



**Leeds Palliative
Care Network**

Annual Report 2019-2020

Prepared for NHS Leeds CCG

June 2020

Foreword

Coming newly to Chair the LPCN I am aware that this report has been produced during unprecedented times as the LPCN is focussing on helping Leeds to manage the COVID-19 pandemic.

The response to the pandemic has seen the fastest and most far-reaching repurposing of NHS, social care and third sector services, teams and capacity.

I'd like to thank everyone working across the breadth of palliative and end of life care for their rapid, coherent response to the evolving crisis and to continued collaboration, support and dedication throughout this time and over the past year.

I'd also like to thank Dr Mike Stockton for remaining on board as co-chair with myself to provide extra resilience during the pandemic.

LPCN will continue to provide support and to help ensure that health and care professionals in Leeds have swift and timely access to palliative and end of life care guidance, information and support in this evolving situation and the year ahead.

I look forward to working with all partners and the LPCN team to ensure we build upon the effective collaborative partnership that has been established.

Dr Adam Hurlow



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LPCN Annual Report 2019-2020

Introduction

Leeds Palliative Care Network 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 purpose of this report is to provide NHS Leeds CCG 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 report will also be useful for LPCN partners to be able to evidence the benefit and impact that we have collectively. It provides a report of activities and achievements during 2019 / 2020.

Maintaining Effective Governance and Communications

In line with LPCN Terms of Reference and Memorandum of Understanding the length of term for each Executive has been carefully considered.

Dr Mike Stockton announced his intent to demit the post of Clinical Lead and Chair at the end of March 2020 and following an open and transparent recruitment process Dr Adam Hurlow, Consultant in Palliative Medicine, LTHT, was successful in applying for the post and will be the Chair as we move into a new financial year.

To enable the Chairperson to function effectively and ensure their employing organisation has adequate representation on the LPCN Executive we agreed to add an additional position. This resulted in the appointment of Lesley Charman, Team Leader CNS, as the LTHT representative. The new representative for St. Gemma's will be Heather McClelland, Chief Nurse, St Gemma's Hospice.

Dr Mike Stockton will continue to support the LPCN via his clinical leadership of the community development work.

LPCN Executives commenced a regular sharing and review process of complaints and incidents, and their respective organisations reported each quarter. This process enables us to consider system wide impact and responses required to improve patient experience and also highlights common themes of concern.

Since the middle of March 2020 the LPCN office has been run remotely with the LPCN team working from home due to the Covid-19 pandemic. Access to files and email has been maintained and Skype or Zoom used where possible to support group meetings.

The website which was launched in May 2019, has been developed considerably throughout its first year. There has been increasing levels of activity particularly by professionals seeking guidance or training information.

The 'contact us' function has also enabled international links to be made and an ability to offer specific help and direction.

A new banner and page section was added in March to share specific Covid-19 guidance and advice for the public and professionals, including both local expert LPCN guidance and links to national documents.

Twitter and partner [bulletins](#) are used to ensure effective and regular cascade of information too. At the year-end there are 299 Twitter followers and 3,944 website users had undertaken 16,408 page views.

The citywide patient information leaflet has been refreshed following feedback from patient's families and frontline professionals. 2,000 copies have been printed and distributed for use by health professionals during patient assessments. Branding standards have been agreed in line with NHS guidance with LTHT medical illustrations so that future copies can be printed as required.

<https://leedspalliativecare.org.uk/wp-content/uploads/2019/11/Palliative-and-End-of-Life-Care-Leaflet.pdf>

LPCN Programme Updates

The programme of quality improvement work continued in line with the agreed LPCN Model with significant input from all partners; see appendix 1.

Monthly project updates have been maintained throughout the year and reported via [programme overview](#).

Below is a summary of achievements within each Workstream over the last year.

Education and Research

Training

A significant amount of education has been delivered throughout the year.

The following training has been provided and positively evaluated:

- YAS Paramedic Ambulance Crews- approximately 50 staff
- YAS Palliative Care Ambulance Crew – 13
- LYPFT The Mount Hospital – approximately 60 clinical staff
- LYPFT Pharmacists working in Psychiatry - 20
- Advance Care Planning for people with Dementia – 72 people
- Communication skills training – advanced / practitioner/ Support Workers – 164 staff
- ECHO for GP Practices – 12 practices on the programme
- ECHO for CNS's in WY&H – 22 CNS's on the programme

Support to colleagues within LYPFT has continued through the sharing of guidance and standard operating procedures for use of the new syringe drivers. Community partners developed phase 1 training to use the new 'Planning Ahead' platform which includes Community ReSPECT forms and started to deliver it to staff. This was paused for the Covid Outbreak but use of community ReSPECT is still being considered.

The EOLC learning outcomes remain one of the highest searched for items within the LPCN website.

ECHO

This tele- education tool is proving to be increasingly popular. A further GP cohort has been commenced with prior GP cohort members requesting an ability to continue to meet.

A process to develop the Care Homes EOLC programme has been agreed but postponed during the Covid-19 outbreak.

Regional Training for Specialist Palliative Care CNS's is also being delivered via ECHO.

The use of ECHO has given IT support and many others experience and confidence in using ZOOM which has helped in wider use of this tool for education and virtual meetings as social distancing to tackle Covid19 became a new challenge.

Patient Experience and Quality Assurance

Metrics and EPACCs

A key collaborative development has been the improvement and redesign of the EPaCCs template so that it can be used more widely for advance care planning. This development is known as **Planning Ahead** and includes the ReSPECT Form for use by community practitioners. It is essential for increasing the numbers of people who make personalised care plans earlier, helping us to plan and manage frailty and long term conditions, as well as EOLC.

Following discussions at the Leeds P&EOLC Strategy Group the LPCN proposed key metrics for measuring the impact of service changes in the end of life population. These were agreed with the CCG.

Initial hospital data about admissions within the last 90 days of life has now started to be reported and LPCN colleagues will work with information analysts to develop this further.

The % of people who died that were recorded as having an EPaCCs record continued to rise to 54%. The number of people with EPaCCs record who achieved their preferred place of death was 79%.

After significant data delays initial findings for the evaluation of Leeds EPaCCS data by Leeds AUPC were shared with the LPCN Executive in March. The final report will be made available by June 2020.

New Syringe Drivers

There was a delay in distributing the syringe drivers due to software issues and battery life concerns. The short battery life has resulted in the decision for the new version 3 edition to only be used in in-patient care environments. The following share was agreed: LTHT = 35, LCH = 0, St. Gemma's = 7, Wheatfields = 6, LYPFT, The Mount = 2. With Leeds Medical Physics support to update the software and ensure the equipment was safe for use, distribution has now been completed. Partner organisations have offered to loan edition 2 syringe drivers to LCH should they require them until an improved model is available.

A recall request has been made to all funeral directors to ensure effective return of existing equipment. All edition 2 syringe drivers requiring repair have been serviced and returned to ensure the community teams have an adequate supply.

It is hoped the manufacturer will resolve outstanding issues so that a new supply can be provided for community use in the future.

Bereaved Carers Survey for 2019/20

All actions that came out of the 2018-19 survey have been completed. The [Completed Action Plan](#) is available on our website.

The survey content for 2019/20 was agreed and the survey has been run between January and the end of March 2020.

For the first time the survey includes primary care who have distributed the survey with the death certificates for community patients.

The response rate was good prior to the Covid-19 pandemic when the death certificate process was changed.

Family members and carers can return the survey up to the end of April 2020.

Healthwatch Leeds are analysing returns and a report is expected during the summer of 2020.

Workforce and Service Development

Transfer of Care

During 2019-20 it was agreed that the broad agenda should be split to provide additional capacity and focus for the work. The 2 groups now focus on Hospital to Hospice transfers and improving the community service delivery model.

Hospital to Hospice transfers

This specific Workstream is looking to optimise use of the hospice EOLC beds, scope out and test a trusted assessor model and develop a hospice response to the hospital's silver command process. Continued monitoring of the daily transfer process has highlighted the need to update the process guidance documents and there is a plan to meet with ED consultants to see if the transfer process and form used can be further improved.

Community Flows Improvement

This new group has now established itself.

To date it has started 2 projects.

1. In December a project agreed a plan of short term / immediate actions that would support the system to function better during winter. This has been successful in supporting partners with simple operational changes and improved communications.
2. The group has agreed to use a Whole Systems Approach supported by Leeds Beckett University to scope out the current community delivery model both from provider and public view point. A project lead has been appointed to support this work. The initial WSA scoping event has been postponed but the project lead and university lead continue to develop supporting documentation in preparation.

Heart Failure

Palliative medicine input into the city wide monthly heart failure MDT continues with evaluation of the impact of the meetings.

Mapping of Leeds against Hospice UK 2017 heart failure and palliative care recommendations to identify gaps in service is underway.

Guidance on the use of subcutaneous diuretics in the community has been implemented and discussions about updating regional guidance on symptom management for patients in the later stages of heart failure are ongoing, now that the Cardiac Network no longer oversee them.

Leeds Palliative Care Ambulance

During this year LPCN agreed to provide oversight and support to the Leeds Palliative Care Ambulance operational group.

The Palliative Care Ambulance new standard operating procedure has been ratified and put into place; available to professionals on Leeds Health Pathways. Training against the agreed standards has been put in place.

Internal reporting and accountability within YAS has improved and LPCN administrates the partner operational meetings. Collection of activity data continues with reports to the LPCN group and a debriefing / supervision system is being put in place to support the ambulance crew members following distressing or challenging care interventions.

Dementia

Following publication of the dementia Advance Care Plan event report the group agreed the next actions. The link to the regional work has resulted in the development of specific [Advance Care Planning](#) documentation for use with people living with dementia.

Work continues to share best practice on pain management guidance for people with dementia and there is a research proposal being developed to review all the existing pain assessment tools available and to understand which are used and why.

The project lead demitted the role at the end of March and a replacement is being sought.

Medicines Management

Anticipatory Medicines.

Following redesign and approval of the audit tool a further audit is being planned within LCH, to commence January 2020 for 3 months to assess anticipatory medication usage and need in the last days of life. This will include quantities of medication in the home pre and post death but may be impacted by the covid-19 pandemic. The first audit was published in BMJ Palliative and Supportive Care journal and was accepted as a poster at the Palliative Care Congress in March 2020, but sadly this was cancelled.

A group met to review and redraft the anticipatory syringe driver guidance in light of the Gosport review and other service developments. Once ratified this will be included as an appendix to the LCH last days of life guidance rather than a stand-alone document

Reviewing and refreshing existing guidance

A guide for the process of review and production of medicines guidance has been produced.

The content for the following guidance has been reviewed and updated and published in hard copy and / or on the LPCN website and Leeds Health Pathways:

- Guidance for self / informal carer administration of subcutaneous medication
- Opioid wheel
- Palliative care patients at Risk of Bleeding
- Palliative Seizure management Plan
- Using morphine and other opioids – patient information

The review of Liver and Renal guidance is almost complete, pending final comment back from the liver and renal specialist teams. We would aim for this to be uploaded to Leeds Health Pathways in May 2020.

Yorkshire and Humber - A Guide to Symptom Management in Palliative Care

This guide was updated by the regional team and LPCN worked with them to ensure that 2,700 copies were distributed across Leeds to all core providers including Primary Care, Nursing Homes and Local Care Direct.

<https://leedspalliativecare.org.uk/wp-content/uploads/2019/09/A-Guide-to-Symptom-Management-in-Palliative-Care-Yorkshire-and-Humber-End-of-Life-Care-Group.pdf>

Following this a useful Symptom Guide App was released and promoted widely through partner newsletters and bulletins.

Apple: <https://apps.apple.com/gb/app/palliative-care-symptom-guide/id1168941132>

Google: <https://play.google.com/store/apps/details?id=com.HYMS.PalliativeCare>

Electronic Prescribing and Medicines Administration

Both hospices are now actively using the electronic prescribing and administration system on the IPU. LCH end of life care discharge facilitation team have also been enabled to access information regarding inpatient medication via SystmOne for hospice in-patients who are planning discharge. Phase 2 of this project will look to further develop the e-prescribing systems, to include syringe drivers and discharge medications.

Strategy Development

LPCN helped to establish, support and facilitate the Leeds P&EOLC Strategy Advisory Group which commenced on 30th April 2019.

There have been several development workshops held during the year alongside CCG colleagues that have helped to produce a new Leeds Palliative and End of Life Framework.

To further enhance the collaborative thinking at the [LPCN Celebration and Strategy Event](#) held on 27th November 2019 partners were asked to consider what might be priorities for future improvement work

Priorities for all aspects of service delivery within the framework were considered. The overall top priorities identified on the day were;

- Creating a Single Point of Access
- Improving Hospital avoidance through further integrated models of care in community
- Increase scale and impact of Dying Matters Campaign – raising public awareness
- Understanding and overcoming barriers by providing adaptable services for all

The refresh of the [Health Needs Assessment](#) was completed in December 2019. This adds further insight into future demand growth for end of life care and identifies areas for further improvement.

The Leeds P&EOLC Strategy Advisory Group have also agreed [Population Outcomes](#) following presentation to the [Health and Wellbeing Board](#) on 16th September 2019 and subsequent consultation on the proposals via Leeds Peoples Voices.

A format for the new strategy document that is designed around the outcomes has been approved and is currently being finalised.

Much of the introductory content has been completed but as key authors are now working on the front line during the Covid-19 pandemic a slight delay of completion is expected.

Other Important Developments and Projects

Frailty

LPCN continues to provide support to the citywide frailty work and is aligned to specific Local Care Partnerships and their projects. There has been a further strengthening of this relationship via the Bronze Command structures put in place during the Covid-19 pandemic. There has also been input into the development of a new [Older people with frailty service](#) with specific palliative care support offered.

Single Point of Access

The need for a SPA for EOLC has been explored and if it remains a priority for the city will require further conversations with commissioners about its development and funding. The discussions to date recognise there is a need to further improve and simplify access to advice and services, and also to improve coordination of care between providers.

Extended access to SPC CNS's advice and support during the pandemic may provide further insight into need and demand.

Breathlessness

The LPCN hosted a partner meeting to clarify purpose and gained agreement for the development of a Leeds Integrated Advanced Breathlessness Service. Dr Chris Kane has been identified as the Clinical Lead for this work.

The existing EOLC Respiratory group will help drive the work forward whilst the LPCN and CCG agree future project structure and leadership.

Care Homes

LPCN is a member of the Leeds Care Homes Oversight Board. The ECHO training programme, website developments and opportunity to be involved in redesign of community services has been fed into this group.

Increased partnership working is also evolving during the Covid-19 pandemic via the Covid Oversight, Assurance and Coordination Group and the Bronze Command Structures.

Dying Matters

Community Grants to a value of £2,000 have been awarded to 14 bidders but as public meetings and training is currently postponed the grants are on hold.

Additional LPCN funds were also provided to Dying Matters Leeds to extend the campaign to target men and BAME populations as these were demonstrated within the Health Needs Assessment to access service less frequently.

In light of the Covid-19 pandemic the partnership group are looking to deliver an appropriate on-line / poster campaign similar to the recent LTHT 'How would they know' campaign which will support public engagement with advance care planning.

Homelessness

A partnership bid was made to the Masonic Charitable Foundation led by St. Gemma's and supported by the LPCN to fund additional clinical capacity for palliative care and homeless services to work collaboratively to better understand need and how it might be met.

This bid has been successful in gaining a grant for £25,800 to support a project for one year. A further £10K has been received from Gwyneth Forrester Trust enabling 18 month project to be supported.

Working to improve inclusion and access

LPCN partners are also working with groups to improve inclusion. Hospices are working with local **BAME** communities and **Leeds Involving People** to better understand how to raise awareness of services and improve access. They are also providing SPC advice and support to **Prisoners** and for **Gypsies and Travellers**. LYPFT has produced specific assessment tools that improve communication and ability to manage pain for people living with **learning disabilities**. It is expected that further work will be undertaken with these and other underrepresented groups in order to increase early recognition, improve access and increase uptake of appropriate EOLC services for all over the coming year, 20/21.

CCG Funding Bid Proposals

The LPCN submitted business proposals to the CCG in August that would add value to the system and benefit from investment. These included funding an Education Lead post for the system, Admiral Nurses for EOLC to support people living with dementia and further syringe drivers as there is now a new model and the existing stock is aging.

Finance Report

The final year-end financial position is shown below

LEEDS PALLIATIVE CARE NETWORK FINANCE REPORT April 19 - March 20									
WORKFORCE									
Roles	Budget 19/20	Q1 actual	Q2 actual	Q3 actual	Q4 actual	Actual 1920	Variance	Comments	
LPCN Management Clinical and Admin	£78,657	£19,050	£18,710	£18,714	£20,027	£76,501	£2,156		
ELM/Comms	£10,000	£2,734	£2,650	£900	£1,228	£7,512	£2,488		
Sundries / expenses	£1,166	£56	£84	£314	£399	£853	£313		
Overheads	£12,877	£3,219	£3,219	£3,219	£3,219	£12,876	£1		
Final amount for recharge purposes 19/20	£102,700	£25,059	£24,663	£23,147	£24,873	£97,742	£4,958		
Total underspend on regular funding 31.3.19	£51,991								
Expenditure from underspend 1920	-£1,047								
Underspend regular funding 1920	£4,958								
Remaining balance underspend regular funding	£55,902								
Remaining balance pipeline bids	£159,545								
PIPELINE BIDS									
Title/Workstream Lead	Received	Spend as at 31/3/19	Actual left 1.4.19	Q1 19/20	Q2 19/20	Q3 19/20	Q4 19/20	Spend to date 1920	Actual left
Develop and promote Palliative Care Website	£13,140	£10,963	-£323	£679		£596	£1,050	£2,325	-£148
Citywide Bereaved Carers Survey	£7,000	£62	£4,938		£1,000			£1,000	£5,938
Project expenses	£56,335	£54,911	£1,424			£1,191		£1,191	£233
Implementation of E prescribing - Moira Cookson	£28,400	£16,654	£11,746			£7,950		£7,950	£3,796
EPaCCS practice engagement - Adam/Sarah	£30,000	£13,067	£16,933					£0	£16,933
End of Life Dementia Care	£15,098	£4,598	£10,500	£1,129	£1,129	£1,449	£1,129	£4,835	£5,666
Project ECHO Hub	£48,000	£10,048	£21,452	£3,181	£3,246	£3,167	£5,782	£15,375	£22,576
Heart Failure MDT cover	£8,000			£2,000	£2,000	£2,000		£2,000	£0
Syringe Drivers	£62,000				£62,000				£62,000
PHM programme backfill	£6,000	£0	£6,000					£0	£6,000
ReSPECT/Planning Ahead training	£40,000								£40,000
Community Flow Improvement project	£50,000						£2,250	£2,250	£47,750
Dementia and Dying Matters campaign	£10,800							£0	£10,800
Total	£374,773	£110,302	£72,671	£68,988	£7,375	£16,352	£12,211	£104,926	£159,545

During the year LPCN received additional income that has been awarded to the Leeds Dying Matters campaign as it was a strategic priority, and to maintain the dementia project work as no further non-recurrent funds were expected.

Funds were also transferred to LPCN to enable a wider partnership approach to be facilitated for community service improvement work; another strategic priority.

The LPCN income from NHS Leeds CCG for 2020/2021 has been confirmed as below:

Description	Actual 2020/21
LPCN (St Gemma's Lead Body) Recurrent	
Financial allocation	104,137.80
Project Echo	16,731.00
Heart Failure MDT cover	8,112.00
LPCN web site	2,535.00
Palliative Care Band 7 Educator	56,784.00
LPCN Sub-Total	188,299.80

The income is as expected and includes a 1.014% inflation factor on last year's income.

Most noteworthy is the recurrent funding received for a full-time Band 7 Educator role. This will give the much needed additional capacity the system requires to deliver all the partnership training and education needed on an ongoing basis.

LPCN Model – Appendix 1



