The Need for a Leeds Single Point of Contact for Palliative and End of Life Care

Scoping Project Background Report
Final

January 2023

Contents

1.0 Introduction

This is the final background report on the scoping project of the need for a Single Point of Contact for Palliative and End of Life Care (SPOC) in Leeds. The scoping considered the needs of patients in the last year of life, their families and professionals involved with their care.

This report covers the background, process, findings, and options for way forward. It supports the scoping report and options appraisal that has been widely circulated within Leeds. It has been produced to ensure that there is a full legacy of the work done once the project has been completed.

Following completion of this scoping project consideration of the options needs to be undertaken and any business plans required will be developed at a later stage.

2.0 Background

The Leeds Palliative Care Network (LPCN) is leading a project Dying Well in the Community in Leeds with the aim to improve the transfer of patients between all providers to ensure continuity of care and the quality of end-of-life care experience for patients and their families.

The focus of the work is community (out of hospital) services and how they interact with each other and hospitals to meet patients and their family's needs. The project is split into two key phases:
Phase 1 – using various methods to obtain different views, to scope out the services on offer across Leeds and look for areas of duplication and gaps.
Phase 2 - to ensure that there is 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.

A summary of key areas for action and improvement from Phase 1 work was developed. One of the key areas was the need for a Citywide Single Point of Access[1] for Palliative and End of Life Care to offer support, advice and information for patients and their families in the last year of life, but also as a hub providing support, advice, and information for professionals.

The outcomes for the project are:

- Desk top review of the requirements nationally and locally for a SPOC/SPA.
- Identification of previous work in this area both locally and at an ICS or regional level.
- Identification of plans for SPOC/SPA where the patient cohort may overlap.
- Identify what key services offer support to those who are receiving palliative and end of life care and their carers currently, including capacity required and capability of staff needed to respond to requests
- Develop an understanding of local models already in existence e.g. Goldline, including cost and pros and cons
- Work with data analysis staff to understand the demand especially for unnecessary hospital admissions
- Develop a model describing what a SPOC/SPA would look like for Leeds
- Production of a series of options to inform the development of a business case.

After conversations were held with the Palliative and End of Life Care national team part of the Primary, Community & Personalised Care Group at NHS England & Improvement, funding was awarded so that Leeds could act as an exemplar site. The aim was to demonstrate the benefits of

[1] It should be noted that a Single Point of Access became more commonly referred to as a Single Point of Contact.

providing a 24/7 Single Point of Contact service for an area and identify some of the barriers there were to implementation. A scoping project to identify if there was a need was commissioned and use of the funding approved by the LPCN executive. A project lead was employed to undertake the project to look at various key areas including what is on offer in terms of a SPOC regionally and nationally; what services currently exist in Leeds for palliative and end of life care out of hospital; identification of any gaps and issues; and develop potential options to develop a SPOC offer for Leeds.

A steering group to support this work was developed with representation from various organisations across Leeds, plus regional services including Local Care Direct and the Yorkshire Ambulance Service.

3.0 Process of scoping

- Previous work undertaken in Leeds including an End-of-Life Health Needs Assessment (2013), a SPOC proposal developed in conjunction with patients and carers and options appraisal (2014), the Dying Well in the Community in Leeds Phase 1 report were analysed.
- An internet search was undertaken to look for national documents relating to end-of-life care, single point of access/contact, out of hours services.
- A literature search was undertaken looking for evidence of the related studies.
- An internet search was undertaken to look for existing SPOC/SPA services (primarily in United Kingdom) and what services were available in other cities with similarities to Leeds. A contact list was then drawn up of services to request further information and e-mail or phone contact initiated requesting meetings. Meetings were held with those who replied agreeing to do so.
- Meetings were held with staff within local organisations including Leeds Community Healthcare (LCH), St Gemma's Hospice, Sue Ryder Care Wheatfields, Leeds Teaching Hospitals Trust, the Lead GP for End-of-Life Care, care homes citywide specialist palliative care consultants, Local Care Direct and Yorkshire Ambulance Service.
- Time was spent observing services including LCH twilight and night services, Local Care Direct and the Airedale Digital Hub including Goldline.
- Local data such as the information in the annual Planning Ahead Report was considered.
- Steering group meetings were held to update and seek guidance as to next steps.
- An interim report and options appraisal were developed.
- Feedback on these was sought from the steering group and key stakeholders within their organisations. Amendments were made as required.
- The report and options appraisal were presented to the LPCN executive group.

4.0 Previous work in Leeds

An End-of-Life Health Needs Assessment (HNA) was commissioned by the three Clinical Commissioning Groups in Leeds in 2013. This found that people struggled to get medical support in the evenings and at weekends, and that this could make patients and their relatives feel very isolated and vulnerable. Some respondents reported that they would react to this situation by ringing 999, NHS 111 or their GP practice, and several respondents indicated that they would attend A&E.

The HNA led to the Leeds End of Life Care strategy (2014-2019). A key recommendation was the creation of a Single Point of Access (SPA) for people at the end of their life and their carers.
The SPA proposal was developed, in conjunction with patients and carers. The Patient Feedback Report (Oct 2014) identified that in particular carers wanted a SPA service that could offer advice and information and access to services 24 hours a day, 7 days a week. Another important consideration was that the SPA should be staffed with people who were experienced and

knowledgeable about end-of-life care, so that they had they were able to manage the situation whatever the patient/ carers were experiencing.

A stakeholder workshop was then undertaken. Discussions included what a SPA could offer, benefits and potential aspects of the service. A service specification for a SPA for end-of-life care was subsequently developed. This outlined a 24-hour service, provided 365 days a year. An options appraisal was also developed. The model was not progressed at this time.

5.0 National documents

Various national reports, guidelines and standards refer to advice and support over 24 hours which include the following. In July 2022, Palliative and End of Life Care, Statutory Guidance for Integrated Care Boards (ICBs), was published. This refers to Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 which provides a framework for each ICS to evaluate commissioning and delivery of their palliative and end of life services. In terms of 24/7 access, it states: '24/7 access – All commissioners have to engage in defining how their services will operate population needs 24/7. ICBs should consider:

- implementing the 24/7 Service specification
- access to medicines

This shall be part of technical guidance.

NICE Guideline 142: End of Life Care for adults (2019) recommends that adults approaching the end of their life, their carers and other people important to them should have access to:

- a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care
- an out-of-hours end of life care advice line.

NICE Quality Standard 13: End of life care for adults (2021) contains the following: Quality statement 4: Out of hours care: Adults approaching the end of their life and their carers have access to support 24 hours a day, 7 days a week.

'Our commitment to you for end-of-life care. The government response to the review of choice in end-of-life care', (Department of Health 2016) contained six commitments the government has made to the public to end variation in end-of-life care. The final commitment is 'know who to contact for help and advice at any time'.

6.0 Evidence for SPA/SPOC

Published evidence of the benefits of SPOC services is limited but does broadly highlight benefits and especially when looked at alongside individual service evaluations and audits. For some studies, the benefits of a SPOC specifically can't always be drawn out clearly as they include other concurrent services such as hospice at home or rapid response. This means it isn't possible to identify the benefits of each component.

Following an evidence review of out of hours services by NICE in 2019, the report concluded that analysis of the evidence for providing a dedicated out-of-hours end of life care advice line and an out-of-hours pharmacy service showed that the costs of providing these services could be balanced by the savings incurred by a relatively small reduction in emergency admissions and length of stay of admissions, and an increase in the number of people remaining in the community.

Lustbader et al. (2017), found that a home-based palliative care programme including an out-of-hours telephone line was associated with a 34% reduction in hospital admission and nearly 200 fewer emergency department admissions per 1000 patients during their final month of life.

The benefits of an out-of-hours telephone line were also observed by Ranganathan et al. (2013). Patients enrolled in the initiative being studied had a 30-day readmission probability of 9.1%, compared with 17.2% in patients receiving standard care.

Purdy et al. (2015), found a phone line supporting patients at the end of life was associated with a lower risk of hospital admission and risk reduction in attendance at emergency department.
Sue Ryder published an evaluation report in 2012 of a pilot initiative, 'Partnership for Excellence in Palliative Support' (PEPS). PEPS is a 24-hour telephone SPOC service bringing together 15 organisations across East England, with senior nurses as the first point of access. Information from a sample of patients was compared with hospital activity data sets before and after registration and suggested that the introduction of a SPOC service could result in 30% fewer admissions, and 30% shorter stay.

An economic evaluation of Goldline, a phoneline based in the Airedale Digital Hub for patients in the last year of life, (2016) found a 23% reduction in non-elective admissions for their patients compared to baseline ($p<0.00001$), equating to a reduction of almost 2000 bed days. Goldline also appears to address some of the known inequalities in end-of-life care support for those with non-cancer diagnosis and/or not known to specialist palliative care services and older people. For example, for those with Goldline support: 63% of deaths had a primary palliative care diagnosis of non-malignant disease, 54% of patients who died had had a referral to specialist palliative care services, and 46% of patients who called Goldline were aged 85 years or older (2020-21).

Feedback from families to various telephone services in England highlights the many benefits of these services including: supporting carers emotionally; enabling improved symptom management; hospital avoidance; reduction in visits from health care professionals; achieving patient preferred place of care; giving information in a timely and easy to understand way; liaison with other services when needed.

7.0 Local and national SPOC services
Local and national examples of telephone advice and support services were sought. In most areas there were a variety of contact numbers and services available to patients in the last year of life, their families and professionals caring for them. These include GPs, community nursing services, local hospices (mainly if patients are known to them), NHS 111 who may refer to out of hours GP services or some may phone 999 (whether in an emergency or not). They were therefore in a similar position to Leeds. However, there is an increasing interest in developing some type of an advice line based on increased need. Organisations looking at doing so generally considered this needed to be a 24 hour/7-day service with close links to services that could respond to identified needs such as a rapid response to visit.

7.1 Local services
7.1.1 The Kirkwood, a hospice covering the Kirklees area, started a new service called 'Connect with the Kirkwood' in June 2022. This offers a 24-hour phone line for patients with a life limiting illness, operating 08.00 -16.30 7 days a week and plans are underway to extend to 18.30. Outside these hours the in-patient nurse in charge is available and can contact a consultant on call if required. Video calls can be used to enhance assessment if needed using the Accurx software on SystmOne. Evaluation of the service has not yet been undertaken but it is perceived to be successful so far and demand is high and increasing. Availability of a Clinical Nurse Specialist within the service is thought to be key as is ability to contact the Kirkwood Co-ordination Service for social care support and care packages. The service is promoted widely in the area and patients don't necessarily need to be known to The Kirkwood to access therefore an opportunity to reach anyone in need exists.

7.1.2 Harrogate
In the Harrogate area patients contact services they are under during the day and out of hours can contact NHS 111 who refer to the out of hours GP service if needed, the community nursing service (which is limited) or the local hospice if known to them. It is felt the service available needs to be improved so a business case has been developed. This has 3 parts, to: increase identification; increase advance care planning; fund a 24/7 advice service. The Harrogate team are working closely with Goldline and aim to commission this service to cover Harrogate if funding becomes available.

7.1.3 Bradford/Airedale/Craven
In this area a service is provided by Goldline within the Airedale Digital Hub. Goldline was launched in 2013 and is a nurse-led, 24/7 telephone service, staffed predominantly by band 6 nurses. It is commissioned by Airedale, Wharfedale & Craven, and Bradford CCGs and serves a population of approximately 650,000. The service is available for patients in the last year of life. The healthcare professional caring for the patient has a conversation with them and their family to address end-of-life care planning and wishes. Patients are given a personal information pack and their GP/DN/specialist palliative care nurse refers to Goldline via SystmOne, ensuring up-to-date information is available on EPaCCS. All GPs in this area use SystmOne and access to this for staff is key. Goldline is not expected to replace patients' use of their own GP and other community services but aims to enhance and co-ordinate their care, especially when daytime services have closed. For note is that 39% of calls required no onward referral. The number of patients on the caseload was 3,383 patients July 2022.

7.2 National services
Nationally services vary considerably. There does not appear to be one consistent model of meeting patient needs in the last year of life. Some examples are as follows.

7.2.1 Sandwell and West Birmingham
In 2016 a contract to act as lead provider in a partnership model bringing together third sector organisations and NHS was awarded. Palliative and end of life care is provided across the region. A palliative care co-ordination hub has been developed for patients, families, and professionals. The team includes administration staff, end of life co-ordinators (band 6 RNs), Clinical Nurse Specialists and a consultant. They hold the end-of-life register and can access hospice end of life beds. The full service runs 08.00-20.00 hours. Overnight there are 2 Registered Nurses and 2 carers who are located with the district nursing service base and work closely together.

An urgent response service runs alongside the hub. Response is generally for symptom management and admission avoidance. A personal care and sitting service is provided by third sector organisations including Age UK and Crossroads. The CQC rated end of life services overall as outstanding in 2017.

7.2.2 St Helena, Essex
SinglePoint is the care coordination hub for out of hospital end of life care in northeast Essex, and the 24/7 advice and support helpline for people in the last year of life or those with specialist palliative care needs. SinglePoint is a service for those who:

- Have a condition making it likely they are in the last year of life
- Have a severe chronic disease for whom a deterioration may be life-threatening
- Are in frail overall health and at risk of sudden deterioration

SinglePoint works alongside other health and social care services such as GPs, community nurses and hospital specialists. Members of the public, patients, relatives, carers, and professionals can get

expert advice over the phone 24/7. The SinglePoint number can also be used for referrals into St Helena Hospice services.

The SinglePoint virtual ward is a nurse-led service. The aim is to maintain patients in their usual place of residence by offering personal care visits and to prevent inappropriate admission to an acute setting. The service can also facilitate discharge from hospital where home is the preferred place of care.

7.2.3 Thames Valley

Thames Valley provides a comprehensive community service. This includes a 24-hour palliative and end-of-life care telephone service to give advice to people with palliative care needs and their families, as well as to healthcare professionals who need guidance and support on delivering palliative care. The service is for people living in East Berkshire and South Buckinghamshire.

The specialist team is available 24/7, 365 days a year, to provide guidance on symptom control, practical advice, and emotional support. Running alongside this is a rapid response service and a Thames Care at home.

7.2.4 Cambridge area

The Arthur Rank Hospice Charity is commissioned to provide the Palliative Care Hub, a phone service for anyone who has a palliative condition or receiving end of life care, across Cambridgeshire and Peterborough (population 950,000). The service is available to patients, relatives, and healthcare professionals and is available by ringing 111 and selecting option 3. There is no requirement to be known to hospice services.

The service launched in April 2021, initially operating in the out of hours period but from April 2022 is available 24 hours a day, 7 days a week. It is broadly promoted for example in GP clinics, by faith leaders, in hospital out-patients. The hub is staffed by band 7 clinical nurse specialists.

Key factors and successful outcomes include:

- Within the first 38 weeks of operation, it is thought the service avoided 148 hospital admissions.
- The ability to assess and make decisions
- Service has been used by ‘hard to reach’ people
- Helped identify the need for verification of death training for nurses
- Proactive calls are successful e.g. for breathless patients

7.2.5 South Oxfordshire

Sue Ryder Palliative Care Hub South Oxfordshire supports people aged 18 and over who are living with life-limiting conditions. A Hospice at Home service, Day Hospice, rapid response and Care Coordination and Advice Line is established. The Hospice at Home service provides care for patients in their own home in the last 12 weeks of life. It is available seven days a week, 08.00-20.00 hours and from July 2022 a new night service runs from 22.00 and 07.00 hours. The advice line operates 08.00-20.00 hours. Calls are answered by the admin team and then put through to a Clinical Nurse Specialist as required. Alongside Clinical Nurse Specialists having the broader community multi-disciplinary team is key with the rapid response service becoming increasingly important as are nurses with non-medical prescribing and advanced skills qualifications.

7.2.6 Mental health

When searching for information on SPOC/SPA services mental health services were often highlighted. A limited exploration of these services was undertaken. It seems a key role of SPA in this field of care is referral and co-ordination, rather than specifically advice and support.

8.0 Services providing palliative and end of life care in Leeds
The current provision of community palliative and end of life care in Leeds is provided by a range of services and organisations including: Leeds Community Healthcare, primary care, Sue Ryder Wheatfields Hospice, St Gemma's Hospice, care homes, Local Care Direct, Yorkshire Ambulance Service, citywide specialist palliative care consultants, private agencies.

Within normal working hours patients can contact any service they are being cared for, which could be several, for example GP, private caring agencies, neighbourhood team, non-cancer nurse specialist such as heart failure, or hospice specialist palliative care community service.

Out of hours patients can ring the Leeds Community Healthcare nursing night service (will be given number by the neighbourhood team if on caseload or hospital/hospice if being discharged), local hospices (mainly if patients are known to them), NHS 111 who may refer to out of hours GP services or some may phone 999.

8.1 Leeds Community Healthcare (LCH)[2].
Key changes within LCH are underway including a review of the Neighbourhood Team model, urgent care response and hospital discharge.

The neighbourhood teams (NT) provide the majority of palliative and end of life care. There are currently 13 bases, with multi-disciplinary teams that are based together.

In addition, there is:

- a Clinical Service Manager (Palliative Care and Community Cancer Support Services)
- 3 Palliative Care Clinical Quality Leads (band 7)
- 6 Palliative Care Leads (PCL, band 6), 1 of these PCLs also supports the night service
- A care home team for end of life (covering nursing and residential), 3 part time nurses, work Mon-Fri, PCLs cover care homes at the weekend if needed, for example to support with syringe drivers.

The twilight service runs from 17.00-22.00, It is currently based in Armley Moor Health Centre. The service is split into 3 areas North, South and West. Visits can be planned or responding to unplanned needs.

As this report was being finalised some of changes were implemented. On 1st November 2022, as part of the Neighbourhood Team transformation 3 new Triage hubs were established. They are located in the North, West, and South of the city and are staffed by a multi-disciplinary team of LCH Nurses, Occupational Therapists, Physiotherapists, SkILs Reablement (LCC) Case Managers and LCH Neighbourhood Team Officers. The hubs will be the point of contact for patients and will operate 7 days a week between 7.00 – 22.00 hours. Further details are awaited on other developments and how the hubs will work in practice.

The LCH night service runs from 21.30 – 07.00 (some staff work during day to co-ordinate referrals and work) and is based in Killingbeck Court, LS14. The service offers planned care and unplanned care. There is a triage nurse (band 6) and administrator office based, Registered Nurses and support workers visiting and sitting staff. The triage role includes overall responsibility for the shift, telephone assessment, co-ordinating visits if needed, point of contact for night sitting staff, effective

[2] LCH is undergoing a period of transformation, so it should be noted the following information is only current at time of writing.

use of resources, the nurses also manage staff so might have to fit in 121 meetings. Staff report effective triage is vital, band 5 nurses doing this role didn't work as well as more senior nurses. Anecdotally demand at night is approximately 70% palliative and end of life, 30% catheter issues with very small number of other reasons. Demand is high and is variable. The number of calls range from 15-40+ per night. Advice is available, if needed, from the hospices via the nurse in charge (NIC) who can then contact the doctor on call or, depending on the level of need, consultant on call. The response to calls is reported as being variable, sometimes it is helpful, and at other times issues include: the NIC can be occupied with other work and there is a delay, NIC knowledge and/or willingness to give advice is variable, inconsistent referral onto a doctor/consultant on call and insufficient access to prescribing (including remote prescribing). We recognise that getting advice about patients not known to the hospices can be difficult. Discussions with the NIC in hospices highlighted similar issues.

Demand for LCH services across the 24 hours is high and end of life care increasing. Managers and clinical staff report staffing challenges, this has especially been so during the pandemic, but continues. This results in limited capacity to meet the demand at times.

Staff had mixed views regarding the need for a SPOC. Some felt it would be helpful: as it would take pressure of them; a dedicated role to assess and support was seen as positive as time to 'do a good job'; extra time as some patients/carers just need time to talk; a service just concentrating on calls and no visits was seen as valuable; ability to do virtual calls could be valuable; staff who had previous experience of Goldline were positive about it. Some staff were less sure of the need and benefit: they felt they would need to triage again as had responsibility for allocating resources; visits might be promised by the SPOC and then they couldn't be offered; the SPOC would need to keep a full understanding of services. The ability of staff in a SPOC to view SystmOne, EMIS and PPM is viewed to be vital. Having non-medical prescribers was also deemed important.

Other LCH services include the virtual frailty ward. It hasn't been possible to meet with staff from this service. Links to this service will be key as there is likely to be interfaces and overlap for some patients.

Various other specialist services come under the lead of the Clinical Head of Service for Cardiac, Respiratory, TB, CIVAS, and HHIT. There is increasing demand on services such as heart failure and respiratory. It can be difficult to discharge patients when they become more stable due to demands in the NT. A SPOC was generally seen as being favourable, one reason being this could be a point of contact for discharged patients, also it would be helpful for patients and families to have 1 number to contact when unsure where to go.

8.2 Primary care

Demand in primary care is high. Practices can vary in terms of ability to meet the needs of palliative and end of life patients. Advanced Nurse Practitioners are having an increasing role with this group of patients, especially in care homes. Some staff reported the ability to arrange a face-to-face assessment by GPs is variable. Various staff reported patients struggle to get through to GP services and are therefore ringing other services more often such as hospice community teams. It was reported also that communication is much smoother if practices use SystmOne rather than EMIS.

8.3 Sue Ryder Wheatfields Hospice and St Gemma's Hospice

The hospices provide in-patient beds (specialist and end of life); community services, day hospice and/or out-patient services provided by a multi-disciplinary team, virtual ward, 24/7 advice. They also have a key role in education, the Academic Unit of Palliative Care is based at St Gemma's Hospice. The Clinical Nurse Specialists (CNSs) provide a 7-day service (minimum 8.30-17.00, often

08.00-18.00 hours). Outside these hours the first point of advice is via the nurse in charge (NIC) who carries a dedicated phone. However, the NIC is also working on the ward and responsible for the hospice in terms of any other clinical or non-clinical issues. They may be logged onto SystmOne when they get a call or may need time to do so. The NIC has varying levels of skill and knowledge and confidence to take advice calls. There is an average of 40 calls per month to the NIC phone. They can be from patients/families or professionals. The demand at the weekends is variable. There is 1 CNS on duty at Wheatfields and 2 at St Gemma's at weekends. Visits and telephone work planned and unplanned is undertaken at weekends. There is an increasing number of calls to the community team, with patients often being unable to get the response they feel they need from other services. There is also a medical on call rota. Senior levels of doctors such as registrars can give community advice, but junior doctors are not authorised to do so. There is also a consultant on call for the city (detailed below).

8.4 Citywide specialist palliative care consultants on call

The 11 Palliative Medicine Consultants across Leeds (based during the daytime at LTHT, Sue Ryder Care Wheatfields Hospice and St Gemma's Hospice) provide an out-of-hours advice service (17.00-09.00 weekdays and 09.00 Saturday to 09.00 Monday) to:

- Hospice on-call doctors
- LTHT medical and senior nursing staff including emergency department
- Senior community nursing staff
- Out of hours GPs, generally Local Care Direct
- Paramedics
- Hospice based specialist palliative care CNSs (weekends)
- LTHT CNSs (weekends)

For community calls (GPs, nurses, paramedics) the consultant is contacted via LTHT switchboard or the Hospice Nurse in Charge. Some advice calls may be taken by a registrar rather than needing to be put through to the consultant. In the hospital there are no specialist palliative care doctors on call other than the consultant.

The frequency of calls from community staff (excluding specialist palliative care CNSs) varies and averages between 1 and 5 per week, more commonly at a weekend than weekday night. There is an impression that calls from out of hours GPs and community nurses has lessened with calls from paramedics increasing.

The complexity of calls varies from advice about medication use including prescribing for syringe drivers to decision making to enable patients to be managed effectively at home rather than be admitted to hospital. This can be for patients not previously known to specialist palliative care but with specialist palliative care needs.

Concerns have been raised that if demand increased this would have impact on a consultant's main day time role and maybe need time back. This would be difficult to manage due to commitments and variability of demand making planning difficult e.g. if on call and demand high but next day the consultant had a ward round, clinic, or meetings this would be difficult to manage.

8.5 Care homes

Care homes can be divided into those with nursing and residential care homes staffed by carers. Residential care home residents with palliative and end of life needs are supported by LCH NTs. In nursing homes registered nurses are available 24/7 to care for patients. Staff appreciate the help of LCH end-of-life facilitators, especially with syringe drivers. The hospice Clinical Nurse Specialists

(CNSs) have some residents in care homes on their caseloads, mainly nursing homes. Advice is available from the hospices 24/7 regarding those patients though call numbers are low out of hours.

8.6 Local Care Direct (LCD)
LCD provide a broad range of services for patients across Yorkshire and the Humber including: a centralised contact centre, GP out of hours services, Urgent Treatment Centres, walk-in facilities. They are contacted via NHS 111. The service aims to respond in 1 hour for palliative patients. A telephone triage is undertaken and if face to face required it is arranged in centres or, if appropriate, at home where most palliative and end of life assessments occur. The main calls in relation to palliative/end of life care received are around:

- Increasing or changing medications - e.g. increased pain, breakthrough pain, agitation.
- Referrals to district nurses for support and care.
- Home visits needed - sometimes just for altering medications or taking a view on a newly identified end of life patient out of hours.
- Warm transfers from 999 where crews need advice on, end of life, advance care planning and DNACPR – this information absent altogether or crews want to know what exists.
- Patients who develop complications - e.g. suspected infection, back pain, fever - looking at reversible causes, treating at home or admitting.
- Constipation.
- Discussions with palliative medicine consultants.
- Hospice bed availability.

Calls from paramedics come through as 'warm transfers' and as such are prioritised. EPaCCS access is key. LCD have SystmOne access but in EMIS the summary care record only. Electronic prescribing is also key – e.g. writing an initial script and increasing medication doses. Practice varies across the region regarding accepting remote prescribing. LCH accept this via SystmOne which is helpful and helps reduce LCD time to visit to prescribe and helps patients get end of life drugs in a more timely way.

The clinical establishment in LCD includes GPs, advanced nurses, and physician associates. In terms of staffing resources, recruitment can be difficult, less experienced GPs can lack experience in palliative care.

Challenges can include access to medicines and hospice beds across the region.

8.7 Yorkshire Ambulance Service (YAS)
There is a palliative/end of life link with YAS and the LPCN. In terms of crews attending patients, they can vary and include paramedics, ECA B3 assistants, technicians e.g. 1st or 2nd year in university. Newly qualified paramedics need to phone in to control for first 2 years when making decisions.

Access to records can be an issue, so it is helpful to ring hospices for more information. The response to these calls can be variable, the CNSs being very helpful, but sometimes mixed response contacting the hospice NIC. Advice and information can lead to reduction in transfer to ED. Hospice admissions are perceived to be limited and this is not just in Leeds.

The training provided via the AUPC is valued.

Paramedics can give 'as required' (PRN) sub cut medication for symptom management when available but sometimes need support regarding decision making and encouragement to do so.

In terms of a SPOC crews do use Goldline in Airedale if the patient is in that area and generally find it helpful, especially in terms of accessing up to date information and advice.

8.8 Leeds Teaching Hospitals NHS Trust (LTHT)
The hospital palliative care team interface with community services in several ways. The consultants are part of the on-call system. The team can be involved with discharge decisions and plans. Emergency departments (ED) may triage patients who require discharge home rather than admission. The palliative care team liaise with ED daily. A new CNS role has responsibility to scope issues related to palliative and end of life in ED. Some challenges in accessing information regarding community patients and securing ongoing care in a timely way on rapid discharge from ED have been highlighted.

9.0 Local data
The Electronic Palliative Care Coordination System (EPaCCS) is an electronic record that supports advance care planning conversations and improves the co-ordination of care for people approaching the end of life. It provides a summary of key recommendations, preferences, and information essential to the high-quality care for patients with palliative care needs and those choosing to plan ahead, irrespective of prognosis. Local and national data shows that when patients are given the opportunity to discuss and share their preferences, they are more likely to achieve their end-of-life care goals.

In Leeds EPaCCS is part of the Planning Ahead template. The data from the latest report (2021/22) shows that that a greater proportion of people are being given opportunities to discuss, document and share their care preferences at an earlier stage and demonstrates improved data quality. Giving patients an opportunity to discuss their wishes regarding escalation of care, preferred place of care/death and have this recorded will be key if a SPOC is established as clinical staff will need this information to aid decision making and support.

The current emphasis is starting to talk to patients and complete this template at an appropriate stage and not necessarily in the last year of life as was previously the case. However, it is generally completed in the last year of life. There are just under 7,000 deaths in Leeds per year (expected and unexpected).

Key findings of the 2021/22 Report (Q1-Q4) report are:

- 46% of adults who died in Leeds had an EPaCCS record compared to 48% in previous year.
- 79% achieved their preferred place of death compared to 80% for the previous year.
- The proportion of patients whose EPaCCS record was started more than 3 months before they died is at 50% compared to 55% the previous year.
- Deaths in hospital for patients with an EPaCCS = 16%
- Deaths out of hospital for patients with an EPaCCS = 70%
- No POD recorded 14%

In Q3 of 2021/22 6% of patients on EPaCCS had 3 or more unplanned admissions in the last 90 days of life. It would be hoped that an outcome of a SPOC would be to reduce this. An economic evaluation of Goldline (2014) indicated a reduction of more than 20% of non-elective admissions compared to patients identified as being at the end of life before the Gold Line was introduced. Work currently being undertaken in LTHT should help inform why patients are admitted and their needs. The table below shows further details of emergency department visits and planned/unplanned admissions and costs.

Activity and cost breakdown (2021/22)

	Q1		Q2		Q3		Q4		Total	
A&E visits	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**
Unique Patients	**371**		**398**		**453**		**398**		**1620**	
Total Activity and Cost	540	£116,716	604	£132,073	670	£150,304	594	£130,705	2408	£529,798
Average Activity and Cost	1.5	£315	1.5	£332	1.5	£332	1.5	£328	1.5	£327
Planned Admissions (EL)	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**
Unique Patients	**25**		**26**		**27**		**19**		**97**	
Total Activity and Cost	29	£90,730	29	£98,833	28	£72,338	25	£89,718	111	£351,619
Average Activity and Cost	1.2	£3,629.20	1.1	£3,801.27	1.0	£2,679.19	1.3	£4,722.00	1.1	£3,625
Unplanned Admissions (NEL)	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**	**Activity**	**Cost**
Unique Patients	**418**		**433**		**489**		**431**		**1771**	
Total Activity and Cost	619	£2,809,526	624	£2,879,982	720	£3,323,986	633	£2,900,446	2596	£11,913,940
Average Activity and Cost	1.5	£6,721	1.4	£6,651	1.5	£6,798	1.5	£6,730	1.5	£6,727

We know that not everyone dies in their preferred place of death and that the actual place of death may vary for many reasons. Some of these are due to the final needs of the dying patient but some are due to system issues. In 2021/22 the preference was 1-2% of people preferring to die in hospital whereas the actual figure averaged 15%. Establishing a SPOC would aim to increase the percentage of patients achieving their preferred place of death and particularly other established SPOCs have shown that there is an increase in people being able to achieve their wish of not dying in hospital.

In 2021/22 the numbers of patients registered on EPaCCS average around 3,400 at any one time and this equates to 50% of people who die in Leeds at any time. If a SPOC was established the number of patients on EPaCCS would be expected to increase, as this has been found in other areas. Extrapolating from the Goldine data, it is estimated that this would rise to approximately 5,000 people.

10. Summary of points to consider

10.1 Perceived need for SPOC

Patients, families, and professionals continue to identify the need for a SPOC from the previous work 9 years ago to present. Families are still given a variety of numbers and services available, and they report issues with difficulty getting through to services at times, sometimes resulting in calls to other services who can't necessarily help.

In terms of professionals those that feel it would be a good idea base this on different reasons. For example, some to reduce workload on themselves and colleagues, some to get more consistency in triaging, the skill and time needed to take calls is recognised, some staff had previous experience of Goldline and considered this to be a good service, staff report patients/families frustration trying to contact services, access to information is seen as vital.

10.2 Demand

It is difficult to accurately predict demand as it is based on various factors, and we know demand on palliative and end of life services is generally increasing. All existing SPOC services are reporting increasing demand. If there was a dedicated service for advice and support patients and professionals may be more likely to contact it.

Around 5,000 people who could benefit from palliative or end of life care die in Leeds each year. The number of patients on EPaCCS at any one time is on average around 3,400 but we know that between 40-50% of people who die are recorded on EPaCCS. This may increase if a SPOC was

established as the service this offers has provided an incentive to professionals to complete EPaCCS in other areas. Goldline covers a population of 650,000 and in July 2022 had 3,383 patients on the caseload.

Scaling this up against the population of Leeds (approximately 800,000) may help predict demand on a SPOC. Considering Leeds has a higher population than the Goldline area the figures suggest having a SPOC could increase the number of patients on EPaCCS to over 5,000 at any one time though not all of these would be accessing SPOC at the same time. The case load for a SPOC would be in the region of 4,200.

Some patients would continue to access services are known to them even when a SPOC was implemented. At the moment, some services, including the hospices, are finding increasing numbers of call during the day. Goldline and other advice line services have reported increasing calls during the day and suspect this is due to patients being unable to get a satisfactory result from other services. Looking at the local situation and experience of other SPOC services already established, although there may be peak times, demand across 24 hours is increasing.

Some patients are not currently receiving services from existing providers as they have been discharged or are not well known to them prior to an end of life diagnosis. Some, including specialist palliative care and cardiac services, have suggested they would be more confident in discharging stable patients if a SPOC existed so this would impact on demand of a SPOC.

Existing services nationally and regionally, have shown that contact has come from over 50% non-cancer patients, a high number of patients not known to specialist palliative care and efforts to reach 'hard to reach' patients, for example, from certain cultures have been successful, all of which potentially increase demand.

Some existing services have also identified areas they have/could develop into including video calls to verify death in care homes, using video calls to assess patients, in particular in rural areas and at times of high demand, using video calls to support family members administering as required medications, proactively contacting patients such as breathless patients who ring the service on a frequent basis or patients discharged from the emergency department or who the ambulance service have assessed and it has been agreed they would stay at home.

An estimate of savings arising from any potential SPOC can be made by approximating activity by scaling up what we know from established services such as Goldline. For example: Goldline estimate approximately 2,000 bed days of unplanned admissions are saved each year. The Bradford adult population is approximately 650,000 compared to the Leeds adult population of approximately 800,000. Therefore if the same bed reduction was applied then we could see in the region of 2,500 bed days saved in Leeds.

An estimate of savings that could be created for any potential SPOC can be made by approximating the costs of unplanned admissions beds as described above (with an unplanned admission costing £350/day) from this the implementation of a SPOC could save just under £0.9 million (£875,000).

10.3 Scope

The scope of a SPOC has been clarified through this work and is proposed in 11.0 below.

The purpose is to provide advice, support, and signposting in the last year of life for patients either who are already registered on EPaCCS or are eligible to be.

Most staff who participated in this scoping work felt there was no need for referrals to be part of any new SPOC service as the existing referrals to neighbourhood teams, health case managers, and hospices works well on the whole. Reports were noted of difficulties with referrals, but it is not clear if this is the system or ability to respond to the request. The transformation work in LCH and developments in hospice responses to acute needs of complex patients may address some of these issues.

The hours of operation of a SPOC should be considered in light of investment available. Other services have started at a minimum of Mon-Fri 17.00-22.00 hours, weekends and bank holidays then expanded. However, there are several arguments for the service to be 24/7. Services nationally are increasing hours and have identified a need for a 24-hour service. In Leeds a SPOC 'in hours' would help reduce calls to other services and Goldline feel strongly from their experience there is no point in doing just 'out of hours' and demand for 'in hours' has increased in recent years. Having a service 24/7 would also achieve the desire for a single number for patients/families and offer a service to patients discharged from other services when stable.

The aim in Leeds is that patients in the last year of life would be identified, discussions started and EPaCCs documentation commenced. With the change to Planning Ahead (of which EPaCCS is part of) the aim is now to start these discussions sooner and we recommend that access to a SPOC would be extended to these patients earlier on.

The latest planning ahead indicates 73% of patients who died on EPaCCS had been on it for less than a year and indeed 50% within the last 12 weeks of life. The experience of Goldline is that a small percentage of patients are on the caseload for longer than a year but that this isn't an issue in terms of managing activity.

10.4 Estate and technical issues

Establishing and operating a clinician-led 24/7/365 SPOC service takes considerable time, resource, effort, and expertise.

Any new service in Leeds would need to be developed with a carefully planned specification in terms of equipment and IT infra structure, current and future space. For example, the appropriate phone system is key having the ability to order calls, inform staff of calls waiting, answer machine facility and allow collation of activity information and other statistics such as number of calls, time to answer, number to answer machine; also key is the ability for video calls; the right workstations for staff, headsets, spacing needs to be planned. Access to information systems including SystmOne, EMIS, PPM is vital. Other generic issues like staff parking and accessibility also need to be considered.

As Goldline is co-located with other services in the Airedale Digital Hub there are many benefits to this. It is well established so experienced in running such a service and the requirements. Leaders have a good knowledge of digital requirements and are linked with the national way forward. It benefits from economies of scale. Immedicare use video calls, including for verification of death in care homes, but this facility is not used in Goldline at present.

10.5 Workforce

There are significant nursing recruitment issues across Leeds, complicated by staff reporting lack of experienced staff, challenges supporting junior staff, lack of specialist nurses, a need for more non-medical prescribers, need for further training, staff feeling stressed and sometimes burnt out, all which are workforce issues that need careful consideration.

From the experience of community and hospice services in Leeds and existing services nationally, senior nurses on at least a band 6 pay scale would be required with the ability to assess, make decisions, resolve issues, refer to other services, document clearly and a non-medical prescriber would be a definite benefit and possibly essential in time.

Recruiting the number of appropriate staff achievable to deliver a SPOC needs to be consider alongside training and retention issues whether a solution was locally provided or commissioned from elsewhere.

Setting up a new service in Leeds would also most likely pull from other specialist services and specialist palliative care services nationally report recruitment issues in terms of both numbers and availability of appropriate staff.

Roles for administrative support and senior clinical roles are key and there may be a place for other roles including emotional support from death doulas, or counsellor type role and care navigators. Some services nationally have employed other professions such as paramedics, therapists, pharmacists, and it may be helpful to explore this further.

10.6 Equality of access

Alongside the technological issues highlighted above any proposed service development would need to consider equality of access. An Equality Impact Assessment has been completed and some specific areas have been highlighted. These include:

- Age - as we are suggesting part use of digital solutions any service would need to ensure we supported anyone who has less access to technology (including older people who are not digital natives), but we will mitigate this by providing access via the phone.
- Disability (both for those with physical needs and a learning disability): though generally phone and video access may support contact from people with a range of needs, telephone calls may be difficult for people who don't have speech or for some neurodivergent people and may lead to more anxiety. A new service will consider multiple methods of contact including e-consultations.
- Gender reassignment: Moving to a SPOC has benefits in terms of ease of access and the trans community are known to present later to services. By its nature, those working in SPOC are likely to be less familiar with the patient's family and carer situation and therefore there is a risk that misgendering. Careful initial phone or video contact will be required to ensure that staff are aware that voices my not be congruent with gender of the person making contact. This will be supported by staff have robust training on gender diverse communities and our literature will include an equality section to ensure trans people feel included. We will also hold focus groups with the community to hear their concerns so they can be addressed before any service goes live.
- Sexual orientation: Moving to a SPOC has benefits in terms of ease of access and the trans community are known to present later to services. By its nature, those working in SPOC are likely to be less familiar with the patient's family and carer situation and therefore there is a risk of increased misidentification of partners and assumed heteronormativity. This may lead to disclosure anxiety and discrimination. We will mitigate this by ensuring all staff have appropriate training and we will ensure demographics are clearly taken as part of the registration procedure for the SPOC. We will also hold focus groups with the community to hear their concerns so they can be addressed before nay service goes live.
- Religion or belief: Having a SPOC will overcome some barriers that minority religions currently feel around issues such as services having faith-based names which can lead to disclosure anxiety and discrimination. If the SPOC request requires intervention from a spiritual perspective, we will need to ensure that practitioners have understanding of and

access to the local services available. Promotion of services through faith leaders has been successful in other areas to improve access. We will also hold focus groups with the community to hear their concerns so they can be addressed before nay service goes live.

10.7 Integration with other services

This scoping project has highlighted where there appears to be a lack of integration and knowledge of services and mixed views of the benefits of services. Some staff reported significant benefits of the specialist palliative care consultant on call service, others felt it was difficult to access or didn't know how to access. Issues were reported with the hospice NIC role and service both from the nurses undertaking it and those contacting it. Challenges include the NIC is undertaking various other activities within the role as well as taking community calls, some nurses are less experienced than others, some are reluctant to refer to the Dr/consultant on call.

The hospice CNSs were often referred to as a good support, during conversations undertaken during the project, especially at weekends. The issue of timely access to specialist palliative care has been identified as an issue in other areas including the areas covered by Goldline. It would be beneficial to look at access to Specialist Palliative Care advice out of hours if a SPOC isn't established and essential if it is.

The SPOC is only a solution as 'part of a jigsaw' whilst it may mitigate the need for a visit in some cases if a visit is still required there needs to be a service who can respond in a timely way. The visit could be the NT, GP in or out of hours, hospices services, virtual ward, increased care package. Linking with the LCH transformation work is vital and considering options such as hospice virtual ward and end of life beds needs to be considered alongside any implementation of a SPOC.

Nationally services reported an increased need to have effective services running alongside a SPOC such as a rapid response, health and social care packages, community nursing services.

There were some reservations of another service being commissioned to provide a SPOC or the development of a standalone SPOC in Leeds, in particular professionals feeling confident about trusting them to triage the needs for visit and SPOC staff to have a full understanding of resources available in the City.

Timely access to prescriptions and medicines is also key.

11.0 Functions of a Leeds SPOC

From the information gathered some key functions for the Leeds SPOC service, should it be fully delivered have now been identified.

- One place to 'contact' (need to be able to offer phone, text, video calls, email response also), predominantly out of hours and patients encouraged to contact usual service in hours if known
- Workforce who can fully assess the situation and be able to
- Offer support to patients, family, carers e.g. helping to cope with anxiety, reassuring family as death approaches, reassuring some symptoms such as fatigue, reduced appetite are to be expected
- Offer support to professionals e.g. supporting paramedics making decisions, reassuring care home staff
- Offer updated information - to patients, family, carers e.g. what is happening regarding an admission or appointments, reinforcing recent information given by professionals such as medication changes.

- Offer updated information to professionals e.g. sourcing medication supplies, advising care home staff regarding out of hour GP visits, giving information to paramedics in patient homes regarding patient preferences and escalation of treatment preferences.
- Offer clinical advice - to patients, family, carers e.g. how to use as required medication, managing acute events such as fits or bleeding
- Offer clinical advice to professionals e.g. advice to care home staff regarding as required medication and use of syringe drivers
- Access up to date patient records

The offer of support, advice, and reassurance to caller will hopefully mean that the call can be completed at that point – **OR if required**

  - Signposting
  - Referring to other services e.g. if visit required
  - Communicating with patients and across services e.g. passing on information, sourcing medication supplies.

The service will be for patients on EPaCCS or those who meet the criteria but not already registered on the system.

This is **not** a service to routinely receive referrals for other services, existing referral systems would exist, however, the SPOC may identify a need for a referral and utilise existing systems to instigate this.

12. Conclusion

This report is the full report of the scoping project to identify the need for a SPOC. A summary report and options appraisal has been circulated to the Steering Group and LPCN executive group for consideration and comment and amended accordingly.

There have been some limitations in undertaking the scoping. It needs to be recognised that this project has been undertaken in a time of change and during a period of continued high demand and significant workforce issues. This has meant establishing appointments and meetings with staff locally and nationally has been a challenge. Some people declined as didn't have time and even once set up meetings have often been changed or cancelled. Various information requested has not been delivered which has resulted in gaps in some areas such as activity statistics and evaluation of benefits. Some organisations locally have been more engaged than others. Feedback on the summary report and options appraisal has not been received from all areas.

There continues to be an identified need for a SPOC for patients, families, and professionals within the last year of life. This is supported by national documents and that ICSs are required to look at systems to support carers in particular over 24 hours. Evidence isn't as strong as it could be, however the range of evidence and qualitative reports from staff, patients and carers does highlight a range of benefits to a SPOC.

Since the original scoping in 2014 there has been an increase nationally in SPOCs. There has also been an increase in demand for palliative and end of life services. There is more information coming through therefore in terms of benefits of a SPOC across the country, key issues in establishing and running a successful service and some limitations. As well as the increase in SPOCs there have also been changes to services which work alongside such as hospice at home, virtual wards, rapid response services. The need for such services to run alongside SPOCs is evident. As established services report that whilst some calls can be dealt with at the point of contact, others will require

timely onward referral to other services, especially if a desired outcome is to reduce hospital attendance/admission or facilitate timely discharge.

Benefits identified are varied and include:

- a better experience for carers offering emotional support through things like time to express feelings, reassurance in the last hours of life, or confirmation that help is on the way.
- offering a service to patients with cancer and non-cancer diagnosis and some defined as being 'hard to reach'; so addressing key inequalities.
- improved symptom management; reduction in hospital attendance/admission; increase in calls being resolved at the point of contact helping to reduce face to face visits from nurses, GPs and the ambulance service; supporting professionals/services by helping to co-ordinate obtaining prescriptions, medication, and information.
- giving advice and support; offering a service to patients discharged from services when the patient is stable and/or their needs are reducing therefore reducing pressure on services with high caseloads and avoid patients 'slipping through the net'.
- improving number of patients achieving their preferred place of death.

Several key factors to consider when seeking to achieve a successful SPOC have been clarified during this project. These include:

- the correct banding and skill of clinicians including ability to assess, make decisions, give advice, resolve issues or make appropriate onward referrals
- clinicians with a key role of working on the SPOC rather than combining with other roles such as co-ordinating staffing
- availability of prescribers/non-medical prescribers
- access to clinical records such as SystmOne including EPaCCS
- up to date EPaCCS records including ReSPECT forms
- access to up-to-date information including available services and medicines
- availability of appropriate estate facilities and technical equipment
- quality assurance considerations such as monitoring calls and evaluation of service users
- effective data collection and interpretation.

An options appraisal has been undertaken for how a SPOC in Leeds could look. There are some key considerations in whichever option is finally taken forward. Workforce issues including recruitment and retention are significant in Leeds. The ability to recruit the number of nurses and other staff and ensuring that they have the right level of skill, experience, and qualifications for working in a SPOC is a significant consideration.

Implementation of a SPOC for Leeds patients may address some of the issues identified during this scoping project but a SPOC whether established in Leeds or commissioned from elsewhere will not solve all the system issues. There is evidence of an increasing need for other services alongside any SPOC implementation such as rapid response, access to specialist advice, prompt prescribing, and effective health and social care packages. There are various developments underway across organisations in Leeds changing the system as this project proceeded. The need for integration is key and offers significant opportunities.

Towards the end of the scoping project, the current financial position became clearer and presents challenges to the Leeds Health and Care Partnership Population Health Board. The financial situation is very challenging and the framework to apply for funding means that applications will need to evidence optimal use of resources, improved outcomes, and better experience.

Without access to new, and considerable funding, it may be that any improvements to how patients and their families and professionals access support and advice will need to happen in stages for now. Using some of the learning from the scoping and with organisations working closely together could offer opportunities for improvements.

Appendix

Gold line information

Because of the detail of information shared with us by Goldline we have significantly more data on their working systems and outcomes. These are included here:

There are 3 arms of the service in the hub, Goldline, Immedicare (care home service nationally), My Care 24 (care co-ordination for patients with non-cancer diagnoses e.g. Parkinson's, respiratory, frailty). Staff come from a wide range of healthcare. They move round the hub on a rota basis. The workforce is therefore able to flex across services and respond to peak demands, ensuring 24/7 resilience and benefits from economies of scale. Daytime calls have increased recently, it is not known exactly why, but it is believed this is due to increased demands on services. The leadership team feel offering a 24-hour service is key.

Calls from Goldline come through to LCD as 'warm transfers' and as such are prioritised. An increase in calls from Goldline is reported by LCD.

It is considered a trained, experienced, senior nurse is key to some of the success of Goldline, most are band 6. The leadership team have been in posts for some time and appear to have a strong clinical and business understanding and vision.

The Goldline (2020-2021) annual report demonstrates key outcomes across the locality:

- Since November 2013 the number of calls (consultations) taken per year has steadily grown from just under 400 in the first 5 months, to nearly 23,000 calls in 2020/21.
- Referrals have grown from 569 in the first 5 months to over 3,057 in 2020/21
- In year ending 31/12/20 51% of all deaths in BDCCG were supported by Goldline at the time of their death
- Goldline has a reach beyond those referred to specialist palliative care (only 54% of Goldline patients who died had been referred to specialist palliative care services at some stage of their illness)
- Goldline supports people dying with a wide range of diagnoses, not just cancer; 63% of patients died with a primary non-cancer diagnosis.
- Goldline co-ordinates well with other services, but can deal with calls without an onward referral (39% of calls required no onward referral)
- 98% of patients remained in their place of residence at the end of the call
- 66% of clinical consultations are taken out of hours (i.e. outside 8.00– 19.00 hours on weekdays)
- 78% of people who expressed a preference for place of death achieved that preference, 77% of people who expressed a preference to die at home achieved this. This figure was 84% for care home residents.

In terms of future plans, an aim is that nurses in Goldline have a non-medical prescribing qualification. Remote prescribing has been noted to be of value when undertaken by GPs who supported Goldline during the COVID-19 pandemic and palliative medicine consultants and CNSs can now prescribe remotely.

As Goldline is co-located with other services in the Airedale Digital Hub there are many benefits to this. It is well established so experienced in running such a service and the requirements. Leaders have a good knowledge of digital requirements and are linked with the national way forward. It benefits from economies of scale. As such it may be more cost effective and straightforward to commission Goldline than establish a new service.

Goldline report they are up to establishment, don't have issues recruiting and have started to support nurses through NMP courses.

Cambridge & Peterborough Palliative Care Hub
Further details include:
The area broad including city of Cambridge, Fenlands, Peterborough which has a higher number of various cultures including eastern European.
The area has 2 hospices, 1 independent and 1 Sue Ryder and various community services across patch including hospice at home. The varying services can be a challenge for hub staff.

The service operates 24/7 – peak times 17.00 hours – midnight, 06.00-09.00 hours, weekends, and bank holidays. Calls drop off during the day when usual, local, services are often contacted.
The establishment is 5.4 WTE, band 7, clinical nurse specialists plus administrative staff. Non-medical prescribing becoming essential. May have option for CNSs to rotate between hub and community specialist palliative care team moving forward and some staff feel losing skills.

All services use SystmOne.

Call data includes:

- The highest number of calls are from families/carers, then community nurses and paramedics.
- 44.5% cancer, 55.5% non-cancer.
- 45% known to specialist palliative care.
- Most calls are regarding symptom management.

The service is currently undertaking further evaluation and re-designing the data set.

In this area Harts Urgent Care are commissioned to run NHS 111. Commissioners drive the use of 111 as the point of contact for various specialists for example, option 2 mental health, option 3 palliative and end of life.

Advantages of using 111 include the infra structure, STORM software used, calls are via the laptop, not phones and are recorded; 111 staff undertake evaluation including listening to randomly selected calls; call handlers can re-direct calls to the hub if option 3 hasn't been used; if hub can't answer the call, it bounces back to 111. Disadvantages include having to 'fit in' with 111 in general for example during pandemic there was an 8-minute message regarding COVID-19 before callers could select the required option.

Leeds Community Health (LCH)
More detail of staffing of LCH services
<u>Twilight service</u>
The service is split into 3 areas north, south and west. There is a triage nurse and administrator for each area and then RNs and health care assistants out doing planned and unplanned visits.

<u>Night service</u>
The establishment is 3 teams, 1 RN and HCA working together, night sitters work 21.45-6.45 (setting off from home), LCH sitters and agencies cover this service. There is a caseload only for patients who have 1-2-1 night-sitting, everyone else for unplanned care is registered and then discharged.

Advice is available, if needed, from the hospices via the nurse in charge (NIC) who can then contact the doctor or, depending on level, consultant on call. Some issues have been highlighted and the

response to calls is reported as variable but there was some positive feedback regarding the NIC and consultant on call.

Demand for LCH services across the 24 hours is high and end of life care increasing. Managers and clinical staff report staffing challenges, this has especially been so during the pandemic, but continues. This results in limited capacity to meet the demand at times. There are various levels to report this and actions to address within each level.

In terms of the triage role, during the day and twilight internal and external staff reported varying skills in the ability to triage effectively, triage nurses sometimes having to leave the role and undertake urgent visits as no one else free. It was recognised that the triage role requires specific skills. These issues are being considered as part of the Neighbourhood Team model transformation project.

Staff reported issues that they 'waste time' over tasks such as trying to track down medicines from different pharmacies.

Staff had mixed views regarding the need for a SPOC. Some felt it would be helpful for reasons including: it would take pressure of them; a dedicated role to assess and support was seen as positive as time to 'do a good job'; extra time as some patients/carers just need time to talk; a service just concentrating on calls and no visits was seen as valuable; ability to do virtual calls could be valuable; staff who had previous experience of Goldline were positive about it. Some staff were less sure of the need and benefit, reasons included: they felt they would need to triage again as had responsibility for allocating resources; visits might be promised and then they couldn't be offered; the SPOC would need to keep a full understanding of services. The ability of staff in a SPOC to view SystmOne, EMIS and PPM is viewed to be vital. Having non-medical prescribers was also deemed important.

Other LCH services include the virtual frailty ward. It hasn't been possible to meet with staff from this service.

Various other specialist services come under the lead of the Clinical Head of Service for Cardiac, Respiratory, TB, CIVAS, and HHIT. There is increasing demand on services such as heart failure and respiratory. It can be difficult to discharge patients when they become more stable due to demands in the NT. A SPOC was generally seen as being favourable, one reason being this could be a point of contact for discharged patients, also it would be helpful for patients and families to have 1 number to contact when unsure where to go.

The transformation work underway includes a review of the NT model and provision of urgent and unplanned care. There is considerable transformation in LCH at present including the Neighbourhood Model Transformation Programme and Urgent Community Response Programme. This potentially offers lots of opportunities and is significant for various reasons including:

- Where does palliative and end of life care fit in with this transformation?
- How will other services be integrated?
- Will the move to 3 neighbourhood hubs for 8.00-22.00 hours service and new numbers help towards the issues for patients/families of having so many numbers and knowing who to contact?
- Will this help with more effective triaging?
- Will triage nurse have enough time, information, skill and confidence to deal with calls so a reasonable amount do not require an onward referral?
- Can appropriate nurses be recruited?

- Would bases have the facilities to provide some aspects that are beneficial such as video calls?
- Is there the opportunity to develop services to help reduce need for visits or admission to hospital e.g. support care homes with advice and remote verification of death, monitor patients after attendance at ED, support families to administer medication.

Meetings with senior staff in LCH provided information regarding transformation work underway. It should be noted this information was provided early in the project and some may have changed since then.

The Neighbourhood Model Transformation Programme

Key objectives

- Triage not to be duplicated by multiple professionals – to be done once at the point of referral
- Review what patient information is gathered by administrators and clinicians (to ensure maximising the admin function prior to going to NT).
- Reduce the variation in clinical triage decision making and improve compliance with agreed processes
- Referral data to be complete and consistently collected prior to reaching the clinician
- LCH & Primary Care referrals to be made directly to NTs & Citywide Services
- Reduce the number of incidents associated with triage decisions
- Parity for all referrals to professionals within the Neighbourhood Model e.g. Nursing/ AHP referrals
- Improved staff knowledge of referral pathways
- Clinical professionals able to triage all referrals
- Triage staff to be co-located with administrators
- Dedicated triage staff (to remove the requirement of ad hoc triage staff and unwarranted variation)

The new model to consist of 3 HUBs North, South and West, operating 07.00-22.00 so 'day' and twilight amalgamated. Changing numbers to free phone 0800 – 1 number for each hub.
The Triage hubs will be located in three areas of the city (North - Rutland Lodge; West -Armley Health Centre and South - Middleton Health Centre) and will be staffed by a multi-disciplinary team of LCH Nurses, Occupational Therapists, Physiotherapists, SkILs Reablement (LCC) Case Managers and LCH Neighbourhood Team Officers.

Urgent Community Response Project

This work is still under development. The proposed model is 12 hours a day, 7 days a week, with extended operating hours where demand necessitates this. Primary purpose is to deliver urgent community response services:
Reducing disruption to people's lives by offering an appropriate alternative to attending an emergency department or being admitted to hospital; as well as shortening the length of time people stay in hospital. Brings together one integrated service offer:

- 2-hour crisis response services delivered through the Neighbourhood Team and same day response from Adult Social Care Rapid Response
- Access to one virtual ward offer delivering a 2-hour crisis response when required; behind which there are specialisms relating to frailty, respiratory, cardiac, diabetes – work regarding palliative care needs to be developed. Palliative care is a key area of the unplanned work and accounts for about a quarter of all calls during the day.

- Enhancement of the current virtual ward model to provide an improved urgent response for people with dementia or who require an overnight urgent response or short-term support with social care needs.
- A 2-hour falls response from Leeds Telecare for people identified by the ambulance service as not requiring conveyance to an emergency department.

Data from EPaCCS

Key findings of the 2021/22 Report (Q1-Q4) report are:
46% of adults who died in Leeds had an EPaCCS record compared to 48% in previous year.
Q1 (685/1431) , Q2 (726/1654) , Q3 (833/1842) and Q4 (736/1566)

79% achieved their preferred place of death in current reporting period compared to 80% for the previous year.

The proportion of patients whose EPaCCS record was started more than 3 months before they died is at 50% in current reporting period compared to 55% the previous year.

Deaths at home recorded in the current reporting period:

2021/22	Q1 263 deaths (38%)	Q2 261 deaths (36%)	Q3 282 deaths (34%)	Q4 267 deaths (36%)
2020/21	Q1 306 deaths (28%)	Q2 233 deaths (35%)	Q3 281 deaths (33%)	Q4 274 deaths (34%)

- Deaths in hospital for patients with an EPaCCS 21/22 = 16%
- Deaths out of hospital for patients with an EPaCCS 21/22 = 70%
- No POD recorded 14%

In 2021/22 the numbers of patients registered on EPaCCS average around 3,400 at any one time:

- Q1 3504
- Q2 3001
- Q3 3254
- Q4 3895

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