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

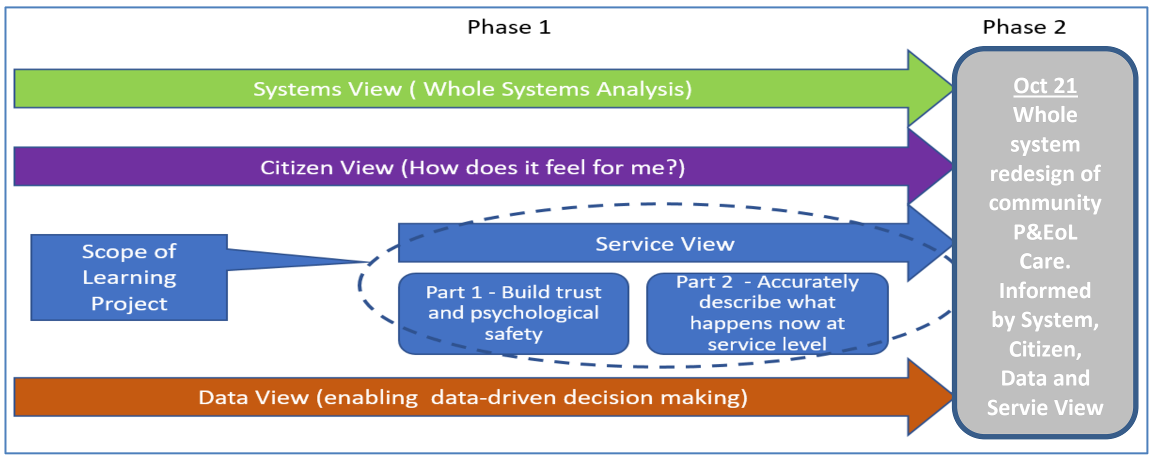
FINAL REPORT, November 2021.

1. Background

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

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

The '**service view'** focus of the development project was identified in response to **insight** from members of the Leeds Palliative Care Network (LPCN) relating to a potential mismatch between the level and responsiveness of care that core providers of community P&EoL care are able to deliver in comparison to that which is described to people and system partners. Unwarranted variation has been magnified through the pandemic with some services reporting a 46% increase in demand.



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

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

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

2. Project Design

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

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

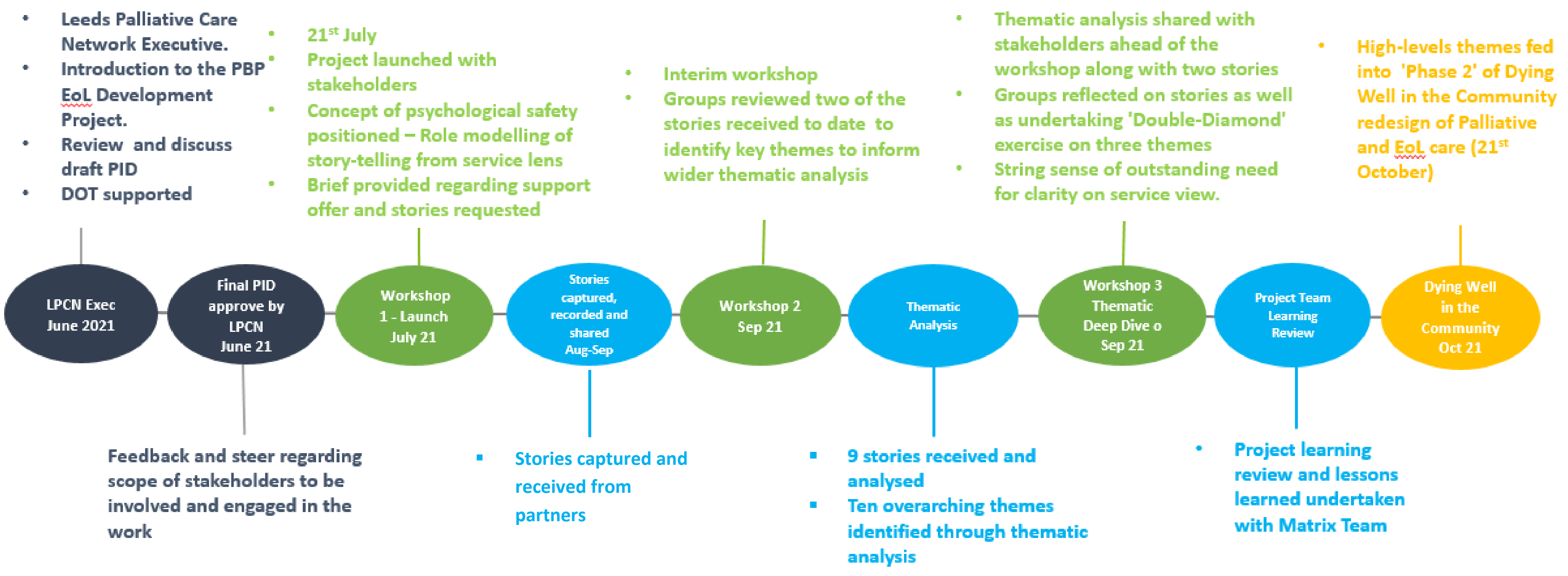


Figure 2 – Project Design Overview

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

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

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

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

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

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

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

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


Barriers to open/honest conversation


Enablers for open/honest conversation

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

3. <u>Stories Received</u>

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

Stories were shared from the following organisations:

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

Unfortunately, due to acute system pressures, Care Homes or Home Care providers were unable to capture and share stories. Examples of Primary Care and Pharmacy stories are provided at Appendix 1.

4. <u>Themes and reflections identified through the stories</u>

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

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

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

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

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

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

	Insight from Community Pharmacy identified the need for staff training to flag and prioritise prescriptions for patients at the EoL and to establish systems to ensure families are not contacted regarding ordering further prescriptions after death. Although knowledge and skills of staff were not <u>explicitly</u> described as a contributory factor in delivering excellent care, this was implicit in the features of these positive examples in relation to effective communication between services, with people and their families, in the timely and frequent updating of advance care plans and ReSPECT forms.
2. Workforce - Staff capacity	A number of stories explicitly highlighted workforce capacity and shortages as a salient contributory factor in the inability to deliver excellent palliative and end of life care. Stories described the impact of staff shortages as affecting : • the continuity of care that could be delivered for people (as staff were required to provide cover for those unable to work), • the (negative) impact of having to undertake aspects of assessments remotely • the ability to always deliver care packages at the required levels e.g. unable to always offer care packages with the required number of daily Neighbourhood Team visits It could also be inferred that staff shortages may be a contributory factor to other issues identified such as tasks not being actioned in a timely way, incomplete/unclear documentation. Workforce shortages and capacity were not identified explicitly in any of the stories that described excellence in care. Indeed a central aspect of these stories was the time taken by staff to communicate and work closely with families and other teams (sometimes through an MDT approach). These stories frequently identified examples of staff going 'over and above' such as the Community Pharmacists who, due to the length of time taken to co-ordinate, secure and prepare a complex prescription for a child at the end of life delivered the prescription in person to a family in the evening, long after the pharmacy had closed.
3. Equipment – Availability and timely delivery	The timely delivery of equipment was identified as an important contributory factor in poor patient experience. Examples include a 4 day wait for the delivery of a profiling bed to a man being cared for at home and significant delays in obtaining a commode – both of which had significant impact on the deterioration of the person's pain, symptoms and quality of life in their final days. Conversely another story highlighted the ability of services (NT, Equipment Service, OT) to work together to secure appropriate equipment (profiling bed, sensors and crash mats) for a patient (and to move the equipment from bedroom to living room as his needs changed) was identified as an element of care that had gone particularly well for a patient being cared for at home.
4. Accurate and Timely Prescribing	Prescribing and securing medication for people with palliative and End of Life care needs in the community was identified as one of the most crucial factors across stories reviewed. Key issues identified are as follows: • Accuracy of prescriptions: A number of stories identified prescription errors (requiring Community Pharmacists to find and contact the prescribing Dr for the prescription to be re-issued) as an issue, resulting in delays in issuing medication in a timely way for people. • Anticipatory Medication: Anticipatory medication not being prescribed at the point of hospital discharge and exacerbated when medication is required over the weekend (resulting in long delays in securing medication via OOHs GP). • Medicines Supply – The medicines supply system is imperfect. Although pharmacies receive two deliveries per day and are able to get any medicine within 12-24h, deliveries can be delayed, be out of stock at the wholesaler and/or be subject to national shortages. Delivery of medication is not an NHS service and pharmacies that choose to deliver medication do so on a 'goodwill' basis. Community Pharmacy identified a number of examples of how networks of pharmacies are working to address these challenges such as prescribing half quantities of medicines that are in short supply to ensure stock for more patients, collaboration between pharmacies to supply prescriptions of medicines that are in short supply. Stories identified how delays in prescribing resulted in pain, poor symptom control and the risk of people dying in pain in addition to stress and anxiety for carers. Insight from Community Pharmacy stresses that medication requirements should be anticipatory wherever possible, allowing pharmacies time to source medication wherever possible
5. Incomplete documentation	Incomplete documentation can be seen as a contributory factor in stories that identify where care was not as we had hoped for. Examples include: • The generation and regular updating of ReSPECT forms preventing unwanted hospital admissions • ReSPECT form updated throughout the patients journey to reflect their changing care needs • Incomplete hand-over information between teams • Incomplete prescriptions

	• Insufficient information in records including: it being unclear from notes if a medical review had previously been undertaken; informal discussion with consultant not documented and information about previous assessment being incompletely documented Clear and up-to date documentation can be seen as a key element in stories identifying excellence in care.
6. Coordinated planning and communication between services	Perhaps the strongest theme emerging across all stories is the impact of effective (and ineffective or absent) coordination between professionals, services and families. The absence of this coordination and communications was equally a significant contributory factor in the stories about care where we had 'hoped for better'. Insights from stories include: • Case - Management – more complex patients are perhaps managed better than less complex ones? • Consistency of case management - frequently a lot of people seeing a patient (including those residing in care homes) – unclear where responsibility and ownership lies for leading the coordination of care • Many agencies were involved with this care, no one was leading to oversee what was happening, allowing crisis point to be reached • Communication between hospice and Community Matron unclear • Communication from hospice to NT not clear • Nursing staff dependent of feedback from care home carers on the effectiveness of treatment Most problems seem to happen around the interface issues Effective and proactive communication and coordination between services was highlighted across a number of stories: • Coordination and review of expert medical care and treatment plan and liaison with GP and NT • Services working well together to provide support and equipment in a timely way • Complex multi-professional care provided by hospice and other community services for complex advance care planning and escalation of care issues • Hospice provided continuous point of contact, advice and reassurance • Review of patient following 999 calls by GP Practice and management in his home provided good symptom control
7. Coordination and planning with family	The absence of coordination and planning with families was a feature of some of the stories demonstrating care where we had hoped for better: • No communication back to family by hospice as assumed this would be done by NT • Carer anxious and panicky, struggling with care and no sleep but unable to secure care package Stories describing excellence described: • Decisions made with the involvement of the family • All of this resulted in the patient being cared for in his chosen place, family were fully involved and thanked practice for the care their farther received • Care for patients and family
8. Services able/unable to respond	The inability of service to be able to provide the expected level of responsiveness of care was highlighted in a number of stories. Examples include: • Referrals to hospice but no beds available • NT unable to provide package of care at the level required by the patient and carer • Carer said that she didn't realise how hard it would be to care for her husband or how long it would take to get a package of care Inherent within the stories of excellence was the availability of a range of services able to support person in different community settings (home/ hospice) • Patient deteriorated and was admitted to our palliative care ward • Service was responsive and flexible • Patient was fast-tracked at appropriate time
9. Proactive, person centred advanced care planning	Almost all of the stories described the existence of an advance care plan that had been developed. One story showed how the existence of a ReSPECT form didn't avoid an unwanted admission: • Admission to hospital at odds with wishes described within ReSPECT form The existence of a ReSPECT had enabled an unwanted admission • ReSPECT form updated continuously to document and reflect changing needs • Ability to work with patient's agenda and at her pace within a very uncertain picture

	• Proactive care coordination and offer of end of life planning, proactive reviews by NT but patient and carer refused • Following numerous admissions, advance care planning was arranged with the family • ReSPECT form generated and regularly updated and prevented unwanted hospital admissions
10. Staff Wellbeing	The theme of staff wellbeing was not identified as an explicit theme within the stories shared. However, the review of stories at the workshop of the 6th of September reflected that this should be identified as a key 'hidden' theme that sits behind the stories of care; we had hoped for more. • We need to record the impact that these stories have on staff – it's common for them to leave the day feeling sad with themselves that they couldn't do more – these feelings don't come through strongly enough in the story(ies) • Staff feeling overstretched and unsatisfied is commonplace • Teams not feeling satisfied – impacting on staff health and wellbeing

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

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

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

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

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

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

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

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

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

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

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

A full overview of the group's breakout room discussions can be found in Appendix 2.

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

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

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

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

5.1 An owned priority to establish a service view

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

5.2 Ten key themes to address in future redesign

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

5.3 Creating trust and psychological safety takes time

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

5.4 Understanding and addressing variation

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

5.5 Ensuring Data-led design

- Much of the analysis undertaken and presented includes the COVID 19 pandemic, however, removal of the peak period of deaths, (those deemed to be special cause variation), between March 2020 and January 2021 could create the new "normal" picture of P&EoL care with which to use as the basis for planning.
- Once we have a normal position we can look at how seasonal variation affects the pattern, we know more people die in winter than in summer. Do our workforce plans reflect this?
- Achievement of preferred place of death may be relevant to this project but may not be a marker of a "good death".
- How do we use this knowledge to forward plan with likely changes in the patterns of deaths from cancer, cardio vascular, stroke as a result of COVID?

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

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

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

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

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

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

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

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

6. <u>Next Steps</u>

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

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

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

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

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Appendix 1 – Examples of Stories

Appendix 1a - Primary Care – EOL care to be proud of

Sam was an elderly gentleman who lived with his wife in a purpose built house in his sons garden. He and his wife had severe frailty.He had carers four times a day, needed assistance to mobilise and was prompted to eat and drink.

During 2019 he had 4 admissions to LTHT ranging from 1 day to 6 days (total of 13 days) for chest infections and falls.

Dec 2019

A discussion was arranged with the son. The son had spoken with his mother and siblings and they were in agreement that Sam did not have capacity to have the discussion re advance care planning but he had always expressed a wish to be cared for at home if possible and to avoid future hospital admissions. The son had lasting power of attorney (health and wellbeing) for his father. Following this discussion a DNACPR was completed. The discussion was recorded on EPaCCS including GSF prognosis, diagnosis, PPOC, PPOD, DNACPR and who the discussion had been held with.

Jan 2020

A call came from the care company. Sam's family had arranged a meeting with the care company, they felt he was palliative and told the carers to stop his medications. Our practice matron arranged an assessment of Sam with his carers. She felt there was general deterioration but was not imminently end of life. Sam was responsive but spent most of the day asleep but easily roused. He had no interaction or conversation. Carers assisted with all personal care.

Sam's advanced care wishes were noted and the practice matron agreed it was not appropriate for admission to hospital. He had a good care package in place to support him in his own home. It was agreed it would be appropriate to look at de prescribing to remove some of his tablet burden and convert others to liquid form.

It was not appropriate for fast track at that time but needed assessment by OT from Neighbourhood team. For provision of profiling bed, sensors and crash mats.

The plan was discussed with the son who agreed with all suggestions and who expressed his wish for his father to be cared for at home until the end of his life.

EPaCCs was updated – with additional information on MCA, treatment escalation plan and change in prognosis.

1 wk later he was reviewed by his GP – who agreed with the general deterioration, he prescribed anticipatory medications but felt not for fast track at that time as he wasn't confident that he would be EOL within 3 months. The neighbourhood team were already involved with Sam.

Sam was discussed at the GSF meeting so all were aware of his condition and everything needed was in place.

May 2020

During Covid pandemic. Family had a well fair check, all was ok. From the wishes recorded in EPaCCS a ReSPECT form was completed and the family made aware that would be sent out.

June 2020

Call from family, Sam becoming more agitated in afternoons, felt he was unable to get comfortable.

An urgent referral was put into the neighbourhood team/ OT - for assistance, as wanted to move profiling bed/hoist from bedroom to living room.

Referral made to CMHT re agitation.

Call from family – the wife being in the same room as her husband was causing a deterioration in her mental health and the carers were asking for a chemical cosh to try and calm him down.

Sam was assessed by his GP and no cause for increased agitation was found. It was explained that the urgent referral had gone in to move the furniture and Sam was referred to adult social services re respite care. Advised against medications at present and to await the cmht input. This was all discussed with the son and he was happy with the plan.

The bed was moved and the above issues became less.

Nov 2020 – March 2021

Sam treated by GP for chest infections and urine infections with oral antibiotics at home.

March 2021

Paramedics called out- following fall and concerns re his chest. Noted advance care wishes and called GP out for assessment. Diagnosed with community acquired pneumonia and commenced on oral antibiotics.

April 2021

Family called 999, increasing shortness of breath on moving. Advance care wishes seen by paramedics on ReSPECT form and GP review arranged. GP assessed felt Sam needed antibiotics for a chest infection and prescribed oral morphine for the breathlessness. This was discussed with the son who agreed not appropriate for admission and further deterioration was discussed. The ReSPECT form was updated. Sam made a recovery over the next 2 weeks.

Aug 2021

Sudden deterioration of Sam, assessed by practice matron in his home. He was unresponsive. He was fast tracked, anticipatory medications were prescribed, and a video call with a doctor to see the patient. The family were made aware that he was entering final hours of life.

Sam died 2 days later in his own home. Condolences and bereavement support were offered to the family.

Appendix 1b Primary Care EOL Care - Not as hoped for.

Albert was an elderly gentleman who lived at home with his wife. He had been active and relatively well prior to rapid deterioration and a cancer diagnosis.

April

Following diagnosis he was referred to medical oncologist to discuss palliative chemotherapy and reviewed by the specialist cancer nurse. A ReSPECT form was generated by the hospital. Advance care wishes were discussed between the oncologist and Albert/wife – they agreed that he wanted quality of life, palliative chemotherapy would make him feel worse with little benefit. The patient's wife became upset when hospice was mentioned and even though the benefits of referral were discussed the wife did not want it at that time.

May

Home visit arranged with GP, went through diagnosis and discussed best supportive care, Albert was aware of palliative nature but did not want to know his prognosis. His priority was to stay at home but did not want to discuss any further advance care planning. He and his wife declined home help and refused referral to community palliative care team. Albert was referred to neighbourhood team.

EPaCCS was updated with PPOC, PPOD, prognosis and on GSF

May

Admission to hospital – 4 days – community acquired pneumonia. Review on discharge, wife declined further support as she felt she was managing. Neighbourhood team placed Albert on regular palliative reviews – wife asked for reduced frequency of visits.

June

Albert had increasing symptoms – abdominal pain and reducing mobility. They again declined additional support as they felt they were managing.

July

Admission to hospital with progression of carcinomatosis and in fast AF. 4 day admission. Discharged for palliative care.

While Albert was in hospital his wife contacted the neighbourhood team to request a package of care prior to discharge as she felt she had hit crisis and wasn't coping. The team contacted the ward to alert them to lack of package of care and the NT were only visiting every 2 weeks. As Albert was independent on the ward and he and his wife agreed to discharge he went home without a package of care.

Albert's wife was providing all care, his mobility was poor and he was a high risk for falling. The wife felt frightened. She was given the number of adult social care to do a self referral for personal care. On review by NT Albert was found to have a pressure area on his buttock.

21st July. Albert was reviewed by his GP, he had been sleeping in his chair, had a pressure area and a high risk of further pressure areas. The GP fast tracked Albert to access support for personal care and for a hospital bed. His ReSPECT form was updated and he and his wife now agreed to referral to specialist palliative care to help with symptom management.

The NHS continuing health care fast track funding was granted the following day and daily palliative care visits from the NT commenced. On the NT review – Albert now needed 2 carers to assist transfers – the wife had hit crisis and carer strain from attempting to look after her husband since discharge from hospital with no package of care. The wife said she did not realise how hard it would be to look after Albert and never realised how long it would take to get a package of care.

A Task was sent to urgently request the equipment needed to support Albert in his own home. It took 4 days for the profiling bed to be delivered.

No anticipatory medications were prescribed when Albert was fast tracked resulting in the ooh drs needing to be contacted on a Saturday as Albert was vomiting and couldn't keep any fluids down. From the time of the review by the neighbourhood team it took 6 hrs for Albert to be given an anti emetic.

26th July. The patient told his GP that he wanted to die in the hospice – at this point he hadn't been seen by the hospice team and was due a telephone appointment that afternoon.

27th July. Review by practice matron. Symptom management and who to contact if help is needed out of hours discussed. Alberts wife was very anxious and panicking, wife again disclosed she was struggling with care and with no sleep, she had previously declined 4 visits a day and was recommended to accept this now. Neighbourhood team was contacted to increase care input / night sitter and ? for admission to the hospice.

28th July Albert deteriorating, further decrease in mobility, hallucinating, recent fall and faecal impaction. A task was sent to CCT to request update regarding outstanding package of care – reply still trying to source package of care.

A night sitter was in place that night, Albert was unsettled and restless but they were unable to get a second carer. Albert was wanting to get out of bed to sit in his chair but it was too unsafe with only one carer present.

29th July still no commode in the house. Albert and his wife now both wanted Albert to be in the hospice, assessed by hospice team and suggest admission as soon as possible as deteriorating rapidly. Syringe driver commenced.

30th July – Albert admitted to the hospice at 15.40 and died that same day.

Appendix 1C – Service View stories and Reflections from Community Pharmacy

There are 540 community pharmacies in West Yorkshire. There is no national specification in relation to palliative care and as independent NHS contractors each pharmacy will have different experiences and processes

Community pharmacy role

Our main role is the supply of medicines.

NHSE&I commission a Palliative Care drugs service. It ensures a specified stock is held from a small number of pharmacies which ensures that each area has an assured stock in place. The service is in place as a back-up in case and should not be the routine route for supply of EOL medicines. NHSE&I reference palliative care drugs provision through the commissioned service for days that pharmacies are routinely closed (bank holidays, Xmas Day and Easter Sunday). Note: A national palliative care drugs service is being developed. We do not have any details of this service but understand that NHSE&I are looking to put a service in place that complements existing services.

Community pharmacy also receives unwanted medicines, including controlled drugs, for safe destruction. We frequently interact with patients' families returning medication following a death.

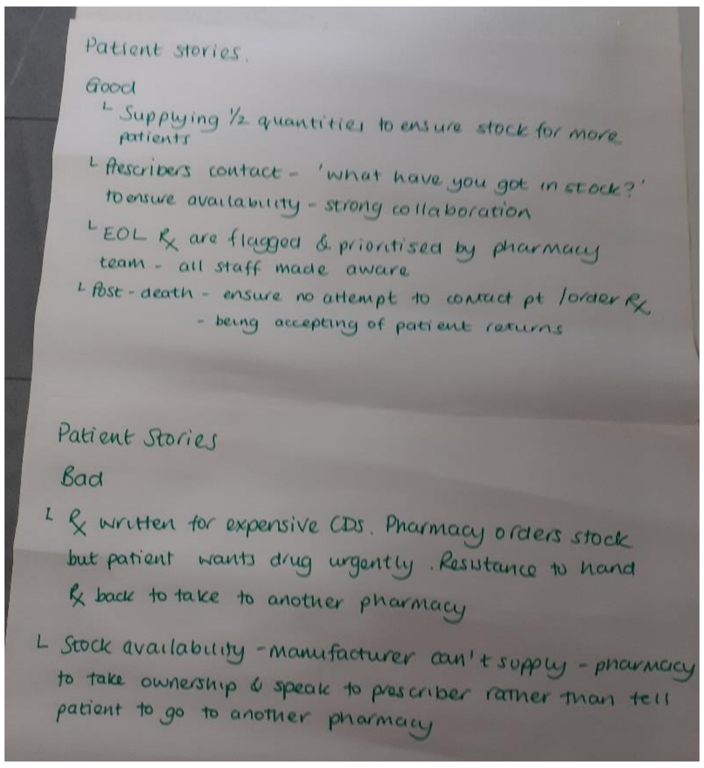
Learning / feedback in relation to EOLC from C19

- Prescriptions, including those for EOL, should be taken to the patients' usual pharmacy. This ensures that the supplying pharmacy has easy access to the patients' previous medications and can better make a clinical check on the suitability of medicines.
  - Many pharmacies will have stocks of the medicines required as part of their usual /regular stocks.
- During the pandemic the NHSE&I commissioned palliative care drugs service was amended to introduce weekly reporting of the stock held. This improved service feedback for pharmacies and provided system assurance as to the minimum drug stocks that could be accessed through the commissioned service.
- Not all EOLC drugs are on the NHSE&I commissioned palliative care service. It would be helpful to know which pharmacies keep the less commonly prescribed (unusual) medications not on the NHSE&I drug list and not routinely stocked by pharmacies
- Script tips – put each EOL item on a separate script (either paper or electronic). This allows flexibility should one of the items not be in stock at the pharmacy but the other items be available.
- Prescriptions should be electronic – as this easily allows them to be forwarded to another pharmacy for supply
- Medication requirements should be anticipated wherever possible. This allows time for the pharmacy to source the medicine if it is not currently stocked / in stock. Urgent need for medicines should not be a routine occurrence.
  - EOLC is usually planned and agreed- community pharmacy need informing early of this
- The medicines supply system is imperfect. Pharmacies routinely receive 2 deliveries in one day and can get any medicine required within 12-24 hours. The system however is not perfect eg deliveries can be delayed, medicines can be out-of-stock at the wholesaler or facing national shortage issues.
- Delivery is not an NHS service.
  - The NHS does not fund a home delivery service from community pharmacies. Those community pharmacies that currently deliver medicines to patients do so voluntarily and as a gesture of goodwill toward patients. Therefore, each community pharmacy can select which patients it chooses to deliver to, and to place a limit on the numbers, in order to contain the costs of this free and voluntary service. Community pharmacies can also choose to charge for a delivery if they wish. Where a voluntary delivery service is offered it is normally on a next working day basis. It is not an on-demand service akin to a food delivery service. This is because community pharmacies will usually employ one driver who will take that day's deliveries each morning and then not return again to the pharmacy until they are all delivered at the end of the day. Interrupting the driver's daily scheduled run to add more same-day delivery requests will significantly increase the cost of the delivery service and is avoided by pharmacies. Some community pharmacies can arrange for a chargeable on-demand same-day delivery service by using third party delivery agents. Patients are likely to be charged if they want an urgent same-day delivery.
- Most of the issues that community pharmacy face are with interfaces
- The patients pharmacy should be informed when a patient dies. This ensures ongoing medicines are not requested and that we can deal with the family sensitively.

Building the Service View - User Stories

At the CPWY committee meeting in September members discussed patient stories and captured what provides a good experience (magic moments) and where care could be better (learning from issues).

The flipcharts are below which capture some points in addition to the ones above



Patient stories.

Good

└ Supplying ½ quantities to ensure stock for more patients

└ Prescribers contact – 'what have you got in stock?' to ensure availability – strong collaboration

└ EOL ℞ are flagged & prioritised by pharmacy team – all staff made aware

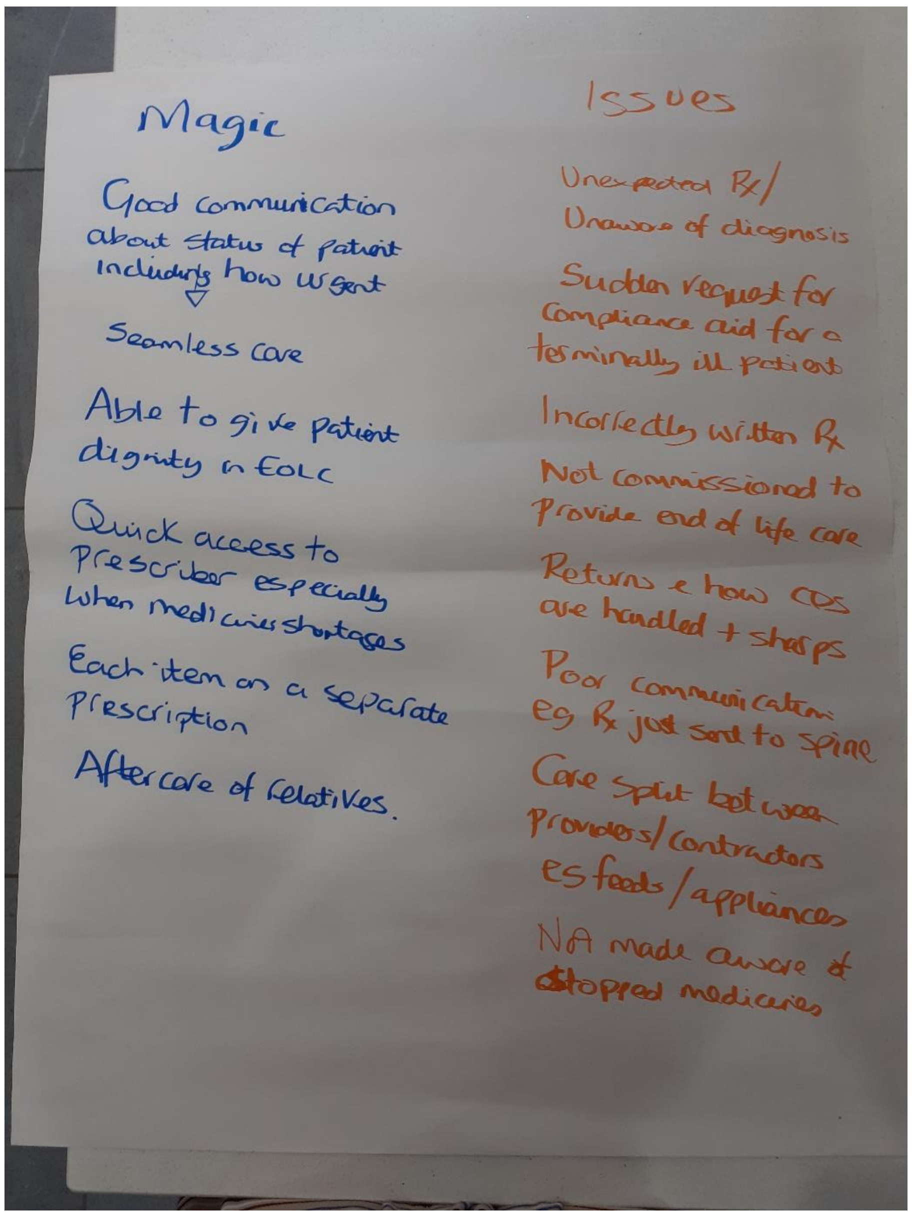
└ Post-death – ensure no attempt to contact pt /order ℞
– being accepting of patient returns

Patient Stories

Bad

└ ℞ written for expensive CDs. Pharmacy orders stock but patient wants drug urgently. Resistance to hand ℞ back to take to another pharmacy

└ Stock availability – manufacturer can't supply – pharmacy to take ownership & speak to prescriber rather than tell patient to go to another pharmacy



Magic

Good communication about status of patient including how urgent
▽
Seamless care

Able to give patient dignity in EOLC

Quick access to prescriber especially when medicines shortages

Each item on a separate prescription

Aftercare of relatives.

Issues

Unexpected Rx/
Unaware of diagnosis

Sudden request for compliance aid for a terminally ill patient

Incorrectly written Rx

Not commissioned to provide end of life care

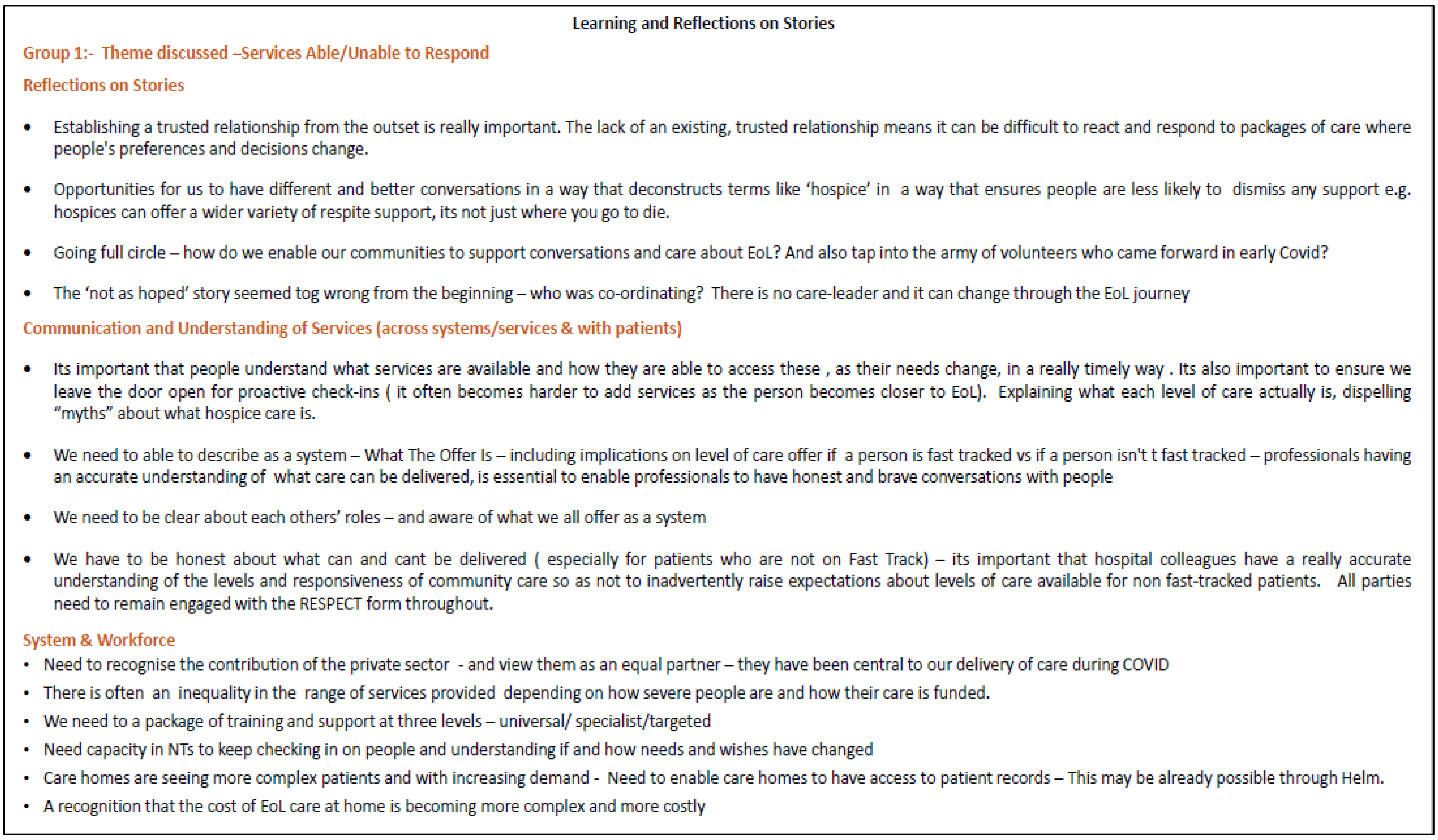
Returns e how CDs are handled + sharps

Poor communication eg Rx just sent to spine

Care split between providers/contractors eg feeds/appliances

NA made aware of stopped medicines

Appendix 2 – Insight gained within ‘Deep Dive’ of themes within final September Workshop



Learning and Reflections on Stories

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

Reflections on Stories

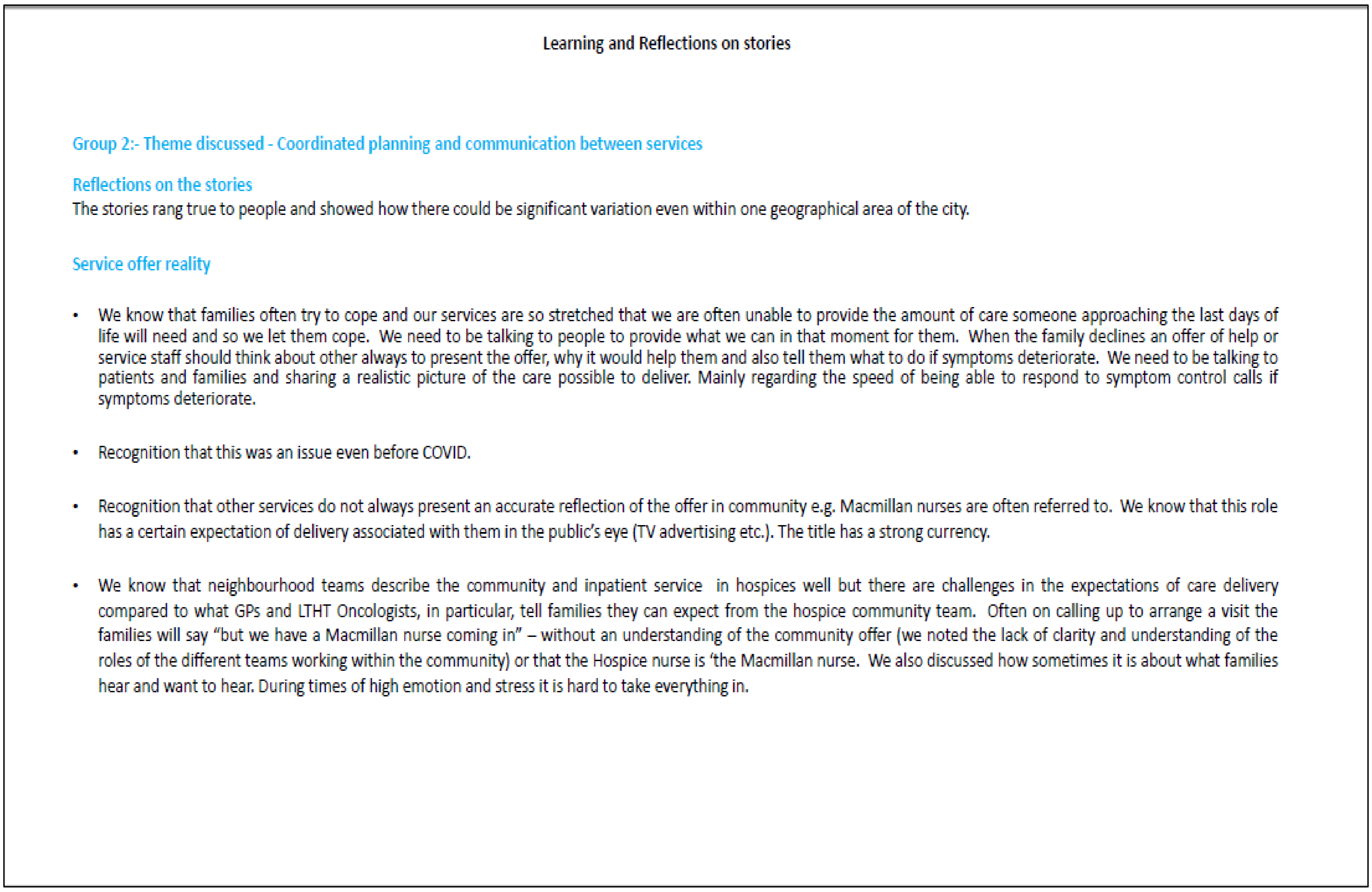
- Establishing a trusted relationship from the outset is really important. The lack of an existing, trusted relationship means it can be difficult to react and respond to packages of care where people's preferences and decisions change.
- Opportunities for us to have different and better conversations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

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

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

System & Workforce

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



Learning and Reflections on stories

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

Reflections on the stories

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

Service offer reality

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

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

Changing service offer

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

Care coordination

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

HCM – to design the total package of care

Case load holder - previously DN to oversee clinical care plan

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

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

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

Domically providers

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

Family resilience

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

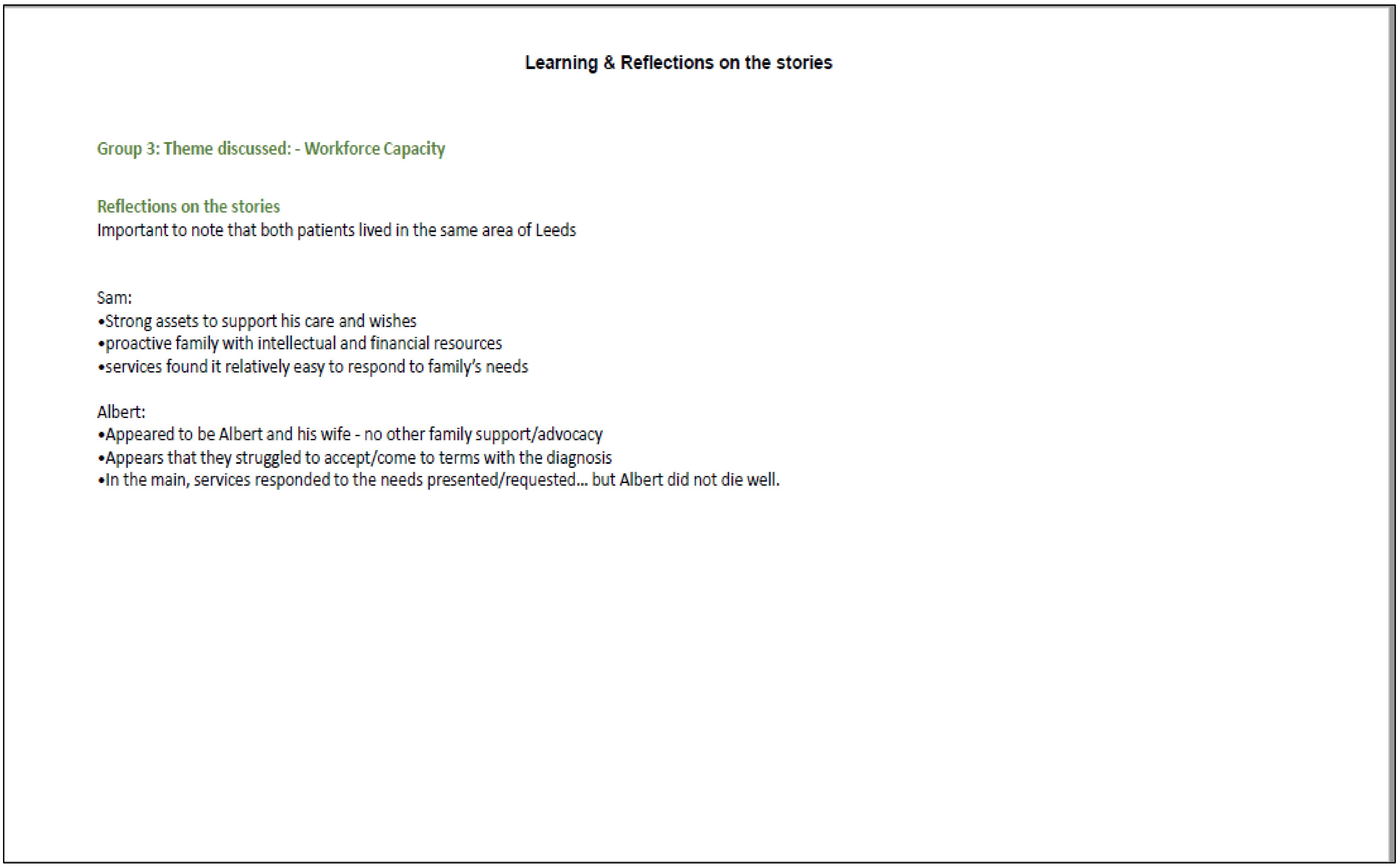
Initial hypothesis

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

Ideas

❖ to create a leaflet on the website with a description of the services
❖ the patient leaflet needs updating

❖ Maybe creating a flowchart about community flow as part of this winter's work



Learning & Reflections on the stories

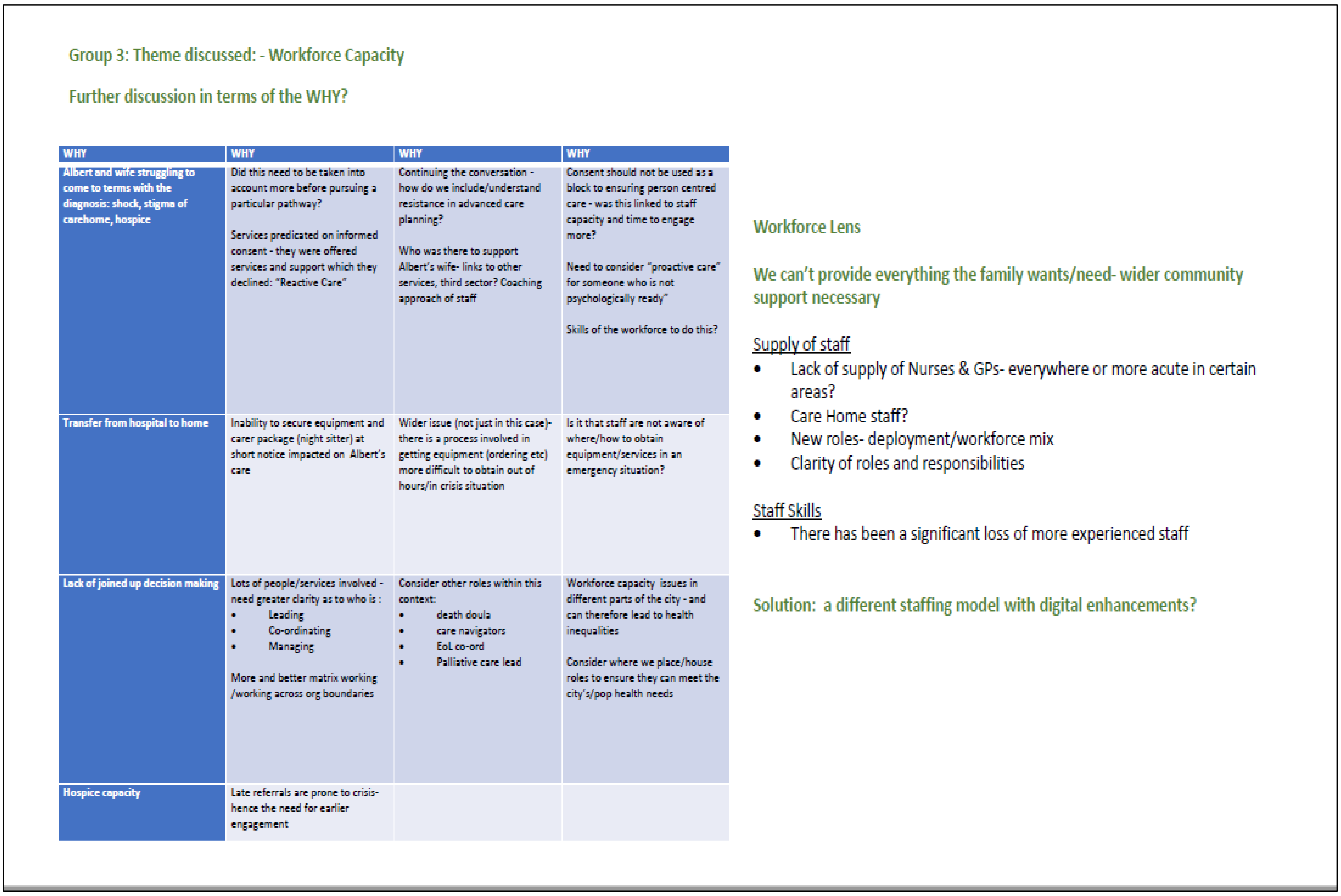
Group 3: Theme discussed: - Workforce Capacity

Reflections on the stories

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

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

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



Group 3: Theme discussed: - Workforce Capacity

Further discussion in terms of the WHY?

WHY	WHY	WHY	WHY
Albert and wife struggling to come to terms with the diagnosis: shock, stigma of carehome, hospice	Did this need to be taken into account more before pursuing a particular pathway? Services predicated on informed consent - they were offered services and support which they declined: "Reactive Care"	Continuing the conversation - how do we include/understand resistance in advanced care planning? Who was there to support Albert's wife- links to other services, third sector? Coaching approach of staff	Consent should not be used as a block to ensuring person centred care - was this linked to staff capacity and time to engage more? Need to consider "proactive care" for someone who is not psychologically ready" Skills of the workforce to do this?
Transfer from hospital to home	Inability to secure equipment and carer package (night sitter) at short notice impacted on Albert's care	Wider issue (not just in this case)- there is a process involved in getting equipment (ordering etc) more difficult to obtain out of hours/in crisis situation	Is it that staff are not aware of where/how to obtain equipment/services in an emergency situation?
Lack of joined up decision making	Lots of people/services involved - need greater clarity as to who is : • Leading • Co-ordinating • Managing More and better matrix working /working across org boundaries	Consider other roles within this context: • death doula • care navigators • EoL co-ord • Palliative care lead	Workforce capacity issues in different parts of the city - and can therefore lead to health inequalities Consider where we place/house roles to ensure they can meet the city's/pop health needs
Hospice capacity	Late referrals are prone to crisis- hence the need for earlier engagement		

Workforce Lens

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

Supply of staff

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

Staff Skills

- There has been a significant loss of more experienced staff

Solution: a different staffing model with digital enhancements?