Leeds Palliative Care Network

Dying Well in the Community in Leeds

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Background

This is the final update on the work of the Leeds wide Dying Well in the Community Project. You have already received the final report, comments are still welcome.

The overall aim of the project was

To improve the transfer of patients between all providers to ensure continuity of

care and patient experience

The project had two phases

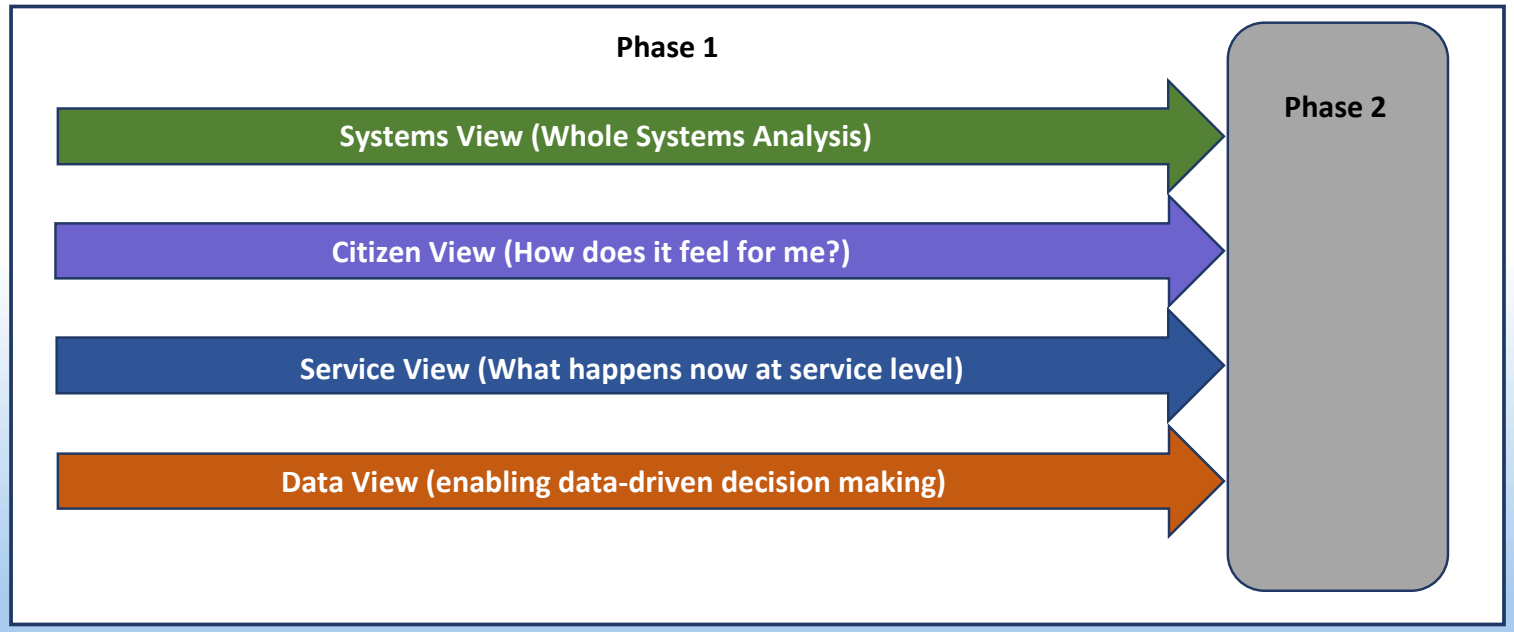
Phase 1 - to use a Whole Systems Approach

- To develop a shared understanding of the whole system for end of life care within the community in Leeds, including interface with hospital-based care

Phase 2 - to ensure 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. This will address the findings of the work in Phase 1

In Phase 1 four views were taken



Phase 1 – WSA

Phase 1 WSA

- The objectives of the WSA work undertaken by Leeds Beckett University :
  - help stakeholders develop a shared understanding of the whole system for PEoLC within the community in Leeds, including interface with hospital-based care.
  - help determine key areas for action in Phase 2
  - create a theory of change to help identify areas to monitor

What we did (November to June 2021)

- A series of eight virtual events were undertaken with over 100 people from different organisations, including: acute and community health care, social care, care homes, as well as voluntary and independent organisations.
- Information gathered during these events was initially collated with findings from a Healthwatch Leeds project (exploring the views of families and carers who have received end of life care)

Outputs

- A stakeholder map showing who is involved in the system
- A systems map showing the many interconnected local factors that make up the systems related to PEoLC in Leeds.

Key points were reviewed

- The LPCN used the systems maps, the commissioned piece of work by Healthwatch Leeds, in conjunction with the 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, during a virtual workshop

Development of priority areas

Five themes emerged from the four views:

1. Updating the service offer
2. Citywide single point of access
3. Increasing resources
4. Recording one up-to-date Advance Care Plan
5. Improve timely prescribing

Development of priority areas

Themes 1-3 were selected for the core of the Phase 2 service redesign. The remaining two themes were identified as already having significant workstreams progressing them.

1. 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
2. Scoping citywide single point of contact
3. Increasing resources
4. Recording one up-to-date Advance Care Plan
5. Improve timely prescribing

What we did (January to March 2022)

- A theory of change involves articulating the many underlying assumptions about how change will happen
- Prior to the workshop, a draft theory of change was produced by core members - analysing the variables and inter-relationships from the systems map
- This draft theory of change, was honed to provide a basis for evaluation and review in Phase 2

Phase 2

Community Integration in Seacroft

Approach

- We were not able to undertake this work across the whole of Leeds as it is too large
- Funded by the LPCN, we looked for two LCP areas that were keen to focus on end of life care – one with links to St Gemma's and one with links to Wheatfields
- A third area linked to the third hub for LCH will be considered in the future

Seacroft challenges

- Establishing the clinical priority actions
- Seacroft staff beginning the journey
- Translating vision into decisions and action
- Leadership, permission and empowerment

Single Point of Contact Scoping Work

Approach

- Review of previous work including published evidence and national documents
- Observing services providing palliative and end of life care & meeting staff including:
  - LCH, hospices, consultant on call, YAS, Local Care Direct, LTHT, Care homes
- Explored other regional and national solutions

What can we learn from existing services regionally and nationally?

- Nationally there are significant drivers for implementation of a 24/7 solution
- SPOC services vary in terms of design, scale, links with other services but all noted an increasing need and a requirement for access to an urgent response service alongside SPOC
- Existing services are stretched and demand is increasing
- Existing services report an increasing role in co-ordination and that calls are generally for advice and support, both to families and patients plus advice on clinical decisions, access to information and support in decision making for other professionals

Ensuring there are adequate resources

Articulating our assumptions

- 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

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