Leeds Palliative Care Network

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

Scoping Report

Final

January 2023

Contents

1.0 Introduction

This is the final scoping report for the project to scope the need for a Single Point of Contact (SPOC) in Leeds, for patients in the last year of life, their families and professionals involved with their care. It will cover the background and findings of the project and options for the way forward. Following completion of this scoping project consideration of the options needs to be undertaken and business plans 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 was the need for a Citywide Single Point of Access for Palliative and End of Life care to support people who are dying and their families and carers but also as a hub for information and advice for professionals (now more commonly referred to as a Single Point of Contact, SPOC).

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 providing a 24/7 Single Point of Contact service for an area and identify some of the barriers there were to implementation. A project to identify the need for this was commissioned and funding approved by the LPCN executive. A project lead was employed to undertake a scoping project to look at various key areas.

The outcomes for the project are:

- Desk top review of the requirements nationally and locally for a Single Points of Contact or Access (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 might look like for Leeds.
- Production of a series of options to inform the development of a business case.

The results against these objectives can be found in the Scoping Project Background Report held by the LPCN. 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 Summary of what we discovered

The scoping project has identified the following key findings:

Local findings

2.1 This project has identified that there is a need for a SPOC for Leeds. This has been identified by patients, families, and professionals across several services.

2.2 Within Leeds there is increasing activity for end-of-life care in the community, and this has remained sustained post the height of the COVID-19 pandemic.

2.3 Community services providing end of life care in Leeds are very stretched and at times struggle to meet the increasing demand within various organisations.

2.4 There have already been changes to P&EoL services since the pandemic and most services continue to transform services including, development of virtual wards in LCH and hospices, development of a rapid response model, and a new model for the Neighbourhood Teams.

2.5 Demand for hospital care is high.

2.6 For some staff there is a lack of knowledge regarding existing services in Leeds and when best to contact the existing opinions for support. This includes the nurse in charge service and the citywide consultant on call service. Clarity regarding how to appropriately contact these services would be helpful regardless of any work on developing a SPOC. There is no indication that this would significantly increase calls but recognise that any significant change would have the potential to impact on planned services Mon-Friday.

2.7 Within Leeds around 5,000 people who could benefit from palliative or end of life care die in Leeds each year. In 2021/22 the numbers of patients registered on EPaCCS average around 3,400 at any one time.

National and regional findings

2.8 There are significant drivers for implementation of a 24/7 solution. Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 provides a framework for each ICS to evaluate commissioning and delivery of their palliative and end of life services including implementing a 24/7 Service specification. NICE Guidelines and standards and other government documents also include 24/7 advice and support.

2.9 Published evidence of the benefits of Single Point Of Contact services is limited (though supported by strong anecdotal evidence from practice). However, it does suggest patient and family satisfaction with SPOC services is high with emotional support and information being valued; professional satisfaction is generally high; benefits include supporting patients to die at home, reduction in hospital admissions and re-admissions and/or shorter stays; a high percentage of issues can be resolved at the point of the call so no onward referral is required (39% of calls in one service), which benefits the caller and reduces demand on other services; improved symptom management; reduction in inequality; supporting prescribing and access to medicines.

2.10 Services providing end of life care are reporting increasing numbers of calls. The demand is traditionally out of hours – with a peak between 17.00 and 22.00 and weekends (including bank holidays) however, it must be noted that this is changing. Those services that are working well identify that the best solution is to provide a 24/7, 365-day service and there has been a recent increased demand for support during the day.

2.11 Calls are generally for advice and support, both advice and support to families and patients plus advice on clinical decisions, access to information and support in decision making for other professionals. Existing services report an increasing role in co-ordination, e.g. sourcing medication stocks, keeping patients updated when waiting for services, passing messages onto services.

2.12 Existing services (SPC and locally) report having a trained, skilled senior clinician (generally band 6) is key to a successful outcome and there is an increasing need to be a Non-Medical Prescriber.
2.13 Timely access to specialist services 24/7 for advice is key.
2.14 There is an increasing need for an urgent response service for clinicians in SPA to refer to, also intensive support services in last days of life which have been met in various ways nationally including hospice at home, Age UK, Crossroads
2.15 Service design needs to include the right workstation design with reliable, up to date IT and phone services, access to SystmOne, EMIS and Leeds Care Record and up to date service and information resources.
2.16 SPOC services nationally vary in terms of design, scale, links with other services etc. Within the region Goldline is a nurse led, 24/7 single point of access, available for patients in the last year of life, based within the Airedale Digital Hub.

4. Functions of a Leeds SPOC Service
From the information we have gathered during the project we identified some key functions for a Leeds SPOC should it be fully delivered.

- 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, reassurance that 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 ceiling of care.
    - 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. a visit to the home.
- 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 be used, however, the SPOC may identify a need for a referral and utilise existing systems to instigate this.

5.0 Workforce role

These functions lead to three clearly defined roles within the service

- Administrative support who could access and update relevant records and follow up on calls.
- Senior Clinical role - support to give advice and offer a clinical opinion or decide when to take further action (could include nursing, paramedic and pharmacy roles).
- Support from staff who can offer advice and emotional support such as a death doula or counsellor type role.

Demand is likely to be variable and therefore careful consideration needs to be made regarding how a workforce for a SPOC sits alongside other services throughout the 24-hour period.

6.0 Options

These are outlined in the attached options appraisal. Feedback from the steering group has created a new option looking at how Leeds could improve the palliative care response through the present and emerging community structures. This has included suggestions of how a role(s) could be effective in supporting the palliative community response already in place. Roles such as a care navigator have been suggested along with ideas of how we could make links to the LCH transformation work and the new triage and unplanned response process in the hubs.

7.0 Conclusion

This is the summary report of the scoping project to identify the need for a SPOC. The 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. Implications of this include: establishing appointments and meetings locally and nationally has been a challenge; some information requested has not been delivered which has resulted in gaps in some areas.

There continues to be a need for a SPOC for patients, families and professionals within the last year of life. This is supported by national documents and the ICS is 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, 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 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.

Benefits identified are varied and include: a better experience for carers offering emotional support through for example time to express feelings, reassuring in the last hours of life, or 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'; 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

getting prescriptions, medication, information etc., giving advice and support; offering a service to patients discharged from services when stable and/or needs reduce 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 in achieving a successful SPOC are clearer. 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 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 with pros and cons listed for each option. 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 those with the right level of skill, experience and qualifications for a SPOC is a significant concern. Implementation of a SPOC for Leeds patients may address some of the issues identified but a SPOC whether established in Leeds or commissioned from elsewhere will not solve all issues. There is evidence of an increasing need for other services alongside a SPOC such as rapid response, access to specialist advice, prompt prescribing, and effective care packages. There are various developments underway across organisations. The need for integration is key and could offer various opportunities.

Towards the end of the scoping project, it became clearer from the Leeds Health and Care Partnership Population Health Board that the current financial position is challenging and the framework needed to apply for funding. 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 project and with organisations working closely together could offer opportunities for improvements, some of which are highlighted within the options appraisal.

8.0 Options Appraisal for the Need for Leeds Single Point of Contact

	Pros	Cons/issues	Comments	Solution order
1. No change to current position	Keeps the status quo Estate, financial and workforce resources to implement significant change not required	Not meeting identified need Failure to meet national guidance, standards, and recommendations. Missed opportunity to improve patient and carer experience Multiple services with differing contact numbers /working hours continues to make navigation of systems for patients /carers difficult, especially in times of crisis Missed potential to avoid unnecessary admissions /interventions Continuation of clinicians in various settings distracted and influenced by other roles and demands therefore may not deal with calls as effectively as possible one impact of this may be missed opportunity to complete call without onward referral for visit by variety of services Missed opportunity to provide an incentive to identify patients at the end of life and start planning ahead/EPaCCS Missed opportunity to provide a service for patients not known to/discharged from community generic and specialist services Capacity pressures continue for OOH services (LCD, LCH, hospice NIC) are not supported Specialist palliative care referrals continue to increase, reducing ability to provide responsive and timely service for those with complex needs Staff burnout due to increasing workload demands, reduced capacity, no change in approach Scoping exercise across ICS around 24/7 SPA not yet commenced	As in previous years, we will endeavour to describe the current service offer at least twice a year. Some work could be done immediately e.g. exploring virtual verification of expected adult death in care homes; clarifying how to appropriately use Specialist Palliative Care OOH services; exploring integration of hospice community teams with 3 new hubs at specific times.	5

2. Create a Leeds specific full SPOC response	Leeds has control over service design and management Knowledge of local services/resources * - see below Opportunity to develop telehealth further which has various benefits e.g. assessing patients more thoroughly if timely visit not possible, verification of death in care homes saving a visit. May be cheaper than option 3 Opportunity for bespoke model ** see below	Funding implications It is perceived that recruitment of sufficient clinicians/workforce (particularly nurses) will be difficult and could de-stabilise current workforce across Leeds Will need significant project management and leadership from a clinical and non-clinical perspective Estate, IT, and telecommunication requirements would need to be met Missed opportunities for economy of scale and dealing with variations in demand that existing SPOCs provide May be challenges in in deciding which organisation would host with a possible perception that partner organisations lose control? Training would need to be provided to ensure SPOC staff/clinicians had skills and knowledge required, including Non-Medical Prescribing Need to reduce potential overlap with existing services.		1
3. Buy in a full SPOC from an existing service	* - see below Doesn't negatively impact on stretched staff resources in Leeds Reduces pressure on Leeds services Benefit from experience of established SPOA Skilled (band 6) clinicians taking calls If Goldline within Airedale Digital hub advantages include: - see *** below	Funding implications - figure to be confirmed but from our conversations with other areas it is likely to be in excess of £250,000 per annum (would need to be considered alongside savings including reduced admissions - plus ambulance service costs, reduce home visits, saving other services time through helping with co-ordination such as accessing medicines) This would be a significant project in terms of time and resources with approximately a year preparation time to roll out and maintaining May at times introduce an unnecessary step in resolving issues – though would also reduce duplication at times Missed opportunity for a bespoke model		2

		There may be issues re confidence in an external service and would need efforts to build and maintain this Would not be integrated into changes in the Leeds systems There is still a need for advice and access to specialist services still required and links would need to improve Depending on the provider: May need to sign a 3-4 year contract so committed if not felt to be working (also a benefit as ensures time to implement and see evaluate) Will the model meet the needs in Leeds e.g. provide scope for specifics such virtual verification of death in care homes? Will an external service be able to meet demand from Leeds, will they be able to recruit staff, will quality be compromised with expansion of their existing service? If the model is essentially for patients on EPaCCS/last year of life, does this exclude people calling that aren't on EPaCCS?		
4. Await a regional or national SPOC solution	Keeps the status quo Estate, financial and people resources to implement significant change not required now – though would be in the future	Will take some time or may never happen Resource demand may not be defined by Leeds As option 1 and some of option 3		4
5. Improve the palliative care response in present and emerging community structures	Potential to improve patient and carer experience and symptom management Offers support and guidance to staff Potential to reduce overlap in services	As per option 1 Risk of increasing demand on Specialist Palliative Care OOH services impacting on ability to work the following day (though significant increase in demand not expected). If there was a large demand it would necessitate review of how the OOH specialist palliative care resource is used as a whole.	Work needs to be done to consider how the remaining money available from the NHSE/I funding could be used most effectively. Whilst there is not sufficient resource to develop a service, we may be able to offer some support in	3

NB see comments in option 2	Integration may help identify need, issues etc and possible solutions Further integration could help consider how urgent response for palliative patients is met. Could be a potential first stage in working towards option 2	Clarity of roles and purpose would need to be outlined and monitored Would take some time for leadership and implementation	integrating community services for example between hospices and the work of LCH transformation and supporting the nurses in the nurse in charge role in hospices to spend a night with the LCH night service to build a greater understanding of services, roles and patient and family needs overnight.	

* - Opportunity to reduce demands on existing services e.g. some issues could be resolved by SPOC at point of contact without onward referral, clinicians could discharge stable patients with more confidence. Potential to reduce hospital admissions or effectively co-ordinate these via SPOC. Improve patient and carer experience e.g. one number to contact, management of pain and other symptoms is timely and effective; reassurance; co-ordination of aspects of care. Would provide incentive for clinicians to discuss wishes with patients and complete planning ahead/EPaCCS. Support people to die in their preferred place of death. Meets national guidance, standards, and recommendations. Create opportunity to address health inequalities e.g. promotion to 'hard to reach patients/groups'

** - a bespoke Leeds model could a reactive and proactive model be developed? – e.g. ringing patients on a regular basis for 72 hours after discharge/attendance at ED/after event such as fall, haematemesis, fit; regular contact with breathless/anxious patient; This could provide reassurance to patients and increase confidence in professionals to discharge, avoid admission etc. plus make model more viable in terms of economy of scale and addressing peaks and troughs in demand

*** – If Goldline advantages include that it is a long standing service with a good reputation and strong, consistent leadership; seems secure with plans to develop e.g. new premises, Non-Medical Prescriber (NMP); offers economies of scale; ability to cope with peaks and troughs; 97% calls answered with 2 minutes 39% calls dealt with without onward referral; need to sign a 3-4 year contract so time to develop and evaluate; access to SystmOne to read and write, EMIS read only; access to electronic prescribing and increasing number of NMPs; fully established at present with no historic issues to recruit