Leeds Palliative
Care Network

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Update on Leeds Dying Well in the Community Project

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PARTNERSHIP

Overall aim

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

care and patient experience

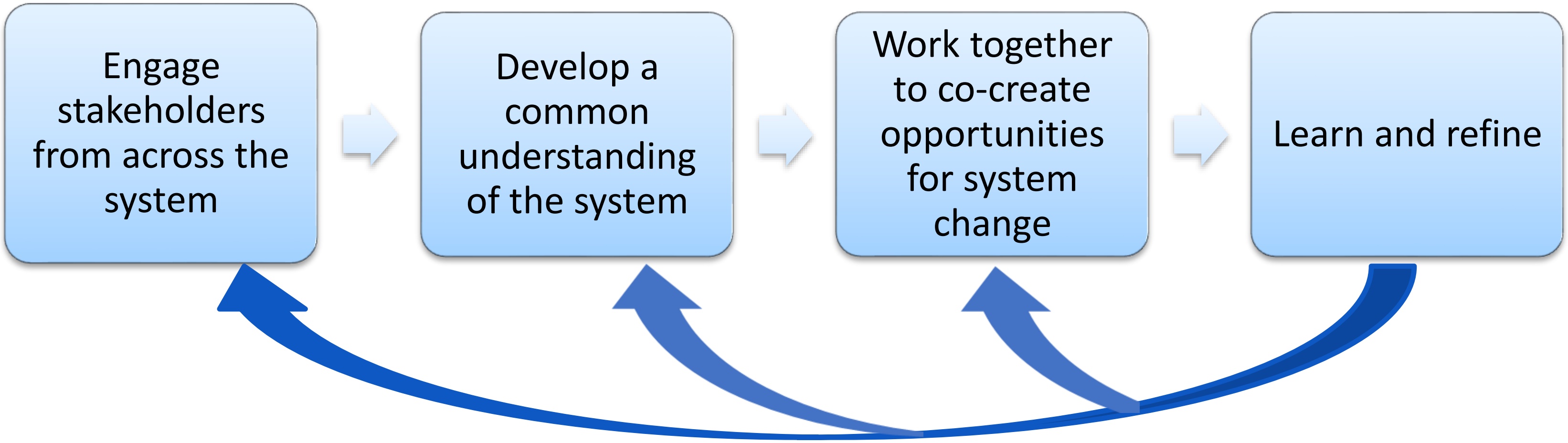
The project has two phases

- Phase 1 is to use a Whole Systems Approach
  - To develop a shared understanding of the whole system for end of life care within the community in Leeds, including interface with hospital-based care.
- Phase 2 is to ensure effective service redesign
  - to make the best use of the resources available to deliver the most effective and compassionate care outside of hospital for those people who are dying and for their carers and families. This will address the findings of the work in Phase 1

Who is involved?

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

Whole System Approach methodology



Engage stakeholders from across the system

Develop a common understanding of the system

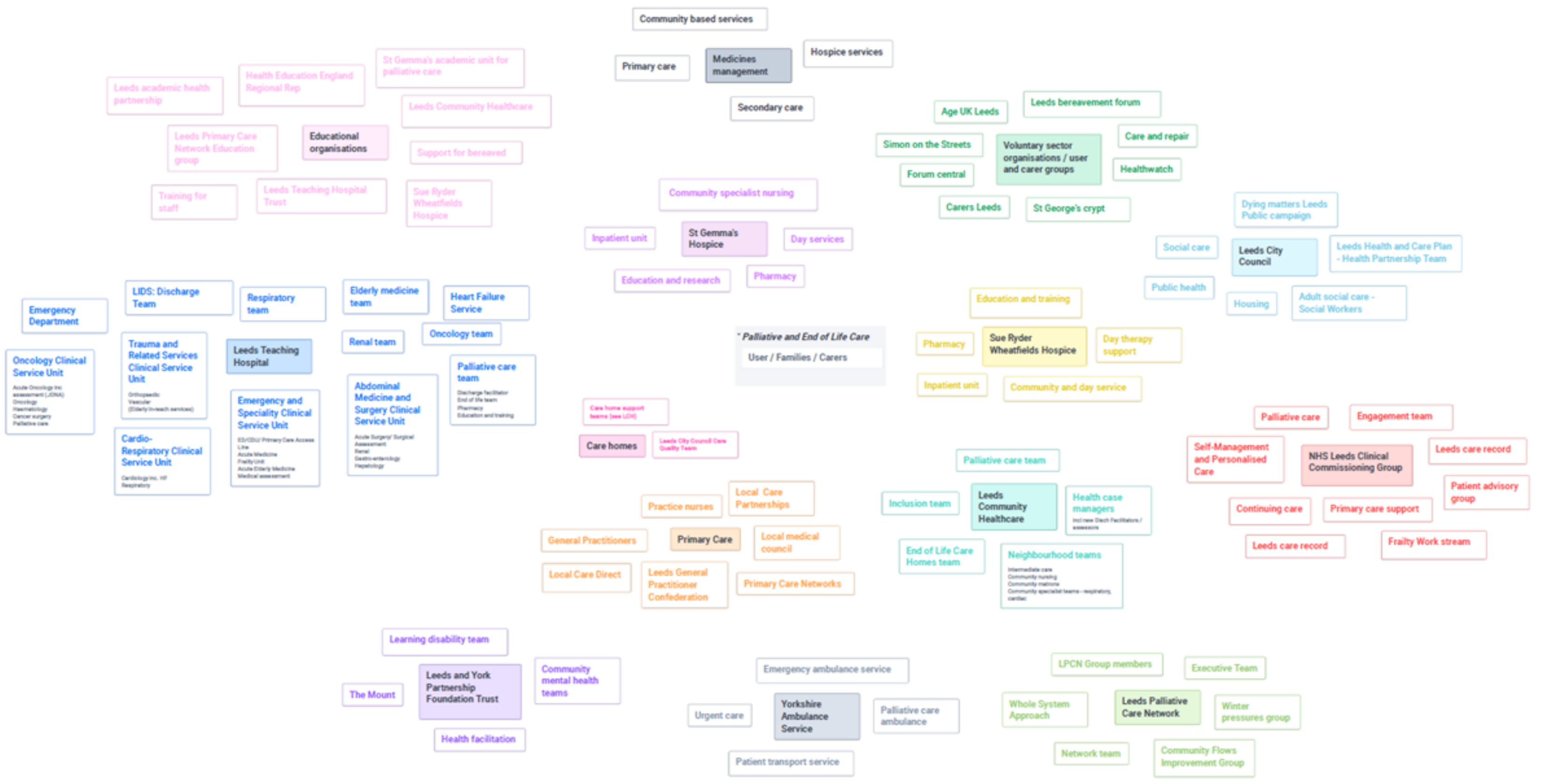
Work together to co-create opportunities for system change

Learn and refine

Progress so far

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

Stakeholder Map



Community based services

Primary care

Medicines management

Hospice services

Secondary care

Leeds academic health partnership

Health Education England Regional Rep

St Gemma's academic unit for palliative care

Leeds Community Healthcare

Leeds Primary Care Network Education group

Educational organisations

Support for bereaved

Training for staff

Leeds Teaching Hospital Trust

Sue Ryder Wheatfields Hospice

Community specialist nursing

Inpatient unit

St Gemma's Hospice

Day services

Education and research

Pharmacy

Age UK Leeds

Leeds bereavement forum

Simon on the Streets

Voluntary sector organisations / user and carer groups

Care and repair

Forum central

Healthwatch

Carers Leeds

St George's crypt

Dying matters Leeds Public campaign

Social care

Leeds City Council

Leeds Health and Care Plan - Health Partnership Team

Public health

Housing

Adult social care - Social Workers

Emergency Department

LIDS: Discharge Team

Respiratory team

Elderly medicine team

Heart Failure Service

Renal team

Oncology team

Oncology Clinical Service Unit
Acute Oncology inc assessment (JONA)
Oncology
Haematology
Cancer surgery
Palliative care

Trauma and Related Services Clinical Service Unit
Orthopaedic
Vascular
(Elderly in-reach services)

Leeds Teaching Hospital

Cardio-Respiratory Clinical Service Unit
Cardiology inc. HF
Respiratory

Emergency and Speciality Clinical Service Unit
ED/CDU/ Primary Care Access Line
Acute Medicine
Frailty Unit
Acute Elderly Medicine
Medical assessment

Abdominal Medicine and Surgery Clinical Service Unit
Acute Surgery/ Surgical Assessment
Renal
Gastro-enterology
Hepatology

Palliative care team
Discharge facilitator
End of life team
Pharmacy
Education and training

Palliative and End of Life Care

User / Families / Carers

Education and training

Pharmacy

Sue Ryder Wheatfields Hospice

Day therapy support

Inpatient unit

Community and day service

Care home support teams (see LCH)

Care homes

Leeds City Council Care Quality Team

Palliative care team

Inclusion team

Leeds Community Healthcare

Health case managers
incl new Disch Facilitators / assessors

End of Life Care Homes team

Neighbourhood teams
Intermediate care
Community nursing
Community matrons
Community specialist teams - respiratory, cardiac

Palliative care

Engagement team

Self-Management and Personalised Care

NHS Leeds Clinical Commissioning Group

Leeds care record

Patient advisory group

Continuing care

Primary care support

Leeds care record

Frailty Work stream

Practice nurses

Local Care Partnerships

General Practitioners

Primary Care

Local medical council

Local Care Direct

Leeds General Practitioner Confederation

Primary Care Networks

Learning disability team

The Mount

Leeds and York Partnership Foundation Trust

Community mental health teams

Health facilitation

Emergency ambulance service

Urgent care

Yorkshire Ambulance Service

Palliative care ambulance

Patient transport service

LPCN Group members

Executive Team

Whole System Approach

Leeds Palliative Care Network

Winter pressures group

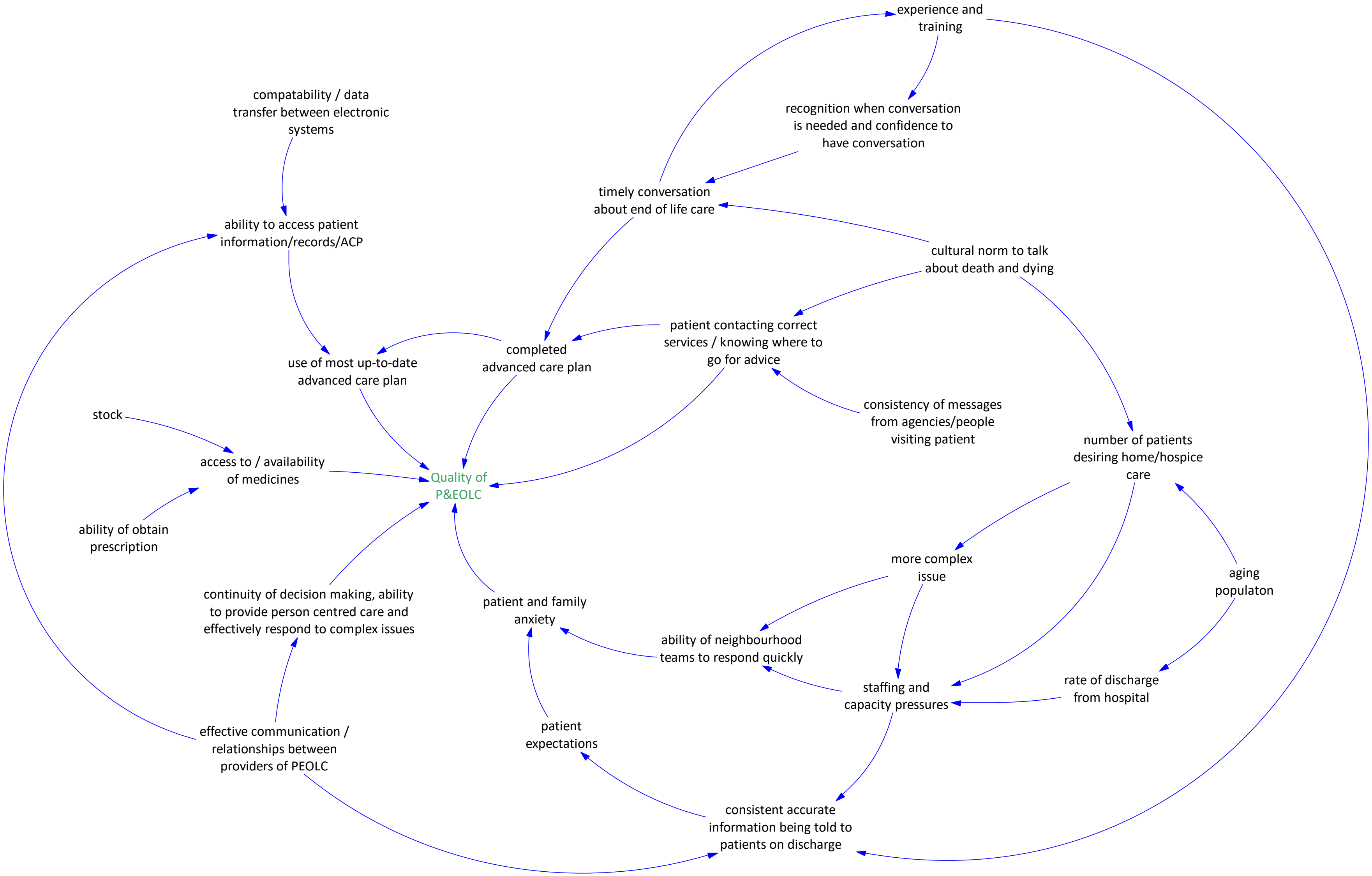
Network team

Community Flows Improvement Group

Draft – not for distribution

Systems mapping

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



experience and training

compatability / data transfer between electronic systems

recognition when conversation is needed and confidence to have conversation

timely conversation about end of life care

ability to access patient information/records/ACP

cultural norm to talk about death and dying

patient contacting correct services / knowing where to go for advice

completed advanced care plan

use of most up-to-date advanced care plan

consistency of messages from agencies/people visiting patient

stock

number of patients desiring home/hospice care

access to / availability of medicines

Quality of P&EOLC

ability of obtain prescription

more complex issue

aging populaton

continuity of decision making, ability to provide person centred care and effectively respond to complex issues

patient and family anxiety

ability of neighbourhood teams to respond quickly

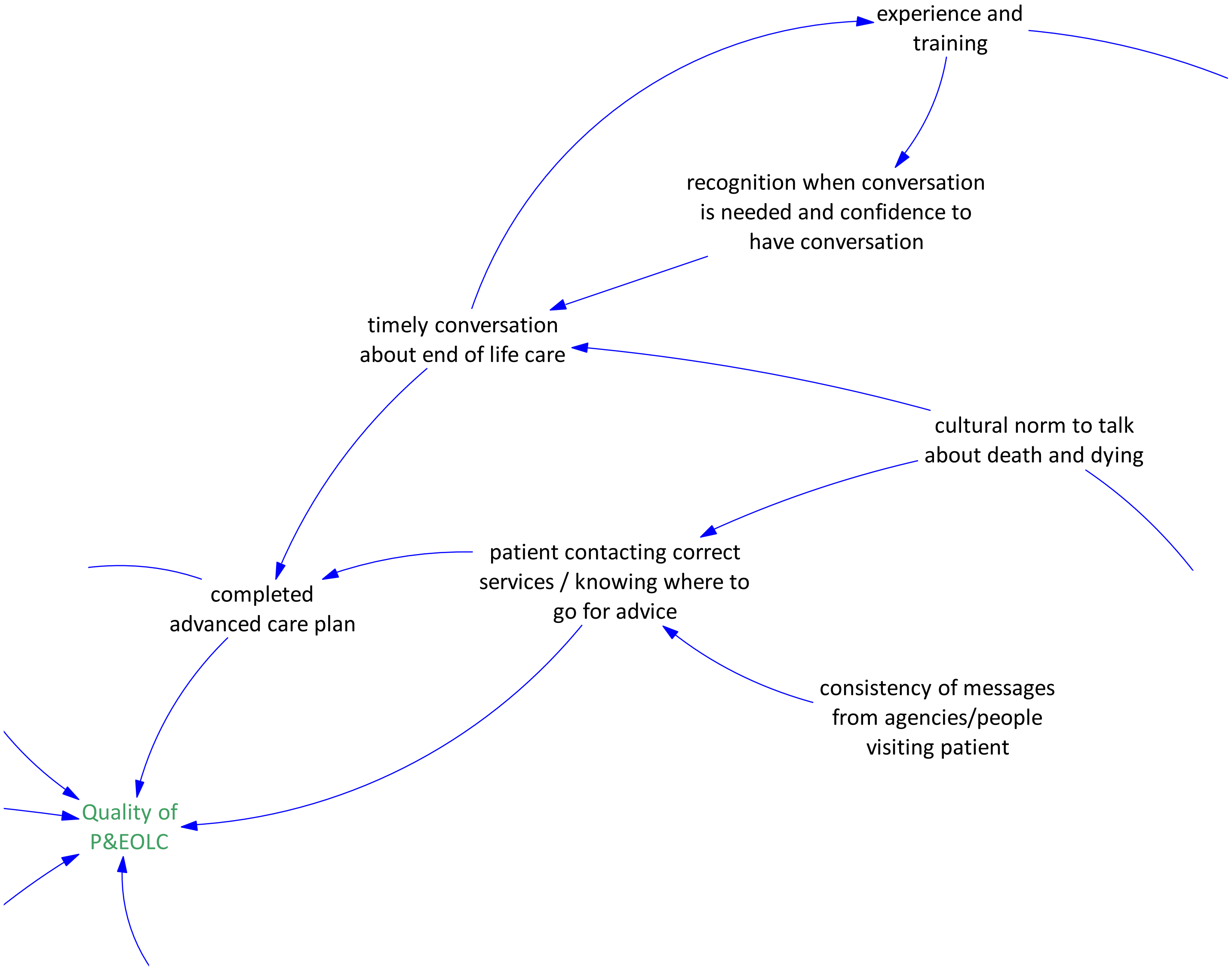
rate of discharge from hospital

staffing and capacity pressures

patient expectations

effective communication / relationships between providers of PEOLC

consistent accurate information being told to patients on discharge



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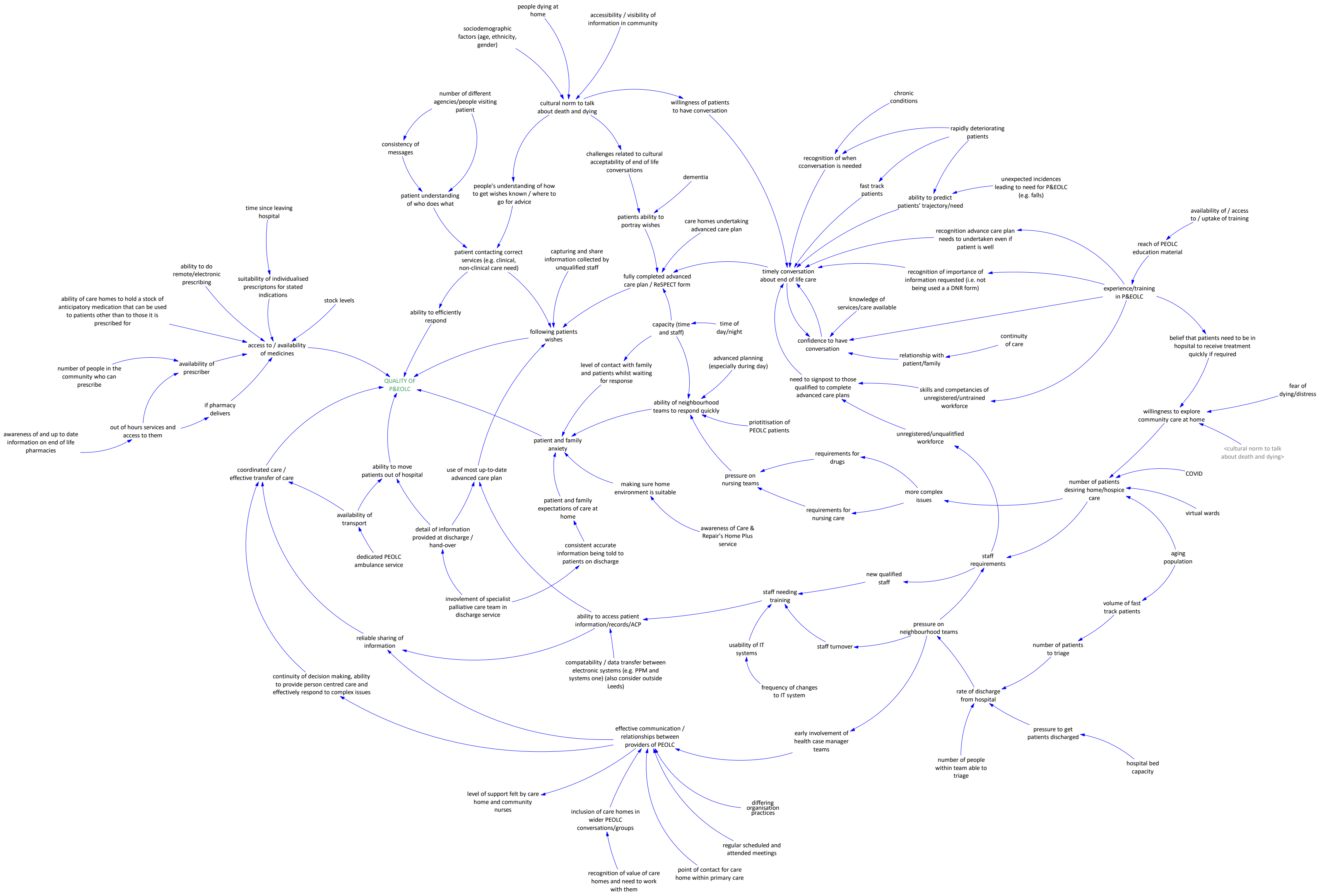

people dying at home

accessibility / visibility of information in community

sociodemographic factors (age, ethnicity, gender)

cultural norm to talk about death and dying

willingness of patients to have conversation

number of different agencies/people visiting patient

consistency of messages

patient understanding of who does what

people's understanding of how to get wishes known / where to go for advice

challenges related to cultural acceptability of end of life conversations

dementia

patients ability to portray wishes

care homes undertaking advanced care plan

chronic conditions

rapidly deteriorating patients

recognition of when cconversation is needed

fast track patients

ability to predict patients' trajectory/need

unexpected incidences leading to need for P&EOLC (e.g. falls)

availability of / access to / uptake of training

reach of PEOLC education material

recognition advance care plan needs to undertaken even if patient is well

time since leaving hospital

ability to do remote/electronic prescribing

suitability of individualised prescriptons for stated indications

ability of care homes to hold a stock of anticipatory medication that can be used to patients other than to those it is prescribed for

stock levels

access to / availability of medicines

number of people in the community who can prescribe

availability of prescriber

if pharmacy delivers

out of hours services and access to them

awareness of and up to date information on end of life pharmacies

patient contacting correct services (e.g. clinical, non-clinical care need)

capturing and share information collected by unqualified staff

fully completed advanced care plan / ReSPECT form

timely conversation about end of life care

recognition of importance of information requested (i.e. not being used a a DNR form)

experience/training in P&EOLC

ability to efficiently respond

following patients wishes

capacity (time and staff)

time of day/night

knowledge of services/care available

confidence to have conversation

continuity of care

relationship with patient/family

belief that patients need to be in hospital to receive treatment quickly if required

QUALITY OF P&EOLC

level of contact with family and patients whilst waiting for response

advanced planning (especially during day)

need to signpost to those qualified to complete advanced care plans

skills and competancies of unregistered/untrained workforce

fear of dying/distress

ability of neighbourhood teams to respond quickly

priotitisation of PEOLC patients

willingness to explore community care at home

patient and family anxiety

unregistered/unqualitfied workforce

<cultural norm to talk about death and dying>

coordinated care / effective transfer of care

ability to move patients out of hospital

use of most up-to-date advanced care plan

requirements for drugs

pressure on nursing teams

COVID

making sure home environment is suitable

more complex issues

number of patients desiring home/hospice care

patient and family expectations of care at home

requirements for nursing care

virtual wards

availability of transport

detail of information provided at discharge / hand-over

awareness of Care & Repair's Home Plus service

consistent accurate information being told to patients on discharge

staff requirements

aging population

dedicated PEOLC ambulance service

new qualified staff

staff needing training

involvement of specialist palliative care team in discharge service

volume of fast track patients

ability to access patient information/records/ACP

pressure on neighbourhood teams

reliable sharing of information

usability of IT systems

staff turnover

number of patients to triage

compatability / data transfer between electronic systems (e.g. PPM and systems one) (also consider outside Leeds)

continuity of decision making, ability to provide person centred care and effectively respond to complex issues

frequency of changes to IT system

rate of discharge from hospital

effective communication / relationships between providers of PEOLC

early involvement of health case manager teams

pressure to get patients discharged

number of people within team able to triage

hospital bed capacity

level of support felt by care home and community nurses

differing organisation practices

inclusion of care homes in wider PEOLC conversations/groups

regular scheduled and attended meetings

point of contact for care home within primary care

recognition of value of care homes and need to work with them

Work with patients and carers

- We commissioned Healthwatch to undertake a survey (31 responses) and develop case studies (15) to understand people's recent experience of end of life care

- Experiences were reported with a 50/50 split of positive and negative experiences

- Key themes
  - Dignity, kindness and compassion
  - People asked for 2 things, to be with their loved one and for the loved one not to be in pain
  - People reported feeling they had to 'battle' for things which was exhausting at an already difficult time
  - There was also often confusion over the number of people who 'go up the path', who is in charge of care?

A public version of the report from the survey results will be available soon, along with a showreel and a series of short videos using quotes from some of the interviews.

Workshop and family/carer headlines

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

Headline	What could be done
Patient and professional knowledge of who does what	Clear service offer Ensuring that a clear case manager/named nurse is identified – what is already commissioned? Workshops and public engagement work suggest it is not always available across the city Process to clarify continuity of decision making – including response to increase in complexity Clear processes at transition points
Advance Care Planning	Advance Care Plan – needs to be up to date, useable and accessible Process to ensure there is only one ACP (not multiples) using same or similar format across the system Training for staff Clarity about where the latest version is stored – paper vs electronic Is everyone confident to start/have the conversation? More understanding of different cultural norms around death
Early recognition of deterioration	Can we start conversations "if the treatment is not successful" very early on? The right people to have the conversation are the ones the patient and family knows well – need to ensure that they are skilled, knowledgeable and confident More systematic recognition process for identification and recognition of the start of end of life
Willingness to explore care at home	Clear service offer Ensure that information which patients are told is accurate Development of SPA Updated patient and carers information across all community providers Keeping improved MDT process especially when home is a care home
Issues of capacity and adequate staffing	Development of a gap analysis of service delivery – with capacity vs demand and desired role / level of intervention by each agency Compare this to commissioned services Develop preferred service model Develop new commissioning intentions
Access to medicines	Keep anticipatory medicines available in care homes (national issue) Work to speed up supply of medication on discharge Support for carers on what to do (who to contact) if new symptom e.g. increased pain arises (clear process)

Next steps

- Finalise key findings with full analysis to share with all those involved in the workshops

- Develop the options for the focus of Phase 2

- Work with the Community Flows Improvement Group to identify the area(s) for Phase 2

- Develop a full action plan for Phase 2

- Within this we recognise the impact of COVID-19 on the shift of care into the community (LCH reporting 30-40% increase on caseload for EOLC) and increased partnership working. There is already a new normal!

Further Reading

- Below are two published articles for further information:

- https://www.leedsacademichealthpartnership.org/news-and-events/leeds-launches-novel-approach-to-improving-palliative-and-end-of-life-care/

- https://edition.pagesuite-professional.co.uk/html5/reader/production/default.aspx?pubname=&edid=a522a40c-885e-4ae6-8778-6600fa998bbc