

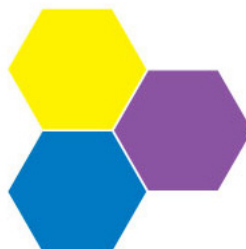
The Leeds Citywide Palliative & End of Life Care (EoLC) Managed Clinical Network (MCN)

April 2016 - March 2018

MCN Project Report - Final

Leeds Palliative
& End of Life Care
Managed Clinical Network

Working Together. Improving Care.



“The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference”.

The Foreword: Ambitions for Palliative and End of Life Care 2015-2020

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Meet the Palliative & EoLC MCN

Introducing the MCN Executive Members



Mike Stockton
MCN Clinical Lead
& Chair

Director of Medicine
& Consultant in Palliative
Medicine
St Gemma's Hospice



Lynne Russon
MCN Quality Assurance
& Patient Experience
Workstream Lead

Medical Director and Consultant
in Palliative Medicine
Sue Ryder Wheatfields Hospice



Trish Stockton
MCN Education &
Research Workstream
Lead

Head of Learning
& Teaching,
St Gemma's Hospice



Moira Cookson MCN
Medicines Management
Workstream Lead

Advanced Clinical
Pharmacist Palliative Medicine,
Leeds Hospices



Adam Hurlow
MCN Workforce & Service
Improvement Lead

Consultant in Palliative
Medicine, Leeds Teaching
Hospitals Trust



Veronica Lovatt
MCN Network Manager

Commissioning Manager
NHS Leeds Clinical
Commissioning Group



Sarah McDermott
MCN Workforce & Service
Improvement Lead

Palliative Care Lead, Leeds
Community Healthcare Trust



Amanda Storer
MCN Administrator

Introducing the Full MCN Group Membership

Organisation	Name	Substantive Role
Leeds Teaching Hospitals Trust (LTHT)	Adam Hurlow	Consultant in Palliative Medicine
	Suzanne Kite	Lead Clinician/Consultant in Palliative Medicine
	Elizabeth Rees	Lead Nurse for EoLC
	Deborah Borrill	Palliative Care Discharge Facilitator (Strategic)
Leeds Community Healthcare Trust (LCHT)	Sarah McDermott	Palliative Care Service Lead
Leeds & York Partnership Foundations Trust (LYPFT)	Nicky Needham (Dementia lead)	Consultant Practitioner, Dementia Care.
	Paul Exley	Matron, The Mount
Sue Ryder Wheatfields Hospice	Lynne Russon	Medical Director and Consultant in Palliative Medicine
	Julie Marshall-Pallister	Community Clinical Nurse specialist
Leeds Hospices	Moira Cookson	Advanced Clinical Pharmacist Palliative Medicine
St Gemma's Hospice	Cath Miller	Director of Nursing
	Valerie Shaw	Head of Communications & Day Services
	Mike Stockton	Director/Consultant in Palliative Medicine
	Trish Stockton	Research and Education Lead
	Clare Russell	Head of Transformation
	Veronica Lovatt	MCN Network Manager
	Amanda Storer	MCN Administrator
Adult Social Care (ASC)	Janet Humphrey	Team Manager
Primary Care	Gill Pottinger, South East CCG	GP/MCN Workforce & Service Development Lead.
	Simon Hall, North CCG	GP/MCN Education & Research MCN Lead
NHS Leeds Clinical Commissioning Group Partnership (CCG)	Diane Boyne Barbara Igbafe	EoLC Commissioning Manager Medicines Optimisation Pharmacist

Introducing the Full MCN Group Partnership



What is the Leeds Citywide Palliative & EoLC MCN?

Introduction

In 2016 Leeds Palliative & EoLC Provider Organisations committed to working in partnership through an MCN to develop and improve Palliative & EoLC services across the city. The initiative was supported and commissioned by NHS Leeds Clinical Commissioning Groups (CCGs). The partnership was secured through a Memorandum of Understanding which each organisation signed up to at a senior level. The initial remit of the MCN was to improve the gaps in service identified in the Palliative & EoLC Strategy (2014-19) action plan. The actions were derived from the Palliative & EoLC Health Needs Analysis undertaken in 2013. The network was initially funded for 2 years. Outside of this project, it is recognised that individual providers will have their own organisational priorities and issues. The MCN was launched in April 2016 following a period of shadow working from December 2015.

Our Vision

As organisations with experience of, and responsibility for Palliative & EoLC, we have made a collective decision to act together to do all we can to achieve for everyone what we would want for our own families. (Adopted from Ambitions for Palliative & EoLC 2015-2020).

Our Purpose

The purpose of the MCN is to work in a collaborative and co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality, clinically effective, Palliative & EoLC and to improve management, monitoring and evaluation through strengthened accountability.

Memorandum of Understanding (MOU) – Our Principles of Engagement

MCN member organisations have agreed to:

- Work together openly, transparently and constructively
- Co-operate in pursuit of our shared objectives
- Appropriately reflect the content and the spirit of the Memorandum in each other’s business plans and strategies.
- Brief each other on matters of mutual interest and alert each other to emerging issues which may raise concerns.
- Subject to reasonable confidentiality restrictions, advise each other of matters of mutual concern

Our Accountability Framework

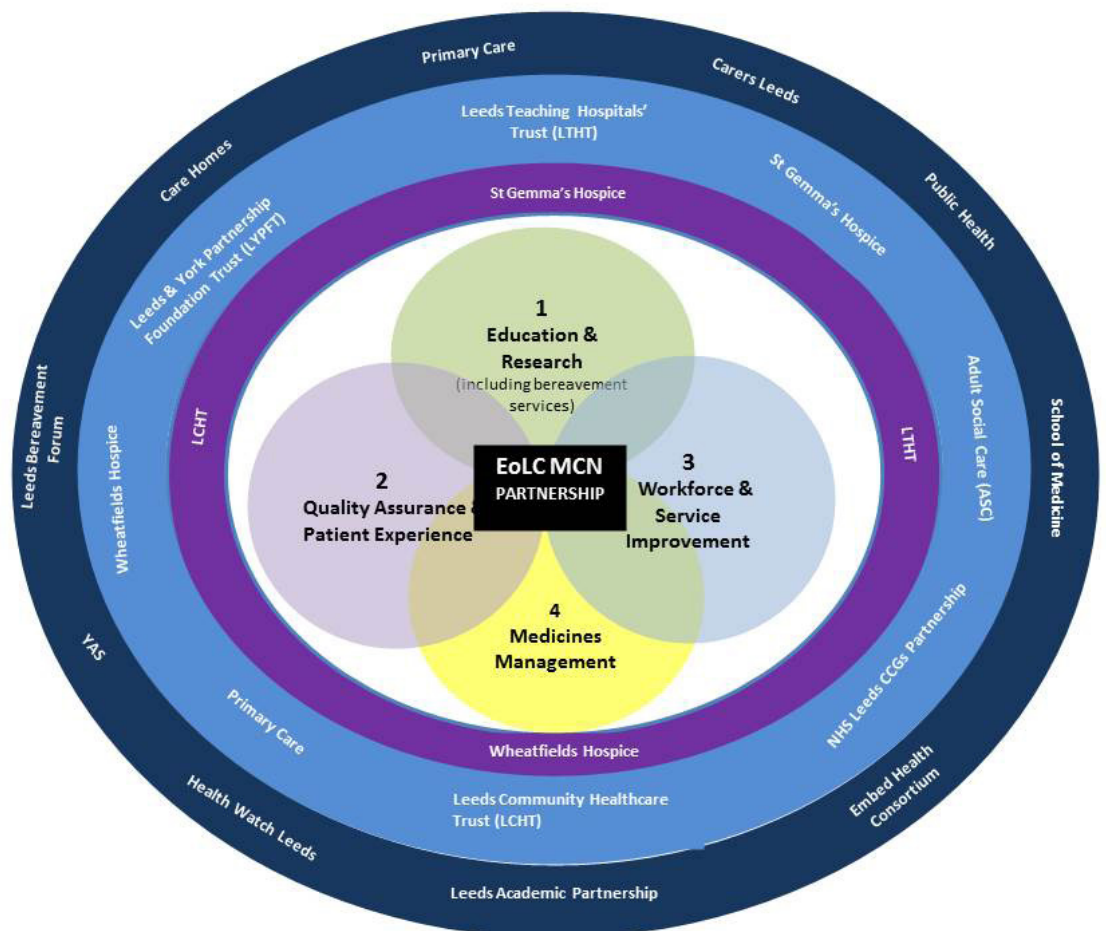
The MCN is accountable to the Palliative Care Strategy Group who report to Leeds CCGs Senior Management Team and the Provider Management Groups. From autumn 2017 lines of accountability will change to comply with the new One Voice structure.

The MCN Model – Working in Partnership

The MCN working model (Fig 1) was designed keeping the quality of services for patients and efficient use of limited resources at the very centre of what we do. The chances are, if you ask the person next to you, they will have a personal story of when things have or have not gone well in their health service experience. We thought about how we could design a model that would capture the key components of service quality. The model needed to be clinically led, facilitate development of a network, engagement with other stakeholders, be clearly accessible and monitor and account for the work it undertakes to drive continuous improvement in Palliative & EoLC. The model in Fig 1 was agreed and adopted by the MCN as the working model.

Fig 1

Fig 1 Legend
MCN Workstream 1
MCN Workstream 2
MCN Workstream 3
MCN Workstream 4
MCN Executive Organisations
MCN Member Organisations
MCN Wider Partnership



Executive Statement

Welcome to the first official report of the Leeds Palliative and End of Life Care (EoLC) Managed Clinical Network (MCN). The MCN is a pilot project funded by NHS Leeds CCG.

The purpose of this report is to provide Leeds CCG with assurance of the effectiveness of the Palliative & EoLC MCN as a delivery model for the improvement of services for the people of Leeds. In doing so we are seeking continued investment in this innovative, patient focussed, locally led, partnership model. The MCN model was agreed following lengthy citywide consultation on collaborative working models. It was felt that the MCN was the most pragmatic and well supported at the time. This report presents the development, the activity and the outcomes of the MCN since April 2016.

Every year of our life is important but the last year often holds special significance and previously uncharted challenges that make it different from all others. The Leeds Palliative & EoLC MCN exists to improve that last chapter of life.

The MCN:

- Is committed to the highest quality, consistent, equitable and sustainable care in the final phase of life
- Brings together palliative and end of life health, social care and academic professionals across Leeds
- Provides strong partnerships, transcends traditional boundaries, and fosters collaborative efforts and cross-Leeds systems change
- Engages, listens and responds to patients, carers and the public
- Takes ideas from the clinical front line, understands the needs of Leeds and draws on national strategy and best evidence
- Is an important partner in developing the future Palliative Care Strategy for Leeds

The MCN has been a long cherished aspiration for the Leeds palliative care community. It has built upon many years of dedicated efforts of those involved in Palliative & EoLC services.

Leeds has a long history of palliative care services;

the hospices are now nearly 40 years old, the palliative medicine training programme established in the early 1990s and a hospital team has operated for over 20 years. Within community services palliative care is a core function of the 13 integrated Neighbourhood Teams and NHS Leeds Clinical Commissioning Groups (CCGs) have introduced GP end of life care lead roles to support improvements within Primary Care. Palliative care in Leeds has evolved and developed to the stage we are at today. We have a service to be proud of.

The heart of what is delivered remains constant; high quality, person and family centred care to enable people to live and die as well as possible. What has changed is society's expectations, the complexity of health and social care, the volume of need, plus the challenge of funding and workforce capacity.

Future projections estimate a rise of 25 % in the number of people dying in the UK over the next 25 years. This translates to an increase of palliative care need of between 25-40% over the same period of time. People will be dying at an older age and this will be driven predominantly by cancer and dementia, alongside common long term conditions. ⁽¹⁾

Continuous improvement and transformation will be required to address this growing demand. The MCN will provide the fulcrum for this work.

Focussing on improving the care for people at the end of life will not only improve the outcomes and experience for patients, it has broader positive effects on adjacent services and care. It will serve to improve health and care flow, reducing pressure on ambulances, urgent and emergency care and hospital beds through timely and appropriate response to urgent unscheduled needs in the usual place of care. It will also help reduce unnecessary and unwanted admissions and improve early supported discharge to a place that best meets the needs of the patient, thus reducing the risk of unnecessary re-admission and occupied bed days. ⁽²⁾



The MCN was established just 18 months ago with funding provided by NHS Leeds CCGs, and in that time has created a broad network of health, social care and academic providers, has delivered a number of important quality improvement projects and is ready to set a critical vision for the coming years. The key achievements that are described in this report are:

- Improving the transfer of care from hospital to hospice
- Improving end of life care for people with heart failure
- Cross Leeds implementation of opioid guidelines
- Implementation of PPM+ and LCR across community specialist palliative care
- Electronic palliative care coordination system (EPaCCS) has been further embedded in routine clinical practice.
- Expanded clinical leadership capacity by forming a medicines management workstream and pharmacy lead position
- Improved visibility and influence of the MCN

The MCN is an emerging organisation and the value and outputs of the MCN will gain momentum over time. The early phase of its existence has involved developing a stable and workable structure, engaging key colleagues around the city and completing the delivery of the current Leeds Palliative & EoLC Strategy. The next phase will be focussed on delivering important systems change, quality improvement, extending the reach of Palliative & EoLC and co-producing the next Leeds Palliative & EoLC Strategy. The MCN supports and cultivates clinical leadership to deliver change at a local level, a key strand of the 'Ambitions for Palliative and End of Life Care' document 2015-2020.

The key objectives for the future are:

- Greater integration with long term conditions, especially frailty and dementia, in conjunction with stronger links to care homes
- Improve anticipatory prescribing at the end of life in order to increase safety, reduce waste and create consistency
- Implement a novel tele-education system (ECHO) to support workforce development and training
- Greater integration of the Academic Unit of Palliative Care into the MCN with the goals of influencing and supporting the research agenda, and using evidence optimally to guide clinical practice and models of care

- Report on Leeds wide end of life metrics based on an agreed set of data, in order that we improve the ongoing understanding of patient flow and quality of service
- Redesign the bereaved carers survey to provide information that has the power to support positive change
- Support the implementation of the ReSPECT documentation to provide clarity on end of life care and treatment decisions
- Commence the work of determining the strategic objectives needed for the next strategy which will be active from April 2019

There are significant changes occurring across the Leeds Health and Social Care commissioning landscape. The Leeds MCN fits in well with these new ways and could prove to be a fore runner and prototype for the future of care commissioning, development, coordination and delivery.

The scale of the challenge requires a long term view and planning, which in itself requires support and investment of the MCN by Leeds NHS CCG. In the absence of the MCN there is a significant risk that momentum, partnerships and positive change will diminish.

In the end we all want to live well and eventually die well. The MCN plays a core role by bringing together the best ideas and evidence across all partners to deliver that basic human need.

(1) BMC Medicine article - <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

(2) End of Life Care: Sustainability and Transformation Partnership Support Tool. August 2017. Public Health England, Care Quality Commission, NHS England



Spotlight on MCN Achievements 2016 to Date

Transfer of Care



The MCN is driving the strategic objective to improve the transfer of care from hospital to hospices, ensuring that all patients are transferred from Leeds Teaching Hospital NHS Trust to St Gemma's Hospice & Sue Ryder Wheatfields Hospice at the right time and as efficiently as possible

The enhancement of digital technology across the city in the form of SystemOne, PPM+ and Leeds Care Record are a real enabling tool in driving efficiency and reducing duplication across the whole Palliative & EoLC care system

A citywide collaborative group identified and agreed the priority areas for innovation and service improvement. The following summarises the key improvements to date and planned next steps:

Action: We have developed a citywide E-Referral system to receive all hospital to hospice referrals

Improvements: Driving efficiency, reducing duplication, ensuring consistency, improving information governance standards and streamlining operational processes. Development of citywide electronic templates, for referral and Nurse to Nurse handover

Next Steps: To transfer the E-Referral system into PPM+

Action: We have improved our booking process for palliative care ambulances, enabling patients to be transferred efficiently and comfortably to the hospices once the referral has been accepted

Improvements: Quality of care, facilitating timely discharge, patients arriving in their preferred place of care, efficient use of palliative care ambulance.

Next Steps: Raise a potential risk for future service delivery - Leeds requires two palliative care ambulances in operation to meet the demands in service. A reduction in this provision will significantly impact the efficiency and quality of transfer of care for those Palliative & EoLC patients

Action: St Gemma's Hospice is piloting a daily virtual referral meeting directly with our LTH colleagues via Skype for Business

Improvements: Enriching partnership relationships and integrated working, enabling 'real-time' clinical debate, confirmation and challenge, collaborative bed resource allocation – being responsive to patient need

Next Steps: Completion of pilot phase, evaluation and possible roll out to Sue Ryder Wheatfields Hospice

Action: We are improving how we transfer medications from hospital to hospice, focusing on rationalisation of medication and anticipatory medication management

Improvements: Driving efficiency, improvements with waste management. Pharmacist Lead role developed into MCN

Next Steps: Pharmacist to continue to lead this collaborative work stream

This work stream has delivered some real radical change within the Palliative & EoLC system across our City, and we very much look forward to embedding the collaborative practices and creating opportunity for future innovation

End of Life Heart Failure

Action: To improve the quality of care for patients with advanced heart failure in Leeds by September 2017

- Patients with severe symptoms are managed effectively
- Patients are supported with future care planning discussions which are documented
- Patients have appropriate access to specialist palliative care services

Improvements: Project Interventions

- In-reach into cardiology outpatient (OP) department
- Virtual palliative medicine heart failure clinic
- Citywide heart failure palliative care multidisciplinary team (MDT)
- Education and audit/evaluation

We have piloted a weekly virtual palliative care heart failure clinic for 5 months and commenced a monthly citywide heart failure MDT. The MDT meeting has promoted shared learning and joint decision making.

Next Steps: The citywide palliative care MDT is to continue monthly. Palliative medicine input will also continue, along with education and close working with the heart failure team focusing on advance care planning, rationalisation of medication and anticipatory medication management. Further work with cardiology OP department and mapping Leeds against Heart Failure and Hospice Care 2017 (Hospice UK).

Opioid Wheel, Liver and Renal Guidelines

Action: We have launched a standard conversion table for opioids and produced guidance for end of life care for patients with liver and renal impairment. These are evidence-based, cost effective, replicable and accessible across clinical settings in Leeds.

Improvements: By implementing a citywide conversion for opiates and guidance for end of life care for patients with liver and renal impairment across hospital, hospice and community settings and educating providers about its use; we have reduced the risk of prescribing errors, promoted consistent high quality care and ensured optimal dosing across the city.

Next Steps: To reinforce education at TARGET in 2018

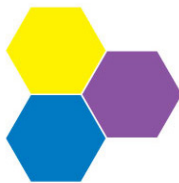
Development of Medicines Management Lead

Action: The MCN recognised the important role of medicines management in delivering high quality palliative and EoLC and the need for a dedicated workstream and leadership role.

Improvement: We have created a medicines management lead and appointed an experienced palliative care pharmacist to this role.

Next Steps: The lead will drive and oversee citywide pharmacy developments, identify systems and issues and create a medicines management strategy.





Our ability to influence Palliative & EoLC across the city is more effective if our network is known about, recognisable and trusted

Action: Design and introduce an MCN logo to create a symbol to help people quickly recognise the work generated by the network

Improvements: Our rationale for developing the logo is that it will help us to build trust and connect with our Palliative and EoLC partners and colleagues in Leeds to inform and share information about the projects, service improvements and changes that result from MCN activity. More importantly, they will understand at a glance that the work is underpinned by a collaboration of the key EoLC providers in Leeds enabling the network to perform more effectively

Next Steps: Embed widespread use of MCN logo

We have built our networks, connections and influence

Action: A key task of the MCN is to build a comprehensive network of partners and influence Palliative & EoLC across the whole of Leeds, both operationally and strategically

Improvements: To work in a co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality clinically effective Palliative & EoLC in Leeds. The MCN has succeeded in widening its broader network with new partners such as Carer's Leeds, Leeds Academic Health Partnership, and the Leeds Clinical Senate

Next Steps: To continue to engage and establish links with Palliative & EoLC services providers. To engage and strengthen links with Care Homes in Leeds

We have developed our website

Action: The Leeds Palliative Care Website is being modernised to sign-post and provide information to the public about Palliative & EOLC services in Leeds as well as other options available to support them

Improvement: The new website design aims to achieve up to date, clear and accurate information which is user friendly and requires minimal input to maintain

Next Steps: Finalise the website design and launch



Spotlight on MCN Information Management & Technology (IM&T) Achievements

PPM+ and LCR

Action: We have supported the comprehensive implementation of PPM+ and LCR across both hospice unit and specialist palliative care community teams. This has been achieved by working collaboratively across a number of partners including LTHT, SECCG, LCR, Wheatfields and St Gemma's Hospice

Improvements: The MCN recognises the need for timely, accessible, high quality health and social care data that supports clinical decision making and improves quality and safety. Access to hospital clinical information including digital images, improved cross boundary communication and new systems of referral. This all has the effect of improving shared decision making, reducing wait times, and limiting the potential for error

Next Steps:

1. Development of a virtual ward system enabling hospices to see their patients in hospital beds
2. Access to e-meds (hospital prescribing system)
3. Implementation of Order Comms (electronic investigation & ordering system)

Metrics framework

Action: The MCN has agreed a set of citywide measures to assess the combined impact of its workstreams and drive improvements in patient care

Improvements: Essential data sharing agreements being progressed to support the collection of data concerning the equitable use of EPaCCS, care and death in patient's preferred location and utilisation of hospital inpatient beds

Next Steps: We aim to launch routine reporting by April 2018

Electronic Palliative Care Co-ordination System (EPaCCS)

EPaCCS provides a shared locality record for healthcare professionals. It allows rapid access across care boundaries to key information about an individual's approaching the end of life including their expressed preferences of care

Action: We have revised the community EPaCCS template and rolled it out across NHS Leeds CCGs/GP practices, Leeds Community Healthcare NHS Trust and Leeds hospices

Improvement: GP practices receive quarterly reports showing patient deaths in that quarter, giving details of the number identified as end of life and having had an advanced care plan. The data has shown an increase in the number of patients being identified. The regular feedback and support offered to practices is encouraging primary care teams to use the EPaCCS template and improve co-ordinated care of patients at the end of

life and helping them achieve their preferred place of care and death

Next Steps: A hospital version has been developed for implementation in 2017-18 within LTHT



Spotlight on MCN Achievements

Education delivered in 2016-17 in relation to money received from the CCG to support education delivery in Leeds

54
community staff received communications skills training



80
community staff received training in bereavement and complex grief



Opioid wheel launched
Further education planned at a future TARGET session

62
OOH's GPs received training on symptom management and anticipatory prescribing



10
GP's have undertaken the 2 day Advanced Communication Skills training course (St Gemma's Hospice)



Working to become
Dementia Friendly

20
20 care home staff received end of life and dementia care training



30

GP's have received GP Masterclass training in symptom management at the end of life. Totalling 140 overall to date (St Gemma's Hospice and Sue Ryder Wheatfields Hospices)



Quality End of Life Care for All (QELCA) programme for a total of 6 LTHT and LCHT staff where generalist nurses spend a week at St Gemma's Hospice, have training sessions, work in clinical practice and focus on an area of practice they would like to change or implement in their own clinical setting. (St Gemma's Hospice & LTHT)



14

Care Home Managers received Adult Social Care (ASC) "Lead & Manage EoLC". To enable change in the Care Home Sector. (St Gemma's Hospice and Sue Ryder Wheatfields Hospices)



2

Facilitators from LTHT & St Gemma's Hospice received Train the Trainers for Advanced Communication skills training citywide



102

Care Home Staff received training on Advanced Care Planning/End of Life Communication skills (Sue Ryder Wheatfields)

50

LTHT nurses attended a "Nurses - Making a difference in Palliative & EoLC" conference



Other Education

Various providers have delivered a citywide comprehensive training programme in key areas of communication skills, symptom management, bereavement support, advance care planning and end of life dementia care. This enables staff to have the necessary, confidence skills and knowledge to deliver holistic, compassionate care to patients and their families

Spotlight on MCN Achievements 2016 to Date

Education & Research Workstream

Education

- Established commitment to delivery of the Leeds Palliative & EoLC Education strategy
- Identified education leads in each provider organisation support the delivery of the Education strategy
- Agreed a tool to identify the workforce in Leeds requiring Palliative & EoLC Education
- Completed a full review of the Palliative Care Education Group (PEGs) with a revised structure/ purpose/ communication/ key areas to work on over 2017-18

Research

- Research team at the University of Leeds and the MCN clearly linked with communication process established
- Current research activity in Leeds: (see Appendix 1 for details)
- Research Bids: The MCN are involved in 2 research bids with the Research team at the University of Leeds
 - Optimising engagement with Electronic Palliative Care Coordination Systems (EPaCCS) to support advance care planning and co-ordination of care towards the end of life
 - Understanding Specialist Palliative Care Patients' and Families' Experiences and Needs of Out-of-Hours Support

Quality Assurance & Patient Experience Workstream

Anticipatory Medications

- Initial scoping exercise to define issues around the prescribing, supply and administration of anticipatory medications.

Leeds Citywide Bereavement Survey

- Completed survey April 17 from hospices, hospital and community patients.
- Feedback and evaluation September 17



The Context, the Challenge, the Facts

Death and Dying in Leeds (see Appendix 2 for more details)

- In 2015 there were **6790** deaths in Leeds, **5000** of which may benefit from a palliative care approach.
- In Leeds, there has been a shift in where people die over the past decade, so that now there is a lower proportion of death in hospital and more people dying at home, in care homes and hospice.
- In 2040 the annual deaths in England and Wales are projected to rise by **25.4%** ⁽¹⁾
- In Leeds there will be **8,515** deaths and at least 6,386 may benefit from a palliative care approach.
 - The greatest rise is in the **85+** group.
 - The most significant drivers of these changes are predicted to be cancer and dementia.

Palliative Care Activity 2016/17

- St Gemma's and Sue Ryder Wheatfields Hospices cared for 2200 new patients
- The hospital palliative care team provided 1276 face to face assessments with individual patients
- The neighbourhood teams cared for 2400 palliative care patients
- The duration of time spent in specialist palliative care is similar to national data. This is a median of 46 days for the hospices and 20 days for the hospital service⁽²⁾
- Patients with a non-cancer illness and older patients are referred later than younger patients with cancer

(1) BMC Medicine article - <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

(2) What determines duration of palliative care before death for patients with advanced disease? BMJ Open. 2016; 6:e012576



More Facts to Consider...

Economic evaluation of Electronic Palliative Care Co-ordinated Systems (EPaCCS) indicates financial savings can be made where these systems are in place to share EoLC records – recurrent savings after four years c£270k for a population of 200,000 people⁽⁶⁾

If recent mortality trends continue, 160,000 more people in England and Wales will need palliative care by 2040⁽¹⁾

Hospital costs are by far the largest cost elements of EoLC with care in the final three months of life averaging over £4,500 per person who died. The bulk of this cost is due to unplanned admissions where hospital costs increase rapidly in the last few weeks of life⁽⁵⁾

If access to community-based EoLC improved, £104 million could be redistributed to meet people's preferences for place of care by reducing emergency hospital admissions by 10% and the average length of stay following admission by three days⁽⁴⁾

Approximately 30% of people in the last year of life use some form of Local Authority funded social care⁽³⁾

Advance Care Planning (ACP) improves EoLC and patient and family satisfaction and reduces care home admissions, stress, anxiety and depression in surviving relatives⁽⁷⁾

10% of people receiving hospice care that have engaged in ACP die in hospital compared to 26% of those who have not engaged in ACP⁽²⁾

The voluntary sector are important partners in meeting EoLC needs, both as providers and funders of care. Across the country, the hospice sector, for example, invests over £1 billion of charitable funding in local communities to meet palliative care needs⁽⁹⁾

Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%)⁽⁸⁾

(1) BMC Medicine article - <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>((

(2) Age UK 2017 report - ref: NHS South West review of 960 records in last 2.5 years

(3) Bardsley, M., Georghiou, T. and Dixon, J. (2010). Social care and hospital use at the end of life. The Nuffield Trust.

(4) National Audit Office (2008) End of Life Care. National Audit Office. <https://www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf>

(5) Nuffield Trust report: <https://www.nuffieldtrust.org.uk/news-item/further-evidence-on-the-cost-of-end-of-life-care-outside-of-hospital-new-nuffield-trust-analysis>

(6) Economic Evaluation of EPaCCS - Early Implementer Sites. 2013. NHSIQ. <http://www.slideshare.net/NHSIQ/economic-evaluation-of-the-electronic-palliative-care-coordination-systemepaccs-early-implementer-sites>

(7) Age UK 2017 report - ref: NHS South West review of 960 records in last 2.5 years

(8) National Survey of Bereaved People (VOICES): England, 2015

(9) Hospice UK (2016) Hospice Accounts: Analysis of the accounts of UK charitable hospices for the year ended 31 March 2015. London: Hospice UK

Priorities for Improvement from 2017 Onwards

How our priorities have been developed

The priorities of the MCN have been developed through:

- The Leeds Palliative and End of life Strategy 2014 - 2019
- The Palliative and End of Life Care Health Needs Assessment
- The Leeds Palliative Care Education Strategy 2016-2021
- Ambitions for End of Life Care
- Emerging evidence and opinion of the changing needs of Palliative & EoLC
- Challenges arising from clinical practice, cross boundary working and communication

Education & Research Workstream

Clarify and establish the role of the MCN/PEGS in citywide education

Palliative & EoLC Education Provision

- Review and identify the palliative care workforce in Leeds (groups A,B, C)
- Collate Palliative & EoLC education delivery across Leeds
- Identify the gaps in provision

Palliative & EoLC Learning Outcomes

- Ensuring collaboration across all partners
- Sharing best practice of implementation and evaluation

Communication Skills Training

- Review the Communication Skills Training Strategy 2010-14
- Formulate a new Communication Skills Training Strategy 2018-2022

Preparation to host a TARGET meeting in 2018 focussed on Palliative and EoLC

Explore the use of tele-education and tele-mentoring via the ECHO system to support education to various groups (care homes, GPs, end of life teams)

Collate resources for clinicians on key areas e.g. e-ELCA, DNACPR

Research

- Improve practical links with the research community and in particular the Academic Unit of Palliative Care

Palliative Care Website

- Launch, market and evaluate the new Palliative & EoLC Website
- Future education planned in relation to MCN objectives/ CCG funding
- Care Home: to deliver a further 1 day conference on End of life care and dementia for 30 care home staff with a follow up support visit to individual care homes, November 2017 (St Gemma's Hospice, EOL care home facilitator)
- Master Class Conference: update for GPs in symptom management and communication skills Oct 2017 (St Gemma's)
- 1 day Conference / Update in Advanced Symptom Management for Specialists in Palliative Care Citywide (MCN team)

Quality Assurance and Patient Experience

Palliative & EoLC Metrics

Implement a suite of metrics across Leeds to measure the effectiveness and quality of Palliative & EoLC and develop use of patient centred outcome measures

Bereaved carers survey

- Review the process and relaunch to enhance data quality
- Deliver annually

Design a system to ensure that lessons are learnt from concerns, complaints & incidents across the Palliative & EoLC MCN Partnership in Leeds.

Workforce & Service Improvement Workstream

Transfer of Care Project

Complete implementation of pilot of e-referrals and virtual meetings.
Evaluate the implementation of e-referrals.

ReSPECT

To support the citywide implementation of the ReSPECT approach to discussing, recording and sharing treatment escalation and CPR decisions.

Electronic Co-ordination of EoLC

- Develop an approach to evaluating use and impact of EPaCCS in Leeds
- Collaborate with Leeds Care Record to share EoLC decisions across the city

Single Point of Access (SPA)

Provide MCN representation at the Access (Wiring) Steering Group established as part of the Leeds Health and Care Plan, Urgent Care and Crisis Response programme.

Integration with Long Term Conditions and Multi-morbidity

- End of Life Heart Failure: implement recommendations into routine clinical practice
- Dementia and End of Life – Collaborative and whole system approach to caring for people who are dying with and from dementia
- Frailty: Exploring the relationship between frailty and palliative care

Care Homes

Support NHS Leeds CCGs in their citywide approach to developing care and service models that reflect the Palliative & EoLC needs of residents.



Medicines Management Workstream

Medicines related guidelines

- Map processes currently in situ for the production, ratification and dissemination of specialist and generalist guidelines for the use of medication within Palliative & EoLC
- Define clear pathways to ensure the production of high quality, relevant guidance that is disseminated in a timely and effective manner
- Encourage collaborative working when producing guidelines to increase efficiency

Anticipatory prescribing, continuing from initial scoping exercise in 2016/2017

- Review access to medication in community in conjunction with NHS England and CPWY (Community Pharmacy West Yorkshire)
- Produce summary document of anticipatory medications currently supplied to ensure consistency of approach
- Audit use and supply of anticipatory medications across Leeds.
 - Use data to review current practice to allow efficient, equitable and timely access to essential medication at the end of life

Corporate

Improve MCN visibility, productivity and influence through

- Review of engagement with wider MCN group
- Implement the MCN communications and influence strategy

Strategic

Commence the work of determining the strategic objectives needed for the next strategy which will be active April 2019.

The 2019 strategy will be a collaborative piece of work between the NHS Leeds CCG, the Leeds Palliative & EoLC MCN and other partners.

Self/Informal Carer Administration of injectable medicines

- Work with multiple provider groups to produce guidance and competencies which will allow patients/ carers to administer subcutaneous injections in the community setting; this would lead to the delivery of medications in a timelier and more flexible manner while also giving patients more control over their medication regimens.

Electronic Prescribing

- The introduction of electronic prescribing and drug administration across Leeds Hospices

TARGET

- Involvement in TARGET sessions for GPs in 2018/19 to publicise and provide education around new medicines related guidance



The MCN have the responsibility to bring together the evidence to support change, develop innovative solutions, offer a collective view, and look for opportunities for integration, systems transformation and sustainability.

The Future of the MCN and Palliative & End of Life Care in Leeds

The Leeds MCN is a young and emerging organisation and one which aspires to evolve into a responsive and enduring partnership framework for the continuous improvement and transformation of palliative care across Leeds and in this way become a model and exemplar of best practice for other groups across the UK and beyond.

Palliative care in all its manifestations will be under increasing demand over the next decades. The MCN places Leeds in a strong position to understand the changing need, meet the demand in an evidence-based and coherent way and organise services efficiently and sustainably.

It is hoped that this document provides some insight into the essential work of the MCN, its trajectory of growth and influence and the important part it has to play in shaping the care of people in the final phase of life, in death and dying and for those who are left in grief.

It may be worth considering how we would develop Palliative & EoLC in the absence of the managed clinical network.

- Understanding Leeds would be restricted to a more fragmented and less complete picture in the absence of a citywide metrics approach
- Leeds wide coherent change may be limited as organisations retreat back to traditional boundaries and mind-sets
- Establishing new evidence into practice will have more complex routes to delivery
- Delivering the Leeds Palliative & EoLC education strategy to enable and empower the workforce will become more fragmented and less effective

These are just a few areas where there are likely to be retrograde steps in the absence of the MCN.

The Leeds MCN has been a pilot project over the last year and a half. It is hoped that the added value it has provided in delivering clinical change, creating strong and healthy partnerships and collaborations whilst establishing itself as a workable and effective structure now and for the future are sufficient grounds for ongoing support and investment from Leeds NHS CCG (see Appendix 3 for more details).



Current Research

(Names underlined are members of AUPC &/or MCN)

Improving the management of pain from advanced cancer in the community (IMPACCT)

NIHR Programme Grant for Applied Research £2,294,907 (2012-2019)

MI Bennett, C Allmark, B Bewick, A Blenkinsopp, JM Brown, SJ Closs, K Fleming, M Godfrey, R Foy, G Hall, C Hulme, R Jones, S Pavitt, P Rainey, L Ziegler, D Fox.

[National RCT comparing usual community palliative care support with supported self-management]

5 year Senior Research Fellowship

Yorkshire Cancer Research £322,434 (2016-2021)

L Ziegler, MI Bennett

[Identifying interventions and pathways in Leeds to improve earlier integration of palliative care for cancer patients]

National Hospice survey on duration of contact before death (funded from IMPACCT)

MI Bennett, M Allsop, L Ziegler in collaboration with Hospice UK

[Data on 41,000 patients from 63 hospices being analysed for publication]

National audit of blood transfusion in hospices (funded by NHS Blood and Transplant)

K Neoh, MI Bennett, C Malia, J Boland, R Gray, L Estcourt, J Grant-Casey

[Data on 467 patients from 121 hospices being analysed for publication]

Determining access to palliative care

NIHR Research Capability Funding £37,040

C Craigs, MI Bennett

[Additional analyses of linked routine data building on Time4PallCare project findings]

Recruitment to other NIHR Portfolio Studies

(Kath Black and Angela Wray, NIHR Research Nurses)

Sarcabon

[National RCT comparing usual community palliative care support with supported self-management]

Prognosis in Palliative care Study (PiPS2)

[Multisite NIHR funded study validating prognostication tool]

Recent Research Awards in Set-Up

Accessing medicines at end-of-life: a multi-stakeholder, mixed method evaluation of service provision.

NIHR Health Services and Delivery Research Reference £669,421 (2017-2020)

S Latter, A Richardson, MI Bennett, A Blenkinsopp, N Campling, M Santer, D Meads, S Ewings, L Roberts
[\[National evaluation study to improve medicines access\]](#)

Supporting Timely Engagement with Palliative Care (STEP)

Research for Patient Benefit £248,607 (2017-2019)

L Ziegler, M Bennett, S Taylor, S Kite, H Bekker, P Carder, C Henry, J Gallagher, P Martin
[\[Development of decision and communication aids in Leeds and Bradford to promote conversations about early integration of palliative care\]](#)

5 year Senior Research Fellowship

Yorkshire Cancer Research £378,789 (2017-2022)

M Mulvey, MI Bennett

[\[Developing and testing systematic pain assessment in routine cancer and palliative care in Leeds\]](#)

Marie Curie 3 year Clinical and Academic Research Fellowship £135,000 (2017-2020)

MI Bennett

[\[Developing research activity at Marie Curie Bradford in collaboration with AUPC\]](#)

Analysis of National Bereavement Survey (VOICES)

NIHR Research Capability Funding £25,000 (2017-2018)

MI Bennett, C Craigs

[\[Determining markers for poor quality end of life care and examining effect of community palliative care on pain experience at home\]](#)



Recent Grant Applications

Improving health status and symptom experience for people living with advanced cancer

Yorkshire Cancer Research £1,686,100 (2018-2022)

MI Bennett, F Murtagh, A Blenkinsopp, C Bojke, J Boland, P Carder, M Johnson, M Maddocks, M Mulvey, C Smith, P Taylor, R West, L Ziegler

Resilience in widowhood: Does end of life support moderate health and wellbeing trajectories?

Wellcome Trust £183,998 (2018-2021)

C Craigs, MI Bennett, S Richards, R West

Optimising engagement with Electronic Palliative Care Coordination Systems (EPaCCS) to support advance care planning and co-ordination of care towards the end of life

Marie Curie Research Grants £227,944 (2018-2021)

M Allsop, MI Bennett, P Carder, B Hibbert, S McDermott, G Pottinger, A Hurlow, K Sleeman, M Twiddy, J Hackett

Understanding Specialist Palliative Care Patients' and Families' Experiences and Needs of Out-of-Hours Support

Marie Curie Research Grants £137,755 (2018-2020)

J Hackett, MI Bennett, S Richards, K Flemming, T Farragher, M Allsop, V Shaw, J Marshall-Pallister

Systematic review of effectiveness and cost-effectiveness of digital supportive interventions for people with cancer that cannot be cured

Macmillan Research Grants £116,280 (2018-2020)

AM Bagnall, L Ashley, C Hulme, P Hall, M Wells, I Lawrie, MI Bennett

Does the use of a brief, self-reported, patient-centred digital outcome measure improve patient experience when living with cancer that cannot be cured?

Macmillan Research Grants £98,810

F Murtagh, I Higginson, J Dyson, T Schinkoethe, A Wolkowski, MI Bennett

Mike Bennett

St Gemma's Professor of Palliative Medicine

July 2017

A Picture of Citywide Palliative & EoLC in Leeds

The Need - Now, trends and future

Appendix 2

The Scale

Deaths and Palliative Care Need in Leeds 2015 (ONS Data)

6790
deaths in Leeds



75%

of deaths are estimated to benefit from palliative care approach (Etkind et al, BMC Medicine, 2017)



5000 (75%)

deaths would benefit from palliative care approach in Leeds each year



2700 heart and lung diseases



1900 cancer



1000 also include dementia

Causes of Death in Leeds 2015 (PHE EOL profiles)

27.4%



Cancer

13%



Respiratory

26.6%



Circulatory

At What Age?

Leeds Death by Age Group



0-64yrs

17%



65-74yrs

15.5%



75-85yrs

30.2%







85+yrs

37.3%





Where People Die in Leeds

Deaths in Leeds: UK comparison of place of death
2015 Comparison with National Averages (PHE End of Life Profiles)

	 Hospital	 Home	 Care Home	 Hospice	Other
England	46.7%	22.8%	22.6%	5.6%	2.2%
Leeds	45.3%	23.4%	20.6%	8.4%	2.2%
Note	Lower	Similar	Lower	Higher	Similar

Deaths in Leeds: Past Trends

Changes from 2004 to 2015 (PHE EOL Profiles)

	 Hospital	 Home	 Care Home	 Hospice
2004	56%	19.1%	14.7%	7.7%
2015	45.3%	23.4%	20.6%	8.4%
% Shift	-10.7%	+4.3%	+5.9%	+0.7%

Rising Deaths and Palliative Care Need in England: Future Trend

How many people will need Palliative Care in 2040? Past trends, future projections and implication for services.
Etkind et al. BMC Medicine (2017) 15:102

By 2040...

- Annual deaths in England and Wales are projected to rise by **25.4%**
- Palliative care need is predicted to rise between **25%** and **42%**
- The main drivers of increased need are cancer and dementia
- In Leeds this means an additional **1,250-2,100** patients per year who would benefit from a palliative care approach
- The greatest rise is in the **85+** group

MCN Forecast Spend 17/18	
MCN Pay & Sundries	£77,873
Overheads	£12,877
Total	£90,750

MCN Forecast Spend 18/19	
MCN Pay & Sundries	£79,041
Overheads	£12,941
Total	£91,982

MCN Forecast Spend 19/20	
MCN Pay & Sundries	£80,148
Overheads	£13,071
Total	£93,218

MCN Forecast Spend 20/21	
MCN Pay & Sundries	£81,270
Overheads	£13,202
Total	£94,471

Assumptions

Salaries to increase by 1.5%/1.4%/1.4%

Overheads increase by 0.5%/1%/1%

Glossary of Terms Appendix 4

Term	Definition
ACP	Advance Care Plans
ASC	Adult Social Care
Anticipatory medication	Anticipatory prescribing can be defined as the proactive prescribing of medicines that are commonly required to control symptoms in the last days of life
CCG	Clinical Commissioning Group
CNS	Clinical Nurse Specialist
CPWY	Community Pharmacy West Yorkshire
DNACPR	Do not attempt cardiopulmonary resuscitation
ECHO	Extension for Community Healthcare Outcomes is a tele-mentoring education system
e-ELCA	The e-learning programme End of Life Care for All (e-ELCA) aims to enhance the training and education of the health and social care workforce so that well-informed high quality care can be delivered by confident and competent staff and volunteers to support people wherever they happen to be
E-meds	Hospital electronic prescribing system
EoLC	End of life care
EPaCCS	Electronic Palliative Care Co-ordination System provides a shared locality record for healthcare professionals. It allows rapid access across care boundaries to key information about an individual approaching the end of life including their expressed preferences of care
HF	Heart failure
MDT	Multidisciplinary team is a team of professionals including nurses, doctors, physiotherapists, occupational therapists, social works, spiritual care team, dietician, complementary therapists and others who work together with patients and families to plan, deliver and evaluate care
LCHT	Leeds Community Healthcare Trust
LTC	Long term conditions
LTHT	Leeds Teaching Hospitals Trust
LYPFT	Leeds & York Partnership Foundations Trust
Opioids	Opioids are drugs that act on the nervous system to relieve pain. Continued use and abuse can lead to physical dependence and withdrawal symptoms
PPC	Preferred place of care
PPM+	PPM+ is the LTHT electronic patient record
MOU	Memorandum of Understanding is the document signed up to by the MCN Partners agreeing to work together
Neighbourhood Teams	Neighbourhood teams provide community nursing and therapy services, primarily in people's own homes, in partnership with Adult Social Care and other organisations.

