



**Leeds Palliative
Care Network**

Annual Report 2018-2019

Prepared for NHS Leeds CCG

June 2019

Forward

Welcome to the second annual report of Leeds Palliative Care Network (Managed Clinical Network).

The importance of palliative and end of life care continues to grow and be recognised across Leeds and beyond. We are all aware of the growth in demand for palliative care over the coming years, increasing care complexity and the challenge of workforce capacity. The Leeds Palliative Care Network (**LPCN**) has worked hard this year to raise awareness of this, seek new and better ways of working and bring partners together to consider the strategy to address the long-term challenge.

LPCN is made up of a diverse group of committed staff and teams across Leeds. What binds us together is the common purpose of delivering, developing and transforming care for the benefit of patients, family and carers. Delivering change and making things happen depends on those people, supported and guided by the executive team. Without the wider group, the positive relations and working as a Leeds-wide team, much of what we have achieved would not happen. The whole is greater than the sum of its parts.

It is with great pride and pleasure that we present this annual report as a demonstration of the value of LPCN, but equally to give thanks and acknowledgement to everyone who has contributed to its success.



Dr Mike Stockton, Clinical Lead and Chair, Leeds Palliative Care Network.



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Leeds Palliative Care Network Annual Report 2018/19

Introduction

LPCN is a group of health and social care providers in Leeds, who are working in collaboration to improve services for people with palliative care needs or at the end of their life. It is constituted as a Managed Clinical Network.

The Managed Clinical Network model was adopted following lengthy citywide consultation on collaborative working models led by the 3 Leeds CCG's. This was further developed in response to the Leeds End of Life Care Commissioning Strategy for Adults 2014-2019, work programme (6B).

The main purpose of this report is to provide NHS Leeds CCG with ongoing assurance of the effectiveness of LPCN as a delivery model for the improvement of palliative and end of life care services for the people of Leeds.

The report will also be useful for LPCN partners to be able to evidence the benefit and impact that we have collectively.

Governance

Vision

As organisations with experience of, and responsibility for palliative and end of life care 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 and End of Life Care 2015-2020)

Purpose

The purpose of LPCN is to help organisations work together to plan and deliver care that leads to the best possible outcome for palliative and end of life care patients, their families and carers.

Our **aim** is to make sure that patients, families and carers feel that:

- Each person is seen as an individual.
- Each person gets fair access to care.
- The patient's comfort and wellbeing is paramount.
- Care is coordinated.
- All staff are prepared to care.
- Each community is prepared to help.

LPCN makes this happen by:

- Working together openly and honestly.
- Endeavouring to ensure fair access to services for all.
- Working together to achieve our shared objectives, valuing each other's contribution to care.
- Letting each other know about important matters and alerting each other to any issues.

During 2018/19, following wide consultation, the group agreed to refresh its name, logo and branding. We officially became known as Leeds Palliative Care Network on 19th September 2018.



**Leeds Palliative
Care Network**

This has significantly helped increase wider engagement and recognition of the Network.

LPCN remains a Managed Clinical Network which is formalised through a **Memorandum of Understanding** agreement, with associated **Terms of Reference**.

Both these core partnership documents have been **updated and signed for the period 2018-2021**.

The contract schedule with NHS Leeds CCG for 2019/20 was also updated to reflect these changes.

To further strengthen partnership organisation engagement, the Executive Members have changed their titles and update their job purpose to reflect their responsibility of representing their employing organisation and improving effective two way communications.

The LPCN Executive Members for 2019/20 are:

Mike Stockton	LPCN Chair and Clinical Lead, Chief Medical Officer and Consultant in Palliative Medicine at St Gemma's Hospice
Gill Pottinger	LPCN Primary Care Lead, Clinical Lead NHS Leeds CCG and GP.
Trish Stockton	LPCN Education and Research Lead, Head of Learning and Teaching at St Gemma's Hospice
Moira Cookson	LPCN Medicines Management Lead, Advanced Clinical Pharmacist Palliative Medicine at Leeds Hospices
Sarah Mc Dermott	LPCN Executive Member for Leeds Community Healthcare NHS Trust, Clinical Service Manager (Palliative Care and Neighbourhood Night Service), Leeds Community Healthcare NHS Trust
Sue Waddington	LPCN Executive Member for Sue Ryder Wheatfields, Head of Clinical Services Wheatfields
Adam Hurlow	LPCN Executive Member for Leeds Teaching Hospitals NHS Foundation Trust, Consultant in Palliative Medicine at Leeds Teaching Hospitals NHS Foundation Trust

We also note that at the end of March 2019, Dr Lynne Russon (Consultant Palliative Medicine) retired from her Executive Member role for Sue Ryder, Wheatfields with LPCN. We thank Lynne for all her support throughout the formative years.

LPCN development

We continue to develop working relationships with both Leeds City Council and Leeds and York Partnership NHS Foundation Trust. During 2019/20 we will consider how we might include representation from these organisations further through additional executive membership and also whether we should be constituted as a Managed Care Network to reflect a broader membership and impact.

During 2018/19 LPCN strengthened and built effective links with other collaborative bodies within Leeds. This includes Leeds Academic Health Partnership, Academic Unit for Palliative Care, Leeds Informatics Board, and the Population Health Management work including the Frailty Clinical Strategy Group.

We continue to work with partner organisations within the third sector, particularly those that formed the Leeds Oak Alliance during 2018. We also increased engagement with the Care Homes Sector having a representative within the LPCN group and links to Leeds City Council Care Home Commissioners and the Care Homes Forum.

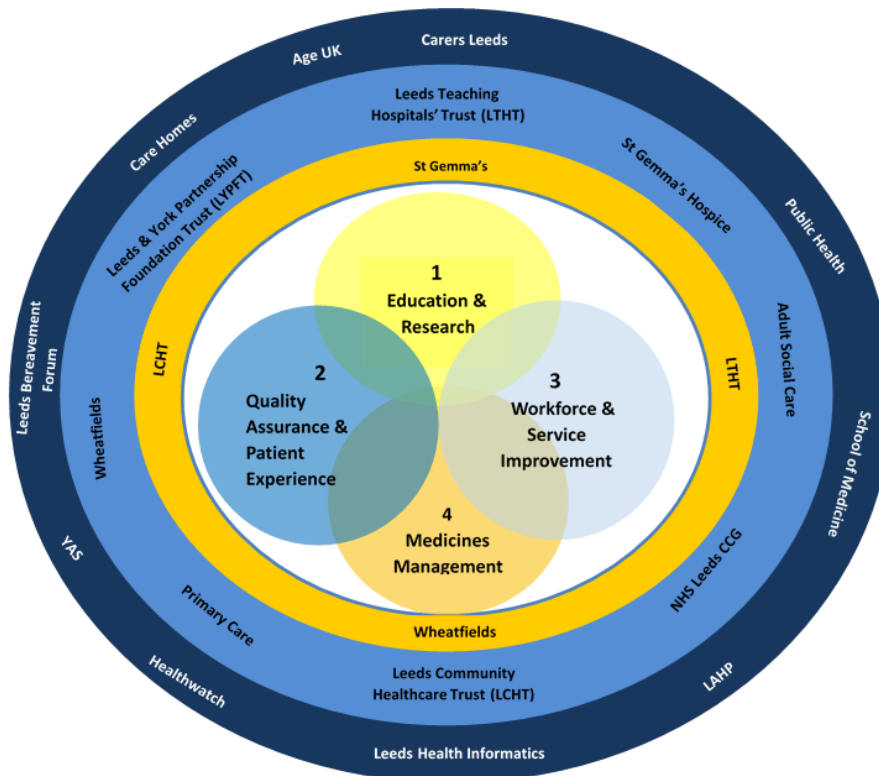
The full distribution list for the LPCN now totals 133 individuals.

To further improve the management of risks and concerns an LPCN Risk Register and a System Issues Log have been developed. This has enabled positive actions to be agreed and the impact tracked. For example pursuing EPaCCs data reports, securing commitment for funding a replacement ambulance for Leeds Palliative Care Ambulance service, raising a Leeds voice regarding the out of hours handover form and sharing concerns regarding the initial launch of ReSPECT.

To maximise the effectiveness of interactions and engagement with patients, their families, professionals and the wider network a part-time communications specialist has been secured. This has already resulted in use of plain English within the new website, development of a patient information leaflet, effective use of Twitter and Facebook, an annual communications plan, links to all partner communications team and better distribution systems. At the time of publishing LPCN have 128 Twitters followers and 1,185 new website users.

Service Quality Improvement Activity

The model for managing and delivering quality improvements remained as below:



The Programme Report has become a recognised tool for recording and sharing all the work delivered through and by LPCN partners. It is updated monthly by all Project Leads and it is planned to share it via the new website during 19/20.

It must be acknowledged that the quality improvement work continues to be undertaken collaboratively by frontline professionals employed within the partner organisations, whose commitment ensures the ongoing success and achievements of LPCN.

The priorities of LPCN were developed through consideration of:

- The Leeds Palliative and End of life Strategy 2014 - 2019
- The Leeds Palliative Care Education Strategy 2016-2021
- Ambitions for End of Life Care
- What's important to me? A Review of Choice in End of Life Care, 2015
- Emerging evidence and opinion of the changing needs of palliative and end of life care
- Challenges arising from clinical practice, organisational changes within health and social care, cross boundary working and communication

Education and Research

Despite it being a challenging year for education focused workforce capacity within the partnership, significant education has been delivered and the LPCN Education group continued to meet.

TARGET Training

During April and May three TARGET training sessions were delivered by Consultants in Palliative Medicine and Palliative Care Multi-Disciplinary Teams to GPs and other practice staff. Almost **300 people** were provided with training in Palliative and end of life care; including pain and symptom management, advance care planning and anticipatory prescribing. It was rated very positively receiving 87% very good or good.

Palliative and End of Life Care Outcomes Learning Outcomes

The End of Life Care Learning Outcomes are nationally recognised standards of high quality end of life care for the workforce. In Leeds these are used with different workforce groups to identify end of life education/training needs and also shortcomings in education provision. The impact of the outcomes are currently being evaluated to show if they support improvements in the delivery of high quality end of life care. Also Leeds is working regionally to support the benchmarking of Clinical Nurse Specialists roles and there is plan to introduce the outcomes in care homes in Leeds.

Communications Skills Training

The existing facilitators of this training have continued to be supported whilst training programmes continue and a new facilitator is being trained to deliver communication skills training in care homes. Links have been made with the Leeds Better Conversations work to ensure training is complimentary. The work to review training materials and refresh the strategy slipped due to lack of capacity. An LPCN bid to fund additional capacity is being made to progress this work during 19/20.

Tele-education (ECHO)

The development and delivery of the ECHO tele-education system has progressed significantly with the first training programme to primary care being delivered and receiving positive feedback. **11** practices agreed to join this first programme which was developed and agreed with the clinicians. To date there has been **93** individual attendances to the ECHO sessions provided.

The next cohort to receive training via ECHO during 19/20 has agreed to be the Care Home sector following a discussion at the Care Home Forum. The programme will also continue to be delivered to more GP practices in Leeds.

Integration of research into the LPCN

Leeds Academic Unit for Palliative Care will be undertaking an audit and survey that will inform future clinical quality improvement work to improve the uptake and use of Electronic Palliative Care Co-ordination Systems (EPaCCs) and ensure training is effectively targeted. This research will provide insight in current use of EPaCCs.

Additional education projects identified for 2019/20 include training for Palliative Care Ambulance Crew, paramedics, and advance care planning for people with dementia and symptom management at the end of life for Leeds and York Partnership NHS Foundation Trust clinicians which will include practical sessions on the use of syringe drivers.

Patient Experience and Quality Assurance

Metrics Suite

Following significant work to finalise information sharing agreements to enable data to flow the report for 2017/18 was received in November 2018.

Data is now flowing for analysis and at the time of writing the 2018-19 report is being finalised but shows continued improvement; the number of people who had preference recorded in EPaCCS continues to increase rising from 42% of those who died in 17-18 to 45% in 18-19, 73% people with EPaCCs achieved their preferred place of death and 67% died outside of hospital compared to 62% last year. There has been improvement in data quality and completion of the records. Work continues to include hospital utilisation data and quality measures.

Improving use of EPaCCs and ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

The EPaCCs group has been working to update the template and enable access and links to the ReSPECT form for community and primary care. The hospital ReSPECT form has been developed to include EPaCCs required information. ReSPECT and EPaCCs will link with an ambition to have a single advance care plan template available in community settings. Ongoing quality improvement work across primary, community and hospice care settings is increasing the earlier completion of EPaCCs and the number of patients being supported by it.

Leeds Academic Unit for Palliative Care has been commissioned to further audit the EPaCCs data to help understand use and help target future training and quality improvement work required.

Bereaved Carers Survey

A new Bereaved Carers Survey was developed this year with support from Leeds Academic Unit for Palliative Care to ensure improved feedback and easier analysis. Healthwatch Leeds provided support in collecting returns and collating the information received. Leeds Academic Unit for Palliative Care are also providing further qualitative analysis.

There has been a significant improvement on numbers of surveys returned. The final report is expected in July 2019.

Learning will inform further service improvements.

For 2019-20 it is planned that primary care will also collaborate with the project enabling them to receive feedback and further increase community returns.

Syringe Drivers

Following a successful bid to NHS Leeds CCG LPCN will deliver **50 additional Syringe Drivers** to partners across the city by September 2019, which will improve patient care and experience through increased access to equipment required for effective symptom management.

Workforce and Service Development

Transfer of Care

A new process with flowchart and guidance has been developed to support the transfer of patients at end of life from Leeds Teaching Hospitals NHS Foundation Trust (LTHT) Emergency Departments to hospices. This went live on 22nd January 2019. Training has been delivered to all ED clinicians with ongoing awareness via team meetings. During 2018/19 170 patients were admitted into the EOL care beds, with 1 being admitted direct from ED and 2 following ED referral when bed available following day(s). The process continues to be monitored for impact.

A hospice to hospital interface project has been established to optimise access to hospice end of life care beds.

The overarching group is in the process of agreeing the priorities for 2019-20 which includes continuing to optimise use of hospice end of life care beds, explore a trusted assessor model within palliative care, better understanding patient pathways in and out of hospital through review of information and data held including Fast Track and understanding how the hospices might respond differently when LTHT is at Silver Command.

Improving EOLC for People with Heart failure

The previous quality improvement work led to improved understanding of patient pathways, training for the cardiac team on managing end of life care and regular joint MDTs for patients with heart failure between palliative and cardiac consultants and their teams. This has improved the management of patients at the end of life and reduced unnecessary hospital admissions.

Additional funding from NHS Leeds CCG from 2019-20 will enable continuation of the MDT meetings and further improvement work including considering how patients gain access to community heart failure team, as these patients were found to have improved end of life care coordination and support.

Dementia and End of Life

There is now an established city wide group which integrates the LPCN, providers of dementia care and dementia commissioners. Through a collaborative and whole system approach the group has started work to

1. increase end of life care dementia care capacity and skills across the system through the development of an Admiral Nurse role for people in Leeds with dementia at end of life
2. improve the use of advance care planning for people living with dementia
3. better understand the clinical tools and support available to help manage pain for people living with dementia

Links have been made with Local Care Partnerships that are undertaking frailty projects that have an overlapping ambition with this work.

From April 2019 LPCN has agreed to provide additional oversight and governance for the **Leeds Palliative Care Ambulance Group**. NHS Leeds CCG remains the lead commissioner and contracts manager for this unique and highly valued service that is delivered by Yorkshire Ambulance Service.

Medicines Management

Access to Medication

LPCN's medicines management lead provided specialist palliative care support to NHS England in developing a service for the urgent provision of palliative care drugs across West Yorkshire. The service is provided by 53 community pharmacies across West Yorkshire who hold an agreed list of medication. The service provision is available during the normal opening hours of the pharmacies chosen by NHS England.

LPCN's medicines management lead sought comment on the list of medications from providers of palliative care across West Yorkshire and also led on the development of an information sheet to accompany the list of medications and list of pharmacies.

The pharmacists' time for this project was funded by West Yorkshire & Harrogate Integrated Care System. The service provision commenced in May 18 and was reviewed in March 19.

Medicine Development of New Guidance and Review of Existing

A Standard Operating Procedure for the development of citywide medication guidance has been produced.

The Opioid Wheel, has been reviewed, updated and republished. Available on Leeds Health pathways and at:

<https://leedspalliativecare.org.uk/professionals/medicines-management/>

Anticipatory Medications

Audit on the use of subcutaneous medication in the last days of life across hospital, hospice and community settings has been completed with further work planned in light of the findings and national debate on the issues.

Patient/Carer Sub Cutaneous (S/C) Medication administration

A policy to enable self / informal carer administration of S/C medications has been produced and implemented within the community to support end of life care and symptom management at home. This guidance is available on Leeds Health pathways and Leeds Palliative Care website;

<https://leedspalliativecare.org.uk/professionals/medicines-management/647-2/>

Electronic Prescribing and Medicines Administration (EPMA) within Hospice Inpatient Units

This project is progressing well having established a reciprocal working relationship with Kirkwood Hospice who are undertaking similar quality improvement work. LPCN has provided the expert Pharmacist input, whilst Kirkwood have provided specialist System 1 skills. The joint formulary has been produced and tested at Kirkwood Hospice. Kirkwood went live with EPMA during May 2019. Leeds hospices have already identified and purchased some hardware and plan to train staff, import the formulary and undertake local testing during summer 2019 with full implementation expected during September / October 2019.

Leeds Palliative Care Website

Following agreement and funding from NHS Leeds CCG LPCN took over the responsibility for designing, developing and maintaining an updated version of the Leeds Palliative Care website. Technical support was commissioned from BML Creative with content being provided from all partners across the system. The website officially went live at a launch event on May 16th 2019 - <https://leedspalliativecare.org.uk/> .

Marketing materials have been designed and distributed widely to all partners, including into care homes and in all public libraries.

Management processes to reply to 'contact us' queries have also been put into place.

Monitoring of utilisation and adding additional content will continue next year. This will include a news bulletin and access to additional LPCN core documents.

Strategy Development - The Future of Palliative and End of Life Care in Leeds

A system wide engagement event was delivered by the LPCN on 21st November to 62 people from all the wider partner organisations. Following key speaker updates this facilitated event used a market place style engagement to determine what future priorities should be considered.

A full write up and slide deck of the event has been widely circulated and is also available on the website:

<https://leedspalliativecare.org.uk/professionals/leeds-palliative-care-network/lpcn-documents/>

The following issues were identified as important for future consideration within a refreshed Palliative and End of Life Care Strategy for Leeds:

1. **People's Voice / Consultation**
 1. How do we harness the strengths / assets of people and communities in end of life care?
 2. What does a good death look like in multicultural Leeds
 3. Talk to people about what they want
2. **Workforce Development** – Training, recruitment, retention, whole system issue
3. **Community / Out of Hospital**
 1. Out of hours access
 2. Further improving palliative care in the community
 3. Capacity and capability to care for elderly in the last months of life (3rd Sector input)
 4. Single point of access for end of life care
 5. Advance decisions
 6. How do we provide timely end of life care? (feeds into others/ cross cutting)
 7. Earlier identification (from within other conversations)
4. **Digital Route maps** – Cross cutting / supporting theme.
5. **Learning Disabilities and Palliative Care** – Plus vulnerable groups
6. **Specialist Palliative Care Services** – Increased collaboration and consistency
7. **Equity of Service Provision and Equality of Access**
8. **How We Pay For It!** – Commissioner Issue; offset by reduced hospital utilisation.

LPCN also worked with Public Health colleagues to secure a refresh of the **Health Needs Assessment** for end of life care to help inform planning and understanding of need.

Through the **Population Health Management** work being undertaken in the city LPCN arranged and facilitated workshops with OPTUM population health analytics team to help determine what additional information could be gleaned about palliative and end of life care needs from the Leeds Data Set.

This work is ongoing with recent consideration of the potential variation of service and access within each Local Care Partnership locality. We hope to further influence data held within the Leeds Data Set and access to population level data about patients that received end of life care in Leeds.

More recently LPCN and NHS Leeds CCG have established a new **Strategy Advisory Group** to oversee the production of an Outcomes Framework and the new Strategy for Leeds.

Working with the Wider Leeds Network

RESPECT (Recommended Summary Plan for Emergency Care and Treatment) implementation

LPCN met with commissioning leads to discuss and influence the ReSPECT roll out requirements and plans for the city adoption. We encouraged clarification of oversight and leadership for the work within the Clinical Senate and encouraged monitoring of rollout impact for all providers and the patients. We continue to receive updates from the Community ReSPECT group and have ensured on going EPaCCs development incorporates the ReSPECT process and documentation.

Frailty - Population Health Management

The LPCN reviewed its membership for all the projects within this citywide piece of work and continue to make active contribution to ensure recognition of people approaching end of life and proactive advance care planning are core components across all work streams.

COPD and Palliative Care Pathways

Representatives from LPCN continue to contribute to the NHS Leeds CCG led work to improve end of life care for those people with COPD.

Consultants in Palliative Medicine from all providers have also been collaborating with Alison Boland Consultant in Respiratory Medicine to undertake audit of activity and provide an MDT management approach for those people with severe COPD. This work was recently published:

<https://www.respiratoryfutures.org.uk/features/leeds-integrated-palliative-copd-mdt/>

Specialist Palliative Care Advice to YAS

Leeds contributed to a regionally led piece of work to enable paramedics quicker and easier access to advise when attending people at home who are at end of life. Single contact numbers were agreed for in hours and out of hours, and a working protocol agreed. Impact and benefit is being monitored and will be reported during 2019/20.

Other Projects

LPCN Executive Team members and colleagues from the main LPCN Group shared information about other important project work they are currently undertaking which may have a wider system impact.

This included work on:

Leeds Mortality Reviews, Learning Disability and End of Life Care, Gypsies and Travellers, Prisons End of Life Care MDT, Homelessness, Primary Care -Care Home Scheme.

Continued updates will be provided on this activity to support and maximise quality improvements where possible for all people in Leeds.

Finance Report

The yearend accounts show the LPCN with underspend for projects and recurrent staffing / running costs.

The Network Manager post was vacant until August 2019 and some funding for projects was received later in the year from NHS Leeds CCG.

Recharges are still expected from partner organisations for Clinical Executive Lead support.

There will be further costs for the Bereaved Carers Survey prior to completion and recruitment of some project support posts has been challenging.

LEEDS PALLIATIVE CARE NETWORK FINANCE REPORT Q4 April 18 - December 18								
WORKFORCE								
Roles		Budget 18/19	Q1 actual	Q2 actual	Q3 actual	Q4 actual	Actual 1819	Variance
LPCN Management - Clinical/Admin		£78,130	£11,395	£16,863	£19,701	£19,719	£67,678	£10,452
Sundries / expenses		£3,000	£150	£928	£76	£325	£1,480	£1,520
Overheads		£12,877	£3,219	£3,219	£3,219	£3,219	£12,877	£1
Additional allocation		£5,993			£3,538	£1,000	£4,538	£1,455
Final amount for recharge purposes 17/18		£100,000	£14,764	£21,010	£26,534	£24,263	£86,572	£13,428
PIPELINE BIDS								
Title/ Lead	Allocated costs	Spend as at 31/3/18	Q1 18/19	Q2 18/19	Q3 18/19	Q4 18/19	Spend to date	Actual left
Coaching to develop exec team MCN - Trish Stockton	£2,000	£569				£1,431	£2,000	£0
Develop and promote Palliative Care Website	£10,640	£1,063		£5,850		£4,050	£10,963	-£323
Citywide Bereaved Carers Survey	£5,000	£0				£62	£62	£4,938
Project expenses	£56,335	£14,911		£40,000			£54,911	£1,424
Implementation of E prescribing - Moira Cookson	£28,400	£0			£5,045	£11,609	£16,654	£11,746
EPaCCS practice engagement - Adam/Sarah	£30,000	£0			£13,067		£13,067	£16,933
End of Life Dementia Care	£15,098			£2,299	£1,149	£1,149	£4,598	£10,500
Project ECHO Hub	£31,500			£2,677	£2,700	£4,671	£10,048	£21,452
PHM programme backfill	£6,000						£0	£6,000
Total	£184,973	£16,543	£0	£50,826	£21,961	£22,972	£112,302	£72,671

LPCN Commissioning Investments for 2019/20

NHS Leeds continues to support LPCN. As well as the core funding investment there is an additional provision of £2,500 for the maintenance of the website and agreement to the following project funding for 2019/20.

	Service	Funding requested	Provider:	Value	Brief details of Scheme
Leeds Palliative Care Network	End of Life Dementia Care: The implementation of a citywide strategic approach to delivering end of life care for people living and dying with or from dementia	Non-recurrent for a further year (currently non-recurrent)	LPCN	£9,900.00	Funding for a post to support implementation of a citywide strategic approach to delivering end-of-life care for people living and dying with or from dementia
	Project ECHO Hub	Recurrent (currently non-recurrent)	LPCN	£31,500.00	To continue the development and rollout of the ECHO Hub - delivering education programmes via video-conferencing technology to large numbers of health care practitioners within Leeds.
	Heart Failure	New Recurrent	LPCN	£8,000.00	Provide EOLC specialist input into the Leeds Heart Failure MDT
	Syringe Drivers	New Non-recurrent	LPCN	£62,040.00	Purchase new syringe drivers for use by professionals across the city
			LPCN Non-recurrent Total	£71,940.00	
			LPCN Recurrent Total	£39,500.00	
			LPCN Total	£111,440.00	

Future Plans

Looking forward into next year LPCN will continue to work collaboratively with partners and NHS Leeds CCG to produce the next Palliative and End of Life Care Strategy for Leeds. It is anticipated this will inform and influence the work programme for LPCN going forward and that we will work to the new strategic priorities.

We continue to develop LPCN and will consider how we gain additional capacity and engage other organisations with the potential for additional Executive Team membership.

It is intended that any funds carried forward to date will be considered a non-recurrent project fund that will be available to help resource additional capacity, patient information materials and events; for example additional project support is required to support the review of the Communications Skills education strategy and programme content. We have also secured communications support from underspend and will hold an annual event.

It may be that we agree to consider ourselves as a Managed Care Network to better recognise the boarder community, third sector and social care aspects of the LPCN.

The Executive Team also agreed the following key actions for 2019:

- Survey and gain feedback from LPCN members – July
- Debate LPCN future – October
- Hold a celebration and forward planning event – November
- Monitor representation at the LPCN group so we can improve engagement
- Provide support to NHS Leeds CCG and the GP Confederation in delivering the Primary Care End of Life Care Quality Outcomes Framework
- Design a News Bulletin that will be distributed alternate months to the LPCN Group.

