Final Report of the Leeds Palliative Care Network (LPCN) Dying Well in the Community in Leeds Project

Overall aim

In 2019, a project was developed to understand the Leeds system of Palliative and End of Life (P&EoL) care. There was an expectation that the number of people dying in the community would increase and that services needed to be reviewed to meet the increasing demand.

The Leeds Health Needs Assessment (HNA) (2019) showed that there were changes in where people die (with a 10.6% decrease in hospital being the place of death compared with 2003); and that there are still a range of inequalities in the access to end of life care in certain populations e.g. males and those under the age of 65. The Leeds Palliative and End of Life (P&EOL) Strategy (2021 - 2026) (which can be found here) had highlighted 7 outcomes to drive the work of the city and inform the future direction. Additionally, the largely positive findings of the bereaved carer's report (which can be found here) are not echoed for every patient's journey. It was recognised that there is lots of excellent work taking place across Leeds under the auspices of the LPCN, but we knew that demand for effective and efficient end of life care would increase in coming years. Therefore, it was timely to establish a project to review the whole of the Leeds system, as is, and identify areas for service improvement or development. Thus, an overarching project was planned to improve Community Flows and people's experience of dying out of hospital as a key piece of work for LPCN from 2020 and beyond. The aim of the project was:

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

Project detail

The focus of the project was community (out of hospital) services and how they interact with each other and hospitals to meet patients and their family's needs. The project was split into two key phases:

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- Phase 1 – used a Whole Systems Approach, to scope the services on offer across Leeds; particularly looking for areas of duplication and gaps. Within this, we aimed to develop a clear, and agreed, understanding of the service offer for people who are at the end of life across all services including the third sector. We also used other methods to obtain different views of services in Leeds

- Phase 2 – was planned to implement effective service redesign to make the best use of the resources available delivering the most effective and compassionate care outside of hospital for those people who are dying and for their carers and families. The area of work in Phase 2 was determined by the outcomes of the work in Phase 1.

Governance

The project was led by a dedicated project manager and reported into Community Flows Improvement Group (CFIG) which was renamed the Community Palliative Care Improvement Group (CPIG) during the project. The CPIG group supported the project and oversaw and advised on implementation, helped overcome barriers and managed risks. Outputs from the work were fed into the LPCN Executive and then the LPCN Group. Outputs were also reported to End of Life Population Board once it was created.

The hypotheses we were testing

In developing the project there were some hypotheses made about the Leeds system. These were not explicitly articulated but gathered as views at the start of the project from the experienced and knowledgeable project team. These included:

- That there was an opportunity for more people to die in their own homes
- That the quality of care for those dying at home could be further improved and service integration could be enhanced
- That applying the WSA approach would work for P&EoL care (it had been previously applied to obesity pathways)
- That the system was complicated and could be better streamlined
- That the system could be mapped but that there was constant change as organisations continued to improve their offer and that any information gathering would be a snapshot of the system
- That there may be opportunities to create an “end of life” organisation that would bring together the teams that support patients and families at end of life

Phase 1 Process

Phase 1 timescales were extended because of the unprecedented pressures on the system during and after the COVID-19 pandemic. We were successful in completing all the information gathering planned, albeit having to make use of different mechanisms such as virtual meetings. The upside of the delay was that there was time to add other views creating a fuller whole system picture. People, both staff and members of the public, were generous with their time and their ideas and thoughts. By the end of Phase 1 four views of the system had been taken:

System view – this view was developed from a series of eight virtual events with professionals during November and December 2020. Over 100 people from different organisations attended, including: acute and community health care, social care, care homes and voluntary and independent organisations. The Whole System Approach was used to create a map; this was facilitated by Leeds Beckett University, commissioned by Leeds Academic Health Partnership.

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 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:

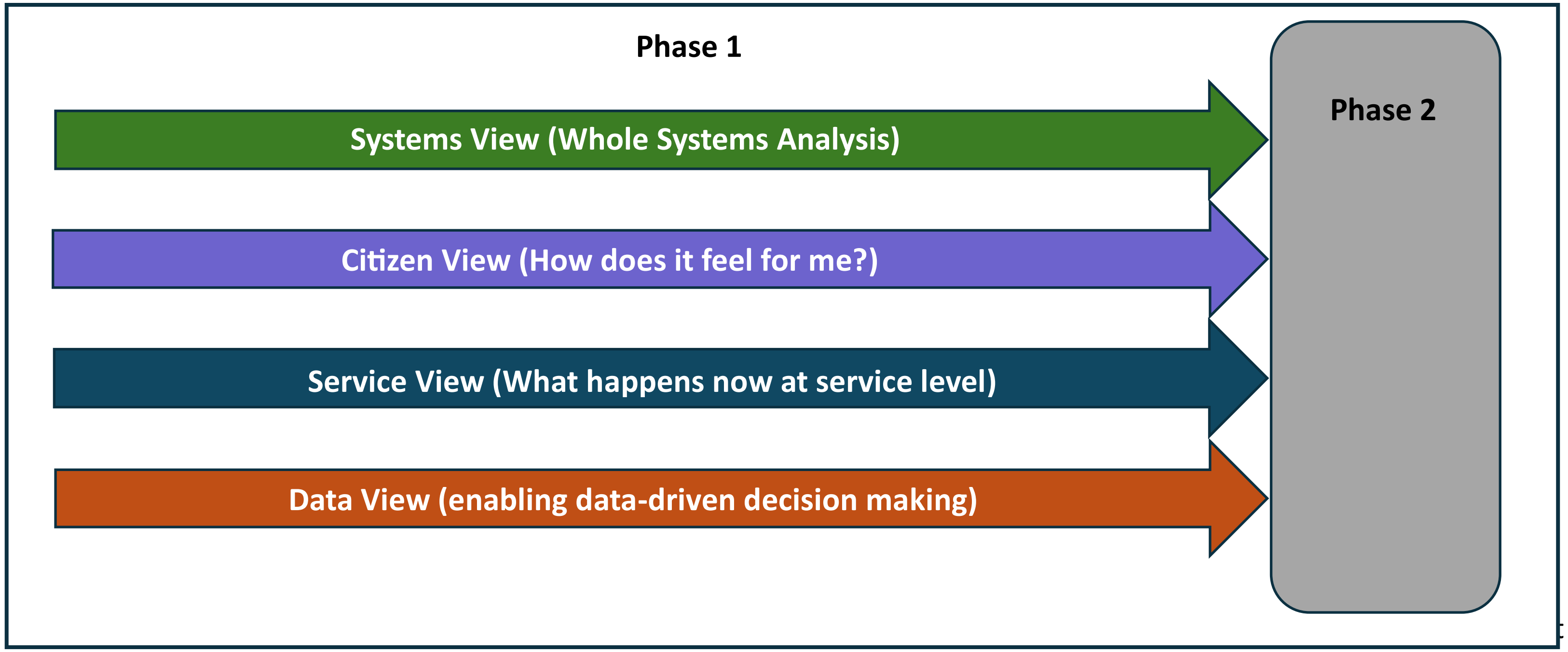
- Stakeholder map (can be found here) - identifies key stakeholders and services, with the detail of what is delivered by these services outlined underneath including those services providing support for patients who are approaching their end of life or offer support after a death has occurred entitled “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.

These initial findings of Phase 1 were supplemented by two additional sources of information: a view from the system exploring the real level of service delivery in Leeds and a data view.

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 can deliver in comparison its description shared with people and system partners. The work used storytelling to seek to understand how services were able to deliver the service offer described on paper and when and where this service delivery was not possible.

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 also secured commitment to look at the data in more detail to inform our decision making about work in Phase 2.

This means that the information we have has come from four key views, described in the picture below.



Identifying key themes from Phase 1

The objective of the latter part of Phase 1 was to determine key areas for action during Phase 2. Between July and August 2021, the LPCN used the systems maps, the commissioned piece of work by Healthwatch Leeds, in conjunction with service views and analysis of healthcare data, to develop key themes and options for action. The proposed themes and actions were discussed with 36 stakeholders from across the system, in a virtual workshop and then we held a workshop with core team members to consider all the information gathered in Phase 1.

The two workshops had 3 objectives:

- Development of a detailed action plan – that was informed by systems map to identify aligned actions and the stakeholder map to identify relevant stakeholders
- Develop a theory of change based on the action plan and an accompanying monitoring framework
- Determine the structure of stakeholder engagement and develop an action plan and monitoring framework for wider stakeholders

Following the workshop, three themes were selected as the core of the Phase 2 service redesign:

1. Updating the service offer
2. Citywide single point of access
3. Increasing resources

For each theme, we used the theory of change methodology to understand whether these were the correct themes to take forward into action. The theory of change offers an entry point for questioning, documenting, and monitoring of what stakeholders believe will happen and provides a basis for evaluation and review during the Phase 2. A theory of change working document was developed and can be viewed here.

Development of priority areas for action from Phase 1

The results from each of the four views were distilled into key themes and developed into an overarching understanding of information gathered which informed the actions needed for Phase 2 of the project. 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 their family and carers and 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 in the process for ensuring that prescriptions are written and filled in a rapid manner.

Summary of key areas for action and improvement from Phase 1 work

There were three key areas where work across Leeds was not already well underway. It was agreed that these would be overseen by Community Palliative Care Improvement Group (CPIG) in Phase 2:

- Updating the service offer
    - Working to integrate community services in local areas

    - Developing a glossary of terms
    - Ensuring that all staff are able to recognise and support people who are at the end of life
- Scoping Citywide Single Point of Access for Palliative and End of Life care
- Working to maximising efficiency and increasing resources available to support death in the community

Within these areas two projects were identified to be taken forward, initiated in the period June 2022 to December 2023. These were:

- A local led and driven project to look at how community services could be better integrated around P&EoL care
- Scoping the need for a Leeds Citywide Single Point of Contact for Palliative and End of Life care.

Project managers were appointed for both projects.

Key findings from the two main projects in Phase 2

Integrating community services

Initially working in Seacroft, but with a plan to pilot in at least one other LCP across Leeds, we explored the hypothesis that better integration of community services leads to improved efficiency and quality of care. Key services involved included, primary care, LCH, hospices, community teams, social care, the third sector and providers of support to people such as domiciliary care providers and care homes.

The theory being tested was that better integration of services will lead to closer working and, in turn, this will reduce duplication. The increased efficiency of working together more closely will allow the right member of staff to visit people who are at the end of life, and their carers, and offer a more timely and better quality services. We also aimed to clarify the service offer so that each service can describe what another service can and can’t offer. We know that lack of clarity between services causes confusion for professionals and the public alike and can raise expectations beyond what is achievable.

The work in Seacroft was led by a local project manager and a core group of professionals. There were several initial scoping meetings and over time the core group was developed. The core group took some time to establish but it then created the capacity and drive to work together to improve care for patients and their carers and family. Many of the partners shown above engaged in the work but some found it more challenging in terms of attendance or consistency of membership. Partners had different views on what is important, and it took some time to develop a consensus. But then the members of this group worked together to develop an understanding each other's roles and identified how the local Seacroft stem worked. Initially the final few weeks of life were the focus of the work but over the time the group met they realised earlier in the patient pathway was where systems needed to be in place to ensure that the pathway was working. This was supported by the work of the ICB Citywide respiratory work. The Seacroft project was able to undertake a case study examination of patients who had been admitted to hospital because of respiratory issues and the group identified key needs of patients from this work. They are now looking to see if they can apply the same approach to patients with different diagnoses.

There were lots of small wins across the time of the project and working with the third sector has allowed a small amount of funding to go a long way to support local people. Excellent work in the community to support conversations about death and dying have taken place. It is recognised that established Seacroft relationships allowed us to engage a breadth of third sector partners more effectively than might be possible in other areas of the city. This hyper local approach was key, and we are now sharing the learning across other localities. This is being enabled by the Local Care Partnership and they are supporting the local PCN to consider how they might invest in improving the integration and pathway for people who move into end of life care having previously been identified as frail.

The Core Group, working in collaboration with the Leeds Palliative Care Network, agreed 3 broad areas of work for the project:

- Clinical pathways and service integration
- Information offer for the Seacroft Community
- Conversations about death and dying with the Seacroft community.

Learning from the Project has shown that the chances of successful development work are greatly determined by a number of key characteristics and strengths that may or may not pre-exist in a given locality.

- Clarity on the locality(ies) and communities you are working with
- A structured and resourced third sector in the locality

- Capacity and drive to improve the experience of EoL
- NHS services that have ‘pro-active’ case management capacity
- Care planning based on what matters to the person
- The care home population

There is a clear legacy from this work as the core group continues to meet and work together to streamline services. Also, there is a community movement “Dying well in Seacroft”. This is made up of a website, literature for citizens, life and loss café. The ethos is to not shy away from a difficult topic plus core group networking. The end of Seacroft project report can be found here. To date no further LCP has expressed a desire to explore their EOLC pathway.

Scoping the need for a Leeds Citywide Single Point of Contact (SPOC) for Palliative and End of Life care

Leeds was an exemplar site looking at 24/7 care for the National P&EOL care team. Employing a project lead we examined key areas needed from an offer both in and out of hours. The project manager undertook a stakeholder analysis of the viability and need for a SPOC, gathering information about different models of delivery both locally, nationally and through an extensive literature search. She also spoke to key stakeholders locally and to staff delivering different models of end of life 24/7 care across the country. The work identified a clear need and desire for an end-of-life SPOC to be in place for Leeds but recognised that there were a series of challenges that any new service would need to address including staffing, estates, technology interoperability and funding. The final report identified what functions are needed in a Leeds quality SPOC. These included:

- One place to ‘contact’ (need to be able to offer phone, text, video calls, email response also), predominantly out of hours and patients encouraged to contact usual service in hours if known
- Workforce who can fully assess the situation and be able to:
    - Offer support to patients, family, carers e.g. helping to cope with anxiety, reassuring family as death approaches, reassurance that some symptoms such as fatigue, reduced appetite are to be expected
    - Offer support to professionals e.g. supporting paramedics making decisions, reassuring care home staff

  - Offer updated information - to patients, family, carers e.g. what is happening regarding an admission or appointments, reinforcing recent information given by professionals such as medication changes
  - Offer updated information to professionals e.g. sourcing medication supplies, advising care home staff regarding out of hour GP visits, giving information to paramedics in patient homes regarding patient preferences and ceiling of care
  - Offer clinical advice - to patients, family, carers e.g. how to use as required medication, managing acute events such as fits or bleeding
  - Offer clinical advice to professionals e.g. advice to care home staff regarding as required medication and use of syringe drivers.
- Access up to date patient records. The offer of support, advice, and reassurance to caller will hopefully mean that the call can be completed at that point – or, if required Signposting
- Referring to other services e.g. a visit to the home
- Communicating with patients and across services e.g. passing on information, sourcing medication supplies.

From this, an options appraisal including the financial case for implementation was created. The final report can be found here. This was presented to the End of Life Population Board, and whilst the board recognised the need the financial position for the Leeds Health and care system at that time did not support development of a business case for an EOL SPOC. After the publication of the report links to local initiatives such as the LCH hubs and the SPUR were explored and the ongoing need for integration of end of life care was recognised.

Other areas of work supported by the overall project

Developing a glossary of terms

This work was integrated into the development of a new leaflet for patients, families and carers “Support for Patients and Carers”. This leaflet aims to ensure that patients, their families and carers hear the same information using the same vocabulary regardless of which services they come into contact with. This will reduce confusion and misunderstanding. A copy of the final leaflet can be found here.

Ensuring that all staff are able to recognise and support people who are at the end of life

Though not directly linked to the work of the Dying Well in Leeds project, links to training offers and the LPCN education team have been made. The training available allows staff at varying levels of experience and grade to receive training that helps them understand the end of life pathway and feel more confident in having conversations about it. Some examples of training offered (not all are ongoing offers) include:

- Delivery of Planning Ahead Training
- A new ECHO programme for GPs and wider Primary Care Network
- A programme for Allied Health Professionals (physiotherapists and occupational therapists)
- LTHT delivered training to 2,000 clinical support workers and organised a conference inviting city wide key organisations supporting PEOL care. They also developed an EOL CSW champion role.
- A report on Palliative and EOL care home education has been developed by the LPCN. Key stakeholders are currently collaboratively working together on recommendations for training and education in care homes, derived from the report.
- Palliative and End of Life education day was run, supporting people that are homeless and vulnerably housed

The LPCN website also provides resources and links to further education and information relevant to P&EOL care.

The Seacroft project made use of this offer, sharing it widely with professionals. This resulted in people going on training together and sharing lifts – one of the successes of the project that is hard to quantify but vital in ensuring that professionals communicate clearly with each other and have a shared understanding.

In addition, the LPCN are leading a Timely Recognition of EOL project. This aims to develop a digital search tool embedded in primary care electronic patient records that enhances recognition of people approaching the end of their life in the community in Leeds. The Yorkshire Strategic Clinical Network and the Leeds Ageing Well Fund supported the project.

Working to maximise efficiency and increasing resources available to support death in the community

The End of Life Population Board are aware of the increased demands for palliative and end of life care across all settings alongside the challenges posed by a shift in people choosing to die in their own home rather than residential settings. Consequently, the Board are seeking to monitor activity levels, the impact on service capacity and on patient experience. Providers are seeking to maximise collaborative efficiency within existing resources. But we recognise that there has been a significant change in the financial position for the Leeds health and social community during Phase 2. At present the situation remains challenging with little scope for investment or the initiation of new work.

The impact of the COVID-19 pandemic

In telling the story of the Dying Well in the Community in Leeds project we must make a reference to the COVID-19 pandemic. When the initial project plan was developed the possibility of a global pandemic was not factored into timings. There were unintended consequences of the pandemic including:

- Project timescales being considerably extended as initial meetings planned as face to face had to be replaced with virtual meetings
- There was a massive increase in the number of people dying in their own home; exacerbated by people not wanting to go into hospital or care homes as restrictions meant that loved ones could not be by the side of those dying during the pandemic restrictions
- This increase in people choosing to die at home continued even after restrictions have lifted and we still see more people dying in their own home than any other setting
- After the pandemic peak was over there was an ongoing impact on staff – many older and experienced staff chose to leave the NHS, and those that remained were often exhausted from all the extra work undertaken during the pandemic
- Many changes took place in organisations to allow them to respond to the pandemic demand and some of these changes remained
- After the initial peak had subsided services had increased waiting lists, with the presenting complexity of patients increased
- Staff and services were not in a place to plan and think about making more changes to the system and engaging with the project
- Staff had not taken their full leave entitlement and staff teams were often depleted in numbers as many of the restrictions were still in place, such as staying at home if you tested positive.

Over the last 4 years the impact of the COVID pandemic has meant that there has been further growth in the community demand for End of life care. We recognise that this presents an ongoing challenge to community services.

Key conclusions of the project

Initial hypothesis	After the project
That there was an opportunity for more people to die in their own homes	This has happened but was influenced by the impact of COVID-19. It has affected the way the system works and the public's views of death and dying
That the quality of care for those dying at home could be further improved and service integration could be enhanced	Much has been done on this and the work in Seacroft has shown how working at a local level can really improve professionals understanding of each other's role and the value of the link to the third sector
That applying the WSA approach would work for P&EoL care (it had been previously applied to obesity pathways)	This worked well and the stakeholder maps demonstrate this. It was further strengthened through the other 3 views taken in Phase 1
That the system was complicated and could be better streamlined	The system was shown to be complicated demonstrated by the WSA system map. Opportunities to work better together was demonstrated through the work in Seacroft
That the system could be mapped but that there was constant change as organisations continued to improve their offer and that any information gathering would be a snapshot of the system	The system hard to map as it is in an ever changing state of flux as organisations work to improve their offer within resources available. The speed of change was exacerbated during the COVID-19 pandemic

That there may be opportunities to create an "end of life" organisation that would bring together the teams that support patients and families at end of life	There was no desire to create an "end of life organisation" – although this was mooted several times in Phase 1 there was no appetite shown for this transformational change. The current financial situation means that any large scale change of this kind is currently less likely. The need for effective collaboration and a shared understanding of the system working was established

Evaluation against the Phase 1 theory of change document

The theory of change documents were reviewed both at the end of the Seacroft project and also for this final report. It was concluded that the thoughts expressed in the theory of change document were still relevant. The projects had delivered the activities described in each area and had offered the capacity needed for the enabling factors described to be put in place. Many of the predicted intermediate outcomes had been delivered (though not all yet) for each project but that it was too soon to tell if the longer term impacts could be described as fully delivered, though in each project there were definite improvements in this area.

Final Thoughts

- There is still a need for further conversations between organisations about how the impacts of changes in one part of the system may affect others. A process for this to ensure that one organisation does not make unilateral changes that affects other parts of the system is still needed. The CPIG group pre-existed the project and it may be a good place to undertake this role
- The last few weeks and months of life are generally acknowledged to work well with good support for patients and their families and carers most of the time. This is not to say that further improvements couldn't be made but recognises that for many in primary care teams, and others, that the patient flow pathway for end of life care is smoother than in many other pathways
- End of Life care is a small percentage of the work for a primary care team, as it generally it works well there are other areas of focus for service improvement

What next?

Though the project has come to an end there is still more work to be done:

- The LPCN will continue to support partnership collaboration through its governance structures and through its existing subgroups as collaboration is essential to the delivery of coordinated and quality end of life care (a video can be seen here)
- The work in Seacroft will continue through the funded work and through the core group continuing to meet and share ideas, challenges and successes. Representatives from the core group will continue to attend LPCN meetings to share their progress, learning and developments
- The citywide respiratory project has also identified a benefit for a SPOC and continues to consider opportunities for improvements
- City Wide organisations are aware of the need to consider people who are at the end of their life as part of any development for urgent and rapid care responses

Thank yous

Without the support of the many staff and members of the public who gave their time this project would not have been possible. Particularly thanks go to the members of CPIG, the project managers of the individual projects (Valarie Shaw and James Woodhead), to Diane Boyne Leeds Palliative Care Network Manager and Dr Mike Stockton as Clinical Lead for this work.

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