Leeds Academic Health PARTNERSHIP

Leeds Palliative Care Network

LEEDS BECKETT UNIVERSITY

Leeds Dying Well in the Community Project
Report on End Phase 1 and Initiation of Phase 2 - Proposed Actions

Background

Leeds Palliative Care Network has been leading a project to improve Palliative and End of Life Care in the Community in Leeds.

The aim is: to improve the transfer of patients between all providers to ensure continuity of care and the quality of end of life care experience

The main focus of the work is community (out of hospital) services and how they interact with each other and hospitals to meet patients and their family's needs.

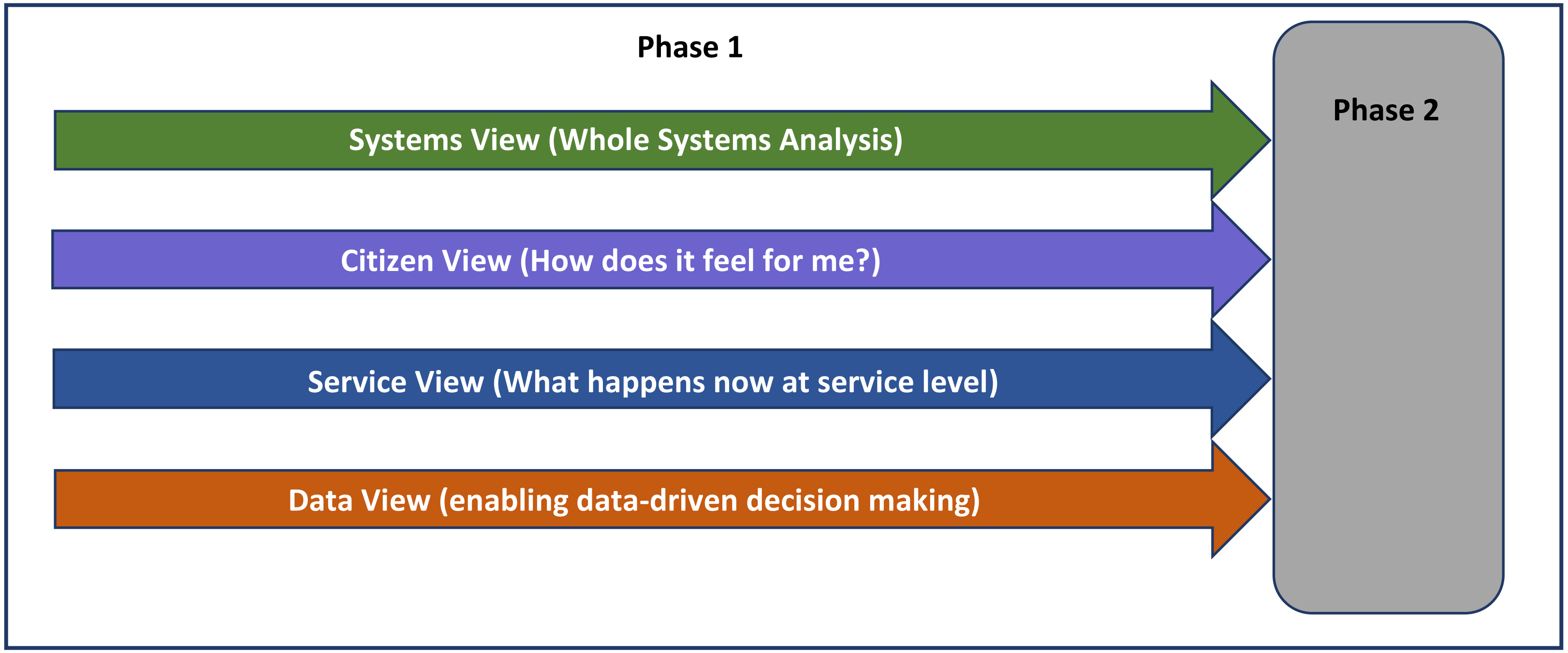
The work is split into two key phases:

- Phase 1 – is a process, using Whole Systems Approach, to scope out the services on offer across Leeds and look for areas of duplication and gaps. Within this, we aim to develop a clear, and agreed, understanding of the position of the service offer for people who are at the end of life across all services in Leeds including those in the third sector and where they interface with community services.
- Phase 2 - to ensure that there is effective service redesign to make the best use of the resources available to deliver the most effective and compassionate care outside of hospital for those people who are dying and for their carers and families.

Results of Phase 1

We have accumulated a large amount of data through the work undertaken in Phase 1 of the Leeds Dying Well in the Community Project. People, both staff and members of the public, have been generous with their time and with their ideas and thoughts. Although there has been a significant delay in timescales into project (because of the unprecedented pressures on the system due to the COVID-19 pandemic) we have still been able to complete all the information gathering planned, albeit virtually.

The work in Phase 1 was added to by two additional sources of information (in addition to the system view from the Whole Systems Approach work and the citizen view from the work that was commissioned from Healthwatch Leeds). These were a view from the system which was led by Leeds CCG and sued storytelling to seek to understand the real level of service delivery in Leeds and also a data view supporting this work. This means that the information we have has come from four key views. We have developed:



Phase 1

Systems View (Whole Systems Analysis)

Citizen View (How does it feel for me?)

Service View (What happens now at service level)

Data View (enabling data-driven decision making)

Phase 2

System view – a series of eight virtual events with professionals during November and December 2020, to which over 100 people from different organisations attended, including: acute and community health care, social care, care homes and voluntary and independent organisations. This used a Whole System Approach facilitated by Leeds Beckett University, commissioned by LAHP.

Citizen view – Healthwatch Leeds were commissioned to ask for the views of patients who have received end of life care and their families and carers. Thirty-one people responded to a survey about end of life care and fifteen in-depth interviews were undertaken about their experiences of receiving end of life and palliative care. The report developed from the questionnaires can be found here and the showreel from the case study interviews can be found here

The system and citizen view produced two maps which are a visual representation of what we found:

- Stakeholder map (can be found here) - shows the identified key stakeholders and services, with the detail of what is delivered by these services outlined underneath including those services providing support for patients who are approaching their end of life or offer support after a death has occurred entitled "additional services".
- Systems map (can be found here) - shows the many local factors that make up the systems related to palliative and end of life care in Leeds. Its purpose is to obtain a deeper appreciation and understanding of all the inter-related component parts involved, thus allowing a more informed foundation to determine possible places for action. The high-level systems map provides a simplified systems map, including only the key factors. The full map may need you to zoom into to be able to read.

Service view – led by NHS Leeds CCG this project focused on a conversation about the potential mismatch between the level and responsiveness of care that core providers of community P&EoL care are able to deliver in comparison to that which is described to people and system partners.

Data view – has looked at information that is already available on the number of deaths in Leeds, the impact of COVID-19, the percentage of people who die in their preferred place of death and other key markers available from EPaCCs data. We have also secured commitment to looking at the data in more detail to inform our decision making about work in Phase 2.

Summary of key outputs from Phase 1 work

Each phase of the work has detailed key themes (shown in Appendix 1). These are worded slightly differently depending on the view used but have many commonalties.

Work has been done to synergise these into an overarching understanding of information gathered that will inform the action plan. These can be summarised as

- **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). Though there will be a core offer this will be personalised to meet the needs of the person who is dying and also their family and carers. This will include support for carers and families in the lead up to death and when they are bereaved. This will also link to the support offered to professionals (of all types including domiciliary staff) to ensure that they have up to date and relevant knowledge. This will also ensure that all professionals are able to recognise the early stage of end of life and feel confident to hold the conversation about the wishes from the patient and their families and carers about care at the end of life (recognising that this may change over time as symptoms change).

- 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.
- Agreeing a clear process for **recording one up to date ACP** that is updated and kept as a single version – with the patient and family and carers holding the updated version so it is available to all professionals
- A clear need to reflect the increase in the number of people being cared for at the end of their life in the Community. This can only be achieved by maximising efficiency and **increasing resources available to support death in the community.**
- Ways to **improve timely prescribing** both in terms of identifying that anticipatory end of life medicines need to be made available to the patient and also in the process for ensuring that prescriptions are written and filled in a rapid manner.

The table below shows how these key themes reflect the findings from each of the different views. This is further described in Appendix 1.

Key area from themes	Systems and Citizen view	Service view	Data view
New service offer/model	Issues of capacity and adequate staffing Willingness to explore care at home Early recognition of deterioration Professional knowledge of who does what	Workforce - Knowledge, skills development Workforce - Staff capacity Equipment – Availability and timely delivery Incomplete documentation Coordinated planning and communication between services Services able/unable to respond Key worker Complexity pathway Sustainable programme of education	Service specifications, leaflets and web information does not reflect current levels of service delivery
Citywide Single Point of Access for Palliative and End of Life care	Sharing of information Willingness to explore care at home Early recognition of deterioration Patient and carer knowledge of who does what Professional knowledge of who does what	Workforce - Knowledge, skills development Workforce - Staff capacity Equipment – Availability and timely delivery Incomplete documentation Coordinated planning and communication between services Coordination and planning with family Services able/unable to respond Proactive, person centred advanced care planning	
Recording one, up to date ACP	Sharing of information Early recognition of deterioration Advance Care Planning	Workforce - Knowledge, skills development Workforce - Staff capacity Incomplete documentation	

	Patient and carer knowledge of who does what Professional knowledge of who does what	Coordination and planning with family Proactive, person centred advanced care planning	
Improve timely prescribing	Access to medicines Professional knowledge of who does what	Workforce - Knowledge, skills development Accurate and Timely Prescribing Incomplete documentation	
Increasing resources available to support death in the community	Issues of capacity and adequate staffing	Workforce - Knowledge, skills development Workforce - Staff capacity	a 59% increase in the number of EPaCCs patients dying at home (slides can be found here).
Develop shared language			

System partners recognise that there are ongoing issues of capacity, capability, adequate staffing and the subsequent impact on staff wellbeing. There is also potential for lack of other resources such as equipment, syringe drivers and medications.

From all the work there is a clear aspiration to create a Leeds service that has

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); personalised to meet the needs of the person who is dying and their family and carers

The action planning stage will be informed by the conclusions of the service view work: there is an owned priority to establish a 'service view', we know creating trust and psychological safety takes time, it is crucial to understand and address unwarranted variation and we need to ensure that there is data-led design. Going forward, this work needs to be underpinned by a range of support including OD support, project management, clinical leadership and increased and up to date data analysis. This would include understanding about what the data tell us about where we could start working for integration; including soft data from staff working in PCNs.

In appendix 1 we start to bring together the key themes that have been identified from each of the views taken and how they could lead to changes in the system

In appendix 2 we start to bring these together to create a series of potential actions for Phase 2 of the project.

Next steps

Action planning

In early 2022 we will hold a workshop with core team members to consider all the information gathered in Phase 1. This workshop will have 3 objectives:

1. Development of a detailed action plan
   - Informed by systems map to identify aligned actions
   - Use stakeholder map to identify relevant stakeholders
2. Develop a theory of change based on the action plan and an accompanying monitoring framework
3. Determine the structure of ongoing stakeholder engagement
   - Outline of action plan and monitoring framework to wider stakeholders
   - Ongoing engagement – stakeholders will need to frequently keep in touch and share intelligence about what is happening

Data analysis

Further work is needed to analyse the data and we recognise, that much of the analysis so far presented has included the COVID 19 pandemic. Moving forward we have to:

- Remove the peak period of deaths, those deemed to be special cause variation, between March 2020 and January 2021 could create the new "normal" picture of End of Life Care with which to use as the basis for planning
- Look at seasonal variation e.g. we know more people die in winter than in summer but we need to understand if our workforce plans reflect this?
- Achievement of preferred place of death may not be a marker of a "good death".
- Consider how we use this knowledge to forward plan with likely changes in the patterns of deaths from cancer, cardiovascular, stroke as a result of COVID

Within the analysis we need to ensure that we use data for the whole system; particularly taking into account those GP practices that use the EMIS system as well as those using Systm1.

Project evaluation

This will involve 4 key steps.

1. Analyse stakeholder feedback from workshop
2. In-depth interviews with LPCN members and key stakeholders
3. Focus groups with wider stakeholders
4. Wider stakeholder questionnaire

The results of the evaluation will be available in Spring 2022.

Appendix 1 Summary of the themes from each view of Phase 1

System and citizen view	From service view	Data view	Phase 1 break out rooms	Summary of key actions from phase 1 review
Issues of capacity and adequate staffing	Workforce - Staff capacity	A 59% increase in the number of EPaCCS patients dying at home The caseload of NTs increased by 21% between September 2019 and August 2021	Lack of resources Integration Complexity	Increasing resources available to support death in the community Describe Service offer/model Develop Shared language
Ability of neighbourhood team to respond	Services able/unable to respond	The caseload of NTs increased by 21% between September 2019 and August 2021	Understanding of Service Offer Integration Complexity	New Service Offer/model
Sharing of information	Incomplete documentation	Patients who died and were included on EPaCCS	Carer support Single point of access Access to information – Single Sharable ACP	Citywide Single Point of Access for Palliative and End of Life care Describe Service offer/model Develop Shared language
Early recognition of deterioration	Workforce - Knowledge, skills development	Duration of time (in weeks) the patients were on EPaCCS	Carer support Societal Change - Death and dying	Increasing resources available to support death in the community Describe Service offer/model Develop Shared language
Advance Care Planning	Proactive, person centred advance care planning	EPaCCS patients who have a ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Code recorded on the system	Carer support Access to information – Single Sharable ACP	Recording one, up to date ACP Develop Shared language

Patient and carer/family knowledge of who does what	Coordination and planning with family	Reasons for Unplanned hospital usage (Non-Elective Admissions) by EPaCCS Patients in the last 90 days of their life	Carer support Societal Change - Death and dying	Citywide Single Point of Access for Palliative and End of Life care Describe Service offer/model Develop Shared language
Professional knowledge of who does what	Coordinated planning and communication between services	Reasons for Unplanned hospital usage (Non-Elective Admissions) by EPaCCS Patients in the last 90 days of their life	Integration Understanding of Service Offer Societal Change - Death and dying	Increasing resources available to support death in the community New Service Offer/model Describe Service offer/model Develop Shared language
Access to medicines	Accurate and Timely Prescribing		Access to meds	Improve timely prescribing
Willingness to explore care at home		Percentage of Patients on EPaCCS who have achieved Preferred Place of Death	Complexity Societal Change - Death and dying Integration	Citywide Single Point of Access for Palliative and End of Life care Develop Shared language
	Equipment – Availability and timely delivery		Lack of resources	Citywide Single Point of Access for Palliative and End of Life care
	Staff wellbeing		Lack of resources Societal Change - Death and dying	Increasing resources available to support death in the community
	Different offers for different P&EoLC pathways	Ethnicity Breakdown of EPaCCS patients	Complexity	Develop Shared language New Service Offer / model
			Sustainable programme of education	Increasing resources available to support death in the community

Appendix 2 Initiation of Phase 2 - Proposed Actions (first draft)

Key area from themes	What would good look like?	What do we need to clarify?	Actions	To be taken on by project?	Timescale
Describe the current service offer	Clarity across the system of what the service offer is on the ground	What each service can actually deliver week by week What does the workforce look like? Especial focus on care homes	This maybe in one area	yes	S
Updating the service offer	Honest conversation about what is available. Key worker for each person at end of life Integrated workforce trial - agree to try in a geographical area – one with deprivation one without? Or look at areas of deprivation so that we start from the bottom up – our most unequal. simplifying	Should it be the DN? Or HCM Is it different for care homes	Analyse data for where we could focus Need to engage large number of staff groups GP engagement would be key	yes	L
Develop Shared language	People use words such as end of life, fast track and complexity to mean different things	Can we agree key definitions as professionals? How do we share this?	Have started to create a list where there are areas of confusion from the work carried out so far	yes	S
Citywide Single Point of Access for	For patients and carers as well as professionals Similar to Bradford's Gold line	Old spec found!	RG and DB to visit Gold Line	yes	L

Palliative and End of Life care			Work to identify funding needed		
Recording one, up to date ACP	Clear lead for ACP for each person and where it is stored Could we make it a handheld record – like a birth plan? Early recognition of death and dying It is tick list	What work is already going on	RG to speak with Sarah/Kulvant	Link to other current work	M
Improve timely prescribing	Too many steps in the process – chance that meds are not prescribed early enough or that tasks are missed. Also prescription repeats after death Patients knowing what to take	Is this issue already being looked at?		Link to other current work	
Increasing resources available to support death in the community	Need to start conversation with the commissioner	Are there any resources available or do we need to make the case or left shift?		Link to other current work	S/M/L

Author
Ruth Gordon
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