Leeds Palliative Care Network

Annual Report 2023-2024

Prepared for

West Yorkshire Integrated Care Board in Leeds

May 2024

Foreword

Over the last year, the Leeds Palliative Care Network (LPCN) made progress against strategic goals, maintained a comprehensive work programme, and provided significant support to the integrated care system in Leeds and across West Yorkshire.

It is important to acknowledge that Leeds has highly effective palliative and end of life services and a proud tradition of impactful provider-led collaboration. As evidenced by the West Yorkshire ICS Healthwatch report, which found high levels of satisfaction with many aspects of palliative and end of life care (P&EoLC) across the city.

Although Leeds compared favourably with the rest of West Yorkshire, the report identified areas for improvement. The provision of information about P&EoLC is one and the LPCN has enhanced its information about services citywide. Available in hard copy and digitally via the LPCN website we anticipate this will make the P&EoLC offer clearer to all people in need of care and support. Upcoming application of the Accessible Information Standard (Easy Read) will enhance this further ensuring written information is user friendly for an increasing range of people.

Enabling more people to discuss and share their priorities for end of life care remains a central commitment. In the last year, almost 60% of adults who died in Leeds had digital advance care plans, with a steady increase in the uptake of ReSPECT. The TIMELY tool may enhance digital recognition of people who would benefit from ACP. If proven effective, citywide implementation would pose fresh logistical, workforce, educational and financial challenges. Barriers to sharing up-to-date digital ACP across settings persist and ReSPECT is key to improving this. It is critical that the LPCN works with clinical and digital stakeholders to resolve this complex issue.

Education and training are essential to high quality P&EoLC. The LPCN has delivered training to a range of professionals, addressing unmet learning needs including clinical support workers within the acute trust. The Evidence into Practice Group has updated essential citywide prescribing guidance and crisis care plans that enable self-management of challenging symptoms such as breathlessness.

Enhancing P&EoLC requires LPCN support for citywide infrastructure such as Planning Ahead whilst harnessing local intelligence, enthusiasm, and resources. The Leeds Dying Well in the Community Seacroft project will release its final report soon. It is anticipated that learning will be shared with partners across Leeds to inform local action. This aligns with ICB goals to understand and mitigate drivers of unplanned hospital admission amongst people with advanced respiratory disease from deprived communities. P&EoLC respiratory pathway optimisation is an established part of the LPCN programme that reinforces this strategic focus. Nonetheless, the LPCN needs to do more to work with diverse communities to understand and meet their P&EoLC needs.

As financial constraints intensify, the LPCN is committed to meeting cost saving requirements by improving efficiency and focussing activity where it will have the biggest impact. This challenge should not be underestimated as the LPCN's ongoing success is dependent on the voluntary collaboration of partners all of whom confront similar financial challenges whilst providing essential services in the face of increasing complex demand. It is important to thank our wide network of partners for their commitment. Their ongoing support is essential to sustaining and enhancing P&EoLC for everyone who needs it in Leeds.

Dr Adam Hurlow, LPCN Chair

CONTENTS

Table of Contents

LPCN Annual Report 2023-2024

Introduction

As a collaborative provider partnership group, Leeds Palliative Care Network (LPCN) is committed to the highest quality, consistent, equitable and sustainable care in the final phase of life. It brings together health, social care and academic professionals across Leeds, provides strong partnerships and transcends traditional boundaries to bring about systems wide change. LPCN is constituted as a Managed Clinical Network.

The purpose of this report is to provide the West Yorkshire Integrated Care Board (WY ICB) in Leeds with ongoing assurance of the effectiveness of Leeds Palliative Care Network as a delivery model for the improvement of services for the people of Leeds. The Leeds End of Life Population Board will also receive the report.

The report will be useful for LPCN partners to be able to evidence the benefit and impact that we have made collectively. It provides a report of activities and achievements during 2023 / 2024 and highlights plans for the future.

The year remained challenging for all partners as the health and care system balances the impact of recovery from the pandemic, increased service demands across the system, recruitment and retention of a skilled workforce and managing prolonged industrial action.

Capacity to deliver frontline services and maintain a programme of service improvement has therefore required commitment, dedication and acceptance of some delay to planned activity.

Throughout, the LPCN continued to provide facilitation and direct support through the administration of system wide meetings, securing additional people to support the project work and the continued development of additional guidance and learning materials hosted on our website, which is accessible to all.

Maintaining Effective Governance and Communications

During 2023/24, the LPCN along with all its partners, the West Yorkshire ICB in Leeds and the End of Life Population Board (the Board) worked collaboratively to agree priorities and deliver change.

The Chair of LPCN is a key member of the Board enabling LPCN to provide insight, inform and influence strategic planning and decision making for the future. LPCN functions as a clinical reference group for the Board and the Network Manager is part of the ICB in Leeds EOL matrix team that supports the Board.

LPCN continued to be an active member of the West Yorkshire ICB level Palliative, End of Life Care (PEOLC) group to maintain input, influence and strong wider partnership links. This included supporting the development of a WY ICB Health Needs Assessment and public engagement activity. LPCN is a key point for onward information sharing from ICB leads across partners.

The LPCN also linked closely with the regional Strategic Clinical Network receiving regular updates from the national team.

There have been significant challenges to maintain LPCN Executive membership and project leadership this year. Trish Stockton, Education Lead demitted her role in June 2023 and Leigh Taylor, LPCN Clinical Educator has provided cover since then. Dr Emily Curran, Sue Ryder Wheatfield's hospice representative is on Maternity leave with Natalie Sanderson providing cover since January 2024. Natalie is also the lead for the Bereaved Carers Survey Group following a change in roles for Claire Iwaniszak and Helen Syme. Temba Ndirigu now leads the Equality, Diversity and Inclusion group following Dr Ellie Kane's departure. LPCN is grateful to all members, past and present for their continued input and support.

Taking account of the continued workforce and system challenges during a time of continued change, Dr Adam Hurlow has kindly agreed to remain as Chair and Clinical Lead for a further year whilst we continue to seek a future Chair across partner organisations.

The LPCN Group maintained good attendance throughout the year with over 40 members at the celebration event in June 2023 where we networked with Board members and shared recent achievements.

The LPCN maintains a **risk register** to note all risks for the LPCN and a **systems issues log** that enables partners to highlight issues of concern that require collaborative action to resolve. These are discussed at every LPCN Executive and LPCN Group meeting and have, for example, resulted in supporting system resilience, sharing information about anticipatory medicines and medicine shortages, working to improve data and interoperability, supporting colleagues from at risk services due to financial challenge. Partners are also able to share incidents that require cross-organisation responses to resolve.

The LPCN Executive team reviewed its projects to agree priorities and monitored actions against the strategic outcomes throughout the year.

LPCN Communications

We manage the LPCN Website a resource for professionals, and the public and a Twitter account.

Twitter Analysis

	1 April 2023 – 31 March 2024
Followers	477
Impressions	4002
Likes	48
Retweets	49

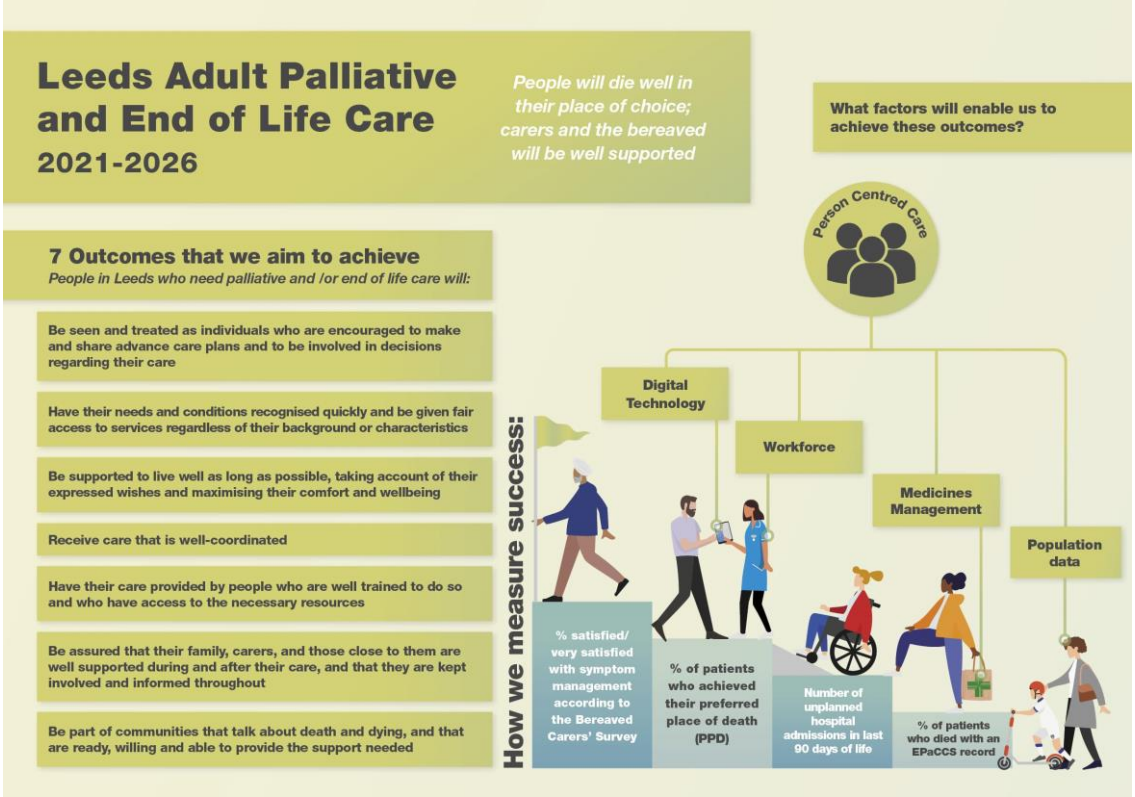
Web stats

	1 April 2023 – 31 March 2024
Users	25,039
Most popular pages:	Education Contact Download – Guide to subcutaneous meds Download – Opioid conversation chart for adults Medicines Management

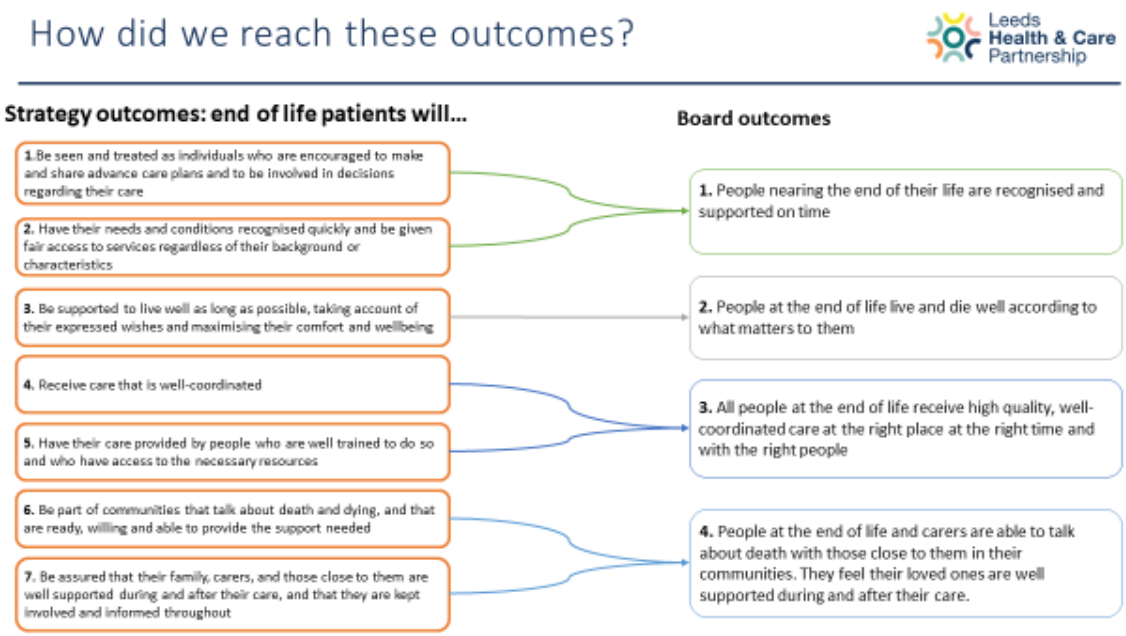
Highlights for the year include:

- A wide range of downloads were added to the website including programme updates, guidance, training resources and news articles.
- Five news bulletins were issued throughout the period to the 132 subscribers on our mailing list.
- The LPCN website has been continually monitored and developed to ensure it is up to date and the information is relevant and useful.
- LPCN's own patient leaflet has also been reviewed and republished, with refreshed, up to date information and images. It is available online and copies will be made available in print if requested.
- Our communications work supported and promoted the Bereaved Carers Survey, Dying Matters Week and the range of courses provided by St Gemma's Hospice by sharing information on social media, on our website and through our bulletins.
- The website is fully translatable supporting accessibility.

The Leeds Palliative and End of Life Care Strategy was finalised and published in June 2021 with LPCN executive members being key authors.



The strategy further informed the development of the Board outcomes as below:



The population outcomes developed for the strategy and by the Board have continued to direct the work plan for the LPCN.

LPCN quality improvement projects and workstreams continue to support delivery of these outcomes.

LPCN Quality Improvement Programme Updates

The programme of quality improvement work continued in line with the agreed Strategic Population Outcomes and Enablers shown above. The programme overview is collated monthly, reporting project updates. Established improvement groups continued to meet regularly and maintained delivery despite the system challenges with workforce capacity and industrial action.

Below is a short summary of achievements over the last year that support each Outcome. Most projects influence more than one outcome but are highlighted against the one where impact is most likely.

Outcome 1 – People that need P&EOLC will be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decisions regarding their care

LTHT Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) Audit

Data from 24,700 unique patient records was analysed by colleagues in the Academic Unit of Palliative Care (AUPC). Initial findings were shared at the event in June 2023 with a paper being published in the Resuscitation Journal.

Progress has been slower than initially planned given slow moving information governance processes, establishing new relationships between NHS and academic bodies and the amount and complexity of data. The final report is imminent and will be published on the LPCN website with recommendations being taken forward within LTHT and informing a citywide ReSPECT audit.

Improving Planning Ahead and Citywide ReSPECT Audit

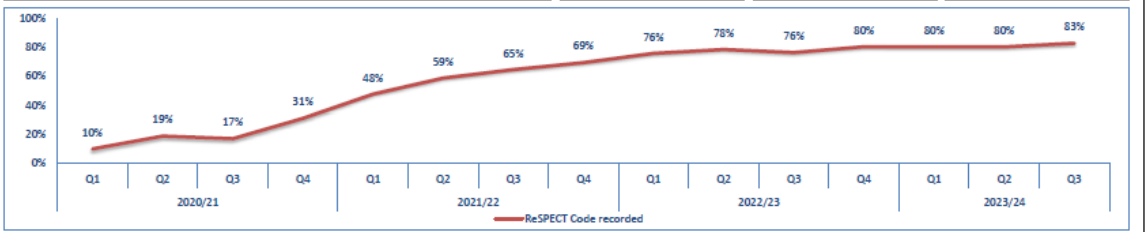
Work continued this year to ensure that the Planning Ahead Template meets the national information standard for end of life published by the Professionals Records Standards Body. Changes required were minimal as the templates and tools used (EPaCCS, ReSPECT and What Matters to Me) meant we were already essentially compliant. Links to emergency care plans are being added.

LPCN commissioned a further audit of community ReSPECT and citywide patient experience. Progress has been slow due to reduced capacity within the AUPC but patient experience of using ReSPECT has commenced; data sharing documents are agreed and data drawn from community records is ready for analysis. A questionnaire to assess the experience of people who have had ReSPECT conversations in LTHT has been developed.

The use of ReSPECT as a care-planning tool has continued to increase over time with 83% of all those with an EPaCCS record now having one in place. This will rise further once LTHT ReSPECT data is reported.

C2.7 Deceased EPaCCS patients who have ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Code recorded on the system.

Patients with ReSPECT Code	Q1		Q2		Q3		Q4	
ReSPECT Code recorded	534	80%	562	80%	606	83%		
ReSPECT Code not recorded	131	20%	138	20%	126	17%		
Total	665		700		732			



Active links with partners leading the Home First and Frailty work will hopefully inform and influence the improvement in interoperability of the ReSPECT plan across all organisations.

Clinicians from all community and primary care partners positively supported the return to face to face delivery of Planning Ahead training.

Outcome 2 - People that need P&EOLC will have their needs and conditions recognised quickly and be given fair access to services regardless of their background or characteristics

Equality Diversity and Inclusion

Temba Ndirigu became the new Chair and clinical lead for this Group from November 2023 following the departure of Dr Ellie Kane. The transition in leadership and reduced capacity to take work forward has been a challenge.

This workstream was voted the top priority at the June 2023 event and we are reviewing the work plan for 2024/25 to ensure we gain further insight and can evidence improvements made. We are actively working with the ICB Learning Disability (LD) Group and partners to ensure there are effective and accessible Advance Care Planning documents available in easy read versions. A task and finish group has been established to take this forward.

LPCN actively supported the production of the West Yorkshire ICB Health Needs Assessment for end of life, expected early in 2024/25. LPCN also helped direct Healthwatch to identify interviewees for their report on end of life experience by marginalised communities across West Yorkshire. Both these documents will be valuable reference resources for LPCN and commissioners.

The project to monitor sexual orientation and gender identity led by Sue Ryder Wheatfields Hospice developed a survey and training package, and a large number of clinical staff were trained. Unfortunately maintaining momentum was difficult due to changes in personnel and the feeling that the project running in isolation within the patient information system proved challenging.

Timely Recognition of EOL

The project aims to develop a digital search tool embedded in primary care electronic patient records that enhances recognition of people approaching the end of their life in the community in Leeds. The Yorkshire Strategic Clinical Network and the Leeds Ageing Well Fund supported it.

A senior Clinical Lead and three other clinicians are working with the Central Local Care Partnership to test the tool. Pilot search tools for use in EMIS and SystmOne have been developed and trialled. To date, 597 patients were identified from 6 practices. Return review visits to each practice are now underway one year later to determine how useful the tool is and to understand how it might be implemented in practice. 234 case have been reviewed so far with the remainder to be completed between June and September 2024.

Data agreements are in place so data can be analysed by AUPC to help validate the tools effectiveness. If the tool proves to be useful in supporting primary care to recognise and support people and their families at end of life and enable increased advance care planning and holistic support, LPCN will support the broader implementation and roll out to primary care in Leeds.

The project group have also been sharing their learning and experience with a regional group and partners across West Yorkshire.

Homelessness / Inclusion Service

The citywide service is driven by Nicky Hibbert (Nurse Consultant) supported by Katie Longbottom (Clinical Nurse Specialist) and Lucy Staveley (peer navigator, a joint post with Leeds Community Healthcare). This service continues to grow. Current caseload is 21 patients with referrals received from different sources across Leeds. A robust reporting structure is in place allowing the monitoring of impact across the service.

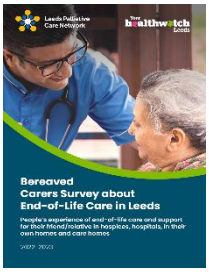
The LPCN funded a training programme for third sector providers to this vulnerable population. This has enabled 80 frontline staff to be able to recognise when someone is deteriorating and know how to access help required in a timely way.

There is no recurrent funding for this service, now considered at risk. West Yorkshire ICB have provided funding for 2024-25 and are working closely with the service lead to identify future funding streams.

Outcome 3 - People that need P&EOLC will be supported to live well as long as possible, taking account of their expressed wishes and maximising their comfort and wellbeing

Bereaved Carers Survey

The Bereaved Carers Survey was open from February to the end of April 2023 with responses received until the end of June 2023. LPCN commissioned Healthwatch Leeds to support the design delivery and reporting of the survey. The survey could be returned electronically, by post or via phone call.



The report published on both LPCN and Healthwatch websites identifies 109 responses received that represent 8% of the surveys distributed. 88% of all respondents were very satisfied or satisfied with pain and symptom management. Recommendations made are informing future improvement actions about care and service delivery by all partners. An updated action plan will be published.

Following discussions at the EOL Board and given the low return and concerns by the registrar's office that registration is not the right time to share the survey we are looking at alternative mechanisms for gaining feedback on quality of experience for future years.

Respiratory / EOL Pathway

This proactive group is an effective partnership. Despite patient demand remaining high across the system a pathway mapping identified key service changes and resulted in the production of service offer documents.

We have prioritised further actions. The first priority being the development of Palliative Oxygen Therapy Guidance. This will be finalised early next year and distributed via websites and potentially the Planning Ahead template to support prescribing in community and primary care.

This group and the LPCN have also been essential partners in supporting the Healthy Leeds plan priority project to review unplanned activity for people at end of life with respiratory conditions. The integrated MDT will assist in further case reviews and patient surveys to further identify where changes might benefit the patient and system.

Heart Failure

Cardiology-palliative medicine MDT meetings have continued monthly with positive feedback and increased attendance from other palliative care staff and specialties such as Geriatric Medicine.

Several education sessions around management of advanced heart failure have been delivered including a National Association for Palliative Medicine event. Dr Jason Ward has authored new symptom management guidelines for patients with Advanced Heart failure. They are now for circulation via LPCN evidence into practice group.

With the reduction in funding for this stream, the focus for the coming year will be the monthly citywide MDT meeting.

Leeds Palliative Care Ambulance

Yorkshire Ambulance Service (YAS) capacity to attend meetings remained challenged during much of the year. Despite this, the following actions were achieved:

- The Standard Operating Procedure for the service was finalised and ratified for use in July 2023.
- Training was delivered to new crew members; future training needs are being developed.
- A second new ambulance was in use from the end of 2023, both with the LPCN logo.
- Feedback on experience is collated from the crew at regular team meetings.
- A new patient pathway hub is in place to manage referrals more effectively.
- Supervision is offered to crew members following difficult transfer cases by Specialist Palliative Care colleagues when required.

The most significant challenge going forward is to re-establish relationships with the community Funeral Directors that provided training opportunities and received bodies where a death in transit occurs. A new solution may be needed if this cannot be resolved.

Occasionally transfer requests at weekends are delayed or declined. We are monitoring requests for transfers to provide further insight.

Evidence into Practice

The now established Evidence into Practice Group meets to ensure Leeds wide practice is utilising up-to date evidence, revising and updating existing guidance, identifying evidence and guidance gaps and providing a forum for clinical and academic partners to discuss and disseminate current research findings.

With a guideline tracker established and gaining agreement on governance processes, the group have reviewed and updated:-

- Patient Information Leaflets for managing bleeding and managing seizure, with reciprocal professional guidance.
- Guidance for prescribing at end of life for patients with liver failure and patients with renal impairments.
- Developed and ratified new symptom management guidance for end stage heart failure.
- Commented on and supported Yorkshire Regional symptom management guidance.
- Worked with partner organisations and community pharmacy to address, understand and improve access to medicines, especially at times of urgent need.

All up to date documents are available on the LPCN medicines management pages

Dementia

This group has reduced the frequency of meetings as the planned actions have been achieved or closed. The proposal is to meet twice a year to enable continued information sharing and retain a forum for the Dementia Strategy to liaise with as required.

Advance Care Planning (ACP)

We continue to actively work with WY P&EOL colleagues to update the My Future wishes plan and an easy read version. We anticipate this will be published shortly. Leeds pre-ACP promotional pamphlet What if things change? was shared at our June 2023 event and via our Seacroft project and is on the LPCN website.

End of Life Admiral Nurse post(s) for Leeds

The proposal for citywide EOLC posts is not being pursued given the financial challenges faced. The posts supported by Dementia UK in primary care and LTHT are members of the group with opportunity to enable EOL support as required.

Pain and Symptom Group – This group is no longer pursuing research funding and has folded.

Outcome 4 - People that need P&EOLC will receive care that is well-coordinated

Transfer of Care – Hospital / Hospice

The group has met regularly and remained proactive with the following achievements.

- The agreed shared waiting list for EOLC beds in hospices continued throughout the year maximising efficiency of beds available.
- The transfer of care referral form has been reviewed and updated.
- The ED to hospice transfer agreement has been revisited and further promoted.
- It has been agreed that patients requiring tracheostomy care at end of life in a hospice will be transferred to St.Gemma's Hospice.
- An agreement made to reduce discharge medication for hospices to reduce cost and waste. The impact will be monitored next year but is anticipated to save circa £10,000 in pharmacy costs.

Leeds - Dying Well in the Community

This ongoing and significant project used a whole systems approach and active engagement of over 100 frontline professionals and feedback via Healthwatch Leeds from patients and their families. All the feedback and academic analysis during Phase 1 resulted in the development of five common themes, with three key actions identified for service redesign during Phase 2 of the project:

i) Updating the service offer – integrating local services

This resulted in a project focused in the Seacroft Locality to consider what opportunities there may be in further integration between frontline staff and engagement with the community / third sector. Following appointment of a project lead a more coherent and consistent group has developed.

To support the Healthy Leeds Plan Priority project considering EOL respiratory admissions from deprived populations, clinicians reviewed cases to help provide further insight into causal factors. This informed the initial clinical workshop for this project. Consideration to how care can be better coordinated within the area is ongoing.

The engagement of third sector partners and local people has significantly increased understanding of wider determinants of health. An appreciation of what other community support is available has enabled local clinicians to offer more support, particularly considering the current cost of living crisis. Regular death and dying cafes will continue and co-designed information about dying well in Seacroft will be added to local leaflets and websites.

Community grants to support people dying at home will be administered by LS14 Trust and consideration is being given to community buddies being developed.

ii) Single Point of Contact (SPOC) for EoLC in Leeds.

Following production of a detailed report, discussed by the EOL Board, it was acknowledged that whilst there may be benefit in a SPOC for EOL in Leeds, the financial climate would not support it and further business case production would not be a good use of resources. Partners have continued to consider how they can further maximise 24/7 professional, patient and family support through current services.

The new LCH Neighbourhood Team Hubs are able to monitor demand for same day EOLC support requests and are currently trialling unplanned 'Quick Response' teams. Similarly, hospices are reviewing their ability to respond urgently. All parties are meeting to ensure a shared understanding of services offered.

iii) Increase in resources to support people being able to die in the community.

The End Of Life Population Board are aware of the increased demands for palliative and end of life care across all settings alongside the challenges posed by a shift in people choosing to die in their own home rather than residential settings. Consequently, the Board are seeking to monitor activity levels, the impact on service capacity and on patient experience. Providers are seeking to maximise collaborative efficiency within existing resources.

Outcome 5 - People that need P&EOLC will have their care provided by people who are well trained to do so and who have access to the necessary resources

Training and Education

Whilst the Education post has been vacant for much of this year, the Clinical Educator continued to support the LPCN and deliver the education programme:

Delivery of Planning Ahead Training – This continued via both virtual sessions and face to face. 93 people booked and 68 delegates completing the training between April 2023 and March 2024; with a total of 198 people now being trained since commencement.

ECHO – A new ECHO programme for GPs and wider Primary Care Network colleagues commenced in June 2023, with 14 people signed up. Unfortunately, low attendance was significant and the course folded

early; alternative primary care training is being considered.

A new programme for Allied Health Professionals (physiotherapists and occupational therapists) commenced in June 2023 with 27 registering for the course that has been well received.

Leeds Care Home's Palliative and End of Life (EOL) Education Report – The aim of the report is to review current palliative and EOL education within care homes. This includes gaining insight into what is working, where the gaps are and where the opportunities are for development. Recommendations for care home education have been developed, taking into consideration a collation of key information and guidance. A workshop including citywide stakeholders linked to care homes has been planned in which the report will be discussed, with a view to look at moving forward with next steps.

Report into Advance Care Planning Training in Leeds – A report about the existing ACP training provided across Leeds by all partners has been produced. It also includes local and national guidance and current education models of ACP education. The aim of the report is to guide consistency and standardisation in training throughout the health and social care sectors of the city of Leeds. The LPCN Education Group plan to meet and discuss potential development opportunities derived from these recommendations.

Homelessness Citywide Training – LPCN approved funding to deliver 6 sessions to non-healthcare frontline and inclusion staff working with homeless and vulnerably housed people. To date 4 of these have been successfully delivered. 76 people registered and 57 people from 10 organisations have completed this training. It has been positively received and evaluated well. 2 further sessions are planned for 2024.

LTHT CSW Training – LPCN funded a post for a year to provide training to 1700 clinical support workers within LTHT and to develop training plans for the future to maintain skills and competence. This has been a very successful project with training rolled out methodically across the Trust and online training modules developed. A further 1000 bank staff have been identified for training and plans are in place to develop EOL champions with an event being planned in June 2024 to drive this forward. Learning from the project is being shared with partners. A further 6 months LPCN funding will ensure effective completion of the plans and legacy delivery.

Resources – Syringe Drivers

The Syringe Driver Group continued to meet until July 2023 to ensure all equipment purchased was fully tested and delivered to frontline clinicians from all partners - LTHT, Hospices, LYPFT, LCH and care homes with nursing. Transfer of ownership documentation was completed where necessary. The group members continue to liaise via email and may be reconvened to discuss new technologies available and the decommissioning of out dated drivers.

Outcome 6 - People that need P&EOLC will be assured that their family, their carers and those close to them are well supported during and after their care, and that they are kept involved and informed throughout

Family and Carers Information

We added a new bereavement support page to the LPCN website following feedback and in light of other services in the city changing or folding. We also provided support to Leeds City Council who are looking to add dying well and bereavement support pages to the Leeds Directory.

A new patient and carers leaflet, End of Life Care and Support in Leeds has been developed with the content also having its own page to enhance accessibility and enable translation to other languages. This leaflet provides clear explanation of services provided, how they work together and what other support is available in the city.

Outcome 7 - People that need P&EOLC will be part of communities that talk about death and dying, and that are ready, willing and able to provide the support needed

Dying Matters

Despite reduced capacity in the Public Health Team in Leeds, the Dying Matters Partnership continued to meet **delivering** a successful Dying Matters Week in May 2023 with a number of activities happening across the city:

- 11 organisations received Dying Matters grants to hold events to mark the week, including a number of Neighbourhood Networks, the BME Dementia Service (Touchstone), People in Action, Leeds GATE, Leeds Involving People. Activities such as legal Q&As, crafting and flower arranging, a partnership roadshow and various peer support events were also organised.
- Successful event held at Leeds Kirkgate Market with over 20 partners attending, discussions with around 100 people and good networking opportunities.
- Trialled hosting a stall at the White Rose Centre, which had some footfall, but due to train strikes the centre was quieter than normal.
- A lot of positive traffic on social media promoting the various events during the week, good engagement across the city
- Dying Matters Survey relaunched this year - received around 1,000 'clicks' but low completion rate (20 completed surveys).

The partnership relied heavily on the Leeds Bereavement Forum (LBF) to promote the events, administer grants and support delivery of death cafes and training. As the LBF has now closed and future funding is at risk the partnership are reflecting on future feasibility. There are, however, plans for 2024 to include a living with death event at Leeds City Museum.

Enablers

Medications Management

Access to Medicines – Particularly anticipatory drugs during out of hours has been an ongoing concern this year. Supply via the warehouses of some drugs has been challenging with advice given on alternative medicines and doses provided by senior clinicians as required. Partners have continued to liaise with West Yorkshire ICB Pharmacy Group and guidance circulated widely about out of hours pharmacy access.

Anticipatory Medicines Audit – Delayed analysis of data following the audit due to lack of AUPC capacity resulted in slippage of this project. A report of findings will be drafted and the Anticipatory Medicines Group will reconvene to consider recommendations made once available.

E- Prescribing for Hospice Outpatients and Community Services – This project is on hold pending adequate capacity within the hospice pharmacy and community teams and effective SystmOne knowledge to undertake the project. The Phoenix Partnership (TPP) report they have resolved the IT issues for access to SystmOne between inpatient and outpatient prescribers but are no longer offering project support. However, Airedale experience suggests information sharing may not be resolved.

Daffodil Standards – Raising the awareness of these standards with partner organisations through the Evidence into Practice and LPCN Group meetings. We also supported the promotion of the Royal Pharmaceutical Society (RPS) promotional campaign for community pharmacies to sign up to the standards via Community Pharmacy West Yorkshire (CPWY) where we were able to have this information included on the palliative care service section on the CPWY website and in their regional-wide newsletters.

Guidance Documents Publication – Overview, reviewing and collating city and relevant regional medicine management documents and linking to these on the LPCN website section. Liaising with relevant stakeholders and authors where documents are overdue for review on behalf of LPCN stakeholders.

Population Needs

All of our collective actions and programme of work supports the delivery of the EOL Boards expected outcomes. This year the LPCN and particularly the Chair has been active in sharing population level data and seeking to help the Board understand this population and their needs. LPCN continue to host and input into the citywide Informatics and Metrics Sub-group. The clinicians support the ICB Data Quality team in

identifying data sources required and interpreting data reported. An expanded data sharing agreement now supports an appendix of further useful data about ethnicity, patient and family engagement in planning, support for different disease groups, ReSPECT status, and prescribing of anticipatory medicines made available alongside quarterly Planning Ahead reports.

EOL Metrics
Planning Ahead reports demonstrate maintained performance against key metrics; over half of all adults who die in Leeds continue to be recognised to be approaching the end of life and supported to participate in digital advance care planning - Planning Ahead (EPaCCS) and/or community ReSPECT. Achievement of preferred place of death, for those who have specified a setting in community digital records, remains at approximately 80%. In contrast to all people who die in Leeds, only a small minority of those with a preferred place of death die in hospital.

National data supplied by the Office for Health Improvement and Disparities shows Leeds to be one of the best performing localities with regards to minimising disruptive hospital admissions for people with a short prognosis with less than 5% experiencing 3 or more unplanned admissions in the last 90 days of life. The most recent Bereaved Carers Survey found that overall, almost 90% of respondents were satisfied with symptom management, though there was significant variation between settings.

Leeds Dataset – Whole City data
Following continued LPCN drive and support, the Leeds Data Model (LDM) now has data inputs from key P&EoLC services: LCH, primary care, LTHT (SUS and ReSPECT), hospice, CHC and LCC (cause of death). This data can be linked to provide an enhanced understanding of the equity of access to core components of P&EoLC for people who die in Leeds and how this relates to key outcomes.

The LPCN and Academic Unit of Palliative Care (AUPC) are collaborating with business intelligence colleagues to establish initial reporting priorities given the wide scope of the linked dataset. Work to flow LTHT ReSPECT data, providing a whole-city picture of digital ACP, is completed. An IG basis to reporting data for people that have died is in place.

Once LTHT ReSPECT data is incorporated in the LDM, it will be possible to provide a citywide report on equity of access to digital ACP, the timeliness and completeness of ACP and its association with hospital utilisation. This would align with citywide priorities and provide a window into equity of access to a core P&EoLC intervention across Leeds.

A narrow focus to initial reporting is necessary due to the richness of the LDM data set and resource constraints. An initial focus on ACP requires subsequent focus on other key components of EoLC including holistic needs assessment, access to generalist and specialist services and CHC Fast Track care. Analytic capacity to support broader analysis is enhanced by enabling AUPC direct access to the LDM.

The EOL Board in December 2023 received a LPCN paper recommending this approach and was agreed.

West Yorkshire Health Needs Assessment for P&EOLC
The LPCN Chair and Network Manager have contributed significantly to the design, development and content review of both the West Yorkshire Healthwatch report into people's lived experience and production of the Health Needs Assessment. This document, expected early 2024/25, will provide a useful reference point though is not likely to provide new intelligence for Leeds health and care system. The document will also inform the forthcoming updated Joint Strategic Assessment for Leeds.

Workforce
Recruiting and retaining a skilled and competent workforce remains a challenge, though specialist palliative care remains an area of high interest practice for clinicians. LPCN ensured representation at the West Yorkshire ICS PEOLC Workforce Group although this group has not met for some time due reduction in leadership capacity. There has been considerable investment in personalisation and advance care planning training, which the LPCN has actively advertised and promoted across Leeds.

Digital Technology

EPaCCS/ReSPECT: sharing care and treatment recommendations between electronic patient records

The inability to share real-time care and treatment recommendations between hospital and community electronic records remains an on-going and intractable source of risk. The LPCN continues to support efforts to address this issue. Work at a regional level through the Yorkshire and Humber Care Record (YHCR) is yet to work and to yield tangible changes for the sharing of critical P&EoLC information in Leeds. Developments in Leeds Care Record sharing linked to citywide Frailty workstream may offer a solution. The LPCN continues to work with clinical and digital colleagues to explore any viable option that address Leeds's risks in a timely way whilst supporting the wider goals of all partners

Other Developments and Projects

The LPCN maintain strong relationships with wider partners across the city and links into projects that are led by others but impact on palliative and end of life care.

Winter Planning / Industrial Action

No specific P&EoLC group to oversee decisions and actions to support system pressures, the impact of winter and industrial action was required this year. Instead, the LPCN Executive had a standing item on the agenda and wider members engaged as necessary via the LPCN Group and fed into the Operational Resilience group for the city. All partners saw an increase in demand against challenging workforce capacity. The agreements formulated via the Transfer of Care group also helped with outflow into available hospice beds.

Mental Health Therapist Post

LPCN facilitated discussions between providers to gain agreement on temporary funding for a psychological therapy post for the year. Both hospices agreed to contribute 50% each and LYPFT waived their overhead charges. In August 2023, the person in post left and no replacement was available and unlikely without recurrent funding. The post no longer exists, though St Gemma's are hoping to develop a business case for an organisation specific role should funding opportunities be identified. The loss of this post remains on the LPCN system issues log.

Community ReSPECT Group

This Group has been instrumental in the development and roll out of ReSPECT outside of hospital. It is an essential part of all the work across Leeds in improving the Planning Ahead template. The Group ended once all actions were complete with a closure report presented to the quality forum of LCH and the ICB in Leeds in January 2024. The number of people at end of life having a ReSPECT plan continues to rise. LPCN Executive Lead for LCH is a member of the National RESUS Council ReSPECT subcommittee, ensuring we retain vital links and remain up to date.

Leeds Directory

With the anticipated closure of the Leeds Bereavement Forum, the LPCN is supporting the ICB in establishing a bereavement and EOLC support section within the Leeds Directory. We expect the website will hyperlink to the LPCN website so that key documents are available to the public.

EOL Respiratory Priority project

This is a priority project for the Healthy Leeds Plan. The population data analysis shows that respiratory conditions is the highest reason for admission for people in the EOL cohort particularly for those living in more deprived areas. The ambition of the project is to identify possible changes to care provision that might reduce hospitalisation and improve patient experience. LPCN has been active in supporting the development and delivery of this project.

The Seacroft Dying Well in the Community project helped with initial case reviews and initial hypothesis development. More recently, we have helped plan a larger MDT case review and also a survey of professional, patient and carer experience.

We anticipate this will remain a key priority project for the Healthy Leeds Plan over the next year.

Finance Report

LEEDS PALLIATIVE CARE NETWORK FINANCE REPORT April 23-March 24							
			WORKFORCE				
Roles	**Budget 23/24**	**Q1 actual**	**Q2 actual**	**Q3 actual**	**Q4 actual**	**Actual**	**Remaining**
LPCN Management Clinical & Admin	£85,460	£22,407	£21,501	£24,399	£21,751	£90,058	-£4,599
Clinical Practice Educator & Admin	£59,562	£13,385	£14,843	£14,185	£14,248	£56,661	£2,901
ELM/Comms	£10,654	£926	£1,500	£1,500	£1,800	£5,726	£4,928
Sundries / expenses	£2,958	£36	£170	£176	£108	£490	£2,468
Website	£2,659		£80	£516		£596	£2,063
Overheads	£13,200	£3,300	£3,300	£3,300	£3,300	£13,200	£0
Final amount for recharge purposes 23/24	**£174,493**	**£40,054**	**£41,394**	**£44,076**	**£41,207**	**£166,732**	**£7,761**

Total underspend regular funding 31.3.23	**£56,158**	B/F prior years					
Left to spend 2324	**£7,761**						
Hotel - event costs	**-£975**						
Seacroft EoLC Integration Project	**-£3,220**						
Remaining balance pipeline bids	**£166,334**						
Total	£226,059						
Balance 2324	£226,059						

PROJECTS			Expenditure				
Title/Workstream Lead	**Actual B/F**	**Income 2324**	**Q1 23/24**	**Q2 23/24**	**Q3 23/24**	**Q4 23/24**	**Actual C/F**
Citywide Bereaved Carers Survey	£1,938	£2,000					£3,938
Implementation of E prescribing - Moira Cookson	£4,029						£4,029
EPaCCS Planning Ahead training and development	£35,525					£390	£35,135
End of Life Dementia Care	£1,340		£225	£225	£225	£665	£0
Project ECHO Hub	£20,153	£17,550	£5,520	£5,940	£5,766	£5,893	£14,584
Heart Failure MDT cover	£216	£8,509	£2,001	£2,001	£2,001	£2,001	£721
Community Flow Improvement project, inc SPOC	£52,126		£3,825	£3,825	£5,175	£5,635	£33,666
Timely Recognition Project	£41,233		£3,176	£1,607	£3,698	£4,620	£28,133
Contingency fund	£15,000						£15,000
Equality Diversity and Inclusion	£21,000						£21,000
LTHT CSW's Training	£30,385			£20,257			£10,128
Homeless Training	£5,500					£5,500	£0
Total	**£228,445**	**£28,058**	**£14,747**	**£33,854**	**£16,864**	**£24,703**	**£166,334**

Dynamic financial management means the LPCN budget remains in a positive position with expenditure, travel, sundries, promotional materials etc. reduced due to continued virtual working.

LPCN has received 2 proposals seeking funding to support LTHT CSW training. Both approved, one of which will be processed and invoiced early next year.

LPCN also incurred costs for the June celebration event; the first one for several years post Covid.

LPCN review underspent funding to consider ongoing need for the funding and where appropriate reimburse the project fund, enabling funding of further activity. The Dementia budget is now fully spent.

LPCN anticipate with increases in salary and other services that next year will see some financial challenge on core budget.

LPCN, as with the whole system, is required to find efficiency savings with a request to find 15% on the recurrent funding. Negotiations have commenced with the ICB, working closely with the EOL Board.

Future Plans 2024 and beyond

During 2024, LPCN will update the Memorandum of Understanding and Terms of Reference once the system governance stabilises and ICB in Leeds colleagues are established in their new posts.

With a request to find 15% financial efficiency from the LPCN's recurrent budget there is likely to be some impact on capacity and prioritisation of activity over forthcoming years. We will work closely with the EOL Board to ensure LPCN remains sustainable with least impact possible and monitor the risk.

With increasing economic burden and strained workforce capacity, maintaining partner commitment and support will be challenging.

Priorities generated by the EOL Board will inform and influence the LPCN programme of work.

We will also take account of the WY Health Needs Assessment findings and any other regional or national policy requirements.

Emerging pieces of work for next year include:

- Sharing the learning, legacy and **service improvement opportunities** presented by the **Dying Well in Seacroft** project evaluation.
- Actively support the Healthy Leeds Plan, **End of Life / Respiratory priority project.**
- Finalise the **Timely Recognition Tool project** review phase, evaluate findings, determine future benefit and possible citywide implementation.
- Finalise, ratify and publish **Palliative Oxygen Therapy guidance** for Leeds.
- Continue to review **clinical guidelines and patient information**, and seeking further opportunities to **improve access to medicines** via the Evidence into Practice group.
- Review and develop the **education offer** to ensure targeted training and **a capable and effective workforce** across all sectors.
- Agree **health inequality priorities**, EDI related education and further support required for marginalised populations. Develop an EDI web page for professionals.
- Supporting the continuation of the **Inclusion service** development to secure recurrent funding.
- Optimise **whole system linked data** to ensure reports for EOL Board as agreed.
- Review the **Bereaved Carers Survey** process and agree future family and carer feedback mechanisms.


Leeds Palliative
Care Network