

**Leeds Palliative Care Network  
Group Meeting**

**Actions of the meeting held on Wed 18th May 2022 via Zoom**

<b>Attendees</b>	<b>Init</b>	<b>Role</b>	<b>Org.</b>
Diane Boyne	Diane B	Leeds Palliative Care Network Manager and Chair	LPCN
Emily Curran		LPCN Clinical Executive Team Member	SRWFH
Lesley Charman	LC	LPCN Clinical Executive Team Member	LTHT
Suzanne Kite	SK	Lead Clinician Palliative Care	LTHT
Sian Cartwright	SC	Head of Health and Development	Carers Leeds
Tom Daniels	TD	Macmillan Leeds Cancer Programme Manager/Senior Commissioner	NHS Leeds CCG
Carla Rogers		Practice development Nurse for OPS & Dementia	LYPFT
Michelle Atkinson		Chief Officer	Leeds Care Association
Jane Robinson		Manager	Leeds Bereavement Forum
Jo Joy- Jones	JJJ	Planning Ahead Co-ordinator	LS25/26 PCN
Julie Marshall-Pallister	JMP	Community Services Lead	SRWFH
Leigh Taylor	LT	LPCN Clinical Practice Educator	LPCN
Lynne Russon	LR	Consultant and Honorary Senior Lecturer in Palliative Medicine	SRWFH
Amanda Storer	AS	Leeds Palliative Care Network Administrator (Notes)	LPCN
<b>Apologies</b>			
Adam Hurlow	AH	Consultant in Palliative Medicine and Chair	LTHT
Mike Stockton	MS	Chief Medical Officer and Consultant in Palliative Medicine	SGH
Clare Russell	CR	Head of Transformation	SGH
Sarah McDermott	SMc	Clinical Service Manager (Palliative Care and Community Cancer Support Services)	LCHT
David Richardson-McDermott	DRW	Service Manager/SACP	VILLA CARE
Trish Stockton	TS	LPCN Education Lead	SGH
Heather McClelland	HMc	LPCN Clinical Executive Team Member	SGH
Gill Warner	GW	LPCN Clinical Executive Team Member	LCH
Gill Pottinger	GP	LPCN EoLC Lead for Primary Care	Primary Care /CCG
Moira Cookson	MC	LPCN Medicines Management Lead	SRWFH/SGH
Chris Bonsell	CB	LPCN Medicines Management Lead	Kirkstall Road Medical Centre
Elizabeth Rees		Lead Nurse End of Life Care	LTHT
Elizabeth Messenger	EM	Head of Public Health (Older People)	LCC Dying Matters
Dave Green	DG	Head of PTS Service & Standards	YAS

No.	Action	Lead(s) for action
<b>1. Welcome and Apologies</b>		
Diane welcomed everyone to the meeting and explained that Adam was unable to attend due to a family bereavement. Apologies were given as shown above.		
<b>2. Approval of Previous Action Log and Matters arising</b>		
The Action Log of the Meeting held on 30 <sup>th</sup> March 2022 was agreed as a correct record.		
<b>Matters Arising</b>		
Prev Action 203 – The SPC Referral form is on the meeting agenda.		
Prev Action 204 – an Update from the EOLC Board is now a standing agenda item.		
Prev Action 205 - Risk 4 Changing Commissioning and Provider Organisation Landscape will be closed on the LPCN Risk Register as it is now resolved.		
<b>3. Chair's Update</b>		
Leeds Adult SPC Access Criteria – A final version of the document was agreed at the LPCN Exec Team Meeting on 12th May and will be circulated with the notes of this meeting for information. – <b>Action 206</b>		
<b>4. Network Manager's Update</b>		
<b>Annual Report</b> – The Annual Report is being drafted and will hopefully be ready by June. The report is required by the CCG and will also be shared with the EOLC Board.		
<b>TOR/MOU</b> - These documents need to be updated now the new governance structure for the LPCN has been agreed. Once amended they will be circulated to the MOU signatories for information.		
<b>H&amp;C Act</b> - The Act has now passed through Parliament which means the new ICS structures will become legal in July 2022.		
<b>5. Planning Ahead Service in LS25/26 PCN</b>		
Jo Joy–Jones gave an interesting presentation about her role as Planning Ahead Coordinator in LS25/26 PCN.		
<ul style="list-style-type: none"> <li>• The role is funded for 2 years initially and was developed in response to the high number of older people in the PCN. There is a lot of frailty and there were a high number of unplanned deaths during Covid. There was a desire to look proactively at having very person centred conversations in a non-clinical setting, usually the patient's homes.</li> <li>• After receiving a referral the patient is contacted by phone for a general conversation about wellbeing and offering the patient the opportunity to have a discussion about what might happen in an emergency and the chance to do some planning. If they agree, the patient is sent a letter which contains information about 'What Matters to Me' and other items such as power of attorney, wills and funerals.</li> <li>• Sometimes the patients say no or want further information first. If the call is not answered a further 2 attempts are made and then a letter is sent.</li> <li>• An appointment is then made, with any carers or family invited to also attend if the patient wishes.</li> <li>• The visit takes place in the patient's home and lasts about an hour. It involves explaining the process and then a lot of listening and taking notes. Sometimes they can be challenging or moving, there can be tears.</li> <li>• There are a range of different resources for signposting or an appointment can be made with a clinician about advanced clinical decisions such as DNACPR.</li> <li>• The outcome of the visit is that the patient gets a ReSPECT form and their patient record is populated with what matters to them.</li> <li>• The ReSPECT form is sent with a supporting letter explaining what it is and how it can be used. It is also explained that it belongs to the patient and can be changed at any time.</li> <li>• Most referrals are patient initiated or as part of the annual review of patients with severe frailty.</li> <li>• Feedback on the service has been positive.</li> <li>• The next steps are to move to seeing patients in care homes. There are some new care coordinators in the PCN to assist with this, then to work with palliative patients and those coming out of hospital.</li> </ul>		

## 6. Planning Ahead Report (EoL) Q3

Diane shared the highlights of the report which are shown below.

### Key findings of the 2021/22 Report (Q3) are:

- 40% (in Q3) of adults who died in Leeds had an EPaCCS record compared to 48% in previous year. (EPaCCS Deaths / All Deaths) 2021/22: Q1 (679/1415) , Q2 (720/1627) , Q3 (726/1833) (EPaCCS Deaths / All Deaths) 2020/21: Q1 (1074/2072), Q2 (675/1308) , Q3 (850/1917) and Q4 (802/1811)
- 81% achieved their preferred place of death in current reporting period compared to 80% for the previous year; with 73% dying outside of hospital compared to 71% in the previous year.
- The proportion of patients whose EPaCCS record was started more than 3 month before they died is at 49% in current reporting period compared to 54% the previous year.
- The proportion of patients without an actual place of death recorded has slightly decreased to 11% from 13% last year.
- Percentage of patients who died and had a RESPECT Code recorded on the system: 2021/22: Q1 (48%), Q2 (59%), Q3 (71%) 2020/21: Q1 (10%), Q2 (19%), Q3 (17%) and Q4 (31%)
- Deaths at home has significantly increased in the current reporting period 2021/22: Q1 258 deaths (38%), Q2 250 deaths (35%), Q3 258 deaths (36%) 2020/21: Q1 306 deaths (28%), Q2 233 deaths (35%), Q3 281 deaths (33%) and Q4 274 (34%)

This report covers a period of unprecedented demand across the health and social care environment: particularly given the impact of COVID-19 on the system. It is a considerable achievement the proportion of patients being supported in their preferred place has been maintained along with the overall proportion of people with an EPaCCS record. This marks a sustained improvement on 2016-2017 when 33% of adults who died had an EPaCCS record.

The findings show that that a greater proportion of people are being given opportunities to discuss , document and share their care preferences at an earlier stage and demonstrate improved data quality.

The full report is on the LPCN website and can be accessed through this link:

[https://leedspalliativecare.org.uk/wp-content/uploads/2022/05/2021-22\\_Q3-Leeds-Planning-Ahead-Report-EoL-V1-Final.pdf](https://leedspalliativecare.org.uk/wp-content/uploads/2022/05/2021-22_Q3-Leeds-Planning-Ahead-Report-EoL-V1-Final.pdf)

## 7. EOLC Population Board

Tom Daniels gave an update on the EOLC Population Board. The Board has now met 3 times. It is currently looking at the 7 outcomes identified in the PEOLC Strategy with a view to refining them to 4 outcomes for the Board with outcome measures to show to what extent they are being achieved.

Work is ongoing to identify what data is available to support the monitoring, there is a renewed interest in OACC measures. A logic model will be used to work backwards from the outcome to look at what actions will influence the measures. Planning will then take place to produce a work programme through the LPCN.

## 8. Risk Register/Systems Issue Log

**Risk Register** - This has reduced as 2 risks have recently been removed, the concerns around governance and the education capacity. The remaining risks concern capacity of members to engage with activities and are ongoing.

**Systems Issue 4** – Interoperability remains a challenge and work continues to escalate the issue wherever possible.

**System Issue 5 – Syringe Drivers System Issue** – The situation is gradually improving but the most recent challenge is the capacity of medical physics to check and approve new devices before they can be deployed. We are also purchasing 24 for Care Homes with Nursing.

**System Issue 7 – EPaCCS reports** – We have had Q3 report and the data is flowing slightly more quickly but does remain slow.

**System Issue 9 – Medication Blister packs** A regional group is looking at this as it is a national issue.

**System Issue 10 - Lack of Palliative Care Drugs available in Community Pharmacy Out of Hours** – This continues to have significant impact across the city. The issue seems to be access to the Warehouses to restock drugs over bank holidays and weekends.

## Finance report

The Q4 Finance Report was shared with the Group. Diane highlighted that in this financial year the LPCN has funded a number of small grants for projects which are now shown on the report.

Tom Daniels updated the Group about a short notice request to bid for funds to tackle health inequalities across the city. This was national money which was then sent to ICS level. All the Population Boards were asked to put forward schemes. The EOLC Population Board put forward 2 projects; a bid to make the funding for the homeless project recurrent and a scheme to undertake some targeted work to improve the capture of gender identity and sexual orientation which builds on national work '*If you're not counted, you don't count*'. The bids are under consideration but we are hopeful they will be successful. The outcome should be available in the next few weeks.

## 10. Programme Update

The Exec Team reviewed the programme at their last meeting and assessed the projects with regards to impact and effort in order to gain an overview of the whole programme and where focus or additional resources may be needed.

**1 LTHT ReSPECT Audit** – this is progressing now, the data has all been shared and is being analysed.

**2 Improving Planning Ahead (ReSPECT/EPaCCS), its use and reporting** – We are working with Public Health citywide to look at key messages around personalisation and care planning.

**3 Equality Diversity and Inclusion** – the group has agreed its ToR and is producing a Year 1 plan. An LPCN Equality Impact Assessment tool is also being developed to use with future LPCN projects.

**6. Bereaved Carer's Survey** – The Group is meeting again on 24<sup>th</sup> May and will have the first draft of the report from this year's survey.

**8. Respiratory /Breathlessness Pathway** – The LPCN have recently taken over administration of the Group and will be arranging a meeting shortly.

**10. Improving EOLC for people living with Dementia** – The Group is due to meet again on 25<sup>th</sup> May.

**12. Community Flows Improvement Group - Leeds Dying Well in the Community Project**– Phase 1 of the project is complete. We are now moving to phase 2. To finalise phase 1 the University will be sending out some questionnaires to those who participated in the workshops to capture any learning from the application of the whole systems approach process. A final report will then be produced for the LAHP who funded this part of the work. This will also be shared with the LPCN.

There are 3 main parts to the phase 2 work and the Programme document will be altered to give them their own sections. These are -

- Updating the service offer – ensuring that there is one clear service offer with staff working in an integrated way with the right skills, knowledge and confidence to support people dying in their own homes (including care homes).
- The need for a Citywide Single Point of Access for Palliative and End of Life care to support people who are dying and their families and carers but also as a hub for information for professionals.
- Maximising efficiency and increasing resources available to support death in the community.

**Education** – This section will be revised and updated by Leigh in her role as LPCN Clinical Practice Educator.

## 13. AOB

**Leeds Bereavement Forum** – Jane updated the group that their annual conference 'The Value of Death: bringing death back into life' is beginning tomorrow (19<sup>th</sup> May), it is sold out and over 100 people are attending. Jane agreed to come and speak about the work of Leeds Bereavement Forum at the next LPCN Group meeting on July 6<sup>th</sup>. – **Action 207**

**LTHT** are recruiting a second post to support their bereavement nurse. A band 7 ACP Nurse post has also been created.

**Carers Leeds** – Carers Week is 6<sup>th</sup> -12<sup>th</sup> June and there are a number of events happening. There are details on the Carers Leeds website <https://www.carersleeds.org.uk/>

## 14. Actions Agreed

206	The final version of the Leeds Adult SPC Access Criteria will be circulated with the notes of the meeting.	AS
207	Jane Robinson will give a presentation to the Group about the work of Leeds Bereavement Forum at the next meeting in July.	JR

## 14. Next Meeting

The next meeting is planned for Wednesday 6<sup>th</sup> July 10:00-11:30 via Zoom