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23 February 2024

Dear colleagues

NHS South Yorkshire's Sheffield team welcomes this detailed Healthwatch Report which presents the insight work you carried out into people's experiences of palliative and end of life care.

We greatly appreciate your expertise in producing this excellent report, it does justice to the sensitive material within it and deserves to be widely read. We appreciate that so many people shared such personal experiences, reflecting on challenging times in their lives, and memories that were no doubt painful to revisit.

It was encouraging to the read more positive accounts of good care in every part of the system, where good planning, smooth co-ordination and compassion had made all the difference.

Some of it was hard to read. Hearing that people have been let down and experienced delays in getting support, or care that was not good enough, or not well co-ordinated, is very disappointing. There is much to be done to improve services, so that everyone can receive the care and support that they need and deserve. It is a clear call to action, and I wanted to brief you about some of the main things we are doing, or planning to do, to improve people's experiences in the future.

1) **Strategy** You are aware that we are developing an all-age ICB Strategy for palliative and end of life care. We will be reflecting the ideas for improvement, cross

cutting themes and recommendations in your report and considering how we can reflect them in Strategy and in the local action plans which will be produced. In order to measure our progress in delivering the Strategy, we will have a set of metrics and these will include issues which are reflected in your Report such as choice around place of death. With your permission, we would like to include some quotes from your report to illustrate our Strategy and help to bring it to life.

2) **Faith and culture** There was a strong theme in the Healthwatch Report around delivery of care which was not culturally appropriate, or where people's spiritual / religious needs were not met. There is a great deal of work to be done here and there is a clear commitment in our draft Strategy to address this. Our partners at Compassionate Sheffield have been working with people from some local ethnic minority communities to promote Advance Care Planning and to raise awareness of how ACPs can assist people to ensure that their wishes are met, and how to open up conversations in primary care.

   We have been working with St Luke's and with our two GP advisors to design a series of online education sessions on palliative care, aimed at primary care clinicians. These have been very well attended. The session planned for 28 March is going to cover faith and culture issues. In addition, the training sessions which have been organised for primary care around the statutory introduction of the Medical Examiner service in April 2024 have included issues relating to faith, death, and the care of the deceased.

3) **Dementia** Another important theme was the difficulties that people experienced when the person who was dying was living with Dementia. Many of the accounts expressed concern about mental capacity, choice, dignity, and support for carers. This feels like an important area where the ICB as system co-ordinator could really make a difference, and I would like to propose it as an improvement project. One practical thing that we are already planning is a large-scale educational event, primarily aimed at GPs, which will link frailty, dementia and end of life care. This is scheduled for 13 November and is intended to set out the latest guidance, evidence and best practice which should be followed.

   Many people living with Dementia and nearing the end of life will be living in a residential or nursing care setting. The national Enhanced Health In Care Homes (EHiCH) Framework is in place to raise the standards of quality of health care for these residents. The ICB has several formal responsibilities with regard to, including particular duties related to the care home workforce, including a systematic approach to training and skills development.

4) **Finance** You will be aware that the ICB is facing a very significant financial deficit in the coming year. Some of the improvement that we would like to make in response to the Healthwatch Report will require investment. We are developing proposals for improvement, for example, a platform for shared electronic health records which will enable agencies to co-ordinate care around the person in a much more effective way. Due to the current financial situation, we cannot say with any certainty as to when we will be able to implement them. We are always

looking for innovative ways to support new services and we are committed to seeking funding streams to support palliative and end of life care.

It must also be said that there is already significant funding embedded in the many services which provide palliative and end of life care. The ICB needs to help the system to make better use of the investment already in the services. Many of the issues highlighted in the report do not require investment to address, but improved communication, and better integration between services, and care for staff so that they in turn can offer compassion.

5) **Earlier identification of palliative care need and advance planning.** Another clear theme in the report centred around people finding it difficult to have conversations about what a person's wishes for their palliative care and end of life might be, and a feeling that this had been left too late, or not handled well. It was also clear that some families and friends had not been made aware how poorly their loved person was, and what the expected outcome might look like. In our Strategy, we are committing to increasing the percentage of people who are identified on their practice's Palliative Care Register. We are undertaking education with practices on a range of palliative care topics, running a series of sessions in conjunction with St Luke's Hospice and our two GP Advisors at the ICB.

   We have identified a person to co-ordinate the actions which are needed across the system to implement the recent NHS England guidance on palliative care for people with Heart Failure. This includes tools and guidance to help clinicians to initiate much earlier discussions about palliative care, and what the person can expect and how they can be supported, at the point of diagnosis.

6) **Fast track** A new initiative is in place between Sheffield Teaching Hospitals NHS FT and the ICB, which is a "test of change" pilot. In essence, the idea is to work with the Intensive Home Nursing team to enable a patient is nearing death (on the "Fast Track" pathway) to be discharged home promptly, rather than waiting for assessment of their Continuing Health Care needs. The assessment will be carried out at home. This very practical change means that the care is put in place and the funding sorted out afterwards; we believe that for some people it will make the difference between being able to die at home, rather than in hospital.

7) **Planning for emergencies** There were many instances in the Report which described difficulties experienced in emergency situations, when a person's health suddenly deteriorated, and when people felt bounced into making decisions, or things happened which people felt they couldn't control. The ongoing roll out of the ResPECT (Recommended Summary Plan for Emergency Care and Treatment) process across Sheffield should make a tangible difference in these situations, and we will be looking at the audit results later this year to ensure that the process is adding value and is well understood by staff, patients and their carers, family, and friends.

8) **Bereavement** Lack of ongoing support with bereavement was another concerning theme in the Report. We recognise that whilst there are bereavement services in

the system (eg attached to the hospice and to the Children's NHS FT), there are gaps and waiting times can be long. We were able to identify funds to commission some re new bereavement services in Sheffield in 2022, however the funding comes to an end later this year. My team are working on this issue, and we are waiting for the outcome of a bid for some funding.

9) **Information that is easy to access** This is theme which is mentioned several times in the Report, that people did not know where to look for reliable and up to date information, and that looking at various sources was confusing and stressful. We are hoping to develop a "one stop shop" website which can be accessed by members of the public and health and care professionals, which will be a source of information about local services as well as having links to national organisations and other official websites, e.g. information about benefits, service, carers' rights etc.

We will keep in touch with Healthwatch as we finalise the ICB Strategy for palliative and end of life care, and as we develop the place- based plans to support implementation. The themes and feedback in the Report will be crucial as we take this work forward.

Turning to the **specific recommendations** in the Report, several of them are operational and apply primarily to providers; however, there are some where we consider that we have a significant responsibility. Please see our initial response below:

1a "In the context of Sheffield's changing population, continue work to understand needs across all communities. Develop inclusive ways of hearing and acting on people's experiences of palliative and end-of-life care on an ongoing basis, in order to improve services." This is a core aspiration in our Strategy. We have not yet developed a costed ongoing engagement plan, but we have stated our intent that o*ur strategy and services will be co-produced with people who have experience of the system, on an ongoing basis.*

3b "Take a system approach to strategically plan, develop and fund joined up services where care is well co-ordinated". This is the role of the South Yorkshire Strategic Partnership Board for all age palliative and end of life care, which I chair. It is early days, and the Board has just met twice so far, but I believe it is well positioned to implement this recommendation. It is a truly multi-agency, multi- disciplinary Board, with representation from all parts of the NHS, as well as social care, public health, and the hospice sector. We have just established a Clinical Reference Group, and we are developing plans for a reference group made up of people who are experts by experience. These two groups will advise the Strategic Board and guide their work.

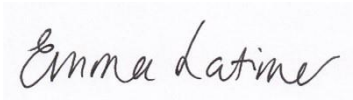
3d "Support voluntary sector organisations in the broad role that they play in end of-life care". The ICB is developing a strategic approach to developing the infrastructure of the voluntary sector across South Yorkshire through our Voluntary Sector Alliance; this includes creating opportunities for organisations to share resources and expertise in recruiting and training volunteers. We have a strong track record of commissioning services from voluntary sector organisations or supporting them through grant agreements, for example the bereavement services provided by Mind, Cruse and Diverse City Development Trust. We also work with the Carers' Centre, Age Concern, and local hospices. Last year we worked with local charities such as the Archer Project and Ben's Centre to deliver the Marie Curie training concerning the palliative and end of life care needs of people who are homeless. We intend to build on this work in the future.

5c "Give staff training to support compassionate conversations with patients and their families about key decisions such DNR and Respect forms". The ICB has a co-ordinating and assurance role in the ongoing roll out of the ReSPECT process in Sheffield. We are represented on the city-wide steering group by a senior manager and a GP advisor who offers advice and contributes to training. Sarah Burt, Deputy Director of Care Outside Hospital at the ICB is the project sponsor, and we will continue to have oversight of ReSPECT implementation.

I hope that this response provides you with some insight and assurance into what the ICB is doing, and plans to do, to support the ongoing improvement of palliative and end of life in all its aspects. This is such a complex area which affects so many patients and the people who love them and care for them, that I would expect that this will be an area for ongoing dialogue between us.

Should any colleagues wish to discuss any aspects of this response please do not hesitate to contact me on the above number, or by email.

Yours sincerely



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