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Leeds Dying Well in the Community Project

Report prepared by Dr Duncan Radley and Dr George Sanders

Leeds Beckett University

November 2022

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Executive summary

Project background

Palliative and end of life care (PEoLC) is considered internationally as an essential health service for all people with chronic progressive conditions, and it is a key part of the required global systemwide response to realign health and social care to the needs of our aging populations[1]. Leeds Palliative Care Network (LPCN) has been leading a project to improve PEoLC in the Community in Leeds. The focus of the project is PEoLC within the community in Leeds, including interface with hospital-based care. This report provides detail of the work undertaken by Leeds Beckett University to support Phase 1 of the project.

Implementation

Project progress up to June 2021

Prior 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 collated with findings from a Healthwatch Leeds project (exploring the views of patients, families, and carers who have received and supported end of life care) to create 1) a stakeholder map identifying key stakeholders and services, and 2) a systems map showing the many interconnected local factors that make up the systems related to PEoLC in Leeds.

Development of priority areas for action

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, during a virtual workshop in October 2021.

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

Theory of change

A theory of change, developed as a working document to be refined throughout Phase 2, was created in February 2022. The theory of change offers an entry point for questioning, documenting, and monitoring of what stakeholders believe will happen and what happens in reality, and provides a basis for evaluation and review during the Phase 2.

Project evaluation

Methodology

Evaluative information on the Phase 1 process and the stakeholders' perception of the approach was collected from three sources: 1) workshop feedback: considering the content of the workshop and

stakeholders' views of the approach, 2) interviews with senior stakeholders, and 3) an online survey sent to all stakeholders who participated in any of the workshops.

Triangulation of findings, key learnings and recommendations

Phase 1 implementation

The rigour provided by the academically validated process was acknowledged as a positive and workshop activities were well received, with participants believing the information to be clearly presented, providing them the opportunity to put forward their views and increasing their understanding of the complexity of PEoLC and the differing options for action to elicit system change. However, it was noted that further clarity of the whole process at the outset and clearer information of the purpose of each activity would have been beneficial.

This learning should be considered during Phase 2 of the project, making it extremely clear what the aims and objectives of each activity are, what outputs will be produced, and how these will be disseminated.

Phase 1 outputs

The largely positive comments regarding the resultant Phase 1 outputs (stakeholder and systems maps) reflect the potential benefits of adopting a systems approach and further adds to the growing literary support for this process. Whilst some interviewees noted that the maps did not unearth any unknown system challenges and complexities, the majority of stakeholders in the workshop felt that activities increased their knowledge of the complexity of PEoLC and helped them to think differently about solutions to improve care.

Moving into Phase 2 implementation, it is important to reinforce the use of outputs from Phase 1. The theory of change also offers a good base for monitoring during Phase 2 and will support an improved and shared understanding of the initiative by the team and other stakeholders.

Relationships between organisations

Stakeholders indicated that the organisations involved welcome new practice, did not view the approach being at odds with the achievement of current national or local policies, believed that there is the supportive senior level leadership in place, and that the multiple staff groups likely to be involved in the implementation of Phase 2 have good working relationships. However, the need for wider community and marginalised group involvement was highlighted.

Overall, a coordinated and sustained effort across all hierarchical levels is warranted to implement and maintain momentum moving into Phase 2.

Ways of working

Although it was felt that staff groups and organisations have good working relationships, concerns were also raised around changing ways of working.

During Phase 2, consideration should be given to building trusting relationships and providing a 'safe space' for sharing findings and time for those involved to 'work through' any identified challenge.

The overall evaluation suggested that stakeholders were favourable toward employing the approach and supported the prioritised themes for action, but at the same time, were concerned about how it would fit into their work without additional resources and support.

Introduction

Project background

Palliative and end of life care (PEoLC) is considered internationally as an essential health service for all people with chronic progressive conditions, and it is a key part of the required global systemwide response to realign health and social care to the needs of our aging populations[1]. The purpose of PEoLC is to improve quality of life by preventing and/or relieving suffering through the early identification, assessment, and treatment of physical, psychological, concerns and spiritual wishes for the person and their family[2,3].

We know that demand for effective and efficient PEoLC is increasing. The world's population is aging, with an unprecedented rise in the number of people aged 60 years and older[1,4]. With advancing age comes multimorbidity and frailty[5], as well as a prolonged and uncertain trajectory of functional decline that often lasts years rather than months. Moreover, by 2040, annual deaths in England and Wales are predicted to rise by 25%[6]. Health and social care needs among older people are diverse and often complex, with multiple interacting factors related to the individual (e.g. ethnicity), his or her health (e.g. morbidities), and environment (e.g. care setting, resources). Hence, the accessibility and quality of PEoLC care must be considered a priority.

Leeds Palliative Care Network (LPCN) has been leading a project to improve PEoLC in the Community in Leeds. The focus of the project is PEoLC within the community in Leeds, including interface with hospital-based care. PEoLC in the Leeds Teaching Hospitals NHS Trust was, with the pressures of COVID-19, considered to be out of scope of this work given the timeframes of this project. Therefore, references to care in the acute setting primarily focuses on the point of discharge and the pathway out of hospital, with the route in, and care delivered within hospital out of scope. Whole system in this context therefore refers to 'community whole system', rather than 'across all settings in the whole system'.

Given the above context, the project was split into two key phases:

Phase 1 - A Whole Systems Approach (WSA) based on the Public Health England guide – Whole systems approach to obesity: A guide to support local approaches to promoting a healthy weight – which was developed over four years by Leeds Beckett University in collaboration with local authorities, the Association of Directors of Public Health and the Local Government Association[7]. The guide provides information on how to develop and implement a WSA in practice. This includes a six-phase process with supporting materials that can be used flexibly, considering existing strengths, relationships and actions that are in place. It should be recognised that the guidance was developed for local authorities and as anticipated certain elements have been adapted recognising the existence of and work already undertaken by LPCN and its partners. This approach is ideally suited for the types of questions encountered in PEoLC because intervention targets are typically multilevel, multi-layered, and embedded within complex social and environmental systems. Phase 1 of the project included the first four-phases of the Public Health England guide.

Phase 2 – The implementation of the action plan developed in Phase 1 to ensure that there any suggestions for service redesign make the best use of the resources available to deliver the most effective and compassionate care outside of hospital for patients, families, and carers.

This report provides detail of the work undertaken by Leeds Beckett University, who were funded by the LAHP, to support Phase 1 of the project.

COVID-19

It is important to keep in mind that during the course of the project, the pandemic spread of COVID-19 was declared a national public health emergency and varying degrees of social distancing advice and restrictions on peoples' movement took place. Major implications of the pandemic and associated government restrictions for the project were twofold. Firstly, the duration of Phase 1 was considerably extended; from a planned 6 months to 18 months. Project timelines were revised on several occasion in light of postponement and or cancellation of in-person events, and in consideration of asking for participation from NHS and care sector staff who were facing particularly challenging working conditions. Secondly, a number of changes were required to the planned methodology. In particular, the majority of in-person events changed to a virtual format and were shorter, as many of the participants had clinical responsibilities. We know that the workforce capacity for creative thinking was reduced during this time as the workload was so significant. People were adapting to challenges and uncertainty about their work arising from sickness and redeployment.

The pandemic also had an impact on the whole system as we were trying to map it. There was a significant shift as the public were avoiding hospital and care home admission and choosing to die in the community because of restrictions that needed to be applied in institutions. This increased activity for community providers has continued even after the height of the pandemic has passed.

The implications of the extended duration of Phase 1 or the methodological amendments cannot be determined for certain, but it is not envisaged that they resulted in a change in the content of the outputs, due to the anticipated variety of stakeholders still being engaged in their development. However, it is important to note that a key aspect of a WSA is the opportunity for formal and informal discussions and relationship building between stakeholders, which would ordinarily occur during in-person events. The effects of these opportunities not taking place, may become apparent during Phase 2 when stakeholders need to work closely to undertake the proposed actions.

Implementation

Project governance

It is necessary to establish the governance structures and support required to effectively implement a local WSA. For the project, Diane Boyne (LPCN Manager), Ruth Gordon (LPCN Project Lead), Amanda Storer (LPCN Administrator), and Duncan Radley (Leeds Beckett University) were identified as the core working team (CWT). The responsibility of the CWT was to co-ordinate the approach, undertake the day-to-day work, and provide administrative support.

The CWT reports through the PEoLC Community Flow Improvement Group (CFIG). This group then reports into the LPCN Executive group and the LPCN group. CFIG and LPCN are established groups that provide the senior leadership. The LPCN includes health and social care providers in Leeds, who are working together to improve services for adults approaching the end of their life. The purpose of the LPCN is to help organisations work together to plan and deliver care, in the best possible way for PEoLC patients, their families, and carers. The CFIG is a sub-group of the LPCN which includes senior leads from across the PEoLC partnership, meeting collectively to discuss, agree, and plan improvements. There is membership from all key organisations involved in palliative care across Leeds. The group aims to ensure that the community service model across all providers delivers high quality care, dignity and respect, patient and family choices, and provides an efficient seamless transfer process between organisations providing PEoLC services for adults in Leeds.

Project progress up to June 2021

A full outline of the work undertaken by Leeds Beckett University prior to June 2021 to support the wider project can be found here[8]. In brief, the objective of this earlier part of Phase 1 of the project was to develop a shared understanding of the whole system for PEoLC within the community in Leeds, including interface with hospital-based care. To achieve this, a series of eight virtual events were undertaken with professionals during November and December 2020, to which over 100 people from different organisations attended, including: acute and community health care, social care, care homes, as well as voluntary and independent organisations.

Information gathered during these events was collated alongside information obtained from a project led by Healthwatch Leeds which collated the views of patients, families, and carers who have received and supported end of life care. As part of the Healthwatch project, thirty-one people responded to a survey about end of life care and fifteen in-depth interviews were undertaken about their experiences of receiving PEoLC. The report developed from the questionnaires can be found here[9] and the showreel from the case study interviews can be found here[10].

The collated data was used to produce two visual representations of the findings:

- Stakeholder map (can be found here[11]) - shows the identified key stakeholders and services, with the detail of what is delivered by these services outlined underneath, including those services providing support for patients who are approaching their end of life or offer support after a death has occurred entitled “additional services”.
- Systems map (can be found here[12]) - shows the many local factors that make up the systems related to PEoLC 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.

Development of priority areas for action

The objective of the latter part of Phase 1 of the project was to determine key areas for action during Phase 2.

Development of proposed themes

Between July and August 2021, the LPCN used the systems mapping and the commissioned piece of work by Healthwatch Leeds, in conjunction with service views and analysis of healthcare data (as outlined below), to develop key themes and options for action to discuss with wider stakeholders during a workshop in October 2021.

- Service provider view – led by NHS Leeds clinical commissioning group (CCG), this project focused on a conversation about the potential mismatch between the level and responsiveness of care that core providers of community PEoLC are able to deliver in comparison to that which is described to people and system partners.
- Healthcare data – analysed existing information 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 electronic palliative care coordinating systems (EPaCCs) data.

Stakeholder workshop (Oct 2021)

Understanding how and where to intervene in a system is key to help identify which actions are more likely to bring about sustainable systems change. In October 2021, a virtual workshop was held with 36 stakeholders from across the system (including representatives from acute and community health care, social care, care homes, as well as voluntary and independent organisations) to discuss the themes and options for action developed by the LPCN to try and identify those that provide the greatest opportunity for system change.

'Six cohering questions' soft systems methodology underpinned the workshop activities[13]. The questions promote the emergence around consensus of purpose for implementing the approach, and a set of actions that the group agree are useful next steps to achieve that purpose. It also promotes clarity over who is involved in delivery, oversight, and the broader constraining factors that must be taken into consideration. Questions embedded with the workshop activities included:

1. What are we trying to achieve? – This question helps to bring out the various perspectives. Generally, the prior appreciation will have aligned thinking, or the purpose or problem may be 'given'.
2. What do we think needs to get done to achieve it? This question draws out the differing belief and value systems of those involved as we all, though our different skills and experiences, will have a different view of what it takes to achieve the purpose, or address the problem agreed in the previous question.
3. Who benefits or is impacted by trying to achieve it? This represents the customer or beneficiary such that you can agree that the outcome is the benefit desired and considered of value.
4. Who is going to get these things done? This helps to consider who will do the activities identified above.

5. Who is in charge / who owns it? This identifies the 'owner' of the problem or system, the one who is accountable for the system's performance.
6. What are the constraints (for us and others)? This is often a key question as it will identify limitations that have to be considered and acted upon. They will constrain decision making and often provide system boundaries.

An outline of the workshop is provided below, including how the above questions were threaded throughout the workshop presentations and activities.

WORKSHOP OUTLINE

Welcome and Purpose (15 mins)
Introduced the established What are we trying to achieve? and Who benefits or is impacted by trying to achieve it? Included an overview of local strategic plans and the place of the project within the changing landscape of healthcare.

What we have done so far (10 mins)
An overview of the work undertaken to date.

What we found out (20 mins)
An overview of the outcomes from the work already undertaken, including final drafts of the stakeholder and system maps, the service user view, the report by Healthwatch Leeds and the key themes and options for action.

Breakout rooms (40 mins)
Discussion of the key themes to obtained consensus on What are we trying to achieve?

Taking action within a system (20 mins)
Presentation of systems change theory that provided a clearer understanding for stakeholder for What do we think needs to get done to achieve it?

Breakouts (60 mins)
Consideration of what good would like, including consideration of What do we think needs to get done to achieve it? Who is going to get these things done? Who is in charge / who owns it? and What are the constraints (for us and others)?

Questions and close (15 mins)
Summary, questions and next steps.

Development of priority areas

Following the workshop, outputs were collated by the CWT team in conjunction with all the previous information collected. Table 1 and Appendix 1 summarise how the five themes reflect the findings from the different data sources. Five themes emerged:

1. **Updating the service offer** – ensuring that there is one clear service offer across Leeds, 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

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

2. **Citywide single point of access** - to support people who are dying and their families and carers but also as a hub for information for professionals.

3. **Increasing resources** - to support death in the community. The increased number of patients choosing to die at home has been sustained and levels of support required remain high and complex. More resources are needed, and it is important to understand where and in what we would want to invest and how this needs to happen in the currently shifting world of commissioning.

4. **Recording one up-to-date Advance Care Pan** - that is updated and kept as a single version; with the patient, family, and carers having access to the updated version so it is available to all professionals.

5. **Improve timely prescribing** - both in terms of identifying what anticipatory end of life medicines need to be made available to the patient and also ensuring that prescriptions are written and filled in a rapid manner.

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

Table 1 Summary of how key themes reflect the findings from the different data sources (this is further described in Appendix 1).

Key themes	System mapping and user data	Service provider data	Healthcare data
New service offer/model	Issues of capacity and adequate staffing Willingness to explore care at home Early recognition of deterioration Professional knowledge of who does what	Workforce - Knowledge, skills development Workforce - Staff capacity Equipment – Availability and timely delivery Incomplete documentation Coordinated planning and communication between services Services able/unable to respond Key worker Complexity pathway Sustainable programme of education	Service specifications, leaflets and web information does not reflect current levels of service delivery
Citywide Single Point of Access for Palliative and End of Life care	Sharing of information Willingness to explore care at home Early recognition of deterioration Patient and carer knowledge of who does what Professional knowledge of who does what	Workforce - Knowledge, skills development Workforce - Staff capacity Equipment – Availability and timely delivery Incomplete documentation Coordinated planning and communication between services Coordination and planning with family Services able/unable to respond Proactive, person-centred advanced care planning	
Recording one, up-to-date ACP	Sharing of information Early recognition of deterioration Advance Care Planning Patient and carer knowledge of who does what Professional knowledge of who does what	Workforce - Knowledge, skills development Workforce - Staff capacity Incomplete documentation Coordination and planning with family Proactive, person-centred advanced care planning	
Improve timely prescribing	Access to medicines Professional knowledge of who does what	Workforce - Knowledge, skills development Accurate and Timely Prescribing Incomplete documentation	
Increasing resources available to support death in the community	Issues of capacity and adequate staffing	Workforce - Knowledge, skills development Workforce - Staff capacity	A 59% increase in the number of EPaCCs patients dying at home

Theory of change

Theory of change involves articulating the many underlying assumptions about how change will happen in a programme of work. A theory of change approach entails that people and organisations involved in intentional change processes explore and make explicit their theories of change and the assumptions underlying their thinking. This exploration includes clarifying how they see cause-effect relations between their actions and the intended changes.

During Phase 1, the preliminary development of a theory of change was undertaken as a process-oriented approach to integrating the complex system in which stakeholders work (identified during the systems mapping workshop) and planned actions stakeholders believed will influence parts of the system in a positive way (the key themes identified as the core of the Phase 2 service redesign of the Dying Well in the Community project).

The preliminary theory of change, developed as a working document to be refined throughout Phase 2, was created in February 2022 by five members of the CFIG team during a 2-hour workshop. Prior to the workshop, a draft theory of change was produced by members of the CWT by analysing the variables and inter-relationships from the systems map created during the earlier stakeholder workshops (map can be found here[12]). The theory of change was then discussed and refined using a digital whiteboard (www.miro.com) during the workshop.

During the workshops, participants were asked to describe relationships between:

- Activities (what you will do)
- Enabling factors (what will your activities produce - why they will lead to the required outcome)
- Outcomes (goals to attain)
- Long-term impact

or more simply:

- If, Then, Because - If we do this (activity), Then we will achieve this (outcome), Because this happens (enabling factor).

Figures 1-4 show the developed theory of change. For the theme 'Updating the service offer,' two theories of change were developed, one considering timely conversations about death and dying (Figure 1) and one considering one clear service offer (Figure 2).

Theory of change offers an entry point for questioning, documenting, and monitoring of what stakeholders believe will happen and what happens in reality. As such, the developed theory of change provides a basis for evaluation and review during the Phase 2 implementation, as it makes explicit what the programme aims to achieve, why and how it is supposed to work, and key assumptions made. Further monitoring and evaluation should seek to substantiate the validity of the theory of change, offering important information and insights for possible programme updates and subsequent evolution, or for learning with similar initiatives.

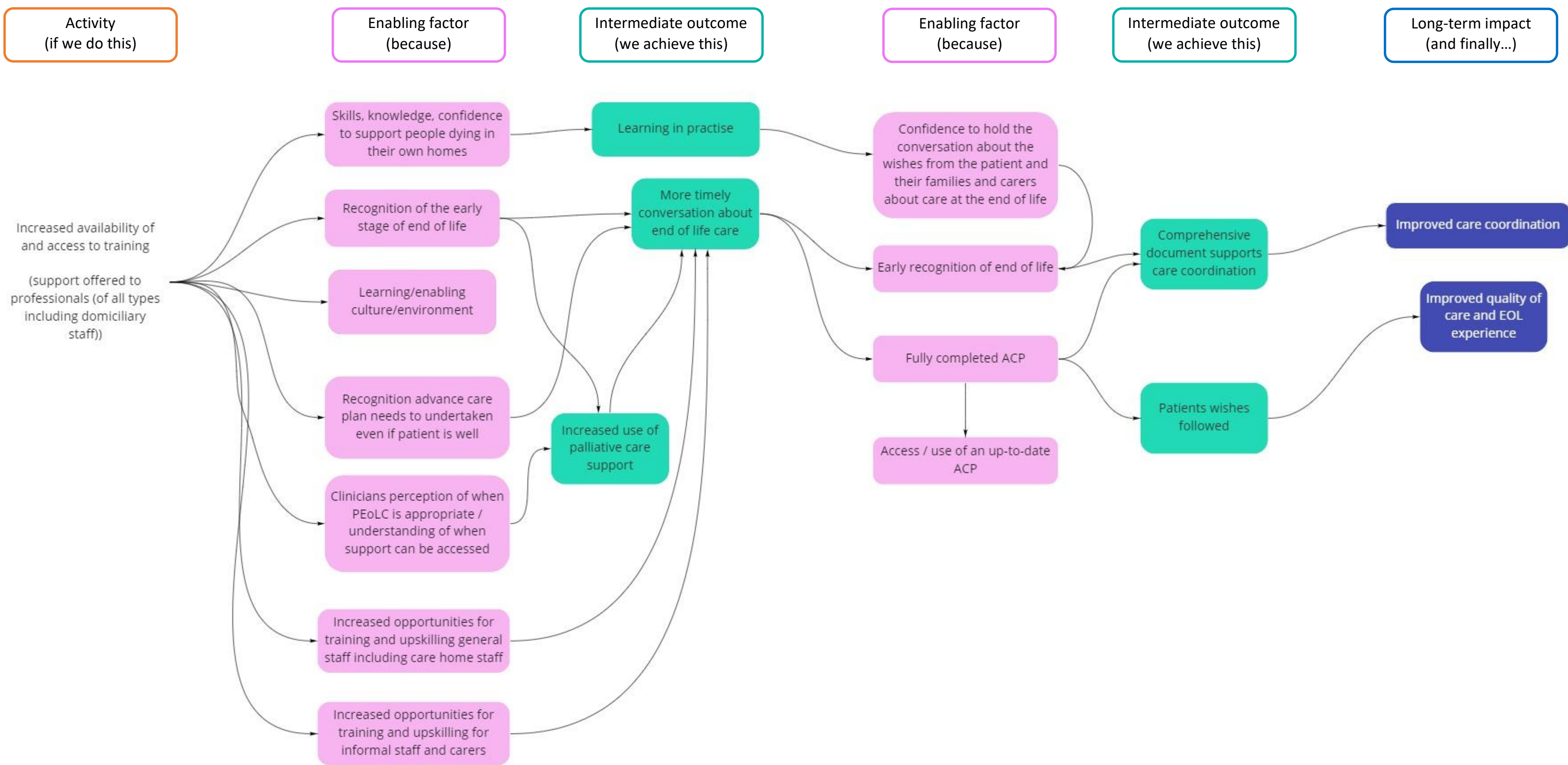

Figure 1. Theory of Change related to updating the service offer (timely conversations about death and dying)

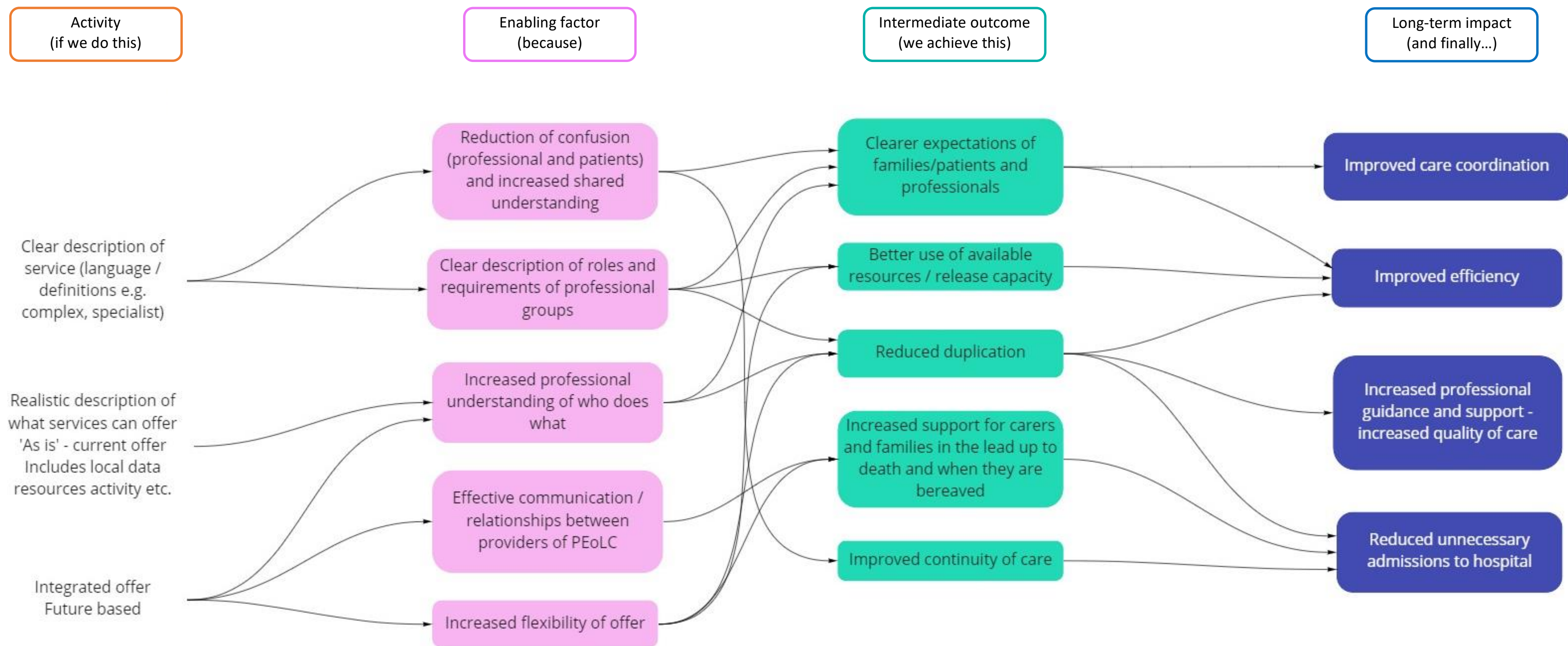

Figure 2. Theory of Change related to updating the service offer (one clear service offer)

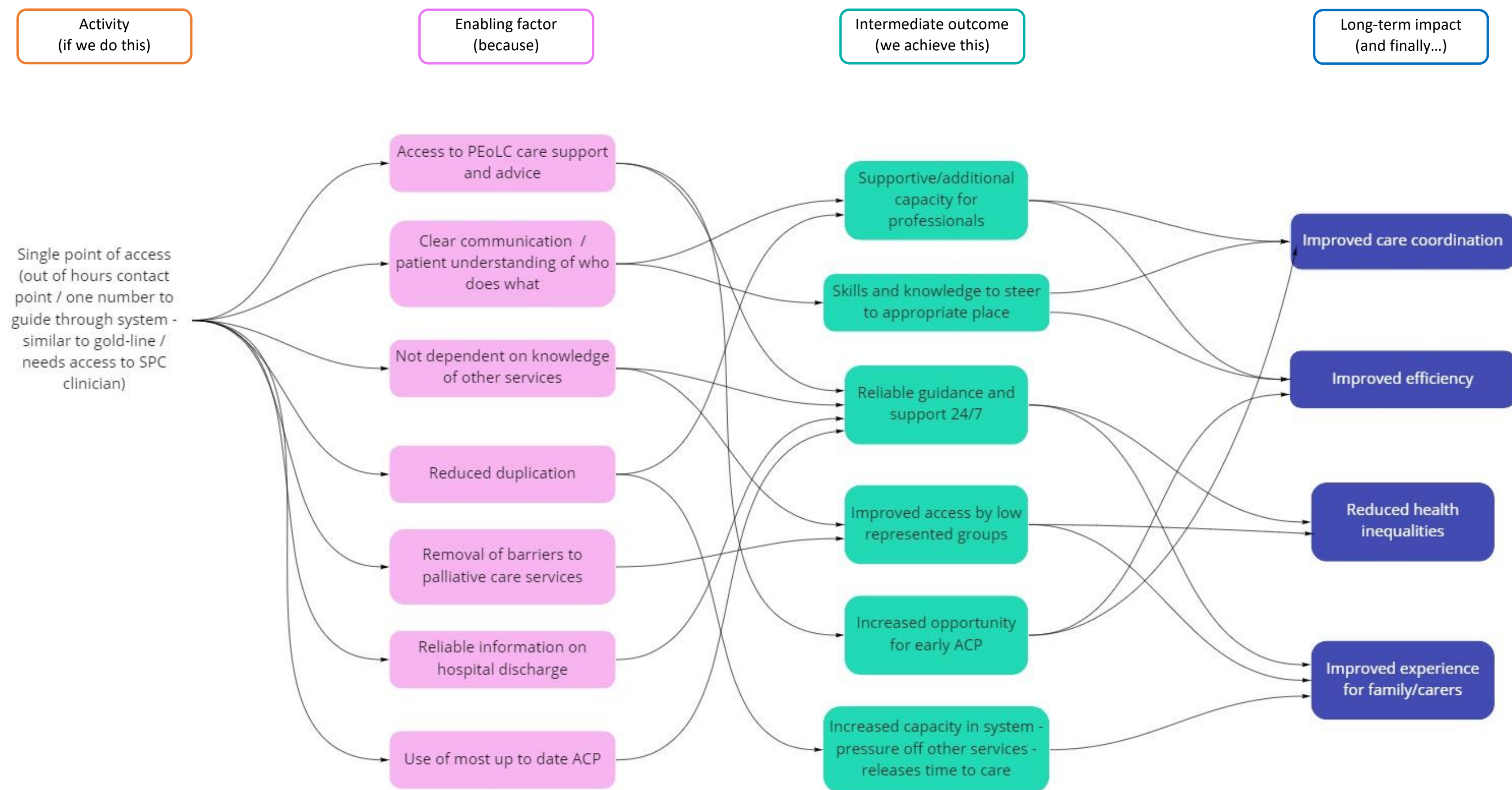

Figure 3. Theory of Change related to a citywide single point of access

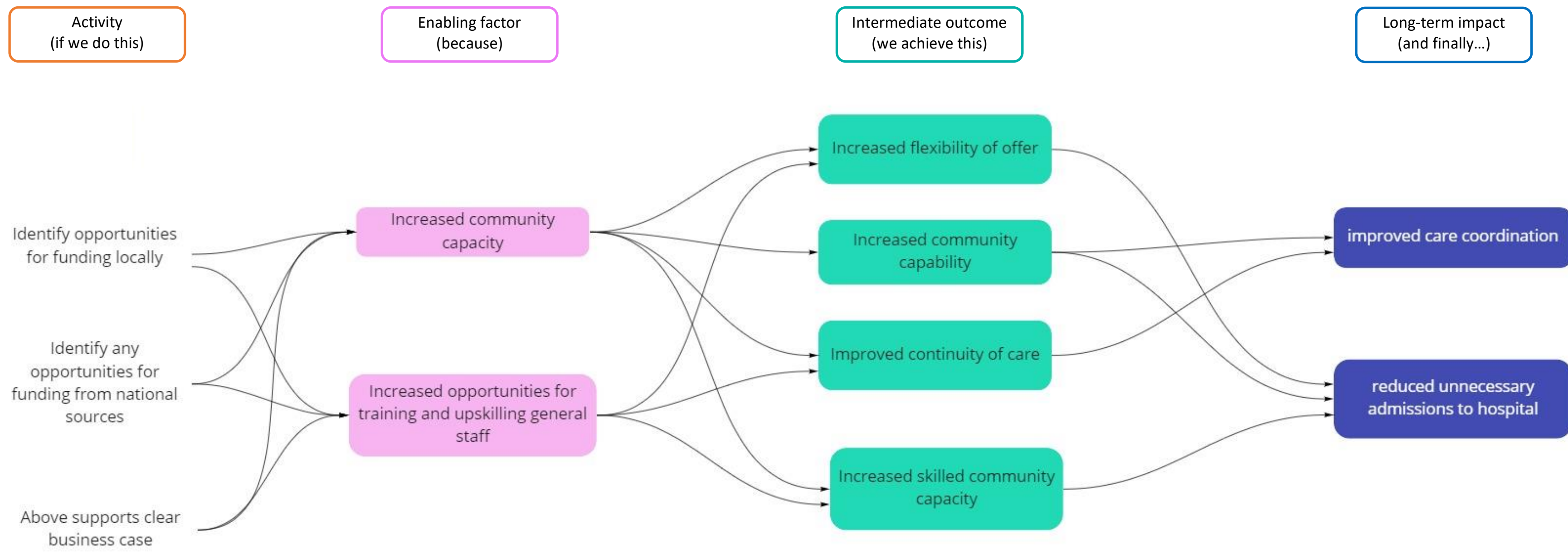

Figure 4. Theory of Change related to increasing resources

Project evaluation

Methodology

Workshop feedback

All stakeholders who attend the October 2021 workshop were asked to complete an online evaluation form, which was co-produced by the CWT to ensure data was relevant both to the local delivery and Leeds Beckett evaluation team.

The first part of the feedback form focused on the content of the workshop (e.g. if participants felt it was relevant and easy to understand) and if it increased participants knowledge of the complexity of any issues and potential solutions to improve end of life care. Responses were captured using a mixture of Likert scale (i.e. strongly disagree, disagree, neither agree not disagree, agree, or strongly agree) and free text responses.

The second part of the feedback form used an adapted version of the e-Health Implementation Toolkit (e-HIT) questionnaire[14]. e-HIT is a guide to help decide whether to embark on an implementation initiative. The original questionnaire consists of 21 statements that aid in evaluating the context of the intervention, its features, and the workforce response to the idea of the implementation. The evaluations are expressed on a scale from 0 to 10. Scores provide a robust way to assess potential issues around how an innovation may be implemented into an organisational practice. The questionnaire was originally applied in relation to e-Health interventions but was modified to only include the ten questions considered most relevant to this stage of the project, and reference to e-Health was changed to 'systems approach' (see Appendix 2).

Interviews

A convenience sample of four individual, online interviews took place with key stakeholders in June 2022. The interview guide was semi-structured in nature and included 11 open-ended questions structured to prompt discussion with probes and follow-up questions adopted as needed (see Appendix 3). Semi-structured interviews were used to guide the direction of the conversation with the interviewee, whilst simultaneously enabling the researcher to develop a rapport with the interviewee. The 'semi-structured' aspect of this approach allowed the interviewer to explore emerging themes as well as salient issues in relation to the project.

Interviews were led by a trained facilitator experienced in conducting qualitative data collection methods. Interviews were digitally recorded and transcribed verbatim. The text for each data collection session was sequentially labelled with numbers to identify the sentences that belonged to the participant or interviewer. All data were anonymised and transcripts were coded throughout to ensure confidentiality. Verbatim transcripts were read and re-read to allow familiarisation with the data. Transcripts were analysed in this manner until data saturation had been achieved and no new information had been obtained. Data was coded, analysed and displayed via the pen profile approach. The pen profile approach presents qualitative findings as a diagram of composite key emerging themes. Each pen profile represents a major theme and associated relevant minor themes identified within the data (for further details of this approach see Sanders et al., 2019[15]).

Stakeholder survey

In June 2022, an online survey was sent to all stakeholders who participated in either of the workshops. Part one of the survey focused on the process undertaken during Phase 1 of the Leeds Dying Well in the Community Project and part two focused on the three priority themes of work. Responses were captured using a 6-point Likert scale (i.e. strongly disagree, disagree, slightly disagree, slightly agree, agree, or strongly agree).

Triangulation

The mixed methodological approach outlined above provided information in a range of forms. The process of triangulation was undertaken to draw together these varied data forms. Triangulation is the cross verification of multiple methods and sources and can lead to a multidimensional understanding of complex issues. Triangulation tests the consistency of findings obtained through different methods to explore convergence, complementarity, and dissonance. This process increases the likelihood that the findings and interpretations will be robust and reflect and a true representation of stakeholder views.

Findings

Workshop feedback

Seventeen (out of 36) attendees provided feedback. Stakeholders overwhelmingly agreed or strongly agreed that the workshop was 'well-paced, and that content was 'easy to understand', 'comprehensive', and 'relevant' (Figure 5). The majority of participants also agreed or strongly agreed that the workshop increased their knowledge of the complexity of PEoLC and helped them to think differently about possible solutions to improve care (Figure 6).

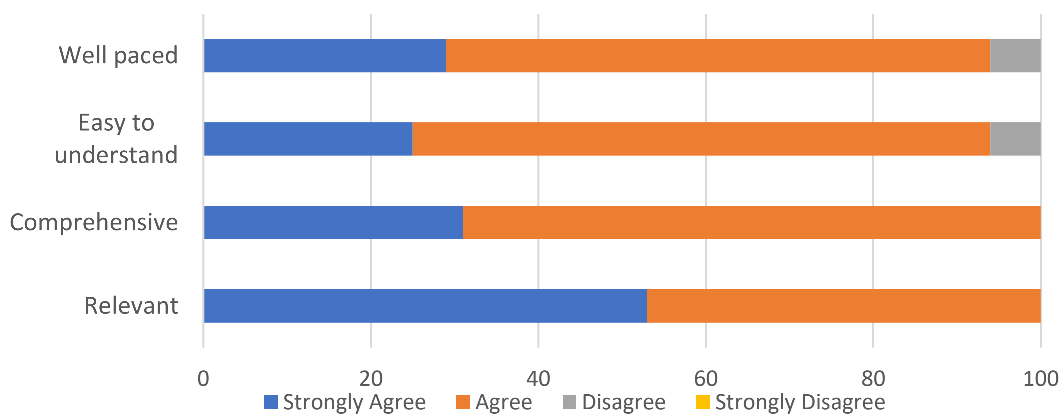

Figure 5. Percentage responses about the workshop content and delivery.

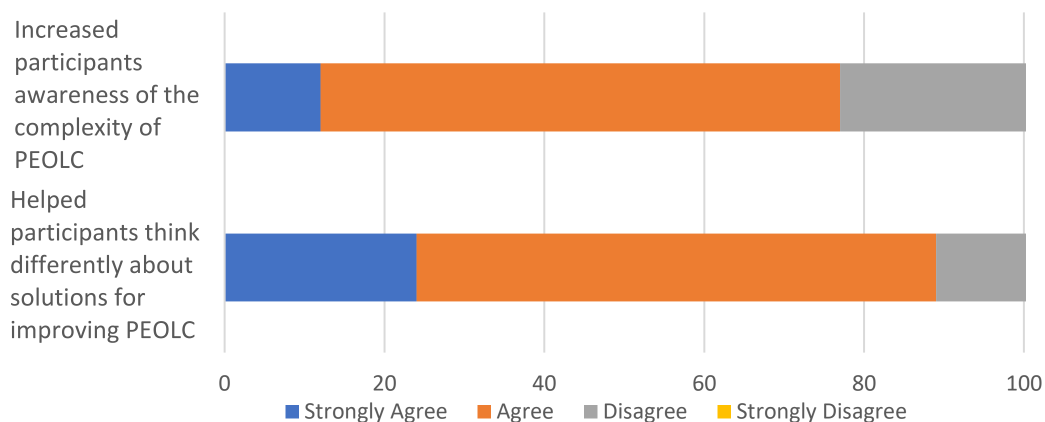

Figure 6. Percentage responses about the increase of knowledge from the workshop.

e-HIT

Given the small sample size, and the fact that e-HIT ratings do not benefit from a validated scale, the results were interpreted by plotting the mean and standard deviation of the ratings and qualitatively appraising the information. Figure 7 shows the mean and the standard deviation for each statement employed in the modified e-HIT. Keywords on the left-hand side provide a reference to the statements (see Appendix 2 for the full statement list). Higher values represent a more positive evaluation.

A visual examination of Figure 2 shows that most scores are in the upper range of values with a moderately large standard deviation. The results are best interpreted considering the two clusters of statements that naturally form. On average, the areas of most significant concern (i.e. that reported the lowest average scores of 4.7 and 5.8) refer to resources, specifically the costs and additional workload required for the implementation of the approach (s8) and the existing allocation of resources or the formal/informal norms by which they are allocated (s9).

The remaining statements scored between 7.2 and 8.2. These are positively evaluated areas suggesting that respondents felt:

- the organisations involved welcome new practice
- staff groups have good working relationships
- the approach is strongly supported by a well-respected local sponsor
- opinion leaders will support the implementation
- the approach is compatible with the system's existing risk management policies
- the approach aligns with the achievement of national or local policies.

The overall evaluation suggested that participants were favourable toward employing the approach, but at the same time, concerned about how it would fit into their work without additional resources and support.

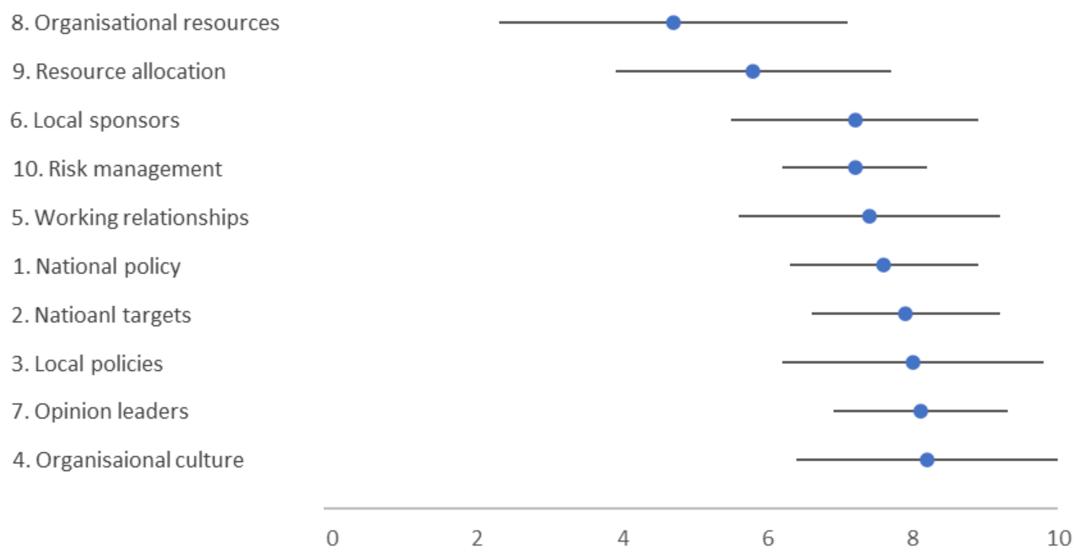

Figure 7. Mean and standard deviation for positive or negative appraisal of a systems approach in relation to 10 statements. Higher numbers represent positive appraisal

Interviews

Context

The first major theme identified within the data was 'Context', which contained four associated minor themes: 1) Expectations, 2) Process, 3) End Result, and 4) Future (Phase 2) Considerations (Figure 8).

Expectations. Positive (55%) comments noted focused upon the rigour provided by the academically validated process, as well as the support, guidance, and partnership with Leeds Beckett University:

> *"The WSA provides an agnostic, systematic and academic way of collating intelligence rather than purely relying upon third party opinions." (P1)*

> *"The guidance of an academic expert instrumental in the design of a WSA was instrumental in us grasping the overall concept." (P3)*

Negative (45%) comments noted revolved around the time intensiveness of the mapping process, and the fact that stakeholders hadn't appreciated and/or expected just how complex local and city-wide systems were after having been highlighted by the Phase 1 mapping process:

> *"We were hoping we would get fairly quickly an academically rigorous process that provided an overview of key stakeholders opinions on current challenges to the area and how to start to overcome these. This wasn't the case and was further exacerbated by obvious challenges thrown into the mix from COVID and its impact on staff workload." (P1)*

Process. Although a WSA is increasingly being advocated as a way of responding to system complexities[16], a formal definition is yet to be agreed upon. Without a clear, shared understanding of the funding, patience (e.g., conflicting views) and time required to plan and implement a WSA from the outset, progress can be delayed and even halted[17]. Such views were reflected in the negative (42%) views regarding the Phase 1 WSA process:

"Unfortunately, everybody involved in the process was extremely busy and so without clarity about where the process is heading from the start it is hard to find motivation to devote time to it." (P2)

"I don't think there was a clear objective of what we were aiming towards, so discussions felt very nebulous initially." (P3)

Contrastingly, positive (58%) comments noted how stakeholder 'buy-in' became stronger, and collaborative ways of working more efficient as the mapping exercises progressed:

"After the halfway point when we started to do the systems mapping and create the key workstreams things became clearer as to the avenues we were going to develop further. I just wish I knew what was going on from the start. Luckily, I stuck with the process but fear others may have been lost before this clarity was gained due to a lack of clear understanding as to each meetings purpose from the outset." (P1)

End Results. The largely positive (92%) comments regarding the resultant Phase 1 stakeholder and systems maps reflect the potential benefits of adopting a WSA and further adds to the growing literary support for this process[17]. Stakeholders in the current project noted that although such maps didn't necessarily 'reinvent the wheel' and unearth any unknown system challenges and complexities, they did however provide a valued, and not attempted before, opportunity for a collaborative and coproduced 'pen to paper' exercise:

"Nothing new was identified by the process but what it did do was further reinforce what was already known and display this is an actionable way." (P1)

"We now have a clear indicator of changes we need to make within the system to improve the level of care for people dying within the community." (P3)

"Without a doubt the process has added value and increased understanding of the areas we need to focus on in the short, medium and longer-terms." (P4)

Future (Phase 2) Considerations.

Three key areas of focus emerged within the theme 'Future (Phase 2) Considerations'. Namely, these included: i) avoiding a 'top-down' approach to systems change; ii) clearly outlining short, medium, and longer-term goals; iii) ensuring that there is sufficient funding for continued stakeholder engagement and integration.

Stakeholders noted:

"We need to disseminate engagement and feedback surveys about the WSA process and its potential benefits to the end user so everyone within the community has the opportunity at least to voice their wants and needs." (P1)

"A wider reach is needed, specific to ground level patients and marginalised groups and in particular how they feel that they can be better supported. We (as high-level stakeholders) assume we know all the needs of the patient. We don't." (P2)

"Need to take baby steps during the implementation phase otherwise colleagues may be overwhelmed by the potential workload." (P2)

"Need to be clever about the incentives in terms of publicity, advertisement and opportunities for involvement and allow very flexible plans and goals to ensure community buy-in." (P2)

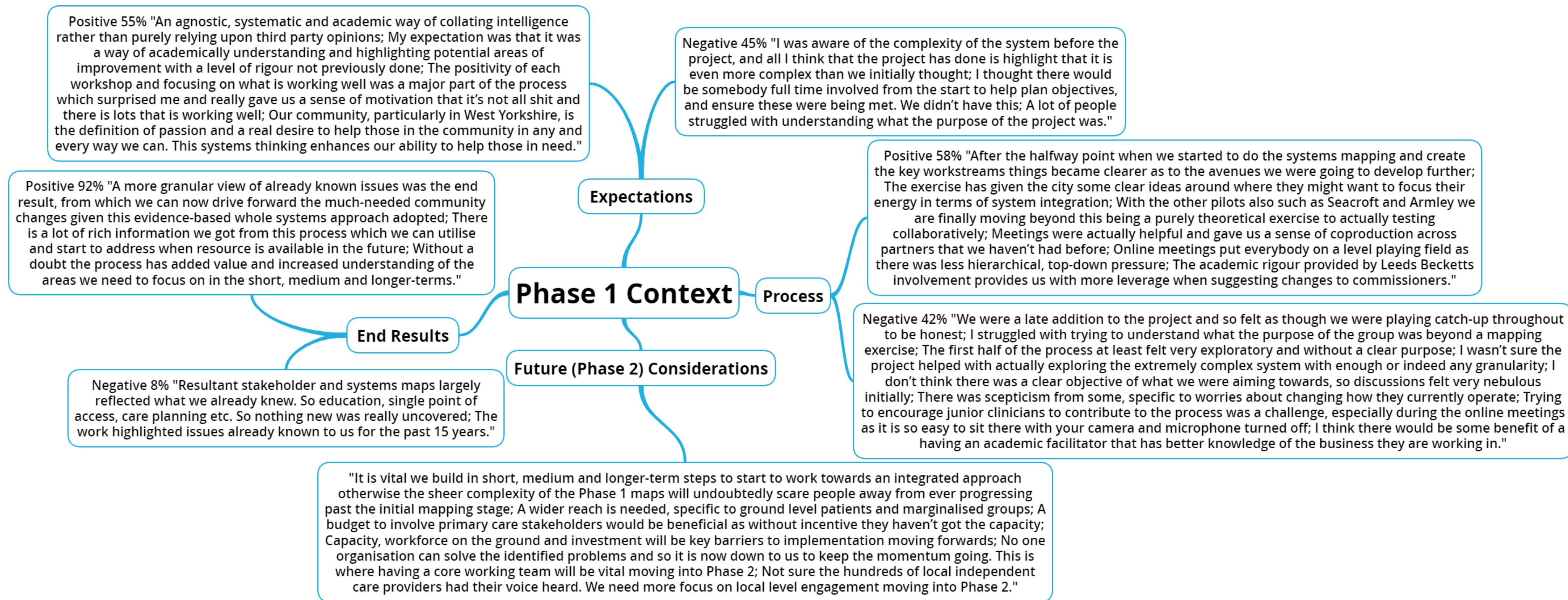

Figure 8. A pen profile representing 'Context' and associated relevant minor themes.

Involvement

The second major theme identified within the data was 'Involvement', which contained three associated minor themes: 1) Engagement, 2) Collaboration, and 3) Integration (Figure 9).

Engagement. Identifying key stakeholders and community members, securing their early participation, and building strong relationships is considered key to influencing effectiveness[18], whilst engaging non-traditional partners such as local community champions can expand reach[19]. Utilising networks and relationships that are already established can be a useful tool to engage partners and link WSA into work that is already happening locally. The mixed (50% positive; 50% negative) comments by stakeholders reflect the challenges in defining what 'successful' engagement looks like:

"We struggled to engage with larger services, hospitals and high-level managers mainly due to lack of capacity from members working within these areas. Representation from patient and marginalised community members were also absent despite discussing the importance of having such on numerous occasions." (P1)

"The Leeds Palliative End of Life Care network has a relatively robust set of resources available anyway but this process allowed us to widen our reach and engage with more front line staff and independent partners and providers." (P3)

Collaboration. Creating a WSA requires sustained coproduction and support from stakeholders with a range of expertise to ensure the approach has sufficient challenge, governance and resource[7]. Both positive (69%) and negative (31%) stakeholder comments specific to the theme 'Collaboration' focused upon concerns, predispositions and wariness of stakeholder influence and power dynamics.

"Threats and wariness of other stakeholders around the table were very obvious in terms of pointing fingers and potentially changing ways of working at the start of the process." (P1)

"Throughout the process colleagues' concerns and predispositions about the process reduced and only then did we start to show that it is possible to not only coexist but also collaborate and coproduce on the palliative end of life care agenda. This felt like a lightbulb moment for everybody involved." (P3)

Integration. Systems integration is a dynamic process with complex interdependencies and evolving systems. It involves integrating existing, often disparate systems in such a way that focuses on increasing value to the end user whilst also balancing change with stability. Largely positive (67%) comments were noted by stakeholders with regards to the theme of 'integration'. Comments noted that in general, there was a strong sense of understanding between organisations in how integrating across Leeds could only strengthen the PEoLC systems currently in place.

"We have just agreed some funding through LPCN to work on moving this Phase 2 forward so things don't stagnate." (P1)

"The project team was a major benefit of this process and our collaborative working and integration throughout differing sectors has and continues to strengthen." (P4)

Although it was recognised that system integration was vital to improve current systems, in line with prior research[20], some negative (33%) comments noted that throughout Phase 1 there remained a disconnect and lack of representation from primary care providers, care homes, social services, and the local authority itself due to a lack of time to engage with a process that remains misunderstood by many.

"The reality is that unless we fully integrate all of the hospice clinical staff, care homes, primary and community care homes that deal with end of life we probably won't get really good integrated services within each area of Leeds." (P2)

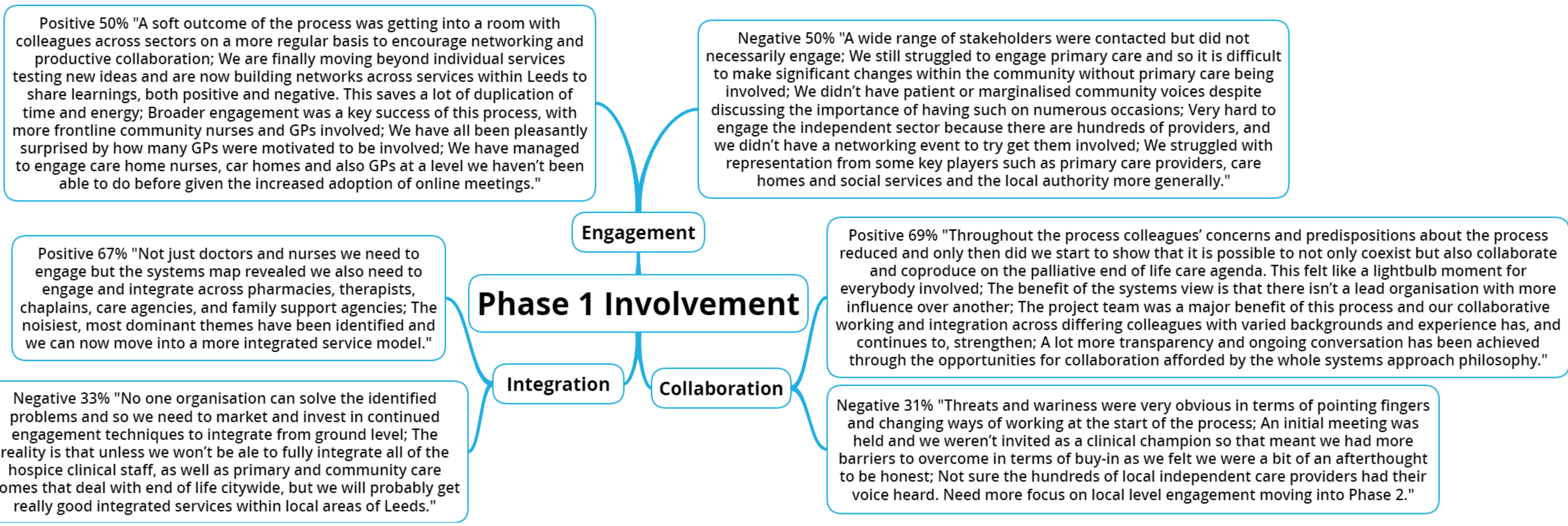

Figure 9. A pen profile representing 'Involvement' and associated relevant minor themes.

Stakeholder survey

Eleven (out of 167) stakeholders provided feedback. Given the low response rate, the findings from the stakeholder survey must be interpreted cautiously and only in conjunction with other findings.

Overall, stakeholders agreed that the process was clear, they felt involved and they felt confident in expressing their views during events (Figure 10). However, this agreement was only partial in a large proportion on stakeholders who only 'somewhat agreed' with the statements.

The majority of participants also agreed or strongly agreed that the workshop increased their knowledge of the complexity of PEoLC and helped them to think differently about solutions to improve care (Figure 6).

Responses to questions concerning the implementation of the three areas of work identified for Phase 2 of the project were highly variable (Figure 11). Over 50% of respondents disagreed that adequate resources are available, and over 45% did not feel staff have the necessary skills. Overall, respondents felt there was adequate leadership support available and that the multiple staff groups likely to be involved in the Phase 2 implementation have good working relationships.

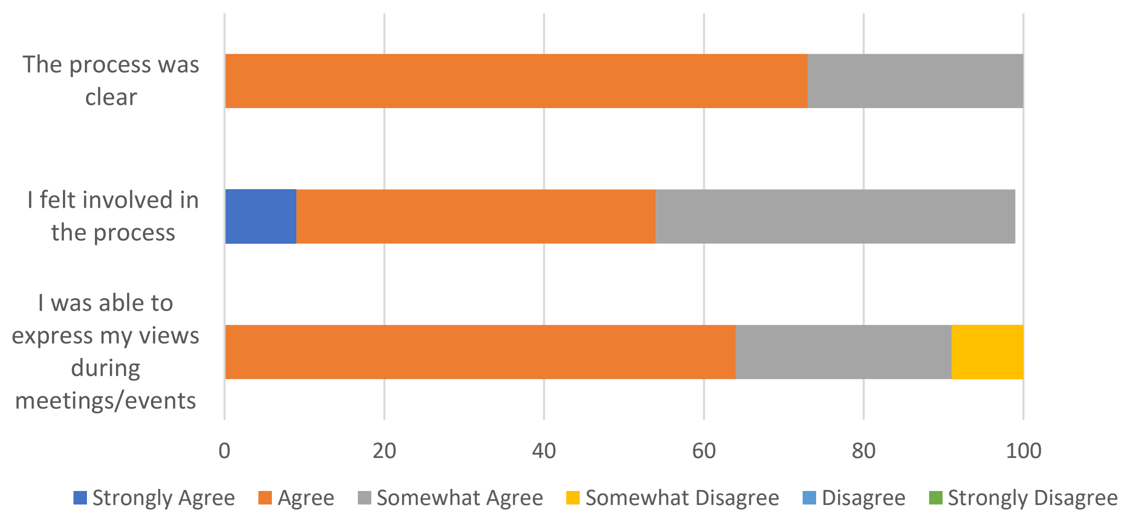

Figure 10. Percentage responses indicating how much stakeholders agreed or disagreed with statement about the process.

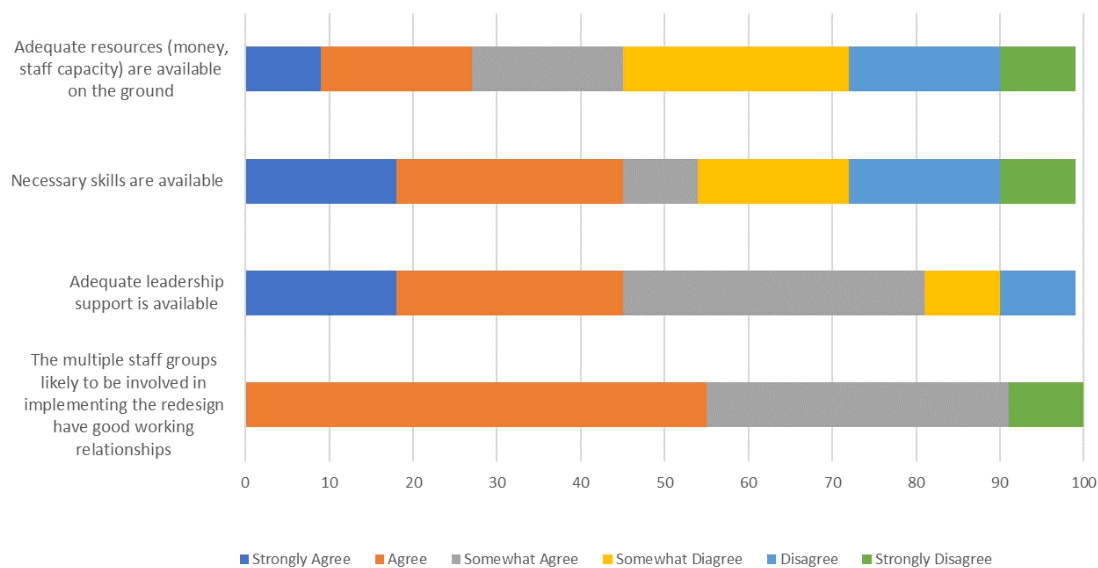

Figure 11. Percentage responses indicating how much stakeholders agreed or disagreed with statement about the implementation of the key themes for Phase 2.

Triangulation of findings, key learnings and recommendations

Phase 1 implementation

- The rigour provided by the academically validated process was acknowledged as a positive during the implementation of Phase 1 and workshop activities were well received, with participants believing the information to be clearly presented, providing them the opportunity to put forward their views and increasing their understanding of the complexity of PEoLC and the differing options for action to elicit system change.

- Further clarity of the whole process at the outset and clearer information of the purpose of each activity would have been beneficial. Stakeholders' receipt of a WSA is largely dependent upon initial and ongoing expectations. Expectations themselves are shaped by project management and structures (e.g. the processes, methods, skills, knowledge, and experience utilised to achieve specific project objectives according to the project acceptance criteria within agreed timescale and budget). These are encompassed by one's initial and ongoing motivation to engage with the project process, as well as perceived individual and organisational project value[21].

- For similar initiatives and for Phase 2 of the project, it is vital to share what is involved in the different stages and make it extremely clear what the aims and objectives of each activity are, what outputs will be produced, and how these will be disseminated.

Phase 1 outputs

- The largely positive comments regarding the resultant Phase 1 outputs (stakeholder and systems maps) reflect the potential benefits of adopting a WSA and further adds to the growing literary support for this process[17]. Both stakeholder and systems maps are well established within complexity science and are increasingly being adopted by those facing complex issues across the

UK to bring stakeholders together to help them identify local assets and work collaboratively and constructively to understand each other's perspectives and encourage joint decision-making[22].

- Whilst some interviewees noted that the maps did not unearth any unknown system challenges and complexities, the majority of stakeholders in the workshop felt that activities increased their knowledge of the complexity of PEoLC and helped them to think differently about solutions to improve care.

- Moving into Phase 2 implementation, it is important to reinforce the use of outputs from Phase 1. The stakeholder map and systems maps are valuable tools to ensure the continued collaboration and integration between as wide a variety of stakeholders as possible. Theory of change offers a good base for continued monitoring during Phase 2 of programme and will support an improved and shared understanding of the initiative by the team and other stakeholders. If used well, a theory of change enquiry is an ongoing process of analysis and reflection. It is not a one-off exercise in the design phase of a programme, but rather involves an ongoing action-learning cycle. This in itself often leads to improvement of implementation and/or a next phase.

Relationships between organisations

- Importantly, stakeholders indicated that the organisations involved welcome new practice, did not view the approach being at odds with the achievement of current national or local policies, and believed that there is the supportive senior level leadership in place.

- Strong, equitable relationships between steering organisations, topic experts, and multisector, high-level stakeholders are vital within whole systems thinking[7], and provide the initiative with a sustainable foundation to promote shared ownership of the approach and further its sustainability into the future[23]. It was generally felt that the multiple staff groups likely to be involved in the implementation of Phase 2 have good working relationships.

- However, the need for wider community and marginalised group involvement was highlighted. Adopting a bottom-up approach can develop greater trust and understanding between public sector organisations delivering a WSA and those in the community to support the transfer of power, particularly around decision making (e.g. changes to ways of delivery and working)[24]. Previous research shows that resistance to change is not uncommon where organisations decide or are required to take an innovative change of approach[25]. To overcome such resistance to change, it is vital that organisations implement a supportive and open communication culture with local communities and people[25]. Furthermore, actively listening to the voice of the community may lead to those engaged in governance, policy, and practice to change their established approaches to better meet the needs and aspirations of local people.

- Overall, a coordinated and sustained effort across all hierarchical levels is warranted to implement and maintain momentum moving into Phase 2.

Ways of working

- WSAs explore interpersonal discrepancies and ineffective processes and hence, assume some level of system change or transformation is required, which could be viewed as being disruptive to current ways of working. Whilst survey results suggested that staff groups and organisations have good working relationships, concerns were also raised around changing ways of working.

- It is imperative to understand how stakeholders and their organisations operate and how their objectives align with the wider project. This helps to build trust and understanding and can help alleviate any concerns regarding ‘hidden agendas’ and a ‘how will any changes be of

benefit/detriment to current processes'. During Phase 2, consideration should be given to providing a 'safe space' for sharing findings and time for those involved to 'work through' any identified challenges in order to direct new approaches.

- The overall evaluation suggested that stakeholders were favourable toward employing the approach and supported the prioritised themes for action, but at the same time, were concerned about how it would fit into their work without additional resources and support.

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Appendices

Appendix 1. Summary of how key themes reflect the findings from the different data sources

System mapping and user data	Service provider data	Healthcare data	Workshop data	Summary of key actions from Phase 1 review
Issues of capacity and adequate staffing	Workforce - Staff capacity	A 59% increase in the number of EPaCCS patients dying at home The caseload of NTs increased by 21% between September 2019 and August 2021	Lack of resources Integration Complexity	Increasing resources available to support death in the community Describe Service offer/model Develop Shared language
Ability of neighbourhood team to respond	Services able/unable to respond	The caseload of NTs increased by 21% between September 2019 and August 2021	Understanding of Service Offer Integration Complexity	New Service Offer/model
Sharing of information	Incomplete documentation	Patients who died and were included on EPaCCS	Carer support Single point of access Access to information – Single Sharable ACP	Citywide Single Point of Access for Palliative and End of Life care Describe Service offer/model Develop Shared language
Early recognition of deterioration	Workforce - Knowledge, skills development	Duration of time (in weeks) the patients were on EPaCCS	Carer support Societal Change - Death and dying	Increasing resources available to support death in the community Describe Service offer/model Develop Shared language
Advance Care Planning	Proactive, person centred advance care planning	EPaCCS patients who have a ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Code recorded on the system	Carer support Access to information – Single Sharable ACP	Recording one, up to date ACP Develop Shared language
Patient and carer/family knowledge of who does what	Coordination and planning with family	Reasons for Unplanned hospital usage (Non-Elective Admissions) by EPaCCS Patients in the last 90 days of their life	Carer support Societal Change - Death and dying	Citywide Single Point of Access for Palliative and End of Life care Describe Service offer/model Develop Shared language
Professional knowledge of who does what	Coordinated planning and communication between services	Reasons for Unplanned hospital usage (Non-Elective Admissions) by	Integration Understanding of Service Offer	Increasing resources available to support death in the community New Service Offer/model

		EPaCCS Patients in the last 90 days of their life	Societal Change - Death and dying	Describe Service offer/model Develop Shared language
Access to medicines	Accurate and Timely Prescribing		Access to meds	Improve timely prescribing
Willingness to explore care at home		Percentage of Patients on EPaCCS who have achieved Preferred Place of Death	Complexity Societal Change - Death and dying Integration	Citywide Single Point of Access for Palliative and End of Life care Develop Shared language
	Equipment – Availability and timely delivery		Lack of resources	Citywide Single Point of Access for Palliative and End of Life care
	Staff wellbeing		Lack of resources Societal Change - Death and dying	Increasing resources available to support death in the community
	Different offers for different PEoLC pathways	Ethnicity Breakdown of EPaCCS patients	Complexity	Develop Shared language New Service Offer / model
			Sustainable programme of education	Increasing resources available to support death in the community

Appendix 2. e-Health Implementation Toolkit

Section II: System Readiness Evaluation

This section helps us understand the context of any actions and potential issues around the implementation of a systems approach.

For each set of statements, please circle the number that, from your perspective, represents the current position.

		0	1	2	3	4	5	6	7	8	9	10	
S1	This approach is completely at odds with current or planned national policy.	0	1	2	3	4	5	6	7	8	9	10	This approach is entirely compatible with current and planned national policy.
S2	This approach will hinder the achievement of nationally directed priorities or targets.	0	1	2	3	4	5	6	7	8	9	10	This approach will enable the achievement of nationally directed priorities or targets.
S3	This approach is completely at odds with current or planned local policies.	0	1	2	3	4	5	6	7	8	9	10	This approach is entirely compatible with all current and planned local policies (at health and wellbeing board level).
S4	My organisation is reluctant to adopt new practice and dreads change.	0	1	2	3	4	5	6	7	8	9	10	My organisation welcomes new practice on complex systems thinking and embraces change.
S5	The multiple staff groups likely to be involved in implementing the approach have poor working relationships and poor communication with no history of problem-solving and co-operation.	0	1	2	3	4	5	6	7	8	9	10	The multiple staff groups likely to be involved in implementing the new approach have good working relationships and good communication with a history of problem-solving and co-operation.
S6	There is no local sponsor, or the local sponsor is not well respected, or is likely to devote insufficient time and energy to promoting the approach.	0	1	2	3	4	5	6	7	8	9	10	The approach is strongly supported by a well-respected local sponsor who will provide the time and energy needed to promote the implementation.
S7	There are particular opinion leaders who are likely to oppose implementation of new practice.	0	1	2	3	4	5	6	7	8	9	10	There are particular opinion leaders who are likely to support the implementation of new practice.
S8	The system is under-resourced, and cannot fully meet the costs and additional workload resulting from the implementation of the approach, including e.g., the training, on-going support, contingencies, publicity.	0	1	2	3	4	5	6	7	8	9	10	The system is well resourced and can fully meet the costs and additional workload resulting from the implementation of the approach, including e.g., training, on-going support, contingencies, publicity.
S9	The approach is likely to disrupt the existing allocation of resources or the formal or informal norms by which they are allocated.	0	1	2	3	4	5	6	7	8	9	10	The approach will make no change to existing allocation of resources or the formal or informal norms governing allocation of resources.
S10	The approach is completely at odds with the system's existing risk management policies.	0	1	2	3	4	5	6	7	8	9	10	The approach is entirely compatible with the system's existing risk management policies.

Appendix 3. Interview Schedule

Interviewer introduces themselves: Explains they are from Leeds Beckett University but have not played an active role in the project.

Introduction: I'm going to ask you some questions about the system approach work facilitated by Leeds Beckett University as part of Phase 1 of the Leeds Dying Well in the Community project. Please be honest and open with all the responses. Just a reminder that they'll remain anonymous. We're interested to know from your point of view the elements that have gone well and those that could have gone better.

1. The first question I want to ask is about your initial expectations from the project. Thinking back to the start of the project, can you remember what your initial expectations were as to what a systems approach would entail?
2. Did your expectation change throughout the project?
3. To what extent do you feel you were able to undertake the systems process as planned?
    i. *prompt: were there specific barriers and facilitators?*
4. Do you feel the process undertaken has been useful?
    i. *prompts: why has it been useful? which elements of the process have been useful? why were these elements useful?*
5. What have been the main outcomes of this process for you?
    i. *prompt: how did the approach help bring about these changes?*
6. Do you think that the project engaged with stakeholders/sectors that were not previously involved?
    i. *prompt: if yes - Has there been a benefit to engaging with these wider stakeholders?*
7. Do the key themes for action differ from the current/previous approach?
    i. *prompt: do the themes reflect the complexity of the local system?*
8. What do you foresee to be the principal barriers to moving the work forward?
9. What strengths did you draw on when implementing the process?
    i. *prompt: how did these strengths aid the implementation?*
10. When you think about your mindset, and that of your colleagues', what is it like now, in contrast to the beginning of the process? Has it changed? If so, how… If not, why do you think that is the case?
11. Finally, I'd like you to reflect on where you are at developing a whole systems approach to palliative and end of life care in the community. A fully operational whole systems approach would involve a shared understanding of the issues by all relevant stakeholders and working together in an integrated way to bring about sustainable change. If you imagine yourself along a continuum where 0 is the beginning of the whole systems work, and 10 is a fully operational whole systems approach, where would you position yourself now?
    i. *prompt: please, expand on why you place yourself there and what you'd need to do to move yourself higher up, say 9 or 10...*