Report to Health Scrutiny Sub-Committee

Report of:	*Louise Potter, Commissioning manager for palliative and end of life care, at Sheffield place, South Yorkshire Integrated Care Board*
Report to:	*Health Scrutiny Sub-Committee*
Date:	*16th January 2024*
Subject:	*Palliative and end of life care*

Purpose of Report:

1. To share details of the South Yorkshire Integrated Care Board's All age Palliative and End of Life Care Strategy and offer members an opportunity to feedback any comments.
2. To introduce the committee to the ReSPECT project and respond to concerns raises by a member of the public.
3. To share details of the current 'live' issue regarding the ongoing funding of specialist therapeutic bereavement services in Sheffield.

Recommendations:

For members of the sub-committee to:

1. **Share any feedback on the strategy by Friday 26th January to louise.potter7@nhs.net focusing on the following questions**

- Have we got the emphasis right?
- Are our priorities appropriate?
- Have we missed anything, if so, what?
- Should anything be removed? and if so, why?
- How will this help us to increase PEOLC profile and visibility within the partnership and wider organisations?
- Any other comments?

2. **To feel better informed on ReSPECT and to feedback on any concerns regarding the ReSPECT project.**

3. **Feedback on the current approach being taken to remedy the need to fund specialist therapeutic bereavement services in Sheffield to ensure fair access for all.**

Part 1 - All Age Palliative and End of Life Care strategy 2023/4 to 2025/6

This paper introduces the draft **'***All Age Palliative and End of Life Care Strategy 2023/4 to 2025/6',* outlines the work completed thus far, outlines the feedback period and next steps.

Statutory duty for palliative care

Since July 2nd 2022 the ICB has had a duty in relation to palliative care.

> *'(1) An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—*
> *(h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service'*
>
> *Health and Care Act 2022 s3(1) NHS Act 2006*

NHSE Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs) provides guidance on how to meet the statutory duty, and a strategy is a requirement.

Appendix 1 is the draft strategy which outlines out latest position, the vision we have for South Yorkshire and our priorities.

Our vision

'To ensure that the people of South Yorkshire living with life limiting illness experience the best care in the last years, months, and days of life and that those left behind continue to receive the support they need after death.'

The strategy is the outcome of work completed over the last nine months across all four places, which includes: a self-assessment audit finding, professional consultation, alongside data and adherence to national strategies and NHSE guidance.

We have also worked with Sheffield Healthwatch and ICB patient engagement colleagues. Collectively we have heard from over 200 people via questionnaire and held over 50 conversations with people in focus groups.

As outlined in the strategy we have heard that many members of our public have good experiences of palliative and end of life care, but we have also heard examples where improvements could be made. These are areas we want to work on. To do this we need to make the system easier to navigate, identifying people earlier so they have an opportunity to access palliative care which can improve their health and wellbeing at the end of their lives, increase choice about where people can die and help carers and members of the public feel better informed.

To do this we have six themes in the strategy each with priorities – which are based on the national Ambitions Framework.

The strategy's aim is for the ICB and its partners to work towards meeting the vision and to improve palliative and end of life care experiences for children, young adults, and adults across South Yorkshire and at Place.

The strategy outlines an ambitious list of priorities. However, indications from the intelligence we have are that the following should be prioritised:

- Workforce development action plan
- Children and young people model offer
- Information for the public
- Building up the community based integrated care offer.
- Standards on what people should expect.
- Electronic systems development

<u>Governance and implementation</u>
A robust action plan will be developed, and progress will be reported on quarterly to the new All Age Palliative and End of Life Care Strategic and Transformation Board. A new quantitative data dashboard is being created to monitor performance against outcomes and qualitative measures will be agreed.

The board includes representations from partners across South Yorkshire, including acute trusts, mental health, adult social care, hospices, public health, adult and paediatric consultants, NHS England, Yorkshire Ambulance Service, primary care, peers and the ICB palliative and end of life

care leads at each Place. The ICB leads for Sheffield are Louise Potter, Commissioning manager and Jane Howcroft, Head of Long-term Conditions and End of Life Care Commissioning.

Implementation will be coordinated by the ICB working with partners. Some will be South Yorkshire actions and others will be place specific; community based, pathways and process based.

Actions will be allocated across the new PEOLC governance structure and supported by the ICB. Alongside the board, the governance structure includes…

- a new Health and social reference group (starting Feb 2024) to assist on clinical, social care and workforce development,
- a new peer leadership / patient engagement group (date TBC) to assist with co-design,
- a children and young people's steering group (established),
- a ReSPECT network group (established)
- Four place-based delivery groups (established). The Sheffield group is called the palliative and end of life care (PEOLC) citywide group and reps include Sheffield Teaching Hospitals, St Luke's hospice, Sheffield health and Social Care, adult social care, Compassionate Sheffield, Sheffield Children's hospital and public health.

Immediate next steps

- The strategy will be updated based on the feedback received. Aim to sign off at the next Board meeting (end of Feb).
- Develop the action plan
- Present the strategy at relevant boards and stakeholder meetings.

Consideration

The committee are being asked for feedback on the strategy to the following questions.

- Have we got the emphasis, right?
- Are our priorities correct?
- Have we missed anything?
- Is there anything we should we remove, and why?
- Would your organisation support this?

Feedback on the following **link** or email louise.potter7@nhs.net

Part 2 - ReSPECT

What is ReSPECT?

The ReSPECT plan acts as a summary of key information for future emergency care and treatment at a time when a patient may not be able to express what matters to them.

ReSPECT is an acronym. This stands for: Recommended Summary Plan for Emergency Care and Treatment. It was a project started by Home | Resuscitation Council UK. Around 80% of ICBs have either implemented or are to implement ReSPECT in the next year.

When and why did Sheffield choose to implement ReSPECT?

ReSPECT was agreed for implementation in Sheffield in 2021. The decision was made by key providers across the city working with Sheffield Clinical Commissioning Group (as was), now part of South Yorkshire ICB.

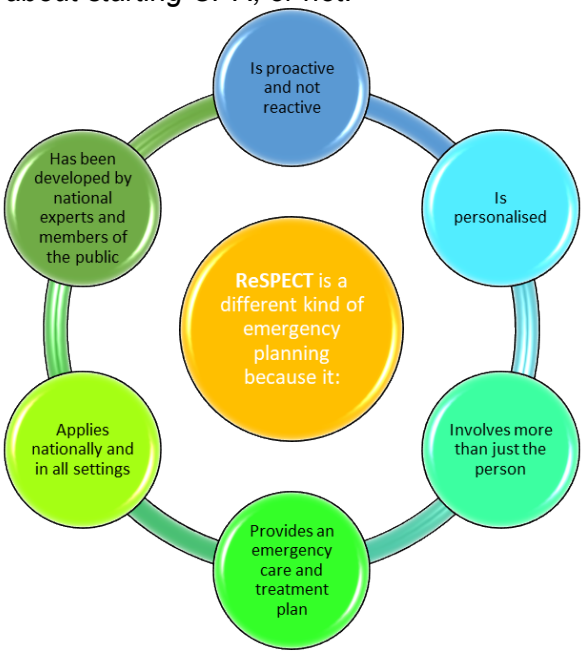
The decision was supported by clinicians and a CQC review CQC Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the COVID-19 pandemic report. Sheffield was one of seven case study areas chosen. The report recommended that ReSPECT was best practice and preferable to the DNACPR process. Page 6 of the report included the following wording below, which also helps explain the difference between the two processes….

'The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

The scope extends far beyond decisions around DNACPR and, if used effectively, should ensure that any decisions about CPR are achieved through a well-structured and person-centred conversation between healthcare professionals and the person about their care and what matters to them.

Decisions about emergency treatments, such as CPR, should fit within a shared understanding of the person's condition and preferences. The resulting clinical recommendations are much broader and can include whether or not a person is to be taken to hospital, admitted to critical care or placed on a ventilator. These recommendations are recorded on a ReSPECT form. In addition, it records a recommendation about starting CPR, or not.'



ReSPECT is priority 1.5 in the draft Palliative and end of life care strategy – as outlines in part 1 of this report. '*We will continue implementing the Resus UK ReSPECT initiative, providing a quality emergency planning process across South Yorkshire'*. It is also priority on the ICB forward plan. ReSPECT also aligns with work to enhance personalised care, emergency care planning and end of life care in care homes as outlined in the Enhanced Health in Care Homes Framework (NHS England » Enhanced Health in Care Homes Framework).

Implementation
The project started on 1st April 2022 and went live citywide on 2nd May 2023. An early adopter area in north Sheffield, included 5 practices started in February 2023.

The project team is hosted by Sheffield Teaching Hospitals, with an ICB clinical lead and senior responsible officer.

A delivery team has representatives from the following Sheffield Teaching Hospital Trust (STH), Sheffield Children's Hospital Trust (SCH), SY Integrated Care Board (ICB), Primary Care, Sheffield Health and Social Care Trust (SHSC), Yorkshire Ambulance Service, and Local Hospice (St Luke's).

The Resus Council have been a key stakeholder and advisor to the project team and delivery group.

The project is in its infancy, and we expect the process of change to take upwards of 2 years to fully embed. We hear verbally of issues with the process, and address these at the delivery group, or as individual organisations.

Training for professionals
The professionals training has been widespread and multi-faceted. Three levels of training are available online. The level is determined by the role the professional will take in the process - e.g., understand the process, respond to the plan, or write the plan. Some may need a combination of the three e.g., if they are to write and respond.

Organisations have championed the online training but also held their own in person training, in house and additional training by the ReSPECT team. Care homes have been supported by an ECHO led learning programme. The ReSPECT team have further provided information sessions to community groups, care homes and to Sheffield City Council. Internal comms and team meetings within organisations has also helped to promote the process.

Training continues across Sheffield. In addition, a South Yorkshire ReSPECT steering group has been established by the ICB. This group is to provide new additional training for any professional working on ReSPECT across South Yorkshire. This has been widely promoted across Sheffield.

Information is available of the public.
A useful leaflet explaining the process can be found at ReSPECT-leaflet-English.pdf (sheffieldhcp.org.uk). This can be read and also printed out. Information is also available in many languages.

Information for clinicians and patients is available on the Sheffield HCP website here: Sheffield ReSPECT Project - Sheffield Health and Care Partnership (sheffieldhcp.org.uk).

Responses to questions from the member of the public

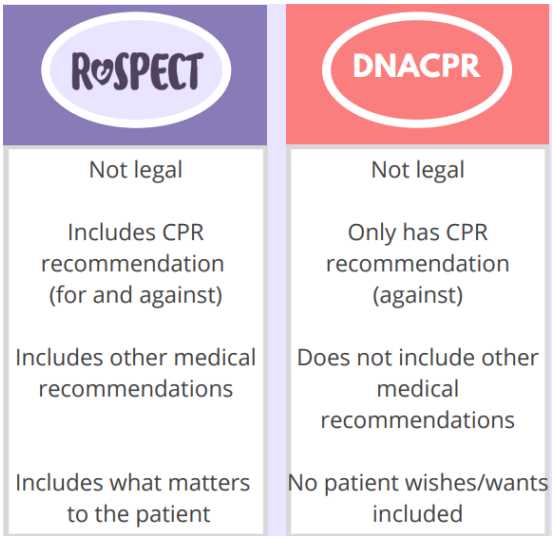
The report may include:
• *information on the legal status of DNR and ReSPECT*

forms
• copies of protocols regarding the two forms
• training of health professionals in the use of and consultation required of the forms
• any statistics on the use of the two forms

Information on the legal status of DNR and Respect forms

The ReSPECT plan nor the old DNACPR form are not legal documents.

This image explains the legal position and differences between the two processes.



The Sheffield ReSPECT policy explains this in more detail.

'ReSPECT plans are not legally binding.

The ReSPECT plan should be regarded as a summary of an advance clinical assessment with recommendations, recorded to guide immediate clinical decision-making in the event of deterioration in a person's physical health or cardiorespiratory arrest. It constitutes an 'advance statement' under the terms of the Mental Capacity Act 2005, rather than an 'Advance Decision to Refuse Treatment (ADRT)'.

The decision regarding whether or not to attempt CPR or other life-sustaining treatment should be made by the healthcare professionals responsible for the person's immediate care at the time of the emergency'.

Copies of protocols regarding the two forms
Sheffield has its own ReSPECT policy.

Some organisations, including Sheffield Teaching Hospitals Foundation Trust have developed their own ReSPECT standard operating procedure for local oversight and implementation, which is based on the Sheffield Policy.

Training of health professionals in the use of and consultation required of the forms – please see the position on training above. Training numbers are monitored internally by each organisation and by the delivery group. In relation to STH -

- Mandatory ReSPECT Level 1 training is provided at STH for all staff, and for roles completing plans level 2 & 3 training.
- Numbers are reported each month and targets are in place. Assurance is provided to the delivery group each time.

- For community advanced clinical practitioners who are new to the process, they complete 5 plans under supervision with a GP then are signed off as competent to independently complete plans.

Any statistics on the use of the two forms

Data is monitored monthly. Latest data (December 2023) from the GP primary care systems (where a record of all plans should be recorded) is as follows -

ReSPECT plans recorded is 1,813 DNACPR status recorded but which is not on ReSPECT is 7,612

DNACPR forms should no longer be being produced, however the data shows that the old process is still being used by some professionals. We continue to address this through education and by working with our professionals leads.

The data also monitors what proportion of people have DNACPR agreed on their ReSPECT plan. This figure reflects national data.

Quality audit
The next stage of the project is to audit.

The audit will review both the process and the quality of the plans completed in each provider organisation. The quality element is to review each part of the form completed. We will measure the audit outcomes against the national standards set by Resus UK.

The audit will be completed in spring 2024 and any recommendations will be included in the evaluation report for the project.

Discussions are being held with the ICB quality team to ensure ReSPECT is audited annually by organisations with an NHS contract with the ICB.

Key Contacts –
Lucy Crowder, ReSPECT project manager lucy.crowder1@nhs.net
Dr. Hannah Weston, ReSPECT clinical lead hannah.weston@nhs.net

Part 3 Bereavement

Prevalence estimates

An estimated 49,000 people in Sheffield were bereaved last year (nine people for everyone who died). Research shows that the vast majority (90%) will not require formal, specialist support, as they will find sufficient support from their own inner resources and family, friends and community (supported by some of the work being completed by Compassionate Sheffield[1]) to manage the distress and changes to their daily lives that result from loss.

However, 10%, or an estimated 4,900[2] people in Sheffield may benefit from specialist bereavement support each year. These people are likely to '*experience persistent high levels of distress and chronic grief symptoms that impact on their physical and mental health and on their functioning for a substantial period (Shear, 2015; Prigerson et al 2009)*'[3].

Specialist bereavement provision in Sheffield

A full range (community engagement, Tier 2, Tier 3) are all currently provided. T2 and T3 services support around 2,500 people per annum in Sheffield. The system commissioned adheres to national guidance[4] and is therefore best practice, however this system is at risk when funding ends – all contracts/ grant agreements end in 2024.

Without T2 and T3 services the remaining bereavement provision offered through St Luke's and at Sheffield Teaching Hospitals would not meet the needs of all Sheffield residents, as eligibility criteria and location would impact on fair access alongside insufficient capacity.

The initial funding for the T2 and T3 services came from non-recurrent COVID response funding alongside Public Health funding. After one year, Cruse was awarded an additional £97,000 by SY ICB Sheffield Place in 2023.

The provision was initially commissioned following the authorship of a Sheffield bereavement strategy. The aim was to offer bereavement support to those traumatised following a COVID death, however we have learned from this project that for many people bereavements can be traumatic event (due to the nature of the death, personal circumstances, reason for death) and many need specialist support.

Running alongside this specialist bereavement provision is Compassionate Sheffield, which promotes a public health approach to death and dying. Facilitating community-based projects, e.g. equipping community organisations and the public to make talking about death an everyday conversation. It is not specialist bereavement support / counselling that Cruse, Faith star and Mind provide which is paramount for the estimated 10%.

Current issues

1. Our learning has found that specialist bereavement services and the model tested has shown a growing need for support, but the funding has ended.

    - The faith star here to hear service, whilst small is growing and building momentum. Offering an alternative offer for people who would need a community based, ethnicity minority approach.

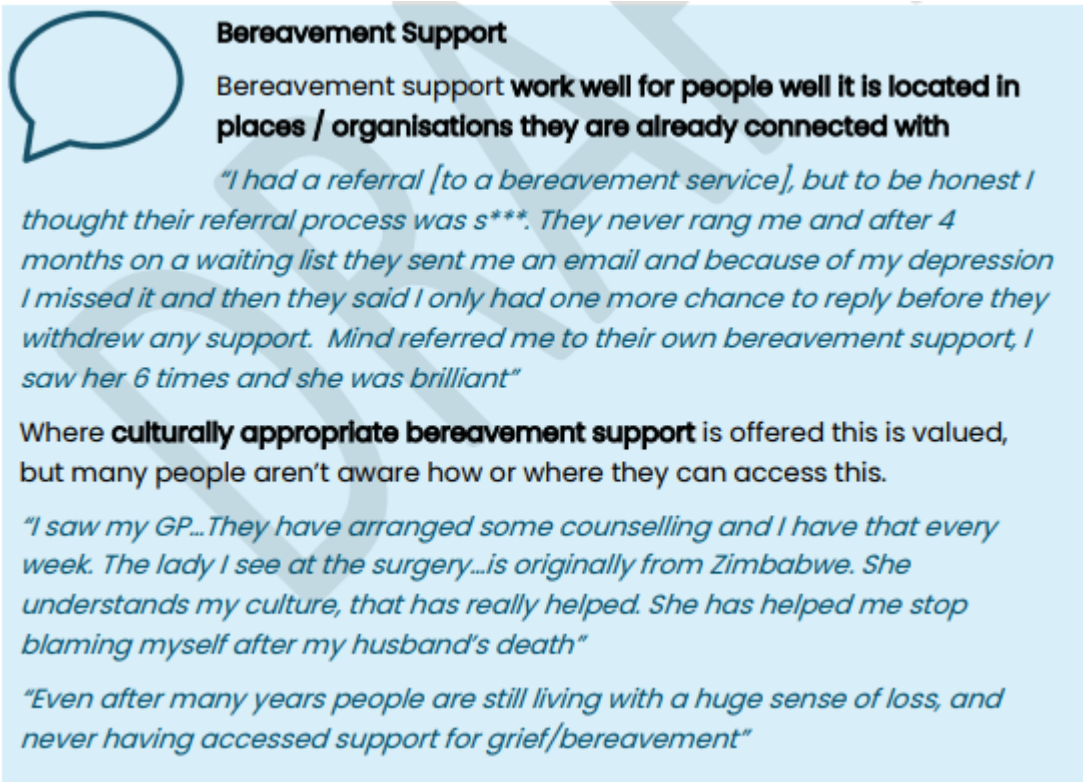
[1] Funding for Compassionate Sheffield is separate.
[2] Calculation based on 5,461 people died in Sheffield in 2022/23, 94% (or 5,133) were 'expected deaths' (based on age related or long-term conditions, research which shows 9 people are affected by each death or 49,149 people in 2022/23 and around 10% of these (4,900) will need some support.
[3] Lundorff M, Holmgren H, Zachariae R, Farver-Vestergaard I, O'Connor M. Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. Vol. 212, Journal of Affective Disorders. 2017 as found in the Sheffield bereavement strategy.

[4] A-Guide-to-Commissioning-Bereavement-Services-in-England-WEB.pdf (nationalbereavementalliance.org.uk)

- Cruse, a service delivered by volunteers and led by paid staff, offer T2 structured counselling sessions online and in person. The funding has reduced their waiting list from 2 years to four months, activity has more than doubled the number originally expected to receive the service and they have broadened their reach into new community areas they didn't previously operate in.
- Mind's Through the clouds service has been well received, with successful outcomes and offers a personalised therapeutic T3 counselling service.
- We have examples of cases studies from Mind and Cruse, which show good practice.
- Current commissioned capacity is an issue, ideally there needs to be more provision funded to reduce waits at Cruse and Mind. Some services have had to close waiting lists and the promotion of services has been limited.

2. Healthwatch have found that there is a need for bereavement services and that the public would welcome services for all ages, reduced waits and some flexibility in the number of sessions offered. Overall, it was reported that only 37% of respondents felt supported emotionally after death.

'we can see that some of the most significant sources of support come from their friends, families and communities. We can also see that some of the support people receive while their relative or friend is receiving end of life care, doesn't extend as well into bereavement, with fewer people feeling supported both physically and emotionally once their loved one has died'.



Lack of bereavement and mental health support for children after death of a family member

"My daughter has not had much help. We have someone from MAST. They have offered her help but it is in Rotherham and that is too far for us to go. She needs counselling but there isn't any here"

GPs are not always signposting people / linking to bereavement services

3. The one-off funding has ended. As this project started during COVID, bereavement support was not funded prior to this and therefore neither SCC nor the ICB has an historic or current ongoing allocated budget for such provision.

4. There is a shared responsibility between ICB and Sheffield City Council. SCC have a duty around suicide and unexpected deaths. The ICB statutory duty (as found in Part 1 of this report) is for bereavement after palliative care deaths, which would be limited provision if these services end.

5. The ICB financial position is challenging. Additional spending came from underspend last year, which is no longer available this year.

6. Procurement procedures would be adhered to.

Options

Together the ICB and SCC are working together to consider a range of options – this includes.

- Papers to boards to try and secure funding going forward.
- Working with our ICB mental health colleagues to consider different ways to offer specialist mental health support using existing metal health service provision.
- Work with our providers to secure charitable funding.

Note - We are aware of the SCC bereavement strategy re: funeral arrangements, burial places, and death registration – this is separate to this work.

This is a live and ongoing piece of work.

Key contacts

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