



**Leeds Palliative
Care Network**



**LEEDS
BECKETT
UNIVERSITY**

Update on Leeds Dying Well in the Community

Ruth Gordon and Dr Duncan Radley



Overall aim

*To improve the transfer of patients between
all providers to ensure continuity of
care and patient experience*


The project has two phases

- Phase 1 is 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 is 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

Who is involved?

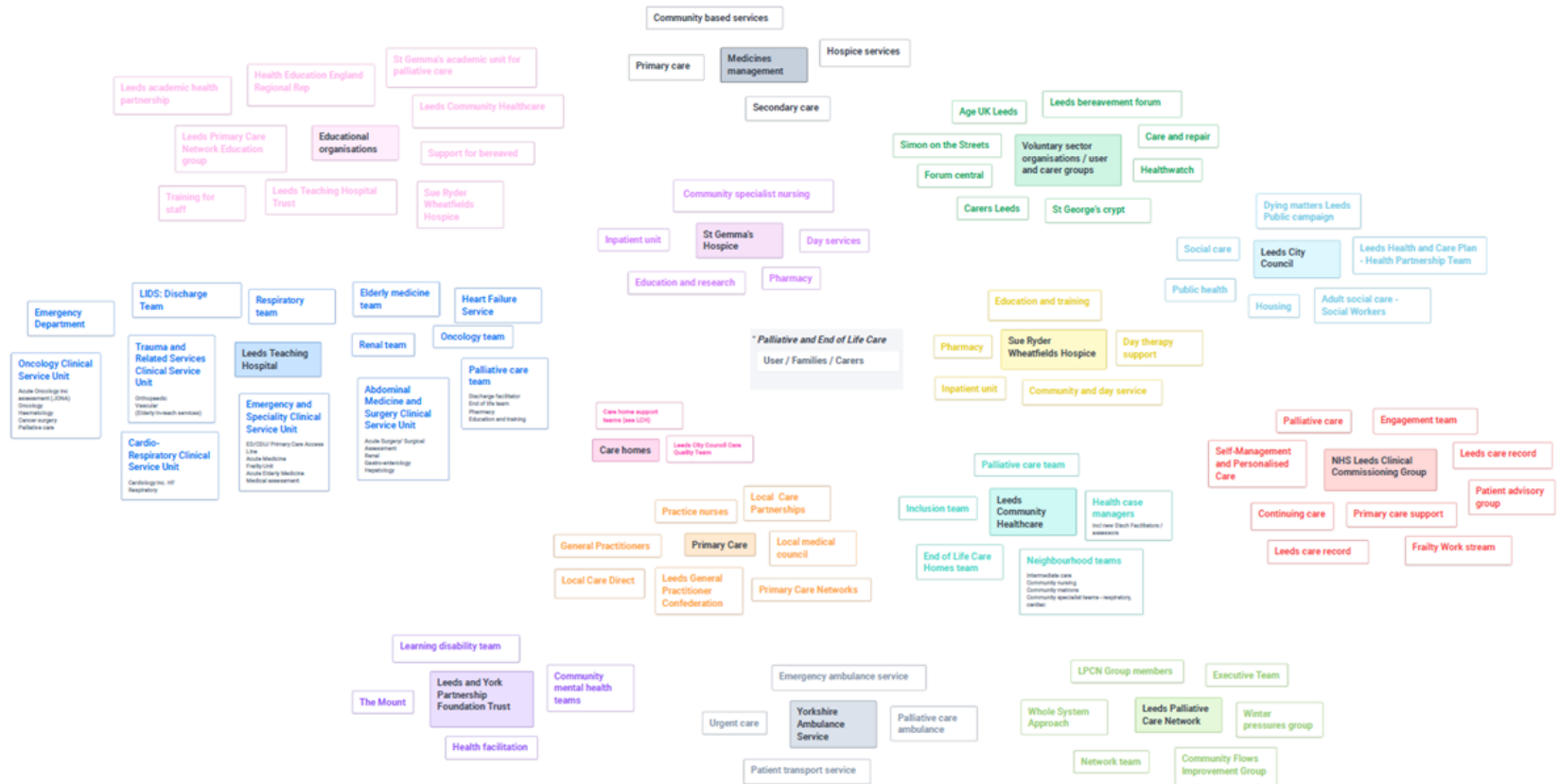
- The work is led by LPCN and funding is by LAHP who have procured Leeds Beckett University to undertake the WSA element.
- This is supported by a System Wide Steering group with a full PID and regular meetings.
- Members include: LCH CCG, hospices, voluntary sector (including carers organisations), LTHT
- Ethics has been approved and clear governance is in place.

Whole System Approach methodology

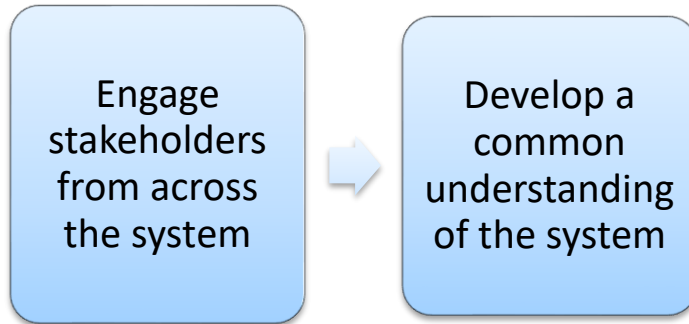


Engage
stakeholders
from across
the system

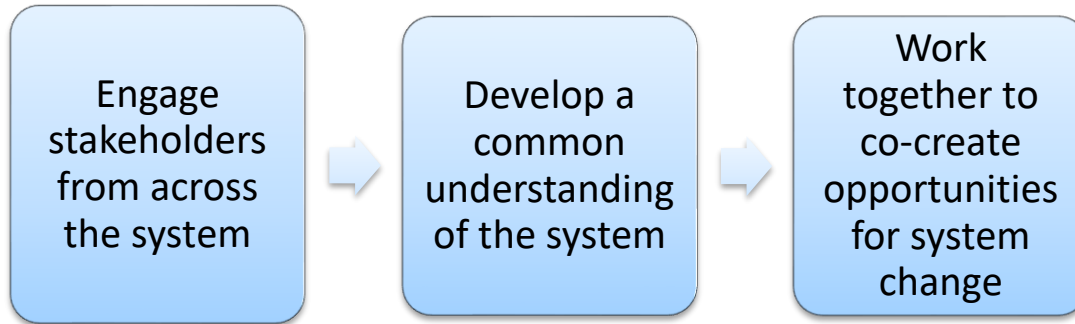
Stakeholder Map



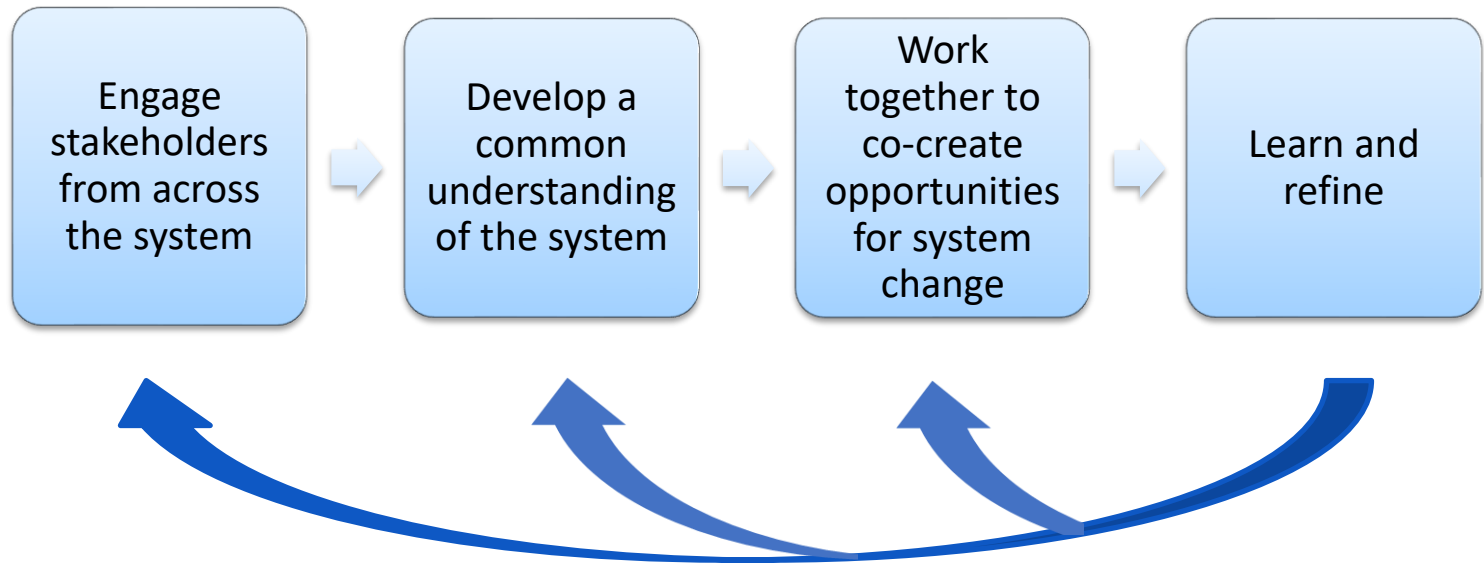
Whole System Approach methodology



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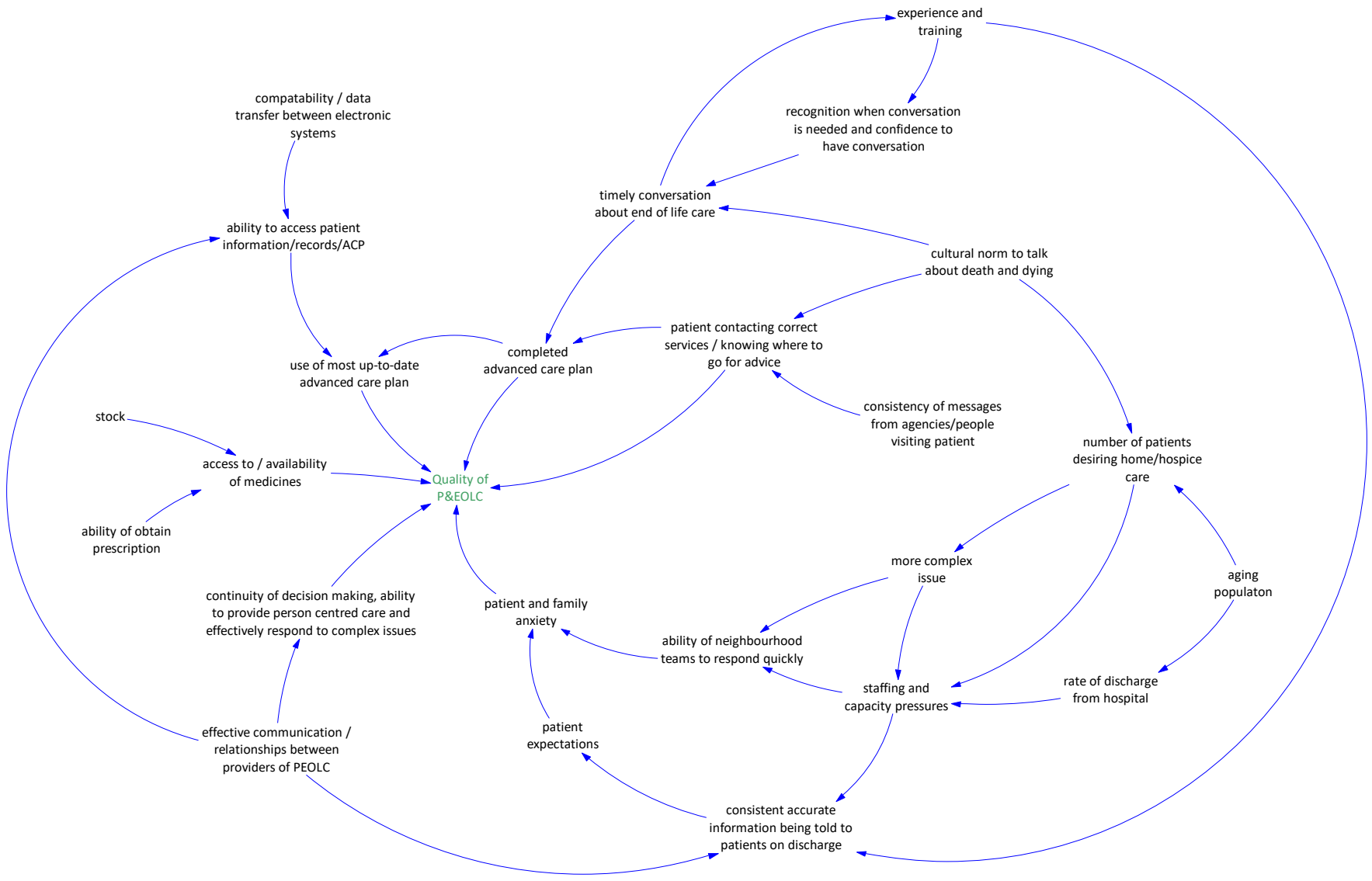


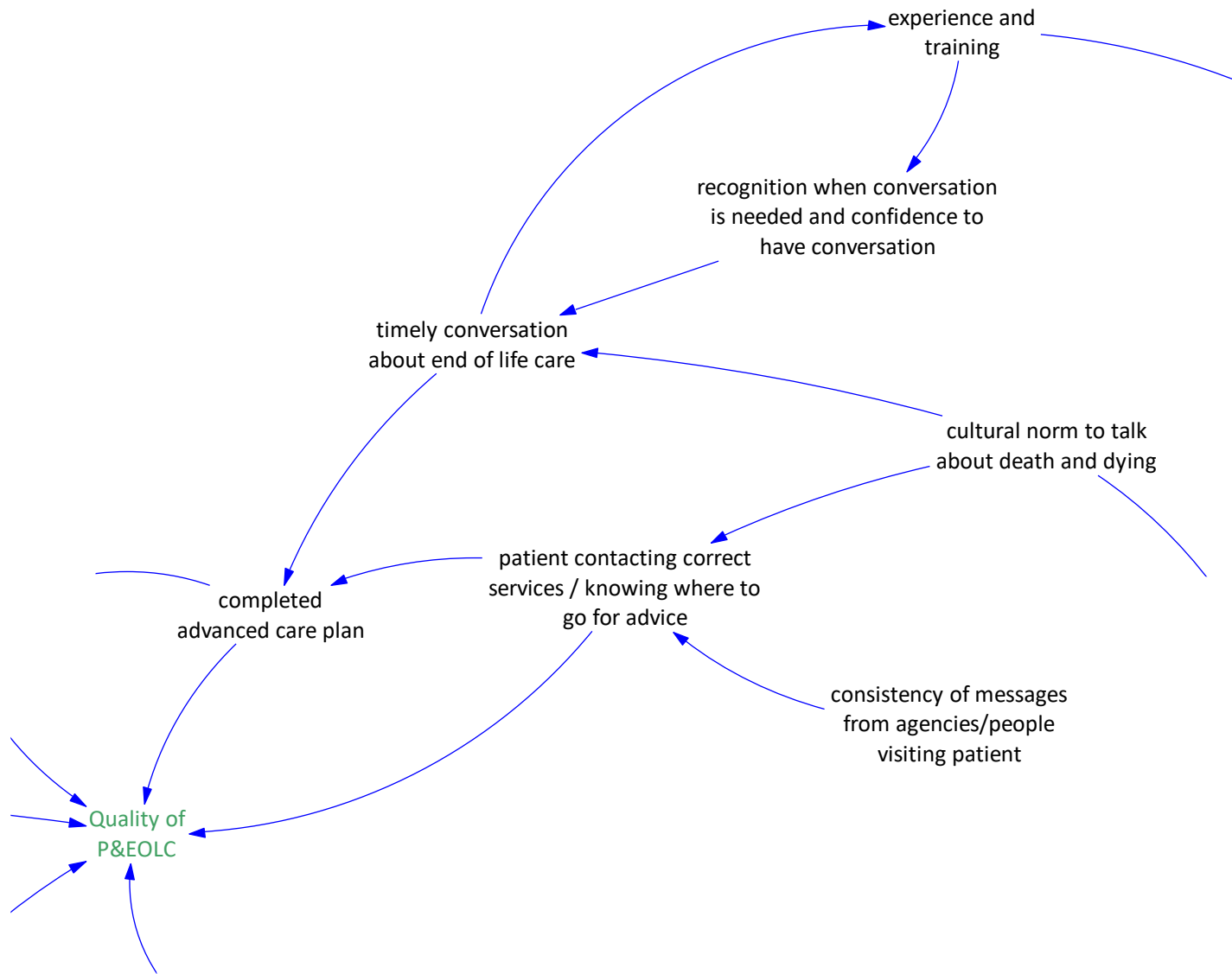
Progress so far

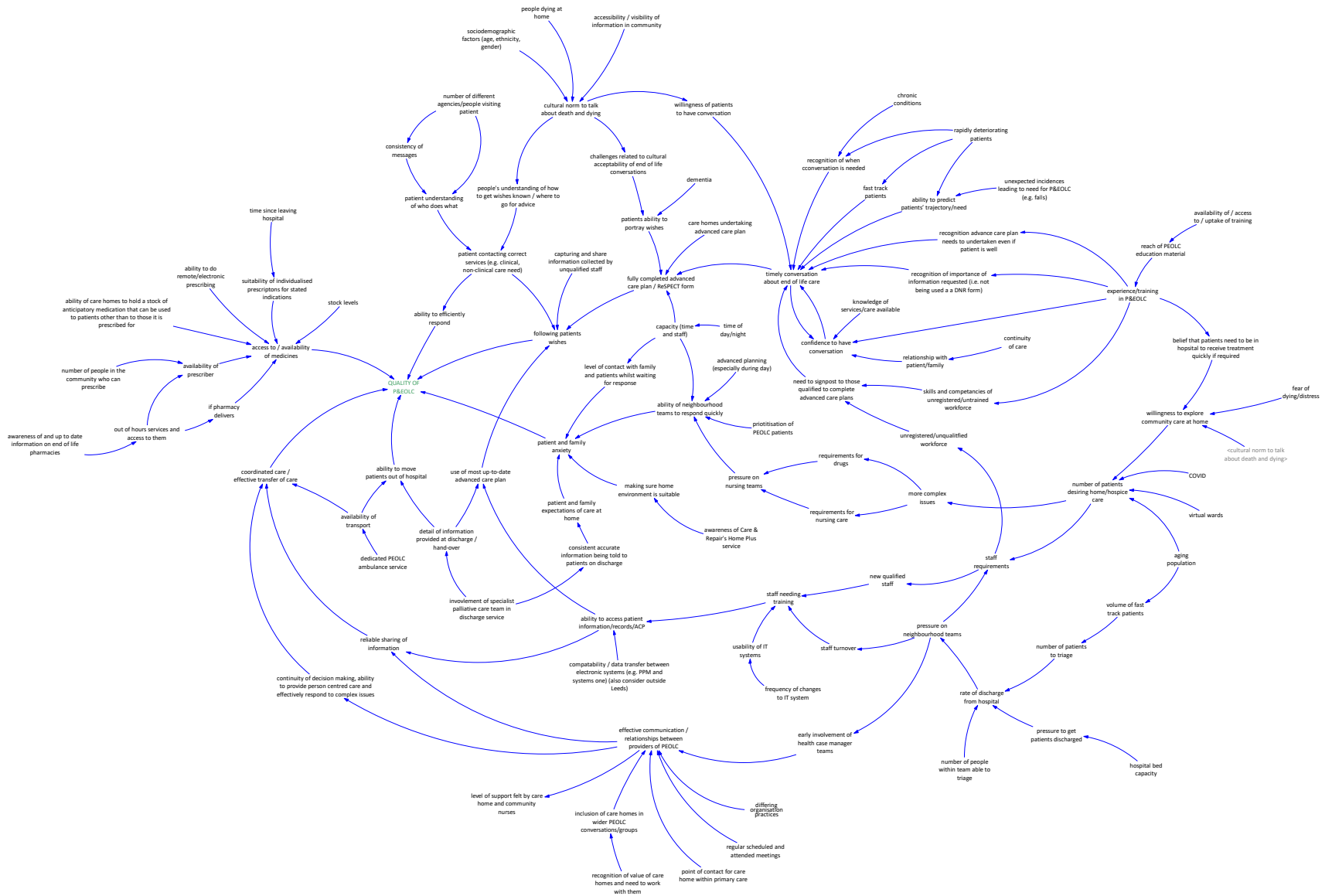
- Stakeholder map has been developed
- We have held 8 events with over 100 people from acute and community health, social care, care homes and voluntary and independent organisations joining
- Work to gain the public (especially carer's view) has been commissioned from Healthwatch
- Headlines from this work has identified lots of positives as well a few key areas to consider for phase 2

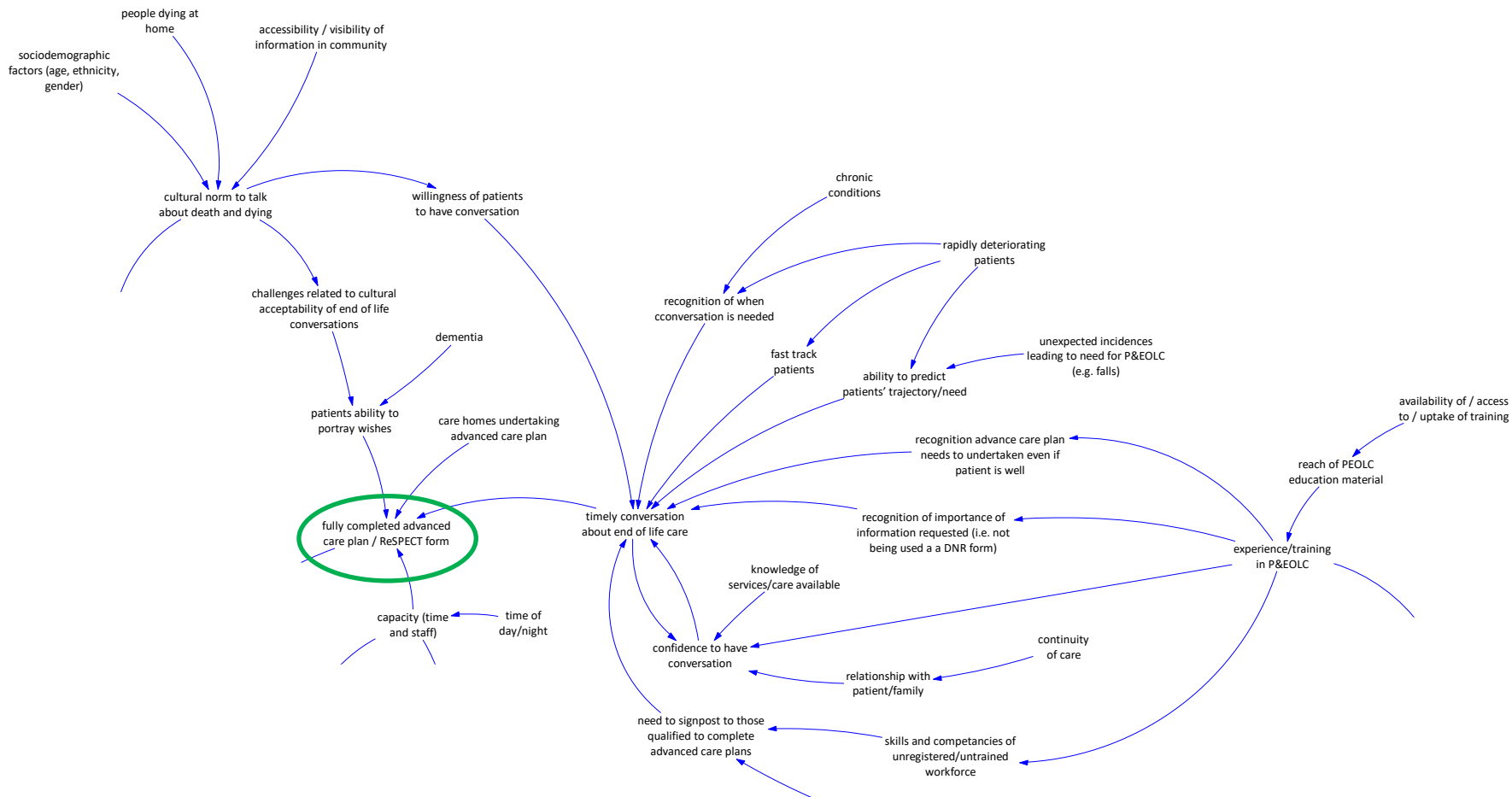
Systems mapping

- A visual representation of a system and their interrelationships
- Engages people in systems thinking
- A representation of stakeholders understanding of the system
- Identifies points to intervene
- Demonstrate how a wide variety of people can contribute
- Identifies knowledge gaps









Workshop headlines

- Access to medicines
- Sharing of information
- Patient knowledge of who does what
- Having an ACP
- Issues of capacity and adequate staffing
- Early recognition of deterioration
- Willingness to explore care at home
- Ability of neighbourhood team to respond

Work with patients and carers

- We commissioned Healthwatch to undertake a survey (31 responses) and develop case studies (15) to understand people's recent experience of end of life care
- Experiences were reported with a 50/50 split of positive and negative experiences
- Key themes
 - Dignity, kindness and compassion
 - People asked for 2 things, to be with their loved one and for the loved one not to be in pain
 - People reported feeling they had to 'battle' for things which was exhausting at an already difficult time
 - There was also often confusion over the number of people who 'go up the path', who is in charge of care?

Edited versions of some of the interviews will also be available. These will be presented in an online book format where the pages can be turned and zoom links to the interviews will be included where participants were happy to share these.

Next steps

- Finalise key findings with full analysis
- Highlight options for the focus of Phase 2
- Work with the Community Flows Improvement Group to identify the area to drill down for Phase 2
- Develop a full action plan for Phase 2
- Within this we recognise the impact of COVID-19 on the shift of care into the community (LCH reporting 30-40% increase on caseload for EOLC) and increased partnership working. There is already a new normal!

Further Reading

- Below are two published articles for further information:
- <https://www.leedsacademichealthpartnership.org/news-and-events/leeds-launches-novel-approach-to-improving-palliative-and-end-of-life-care/>
- <https://edition.pagesuite-professional.co.uk/html5/reader/production/default.aspx?pubname=&edid=a522a40c-885e-4ae6-8778-6600fa998bbc>