.

Both hospices were asked for data around requested admissions that were declined. Both hospices responded that if a patient fulfils the Leeds Eligibility Criteria for Specialist Palliative Care then they are entitled to hospice care and will be admitted. In the last year no patient has been declined admission to a hospice due to lack of capacity. If one hospice does not have capacity, the other hospice will admit that patient. However fluctuating demand sometimes means a patient has to wait for a bed.

9.3.2.3.4 Deaths in hospital
LTHT provided numbers of deaths in LTHT between 1/4/12 and 31/3/13 by postcode area. A rate of death in hospital per 100,000 population was used using the number of deaths in LTHT as the numerator and population footprint allocated to each hospice as the denominator. Between 2012 and 13, there were 1,279 deaths in hospital in the St. Gemma’s footprint which in January 2012 had 392,466 residents and 1,213 deaths in hospital in the Wheatfields footprint which has 421,197 residents. These include all deaths in LTHT, not all of them will have required palliative care. This equates to 326 deaths in hospital per 100,000 population for the St. Gemma’s area and 288 deaths in hospital per 100,000 population for the Wheatfields area.

This is a crude calculation and should be interpreted with caution. It would be useful to look at more than one year’s data. To accurately calculate the death in hospital rate per hospice footprint, these data would need to be collected from any hospital an individual registered with a Leeds GP, may die in. The ONS data in Chapter 7 show that around 10% of deaths of Leeds residents occur in neighbouring hospitals. There may be other factors which would influence this rate e.g. distribution of care homes between footprints, different rates of deprivation etc. A crude calculation has been made and only deaths in LTHT were included.

9.3.2.3.5 Preferred place of death
Wheatfields have undertaken an audit to see if their patients achieved their preferred place of death. St. Gemma’s monitor PPD achieved as a routine Key Performance Indicator.

St. Gemma’s data show that between 1/4/12 – 31/3/13, 68% of patients achieved their PPD (range 57% - 74%).

Wheatfields conducted a PPD audit from 1st January – 31st March 2013. Of the 109 patients who died in that period, 89 (82%) achieved their PPD and 20 (18%) did not achieve their PPD. Reasons were acute medical condition (6%), complex symptoms (5%), patient couldn’t cope (2%), care home managing terminal phase (2%) patient too poorly to move (2%), patient died on day of discharge (1%). Table 4 below shows the differences between preferred and actual place of death. More people than wanted to died in hospital, the hospice and care home. Less people than wanted to died at home.
Table 4: Results from Wheatfields PPD audit

<table>
<thead>
<tr>
<th></th>
<th>PPD (%)</th>
<th>APD (%)</th>
<th>% difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>53</td>
<td>44</td>
<td>- 9%</td>
</tr>
<tr>
<td>Hospice</td>
<td>28</td>
<td>34</td>
<td>+ 6%</td>
</tr>
<tr>
<td>Care home</td>
<td>9</td>
<td>10</td>
<td>+ 1%</td>
</tr>
<tr>
<td>Hospital</td>
<td>0</td>
<td>11</td>
<td>+ 11%</td>
</tr>
</tbody>
</table>

9.3.2.3.6 Pharmacy
Pharmacist input to the hospices was allocated according to bed base. St. Gemma’s has 13 sessions and Wheatfields has 7. Wheatfields and St. Gemma’s both state they need more pharmacy sessions.

9.3.2.3.7 Summary of data
Table 5 below has been compiled from data each hospice submitted for 1/4/12 – 31/3/13, and shows some differences and similarities.

Table 5: Summary of data from St. Gemma’s and Wheatfields

<table>
<thead>
<tr>
<th>Indicator</th>
<th>St. Gemma’s</th>
<th>Wheatfields</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual numbers of patients using the inpatient unit</td>
<td>495</td>
<td>284</td>
</tr>
<tr>
<td>All admissions to the inpatient unit</td>
<td>613**</td>
<td>356**</td>
</tr>
<tr>
<td>First time referral <em>directly</em> to the inpatient unit</td>
<td>147 *</td>
<td>62 *</td>
</tr>
<tr>
<td>Mean average length of stay (days)</td>
<td>12.9</td>
<td>9</td>
</tr>
<tr>
<td>Occupancy rate (%)</td>
<td>69</td>
<td>72</td>
</tr>
<tr>
<td>Registered nurse: patient ratio (early)</td>
<td>1:4</td>
<td>1:4.5</td>
</tr>
<tr>
<td>Registered nurse : patient ratio (late)</td>
<td>1:5</td>
<td>1:4.5</td>
</tr>
<tr>
<td>Registered nurse: patient ratio (nights)</td>
<td>1:8</td>
<td>1:6</td>
</tr>
<tr>
<td>Admissions rate per 100,000</td>
<td>172</td>
<td>80</td>
</tr>
<tr>
<td>Actual numbers of patients using the CNS service</td>
<td>858</td>
<td>999</td>
</tr>
<tr>
<td>All face to face contacts with the CNS service</td>
<td>3,223**</td>
<td>4,247**</td>
</tr>
<tr>
<td>First time referral <em>directly</em> to the CNS service</td>
<td>765 *</td>
<td>805 *</td>
</tr>
<tr>
<td>Actual numbers of patients using the day hospice</td>
<td>190</td>
<td>147</td>
</tr>
<tr>
<td>All attendances at the day hospice</td>
<td>1,393**</td>
<td>1,106**</td>
</tr>
<tr>
<td>First time referral <em>directly</em> to the day hospice</td>
<td>25 *</td>
<td>21 *</td>
</tr>
<tr>
<td>Achieved PPD</td>
<td>68%</td>
<td>82%</td>
</tr>
<tr>
<td>% cancer patients ***</td>
<td>84</td>
<td>84</td>
</tr>
<tr>
<td>% non-cancer patients *** &quot;&quot;</td>
<td>16</td>
<td>16</td>
</tr>
<tr>
<td>% White British using service ***</td>
<td>67.7</td>
<td>64.2</td>
</tr>
<tr>
<td>% BME using service ***</td>
<td>10.4</td>
<td>14.1</td>
</tr>
<tr>
<td>% Ethnicity not recorded ***</td>
<td>21.9</td>
<td>21.7</td>
</tr>
</tbody>
</table>

* Number of individual patients, first time ever referrals.
** Patients will be double counted as they are likely to have used these services twice.
*** Stats for first referrals only
"" all services apart from outpatient clinics

9.3.2.3.8 Issues raised by both hospices
Both hospices raise concerns about capacity in the future, based on the ageing population and the increasing number of deaths projected compounded by the need to reduce the proportion of deaths occurring in hospital. The idea of a hospice for the “simply dying”, that is people who are dying, don’t want to or can’t die at home, but do not require a high input of
SPC was raised. Both hospices raised the need to improve hospice care for the non-cancer population and both hospices are developing work in this area (e.g. dementia, renal failure, MND, heart failure and Parkinson’s disease at Wheatfields and heart failure and Parkinson’s disease at St. Gemma’s). Both hospices strongly support the idea of running a community CNS service seven days a week from each hospice.

9.3.2.4 Martin House
Martin House is a hospice based in Leeds providing services to children and young people from across Yorkshire and Humber (excluding South Yorkshire). New referrals of patients aged between 0 and 19 are accepted. Young people over this age are also accepted if there life expectancy is very short. There is no formal upper age limit although in reality most of the young people die in their 20s. If they reach 30 Martin House formally reviews whether they are using the correct place or not. Martin House aim to provide a home from home environment where families can use a range of services which include respite care, symptom control, nursing and practical care, emotional, psychological and spiritual support, terminal care and bereavement support. This support is also provided in families’ homes. There is no day hospice service. The hospice is currently providing support to 31 young people over 18 in Leeds, 27 of whom have used the inpatient unit and 4 who have required telephone support services.

9.3.2.5 Hospices neighbouring Leeds
There are three hospices that border Leeds: Marie Curie Bradford, Wakefield and Saint Michael’s Harrogate. The Chief Executives of each were contacted and asked for data on usage from patients registered with a Leeds GP that used community nursing, in-patient or day hospice services between 1st April 2012 and 31st March 2013.

Fifteen patients registered with a Leeds GP accessed a Lymphoedema clinic and 5 patients registered with a Leeds GP accessed a Motor Neurone Disease outpatient clinic run by Harrogate hospice.

Two patients registered with a Leeds GP used the community nursing service and 1 used the day hospice service provided by Marie Curie Bradford. If patients who aren’t registered with a Bradford GP wish to be admitted into the Bradford Hospice, ideally permission for funding from the relevant CCG is required before the patient can access this service, although to avoid delays the patient is admitted and funding is sought retrospectively.

A far higher number of patients registered with a Leeds GP use services in Wakefield hospice. Between 1/4/12 – 3/3/13, 34 patients used the inpatient unit (average length of stay 11 days) and 15 patients accessed the day hospice, between 1 – 32 times (average 8.5 visits). In addition Wakefield hospice has provided bereavement support to Leeds clients (144 visits and 229 support telephone calls). This usage is significant and is likely to be because of the location of the Leeds hospices in the north of Leeds.

Figure 21 below plots the activity of patients registered with a Leeds GP who have used day hospice, inpatient and community nursing services.
9.3.3 Marie Curie (in terms of providing nursing staff)
There are a small number of Marie Curie nurses providing services in Leeds. There is a team of Marie Curie nurses, based at Bradford Hospice, who provide a service in Leeds, Sheffield, Bradford, Airedale, Calderdale, Kirklees and Wakefield. These nurses are paid for 50% by the NHS and 50% by Marie Curie. The nurses are based at home and operationally managed by the District Nursing night’s service. In Leeds, Marie Curie nurses provide overnight care for patients who are reaching the end of their life. They provide 18 hours a week of a nurse (one nurse 2 nights per week) and 117 hours of unqualified nurse (2 a night and 1 on Saturday nights).

9.3.4 Macmillan
Macmillan does not directly provide any EoLC in Leeds. However Macmillan does support the Robert Ogden Centre based at LTHT. The Robert Ogden Centre has been at LTHT for 13 years and provides information and support for anyone affected by cancer and other people with life limiting illnesses when capacity allows. The majority of people using services are not nearing the end of their life. There are 7 members of staff, paid for by LTHT with a contribution from Macmillan to pay for half a member of staff (7% contribution to total staffing costs). In the past, Macmillan has funded posts for 3 years then LTHT has picked up the funding. Staff can access Macmillan learning and education. Macmillan is funding an imminent refurbishment of the centre.

9.3.5 District nursing teams
The district nursing (DN) team is part of Leeds Community Healthcare NHS Trust. The district nursing service provides care to adults in Leeds who are housebound. If a patient has a life limiting illness the district nurse will provide care and support to them, their family and carers. The teams are led by qualified district nurses who work with registered nurses.
and health care support workers. There used to be a citywide CAPCCS team (Complex and Palliative Continuing Care Service) to support DNs, however this has now been disbanded and absorbed into local DN teams. DNs cover the whole of Leeds and some surrounding areas and are based in 12 neighbourhoods around the city. GPs, local hospitals, hospices, social services, voluntary sector organisations and carers can refer patients to the district nursing service. The district nursing service is a 24 hour service delivered by three teams, the day service, twilight and nights. EoLC is a core skill for district nurses, all district nurses from the nights team are trained to verify deaths, some DN who work during the day are trained to verify deaths. DNs work closely with other community nurses (e.g. community matrons and community nurse specialists e.g. heart failure, diabetes, respiratory etc.) The day service is provided 8.30am – 6pm. The twilight service works 5.45pm – 9.45pm and the night team work 9pm – 7.30am. There is a debate within the profession in Leeds around whether all DNs should continue to be trained in EoLC or if this should become a specialist skill that a smaller number of DNs are trained in. The DN team works to a Service Delivery Framework which outlines standards of integrated care provided by professionals when caring for palliative care patients and their carers. This includes 3 levels of care: supportive for patients with advanced, progressive life threatening illness, intermediate for these patients with an increasing level of need and intensive for a patient who has a rapidly deteriorating health condition that may be entering the terminal phase, or a patient who has commenced on the LCP or a patient who is eligible for CHC Fast Track status. DNs attend GSF meetings.

The night service is made up of 55 band 3 nurses and 15 registered nurses. There is also a team of carers provided by external agencies. The team provide one to one care (95% of their role) and contribute to continuing heath care assessments during the night (5% of their role). A lot of EoLC calls are crisis calls, where a patient is in pain, vomiting, needs support controlling symptoms, support with syringe drivers etc. Sometimes staff may have to start the LCP in the night.

The District Nursing team has two EoLC Discharge Facilitator posts, created in response to the Marie Curie Delivering Choice project. Their role is to facilitate a smooth handover of care between LTHT and the hospices and the district nursing team. The facilitators have also supported discharges of Leeds patients from Harrogate and Mid-Yorks hospitals. The discharge facilitators represent district nurses at care planning meetings in hospitals and hospices; where the DN responsible does not have capacity to attend, plan care provision for patients; complete the appropriate paperwork, transcribe medications for symptom control; assess and order any other necessary equipment, communicate the care package to the responsible district nurse, lead investigations where a poor EoL discharge has been identified through Datix (the reporting system for incidents) and feedback to ensure mistakes are learnt from.

Between February 2010 and May 2013, the number of WTE community nurses has reduced by approximately 10%, from 310.9 to 279.2. The skill mix has changed, in May 2013 there were 3.5 more band 2 staff, 14 more band 3, 31 less band 5 and the same number of band 6s when compared to February 2010.

The internet tool “Survey Monkey” was used to survey District Nurses. Electronic surveying was chosen as it is low cost and an electronic link can be emailed to district nurses, who can complete and return the survey electronically and instantly. Nine closed questions and one open question were asked. The open question was: “What is good, what is a gap, any other comments around end of life care?” The survey opened on 23rd May and closed on 22nd July. The Survey was distributed via email by Ann Robertson, General Manager Adult Community Nursing, to all district nurse caseload managers. There are 50 district nurses. The EoLC lead for Leeds Community Healthcare reported that these staff may have cascaded the questionnaire to staff nurses and health care assistants, but is unable to
quantify how many staff. Fifty questionnaires were returned. It is not possible to calculate a response rate as the denominator (i.e. people invited to complete the questionnaire) is unknown.

The survey showed:

- 98% of community nurses stated palliative care is a core part of the service they provide, 2% disagree.
- 100% agreed that death at home is preferable if this is desired by their patient.
- 26% think GP palliative care out of hours is adequate, 64% don’t.
- 46.9% feel they have enough time to provide a good service to patients who are at the end of life, 53.1% don’t and one person skipped the question.
- 44.9% have experienced an inappropriate admission to hospital of a patient who is at the end of their life, 55.1% haven’t and 1 person skipped the question.
- 93.9% feel they have been adequately trained to provide good end of life care to their patients, 6.1% don’t and 1 person skipped the question.
- 91.8% stated that they can access palliative care and or hospice care for their patient easily if required, 8.2% don’t and 1 person skipped the question.
- 80% think end of life discharges from hospital to home generally go smoothly, 20% don’t.

- In terms of EoLC tools:
  - 85.7% discussed and record PPC
  - 81% discuss and record DNACPR decisions
  - 71.4% ensure out of hours handover forms are completed
  - 85.7% discuss and record any additional EoL preferences
  - 8 people skipped this question

- This question included an “other” option, seven people responded. Four said they use the Leeds Care Pathway, two said they worked nights / twilight and the tools are used by day time staff, another said “carers family after death”

Leeds Community Healthcare published an EoLC Register Report 2011/12 (McDermott, 2012). A study was conducted comparing completed “Registration Questionnaires” to “Outcome Questionnaires”. The registration questionnaire was the form routinely used for patients reaching EoL, it is currently being phased out and replaced by EPaCCS. Community nurses should complete both forms for all community nursing patients identified as approaching EoL. This was usually district nurses but could be community matrons or community nurse specialists. Between April 2011 and March 2012, 1,370 registration questionnaires were completed for new patients and 951 outcome questionnaires (69.4% of these patients) were completed. Conclusions drawn from these questionnaires were that 88% of patients died in their PPC, 9% of patients died in hospital, 59% of deaths at home or in residential care happened when patients were on the Leeds Care Pathway. 25% of patients who died at home or in residential care had their death verified by a registered nurse. 69% of carers were offered bereavement support, 15% of those declined. 951 completed outcome questionnaires represent approximately 15.9% of expected annual deaths in Leeds. It has been suggested that around 75% of deaths require palliative care (Murtagh et al, 2013). This study shows the importance and effectiveness of early identification, however it is unclear what the outcomes were for patients in contact with community nursing not included in the study along with patients who were not in contact with the community nursing service who perhaps would have been if they had been identified as nearing the end of their life.

9.3.6 Specialist community nurses

Leeds Community Healthcare employs a team of Community Nurse Specialists (CNS). There are nurses employed in the city covering specialisms such as heart failure (13.8 WTE), respiratory, diabetes, Parkinson’s, motor neurone disease and mental health. Two
CNS were interviewed for the HNA, one a heart failure specialist and one a respiratory specialist. They stated that some CNS can prescribe, some can’t. CNSs refer patients for SPC prescribing as there can be contraindications with certain drugs. Heart failure patients are supposed to have three bereavement visits post death. CNSs have had training around EoLC.

9.3.7 Community matrons
Leeds Community Healthcare has a team of 38 Community Matrons (35 WTE), who are attached to GP practices. The community matron service is available citywide Monday – Friday 8.30 – 16.30. Their role is to work with patients with complex health conditions to try and put services in place to avoid unnecessary hospital admissions. Community matrons provide advance assessments, take comprehensive histories, carry out physical examinations, and identify potential diagnoses. They are able to conduct medication review and prescribe medications. They work closely with GPs, consultants and other MDT members. The service is commissioned for people aged 16 and above but the majority of patients are aged 65 years and over. Patients are referred by GPs, nursing colleagues and social workers. There is an overlap with EoLC as everyone on the community matron’s caseload is seen at least twice a month and stays on the case load until they die. Community matrons attend GSF meetings where capacity allows and according to patient need.

9.3.8 Care homes
It is complex to describe care home provision in Leeds as this sector is not directly provided by any one organisation. Care homes in Leeds are provided by the local authority, private and voluntary sector. Leeds City Council produce a care home directory which lists all care homes, and whether they specialise in older people, dementia, physical disability, learning disability, mental health, sensory impairment, younger adults and people who misuse alcohol and drugs. There are 182 care homes listed in the directory. Care Home Managers were interviewed using Survey Monkey. The invitation was sent to care home managers via Mick Ward, Head of Commissioning at Adult Social Care’s team. The survey opened on 23rd May and closed on 22nd July. 32 responses were received, assuming 182 homes received the survey this equates to an 18% response rate. Care home managers were asked 8 closed questions and two open questions: “What helps or hinders your ability to provide good quality end of life care” and “any other comments”. 23.3% of respondents managed residential care homes, 43.3% managed care homes with nursing, 33.3% managed care homes with dementia care, two were dual registered, one was a care home with nursing and intermediate care beds and one was a residential care home for young people with disabilities.

The survey showed:
- 100% of care home managers agreed palliative care is a core part of the service they provide
- 100% of care home managers agreed death in a care home is preferable if this is desired by a resident.
- 81.3% think GP care out of hours is adequate, 18.8% don’t.
- 40.6% had experienced an inappropriate admission to hospital of a patient nearing the end of their life, 59.4% hadn’t.
- 59.4% feel end of life discharges from hospital to the care home go smoothly, 40.6% don’t.
- 100% of care home managers feel adequately trained to provide good EoLC to their residents.
- In terms of EoLC tools:
  - 96.9% discuss and record PPC
  - 100% discuss and record DNACPR decisions
The CCGs commission Leeds Community Healthcare to employ an EoLC facilitator for care homes. This post was also put in place following the Marie Curie Delivering Choices project. The facilitator currently works with the 38 homes in Leeds which are nursing homes that include continuing health care beds. The facilitator audited practice in the homes in terms of ACP, the PCR, PPC and DNACPR orders. Some care homes were performing well and some identified areas for improvement. Syringe drivers were bought for the 36 care homes who said they wanted one and training has been provided on how to use them. An audit showed that they weren’t being used, and often the facilitator or a CNS from St. Gemma’s or Wheatfields are asked to support care homes to set them up. The facilitator is considering now moving from supporting care homes with nursing to care homes without nursing. In addition the SHA funded a large scale EoL training package for care home staff.

Where a person lives in a care home without nursing, they are supported to remain there by the DN service.

9.3.9 The mental health trust
Only one person from Leeds and York Partnership NHS Foundation Trust was interviewed, a consultant liaison psychiatrist. The trust is funded 2 days a week to provide consultant liaison psychiatry to support all SPC providers across Leeds. Patients are mainly referred from SPC services and can be seen at LTHT, Wheatfields or St. Gemma’s. The consultant attends LTHT MDT meetings. The role also includes education and audit. There is a psychology oncology team made up of 3.5 WTE clinical psychologists, based at Bexley Wing providing a “level 4” service (as defined by NICE), and sees around 10% of oncology patients.

9.3.10 Continuing Healthcare
NHS Continuing Healthcare is a complete package of on-going care that is funded solely by the NHS where it has been assessed, against a national framework, that the individual has a primary health need. It is sometimes called fully funded NHS care. The Continuing Care Team in Leeds offers a citywide service to all three CCGs but is hosted by Leeds South and East CCG. The team operates Monday to Friday, 8.30am to 5pm. Some OOH cover is provided by the joint care management team. Weekdays, from 5pm-8pm and weekends 8am-8pm, the JCMTs offer advice and oversee CHC process but then this is authorised by the CC team.

The CHC team receives referrals from any health and social care professional, in the form of a checklist. If the checklist identifies the individual for consideration for CHC then a full assessment is completed using a decision support tool (DST). The DST covers twelve domains e.g. behaviour, cognition, psychological, communication, mobility, nutrition, continence, skin, breathing, medications and altered state of consciousness and other significant health issues. If the DST indicates “clear eligibility” in a priority level of need in one domain or two “severe” in two domains then this indicates a primary healthcare need. If an individual doesn’t have these weightings but warrant consideration for fully funded NHS Healthcare then their case will be presented at the weekly Leeds multi-disciplinary continuing healthcare eligibility panel which makes the decision if a patient is eligible.

Once eligibility is agreed, a package of care is commissioned or existing care with nursing home placements is funded as appropriate to meet identified need. For people at EoL this additional care supplements and enhances services provided by LCH and hospice teams.

If an individual is deemed to have a rapidly deteriorating condition and the condition may be entering a terminal phase then “fast track” status can be applied for. This means that a
primary health need has been identified without the need for completing a DST and to ensure that an individual can be transferred to their preferred place of death. A fast track application is completed by a specialist registrar or higher grade doctor, GP, or in some cases district nurses or community matrons who have met certain competencies. The CHC team and JCM work closely together and prioritise these clients to facilitate a speedy discharge and provision of services. The CHC team are currently producing a single domiciliary care provider for patients eligible for Fast Track which will significantly reduce the number of providers delivering care to people in their own homes.

9.3.11 Out of Hospital Care
Out of hospital care is a service provided by Leeds Community Healthcare Care, comprising Intermediate Care, Joint Care Management teams and Community Intermediate Care (CIC) beds. There are three service managers for the city (each responsible for a geographical area).

The JCMTs assess health and social care need and plan and co-ordinate services for adult patients with complex health needs, each patient having a named care manager. It is a partnership between Leeds Community Healthcare Care and Leeds Adult Social Care. JCMs support a significant number of people at EoL. For patients at the end of life the district nursing service and CHC funded services work in partnership to facilitate the care patients need. There is a target response time of 4 hours for end of life patients who are given fast track status. This is for the service to allocate a care manager who then organises the required services.

Intermediate care teams provide a short term rehabilitation service following illness or accident to adults, generally aged over 60, but with younger adults considered on an individual basis. The service is provided in the person’s own home wherever possible and aims to promote faster recovery from illness, avoid inappropriate hospital admission, support earlier discharge from hospital, avoid the need for long-term care and maintain a person’s independence. Where a patient is unable to be safely managed at home, Community Intermediate Care beds are available in either of two centres managed by LCH (one of these is jointly managed with Adult Social Care). A number of these types of bed are also provided in independent sector Nursing and Residential Care Homes and a small number by Leeds City Council, supported by the Intermediate Care team.

9.3.12 Sheltered Housing
Housing was identified during the workshop as a key area to include in the HNA. In terms of older people there is residential care (which has been covered under care homes), extra care housing and sheltered housing. Extra Care Housing caters for the needs of trailer older people and provides varying levels of personal care and support available on site. Sheltered housing caters for older people (usually over 55) and usually comprises of self-contained flats/bungalows in a small scheme, where all the other residents are older people. There is usually an on-site warden/scheme manager or an alarm call service for emergencies.

Given the time available to conduct the HNA sheltered housing was considered the most relevant sector to explore. Like care homes, sheltered housing is not provided by a single provider. Some are provided by the local authority, some by registered social landlords and some are in the private sector. Training for wardens is not the responsibility of the individual scheme to provide. 23 sheltered housing complexes were surveyed between the 9th and 29th July. 11 responses were received. It is not possible to calculate a response rate because the invitation was sent to the contact manager of the sheltered housing complex and it is unclear who they passed the invitation to. The survey was answered by 2 contract managers and 9 scheme managers.
All respondents agreed that death at home is preferable if this is desired by the tenant.

90.9% of respondents (10) have had experience of caring for a tenant nearing the end of their life.

54.5% of respondents (6) considered themselves adequately trained to care for a tenant nearing the end of life, 45.5% (5) didn’t.

36.4% (4) respondents stated they are routinely informed when a tenant nearing the end of their life has an ACP, 63.3% (7) weren’t.

All respondents gave examples of experiences of good and bad end of life care and suggestions of how to improve EoLC for their tenants.

9.3.13 General Practitioners

GPs are the gatekeepers to the NHS and are therefore likely to be the first person within the NHS that comes into contact with a patient nearing the end of their life. The views of GPs were gathered via an electronic survey. In addition Naomi Penn, lead GP for EPaCCS was interviewed.

The National EoLC Strategy (2008) identified Palliative Care Registers held in primary care as having a key role in improving the coordination of EoLC services. The NICE quality standard for EoLC (2011) states one way to make this happen could be the implementation of an Electronic Palliative Care Co-ordination System (EPaCCS). The main aims of EPaCCS are to:

- Enable key information about patients’ needs and preferences to be recorded in one place by all professionals involved in a patient’s care and shared between these professionals to support decision-making and coordination of care 24/7.
- To monitor the quality of EoLC.
- To support the identification of patients approaching EoL so that they can be offered the opportunity to discuss their priorities and preferences.

Patients benefit from use of EPaCCS in that earlier recognition that the end of life is approaching provides them with the opportunity to consider and express their preferences about future care and have these documented. Patients should also have better coordinated care and more timely access to appropriate services which could reduce the number of crises and unplanned admissions. Patients’ carers are also more likely to have their own needs fully assessed and be offered earlier support to help them cope, plus have access to emotional, spiritual and bereavement support as required.

In Leeds there is a team of staff in place to oversee the role out of EPaCCS, a GP 1 day a week, two band 7 nurses from acute (1 day a week) and community (2 days a week) settings, a Consultant in Palliative Medicine, and an IT lead (3 days per week). The team’s role is to develop EPaCCS, establish the dataset in PPM which will feed into primary care records and train hospital staff, GPs and community nurses in the use of EPaCCS. Currently EPaCCS is being rolled out to GP practices that use SystmOne. The EPaCCS system enables practices to identify patients who may have palliative care needs, so that their care can be reviewed and GPs can decide whether to prioritise their patients onto a palliative care register. For a practice to earn Quality and Outcomes Framework points, they need to have a PCR in place and discuss all patients at an MDT at least quarterly. 42 of the 109 practices (38%) are using EPaCCS. At the time of writing, there are 80 SystmOne practices (73% of practices) others use Emis, Emis Web, Emis LV and there is one on a unique system. There is a plan in place for all practices to be using SystmOne or Emis Web by March 2014 and for EPaCCS to be modified to run on Emis Web.

GPs were interviewed using Survey Monkey. Eight closed questions and two open questions were asked. The open questions were: “What works well and what gaps are
there around End of Life Care at your surgery” and “Any other comments”. The survey opened on 23rd May and closed on 22nd July. The Survey was publicised via the three CCG primary care leads but the initial response was poor. There was additional information shared with GPs about the survey via the CSU communications team and the response improved. 104 surveys were completed. WYSCA estimate there are 554 GPs in Leeds (personal correspondence), which means the response rate was 19%.

The survey showed:

- 97.1% of GPs consider palliative care a core part of the service they offer. 3 GPs (2.9%) disagreed and 2 skipped the question.
- 100% of GPs agreed death at home is preferable if this is desired by their patient 1 GP skipped this question.
- 52.5% of GPs consider that GP care out of hours is adequate, 47.5% don’t. 3 GPs skipped this question.
- 25.9% of GPs think the District Nursing service is adequate, 47.1% don’t.
- 71.2% of GPs have experienced an inappropriate admission to hospital of a patient who is at the end of their life, 28.8% haven’t.
- 77.9% of GPs feel they and their staff have been adequately trained to provide good end of life care for their patients, 22.1% don’t.
- 83.2% of GPs state they can access specialist palliative and or hospice care for their patient easily if required, 16.8% don’t and 3 GPs skipped this question.

- GPs were asked what EoLC tools they used
  - 37.5% use EPaCCS
  - 86.5% discuss and record PPC
  - 92.3% discuss and record DNACPR decisions
  - 90.4% ensure out of hours forms are completed
  - 68.3% discuss and record any additional EoL preferences
- Eight GPs ticked “other” and their responses were:
  - These tools are not useful generally, people spent too much time filling in unnecessary paperwork at the expense of talking with patients
  - None known
  - LCP
  - Just started, am v clumsy
  - Liaising with partners where I locum as a GP
  - We use a palliative care template on our clinical system (SystmOne)
  - GSF meetings with full team, EPaCCS not working yet on EMIS

9.3.14 Pharmacy services

In Leeds there is a Head of Medicines Management for the city based at Leeds South and East CCG. She contracts services for EoLC medicines from dispensing chemists and hospice pharmacists via LTHT. The Head of Medicines Management is planning to commission an enhanced service, via the CSU.

In addition each CCG has a medicines management team in place to support practice. One local pharmacist was interviewed and she has been in touch with the St. Gemma’s pharmacists and used their guidance.

There is also a Medicine Governance Lead who works to the Medicines Management Collaborative for the Leeds CCGs who manages the contract for pharmaceutical supplies and pharmacy services for hospices. The service developed because commissioners have a duty to supply and fund drugs to hospices but have no controls on prescribing and spend (unlike acute Trusts that are paid by tariff so have cost controls and GPs who have indicative
budgets). It was therefore developed as a “bedside model” to improve patient care and manage the inpatient drug costs. Pharmacists’ time is allocated according to bed numbers.

Patients based in community have no input from specialist pharmacy to the MDT meetings discussing their care. There is no data at present to show that this will improve care and costs in this population but there is evidence (from incidents) to show that community pharmacists (generalists) do not have the knowledge and skill set to question mistakes in prescriptions.

There are two WTE clinical pharmacists employed via LTHT supporting St. Gemma’s and Wheatfields. On the inpatient unit, the pharmacists deliver a comprehensive clinical pharmacy service. 7 sessions are allocated to Wheatfields and 13 to St. Gemma’s. One pharmacist leads for each hospice but provide cross cover between hospices. They undertake individual patient and carer medicines education and have run group sessions. They manage the stock and supply processes of all medicines and manage and supervise technicians, employed by Lloyds pharmacy. The technicians check the medicines stocks on a Monday / Tuesday and put the order away on a Thursday. There is no pharmacy dispensary in the hospices and clinical pharmacists do not dispense medicines. The pharmacists have a role in the development of hospice policy and procedures related to medicines. OOH the technician carries a bleep to facilitate access to medicines 24/7 from the LTHT OOH pharmacy service. Hospice pharmacists are not contracted to deliver work citywide outside of hospice medicines management.

9.3.15 Local Care Direct
Local Care Direct (LCD) is the organisation that provides OOH primary care in Leeds. It is Yorkshire wide with 15 bases and palliative care is led from the Leeds base. LCD is an “extension of GP practices”, when they are closed LCD takes over primary care. It is not an emergency service and they can’t do anything that can’t be done in primary care by a GP. It is part of the 111 service, partnered with Yorkshire Ambulance Service (YAS). People access LCD by dialling 111, this call is handled by YAS (YAS have taken over from NHS Direct). The call handlers are non-clinical and use an algorithm to assess calls. There is a dedicated palliative care OOH number.

If a patient is considered to have palliative care needs, they are given a priority number via district nurses and GPs, this number comes into the same system, but bypasses all the queues and identifies the patient as having palliative care needs. Local Care Direct receive OOH handover forms from GP practices, district nurses and hospices, which record a patient’s PPC, DNACPR status and which anticipatory drugs are in the home. This is on the system attached to patients OOH record, so the doctor has this information when they do a home visits. LCD are on SystmOne, YAS are on Adastra. LCD get a lot of calls for drugs and carry all palliative care medication, kept in a sealed briefcase, bolted into car boots. Many OOH doctors are unaware of EPaCCS. There are around 430 GPs working for LCD; some only do 2 sessions a month. LCD expects GPs to have been trained on EoLC as part of their core training and CPD.

9.3.16 Yorkshire Ambulance Service
It was not possible to interview a representative from Yorkshire Ambulance Service. Information was gathered by email correspondence. There are two bespoke palliative care ambulances operating in Leeds staffed by the Patient Transport Service. A recent survey (2010) of staff at St. Gemma’s and Wheatfields hospices found the YAS palliative care ambulance to be highly valued. All survey respondents (n=72) rated the responsiveness of PC transport, its adaptability, punctuality and the professionalism of the crew as good or excellent. YAS have developed a training resource for all crews to help decision making for patients at EoL which is being implemented this year. YAS has also worked with LCH to
develop an admission avoidance scheme to maximise patient choice at the EoL which has been implemented.

9.3.17 Adult Social Care
There are social workers based in the community and social workers based in LTHT. There are 181 social workers and 55 occupational therapists (qualified and unqualified, excluding those who work in mental health and with people with learning disabilities) for adults. Social workers will become aligned to the 12 multi-disciplinary neighbourhood hubs as part of the integration agenda. Social workers support people in times of crisis and are therefore relevant to the EoL agenda.

All social workers can complete Advance Care Plans for people nearing End of Life, these are recorded on ESCR (the social care record). The ACPs link to power of attorney, health, welfare and finances. The ESCR does not link to EPaCCS or any NHS record.

18% of people in Leeds who are eligible for social care support are in receipt of direct payments (Individual Care Budget) which means they can purchase care from Personal Assistants. Training is not mandatory for Personal Assistants although ASC will provide it if requested. A pilot is running in Leeds with 10 patients who are in receipt of personal health budgets.

41 social workers are based in LTHT, covering different specialities including EoLC. There are 9 social workers who are specialists in oncology and who have considerable experience in EoLC. They are a resource for nurses on the ward. They will attend MDTs at the request of consultants. They receive 450 outpatient referrals a year; this is not required generally in other specialities but is with oncology. They assess patients for help and support on discharge from hospital. They also advise on welfare benefits and rights, determine what services are needed at home, this could be reablement, or a longer term package of care. They are gatekeepers for private home care, a financial assessment is made, there is a sliding means tested scale. If someone is eligible for continuing health care, the packages are funded, this goes to Leeds City Council for approval and then there is a process where a home care service is brokered. They also make placements to nursing homes.

Hospital Social Work teams are based within LTHT to meet the statutory responsibilities of the Local Authority to provide a variety of assessments to patients carers and families. The social work teams work as part of the Multi-Disciplinary Team to assess and provide services to facilitate a safe and timely discharge for the patient. In addition to this ASC within LTHT undertakes and facilitates broader roles and responsibilities for Leeds City Council such as re-housing. Staff provide a screening and assessment service establishing the most appropriate response to referrals which include, advice and sign posting, referral to other health and social care authorities, safeguarding processes, reablement services and the commissioning of services as appropriate under FACS eligibility. The team in Bexley will also progress CHC cases on behalf of LCH as part of a partner arrangement involving trust funded posts.

9.3.18 Bereavement Services
District nurses have a policy that all carers are given a bereavement leaflet and letter, along with three bereavement visits and an offer of support if people are struggling to come to terms with their loss. If DNAs are concerned that the bereaved are not experiencing “normal” grief, then they would refer to the GP for onward referral for bereavement support or liaise with the hospice bereavement services if they are attending there.

In LTHT, there is a bereaved carer’s user group which provides input and feedback on service development to the SPC team. There is a trust bereavement booklet which is provided to families and carers when the death certificate is collected.
St. Gemma’s have a bereavement policy, which is delivered by their social work team. The service aims to offer or provide bereavement support or counselling to targeted relatives, carers or friends of those who have died. They are assessed using a Bereavement Risk Assessment Form to assess if they are considered vulnerable or at risk in their bereavement. Individual bereavement support is carried out by the social workers, bereavement worker or a bereavement visitor. A bereavement support contact or visit is usually made to the family of a deceased patient by the CNS who has been involved in the patient’s care in the community.

The Wheatfields policy states that following the death of a patient a bereavement referral is made via SystemOne either for information or to access the bereavement service. A card and information booklet is sent to the bereaved relative. The decision to follow up with a phone call is made by the CNS who was involved in the family’s care. Wheatfields has an internal bereavement care coordinator who triages referrals and allocates to himself, another part-time bereavement support worker or one of our bereavement volunteers. If another member of the Family Support Team, i.e. a social worker or a Spiritual Care Coordinator has been involved pre-bereavement and it is a complicated situation, it may be appropriate for them to provide continuity and post bereavement support for a period of time. The hospice offers a range of bereavement services including one to one support, group support and “Time for Remembering” events that run throughout the year.

9.3.19 Leeds Community Equipment Service
Leeds Community Equipment Service is run by LCH and provides equipment to enable people to live independent inclusive lives. It is open Monday - Friday and Saturday mornings. It is an integrated service delivering all aspects of equipment for health and local authority customers of all ages in Leeds. LCES oversees all aspects of relevant staff training, information and advice to actual and potential users of equipment, service development and the storage, delivery, installation, collection and cleaning of community equipment. Equipment is delivered and installed in homes at the request of a range of people who assess patients’ needs, such as occupational therapists, district nurses, physiotherapists and others. The equipment is also delivered to hospitals and other stores to be taken to service users’ homes.

9.3.20 Independent Sector Domiciliary Care
Domiciliary care in Leeds is also provided by the independent sector. In Leeds this is provided by Prestige Nursing Limited. The Leeds branch consists of a management team of 2 TE, 2 branch assistants 3 field supervisors and 75 care staff. The management team and 2 field supervisors provide cover for an on-call service out of hours. The company offers a comprehensive care package for clients with complex needs and end of life. Services are available on a 24 hours basis. Blocks of time can be allocated in any combination but not less than 3 hours. The service is available to anyone with a Leeds postcode, or Wakefield postcode if Leeds GP. Prior to engagement staff are required to have 1 year’s practical care experience. New starters undertake a comprehensive training programme before employment commences. All staff are trained in end of life care and bereavement. All 75 members of staff are either trained to NVQ level 2 or 3, or are studying for level 2. All new members, without NVQ qualification, joining Prestige make an undertaking to study for the qualification with Prestige. Some members already have NCFE level 3 in Palliative Care and others are currently studying for it. All members complete classroom based and eLearning for End of Life Care.

New starters shadow an experienced member of staff where they observe and understand the different components of their role. At their first shift, an experienced supervisor will attend for 2 – 3 hours or until the new staff member is comfortable to proceed on their own. Further training is provided in specialised topics as required. Prestige receives referrals.
through Joint Care Management (JCM) or the hospital social workers. Daytime referrals are received from 8am to 8pm. Prestige works in conjunction with the District Nursing Night Service to co-ordinate any referrals received out of hours. A good working relationship was reported between the 2 services.

The team of 75 carers consist of some part time some full time. They work between 7am and 10pm. The company have achieved their CQUIN Award for care plans in place within 24 hours for fast track clients and Support Plans within 72 hours for Complex Clients (100%). All staff are spot checked and supervision is in place on a 3 monthly basis. A standard is in place to ensure that all male patients are attended by male carers.
9.4 Perspectives of staff delivering these services

Below are the results of the thematic analysis of the interview notes and survey responses gathered from interviewing staff delivering EoLC services in Leeds. The themes that emerged most powerfully are:

- 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
- Need for earlier recognition and acknowledgement of the EoL stage
- Concerns around the PPD target and meaningful patient choice

Themes that emerged strongly include:

- Importance of strong, flexible working relationships
- Variation in provision and quality of services across the city
- Inadequate and unclear provision of bereavement services across the city
- Positive experiences of the LCP and concerns around public perception
- Increasing patient complexity, it’s not “just cancer”
- Continued need for a comprehensive education and training strategy
- Issues arising from the use of independent sector staff
- “Culture of cure” and lack of willingness to communicate with dying patients
- Importance of good communication between staff and patients
- Debate between specialist and generalist roles
- Potential to improve access to medicines
- Lack of support for carers

Other themes identified by some respondents include:

- Need for senior colleagues support to facilitate change
- Potential to use volunteers
- Positive role of care homes in palliative care provision

9.4.1 Strongest themes

9.4.1.1 A high level of personal motivation and skill amongst most staff

A recurrent theme from the interview findings was the high level of skill and personal motivation of individual staff and recognition that high quality care for someone nearing death is crucial. There were many examples provided where staff work outside of their contracted hours to ensure a good service is provided to patients. E.g. the pain management consultant who said:

"Management of patients with intrathecal drug delivery systems can be complex and can require me to see patients in Leeds hospice for pump refills; this is often done in my own time"

One discharge facilitator is employed weekdays, 9 – 5 but regularly works longer:

"on a Saturday morning if there is a late Friday discharge, this happens a couple of times a month. Or I will work late and hand over to the twilight service at 6.30"

One GP stated:
“I give my personal mobile number to my patients receiving terminal care at home so they can contact me directly with any problems / queries OOH - very seldom do they ring and always quite appropriate when they do.”

Social workers based in LTHT who noticed when organising care in the community:

“Some agencies move heaven and earth for end of life patients”

Staff are skilled at working around issues and gaps in the system and are proactively and continuously devising local solutions to problems they have identified. All staff had ideas of how their services could be improved and most staff had devised and implemented new ways of working, showing their commitment, reflective working and professional freedoms they were trusted with. For example staff working with patients who have dementia have formed an EoLC group and

“produced symptom management guidelines for dying dementia patients which are about to be distributed”.

And discharge facilitators from across organisations who

“developed a flow chart to support care home managers without nursing and questions to ask the ward when they are trying to discharge EoLC patients home”

Generalist staff volunteered that EoLC is an important part of what they do which provided high job satisfaction when they were able to do it well. For example a care home manager who stated

“I have a motivated and enthusiastic team who are prepared to go the extra mile to deliver good end of life care”.

And a GP who said

“This is a very rewarding aspect of my job and it would be nice to have more time to do it better, but we do our best I feel”

9.4.1.2 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

A recurring theme mentioned by almost all interviewees was concern about reduced staffing capacity. The most concern was raised about the capacity of the district nursing service, followed by ward based nurses.

There was a perception that district nursing staff are not able to deliver care according to the LCH EoLC Service Delivery Framework (Leeds, 2010). It was perceived that district nurses were delivering excellent level 3 EoLC; in the last days to short weeks of life but were not delivering level 1 and 2 care (6 – 12 months, supportive visits and routine phone calls and at the intermediate level a monthly visit of phone call). A CNS stated:

“The DN framework is excellent on paper, but levels 1 and 2 rarely work due to capacity and skills issues. Care for level 3 can be excellent (last days and hours of life) patients without a high level of need on assessment can slip through the net and not know where to turn to when they deteriorate or hit a crisis”.

A sheltered housing manager gave an example:
“I had a lady who just did not receive the amount of care needed to keep her comfortable in her final weeks and no matter what I tried I could not get her more than four visits a day for her, unfortunately this lady was alone for a great length of time during the day and all night. It was heart-breaking to see a previously happy lady deteriorate without the dignity she deserved.”

Evidence was provided about staffing levels, demand and skill mix which showed that the service has had a 25% increase in demand, 10% reduction in numbers of staff and reduction overall in experienced district nursing staff. Examples of the consequence of this is that newly qualified staff were not experienced enough to identify when people needed medical referrals and continued to treat symptoms e.g. providing bandaging to leaking oedematous legs rather than referring for review of medical treatment. Examples of some GP comments include:

“District nurse service is worrying, lack of experienced staff some days, not enough staff in general … I do not think it is acceptable for patients dying at home to wait for two hours for a PRN dose of medication to alleviate suffering due to a lack of resource. Families panic and call ambulance”.

“District nurses locally very good but stretched in terms of workload and bureaucracy.”

“DN service often seems to let families down – when they are there they do good work, but it is often different people and patients have to wait for pain relief etc. which is very difficult for themselves and their relatives.”

Some GPs commented on the reorganisation of the DN service:

“There is noticeably less communication, joint working and participation in gold standard meetings than prior to the reorganisation of DN teams.”

A district nurse manager stated:

“Not many staff, increasing demand, can deliver the service but response times are getting longer and longer. There seem to be more complex palliative care patients coming out into the city, need enough staff to spend time to do this”

Concerns were raised about the impact capacity issues within the DN service were having on the relationship between DNs and their patients. This concern was recognised within the community nursing team themselves:

“There should be more quality relationships between DN and people who are dying. DNs are task orientated … you are told to build up a relationship etc. but we don’t have time to go in for tea and a chat.”

Another nurse observed:

“It has become quite task orientated – losing the assessing a patient holistically bit, the psychological and social care is important but being missed.”

Turning to LTHT, a ward sister commented:

“It is quite difficult to tell someone they have cancer, and look after your other 11 patients,” and that “with staffing down, it’s no frills nursing.”
Concerns were consistently raised about the agenda to move care from the acute trusts into the community without the reallocation of resources to fund additional community staffing levels. Related to this were concerns raised about the lack of capacity among general health and social care staff to support people being discharged to home, the need to use agency staff and at times the lack of agency staff. Concerns were also raised about low staffing levels amongst ward based night staff and community night staff.

There were concerns raised about services delivered by a single worker, e.g. the LTHT Consultant Anaesthetist in Pain Management and the EoLC Facilitator for Care Homes (who supports some care homes with syringe drivers) who find it impossible to cover sickness and holidays.

In terms of facilities concerns were raised about lack of appropriate hospital beds for people who were dying. Interviewees gave examples of the impact of this, e.g. staff moving a dying patient to a different ward in the middle of the night or a patient dying in a bay rather than a side room. Interviewees also identified a lack of facilities for relatives and carers in some parts of LTHT e.g. quiet rooms to hold sensitive discussions, rooms to relax away from the bedside, facilities for a hot drink. Examples were given where staff had to use the ward sister’s office which is inappropriate to hold sensitive discussions, as the environment was not suitable and there are lots of interruptions.

There were several comments about the Leeds Equipment Service. Some interviewees thought the service should run seven days a week whilst others thought unless this was matched by all other services it is not required. A small number of interviewees gave examples of equipment not being collected from a home for a considerable amount of time after a death; and delays in accessing equipment if a patient was not in receipt of Continuing Healthcare funding.

“LES work very hard and pull out all the stops to get the equipment out, but sometimes struggle to collect it.”

Although the vast majority (83%) of GPs stated they could access SPC in the community and hospice beds easily, a significant number mentioned difficulty accessing hospice beds e.g.

“Not enough hospice beds in Leeds when patients needs them”

“Difficulties in accessing St. Gemma’s care during the weekend due to shortage of beds, once I needed to admit patient to hospital which is not ideal for the patient but no other alternatives at home or hospice at that time.”

GPs and hospital doctors identify that they need longer time to have meaningful conversations with dying patients. A GP stated:

“Despite being a core service we don’t have the time to spend with patients”

A hospital consultant stated:

“There needs to be a culture of having time to have EoLC discussions … I do not think that 10 – 15 minutes in a clinic is sufficient to explore these issues with a patient. Therefore there would need to be development of a system that would allow more flexible appointments to accommodate these difficult conversations.”

Local Care Direct has experienced increased demand since 13h March (the advent of 111) with calls increasing between 35 and 68%. Clinical rotas have increased three fold but end
service users are still experiencing delays. The quality manager at Local Care Direct commented:

“The main complaints are around delays.”

This links to the section around OOH care.

Concerns were raised about future capacity in relation to the Palliative Care Funding Review:

“Proposed Palliative Care Funding doesn’t include education or strategic change, palliative care is about so much more than individual patients”.

There is anecdotal evidence that care homes struggle at times to secure medical support for EoLC decisions.

9.4.1.3 Patchy out of hours care, and high workload

There were a large number of concerns raised about OOH care, in terms of provision being patchy and often overwhelmingly busy.

There were many views expressed that EoLC should not be a 9 – 5 Monday – Friday service. Services that don’t offer provision at all at weekends and bank: holidays include; palliative care clinical nurse specialists in the community and in the hospital, palliative medicine physicians (although provide 24 hour on-call telephone advice service and will visit as necessary), community discharge facilitators, the Leeds Equipment Service (works Saturday morning), specialised pain services, LTHT EoLC discharge facilitators, LCH EoLC facilitators, EoLC care homes facilitator and specialist LTHT social workers. Systems don’t support easy access to palliative care drugs OOH. The EoLC Facilitators based at LTHT suggests this pattern of working leads to:

“Frantic Fridays and Manic Mondays.”

There was a consensus that working seven days a week would be good, and for this to work, most services would need to be provided seven days a week. It was not felt that 24 hour services are necessary for all services provided. A comment was made that:

“There is a density of distress and suffering, if there are services 7/7 on the community they need to be 7/7 in hospital.”

LTHT data shows that most discharges from hospital happen on a Friday. The discharge facilitator suggests:

“No one in a hospital on a Saturday or Sunday is willing to make decisions to get people home; the palliative care ambulance is not used at all on a Sunday”

There is a lack of capacity amongst community night staff and JCMs to arrange discharges from hospital and arrange care planning meetings at the weekend. District nurses are too stretched (twilight, nights and weekends). There is one doctor at each hospice covering care for all the patients, they can’t take too many OOH and weekend admissions because it pushes their hours over what is permitted in their contracts. Workload for hospital ward nurses and doctors for can be very high during weekends and nights. Doctors can be covering a number of different wards and nurses can have very high patient to nurse ratios, we were told of a case where one nurse was nursing 30 patients overnight.
Local Care Direct was mentioned frequently in terms of long delays for call backs, long delays for visits, sometimes suggesting care homes call 999 without a patient being visited by a GP, concerns about the quality of some GPs employed by LCD and their knowledge and skills around EoLC. Various staff groups reported significant delays in accessing GP advice and visits from Local Care Direct through the new 111 system; this is evidenced by the YAS Datix reports on complaints. One GP stated:

“OOH care is in chaos”

YAS undertake the assessment; this is done by non-clinical call handlers using an algorithm. If palliative patients call 111 instead of the dedicated PC OOH number, and do not highlight that they are a patient receiving palliative care at the outset the call handler will take then through a routine algorithm that may lead to inappropriate admission.

A DN stated:

“The current OOH GP services are not adequate for the needs of OOH community nursing services. There is no speedy access to a GP should we require advice or to discuss a particular case. There are instances where messages for a GP call back have been requested and quite simply this has not occurred. This is not good enough if we are to continue and provide a high level of EoLC in community.”

In addition concerns have been raised about the standard of care and skills of OOH GPs. Hospice colleagues stated:

“OOH GPs are an issue. Often the OOH GP doesn’t provide an accurate or comprehensive assessment”.

A care home manager stated:

“Lack of support from OOH GP service in recognising when someone is at EoL should they become unwell over the weekend.”

There are also examples where no GP was provided, e.g. an example by a care home manager where:

“LCD requested [hospital] admission before visiting but this was dealt with by the nurse in charge to prevent inappropriate hospital admission.”

On the flip side, the surveys show not all staff fill in the OOH forms. These forms record PPC, DNACPR and which anticipatory drugs are in the home. This information is used by YAS and Local Care Direct. If it is not available it hinders appropriate OOH assessment and management. Local Care Direct receives a large number of requests for Palliative Care Medication and carries all PC medication. One GP recognised this:

“Anticipation as far as can do is really important – minimises problems for any OOH services involved”

Wheatfields hospice audited OOH calls to the hospice in 2011. In a three month period 145 calls were received, around half of these were between 9am and 5pm. The majority of calls were in relation to symptom advice. There were 15 requests for admission to the hospice, 9 resulted in admission. The report concludes that providing a seven day a week telephone advice service may reduce calls to OOH GPs.
9.4.1.4 Problems arising at physical and electronic interfaces between services

The interfaces between services potentially create issues. The largest area where this is a problem is upon discharge which is discussed as a distinct and separate theme in 9.4.1.5. The majority of issues arising at service interfaces relate to data and information sharing. Some relate to processes and paperwork and others relate to personal interfaces.

9.4.1.4.1 Electronic interoperability

One of the biggest issues raised was interoperability of IT systems and data and information sharing.

Social workers support clients to develop Advance Care Plans which supports the early recognition agenda, however these aren’t recorded anywhere the health service can read. The ASC system does not link with the EPaCCS system. The heads of service are looking at how to share PII data between health and social care and point out that:

“Integration is going to become a crashing reality”

YAS can’t access EPaCCS. There are issues for ambulance crews in general around lack of DNACPR forms and it is perceived by some YAS staff that some GPs do not see DNACPR forms as part of their job. Local Care Direct is on SystmOne but YAS can’t see those data as they are on Adastra.

LTHT can’t access EPaCCS and hospital systems cannot be accessed outside of LTHT.

It is welcomed where data can be shared. One GP stated:

“Allowing shared records and tasks between palliative care and the practice is essential and now working well.”

In LTHT the eDID (electronic discharge document) is being piloted, however system is currently unable to include fast track documentation.

9.4.1.4.2 Processes

The pain consultant reports that there are no provisions for refilling pain relieving pumps outside hospital premises.

Social workers based in LTHT can’t take actions to start discharging patients until they have fast track paperwork:

“even though we know it will be approved”.

Some social workers based at LTHT feel that wards often forget to fill out OOH forms and some wards can be slow to refer to SPC.

A GP stated there can be delays caused by waiting for letters from secondary care.

Some GPs expressed frustration with paperwork:

“If we have to tick many more boxes then I shall be packing in general practice and so will many more over 50s.”

“Fast track forms ridiculous, have to obtain signed consent from the patient when they are already receiving care. This delays applications and adds no value.”

“Starting to feel we’re just expected to sign the scripts and organise the drugs.”
Issues were raised about paying for equipment across services. A care home manager stated she thinks:

“Continuing Healthcare should be able to provide specialist dying sets, such as for syringe drivers, which cost the home vast amounts of money. One had a resident who had to have chest drainage kits and we had to buy them and charge back at hundreds of pounds a time, again we ended up out of pocket, not really fair”.

9.4.1.4.3 Personal interfaces
There are issues arising from personal interactions across services.

Different services use different language. The AMBER care bundle used in secondary care but not primary care, and the GSF is used in primary care but not secondary care.

Community Nurse Specialists state they need more information in referrals from consultants.

One GP raised concerns about which services should be the lead link with a patient:

“The palliative care services need to decide how involved they are with a patient’s EoLC. All too often I will see a patient who has been largely cared for by the hospital services and palliative care but when they reach extremis the patient calls them to be told call your GP who has been largely uninvolved to this date and has the awkward position of trying to sort out urgent EoLC when this could have been predicted and prepared for. I would like to see a truly integrated service that involves the consultants, community services and GPs to provide a complete service rather than the fragments service which exists currently”

Where MDT meetings are in place they are valued. One GP said:

“Our Gold Standards Framework meetings are well attended and really useful and we have good practices in place for recording our discussions”

A sheltered housing manager gave an example of poor care resulting from poor personal interfaces between services:

“Gentleman with cancer with EoLC. No communication between carers, court manager, nursing staff… Ambulance men were not aware of his condition… patient ended up dying in hospital some weeks later.”

9.4.1.5 Concerns around hospital discharge
The importance of well-planned timely discharge from hospital was highlighted by staff from all professional groups both inside and outside of LTHT, with many examples of where it has been done well and the difficulties that arise when something has been missed.

Discharging a patient with palliative care needs is complicated and time-consuming; it is currently the responsibility of the ward.

There are different models of discharge practice within LTHT. Patients can be discharged home without support if it is not needed.

If patients need extra care on discharge, all discharges from LTHT that are not fast track or for the over 65s are supported by the social worker team at LTHT. The social workers assess packages of care, which may include things like reablement, housing, temporary placements, referring on to community matrons etc. Discharges are processed through the
Single Point of Referral System (SPUR). The Bexley Wing discharges do not currently go through the SPUR but will be required to once the eDiD is rolled out.

There is a difference in the role of social workers supporting discharge where a Fast Track application for continuing health care finding has been approved. In the Institute of Oncology (Bexley Wing) there are dedicated social workers who take on the role of the joint care manager and commission community services for patients on discharge, however the nursing staff still have to do the nursing assessments and the medical staff fill in the forms for fast track applications. In the past there was a dedicated band 5 nurse discharge coordinator piloted on one ward in Bexley wing and feedback from the nursing staff on that ward was it significantly improved the quality and reduced nursing time taken to support discharge; however there wasn’t funding available to continue the pilot.

In the rest of the trust, when the fast track forms are approved a Joint Care Manager is appointed from a relevant base in the community and they organise the care. Past LTHT audits have shown that fast track discharges take around seven days and this is the same time for the Bexley and general hospital services.

Therefore discharges can be complicated and time consuming with many potential delays if managed by an inexperienced member of staff. Currently nurses lead the majority of discharges although much of this is an administrative task. It has been commented that as discharges can be so complex and time consuming, and there is a turnover of staff on wards, keeping ward staff up-to-date has been

“A massive uphill struggle”

A number of issues were raised by interviewees, e.g. joint care managers giving appointments for the care planning meeting outside of acceptable time scale may not be challenged by inexperienced ward staff.

The rapid discharge pathway is only on 9 wards in the Trust at the moment. Further implementation is currently on hold. There is a difference in understanding between hospital and DN staff around fast track discharges and what they mean, there is some confusion with rapid discharge pathway.

Some district nurses stated that patients had been discharged from LTHT with unrealistic expectations about the level of service available in the community. Examples were given by district nurses, where patients they saw had the impression that the district nurse would be at the front door waiting for the patient to arrive at home following discharge. Staff at LTHT said that in the past patient panicked when they arrived home about the lack of support and ended up begin readmitted. One DN gave an example:

“We are finding recently that many discharges are happening after 5pm at night, if the discharge has not been set up properly this can leave the patient, their families and the nursing staff in a very vulnerable position”.

The EoLC facilitators have observed that:

“Relatives often envisage having a nurse at home for 24/7 care, however this is not the reality and this often effects the decision for them to go home and can lead to patients being readmitted shortly after being discharged home from hospital”.

In response to these incidents a leaflet was developed to explain to patients what to expect upon discharge and included useful numbers.
The district nurses gave many examples of issues arising where anticipatory medicines haven’t been prescribed to be taken home with the patients.

The eDAN (electronic discharge advice notes) are crucial in giving community staff the right detailed information about patient expectations and management, several comments were made that this was improving but not universally done well.

Leeds Community Healthcare staff feedback incidents arising from discharges through the Datix reporting system. These are sent to the LTHT Discharge Facilitator who uses them as an training and feedback resource. Between 1/4/12 and 31/3/13, there were 37 incidents reported. 35% of these incidents happened on a Friday. Incidents included:

- poor communication and care planning e.g. family not aware of prognosis or severity, no referral to a DN, no discharge summary letter;
- medication issues,
- issues with poor documentation (e.g. no DNACPR documentation competed),
- equipment missing and
- discharge delayed as no transport and issues around safety.

One GP gave an example of a poorly managed discharge and its impact:

“Recurring problems with poorly planned / poorly communicated discharges from secondary care. eg lady discharged on Friday night of a bank holiday weekend for terminal care at a nursing home with no anticipatory drugs prescribed, nobody at the home who was trained to set up a syringe driver and no communication with GP prior to discharge – that lady died on the Tuesday am having had poor symptom control for the last three days of her life.”

Many staff suggested the idea of an EoLC discharge team based at LTHT who completed discharges for generalist ward staff, one for each medical speciality. It was suggested if the service was pump primed it would shortly self-fund using an invest-to-save model. One consultant stated:

“These people need to come and sort it out for the ward nurses who simply don’t have the time to do it themselves”

9.4.1.6 Need for earlier recognition and acknowledgement of the EoL stage

The strongest call for earlier recognition and acknowledgement of the EoL stage came from social workers and consultants.

The social workers based in hospital explained that much more could be put in place for patients who were dying but it was not their place to tell patients. They had to wait for doctors to have this conversation.

“This could all do with coming upstream, if EoLC could be talked about in the next 12 months this would be useful… this opens us up to so much more ability to assess, plan and give more choice, ACP and making life choices, wills, discussion about children and schools etc… the more you can get people to speak and start planning early, the less likely you are to have a crisis intervention and you can build carers support into that.”

It is perceived by one SPC consultant that

“A lot more education around EoLC needs to happen, it’s not simple, there are reasons why people aren’t having this conversation”
The same SPC consultant suggested it is important to time conversations: public health should lead the dying matters campaign when people are well, all patients need advance care plans, when you are ill you need a discussion around PPC and revisit it when patients have a prognosis of weeks or months of life.

Consultants from other specialities expressed views about earlier recognition:

“Not sure all patients have an ACP. The evidence for COPD is that ACP discussions during exacerbations are not helpful... I believe this is better taken up in the OPD or in primary care.”

“We’re still hopeless about consistently identifying patients in last phase of life, initiating difficult conversations and passing on to GPs.”

“Advance statements and advance decisions to refuse treatments … not widely used or promoted amongst patients with dementia … people with dementia, while they have capacity, should be given the opportunity to discuss the use of advance statements and local protocols should be put in place to formalise these arrangements.”

The last comment was echoed by the health and social care dementia lead for Leeds who suggested we should be giving information about lasting powers of attorney at the same time as diagnosis and points out that dementia is different to other diseases as early on there is an opportunity to plan in advance, people are less able to have these conversations later on.

The benefits of EPaCCS and palliative care registers were acknowledged. One GP stated:

“I think once on the register there is good all round care, but I still find it hard to decide which patients should be on it.”

One GP identified late discussions as an issue:

“Sometimes not having discussions about EoLC early enough with patient and family, but we are getting better at this. Especially considering non-cancer diagnosis and accepting the end stage of other chronic conditions.”

YAS stated

“People need to have very clear advance plans”.

9.4.1.7 Concerns around the PPD target and meaningful patient choice
A large number of interviewees criticised the blunt application of the PPD target.

Social workers stated:

“Recent reports criticise the obsession with PPD rather than personalisation and choice, decisions change as people approach death, at 12 month they say home, 3 weeks before they need to be confident they have someone medically qualified who can respond 24 hours a day.”

This is echoed by the LTHT EoLC facilitators, who explained

“The steps get steeper the nearer the grave you get”

And gave examples where
“You have a family whose plan of care is being at home, then they are dying and the relatives don’t want to move them – too poorly and don’t want them to die in the ambulance and they don’t want to be on their own without 24 hour care and don’t want to be moved. So in terms of PPD we need to ask people where they want to die nearer the time.”

One GP commented:

“Patients family don’t want them dying in their house but won’t admit it because it sounds too mean.”

A broad range of respondents discussed patient choice and the fact that the role of hospices is to provide specialist palliative care to people with complex care needs. Often hospice is or becomes a patient’s PPD, however if they are “simply dying” they may not be eligible for hospice care. CNSs from both hospices stated:

“Patient cannot choose hospice for straightforward care if they don’t have specialist needs in the Wheatfields area. Often kept at home unless really not suitable, even if not patient preference. St. Gemma’s more able to admit these patients as have more beds.”

Some staff suggested setting up hospice at home schemes, or EoLC wards in LTHT.

One consultant pointed out:

“When you ask people what are the attributes of a good death, about number ten on the list is place. Before that is dignity, pain free, affairs in order, being communicated with and informed – quality really.”

If a person is discharged to a new nursing home, this is counted as a death in usual place of residence which gives a false picture.

Issues were raised with other targets as well. For example there is a QoF requirement to deliver palliative care in the GMS contract 2013/14. To secure the QoF points, GPs need a register and to have at least three monthly MDT meetings where all patients on the register are discussed. However, not all patients need to be discussed, and quarterly meetings are not frequent enough for some patients care.

9.4.2 Other strong themes

9.4.2.1 Importance of strong, flexible working relationships

People identified the strength of forging good professional working relationships in delivering high quality EoLC. It was acknowledged by many that cooperation between service providers, commissioners, LCT, hospices, LTHT and social care is good; and that there is a high level of confidence in other services.

The two hospices appear to work very well together. Attention was draw to the statement around cross city working in one hospice’s SOP. It states the SPC teams work closely together and counterparts meet together 6 week to bi-monthly. Operational policies are shared for comments and kept as similar as possible. Much education provided is delivered jointly. There is an understanding between St. Gemma’s and Wheatfields that they take patients if each other are full:

“We don’t argue about money / payments, it’s done on good will.”

“We see Leeds as a collective, we don’t charge for patients from XXX hospice.”
The benefits of co-location were highlighted. The hospital based social workers are co-located with multidisciplinary teams. Most staff have been in post for a long time which means connections with nursing staff colleagues are strong. The workers felt that co-location enables a very fast response, issues are picked up quickly, patients are not asked the same questions and it has created a multi-disciplinary problem solving team.

The benefits of good relationships within a geographical area were also recognised. Community SPC CNSs on both side of the city are linked to GP practices and build good working relationships with GPs, know their working patterns and local populations and have local knowledge of hospitals on the boundaries of Leeds. One community nurse specialist stated:

“We go to gold standard meetings, it has improved communications from all angles, feel more comfortable talking to a GP, they know who you are and have met you, also you might have a patient on your case load who isn’t on the register – can raise that and discuss a the meeting.”

Although some GPs commented on the change in relationships with DN since they had been reorganised:

“Less communication directly with DNs than previously due to their reorganisation”.

It was also noted the impact that bad relationships had. For example one neighbouring hospice reported there has been:

“a long and bloody battle with Leeds PCT for funding” and that there has been “a lot of tension about this”.

And one GP commented:

“Macmillan nurse works poorly with GPs and this sometimes causes conflict which is always under the surface. Macmillan nurse has her own agenda which always involves medication”.

There are also areas where relationships are being built:

“There is a long way to go before relationships are built between community nurse specialists and DNs, don’t speak to them face to face, need a good hot desk site to have a coffee and catch up… The idea of integrated working is fantastic.”

9.4.2.2 Variation on provision and quality of services across the city

Many interviewees described variations both in quality and capacity within organisations providing the same service.

There is variation in JCMs in the community, and their ability to get people discharged from LTHT quickly, some have a “can do” attitude and push for the discharge to happen but this is not universal.

People have different experiences depending on what people were diagnosed with. Specifically staff and patients identify the EoL phase more easily with a cancer diagnosis which is significant in terms of care planning and access to all additional services.

Some services are diagnosis specific leading to clear gaps for some patient groups e.g. the provision of psychology services (level 1 – 4 according to the NICE Guidance for Supportive and Palliative Care, 2003) is only currently offered to cancer and renal patients.
Although their eligibility criteria are not diagnosis specific, the vast majority of patients who access hospices services particularly inpatient beds, have a cancer diagnosis. Some conditions require differences in care planning, notably people with dementia for whom routine and early discussions around preferences for treatment and care are crucial. Work is underway in the Leeds hospices around developing pathways and service models for non-cancer diagnoses.

There is a huge difference in experience between people who have been identified and placed on the palliative care register and people who haven’t. The majority of people in Leeds who die aren’t on the PCR. Between GP practices there is variation in which member of staff (profession) creates the report identifying possible EoLC patients.

Interviewees reported a variation in the quality of support offered by GPs, in and out of hours. Hospice community nurse specialists have noticed the differences between GP practices in their knowledge and approach to EoLC. District nurses have reported variations in skills and confidence in GPs in and out of hours, lack of skill has resulted in inappropriate admissions:

“Variability on GP palliative prescribing disappointing.”

“Services are good depending on the GP support.”

One DN commented on differences within their own service:

“I feel that the empathy and compassion and care delivery from the majority of community nurses is outstanding, particularly when the fast track status has been given by the GP. Unfortunately I have been to some patients who fall out of this category and we have struggled to bring in all the support services and resources. It is these patients who I see an inequality for.”

One GP commented:

“We cross two DN teams and find we have a better relationship with our main team and very little input from our secondary team.”

There were comments about the variation in the quality of LTHT discharge letters, some people praised them and some people said there was not enough information on them about information given, discussions about choices and future options for treatment. The social work manager perceived EoLC across LTHT to be uneven.

There is variation in terms of extended roles; some staff have extended roles e.g. community matrons are all nurse prescribers, some clinical nurse specialists and some heart failure nurses are either nurse prescribers or being trained. A significant number of DNs have been trained in verification of death in which case they can avoid a call out to the GP OOH, and a significant number of DNs have been trained to apply for FT funding but not many have achieved competence.

There is uneven hospice provision across Leeds; there are two hospices in the north, covering approximately similar populations, one with 18 beds and one with 32 beds. There are no specialist palliative care beds in LTHT or in the south of Leeds. 35 patients from south Leeds accessed Wakefield hospice in the last financial year this equates to 385 bed days. There is a perception amongst hospital staff that although hospices share the same eligibility criteria for admission, their thresholds do vary. One GP commented:
“Recent refusal of admission to XXX hospice for rehab / physio (in the face of consensus view of patient, family, Macmillan nurse, DN and me) has undermined my confidence in this service.”

Although both hospices will accept special requests for admission to their unit from people out of their catchment area this is not offered as a routine choice.

9.4.2.3 Inadequate and unclear provision of bereavement services and mental health services across the city

St. Gemma’s identified a gap in psychological support:

“There is a gap in levels 1 – 3 where people need a therapeutic approach. The hospice has very little level 4 service. Sarah Catesby’s team is funded for cancer diagnosis only; there is no formal pathway to access her support.”

This issue is acknowledged by Chris Hosker, Consultant Liaison Psychiatrist at the mental health trust:

“Although provision of level 4 psychology services for cancer patients in good, provision of lower level support is rather ad hoc with no systematic approach and governance is unclear.”

He was also unsure what arrangements the specialist palliative care teams have for managing complex grief. He suggests:

“This requires a full MDT and governance structures and it is not clear if this is in place.”

The Leeds Bereavement Forum published an audit report (January 2011) which recommended a process and criteria are developed to ensure clear signposting and routes to access services at the right level. This should include identifying people with complex bereavement needs to ensure they are referred to the appropriate health and social care professional.

St. Gemma’s also raised a problem with mental health services more generally:

“There is also a problem with crisis mental health support, St. Gemma’s have had patients who are suicidal, have delirium or are psychotic, The Mount can’t help because the patients are not poorly enough yet.”

9.4.2.4 Positive experiences of the LCP and concerns around public perception

The majority of interviews took place whilst the Neuberger review of the LCP was being undertaken. Many staff shared positive experiences of using the LCP but also acknowledged anxiety patients and their carers showed about it being used. A ward sister commented that:

“Things are difficult with the LCP at the moment. From my point of view, the medics are good at reviewing DNRs or the LCP and if someone jumps up and has a new lease of life they are very good at withdrawing from the LCP.”

A consultant points out that the LCP links to a culture change, and

“The solution is only partly in the clinic room.”
Some staff expressed concerns that because of the LCP controversy, doctors will be less likely to use the LCP, they may be:

“More reluctant because they haven’t got the time to have those conversations with relatives.”

9.4.2.5 Increasing patient complexity, it’s not “just cancer”
Interviewees raised the issue of increasing patient complexity. One consultant commented:

“The patients we are seeing are more complex, some measure of complexity, frailty, co-morbidity, living alone, sometimes have to do a lot of homework to provide the right answer.”

A colleague working in a hospice listed increasing patient complexity as a concern in terms of resources and staffing ratios in order to care for patients with increasingly complex needs.

The same colleague discussed the issue of transporting patients to the day unit at the hospice, and issues as their needs are becoming more complex.

“We have had to escort a number of patients home in taxis due to the complex nature of their illness and for their safety. So for example a patient may be brought in by a volunteer driver or taxi and then deteriorate, for example they may have had a seizure or mobility. We cannot book an ambulance to take them home so we have to escort them home.”

The specific needs of dementia patients were raised by a number of staff, including a non-dementia consultant:

“There is a gap for people identified with early dementia and dementia to palliative care (managing co-morbidity)”. 

The Leeds dementia strategy points out that

“the complexity in the late stages of the condition means that the majority of people die in a care home or hospital. This may be the choice of the person or family and is entirely appropriate when a care home has been the person’s home for a long time. However unplanned admissions very near to the end of life can be upsetting and can often be prevented by community services”.

The same consultant highlighted the complexities faced by the ageing population and the need for EoLC discussions with people with a non-cancer diagnosis.

“All the issues raised are only going to increase with the ageing population and multi-morbidity. Maybe we should be more frank with patients at the beginning i.e. you have COPD, this is a chronic incurable condition”

A hospice consultant discussed the non-cancer agenda:

“This area has been very successful with the demand for non-cancer clinics outstripping available places in both day hospice and outpatient clinics but need to link with additional senior personnel to develop services.”

Both hospices are pro-actively developing non-cancer EoLC.
9.4.2.6 Continued need for a comprehensive education and training strategy
A number of staff raised the need for on-going training. It was observed that it was hard to reach some colleagues through training:

“Often when you are training senior staff you are preaching to the converted, the ones on board. It is hard to catch the reluctant ones”.

Concerns were also raised about the challenge of keeping a huge workforce trained. In relation to education around discharge processes, a LTHT consultant commented:

“Concerns at the moment are the size of the organisation and how do you train everyone to a gold standard of being able to discharge because of staff turnover, newly qualified staff, so many processes to discharging someone, takes so much time, not time on the wards to do it”

Information received through feedback is used to educate staff e.g. the LTHT discharge facilitator reports back on issues included in the Datix reports, to relevant members to staff as an educational opportunity.

A social worker commented on education of the public:

“There is a gap in education and information for patients and carers, they have unrealistic expectations”.

A social worker who worked in general hospital wards said that social workers would like more education on:

“Specialist palliative care, the SPC team’s role, indications for referral, services available etc.”

The need for education and training around EoLC was raised by other professionals outside of SPC providers e.g. a consultant from the Mental Health Trust:

“There is a need for a comprehensive education and training plan for health and social care professionals involved in care of people with dementia, at present there is considerable variation in the quantity and quality of training provided across organisations with an undue focus on task-oriented care.”

The Leeds dementia strategy points out that people with dementia, especially at the late stages, might struggle to communicate feelings and symptoms.

LCH Community Nurse Specialists also raised this issue:

“Need to increase staff skills and confidence around EoLC, especially as some nurses trained in rehab”.

And GPs:

“GPs to have further training, especially around prescribing for EoL.”

The interpreting service manager also stated the interpreters would benefit from regular training.

9.4.2.7 Issues arising from the use of independent sector staff
Some interviewees raised issues arising from the use of independent sector staff.
Issues were raised around capacity of the workforce and problems patients using individual care budgets have experienced. The leads for social work in the local authority commented:

“There is an issue around market development – lots of people are not attracted to working in home care, people with individual budgets are struggling to retain personal assistants, there is a limit around the structure and regulation with these staff, personal assistants are not regulated in the same way as other local authority or agency employed staff, there are issues around safeguarding.”

Social workers based in hospital have experienced a lack of providers of home care in some areas:

“There are areas of Leeds where there are few providers, the capacity of providers and placements is an issue.”

The manager or CHC is aware of this issue and is in the process of procuring a contract with one provider in Leeds for Fast Track to ensure that there are always staff available in Leeds to meet additional personal care needs.

Some staff gave examples where agency staff were provided, but the NHS service managed them, this was not formally arranged but was required in order to deliver a high quality service. A DN manager commented:

“We feel we are supporting the independent provider to deliver a good service, this needs to be quantified and acknowledged”.

Hospice CNSs expressed concerns around the use of agency staff:

“Agency staff are used a lot to fill gaps. They are sometimes hard to access and quality varies. Each agency keeps separate notes to patients can have several sets in the house – adds to the complexity and risk.”

One GP gave examples of poor care that they perceived was due to the use of agency staff:

“The two instances that spring to mind of inappropriate action OOH both stem from actions of bank nursing staff in nursing homes, calling ambulance in terminal phase / point of death due to inadequate handover in the nursing home... family complained, one patient taken to hospital and returned a few hours later, the other case the ambulance crew acted appropriately and did not transfer the patient”.

The independent domiciliary care provider, Prestige, identified lack of communication from the DN day service as a key issue:

“This impacts on the quality of their service e.g. care plans are not updated, specialist training not given, reactive rather than proactive care, leaves staff more vulnerable (e.g. fails to inform them about dogs, smoking etc.) and is upsetting for families when their relative has died or been admitted to hospital and staff attend for an appointment. There is also a cost implication to consider for any appointments that are wasted for this reason”.

9.4.2.8 “Culture of cure” and lack of willingness to communicate with dying patients
Some interviewees spoke about doctors reluctance to accept a patient is dying and or discuss this with them; and reflected the culture of palliative care was not universally understood outside of specialist palliative care services. One ward sister commented:
“Medics have issues about making decisions about withdrawing treatment and looking at quality instead of quantity… doctors get the result then give them the news, I think you’ve got a tumour there: they [the patient] are shell shocked, so we go back but would like more time to dedicate.”

The same nurse commented that doctors:

“Drop the bomb then run”

One social worker commented:

“Some [doctors] aren’t able to have the bad news conversation”

Another social worker commented that:

“The discussion about the surprise question is not in the mind of 75% of the staff in the hospital … there are different cultures in different specialities, having the difficult conversation with patients, the understandable pressure to be optimistic.”

A GP commented:

“I still think some of my colleagues remain reluctant or find it difficult to initiate difficult conversations around EoL.”

And another stated:

“It is difficult to discuss future care planning.”

A different GP gave an example of the sensitivities from the carers perspective in understanding EoLC:

“Failure of families to really believe this is the final illness – they still want a miracle”

One consultant notes that there is an issue around perception of palliative care:

“There is a perception amongst healthcare workers and population in general that palliative care equals no active treatment. Need to address the issue so we can do both at the same time”.

The complexity around when people die was acknowledged. One consultant stated:

“More and more it is technically possible to do more and more later in life, seeing a group of patients who wouldn’t have been offered treatments, increasingly health professionals as being called to work in partnership with patients to see what is of benefit.”

A SPC CNS commented:

“Heroics are fantastic in the right place, but there comes a point in non-curative degenerative diagnosis where active invasive treatments are inappropriate.”

9.4.2.9 Importance of good communication between staff and patients

Related to the willingness of staff to accept that patients are dying, and discuss this with their patients, is the importance of good communication between staff and patients.
A SPC consultant commented that:

“The first communication course was run in 1994, breaking bad news, now feels out of date, because we are being asked to communicate risk and uncertainty and work in partnership with patients to establish a management plan in the is context”.

The same consultant noted the way this conversation is presented is important:

“The first conversation should be how do you want to spend your life not where you want to die.”

The DN team recognise the importance of relationships and try very hard for continuity in response to patient feedback.

GPs gave examples of where communication was a challenge. One GP raised an issue of cultural and language barriers with extended families. Another GP said that when patients were discharged from hospital, it was not always clear if the EoL conversation had happened.

GPs also gave examples where good communication was in place. A GP stated what works well is the personal care from a patient’s own GP. Another surgery has a policy where continuity is maintained with 1 doctor in charge when the

“situation becomes end stage”.

Another GP said their receptionists had been trained around patients who are dying and say this is an area that was working well.

9.4.2.10 Debate between specialist and generalist roles

A recurring theme was the debate between the need for generalist staff to be skilled in palliative care, or specialists in palliative care to deliver all palliative care. Some tasks are so specialised that generalist staff who use them infrequently are not always confident.

For example, a discharge facilitator stated:

“If you go in as a specialist team, to assist with discharge, there is a fine line between disempowering generic staff on how to do it, but at the moment it is so confusing people give up on it, hard to know what model we could put into place to change that…wards can come to rely on a specialist service to lead the discharge process and not take responsibility, see the discharge of EoL patients as separate as opposed to being something that is integrated into existing ward practice”

An issue that was raised a number of times from both care homes and district nursing was the provision of district nurse support in care homes with nursing around the use of syringe drivers in particular. Care homes without nursing have this support provided by district nurses routinely. The care homes that don’t often have residents that need syringe drivers struggled to maintain their competence. The Leeds Care Home EoLC facilitator does support care home nursing staff to use syringe drivers but as a lone worker is not available OOH or when she is on leave, so there have been instances where residents that needed syringe drivers did not have them.

There is a debate within the DN service. A leader within the DN service said:

“EoLC is a core skill for DN… DNs are good at EoLC, it is a big part of their job, would demoralise staff not to do it”
Whilst another leading DN stated:

“Demand for EoLC at home will continue to overwhelm the service at times and for many reasons patients may not always receive the care they need from a confident, competent workforce. Therefore, I very reluctantly think the time may have come to develop a palliative care team made up of competent confident DN’s … to ensure patients receive the best possible care.”

This dilemma was articulated by one GP who stated:

“We are becoming de-skilled by deference to specialist services, but must be prepared to update skills and offer ready access to patients”

9.4.2.11 Potential to improve access to medicines

The interviews identified issues with access to EoLC medication. The head of medicines management at the CCGs, sees one of the hospice pharmacists as the lead for EoLC in the city. It is planned that the CSU will follow up and put in place an enhanced service with the hospice pharmacists, possibly the provision of a “super-pharmacy” in the city.

The hospice pharmacist mentioned has a number of ideas of how to improve EoLC medication in Leeds but the hospice is not contracted to do anything citywide.

The hospice pharmacist has identified a number of issues around accessing EoLC medication in the community:

“Access to drugs OOH, chemist can ring a wholesaler and pay £50 to go to a warehouse to pay for a drug … Pharmacy services in the community are private businesses or GP dispensaries, there is an issue around drug stocks and how they are ordered… would love there to be information on the Leeds palliative care website… could include top tips e.g. chemists order twice a day. In the worst case scenario relatives are trawling around for drugs. You can get a lot of them at Moortown pharmacy but it is not city centre and can be a long journey for people.”

This pharmacist also identified a number of solutions, which had been in progress in 2001 before the changes in the NHS, which resulted in the plans stalling:

“An arrangement for pharmacists to hold a stock list of drugs … A reimbursement scheme to pay pharmacists for drugs that go out of date … update the generic list of drugs and create a north and south super-holding pharmacy”.

The lead for medicine governance at the CCGs for the hospices also noticed a gap in medicines management for patients based in the community:

“There is evidence from other settings to show that pharmacy input to MDTs improves medicines management. At present, patients based in the community to not have access to specialist pharmacy as part of the MDT”

DN report issues with accessing EoLC medications:

“Sometimes there is a problem with GPs centralised prescribing which causes delays. Can be hard getting drugs prescribed in large quantities, and then hard to find them available. This is even worse OOH… some GPs don’t believe in anticipatory prescribing, this is not a problem if the DN is an independent prescriber.”
A number of nurses have been trained as nurse prescribers including some DN and some hospice nurses. One GP stated that anticipatory drugs have changed since they were trained and they would welcome more training.

Local Care Direct has an effective system for access to medicines OOH as they keep a full stock of EoLC medication that all their staff can access.

9.4.2.12 Lack of support for carers
A number of interviewees raised carers support as a gap.

A consultant psychiatrist stated that:

“Carers of patients with dementia are able to access an assessment of emotional, psychological and social needs; however these are not consistently promoted by services.”

The DN team see the consequences of lack of support for carers, and note day time respite as a gap:

“A significant number of carers suffer from carers strain – can’t escape the house and feel guilty. Could avoid a lot of care package breakdowns. Day time respite is as rare as hen’s teeth. It would be good to have as part of a community nursing service. It could be delivered by a health care assistant.”

Wheatfields suggested more carers support would reduce triggers to hospice and hospital in the last couple of days of life:

“It would be good if Leeds had a rapid response outreach team, other areas have trailed a mobile hospice and have a crisis team.”

This was echoed by the community matrons:

“There might be patients who go into LTHT due to carers fatigue, they feel ill, will ring 999, the ambulance crew will ask if they want to go in.”

The dementia lead spoke about the difficulty uncertainty creates for carers:

“With any long term condition that causes deterioration, there becomes a point where family and carers are struggling to cope. They face heartache and decision making about care home or not… If at that point social workers and families had a better context about how long someone had to live, this would reframe decision making.”

9.4.3 Other themes identified

9.4.3.1 Need for senior colleagues support to facilitate change
Some interviewees expressed a need for more senior support to facilitate change. A specific example was the need expressed for an EoLC lead nurse at LTHT (as opposed to palliative care lead nurse or cancer lead nurse).

9.4.3.2 Potential to use volunteers
The ward sister interviewed suggested volunteers who have had similar experiences to patients could come and have conversations with patients, with the aim of supporting patients come to terms with their diagnoses. The Leeds hospices extensively use volunteers in administration, driving and fundraising roles. St. Gemma’s spoke of the possibility of developing community companionship projects.
9.4.3.3 Positive role of care homes in palliative care provision

The results from the care home managers’ survey was very positive with 100% of staff who feel EoLC is a core part of their role and they should support people who want to die at home in home. There was an impression from care home staff that they don’t receive the recognition that is due to them about quality of care they deliver to their residents at the end of life. One manager stated there was a:

“lack of support and recognition that as a residential home we can provide excellent EoLC”.

There was recognition that the care homes with nursing that the EoLC Facilitator has worked in, calls to the ambulance service have reduced.
10. Perspectives of service users, carers and the bereaved

10.1 Introduction
This chapter aims to capture the perspectives of service users, carers and the bereaved. It includes a summary of the national VOICES survey which includes evidence of how Leeds is performing in comparison with other areas. This chapter also documents the findings from research conducted by Angwen Vickers who undertook research commissioned by the CCGs from the CSU and results of the recent LTHT bereavement survey.

10.2 National perspective

10.2.1 The annual national VOICES survey
The Department of Health commissions the Office of National Statistics to undertake national bereavement surveys. The first survey was conducted during 2011 and published in 2012. The second was conducted in 2012 and recently published (July 2013). There are plans for the survey to be carried out each year.

The survey was based on the Views of Informal Carers for the Evaluation of Services (VOICES) approach. Questions are asked about:
- Details about the respondent (e.g. age, sex and relationship to the deceased).
- Details about the deceased (e.g. duration of final illness and settings where the deceased had received care in the last three months of life and ethnicity and religion of the deceased).
- Perceptions of the quality of care delivered in each care setting including overall quality of care and dignity and respect given to the deceased person by staff.
- Coordination of care within the community and between hospitals and community services.
- Quality of care given in the last two days of life.
- Decision making toward the end of life.
- Awareness of likely death and preferences and choice about where to die.
- Respondents' views on ultimate place of death.
- Support provided to family/friends in the last three months of the person’s life and after the death.

10.2.2 Results from the 2012 VOICES survey
The 2012 survey was also commissioned by the DH and carried out by the ONS. The survey asked the bereaved about care in the last three months. 49,207 people were surveyed with a response rate of 46%. Headline results have been pulled out here.

10.2.2.1 Quality of care:
- 13% rated care as outstanding, 31% as excellent, 34% as good, 14% as fair and 9% as poor.
- Combining cause of death and place of death shows that overall care rated as outstanding or excellent was greatest for cancer patients who died at home.
- Using place of death only, care rated as outstanding or excellent was highest in hospices (59%) followed by care homes (50%), home (49%) and lastly hospital (35%)

10.2.2.2 Dignity and respect:
- Staff in hospices received the highest proportion showing dignity and respect “always” in the last three months (84% for hospice doctors and 82% for hospice
nurses. Hospital staff received the lower proportion showing dignity and respect always (59% for hospital doctors and 52% for hospital nurses).

10.2.2.3 Coordination of care
- 45% of respondents said community services worked well together and a further 41% said services worked well together to some extent.
- In relation to patients who had spent some time in hospital, 33% responded that hospital services worked well with GP and other community services, and a further 36% said they worked well to some extent.

10.2.2.4 Relief of pain and suffering
- Relief of pain provided “completely, all of the time”, highest in hospices (63%), followed by care home (46%), hospital (38%) and lowest at home (19%).

10.2.2.5 Decision making
- Two thirds of respondents reported that no decision had been made about care which the patient would not have wanted. However 17% of respondents said yes to this question.
- Respondents said the majority of patients (86%) were involved with decisions about their care as much as they wanted.

10.2.2.6 Preferences about choice at the end of life
- Only about 40% of family members reported that their relative had expressed a preference of where they would like to die and gave further details.
- For those who expressed a preference, the majority preferred to die at home (81%) and 49% of people did), the minority expressed a preference to die in hospital (2%) although 52% did.

10.2.2.7 Support for relatives, friends or carers at the end of life
- 60% said they had definitely been given enough support at the time of death, a further 26% said they had to some extent.
- 68% said since the death, they had not or did not want to talk to anyone from support services, 18% said they had not but would like to.

10.3 Benchmarking Leeds Nationally
The findings of the 2011 VOICES study were summarised by The Yorkshire and Humber Quality Observatory by PCT cluster. The PCT clusters were benchmarked against results nationally. PCT clusters could be scored in the bottom 20%, border of middle 60% / bottom 20%, middle 60%, border of middle 60% / top 20% or top 20%.

Leeds benchmarked in the top 20% for:
- Dignity and respect shown by nurses all the time in the last two days
- Pain management: reported relief of pain in the last two days.

Leeds was benchmarked in the bottom 20% for:
- Patient involved in decisions about care as much as they wanted
- Preferred priorities: expressed preference where they would like to die

and in the border of middle 60% / bottom 20% for:
- Preferred priorities: respondent considered decedent died in the right place

Leeds scored in the middle 60% for:
- Overall quality of care rated as excellent across all services
- Coordination of care when the patient was at home
• Coordination of care: hospitals and services work well with GP and other services while the patient was at home
• Dignity and respect shown by doctors all the time in the last two days
• Support for carers while the patient was at home
• Support for carers: able to discuss worries or fears with the GP.

10.4 Leeds research
As part of the HNA, the views and experiences of people who have needed EoLC services in Leeds were gathered. The West and South Yorkshire and Bassetlaw Commissioning Support Unit (WSYBCSU) led this piece of work.

104.1 Methods
It was agreed between the HNA working group and CSU that 25 in depth qualitative interviews would be conducted with families and carers who have been bereaved during the last 12 months, people facing the end of their life in the next 6 - 12 months at the time of the interview and families and carers of people who are facing the end of their life in the next 6 - 12 months.

The interviews were based on the steps identified by the Department of Health in end of life care:
• Step 1 Discussions as the end of life approaches;
• Step 2 Assessment, care planning and review;
• Step 3 Coordination of care for individual patients;
• Step 4 Delivery of high quality services in different settings;
• Step 5 Care in the last days of life; and
• Step 6 Care after death.

An interview script was developed based on NICE Quality Standard QS13 End of life care for adults, the Yorkshire Cancer Network Palliative Care (End of Life) Pathway September 2012 (in appendix 8) and the National VOICES survey.

An option to use different methods of engagement (e.g. patient narratives and creative methods) to meet individuals or groups needs was available on request. Interviews were to be undertaken in person or by telephone.

A recruitment plan was developed to ensure the invitation was widely shared with the aim that the sample would be representative of Leeds. An invitation was then sent out by email or post to:
• The Leeds CCGs for dissemination via GP practices, staff bulletins, newsletters, websites and patient groups both at commissioning and service level;
• Macmillan, Marie Curie, Alzheimer's Society; St. Gemma's and Wheatfields hospices, Leeds City Council, Leeds Teaching Hospitals NHS Trust, Leeds Community Healthcare NHS Trust and the Robert Ogden Centre;
• Leeds Palliative Care Strategy Group, Leeds Palliative Care Operational Group and Leeds Palliative Care website;
• Leeds Bereavement Forum, Neighbourhood Networks and Carers Leeds;
• Third sector organisations, faith groups and forums with links to BME communities across Leeds.

Follow up meetings, emails and phone calls were also undertaken to try to increase the level of participation to ensure a representative sample.
10.4.2 Results

10.4.2.1 Demographics of respondents
Fifty one patients, carers, and family members were involved in the consultation. Twenty nine interviews were completed with individuals or two people at a time and two focus groups were held: one at Wheatfields Hospice and one at the Shakti Project. St. Gemma's and Wheatfields were visited twice. Equality monitoring was undertaken as part of the interviews and focus groups.

Certain groups were not represented in the consultation. These included adults under the age of 30, people with learning disabilities, the transgender community and people from some Black and Minority Ethnic communities.

60% of people interviewed were patients, 40% were carers and or family. The age range of people interviewed was 31 – 94 years. 68% of interviewees were female, 30% male for 2% gender was not recorded. Interviewees were White British, Asian British, Irish, Indian or Asian. They either had no religion or were Catholic, Christian, Hindu, Jewish or Sikh. The patients involved had a wide range of health conditions including various forms of cancer, Parkinson's, dementia, COPD, liver and kidney failure, Motor Neurone Disease, heart conditions, Leukaemia and lung conditions. Families and carers interviewed also shared experiences of sudden death.

10.4.2.2 Discussion as the end of life approaches
The experiences of participants varied with some people experiencing poor communication or no communication at all:

“Things went on as normal with dad continuing his routine of hospital and GP appointments and then in October suddenly mum got a letter from the Palliative Care service asking them if dad needed any support. We were all really surprised and upset because when the hospital had seen dad no-one had sat us down and made sure we understood he was terminally ill. We didn’t know this service was going to contact us at all. Mum was in shock and really upset. Why did we have to find out this way?”

“I found the communication really poor from hospital staff. We only found out that dad’s condition was palliative when we saw that word next to dad’s name displayed on the whiteboard the staff use to record basic patient information. It’s near the staff desk and anyone can see it so there is no confidentiality at all. I don’t think dad understood his condition was terminal we did finally get told he had cancer after challenging staff.”

Whilst others felt they had been informed well but had difficulty absorbing and processing all the information given. Having someone to advocate on their behalf was considered to be helpful:

“I went with mum when she got the diagnosis we had a Registrar and a Macmillan nurse there. It was explained well but it was very overwhelming, all you hear is the cancer word and that it’s a life limiting illness. He sort of went “I can’t do anything” and then waited … and we didn’t know what do whether we had to fill the gap or what? Mum wanted to know how long she had got and the reply was quite a clinical one which didn’t really help. Mum just looked at me. We were both so helpless, so hopeless. It did feel a bit scripted but he then gently led into her options and was very clear but very stark about what was going to happen. I listened but mum just couldn’t take it all in. Made me wonder what would happen to people who didn’t have someone to advocate for them? It was an overload of information in 40 minutes.”
It was also suggested that it would be helpful to share the information over a period of time rather than all at once:

“She saw a consultant who gave her more time and gave her options. I think they gave her too much information at diagnosis, it would have been better to give some of the information a bit later on at relevant points in her care”.

Some participants felt that they had an arduous process to get a diagnosis which took longer than necessary:

“I went to A&E as I was in a lot of pain with my hip and they did an x-ray and found that I had cancer in my pelvis and femur. The young registrar explained it really well but said I had to go back to my GP to get referred. Then I heard nothing for some time but as I had a good relationship with St. Gemma’s having worked there and kept in contact they got involved and I finally got to see a consultant. After a bone scan and further tests it appears I have cancer in my pelvis, femur, right shoulder and ribs.”

Participants felt that clinicians can make assumptions that patients or carers know more because of their academic background or profession and forget they are still patients:

“I didn’t get much information from the consultant I presume it’s because I am a retired doctor. I was told what treatment I was to have: a hormone treatment and I don’t know how long for he hasn’t said.”

“I think on reflection that because my wife knew so much about the condition we were all viewed as being competent, informed and capable so didn’t require extra support. In reality my wife listened to the doctors and had interpreted what they said for me. I hadn’t really listened and when she grew too ill to do this I felt impotent, unable to save her and having to make decisions I didn’t feel competent to make.”

For families experiencing sudden death the experience can be very traumatic and participants described how difficult it is to hear bad news when delivered badly and what a difference it makes when delivered well:

“The day after they reduced his medication and did a brain scan which they said was okay. Then they changed their minds and said there was damage. I asked for a CT or MRI scan to see some evidence that this was true or not but I was told it wasn’t an option. I was really upset and wanted a second opinion. The doctors were wonderful and two in particular were very good. They explained things and talked to us and listened. Others didn’t. It would have been so much easier to accept if there had been some visible tangible evidence that he wasn’t going to get better.”

10.4.2.3 Assessment, care planning and review

A significant number of participants fed back that they felt that there had been no effort in understanding the needs of individual patients. Rather that there was a standard format of care planning that didn’t require involvement of patients or relatives:

“I have terminal throat cancer. I just feel like the health services want me to go away and die. I was told I would die within 6 to 12 months in August last year and I am still here. I had one consultant who tried me with radiotherapy which seemed to work a bit and then planned to do chemotherapy. Then he left I got a new one and he says no you can’t have anything there’s no point. It made me feel awful. There was certainly no patient choice, no involvement in my own care. The decision was made by him even before we had the conversation. Why did the other chap think differently, is it just down to individual consultants whether you live or die?”
“We get called into meetings about her care but are not involved by health or social care. If she wants more hours to give the carers time to feed her properly we have been told it would affect her benefits. But we are working without any proper information. It is difficult to tell whether her condition is getting worse due to her health condition or because of the poor care”.

“When we planned to have him come home we were clear we didn’t want to do personal care we ended up doing so. Unfortunately it’s that which stays in your memory. One of the district nurses had an unpleasant conversation with us to say that as he hadn’t died when everyone thought they would need to reduce the level of care he was getting. The next day he deteriorated. She also implied that as we were always there for him and active in his care that we somehow didn’t need the support we were getting. We really think that they should provide a reactive service based on person centred care.”

There was also a discrepancy for many with regard to the quality of care planning and assessment of need between specialist services and care in the community:

“The cancer services at the hospital involved mum and us in her care but once in the community there was a massive gap until we were 10 months into the whole process. My sister phoned the Macmillan team after a colleague at work gave us the number (their partner was an oncology nurse). Turned out the GP had never made any referrals.”

Participants who had family members with dementia or communication difficulties were often struggling in hospital to make their needs understood.

“I don’t know if anyone had tried to explain to mum how poorly she was, the staff at the hospital would tell her stuff but she didn’t understand it. But they didn’t tell us anything or involve us in her care and mum wasn’t capable at some points of making any decisions.”

This was particularly relevant for one participant from the Sikh community who struggled with staff on a hospital ward to get her family member’s needs met or even understood despite the information being on her notes:

“We had trouble with the ward she was on. Aunty was not looked after well. She was a baptised Sikh which means she was on a strict vegetarian / vegan diet. This was on her notes and Uncle had told them. I found them feeding her chicken curry. I took it off her and explained that she couldn’t eat this and was told “it’s alright its Halal”. The staff couldn’t understand why I was making a fuss. I explained that she was not Muslim but Sikh that she was a strict vegetarian / vegan. So instead of asking me what she could have they brought an omelette. Again I had to explain she couldn’t eat this and asked them to bring me some Weetabix which I fed to Aunty. They really couldn’t understand why I was upset and I couldn’t tell Uncle it would have devastated him. I had to get her re-baptised because she had lost her baptism by eating the meat. It had significant religious repercussions particularly if she had died un-baptised. Cleanliness is also really important as part of our faith and there are religious items we have to keep on our bodies at all times. Aunty wore special religious underwear that she had to keep on her body all of the time so it’s a step by step process to remove one and put a fresh pair on. I don’t think any of the staff were aware of this or to be honest were interested either. So I had to bathe her every day”.

Recognition from staff showing an understanding of how difficult it is to know you could die at any moment, were considered invaluable. Several people described the sheer desperation, one man said:
“You know I say to my wife every night when I go to bed “I love you and see you in the morning”. Because the thing I want more than anything at that very moment every night is to know I will wake up the next morning.”

Services that listened and responded to patients and families were greatly appreciated:

“Her care was managed well and we were pleasantly surprised how the cancer specialist services were supportive to mum within the hospital.”

“We were very well supported with district nurses, carers, her GP. Everything was well explained.”

“St. Gemma’s is very helpful my needs get assessed and I can talk things through here. I am in the process of finding out how I can get a live-in carer. I would like to say I was very impressed with the care I received from Intermediate Care at Seacroft Hospital.”

“Wheatfields it is a lifeline for me they help to manage my symptoms effectively”

There were several very positive comments about the Intermediate Care Team and CIC beds, and the support, involvement and assessment done within those teams. Both hospices were also highlighted as being very good at care planning and the staff managing coordination for fast tracking from hospital to home:

“We were very well supported with district nurses, carers, her GP. Everything was well explained. I have to say the coordinator who made sure she was discharged with full care in place was great supporting my choice and saying mum wanted it despite some doubts from family that it was a good idea.”

Participants said that sometimes understanding your own needs or your family member’s is difficult if you have no experience of the care system or what it can provide. It would be useful to have someone to help you identify those needs when assessing them:

“I do think there should be more information for carers, continuing care asked my husband what his mother needed in help at home. But he didn’t know. He needed someone to go with him and identify what could help in his mother’s care”.

10.4.2.4 Coordination of care

Family members and carers described difficulty in coordinating care for their family members and described struggling to manage:

“Getting support from different teams was difficult and knowing who to go to, there was nobody coordinating things. It was like mum had to do it and that meant we had to do it as mum wasn’t able. We struggled to access one service he needed because one form the hospital or GP needed to complete hadn’t been filled in, we were none the wiser. It was all very stressful we were dealing with ordering pads for dad, ordering prescriptions, personal hygiene, extra washing due to the incontinence.”

Another person described finding his mother in great distress as she went unsupported in the community whilst receiving chemotherapy in hospital:

“Her first round of chemo went okay but the second time she had more adverse reactions. She wasn’t eating or drinking well and had diarrhoea and was dehydrating, she got grade 4 piles which were incredibly painful. I found her on the floor at home collapsed, soiled due to incontinence, crying. I had to clean her up. No one from Community Healthcare care services was visiting mum on any regular basis.”
It took a complaint to a Macmillan nurse at the hospital to get his mother’s needs addressed:

“For 10 months we had no one, no support, and no information and we had to struggle. Why? We have been organised, we have discussed with mum whether she wants to be resuscitated. She has made a will and we know what she wants regarding when she goes and where. But we have had to lead this without support”

The person coordinating care is variable. Some people had consultant or GP led care. Other patients relied on their family, hospices or community matron.

Communication between services and families is a key issue that the majority of participants felt needed to be addressed.

“It was St. Gemma’s who took control and created a plan for dad’s care. It was they who explained everything to us about what we needed to do next. We had palliative care support for 5 weeks before he went into St. Gemma’s.”

“The hospital’s focus was to get her out and we were made to feel that she was blocking a bed now they couldn’t do anything for her. Communication was really hit and miss from staff as we are a big family, in hindsight it would have been useful to nominate one person to be the main point of contact. If they couldn’t catch one of us they tried another and some of us were able to make decisions that affected mum and others were not.”

There was difficult for some in knowing who was leading what and how to communicate their needs or their family members needs effectively. They suggested a central recording file where everyone including family could record care and medication given. With family being asked to help.

“The district nurses provided care around his tubes and medication. There were lots of issues about how the medication was managed and administered. With all the different people involved in dad’s care it was hard to keep up. Some people could give certain things, others not authorised and the GP was involved as well. When we gave him medication we had nowhere to record it. Consequently we got interrogated by nurses demanding to know when we had given certain things “I felt like a criminal, like they thought I was going to harm my dad on purpose”. There was no clear coordinated plan of care and no central recording place either. Each service had its own paperwork for recording purposes.”

Others fed back really positive experiences of good coordination:

“I couldn’t believe the sheer amount of help we got, it was beyond any expectation. I had made the decision to have mum home I didn’t expect to have help as well. Having the carers was really helpful, so was being told to take meter readings with regard to the oxygen machine so I could claim the money back, they reassured me and offered a night sitter. The nurses told me what to expect because I was scared and I wanted to make the right choices for mum.”

10.4.2.5 Delivering high quality services in different settings
Participants discussed mixed experience of care or being able to access care, with some having to take the lead particularly having to advocate on behalf of their family members. This meant that they themselves felt unsupported as carers:

“I am a health professional, a nurse and this meant that I was able to ask the right questions and get the support my dad needed. Particularly in the last two weeks of his life
as my mum wouldn’t have known how. However this meant that I wasn’t allowed “just to be a
daughter”.

Participants also had a mixed experience of how services react to need particularly if it’s out
of hours

“As retired doctor I do think that palliative patients should have access to round the
clock care and that the current ‘out of hours’ system does not meet the needs of such
patients. Continuity is key for all patients. I think patients should have one point of contact
rather than having to coordinate the healthcare and social care system on their own.”

“We contacted the GP practice who sent out a GP who came out to check on dad
and write up his medication for the syringe driver. The GP didn’t know what to write up or the
dosage I had to explain to them how to do it.”

Whilst others felt that they had experienced really good care both in the community and in
hospital:

“My dad died recently, he had been diagnosed with Mesothelioma two years ago and
it was found to be untreatable. He had excellent care at the Bexley Wing and had
chemotherapy and radiotherapy. He was referred to palliative care and to St. Gemma’s. He
was able to access the palliative care nurses, day care and district nurses.”

“She has a new GP now who is excellent, she checks on mum on her day off,
ensures she has her prescription, calls on the phone in the evening and will answer any
questions, has even visited twice in one day if she is concerned about mum. She is really
good.”

“The district nurses were wonderful, we all worked as a team to support my wife.”

Hospital care was a big issue for participants particularly around not delivering patient
centred care. This was found in general, specialist wards and Accident and Emergency
departments. On the wards families were concerned about poor communication leading to
poor care:

“Staff need to communicate with and involve family members particularly when an
elderly relative is so confused. I remember finding her soiled nighties in bags in her bedside
cabinet. They were soiled with all sorts, she was incontinent and someone had bagged them
and left them in there for days without telling us. I was so embarrassed I had to sit on the
bus with this large bundle of foul smelling clothes. In the end she had to wear hospital
nighties because I couldn’t keep up with the washing.”

Wasting time was also an issue for participants, they felt they did not have time to waste and
felt a lot of appointment times were organised inefficiently with lots of time wasted between
appointments or they were spread over three days rather than done in one.

“Waiting time, we wasted so much precious time waiting for things. He went in for a
blood transfusion on a Friday during the day meaning he could go home that day. He was
left for hours with nothing happening and then the nurse decided he couldn’t go home it was
too late and too much paperwork he would have to stay in. We were powerless dependent
on doctors and nurses. We asked a nurse once if she could chase up a blood sample dad
was waiting for ages for and was told if she did enquire “Biochem will put you to the back of
the queue it is better you wait.”
Poor pain management on general and specialist wards was a major issue for patients who felt very strongly about the issue. They were very concerned that they had to wait very lengthy periods for their medication leaving them in pain. Some reported relying on family to bring in medication from home and then ‘being told off by staff’:

“In hospital they are always helpful but they always give me my medication late which means I can’t eat as I have to have it before a meal and wait half an hour. It would really help if I had more control over my medication”

“She was having chemo so was supposed to have barrier nursing but the ward didn’t seem to know how to do this. She was writhing in agony for 3 or 4 days until I had to “have a go” at the nurses and insisted I spoke to the registrar or consultant. I demanded to know why she was in so much pain. It turns out although she was written up for Instagel for her piles and it was being signed for by the nurses it had never been given it was still in the pharmacy.”

Participants emphasised the need for Accident and Emergency to have a better system of managing End of Life Care patients. They suggested it would be useful for the department to have a record of such patients and then treat them according to their existing care plan. They felt this would manage their care better and reduce waiting times. One participant actively avoids Accident and Emergency to the potential detriment of his health because of the experiences he has had:

“If I have a seizure I am supposed to go to A&E and I have chronic pain from horrendous headaches, I am really super sensitive to any noise and sometimes the pain is so bad I can’t think. I had one of these days and had to go to A&E and was left 4 or 5 hours with no pain relief or medication. The pain was so bad and the noise of the other patients and the department were driving me mad. I got told it would be another 2 or 3 hours to see a doctor. In the end I had to discharge myself, it was better to be in agony at home than there. You would think they would have a system in place that could deal with people like me, after all A&E have my records don’t they? Now I won’t go to A&E even if I have seizure, I know I could die but I would rather that happen than go there.”

Participants felt that there were gaps in training and education for nurses, doctors and care staff around end of life and palliative care both in hospital and the community.

“The carers were lovely but they were agency staff and had gaps in their knowledge and training particularly about supporting a palliative patient. Several of them didn’t realise he was terminal and this upset them greatly, they were used to working with patients who would get better. This in turn gave us stress because we were then having to support the carers come to terms with this. They didn’t seem to have any supervision or support from the agency.”

“I do think there is a gap for district nurses in understanding End of Life Care and providing a holistic approach. There needs to be training for district nurses on this and better mentoring and governance.”

10.4.2.6 Care in the last days of life

The majority of participants who have used Wheatfields and St. Gemma’s felt that the hospices provided excellent care:

“Dad seemed to know he was going, he started wanting us to take stuff home saying he wouldn’t need it any more. He had a mild stroke which resulted in a fall and he deteriorated after that. St. Gemma’s was excellent explaining things simply so we understood the process of death and what to expect. We were able to stay with him till he
went. We had mugs of tea, the radio on and doors open it made a big difference, it made it more normal. Our only regret was that we couldn’t donate any of his organs. St. Gemma’s made sure dad was treated as a person and not a patient number.

“It was a good death in a good place with family around him. We had been encouraged to stay with him. Yes I think he had the best possible death. Wheatfields made the difference because unlike the hospital the staff were there all the time. They supported us as his family not just dad. After all it is a once in a life time experience that you have to get right.”

Another participant recalled that dealing with the trauma of the impending death of a partner was made far worse by the insensitivity of a hospital doctor:

“It was at this time that another doctor decided my husband should be moved from ICU to Coronary care even though they had promised not to. They had 1 bed empty but not enough nurses should anyone come in who needed it, so my husband should be moved. The doctor said if we didn’t like it we should complain to the Chief Executive and then we might get more nurses on the ward and my husband could stay. It made me feel awful like my husband was of no value anymore and that he was a liability. We can’t use your organs so you are no use to us anymore. After much discussion and feeling brow beaten (I spent all of Saturday arguing with the doctor) I gave in I said he could go to Coronary care but only if they kept him on his existing bed. They said he had to go on a different bed. I complained. They then agreed to keep in ICU till they really needed the bed. I said he could go to Coronary care if they could promise he had proper mouth care and was turned regularly. I had been doing his mouth care and I was scared he would die on his own. No one should die on their own. All this time I have to say the nurses were brilliant but the doctor was awful.”

However in this case a nurse advocated on behalf of the participants partner saying that the ward needed to be focusing on quality of life and the patient was able to stay:

“Saturday evening we were told he was going to be moved and would be given a soft mattress. His mum wanted to know if the nurses would have time to do his mouth care. He had to have it done every 2 to 3 hours. I had been doing it every 10 minutes and I said I would stay with him. So I went home to change and sort things out at home. My brother in law stayed with him. At 8pm a new nurse started her shift on the ward and refused to let them move my husband she said “Quality of Life” was important and he wasn’t going anywhere whilst she was on shift. He started to deteriorate and his breathing began to rattle and he was put on morphine and other drugs, the noises started to get worse.”

Families where relatives refused to acknowledge or deal with facing their own mortality found it very difficult to manage as they were unable to plan or support their relative effectively. They acknowledged this meant that services also struggled:

“She refuses to acknowledge that she is at end of life and won’t consider respite or going to a hospice. The poor GP tried to discuss the DNR form with her and she verbally threw him out the house. She is in denial about her condition.”

However other participants also described the difficulty of accepting that their relative was going to die:

“I know St. Gemma’s took him in for a blood transfusion to make him feel better but it really felt like it was to get dad in under false pretences. It felt like “we have him now and we can help him die”, I know he had a peaceful and dignified death but mum and I really struggled with letting him go.”
Participants also described conflicting feelings, they respected and accepted the support they received in the hospices for their relative but also felt that sometimes the hospice staff took too much control and forgot to listen:

“There was one incident that I would have changed at the hospice when dad was admitted and they asked us to leave and dad looked terrified. They sort of said “we’ll take care of him now” and “you can go”. But I refused and stood my ground and stayed with him and dad was much happier, they hadn’t asked him if he wanted me or not they had assumed they knew better.”

The Liverpool Care Pathway was a topic which was raised by several participants with both positive and negative views. Central to all of the views was the need for clinicians to explain the process properly and listen to family member’s, Several felt that the clinician involved had told them their relative was on the pathway without any discussion as if it were a matter of course with no other option, very few felt they had the process explained well:

“We were told he could no longer have anything to eat or drink. Watching him go without fluids was horrible and we were making sure he had good mouth care. Tuesday he was still conscious and communicating. Wednesday he had the syringe driver put in and it was really noisy it kept beeping and the nurse had to come out to sort it several times. He wasn’t well. The last 48 hours were horrendous we felt like we were starving him to death”.

“She explained that they could only use the organs if he died within 3 hours and it would take 6 hours to get team together to do the operation. I asked if they would put fluids up if he continued to breathe on his own after the 3 hours and she said yes. His mum didn’t want him to be on the Liverpool Care Pathway and was told he wasn’t he would be on the End of Life Care Pathway. The nurse took me aside and explained afterwards it was the same thing. So I asked about putting up fluids and was told by the doctor “they had no intention of reintroducing fluids”. My nephew got really upset so he and my sister in law had to leave at this point. The doctor did apologise and said that we could put up fluids but it would only make my husband linger for longer. I didn’t want him to suffer. “

“I think it is really important that doctors are open and honest about outcomes and explain properly what the Liverpool Care Pathway means.”

However some participants felt that it was a positive method of care and worked for their family member. One participant who was happy that her relative had followed the pathway said:

“As a nurse I would like to say that the Liverpool Care Pathway (LCP) when used properly is a clear, concise system of care which manages end of life in a dignified and respectful way. There needs to be a good system in place and I am not sure that at such an emotional and distressing time family members are aware of what exactly they are agreeing to even if it is explained to them well. This is why I think it has a negative reputation.”

She felt that the doctor and the care home worked with her to enable her relative to achieve a peaceful and dignified death:

“It was absolutely brilliant, they understood end of life care. Dad and I had discussed in the past what he wanted and I was able to speak openly and honestly with the GP. I was clear I didn’t want him hospitalised. It was about quality of life. There is a need for discussion around end of life care in care homes. The process should be started much earlier on discussed as a team including the patient and family.”
There was a consensus across the participants about the importance of discussion and support around bereavement well before it happens.

“There should be far more preparation in place with families around bereavement well before their family member dies.”

The withdrawal of support after being well supported up until death was keenly felt by relatives and friends who were dealing with grief alone. Aftercare support in the form of bereavement counselling or even someone from a service acknowledging their grief and signposting them to support would be appreciated:

“Then we were left without him and with no support. There really should be some aftercare.”

“I also think there is a need for counselling for families after such an experience. No one rings you up either to say “Hi how are you, how are you coping?”

For all the importance of knowing their loved one was able to die without pain and in a dignified and respectful way was incredibly important:

“Dad was able to die though with dignity and respect.”

“It was all very peaceful and his mum and my sons were able to say goodbye.”

Certification and verification of death does not always run smoothly for people and participants felt this could be improved:

“The GP certified his death but we found out that we couldn’t register his death because he had died of a notifiable disease and were told it would have to go to the coroner and might have to have a post mortem. This was extra stress and trauma for the family and as it turned out he didn’t need one in the end.”

“It should have been a peaceful respectful experience but the DNR form hadn’t been completed and we didn’t know what to do so we had to ring 999. The man on the end of the phone was awful, he kept repeating himself and he just wouldn’t listen to what we were explaining. She had been dead a good half an hour but he still kept on and on. Two ambulances, a paramedic and the police arrived. It was horrible! We eventually got the death verified and certified. It was so quick her death, only 7 days from going to A&E to passing on. Her carers arrived for their shift and tidied mum up.”

Waiting for someone to verify a death was also dealt with differently all over the city. Some people felt it was done sensitively and well whilst others felt that it was dealt with very insensitively. A participant described the attitude of a district nurse when she asked when the GP would be arriving:

“The district nurses attitude was that “it wasn’t urgent so could wait till the GP had finished his surgery”.

Another person described the bad experience of visiting a deceased relative in hospital and how traumatic it was for their daughter. They felt it could have been handled much better:

“On Tuesday we hadn’t heard anything so we rang up to check and were told that she wasn’t going to come home that day. So I said okay I’ll come up to see her at 2 then. At 12 noon we got a call to say she had passed away it was said in such a cold matter of fact
way by the person who rang. I was in shock I went and found my wife and picked up my daughter from school and explained what had happened. The ward rang to say we could come and see her and I told them my daughter and wife and I would be straight up. We got to the hospital and as I parked up my wife and daughter went on ahead to the ward. It was a horrendous experience because the staff hadn’t explained or prepared us for what we would see. It was particularly bad for my daughter as a teenager, to see her grandma like that. I have seen deceased relatives before and my mother in law did not look in a good state.”

Registering the death was also difficult due to the bank holiday weekend and this experience was relayed by several people that they felt that lengthy waits made the bereavement process more difficult:

“We had difficulty registering the death quickly because of the Easter Bank holidays and had to argue before we could get an earlier appointment due to a cancellation. Otherwise we would have had to wait a week to register the death which would have held up the funeral.”

Equipment being left after patients who are fast tracked have died was a big issue for a lot of people. The fast track system works very well most of the time to get equipment into homes but families reported having to live with equipment and medication for weeks. Participants wanted a system that removes equipment and left over medication. Several said they had to struggle to dispose of pain relief and other medication as no one would take it.

“We were left for 4 weeks with all the equipment after dad’s death and it was upsetting living with a bed downstairs as a constant reminder.”

District nurses were seen as playing a major part in end of life care at home especially after the death. They were often the first person who attended and many felt they were very helpful. However there were quite a few people who were surprised that the service stopped so suddenly and felt that after the death there should be a follow up visit or call from the nurse to discuss any outstanding issues and also to acknowledge the death and say goodbye.

10.4.2.8 Any other comments
Some participants felt that the services for end of life varied depending on locality:

“I get really frustrated that the services aren’t the same in Leeds, it depends where you live.”

When services are provided in the home participants wanted staff to remember that this was a private space, a home and that it was important to respect that:

“All of a sudden the house was full of people and equipment. Mum got overwhelmed, quite upset, strangers were traipsing through her house, invading it. Mum was house proud and they all seemed to have forgotten that it was my parent’s home. The little action of a female GP taking her shoes off at the front door before she came inside, that small sign of respect made a big difference for mum.”

Information sharing at hospitals for non-relatives was an issue for several people who cared for neighbours or friends who had communication difficulties or dementia. They felt that medical and nursing staff would ask them for lots of information as the primary carer but when they then tried to ring up to ask how the person was they were refused any information in return.
“It was really frustrating as I am not a blood relative I couldn’t get any information when I rang the ward. Yet the doctors would ring me for information about her.”

Another person felt that the organ and donor transplant team needed to be clearer about the process when explaining it to families:

“I also think that the transplant team needed to be clearer about the process of organ donation. Family members thought he was going to have the procedure on the ward and they would have to see him afterwards and were so horrified they didn’t visit again.”

A participant wanted to note that the new 111 system is causing problems for clinicians when they need to arrange medication for end of life care patients:

“As a clinician I would like to add that at present it can take 2 hours to contact a doctor via 111 to get end of life medication changed for patients. We go through to a call handler. We used to have a quick separate number via NHS Direct that took us straight through to a qualified clinician.”

Key issues for the Asian Elders group that were visited were around ensuring there was information provided in their community languages about end of life care services, that NHS staff should not assume they are supported by family and should check, that they would use these services particularly services that could be received at home. They were keen to learn about the services and wanted further information in Punjabi preferably.

10.4.2.9 Key Themes
These themes emerging from the interviews with service users and carers include: communication, coordination, continuity of care, full patient and carer involvement in care planning, honesty, support for the bereaved, provision of an advocate for patients and families, provision of accessible information, improved urgent care, integrated team working, pain relief management, maintaining dignity and respect.

10.5 LTHT research
The SPC team at LTHT have also recently surveyed bereaved carers with the aim of providing relatives the opportunity to feedback on their experience of the care their relative received in the last days and hours of their life. Between March and May this year, 627 survey questionnaires were given to families collecting death certificates. Families were included if a death was sudden or unexpected. Neonatal child and A&E deaths were excluded. 146 completed questionnaires were returned (23% response rate)

The results are as follows:
- Respect, Privacy and Dignity: excellent 55%, good 26%, average 10%, poor, 2% very poor 2%, no response 5%
- Communication: excellent 45%, good 28%, average 15%, poor 2%, very poor 3%, no response 6%
- Information giving:
  - Did the hospital doctors or nurses clearly explain what the Liverpool Care Pathway (LCP) is, in a way you were able to understand? Yes 94%, No 6%
  - Did a member of staff tell you that your relative may die? Yes 86%, No 12%
  - Blank 2%
  - Did you feel you received enough information at the time of your relative's death from the ward staff? Yes 92%, No 5% Blank 2%
- Involvement in decision making (relatives): not involved 10%, involved 84% no response 6%
• Care-giving/compassionate care (emotional support): excellent 46%, good 30%, average 15%, very poor 2%, no response 7%

• Facilities:
  o Did the staff offer you somewhere you could take a break/rest while visiting your relative? yes 68%, no 25%, N/A 1%, no response 6%
  o During this stay were you told about the hospital facilities e.g. restaurant opening hours? yes 51%, no 40%, N/A 1%, no response 8
  o Did you feel the environment (e.g. room/ward area) in which your relative spent their last days was appropriate? yes 76%, no 12%, don’t know 4%, no response 8%

• Bereavement Support: less than was needed 3%, right amount 79%, more than 7%, no response 11%.

• Support on collection of medical cause of death certificate: yes 97%, no 1%, no response 2%.

• Patient preferences/choices
  o Did you feel that your relative’s personal wishes were respected by those caring for them? yes 68%, no 3%, don’t know 18%, no response 12%
  o Do you think your relative was given a choice about where they could die?: yes 18%, no 38%, don’t know 19%, no response 25%, N/A 4%.

LTHT concluded that the survey gives reassurance that they are providing good or excellent end of life care for the majority of patients and their families. However there are areas that do require further work and input and they are in the process of addressing these. Notably, further work is required in understanding how we can involve patients more in decision-making, and in improving facilities for families. We can also make links with other work in development across the trust, such as improving care for patients with dementia.
11. Comparing Leeds

11.1 Introduction
Comparative HNA enables comparison between services provided and the impact this has on outcomes between different populations. Large variations in services and outcomes may be influenced by a range of factors (e.g. demographics) and not just differing needs. A comparative HNA was conducted as part of the larger HNA. This chapter documents how it was conducted, the comparators, the data sources used and presents the results from the comparative data and interviews.

11.2 Methods

11.2.1 The comparators
The Public Health Information team advised that comparitors used are usually the core cities (Birmingham, Bristol, Leeds, Liverpool, Manchester, Newcastle, Nottingham, Sheffield) or “statistical neighbours”, areas with similar demographics to Leeds (Sheffield, Bolton, Stockton-on-Tees, Darlington, Calderdale, St.Helens, Derby, Kirklees, North Tyneside, Milton Keynes). For this HNA a different list of comparitors was developed. Areas selected were: Solihull, Sheffield, Liverpool, Newcastle, Torbay and North Somerset.

The first four areas were chosen as they are cities, outside of London, with the most similar sized populations. Bradford was excluded as it does not have tertiary services e.g. a cancer centre or liver centre, as Bradford patients use LTHT. Manchester and Liverpool were considered similar so Liverpool was included. In addition, the ONS data on all deaths and number of deaths occurring in usual residence identify Torbay and North Somerset as the best performing areas. Although the populations are likely to be very different it was felt useful to include the highest performing areas as comparitors to learn from. All comparitors are benchmarked against the data for England.

11.2.2 Data sources used
The footprint used is PCT boundary (pre April 2013). This is because the main data source are the PCT profiles collated by the National EoLC Intelligence Network published in August 2012. The quantitative data are from the National EoLC intelligence network. The plan was to gather qualitative data from lead commissioners from each comparator area who were interviewed.

11.3 Results

11.3.1 Demographics of comparator areas
The demographics for each PCT area are described below. These data were published in August 2012 by the National EoLC Intelligence Network.

Figure 22 below shows that Leeds is by far the biggest PCT. The city of Birmingham used to be served by three PCTs, data for Solihull has been included as it was the only area where a commissioner was available to talk to. The two areas which perform best in England have the smallest populations of the comparitors. (Primary source: ONS data 2008 – 10).
Figure 23 below shows the percentage of the population for that area falling into the over 65, 75 and 85 year old age groups. Leeds has the second least proportion of population in the older age groups. Liverpool has the least. Torbay has the highest proportion. (Primary source: ONS data 2008 – 10).

Figure 24 below shows the percentage of the population who are from a BME community. All comparators are below the national average, with North Somerset and Torbay significantly below. (Primary source: 2001 National Clinical and Health Outcomes Database data)

Figure 25 below illustrates what percentage of the population is resident in an urban setting. (Primary source: ONS data 2008 – 10). All areas apart from North Somerset have more residents in the urban setting than the national average.
Figure 26 below shows the proportion of people living in the more deprived fifth of the population. Liverpool, Newcastle, Sheffield and Leeds populations have higher than national average population residing in the fifth most deprived areas nationally, Torbay, Solihull and North Somerset have less. (Primary source: 2008 – 10 data from Department for Communities and Local Government).

In conclusion, compared with the 5 other areas, Leeds PCT footprint has the largest population and the second youngest age structure. Leeds has the second highest BME population, although all areas are below that national average. All areas apart from North Somerset have more than the national average proportion of the population living in urban areas. Leeds has the median average proportion of population living in the fifth most deprived communities.

11.3.2 Key EoLC data

Figure 27 below shows place of death of the population in each comparators. North Somerset and Torbay have a far higher proportion of deaths in care homes and far lower proportion of deaths in hospital. Of the other comparators Leeds has the smallest proportion of people dying in hospital and the greatest proportion dying in hospices and second lowest proportion dying in their own home.
Figure 28 below shows leading causes of deaths. The proportion of deaths for the three leading causes of deaths are similar.

Turning to deaths in hospital. Figure 29 below shows terminal admissions that are emergencies. They range from 95.3% - 83.5%, with the national average of 89.7%.
Figure 30 below shows terminal admissions that are 8 days or longer. These range from 53.5% to 37.6% with a national average of 48.8%. The proportion in Torbay is significantly smaller.

Figure 31 below shows average number of bed days per admission ending in death. Bed days range from 15.3 to 8.1 with a national average of 12.9%. Again the average number of bed days per admission ending in death is significantly smaller in Torbay.

Turning to spend. Figure 32 below shows total NHS spend on hospice care per death, and figure 33 below shows total NHS spend on EoLC before death. These data were sourced from the DH and that National Clinical and Health Outcomes Knowledge base. The total hospice spend, was the amount declared by PCTs in 2010/11 per death in 2009, for spend on voluntary and NHS managed hospices and specialist palliative care units both in inpatient and community settings. The data on total spend on EoLC per patient was what each PCT declared. It is questionable how comparable these data are as although what should be counted is clear the methods and calculations the PCTs used to report these figures is unclear. The cost per death on hospice care ranges from £2,047 - £314, with an average cost of £910. Leeds is the area with the highest proportion of hospice deaths and the spend in Leeds is £686 (compared to an English average of £525). In terms of total spend on EoLC per death, the range is similarly broad, between £2,803 and £340, with an average of £1509. The Leeds cost per death is higher than average at £1841 and significantly higher than the English average of £1,096.
11.3.3 Interview findings

11.3.3.1 The interviews
Interviewees were asked about their role, their area, their EoLC services including EoLC OOH services, their hospices, any public awareness campaigns, if they have undertaken a HNA or developed a commissioning strategy, what they are proud of, what they are developing and what issues they are aware of.

11.3.3.2 Role and area
The plan was to interview lead commissioners for EoLC responsible for the relevant PCT footprint. This was not possible due to the changes happening in the NHS, colleagues professional roles and organisations had changed and a number of posts were vacant. Instead, the person identified as the lead for EoLC was interviewed. They were not always responsible for the whole PCT footprint area. One consultant, one GP and three commissioners were interviewed.

Colleagues from North Somerset and Newcastle are medics. The colleague interviewed from North Somerset was a Palliative Care Medical Consultant. He works half time for the local hospital and half time for the local hospice. The patch he is responsible for (Weston-super-Mare) covers two thirds of the North Somerset footprint, the other third is Bristol. The Newcastle colleague is a Macmillan GP and lead for cancer and EoLC for Newcastle North East CCG.

Colleagues from Liverpool, Sheffield and Birmingham were all responsible for EoLC commissioning. The colleague interviewed from Liverpool was a transformational change manager, responsible for Cancer and EoLC. She worked for Liverpool CCG. The Sheffield
colleague was a commissioning manager at Sheffield CCG, responsible for long term conditions and EoLC. The colleague from Birmingham is a Senior Redesign Manager for frailty and EoLC, for Solihull CCG.

11.3.3.3 Services

11.3.3.3.1 North Somerset
North Somerset take a “whole health community” approach. The SPC team lead EoLC but work closely with GPs, DN, community wards and the acute hospital. They have a high number of nursing homes and support them to facilitate EoLC. There is an EoLC coordination centre staffed with generic workers who support fast track applications and who have sped up the process of organising care packages significantly.

11.3.3.3.2 Liverpool
In addition to the hospice care, Liverpool CCG also commissions 5 palliative care beds in two care homes to support people to die in their preferred place of residence. The beds are linked to GP practices that have an interest in EoLC, who provide specialist EoLC advice and help.

There is also a Discharge and Care Management Project, open to patients in hospital who are likely to die within the next 72 hours. Marie Curie provides transport to get a person home, and supports them in their home for 72 hours, which removes the need to wait for health and social care packages. If they get better, packages can be put in place in this time.

Liverpool also run a Care Programme, Marie Curie and Crossroads provide up to 58 hours of personal and social care for patients in the last three months of life, supporting them to live at home. It complements the DN service and can give carers a break. Liverpool is developing a website for service users and professionals. Liverpool has also amended the GSF template, there are 3 Macmillan GPs working one day a week on the agenda supporting other GPs to use the GSF template.

Liverpool also have a Marie Curie Helper Service, the CCG provides a small amount of funding. The service provides companionship and emotional support. The CCG pays for a coordinator and administrator who recruit volunteers to deliver the service. Volunteers provide 3 hours a week and there are 51 volunteers in total.

Liverpool is currently getting trusts together to try and roll out the DNACPR forms. There is a project being run by Marie Curie in the Royal Liverpool Hospital and care homes around ACP. This is currently being developed. There is a 24 hour Marie Curie helpline for patients and families, staffed by a nurse but with access to a doctor.

11.3.3.3.3 Sheffield
Sheffield is one of the sites for the palliative care funding review. All GPs are delivering EoLC to receive their QoF points. There is work underway to increase palliative care skills amongst the generalist workforce. The highest priority for Sheffield is the intensive nursing home service which focused on supporting people to live their last week of life at home. Community and district nurses are managed through Sheffield Teaching Hospitals Trust, there are variable levels of confidence around EoLC. OOH care is missed. It is provided by a local GP collaborative. There have been issues where a patient is dying but an ACP wasn’t in place. There are no issues with accessing EoLC medicines as there is a pharmacist in each locality who holds a stock.
11.3.3.3.4 Solihull
Solihull has a community SPC team. They have also commissioned additional DN support. All DN manage an EoLC care load. Depending on where patients are in terms of the supportive care pathway (as defined by the GSF codes) determines whether care is provided by the DN team or SPC team. The SPC team is hosted by the hospice and all SPC staff have a base there. There is a hospice at home service, where patients are supported by SPC staff in their own home. There are 2 SPC consultants (not full time) who support the hospice at home service. DNs meet people who are “green” on the GSF to develop their ACP and record PPC.

There is a rapid response service in place. In the event of carer breakdown, the rapid response team can provide support within 2 hours and refer them into whatever care is needed. If a dying patient is admitted to hospital, the rapid response service will take action to see if this is necessary and if not will arrange for them to be discharged.

Patients have “just in case” (also called “comfort care boxes”) in their homes, to access urgent pain relief in the dying phase. There is a patient and carer information booklet explaining ACP. There is a DNACPR policy and template agreed between GP practices and the ambulance service. If a DNACPR is in place, the OOH team, acute trust and ambulance service are made aware. All GPs use the GSF approach and a good proportion of GPs hold monthly MDTs. All but one of the GP practices in the CCG are on the same IT system as are the community services and hospice. There are signed information sharing agreements in place. There is a part time input from a clinical psychologist who provides clinical psychology support to level 3 and 4 patients who are struggling with their mental health. The Birmingham Public Health Observatory provides performance management data, which is updated 6 weekly and encompasses the latest monthly data and overall yearly position using the ONS mortality dataset.

The OOH service is good because additional investment has been made into the DN service. There are some problems with OOH GPs, who panic and call 999. It helps that patient notes are on the system. No complaints are made about the equipment service.

Work is underway to increase the number of non-cancer dying patients accessing EoLC. Work has been done around respiratory and heart failure patients, dementia patients are next. A lot of work was done with GPs to support them to identify respiratory patients who are dying. Work is beginning to look at implementing the AMBER care bundle in the acute trust.

11.3.3.3.5 Newcastle
All GPs practices have a palliative DN attached, the DN delivers most of the EoL care. Practices that deliver good EoL care have committed GPs and DNs. DN teams work 24 hours and are the first port of call for palliative care patients that have a plan in place. Newcastle don’t currently have EPaCCS. GPs fill out OOH forms for the OOH service so they are aware who is on the PCR. OOH aren’t aware of all the patients they should be. OOH only have information that a patient is “vulnerable”, this includes patients on the PCR but also people addicted to drugs. Community staff are managed by the acute trust.

11.3.3.4 Hospices
North Somerset: There are two hospices on the patch. One hospice delivers a high proportion of CNS care and keeps patients on the hospice caseload until they die. The CNS are attached to GP surgeries and act as champions for ACP and EPaCCS. The number of non-cancer patients on the case load is increasing. About 80% of people who die with an ACP in place are known to the hospice. The hospice CNS are supported by community DNs, GPs and community matrons. The other hospice doesn’t make as many community visits and discharges patients and welcomes them back again when needed. One hospice
received 25% NHS funding the other receives 17% NHS funding. The OOH system uses EPaCCS so are fully informed about patients who are on the EPaCCS system.

Liverpool: there are two hospices. The CCG commissions one, which is also funded by surrounding CCGs. The other hospice is nurse led. Some patients have been there for years. Liverpool CCG commissions 5 beds from there. Liverpool CCG has contracts with the hospices, in the past in the form of SLAs but from April 2014 they will use the NHS contract.

Sheffield: There are two hospices. There is a Macmillan hospice unit within the NHS hospital grounds. This provides 18 or 19 beds. The hospice hosts a SPC team which also supports the hospital in terms of providing in-reach, community and outpatient support. The team was made up of consultants, SPC nurses and a pharmacist. There was a social worker but this has been difficult to maintain. There is an additional hospice in the city, which is grant funded. Next year it will be commissioned through the NHS contract, pending findings from the Palliative Care Funding review. This hospice hosts the SPC community nurses for Sheffield.

Solihull: has one hospice. The CCG commission the hospice, through the NHS contract, to provide in-patient care, lymphedema services, night sitting and OOH nursing care for dying patients. The contract includes a CQUIN and key performance indicators. The hospice receives funding from the 4 CCGs covering Birmingham. The CCG has small contracts with a couple of other hospices.

Newcastle: There are two hospices in Newcastle. Specialist cancer consultants work in the hospices 9 – 5, and train GPs. They have a 24 hour phone advice line which is staffed by nurses. If there are problems accessing medicines the hospice will lend the medication at night. The hospices are part NHS funded and work well together.

11.3.3.5 Issues

- That CCGs work slowly.
- 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, processes haven't been embedded and formalised. X2
- 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.
- Need 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 that 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 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
- 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.
11.3.4 Conclusion
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. Leeds 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.

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
- A local Public Health Observatory providing performance management data
12. Discussion

12.1 Introduction

12.1.1 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.

12.1.2 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 all settings 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)
12.1.3 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.

12.1.4 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 saves 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.

12.2 Strengths and weaknesses
12.2.1 Strengths
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.

12.2.2 Weaknesses
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.

12.3 Direct improvements required to deliver better EoLC

12.3.1 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.

12.3.2 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 word 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 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.

12.3.3 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.

12.3.4 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.
12.3.5 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. Hospices provide EoLC 24/7 for inpatients, DNs provide 24 hour cover 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 super-holding pharmacy in Leeds which stocks a broad range of 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.

12.3.6 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. The role of a specialist EoLC DN would be distinct from the specialist palliative care CNS role. 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.

12.3.7 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. 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.

12.3.8 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 rates 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.

12.3.9 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.

12.4 Underpinning actions required to support EoLC service delivery

12.4.1 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.

12.4.2 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.

12.4.3 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 transgndered 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.

12.4.4 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 LTHT 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.

12.4.5 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.
12.4.6 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 and PPD recorded
- Number of patients with a DNA CPR order recorded
- 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 (or equivalent)
- % 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.
1.4 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 EoLC are 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.
13. Recommendations

13.1 Introduction
This section includes recommendations to support the on-going improvement of EoLC delivery in Leeds as well as underpinning recommendations to support the EoLC agenda.

13.1.1 Recommendations to support the on-going improvement of EoLC delivery in Leeds

13.1.1.1 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.

13.1.1.2 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.

13.1.1.3 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 wardens).
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.

13.1.1.4 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.

13.1.1.5 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; AHP, specialised pain services; LTHT EoLC discharge facilitators; EoLC care homes facilitator; oncology social workers based at LTHT.

23 Improve access to SPC drugs OOH.

13.1.1.6 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.

13.1.1.7 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.

13.1.1.8 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

13.1.1.9 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.

13.1.2 Underpinning recommendations to support the on-going development of the EoLC agenda in Leeds.

13.1.2.1 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.

13.1.2.2 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 39, hospices to continue to develop the non-cancer agenda, evaluate the impact of initiatives and implement good practice across both hospices.

13.1.2.3 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.
<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Advance Care Plan</td>
</tr>
<tr>
<td>ADRT</td>
<td>Advance Decision to Refuse Treatment</td>
</tr>
<tr>
<td>AHP</td>
<td>Allied Health Professional</td>
</tr>
<tr>
<td>ANP</td>
<td>Advanced Nurse Practitioner</td>
</tr>
<tr>
<td>ASC</td>
<td>Adult Social Care</td>
</tr>
<tr>
<td>BAME</td>
<td>Black Asian and Minority Ethnic</td>
</tr>
<tr>
<td>CCGs</td>
<td>Clinical Commissioning Groups</td>
</tr>
<tr>
<td>CE</td>
<td>Chief Executive</td>
</tr>
<tr>
<td>CHC</td>
<td>Continuing health care</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>CPD</td>
<td>Continuing professional development</td>
</tr>
<tr>
<td>CSU</td>
<td>Commissioning Support Unit</td>
</tr>
<tr>
<td>DiUPR</td>
<td>Death in usual place of residence</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DN</td>
<td>District Nurse</td>
</tr>
<tr>
<td>DNACPR</td>
<td>Do Not Attempt Cardio Pulmonary Resuscitation</td>
</tr>
<tr>
<td>DST</td>
<td>Decision Support Tool</td>
</tr>
<tr>
<td>eDID</td>
<td>Electronic Discharge Document</td>
</tr>
<tr>
<td>EoL</td>
<td>End of Life. People are classed as reaching the end of life when they are likely to die within the next 12 months</td>
</tr>
<tr>
<td>EoLC</td>
<td>End of Life Care</td>
</tr>
<tr>
<td>EPaCCS</td>
<td>Electronic Palliative Care Coordination Systems</td>
</tr>
<tr>
<td>FT</td>
<td>Fast track</td>
</tr>
<tr>
<td>Fast track</td>
<td>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.</td>
</tr>
<tr>
<td>GMC</td>
<td>General Medical Council</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GSF</td>
<td>Gold Standard Framework</td>
</tr>
<tr>
<td>HCA</td>
<td>Health Care Assistant</td>
</tr>
<tr>
<td>HNA</td>
<td>Health Needs Assessment</td>
</tr>
<tr>
<td>ICD10 codes</td>
<td>World Health Organisation system of classifying diseases using standardised codes</td>
</tr>
<tr>
<td>Intrathecal</td>
<td>Giving medications directly into the spinal fluid</td>
</tr>
<tr>
<td>IT</td>
<td>Information Technology</td>
</tr>
<tr>
<td>JCM</td>
<td>Joint Care Managers</td>
</tr>
<tr>
<td>JCMT</td>
<td>Joint Care Management Team</td>
</tr>
<tr>
<td>LCC</td>
<td>Leeds City Council</td>
</tr>
<tr>
<td>LCH</td>
<td>Leeds Community Healthcare</td>
</tr>
<tr>
<td>LCP</td>
<td>Liverpool Care Pathway for the Dying Patient</td>
</tr>
<tr>
<td>LTC</td>
<td>Long term conditions</td>
</tr>
<tr>
<td>LTHHT</td>
<td>Leeds Teaching Hospitals Trust</td>
</tr>
<tr>
<td>LSE CCG</td>
<td>Leeds South and East Clinical Commissioning Group</td>
</tr>
<tr>
<td>LYPFT</td>
<td>Leeds and York Partnership NHS Foundation Trust</td>
</tr>
<tr>
<td>MD</td>
<td>Multi-Disciplinary</td>
</tr>
<tr>
<td>MDT</td>
<td>Multi-Disciplinary Team</td>
</tr>
<tr>
<td>NCPC</td>
<td>National Council for Palliative Care</td>
</tr>
<tr>
<td>NEolCIN</td>
<td>National End of Life Care Intelligence Network</td>
</tr>
<tr>
<td>NMC</td>
<td>Nursing and Midwifery Council</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>---------</td>
<td>-------------</td>
</tr>
<tr>
<td>OOH</td>
<td>Out of hours</td>
</tr>
<tr>
<td>PCR</td>
<td>Palliative Care Register</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>PII</td>
<td>Patient Identifiable Information</td>
</tr>
<tr>
<td>PPC</td>
<td>Preferred Place of Care</td>
</tr>
<tr>
<td>PPC</td>
<td>Preferred Place of Care</td>
</tr>
<tr>
<td>PPD</td>
<td>Preferred Place of Death</td>
</tr>
<tr>
<td>PPM</td>
<td>Patient Pathway Manager</td>
</tr>
<tr>
<td>PPI</td>
<td>Patient and Public Involvement</td>
</tr>
<tr>
<td>PRN</td>
<td>As required (medication)</td>
</tr>
<tr>
<td>PROMS</td>
<td>Patient Reported Outcome Measures</td>
</tr>
<tr>
<td>QIPP</td>
<td>NHS cost saving agenda; Quality Innovation Productivity Prevention</td>
</tr>
<tr>
<td>QoF</td>
<td>Quality and outcomes framework</td>
</tr>
<tr>
<td>RDP</td>
<td>Rapid Discharge Pathway</td>
</tr>
<tr>
<td>Rapid discharge pathway</td>
<td>Is designed for people within the last days and hours of life, who need to be discharged within 24 – 48 hours</td>
</tr>
<tr>
<td>Simply dying</td>
<td>People who are dying but do not need specialist palliative care input</td>
</tr>
<tr>
<td>SPC</td>
<td>Specialist Palliative Care</td>
</tr>
<tr>
<td>SPCT</td>
<td>Specialist Palliative Care Team</td>
</tr>
<tr>
<td>SPICT</td>
<td>Supportive and Palliative Care Indicators Tool</td>
</tr>
<tr>
<td>Statistical artefact</td>
<td>Error in data caused by collection or recording methods</td>
</tr>
<tr>
<td>VOICES</td>
<td>Views of informal carers for the evaluation of services</td>
</tr>
<tr>
<td>WTE</td>
<td>Whole Time Equivalent</td>
</tr>
<tr>
<td>YAS</td>
<td>Yorkshire Ambulance Service</td>
</tr>
<tr>
<td>YCN</td>
<td>Yorkshire Cancer Network</td>
</tr>
</tbody>
</table>
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## 17. Appendices

### Appendix 1: Key themes raised at the HNA workshop in March

<table>
<thead>
<tr>
<th>Discussions as EoL approaches</th>
<th>Good practice</th>
<th>Gaps</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Palliative care website with information for the public</td>
<td>Public awareness and willingness to embrace EoLC issues. Patchy information available (including Dying Matters leaflets and website flyers).</td>
</tr>
<tr>
<td></td>
<td>Some services using advance care planning (ACP)</td>
<td>Misconceptions about what palliative care is &amp; that it can coincide with active treatment</td>
</tr>
<tr>
<td></td>
<td>Some care homes use ACP routinely (including DNACPR)</td>
<td>Patients are not being identified for EoLC - especially non-cancer patients - and the evidence base in many conditions is poor</td>
</tr>
<tr>
<td></td>
<td>Regional DNACPR form</td>
<td>Early conversations are not routine practice in primary or secondary care, especially for non-cancer patients</td>
</tr>
<tr>
<td></td>
<td>Seven consultants in LTHT are working to implement this into routine practice in their departments</td>
<td>EoLC issues are often not discussed with patients (or carers)</td>
</tr>
<tr>
<td></td>
<td>Dementia strategy encourages discussion early</td>
<td>Patchy implementation of ACP in most organisations. Not embraced by generalist staff</td>
</tr>
<tr>
<td></td>
<td>Communications skills training strategy developed and being delivered</td>
<td>DNACPR form not routinely used appropriately</td>
</tr>
<tr>
<td></td>
<td>Leeds prognostic tool can help to identify patients earlier</td>
<td>EoLC is not linked to LTC agenda</td>
</tr>
<tr>
<td></td>
<td>Some people are asked re preferred priorities for care (PPC) and preferred place of death (PPD)</td>
<td>Lack of knowledge about AMBER in primary care</td>
</tr>
<tr>
<td></td>
<td>“Transform” programme (including AMBER) in LTHT implemented in respiratory medicine and oncology</td>
<td>Early discussions for patients with dementia are not routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Staff lack knowledge on the range of services available so are unable to give patients full choices</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assessment, care planning and review</th>
<th>Good practice</th>
<th>Gaps</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPaCCS is in several GP practices and data can be shared with community nursing and hospices</td>
<td>EPaCCS is not available in all practices or LTHT. LTHT information cannot be added. EMIS practices are currently excluded</td>
<td></td>
</tr>
<tr>
<td>DN in-reach discharge service</td>
<td>Current clinic slots in primary and secondary care are too short for these discussions</td>
<td></td>
</tr>
<tr>
<td>LTHT nursing assessment include EoLC fields</td>
<td>Letters outlining possible treatments/ceilings of care are not routine between secondary &amp; primary care</td>
<td></td>
</tr>
<tr>
<td>GSF meetings embedded in most GP practices</td>
<td>Capacity issues - delays in conducting assessments, time taken for holistic assessments/reviews</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care services available in all settings</td>
<td>GSF meetings not held frequently enough</td>
<td></td>
</tr>
<tr>
<td>DN services available 24/7 &amp; workforce have substantial training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-ordination of care</td>
<td>Programme</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Some care homes have supportive/palliative care registers &amp; discuss patients routinely with GPs</td>
<td>“Skeleton” services OOH in primary and secondary care</td>
<td></td>
</tr>
<tr>
<td>GSF meetings embedded in most GP practices</td>
<td>SPC face-to-face assessments in hospital and at home are limited to Mon-Fri</td>
<td></td>
</tr>
<tr>
<td>DN in-reach discharge service</td>
<td>Care planning for EoL patients who are not eligible for fast track funding for continuing care</td>
<td></td>
</tr>
<tr>
<td>EPaCCS is in several GP practices and data can be shared with community nursing and hospices</td>
<td>EoL care planning and review is not routine in some care homes</td>
<td></td>
</tr>
<tr>
<td>Detailed SPC discharge letters from LTHT</td>
<td>Only some care homes have supportive/palliative care registers &amp; discuss patients routinely with GPs</td>
<td></td>
</tr>
<tr>
<td>OOH handover forms</td>
<td>GSF meetings not held frequently enough</td>
<td></td>
</tr>
<tr>
<td>DN single point of access OOH</td>
<td>Discharge from hospital is inefficient and time-consuming</td>
<td></td>
</tr>
<tr>
<td>Rapid discharge pathway (RDP)</td>
<td>EPaCCS is not available in all practice or LTHT. LTHT information cannot be added.</td>
<td></td>
</tr>
<tr>
<td>Palliative care ambulance</td>
<td>Systmone does not have “open shares”</td>
<td></td>
</tr>
<tr>
<td>Pathways under development for heart failure and Parkinson’s disease</td>
<td>Care planning is complex and time consuming with a number of providers involved</td>
<td></td>
</tr>
<tr>
<td>OOH access to equipment</td>
<td>Knowledge of prescribing in primary and secondary care</td>
<td></td>
</tr>
<tr>
<td>OOH access to drugs</td>
<td>Lack of leadership in decision-making. Looking at the whole patient.</td>
<td></td>
</tr>
<tr>
<td>OOH service sometimes encourage hospital admission rather than review</td>
<td>Communication between primary and secondary care and what the patient knows</td>
<td></td>
</tr>
<tr>
<td>Long waits for reviews OOH by GPs and hospital doctors</td>
<td>OOH numbers given to patients can be confusing</td>
<td></td>
</tr>
<tr>
<td>OOH numbers given to patients can be confusing</td>
<td>Capacity of joint care managers to attend planning meetings OOH</td>
<td></td>
</tr>
<tr>
<td>SPC face-to-face assessments in hospital and at home are limited to Mon-Fri</td>
<td>Information available to care homes</td>
<td></td>
</tr>
</tbody>
</table>
| **Delivery of high quality care in different settings** | **Home** | High % of people on DN caseloads achieve PPC
*DN night service focussed on EoLC*
DNs can access continuing care funding for patients
SPC community teams available with CNSs supported by consultants, day hospice and outpatient services
24hr SPC advice to professionals
Lack of carers - capacity of agencies
Carers not always able to use specialist equipment
Fragmentation in use of the private sector
OOH access as above
Lack of respite care
Capacity of DN
Planning for demographic changes
Inconsistent staff knowledge and skills
Multiple providers
Lack of provision for 24 hr care at home
| **Hospital** | “Transform” programme on selected wards
Senior clinician development programme with clinical champions in 7 specialties
SPC service covers all wards Mon-Fri and 24hr SPC advice to professionals
Inconsistent staff knowledge and skills
Capacity of staff esp OOH
| **Hospice** | Two hospices provide SPC 24/7 including OOH admissions
Co-operation between hospices
Variable waiting lists for admission
| **Care home** | Additional funded care from independent sector
Education/training and commissioning in place to support high quality EoLC
LCP framework being introduced
Inconsistent staff knowledge and skills
OOH access to medical review, drugs
| **Last days of life** | LCP is well embedded across LTHT with a long-term training plan
Dying phase recognised late, esp LTHT
Capacity, knowledge, skills and confidence of
<table>
<thead>
<tr>
<th>Feature</th>
<th>Staff in all (non-hospice) settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>High % achieve PPD if known to DNs</td>
<td>Information and training for informal carers who may like to be more involved in all settings</td>
</tr>
<tr>
<td>LCP implemented in community</td>
<td>Lack of flexibility in some services</td>
</tr>
<tr>
<td>Excellent hospices</td>
<td>Rigid “slots” of care agencies</td>
</tr>
<tr>
<td>Palliative care ambulance available 7/7</td>
<td>Variable care in care homes</td>
</tr>
<tr>
<td>Rapid discharge pathway being implemented</td>
<td>Lack of discussion with patients and carers about preferences</td>
</tr>
<tr>
<td></td>
<td>Variable waiting lists for admission</td>
</tr>
<tr>
<td></td>
<td>OOH access to equipment at home</td>
</tr>
<tr>
<td></td>
<td>Facilities for relatives/carers in parts of LTHT</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care after death</th>
<th>Mortuary facilities and bereavement office refurbished in LTHT</th>
<th>Lack of Registrar in LTHT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>Nurses can verify death at home</em></td>
<td>Bereavement service design, capacity and delivery</td>
</tr>
<tr>
<td></td>
<td>Both hospices offer bereavement support</td>
<td>LTHT verification of death by nurses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Waiting list for CRUSE</td>
</tr>
</tbody>
</table>
Appendix 2: Summary of DH EoLC Strategy actions required

- Raising the profile of EoLC amongst the NHS, local authorities and communities.
- Strategic commissioning, led by health and local authorities in partnership with all relevant provider organisations
- Identifying people approaching the end of life by ensuring staff are trained and have the skills to begin discussions around EoLC.
- Good care planning, based on needs, wishes and preferences of patients, recorded in a care plan. In some cases people may want to make an advance decision to refuse treatment should they lack capacity to make such a decision in the future, others may want to set out more general wishes and preferences about their care and where they would wish to die. The care plan should be reviewed and available to all who have a legitimate reason to access it (e.g. OOH).
- Care should be coordinated; the care plan should be available across sectors at any time of day or night. In addition local areas should have palliative care registers.
- 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.
- Delivery of high quality services in all locations, including hospitals, hospices, care homes, sheltered and extra care housing and ambulances. Interestingly the strategy does not mention high quality services at home although it acknowledges studies show the majority of people want to die at home.
- Last days of life and care after death. The strategy mentions the Liverpool Care Pathway and the need for care after death especially for people who die suddenly.
- Involving and supporting carers, acknowledging that family, friends and informal carers have a vital role in provision of care and should be involved in decision making and have their own needs recognised.
- Education, training and continuing professional development, so that health and social care staff have the knowledge, skills and attitudes related to care of the dying. Core competencies should be developed by organisations such as Skills for Care and Skills for Health.
- Measurement and research. Good information is needed by patients, carers, commissioners, clinicians, service providers, researchers and policy makers. Measurement of EoLC provision is essential to monitor progress.
- Funding. The strategy committed resources for 2009/10 and 2010/11 and suggests improvements by better use of existing health and social care resources e.g. the additional costs of providing improved care in the community and care homes will be offset by reductions in hospital admissions and length of stay. Although the strategy acknowledges there will be financial implications of establishment of coordination centres, provision of 24/7 home care services, improved ambulance transport services, additional specialist palliative care outreach services and improved education and training.
Appendix 3: NICE Quality Standards for EoLC

- People approaching the end of life are identified in a timely way.
- People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
- People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
- People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
- People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
- People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
- Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
- People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
- People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
- People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
- People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
- The body of a person who has died is cared for in a culturally sensitive and dignified manner.
- Families and carers of people who have died receive timely verification and certification of the death.
- People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
- Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
- Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.
Appendix 4: DH quality markers for EoLC

- Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
- Institute effective mechanisms to identify those who are approaching the end of life.
- Ensure that people approaching the end of life are offered a care plan.
- Ensure that individuals’ preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
- Ensure that the needs of carers are appropriately assessed and recorded through a carer’s assessment.
- Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
- Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
- Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
- Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
- Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.
Appendix 5: Description of the main EoLC tools and how they are being used in Leeds

i) Gold Standard Framework
The Gold Standard Framework (GSF) aims to provide a framework to deliver gold standard care for people nearing the end of life. It is a systematic approach formalising best practice. The GSF involves three steps:
- Identify patients’ who may be in the last year of life and identify their stage
- Assess current and future clinical and personal needs
- Plan and develop and action plan of care

The GSF has five goals: to ensure consistent high quality care, alignment with patients’ preferences, improved staff confidence and team work, more home-based, less hospital based care and pre-planning and anticipation of needs.

Patients prognosis can be coded. Blue is the code for a stable patient with a year plus prognosis; green is for a patient with advanced disease and months prognosis; yellow is a deteriorating patient with weeks prognosis, red is a patient in their final days and navy is the code for after-care.

Strictly speaking the “Gold Standards Framework” is a term with copyrights, and the GSF programme is run by a social enterprise. In practice in Leeds GPs refer to their Multi-Disciplinary Team (MDT) meeting or palliative care meetings. GSF is used by some as a loose term meaning a practice has a register of EoLC patients and meeting every 3 months to gain Quality and Outcome (QoF) Framework points. It is used as shorthand for a structured model of care which means patients who are dying are identified early, on a list and case managed. In Leeds the overwhelming majority of GP practices use this approach.

Data from the Health and Social Care Information Centre show that in 2011/12, there were 111 GP practices in Leeds. Each QoF target attracts 3 points. For PC03, having a register, 330 points were achieved, suggesting there was only one practice in Leeds which didn’t have a register. For PC02, holding 3 monthly meetings, 309 points were achieved, suggesting 8 practices were unable to score these points.

ii) Electronic Palliative Care Coordination Systems
Electronic Palliative Care Coordination Systems (EPaCCS) enable the recording and sharing of key information about an individual at the end of their life, including their care and preferences. This information can be accessed by a range of services and the ultimate aim is to improve co-ordination of care to that EoLC preferences can be supported, facilitating more people to die in their place of choice. In Leeds work is on-going with the aim of rolling EPaCCS out to all GP practices. Further information is included in section 10.3.12.

iii) Amber Care Bundle
The AMBER care bundle was developed at Guys and St Thomas’ Hospital to support teams in identifying and responding to a person’s EoLC needs when their recovery is uncertain. AMBER stands for Assessment, Management, Best Practice, Engagement of individuals and carers for people whose Recovery is uncertain. It is designed to enable treatment to occur alongside palliative care. The tool is supported by a package of interventions which includes staff training and development required to embed the tool in daily ward and operational practice.

The AMBER tool is being implemented for use in some wards in LTHT. This tool is used to help clinicians identify patients who are presenting as clinically unstable with limited reversibility of their current deterioration in condition and with an uncertain recovery. Quality standards are in place; within 4 hours, an agreed treatment and escalation plan has to be
agreed and documented in the notes. Within 12 hours a nurse needs to ensure either the patient’s doctor or nurse talks with the patient to discuss their plan of care, their uncertain recovery and prognosis and discuss future options for their care including place of care. Staff are being taught the importance of making sure they communicate that information to GPs and DNs on discharge.

iv) Advance Care Planning
Advance Care Planning is a voluntary process of discussion and review to help an individual who has the capacity to anticipate how their condition may affect them in the future. If the person wishes, they can set on record choices about their care and treatment, and record an advance decision to refuse treatment in specific circumstances. These choices can then be referred to those responsible for the care and treatment in the event the person loses their capacity to decide once their illness progresses. Advance care planning should involve a series of conversations in which a person’s wishes are explored, identified then recorded. In Leeds, a record of ACPs is kept in the patients GP records and EPaCCs record if they have one. It should also be recorded on the OOH handover form so YAS and Local Care Direct have this information.

v) Find your 1%
Find Your 1% is a campaign, led by the National EoLC Programme, working with Dying Matters, Doctors.net, the Royal College of GPs and other key partners, to encourage clinicians to commit to identifying the 1% of people on their list who might be in their last year of life. The rationale is this will open the way for GPs to plan high quality palliative care. The DH (2012) reports that 2,900 clinicians have signed up to date and this has led to a greater number of GPs with an EoLC register, more patients on the EoLC register, more patients with primary diagnosis other than cancer on the EoLC register and more patients with an ACP in place.

vi) DNACPR
This stands for Do Not Attempt Cardiopulmonary Resuscitation. As part of a patient’s ACP, they may wish to include a DNACPR order. In 2011, Leeds implemented a new DNACPR form. This was overseen by a multiagency citywide task and finish group. Post implementation audits have demonstrated increasing improvement in the completion of the forms. A READ code has been agreed with SystmOne for the DNACPR form which has improved communication between healthcare professionals across organisations regarding a patients’ DNACPR status. The form has also been added to the EPaCCS system.

vii) Rapid Discharge Pathway
The rapid discharge pathway (RDP) aims to support people to die at home and discharge dying patients from hospital within 4 hours. There is a rapid discharge pathway in place in Leeds which has been adapted locally from the national LCP/ RDP model of care. The rapid discharge pathway provides guidance for nurses and doctors caring for a dying patient with a recorded preferred place of death identified as their home (including their care home). The rapid discharge pathway paperwork incorporates guidance on clinical care, communication, anticipatory prescribing, the palliative care ambulance service and coordination of care with staff in the community who will provide care for the patient e.g. the GP, DN, joint care manager etc. It also includes the patient's care plans and a discharge checklist.

The rapid discharge pathway agreed in Leeds was developed by district nursing services, continuing healthcare, joint care managers, ambulance and equipment services. In Leeds there is an aim for a safe transfer of care within 24 hours. It was not considered safe or realistic to deliver within 4 hours. Staff aim to get someone home as soon as is safely possible within the 24 hour period. The pathway has taken over a year to develop and implementation has been slow due to identified gaps in services that support the process. The rapid discharge pathway is currently operating on 9 wards in LTHT. Patients are not
accompanied home as there is no capacity in the Trust to support this. There was a Marie Curie “meet and greet” service running in Leeds however this project has ended as it was underused.
Appendix 6: List of staff interviewed or surveyed

- Phil Schofield, Service Delivery Manager, Medical Social Work, LTHT
- Liz Ward, Head of Service, Access and Inclusion, Adult Social Care
- Julia Suddick, Head of Service, Access and Inclusion, Adult Social Care
- Julie Bootle, Head of Service, Access and Inclusion, Adult Social Care
- Claire Iwaniszak, End of Life Care Pathway Facilitator
- Chris Stothers, End of Life Care Pathway Facilitator
- Anonymous ward sister from LTHT
- Janet Fearnley, Manager Medical Social Workers, LTHT
- Jan Dolan, Medical Social Worker, LTHT
- Catherine Roberts, Medical Social Worker, LTHT
- Helen Liddell, Head of Medicines Management, Leeds South and East CCG
- Monica Kapoor, Pharmacist, Leeds South and East CCG
- Paul Westerman, Associate Trainer, Leeds South and East CCG
- Sarah Best, Programme Management Officer, Strategy & Commissioning, Environment & Housing, Leeds City Council
- Suzy Hansford, Interpreting Services, LTHT
- Karen Crawshaw, Chief Executive, Wakefield Hospice
- Susan Doubtfire, Service Manager, Out of Hospital Care, Leeds South and East CCG
- Dr Suzanne Kite, Palliative Care Medical Consultant, Lead Clinician for Palliative Care and SPC Consultant Lead for EPaCSS, LTHT
- Deborah Borrill Discharge Facilitator, LTHT
- Mags O’Brien, Clinical Nurse Manager, Macmillan
- Dr Tom Mason, Business Intelligence Manager, Leeds South and East CCG
- Liz Eastman, District Nurse Manager (Nights), Leeds Community Healthcare
- Julie Greenwood, Advanced Nurse Practitioner, St. Gemma’s
- Dr Mike Stockton, Medical Director, St. Gemma’s
- Cath Miller, Director of Nursing, St. Gemma’s
- Kerry Jackson, Chief Executive, St. Gemma’s
- Lorraine Hunt, Day Services Manager, Wheatfields Hospice
- Dr Lynne Russon, Consultant in Palliative Care medicine and Medical Director, Wheatfields
- Helen Ankrett, Palliative Care Services Manager, Wheatfields
- Valerie Shaw, Specialist Palliative Care Community Nurse Team Leader, St. Gemma’s
- Julie Marshall-Palister, Specialist Palliative Care Community Nurse Team Leader, Wheatfields
- Dr Annette Edwards, Palliative Care Medical Consultant (Dementia), LTHT / Wheatfields
- Everjoyce Byte, Medical Social Worker, LTHT
- Diane Boyne, Commissioning Lead - Community Services and Continuing Care, Leeds South and East CCG
- Bev Kingswood-Smith, Quality Assurance Manager, Continuing Care, Leeds South and East CCG
- Gillian Cheesbrough, End of Life Facilitator for Care Homes, Leeds Community Healthcare NHS Trust
- Alison Russell, Clinical Governance Lead and Quality Manager, Local Care Direct
- Dr Naomi Penn, GP, EPaCCS Lead
- Ann Robertson, General Manager, Adult Community Nursing, Leeds Community Healthcare care NHS Trust
- Angela Gregson, Practice and Professional Development Lead - Palliative and End of Life Care, Leeds Community Healthcare NHS Trust
- Sue Ayres, Clinical Pharmacist, St. Gemma’s
- Melody Goldthorp, Continuing Care Lead, Leeds South and East CCG
- Tim Sanders, Integrated Commissioning and Transformation Manager, Dementia, NHS Leeds North CCG / Leeds City Council
- Sadie Smith, Manager, Robert Ogden Centre
- Josie Sharp, Information and Support Specialist, Robert Ogden Centre
- Karen Henry, Joint team leader for PC team at LTHT and EPaCCS representative.
- Elizabeth Rees, Joint team leader for PC team at LTHT
- Anne Wilkinson, Clinical Nurse Specialist (respiratory), Leeds Community Healthcare NHS Trust
- Julie Mountain, Community Matron, Leeds Community Healthcare NHS Trust
- Maureen Broadbent, Clinical Nurse Specialist (cardiac), Leeds Community Healthcare NHS Trust
- Jane Wild, Discharge Facilitator, Leeds Community Healthcare NHS Trust
- Dr Chris Hosker, Consultant Liaison Psychiatrist, LPFT
- Judy Kesler, Quentin Fowler and Ben Francis, Leeds Quakers
- Tony Jamieson, Medicines Governance Lead, Medicines Management Collaborative, Leeds North CCG, Leeds South and East CCG and Leeds West CCG
- Dr Paul Hatfield, Consultant Clinical Oncologist, LTHT
- Dr Liz Berkin, Cardiology Consultant, LTHT
- Dr Ian Clifton, Respiratory Consultant, LTHT
- Dr Wendy Neil, Associate Medical Director for Older People’s Services/Consultant Psychiatrist, Leeds and York Partnership Foundation Trust
Appendix 7: The Leeds Eligibility Criteria For Access To Adult Specialist Palliative Care

Adult Specialist Palliative Care refers to those services where the core purpose and function is to provide palliative care to people aged 18 years and above. In Leeds these services are the Hospital Palliative Care Team, St. Gemma’s Hospice and Sue Ryder Care Wheatfields. Eligibility to access Specialist Palliative Care (SPC) services is based on patient need and not diagnosis.

1. The patient has active, progressive and usually advanced disease for which the prognosis is limited (although this may be several years) and the focus of care is quality of life.

AND

2. The patient has unresolved needs that exceed the expertise of the referring team. – These needs may be physical, psychological, social and/or spiritual.
   – Examples may include complicated symptoms, difficult family situations, ethical issues regarding treatment choices, and complex advance care planning and end of life care.

AND

3. The patient has been assessed by a SPC professional: – Hospital, Community, and Day Services:
   The patient can be assessed on the first meeting by the SPC professional.
   – Hospice Inpatient Referral:
   The patient will be assessed by a SPC professional before admission.

4. Discharge Criteria: – Patients who no longer meet the above criteria may be discharged from the specialist palliative care service.
   – The patient can be re-referred should they subsequently meet the eligibility criteria.

Original Document: 2000
Latest Review Date: July 2012
Next Review Date: July 2015
Appendix 8: Yorkshire Cancer Network End of Life Care Pathway

**Quality Criteria**

1. Professional with appropriate skills, knowledge and competency to undertake the holistic assessment.
2. Use of appropriate assessment tools e.g. CAF.
3. Use of recognized assessment tools: GSF & PPC. Also ACP and bereavement risk assessment for carers.
4. Workforce competent in EOL care in all care settings including care homes.
5. 24/7 accessibility of competent workforce in all care settings.
6. Use of recognised tools, guidance and documentation; LCP, OOH, DNAR.
7. Single point of contact for patients and carers identified
8. Bereavement services are available

**Criteria 1**
Senior Professionals of treating teams are competent in advanced communication skills e.g. level 4 in KSF or have undertaken advanced communication skills training.

**Criteria 2**

**Criteria 3**

**Criteria 4**

**Criteria 5**

**Criteria 6**

**Criteria 7**

**Criteria 8**

**Criteria 9**

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**YCN Palliative Care (End of Life) Pathway – June 2010**

- **Supportive pathway**
  - **Recognition of and the start of conversation about End of Life Care**
    - Use of the surprise question, disease specific prognostic indicators and/or patient decision for best supportive care as triggers for recognition (see GSF Framework).
    - Cancer MDT decisions in acute trusts for Best Supportive Care/Palliative Care (for some patients this will include undergoing palliative treatments e.g. chemotherapy, radiotherapy).
    - Other holistic assessment and care planning. Identify where and who will undertake the assessment (this may take place at the same time as starting the conversation).
    - Transfer appropriate information to enable the assessment to take place.
    - Patient added to GSF register in primary care.

- **Assessment of individual patient and carers needs and preferences**
  - Patient and carers needs to be assessed separately.
  - Share information with all appropriate professionals. Will require long term IT solution.
  - Access to interpreting services and communication aids.
  - If patient has complex needs that meet Specialist Palliative Care criteria, referral made.
  - Use of EoL care tools e.g. GSF, PPC
  - Use of ACP (inc. advance decisions, resuscitation status, organ donation, post mortem requirement, mental capacity) and bereavement assessment

- **Last days of life**
  - Diagnosis of dying & use of LCP
  - Timely access to drugs and equipment.
  - Sharing patient information across care settings – will require long term IT solution.
  - Access for carers (when not in their home setting) to refreshments, accommodation and car parking.
  - GP to visit within appropriate timescale to avoid inappropriate referral to coroner.
  - Anticipatory symptom management including prescription of drugs.

- **Care at the time of death**
  - Use of appropriate documentation.
  - Prompt verification and certification of death (esp. OOH) with appropriately trained professionals as per local policy.
  - Culturally sensitive last offices performed.
  - If appropriate discussion about post mortem and/or organ donation.
  - Inform the coroner as per legislation.
  - Assessment of carers immediate bereavement needs. Referral to appropriate bereavement service if at significant risk of abnormal response.
  - Information for carers regarding what happens next and bereavement advice.
  - Disposal of controlled drugs as per local policies.

- **Bereavement**
  - Use of bereavement risk assessment tool and appropriate onward referral to bereavement services.
  - Range of accessible bereavement services available to meet needs in all settings including support for children/family members.

- **Care planning**
  - Timely access to other appropriate services/equipment to meet identified need: including symptom management; rehabilitation services; benefits advice; spiritual; psychological; social care; support for children/family members and complementary therapies available.
  - Care planning in partnership with patient and carers.

- **Co-ordination of care**
  - Coordination of care – single point of contact.
  - Patient and carer know number to contact 24/7.
  - Timely sharing of information across all care settings.
  - Clear agreed plan of who is responsible for care/service provision.
  - Completion of all sections of OOH documentation in primary care.
  - Seamless and prompt transfer of patients between care settings.

- **Delivering high quality care**
  - Rapid response services. 24 hr community nursing services.
  - Access to: responsive ambulance services; 24 hr Specialist Palliative Care advice; Specialist Palliative Care assessment and in patient beds; social care; sitting services; carer support services; bereavement support services and other support services.
  - Identification and recording of unmet needs for future service development.

- **Regular review**

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Note: The diagram shows a pathway for palliative care with various stages and considerations. The text provides detailed information on each stage, including recognition of the start of conversation, assessment of patient and carer needs, last days of life, care at the time of death, bereavement, care planning, co-ordination of care, and delivering high quality care. The quality criteria are also outlined, emphasizing the importance of professional competence and use of appropriate assessment tools. The diagram is visually represented to illustrate the flow and integration of care processes, with key points marked for recognition and action.