

## Building the 'Service View' to inform the re-design of Community Palliative and End of Life Care in Leeds

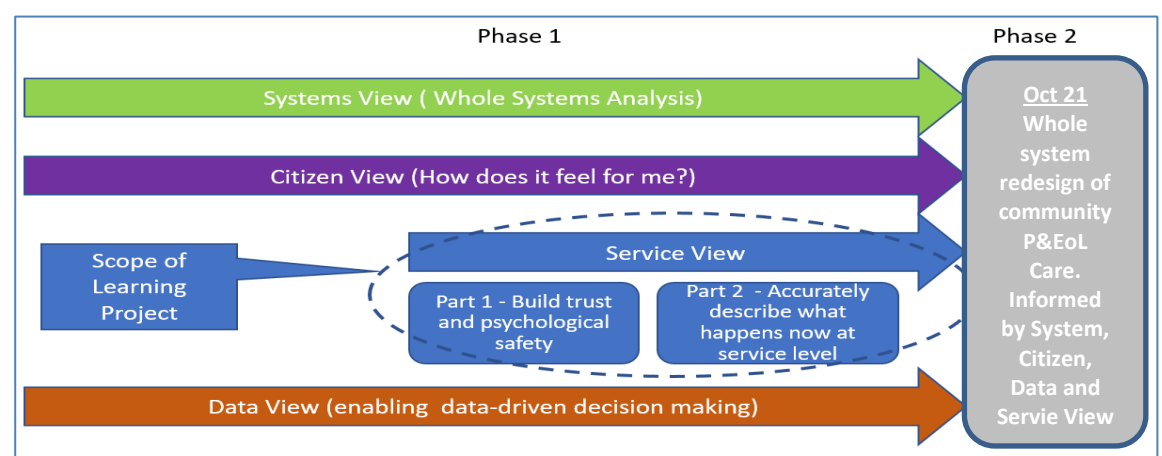
FINAL REPORT, November 2021.

### 1. Background

Chief Executives and those leading the development of the Leeds Place Based Partnership (PBP), have identified three existing priority work areas as 'PBP Development Projects' - Palliative and End of Life Care, Transitions from Children's to Adult Mental Health Services and Frailty. Working on the basis that 'real change happens in real work', the hypothesis is that by applying a learning lens to these projects, it will be possible to understand and identify 'real life local learning' about the behaviours, infrastructure, and ways of working that both enable and work against integration. The three projects were established in June 2021 with the intention that learning, and insight generated through the projects drives the establishment and development of the Leeds PBP.

The primary focus of the Palliative and End of Life care (P&EoLC) Development Project was to work with core service partners seek to build a '**Service View**' of the current level and responsiveness of care being delivered by core community providers of Palliative and End of Life Care (P&EoLC) in Leeds.

The '**service view**' focus of the development project was identified in response to **insight** from members of the Leeds Palliative Care Network (LPCN) relating to a 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. Unwarranted variation has been magnified through the pandemic with some services reporting a 46% increase in demand.



This Service View, triangulated alongside the Citizen View, System View and Data View provide a key foundation for the Phase 2 redesign process, launched by the LPCN in October 2021. See figure above.

The project aimed to develop an understanding of what each service is able to deliver with current resources (this may be different to what is officially described and documented on websites or in specifications) creating the opportunity to surface and share the difference between rhetoric and reality in terms of service delivery and identify where we have unwarranted variation. This accurate understanding really is important to:

- enable the redesign of care (commencing at the LPCN workshop in October 21) to be built from a position of reality and to enable informed decision making regarding how we use our collective resources differently to deliver the best possible outcomes for people at the end of life in Leeds and reduce unwarranted variation.
- enable professionals to provide people, and their families and carers, with an accurate understanding of the level and responsiveness of care they can expect to receive in the community.
- enable people and their carers to make better informed decisions about P&EoLC planning.

### 2. Project Design

The project ran between June and October 2021 and involved stakeholders involved in the provision of P&EoL care from Leeds Community Healthcare NHS Trust, Specialist Providers (St Gemma's and Wheatfields Hospices), Leeds Teaching Hospitals Trust, Continuing Care, General Practice, Community Pharmacy and the Leeds Palliative care Network. The project was supported by a blended matrix team with expertise in project management, improvement, organisational development, analytics from NHS Leeds CCG, the LPCN and the Leeds Health and Care Academy. Dr Mike Stockton and Diane Boyne, on behalf of the LPCN, were the overall clinical and managerial sponsors for the project.

The project was structured around three stakeholder workshops to support stakeholders in the identification, capture and review of service level stories (from the perspective of those delivering care), that identified excellence in care delivery and also examples of care that was 'not as we would have hoped for'. The project acknowledged the challenges and discomfort of sharing stories reflecting care that was 'not as we would have hoped for' and that this honesty about our current realities of service delivery was the crucial starting point in using our (limited) available resources to redesign care that improves outcomes. The diagram below provides an overview of the project design.

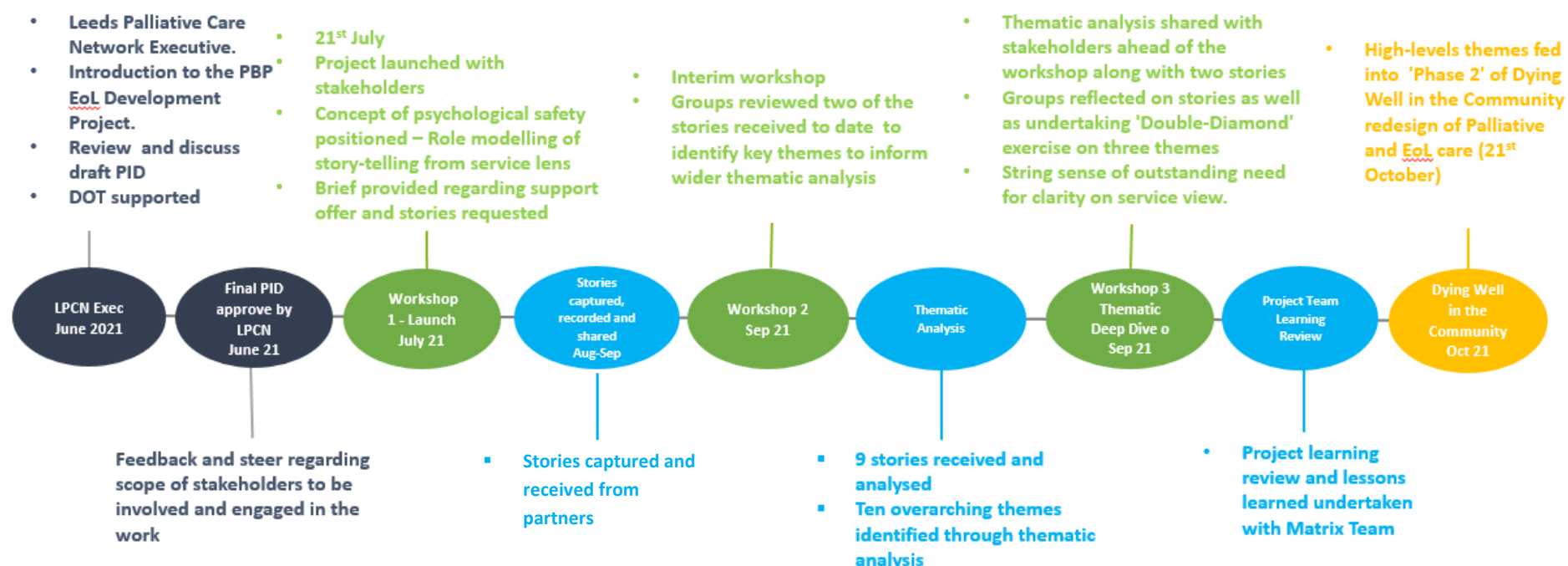


Figure 2 – Project Design Overview

The project was launched at a workshop on the 20<sup>th</sup> of July 21 involving senior managers of organisations and services delivering core community Palliative and End of Life services in Leeds.

At the workshop, representatives from each organisation were asked to work with front line staff to develop two stories

- One that demonstrates **what parts of the service work for the user (magic moments)**
- One that demonstrates **what parts highlight outcomes that could be improved or mean that there is unwarranted variation for whatever reason** (trouble spots/ frustration points)

It was acknowledged that whilst stories may involve inter-dependencies with other teams/organisations, it was not our intention to apportion blame or comment on how other partners have helped or hindered the care in our stories. The aim was to elicit key learning points for each organisation's **own** service/s that identify areas of excellence as well as areas of poorer outcomes or unwarranted variation and the reasons for this. The intention was that this would allow us to understand where the key gaps are between what services say they can deliver and the reality for people. Ultimately the goal is to use our available resources to improve end of life care outcomes for people in the community.

A key line of enquiry within the project was to understand unwarranted **variation in care**, especially when it can impact negatively. We were particularly keen to look at the difference in described care and actual care. Is our service offer the same at 2 pm on a Tuesday afternoon compared with 2am on a Sunday morning? Do we deliver the same standard of care to different communities across the city? We know that it is unlikely to be the same but which parts of that variation are warranted?

The project recognised the importance of **psychological safety** in enabling service providers to openly share where there are gaps in services that result in unwarranted variation in the delivery of care. At the launch event, an anonymous poll was used to explore levels of openness and trust between partners participating in the project

- 100% of participants agreed or strongly agreed that they felt confident to bring up difficult issue at **organisational level**
- 19% of participants disagreed or strongly disagreed said they are able to bring up problems and difficult issues at **system level**
- 50% of participants agreed or strongly agreed that challenging someone from another organisation would damage their working relationship
- 19% of participants agreed or strongly agreed that it was difficult to ask other organisations in the system for help

The visuals below demonstrates the key barriers, identified by participants, to open and honest conversations, as well as the factors identified as enablers to greater honest between partners. These themes will feed into both Phase 2 of the Leeds *Dying Well in the Community* project as well as the design of the next phase of the systems leadership programme being developed by the Academy.

## Barriers to open/honest conversation

## Enablers for open/honest conversation



Each organisation was offered facilitation support in the capture of the stories and in addition an offer of coaching was made to individuals participating in the project as well as for Executives within the organisations participating in the project.

### 3. Stories Received

Despite Covid-related system pressures and August holidays, the majority of organisations invited managed to capture and share stories by September. Although this was slightly later than planned a delay to the overarching *Dying Well in the Community Project* launch meant that the learning and insight from this project is able to inform the re-design work as planned.

Stories were shared from the following organisations:

- Leeds Community Healthcare NHS Trust
- Leeds Teaching Hospitals Trust
- Specialist Palliative Care Providers – Wheatfields Hospice and St Gemma's Hospices
- General Practice
- Community Pharmacy (via Community Pharmacy West Yorkshire)

Unfortunately, due to acute system pressures, Care Homes or Home Care providers were unable to capture and share stories.

### 4. Themes and reflections identified through the stories

The thematic review of the stories received commenced at the 6<sup>th</sup> September stakeholder workshop. At this workshop, stakeholders reviewed one of the stories submitted and identified key themes as follows:

- Continuity of Care
- Workforce Pressures
- Interfaces between services
- Staff Wellbeing

An overarching reflection from stakeholders was that the story shared reflected cross-cutting issues and themes relating to multiple providers as opposed to the organisation and service 'telling the story'. Indeed, although the stories that were reviewed at this workshop were from LCH and Wheatfields, it was felt that these were as much 'Leeds Stories and Leeds Patients' as LCH or Wheatfields stories.

Following the 6<sup>th</sup> September workshop, a thematic review of all the stories submitted was undertaken by the project team. The stories submitted predominantly identify and highlight areas of excellence and challenge relating to a *range of community Palliative and End of Life services*, beyond the scope of the organisations 'telling the story'. As such, the thematic analysis predominantly focussed on cross-cutting themes identified across different stories as opposed to focusing on insight about care provided by individual providers. The reflections and feedback from the 6<sup>th</sup> of September workshop have been incorporated into the themes summarised below.

A summary of the cross-cutting themes identified within the stories shared is provided below.

Themes	Story examples (Including Good and Could be better)
1. Workforce - Knowledge, skills development	The development, training and skills development of staff was identified as an issue in a number of stories. Examples include: the impact of a palliative care vacancy in the ability to support and develop more junior members of neighbourhood teams (NTs). Similarly, knowledge and understanding of palliative care across staff working in residential homes was also identified as a challenge. It was noted that assumptions are frequently made about the skills and competencies of staff in different organisations.

	<p>Insight from Community Pharmacy identified the need for staff training to flag and prioritise prescriptions for patients at the EoL and to establish systems to ensure families are not contacted regarding ordering further prescriptions after death.</p> <p>Although knowledge and skills of staff were not <u>explicitly</u> described as a contributory factor in delivering excellent care, this was implicit in the features of these positive examples in relation to effective communication between services, with people and their families, in the timely and frequent updating of advance care plans and ReSPECT forms.</p>
<p>2. Workforce - Staff capacity</p>	<p>A number of stories explicitly highlighted workforce capacity and shortages as a salient contributory factor in the inability to deliver excellent palliative and end of life care. Stories described the impact of staff shortages as affecting :</p> <ul style="list-style-type: none"> <li>• the continuity of care that could be delivered for people (as staff were required to provide cover for those unable to work),</li> <li>• the (negative) impact of having to undertake aspects of assessments remotely</li> <li>• the ability to always deliver care packages at the required levels e.g. unable to always offer care packages with the required number of daily Neighbourhood Team visits</li> </ul> <p>It could also be inferred that staff shortages may be a contributory factor to other issues identified such as tasks not being actioned in a timely way, incomplete/unclear documentation.</p> <p>Workforce shortages and capacity were not identified explicitly in any of the stories that described excellence in care. Indeed a central aspect of these stories was the time taken by staff to communicate and work closely with families and other teams (sometimes through an MDT approach). These stories frequently identified examples of staff going 'over and above' such as the Community Pharmacists who, due to the length of time taken to co-ordinate, secure and prepare a complex prescription for a child at the end of life delivered the prescription in person to a family in the evening, long after the pharmacy had closed.</p>
<p>3. Equipment – Availability and timely delivery</p>	<p>The timely delivery of equipment was identified as an important contributory factor in poor patient experience. Examples include a 4 day wait for the delivery of a profiling bed to a man being cared for at home and significant delays in obtaining a commode – both of which had significant impact on the deterioration of the person's pain, symptoms and quality of life in their final days.</p> <p>Conversely another story highlighted the ability of services (NT, Equipment Service, OT) to work together to secure appropriate equipment (profiling bed, sensors and crash mats) for a patient (and to move the equipment from bedroom to living room as his needs changed) was identified as an element of care that had gone particularly well for a patient being cared for at home.</p>
<p>4. Accurate and Timely Prescribing</p>	<p>Prescribing and securing medication for people with palliative and End of Life care needs in the community was identified as one of the most crucial factors across stories reviewed. Key issues identified are as follows:</p> <ul style="list-style-type: none"> <li>• Accuracy of prescriptions: A number of stories identified prescription errors (requiring Community Pharmacists to find and contact the prescribing Dr for the prescription to be re-issued) as an issue, resulting in delays in issuing medication in a timely way for people.</li> <li>• Anticipatory Medication: Anticipatory medication not being prescribed at the point of hospital discharge and exacerbated when medication is required over the weekend (resulting in long delays in securing medication via OOHs GP).</li> <li>• Medicines Supply – The medicines supply system is imperfect. Although pharmacies receive two deliveries per day and are able to get any medicine within 12-24h, deliveries can be delayed, be out of stock at the wholesaler and/or be subject to national shortages. Delivery of medication is not an NHS service and pharmacies that choose to deliver medication do so on a 'goodwill' basis. Community Pharmacy identified a number of examples of how networks of pharmacies are working to address these challenges such as prescribing half quantities of medicines that are in short supply to ensure stock for more patients, collaboration between pharmacies to supply prescriptions of medicines that are in short supply.</li> </ul> <p>Stories identified how delays in prescribing resulted in pain, poor symptom control and the risk of people dying in pain in addition to stress and anxiety for carers.</p> <p>Insight from Community Pharmacy stresses that medication requirements should be anticipatory wherever possible, allowing pharmacies time to source medication wherever possible</p>
<p>5. Incomplete documentation</p>	<p>Incomplete documentation can be seen as a contributory factor in stories that identify where care was not as we had hoped for. Examples include:</p> <ul style="list-style-type: none"> <li>• The generation and regular updating of ReSPECT forms preventing unwanted hospital admissions</li> <li>• ReSPECT form updated throughout the patients journey to reflect their changing care needs</li> <li>• Incomplete hand-over information between teams</li> <li>• Incomplete prescriptions</li> </ul>

	<ul style="list-style-type: none"> <li>Insufficient information in records including: it being unclear from notes if a medical review had previously been undertaken; informal discussion with consultant not documented and information about previous assessment being incompletely documented</li> </ul> <p>Clear and up-to date documentation can be seen as a key element in stories identifying excellence in care.</p>
<p>6. Coordinated planning and communication between services</p>	<p>Perhaps the strongest theme emerging across all stories is the impact of effective (and ineffective or absent) coordination between professionals, services and families.</p> <p>The absence of this coordination and communications was equally a significant contributory factor in the stories about care where we had 'hoped for better'. Insights from stories include:</p> <ul style="list-style-type: none"> <li>Case - Management – more complex patients are perhaps managed better than less complex ones?</li> <li>Consistency of case management - frequently a lot of people seeing a patient (including those residing in care homes) – unclear where responsibility and ownership lies for leading the coordination of care</li> <li>Many agencies were involved with this care, no one was leading to oversee what was happening, allowing crisis point to be reached</li> <li>Communication between hospice and Community Matron unclear</li> <li>Communication from hospice to NT not clear</li> <li>Nursing staff dependent of feedback from care home carers on the effectiveness of treatment</li> </ul> <p>Most problems seem to happen around the interface issues</p> <p>Effective and proactive communication and coordination between services was highlighted across a number of stories:</p> <ul style="list-style-type: none"> <li>Coordination and review of expert medical care and treatment plan and liaison with GP and NT</li> <li>Services working well together to provide support and equipment in a timely way</li> <li>Complex multi-professional care provided by hospice and other community services for complex advance care planning and escalation of care issues</li> <li>Hospice provided continuous point of contact, advice and reassurance</li> <li>Review of patient following 999 calls by GP Practice and management in his home provided good symptom control</li> </ul>
<p>7. Coordination and planning with family</p>	<p>The absence of coordination and planning with families was a feature of some of the stories demonstrating care where we had hoped for better:</p> <ul style="list-style-type: none"> <li>No communication back to family by hospice as assumed this would be done by NT</li> <li>Carer anxious and panicky, struggling with care and no sleep but unable to secure care package</li> </ul> <p>Stories describing excellence described:</p> <ul style="list-style-type: none"> <li>Decisions made with the involvement of the family</li> <li>All of this resulted in the patient being cared for in his chosen place, family were fully involved and thanked practice for the care their father received</li> <li>Care for patients and family</li> </ul>
<p>8. Services able/unable to respond</p>	<p>The inability of service to be able to provide the expected level of responsiveness of care was highlighted in a number of stories. Examples include:</p> <ul style="list-style-type: none"> <li>Referrals to hospice but no beds available</li> <li>NT unable to provide package of care at the level required by the patient and carer</li> <li>Carer said that she didn't realise how hard it would be to care for her husband or how long it would take to get a package of care</li> </ul> <p>Inherent within the stories of excellence was the availability of a range of services able to support person in different community settings (home/ hospice)</p> <ul style="list-style-type: none"> <li>Patient deteriorated and was admitted to our palliative care ward</li> <li>Service was responsive and flexible</li> <li>Patient was fast-tracked at appropriate time</li> </ul>
<p>9. Proactive, person centred advanced care planning</p>	<p>Almost all of the stories described the existence of an advance care plan that had been developed.</p> <p>One story showed how the existence of a ReSPECT form didn't avoid an unwanted admission:</p> <ul style="list-style-type: none"> <li>Admission to hospital at odds with wishes described within ReSPECT form</li> </ul> <p>The existence of a ReSPECT had enabled an unwanted admission</p> <ul style="list-style-type: none"> <li>ReSPECT form updated continuously to document and reflect changing needs</li> <li>Ability to work with patient's agenda and at her pace within a very uncertain picture</li> </ul>

	<ul style="list-style-type: none"> <li>• Proactive care coordination and offer of end of life planning, proactive reviews by NT but patient and carer refused</li> <li>• Following numerous admissions, advance care planning was arranged with the family</li> <li>• ReSPECT form generated and regularly updated and prevented unwanted hospital admissions</li> </ul>
10. Staff Wellbeing	<p>The theme of staff wellbeing was not identified as an explicit theme within the stories shared. However, the review of stories at the workshop of the 6<sup>th</sup> of September reflected that this should be identified as a key 'hidden' theme that sits behind the stories of care; we had hoped for more.</p> <ul style="list-style-type: none"> <li>• We need to record the impact that these stories have on staff – it's common for them to leave the day feeling sad with themselves that they couldn't do more – these feelings don't come through strongly enough in the story(ies)</li> <li>• Staff feeling overstretched and unsatisfied is commonplace</li> <li>• Teams not feeling satisfied – impacting on staff health and wellbeing</li> </ul>

A final workshop took place on 5<sup>th</sup> October, where we utilised the 'double diamond' method and the '5 whys' analysis model to deep-dive into three of the ten themes identified as part of the thematic analysis. The scope was to identify the root cause and to define the problem with the understanding that the solutions-seeking stage would be progressed as part of the 'Phase 2 Re-design work. Two of the stories, as well as a description of the ten themes were shared with participants ahead of the workshop.

Attendees were split into three small breakout discussion rooms. Before undertaking a deep-dive into one of three themes, participants were given time to reflect on the two stories in their entirety. The three themes explored in the breakout groups are as follows:

- Services Able/Unable to Respond
- Coordinated planning and communication between services
- Workforce Capacity

There was an overarching theme spanning across all these areas about the importance of relationships and how establishing trusted relationships from the outset is key to all that follows and ultimately can make a huge difference to patients and their families, both in terms of outcomes and patient/family experiences. Strong communication links and coordination between all community staff including independent agency staff is also pivotal to good patient care.

There was also a strong emphasis around patient/family expectations and knowing the reality of the service offer /care delivery and recognition that other services do not always present an accurate reflection of the offer in community. Examples shared highlighted that there can sometimes be a disconnect between what GPs and LTHT Oncologists tell families they can expect from the hospice community teams and neighbourhood teams and the reality of what these teams can provide.

It was also identified that in some cases the service offer is not clearly coordinated in any one place or clearly by specific roles. It was discussed that there should be two key care coordination roles in place:-

- Health Care Manager (HCM) – to co-design the total package of care
- Case load holder - previously DN to oversee clinical care plan

There was recognition that the system would benefit from an increase in workforce capacity, both in terms of different roles, able to respond to changing needs of this patient group and to be able to respond to the more intense needs of this group as people come towards last few days of life. To respond to inequalities, it was acknowledged that the way in which we deploy and design our workforce needs to respond to differential needs across the city at LCP level.

As part of the session, a piece of data analysis relating to predictability and variation in demand for P&EoL care provided by LCH was presented. The data that highlighted the increase, predictability and geographical variation in the number of people dying at home in Leeds.

- Comparing pre COVID April 2019 to post peak COVID April 2021 to August 2021 there has been a 59% increase in the number of EPaCCS patients dying at home.
- The caseload of Neighbourhood Teams, since 1st September 2019 until 1st August 2021 has increased by 21%
- There is also significant variation in the number of patients on EPaCCs across each Neighbourhood Team. Meanwood, Seacroft and Middleton are the largest Neighbourhood Teams in terms of caseload. Beeston, Wetherby and Hold Park are the smallest Neighbourhood Teams in terms of caseload

The data highlights the importance of understanding existing demand and variation as a starting point in choosing how we may use our existing resources differently as part of the phase 2 redesign.

A full overview of the group's breakout room discussions can be found in Appendix 1.

## **5. 'Take Home' learning and reflections for redesign and wider development of the Leeds Health and Care Partnership (Place Based Partnership)**

The project set out to test the **hypothesis** that by developing psychological safety and the conditions for honesty and truth, we will establish an accurate and common understanding of the level and responsiveness of community P&EoLC currently offered to people in Leeds. This 'service view' will

- enable people and their carers to make better informed decisions about P&EoLC planning (and in particular place of death).
- enable professionals to provide people and their carers with an accurate understanding of the level and responsiveness of care they can expect to receive in the community.
- enable the redesign of care (commencing at the LPCN workshop in October) to be built from a position of reality and to enable informed decision making regarding how we use our collective resources differently to deliver the best possible outcomes for people at the end of life in Leeds.

The service-view themes identified through the stories identify a range of salient issues inherent to excellent examples of service delivery and to enable people to "die well in the community". The key take home messages to take forward through the Dying Well in the Community Redesign can be seen as follows:

### **5.1 An owned priority to establish a service view**

- An accurate and honest understanding about what services can and can't deliver it essential underpins how we choose to use or resources to redesign care
- Professionals need the support required to be 'informed and brave' to honestly convey the range and level of services that people are likely to receive
- This is fundamental in the immediate delivery of care and also in long term redesign
- Through the project, partners have acknowledged the importance of this overview – its important that the next phase of the project creates the conditions and method to collect and share this overview of current service delivery

### **5.2 Ten key themes to address in future redesign**

- Future redesign should respond and incorporate the ten themes and reflections identified through the thematic analysis of the stories and in particular the deeper insight gathered through the three 'deeper dives' on workforce, coordinated care and accurate understanding of service levels.

### **5.3 Creating trust and psychological safety takes time**

- The project acknowledged the importance of trust and psychological safety in creating the conditions to enable people to share difficult stories highlighting where services were and weren't able to deliver levels of care that we hope for. Anecdotal feedback has been received about the fact that greater awareness of psychological safety has implicitly supported more open and conversations between partners.
- It is recognised that the necessity to progress this project at pace provided less time to position and explain the project and its objectives within individual organisations and supporting the psychological safety required to share difficult stories. A reflection is that this may have resulted in a number of the stories highlighting challenges and shortfalls with 'other' services (as opposed to being primarily focussed on the service telling the story).
- Although coaching and facilitation support was offered as part of the project, those participating in the identification and collection of the stories did not choose to take-up these offers.
- A key recommendation is that sufficient time and Organisational Development (OD) support is provided to the teams involved in the Phase 2 re-design to support the trust and openness required to understand the 'warts and all' as-is position across the services and organisations participating in the re-design. This may include positioning and describing the benefits of coaching and facilitation support to those participating in the project in more detail, from the outset.

### **5.4 Understanding and addressing variation**

- The most explicit variation identified through the thematic analysis is that of the care received by people whose diagnosis means they have a clear end of life pathway (such as a cancer) and those patients with a less defined range of palliative and EoL needs. As a city, we invest resources in a way that enables us to deliver 'gold-standard' care for a defined group of patients at the EoL, some of who have a 'fast track' status that enables expedient decision making and delivery of care. The city's success in delivering this standard of care to a cohort of patients inevitably creates variation in the standard and responsiveness of care that other cohorts of patients with palliative and EoL care needs receive. A recommendation from the project is that the Phase 2 redesign work explores the possibility of focussing this work on the cohort of patients with Palliative and EoL needs with a less defined pathway.

### **5.5 Ensuring Data-led design**

- Much of the analysis undertaken and presented includes the COVID 19 pandemic, however, removal of 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 P&EoL care with which to use as the basis for planning.
- Once we have a normal position we can look at how seasonal variation affects the pattern, we know more people die in winter than in summer. Do our workforce plans reflect this?
- Achievement of preferred place of death may be relevant to this project but may not be a marker of a "good death".
- How do we use this knowledge to forward plan with likely changes in the patterns of deaths from cancer, cardio vascular, stroke as a result of COVID?

The following themes and learning from the project will be taken forward into the wider development of the broader Leeds Health and Care Partnership arrangements.

### **5.6 Matrix working can deliver innovation at pace by drawing on expertise**

The design and implementation of the project through a matrix teams has generated valuable learning about the leadership and functioning of matrix teams. Key learning includes:

- The importance of explicitly defining the individual roles and responsibilities (in both the design and implementation stages) of people within matrix teams.
- There needs to be a specific understanding around roles and responsibilities in identifying and analysing the most appropriate data to support improvement. This includes the contribution and involvement of Business Intelligence and data/intelligence experts to be able to present the data in such a way to understand the variation across the city and through a health equity lens.
- The importance of experienced clinical leadership to steer the project within the broader context and politics in which the project is operating.
- The opportunity to test and refine the contribution and expectations of project management and Quality Improvement support provided through the CCG's Programme Improvement and Integration (PII) and Quality Business Units.
- Recognising the invaluable contribution of Organisational Development expertise (within the matrix team) from the city's Health and Care Leadership Academy. Key learning has been generated regarding defining roles and responsibilities through the project and at the design stage
- The expertise and time taken to develop and refine the PIDs was an important success factor in establishing the projects and that *"this works well when you have an experienced lead to drive this...in this current time I doubt people would have time, drive and ability to do this without significant support"*

### **5.6 Enabling and supporting meaningful engagement from non-statutory, networked providers (Care Homes and Home Care)**

An area of learning and challenge across all three PBP Learning projects has been the ability to establish representative engagement with non-statutory partners operating through networks. Since the establishment of the project, arrangements for ensuring meaningful and representative engagement from General Practice within partnerships groups and projects have become clearer. There is an emerging approach (through the PCN Clinical Director forum) for how GP representatives on Population Boards (and in other partnership forums will engage and secure the support of the network of GP across the city.

Progress has also been made in relation to how the third sector are represented and recognised as voting members on Population Boards. Positive feedback has been received in relation to the way the third sector has been a key partner and collaborator in the development of collaborative Business Case for the SDF monies in the way in which the network of third sector partners are engaged within the Transitions project.

This project has highlighted a disparity in existing arrangements and infrastructure to engage with networks of home care and care home providers. The insight from this projects identifies these providers as being central to the delivery of improved outcomes for people at the end of life.

## **6. Next Steps**

Final drafts of the stakeholder map, the system map, the service view from the PBP work, and the report by Healthwatch Leeds from surveys completed by family and carers were presented at the launch of the Phase 2 re-design work on 21st of October. Breakout rooms were held to confirm these findings and consider the options that had been developed for the service design work of phase 2.

The workshop on the 21st October launched Phase 2 of the Leeds Dying Well In the Community has used the feedback from this service view along with the citizen and system view to develop some key areas for work. As well as the 10 themes the importance of building the OD and data support has been fed into this group and is being considered as the action plan is being developed.

The EoL PBP development project work has been completed and a final report is being finalised to share with the LPCN executive in December. A report summarising learning from all three PBP Development projects will be presented to the shadow Leeds PBP Board in early December and will also be shared with the LPCN executive.

Insight and learning from the project is being used to actively shape a range of development opportunities (being led by the Academy) for people supporting improvement within the Leeds PBP. This includes modules within the System Leadership programme on supporting psychological safety and trust as well as a practical toolkit on building, working within and leading effective matrix teams.



#### Learning and Reflections on Stories

##### Group 1:- Theme discussed –Services Able/Unable to Respond

##### Reflections on Stories

- Establishing a trusted relationship from the outset is really important. The lack of an existing, trusted relationship means it can be difficult to react and respond to packages of care where people's preferences and decisions change.
- Opportunities for us to have different and better conversations in a way that deconstructs terms like ‘hospice’ in a way that ensures people are less likely to dismiss any support e.g. hospices can offer a wider variety of respite support, its not just where you go to die.
- Going full circle – how do we enable our communities to support conversations and care about EoL? And also tap into the army of volunteers who came forward in early Covid?
- The ‘not as hoped’ story seemed to go wrong from the beginning – who was co-ordinating? There is no care-leader and it can change through the EoL journey

##### Communication and Understanding of Services (across systems/services & with patients)

- Its important that people understand what services are available and how they are able to access these , as their needs change, in a really timely way . Its also important to ensure we leave the door open for proactive check-ins ( it often becomes harder to add services as the person becomes closer to EoL). Explaining what each level of care actually is, dispelling “myths” about what hospice care is.
- We need to be able to describe as a system – What The Offer Is – including implications on level of care offer if a person is fast tracked vs if a person isn't t fast tracked – professionals having an accurate understanding of what care can be delivered, is essential to enable professionals to have honest and brave conversations with people
- We need to be clear about each others’ roles – and aware of what we all offer as a system
- We have to be honest about what can and cant be delivered ( especially for patients who are not on Fast Track) – its important that hospital colleagues have a really accurate understanding of the levels and responsiveness of community care so as not to inadvertently raise expectations about levels of care available for non fast-tracked patients. All parties need to remain engaged with the RESPECT form throughout.

##### System & Workforce

- Need to recognise the contribution of the private sector - and view them as an equal partner – they have been central to our delivery of care during COVID
- There is often an inequality in the range of services provided depending on how severe people are and how their care is funded.
- We need to a package of training and support at three levels – universal/ specialist/targeted
- Need capacity in NTs to keep checking in on people and understanding if and how needs and wishes have changed
- Care homes are seeing more complex patients and with increasing demand - Need to enable care homes to have access to patient records – This may be already possible through Helm.
- A recognition that the cost of EoL care at home is becoming more complex and more costly

#### Learning and Reflections on stories

##### Group 2:- Theme discussed - Coordinated planning and communication between services

##### Reflections on the stories

The stories rang true to people and showed how there could be significant variation even within one geographical area of the city.

##### Service offer reality

- We know that families often try to cope and our services are so stretched that we are often unable to provide the amount of care someone approaching the last days of life will need and so we let them cope. We need to be talking to people to provide what we can in that moment for them. When the family declines an offer of help or service staff should think about other ways to present the offer, why it would help them and also tell them what to do if symptoms deteriorate. We need to be talking to patients and families and sharing a realistic picture of the care possible to deliver. Mainly regarding the speed of being able to respond to symptom control calls if symptoms deteriorate.
- Recognition that this was an issue even before COVID.
- Recognition that other services do not always present an accurate reflection of the offer in community e.g. Macmillan nurses are often referred to. We know that this role has a certain expectation of delivery associated with them in the public's eye (TV advertising etc.). The title has a strong currency.
- We know that neighbourhood teams describe the community and inpatient service in hospices well but there are challenges in the expectations of care delivery compared to what GPs and LHT Oncologists, in particular, tell families they can expect from the hospice community team. Often on calling up to arrange a visit the families will say “but we have a Macmillan nurse coming in” – without an understanding of the community offer (we noted the lack of clarity and understanding of the roles of the different teams working within the community) or that the Hospice nurse is ‘the Macmillan nurse. We also discussed how sometimes it is about what families hear and want to hear. During times of high emotion and stress it is hard to take everything in.

## Group 2:- Theme discussed - Coordinated planning and communication between services

### Changing service offer

We know that services move quickly and changes can be made which means it is hard for all other services to keep up with the current offer. We also know that for the charities the funding raised by gifts associated with the loss of a person can be significant ;so it is important to understand which agencies are involved. We also know that not all professionals are comfortable talking about moving on to palliation. This can be particularly true in the acute trust who are focused on curing people. Staff can feel helpless.

### Care coordination

The service offer is not clearly coordinated in any one place or by clearly by specific roles. There are two key care coordination roles:

HCM – to design the total package of care

Case load holder - previously DN to oversee clinical care plan

(LCH are working to increase numbers of DN's)-

There is also a question about how changes in symptoms or family resilience are fed back – and this may depend on the GP practice. People feel that they should feedback to the DN. The aim is to have a single plan overseen by LCH – there should be a pink folder left in the homes. It is unclear how often or how well this is used between all community staff including independent agency staff LCH is also planning to have a case manager for of end of life care – but we know things are not yet where they should be; and it will take some time. LCH would also like to have increasing input as people come towards last few days of life but capacity during the day does not allow for this.

## Group 2:- Theme discussed - Coordinated planning and communication between services

### Domiciliary providers

- We know that the independent domiciliary care providers contribute significantly to the actual packages of care provided to people in their own homes.
- The issue of who to feedback applies to this group of staff as well. Recognise that they have no sight of S1 or any shared electronic patient record. This is down to IG related issues and we know that there are lots of providers (180?). Do LCH and hospice staff communicate changes to domiciliary care providers and vice versa? Do the domiciliary care staff have the skills to recognise changes early and know when to ask for help? How do they ask for help?
- We also know this can be a challenge for YAS and the equipment service too.

### Family resilience

- The different abilities of families to manage their loved one at home was also reflected in the stories. Family members can feel that they are failing their loved one if they are not able to cope with caring for them at home right until the end. It can place high expectations on staff.
- Impact of cultural norms and health inequalities
- The challenge of families able to cope as the situation deteriorates can be exacerbated by cultural norms whether that be religious or due to views about traditional caring roles of wives for example.
- Elaine talked about her work in Bradford where she was able to have an effective response to religious needs within an inpatient setting.
- Other health inequalities were discussed including the idea that those patients who had many complex comorbidities but were not following a particular, clearly defined pathway, such as cancer, may receive poorer access to palliative care services and often less clarity about who is the case manager and input may be provided later in the palliative care needs journey.

### Initial hypothesis

- There is clearly a need to revisit the initial hypothesis of what the service offer is and a recognition that in the different areas of Leeds this may change from week to week or even day to day.
- Do we require a service offer describing both city wide and by place based areas?
- In terms of gathering this for the work going forward there was a commitment to ensuring that if two geographical areas were taken for the next step of the Dying Well in Leeds project that we need to ensure that we have fully accurate picture of the service offer at the time of the change and during the pilot phase. This will need to include staff vacancies including sickness, maternity as well as demand on the system (numbers of people at end of life and complexity of the cases).

### Ideas

- ❖ to create a leaflet on the website with a description of the services
- ❖ the patient leaflet needs updating
- ❖ Maybe creating a flowchart about community flow as part of this winter's work

## Learning & Reflections on the stories

### Group 3: Theme discussed: - Workforce Capacity

#### Reflections on the stories

Important to note that both patients lived in the same area of Leeds

Sam:

- Strong assets to support his care and wishes
- proactive family with intellectual and financial resources
- services found it relatively easy to respond to family's needs

Albert:

- Appeared to be Albert and his wife - no other family support/advocacy
- Appears that they struggled to accept/come to terms with the diagnosis
- In the main, services responded to the needs presented/requested... but Albert did not die well.

Group 3: Theme discussed: - Workforce Capacity

Further discussion in terms of the WHY?

WHY	WHY	WHY	WHY
Albert and wife struggling to come to terms with the diagnosis: shock, stigma of carehome, hospice	Did this need to be taken into account more before pursuing a particular pathway?  Services predicated on informed consent - they were offered services and support which they declined: "Reactive Care"	Continuing the conversation - how do we include/understand resistance in advanced care planning?  Who was there to support Albert's wife- links to other services, third sector? Coaching approach of staff	Consent should not be used as a block to ensuring person centred care - was this linked to staff capacity and time to engage more?  Need to consider "proactive care" for someone who is not psychologically ready?  Skills of the workforce to do this?
Transfer from hospital to home	Inability to secure equipment and carer package (night sitter) at short notice impacted on Albert's care	Wider issue (not just in this case)- there is a process involved in getting equipment (ordering etc) more difficult to obtain out of hours/in crisis situation	Is it that staff are not aware of where/how to obtain equipment/services in an emergency situation?
Lack of joined up decision making	Lots of people/services involved - need greater clarity as to who is : <ul style="list-style-type: none"> <li>• Leading</li> <li>• Co-ordinating</li> <li>• Managing</li> </ul> More and better matrix working /working across org boundaries	Consider other roles within this context: <ul style="list-style-type: none"> <li>• death doula</li> <li>• care navigators</li> <li>• EoL co-ord</li> <li>• Palliative care lead</li> </ul>	Workforce capacity issues in different parts of the city - and can therefore lead to health inequalities  Consider where we place/house roles to ensure they can meet the city's/pop health needs
Hospice capacity	Late referrals are prone to crisis- hence the need for earlier engagement		

Workforce Lens

We can't provide everything the family wants/need- wider community support necessary

Supply of staff

- Lack of supply of Nurses & GPs- everywhere or more acute in certain areas?
- Care Home staff?
- New roles- deployment/workforce mix
- Clarity of roles and responsibilities

Staff Skills

- There has been a significant loss of more experienced staff

Solution: a different staffing model with digital enhancements?