Agenda item:	8.1
Date of meeting:	16 July 2025
Report to the:	Group Trust Board
Title of report:	CCS Learning from Deaths (Quarter 4)
Report author:	Liz Webb, Deputy Chief Nurse
Executive sponsor:	Dr Caroline Kavanagh, Chief Medical Officer
Recommendation:	Note

Assurance level:	**Substantial** ✓ **Reasonable** ☐ **Partial** ☐ **Minimal** ☐
Rationale:	This Quarter 4 report outlines the requirement for Trusts to review the deaths of people who we care for as per the National Quality Board (NQB) guidance (2017) for NHS providers on how they should learn from the deaths of people in their care. We consider both expected and unexpected deaths and seek to learn from care that could have been better and good care. This has been discussed at the Quality Improvement and Safety Committee June 5, 2025.

1.0 Executive Summary

1.1 This Quarter 4 report outlines the requirement for the Trust to review the deaths of people who we care for as per the National Quality Board (NQB) guidance (2017) for NHS providers on how they should learn from the deaths of people in their care. We consider both expected and unexpected deaths and seek to learn from care that could have been better and good care.

2.0 How the report supports tackling Health Inequalities

2.1 The various reports and discussions that take place at the Learning from Deaths meeting include understanding the impact of health inequalities; however, this is an evolving area with work still required to fully understand.

3.0 Links to Board Assurance Framework / Trust(s) Risk and Issue Registers

3.1 Risk 3653 (Risk Rating 12): With competing clinical priorities and internal/ external pressures, there is a risk that quality and patient safety could be compromised.

4.0 Legal and Regulatory requirements

4.1 This report meets the requirements of the National Quality Board (NQB) guidance (2017) for NHS providers on how they should learn from the deaths of people in their care.

5.0 Previous consideration by Committee or Executive

5.1 13 March 2025, Quality Improvement and Safety Committee

6.0 Report

6.1 Introduction

6.2 This Quarter 4 report on Learning from Deaths across the Trust is detailed below as per the Trust's Learning from Deaths Policy, in line with National Quality Board (NQB) guidance (2017). The Learning from Deaths Group meets quarterly, and Service Leads provide individual reports and analysis which makes up the content of this report.

6.3 This report was previously discussed at the Quality Improvement and Safety Committee and gives substantial assurance that the Trust is proactively seeking to improve care provided at the end of life and seeking to learn from cases when things go wrong.

7.0 Luton Adults

7.1 The review of deaths has been conducted according to the general principles laid out in the Trust's Learning from Deaths Policy 4.0. Data, generated from SystmOne, was obtained by the Trust's Informatics team and included patient deaths that occurred in the review period for those patients who had open episodes of care with CCS Luton Adults Unit at the time of their death. Patients who were not under the care of a CCS clinical team at the time of their death were excluded from the review.

7.2 The NHS numbers in the list were used to access S1 records. For each patient record, the following information was reviewed:

- Died under the care of CCS Luton Adult Unit (Y/N).
- Age.
- Gender.
- Ethnicity.
- Electronic Palliative Care Coordinating Systems (EPaCCS) template.

7.3 During quarter 4 (data up to 24th March due to meeting dates), Luton Adults had 62 patients die whilst under the care of the service.
Of the 62 patients,

- 18 had a documented preferred place of care and death
- 16 died in their preferred place of death
- 2 did not die in their preferred place of death
- 38 did not have a place of death documented
- 6 Preferred Place was undecided.

7.4 Previously thematic reviews of this data taken from the EPACCS system found that on direct review of individual records the preferred place of care and death is documented elsewhere and does not come through on the EPACCs data. This makes accurate reporting difficult, but work continues having a single place to report from. Our staff have been requested to input actual place of death on the EPACCS template. The Specialist Palliative Care Team Continue with a rolling education programme for Luton Adults.

7.5 Demographic data is reviewed regularly, and a focused project has commenced with the co- production team on how we support people from all our diverse communities in Luton to access the services. Data shows that the ethnicity of our patients is not as reflective of the overall population as we would like. This is a well-documented issue across England.

7.6 In addition to the data analysis the service randomly selects the records of 10% of those who died to review the quality of care, good practice and improvements. The six cases reviewed in this quarter highlighted the following good practice and areas for improvement.

7.7 **Areas of good practice included:**

- Good evidence of support to patients and families to die in their preferred place.
- Evidence of bereavement calls to families, with positive feedback about care and experience
- Care provided collaboratively across the community and hospital services.
- Good Collaborative working from the Community Cancer team and secondary care oncology teams
- Anticipatory medications prescribed and available
- EPACCS template completed by Community Respiratory Team and good record keeping. This is building on work to ensure that all areas our services have conversations about end of care planning with people we know have life limiting illness.

7.8 **Learning Identified**

- To ensure that all teams (not only the Palliative Care team) document any Advance Care Planning Conversations on EPACCS template so this information can be seen by the whole multi-disciplinary team.
- Recognition by all members of the multi-disciplinary team that rapid deterioration was expected due to the patient's diagnosis, to enable additional support as needed.
- Documentation for do not attempt resuscitation available
- Ensuring family members know who and how call the 24-hour support numbers to facilitate care at home care rather than admission to hospital.

7.9 **Complaints**

There was one this quarter under Luton Adults regarding equipment provision, which was opened and closed in December 2024, pending further enquiries from the family.

8.0 Children's Community Nursing (CCN)

8.1 **Cambridgeshire Children's Community Specialist Nursing Service**

There were 2 deaths this quarter: one unexpected and one expected:

Case 1: 2-year-old child who had cerebral palsy died unexpectedly from a respiratory illness. This is being reviewed through the Child Death Overview Panel (CDOP) and the coroner.

Case 2: An under one year old child with a late diagnosis of a rare genetic condition. This was an expected death. Due to the late diagnosis of their condition, they had a missed opportunity for gene therapy. CDOP is taking this forward with regard to recognition of symptoms suggestive of generic conditions and education for staff. The child did have a ReSPECT document, and the preferred place of death achieved. It was a peaceful death, and the Parents had time with their child.

8.2 **Bedfordshire and Luton Children's Community Specialist Nursing Service**

There were two deaths within Luton this quarter, both were unexpected but on the palliative caseload. They did not have an advanced care plan in place.

Case 1: A sudden death at home, of a patient with a neurological disease known to the team. This case was referred to the coroner but cause of death was influenza. An update will be provided at the next meeting. The learning from this is around the process not being smooth due to the safeguarding concerns and a delay in receiving that information.

Case 2: A sudden death at home of a young person from influenza, the patient had a complex diagnosis and learning difficulties. This is with the coroner and the CDOP process has been followed.

We discussed the risk of influenza with patients with complex neurological disease and that this can cause severe illnesses and death in some cases.

8.3 Integrated Contraception and Sexual Health Services (iCaSH)

All Human Immunodeficiency Virus (HIV) deaths are reviewed at weekly and monthly HIV Multi-Disciplinary Team (MDT) meetings. They are reported via the National HIV Mortality Review (NHMR).

8.4 There were 11 deaths within Q4 – none related to HIV care and treatment.

9.0 Safeguarding Report

9.1 Data was reviewed across the CDOP data, Datix and CDOP SystmOne templates. There were 22 child deaths (12 neonates 10 children) across the trust's geography.
Total number of Datix reported: 7 (10 should have been Datix)
Norfolk -9
BLMK- 10
Cambridgeshire -3

9.2 Datix process:

- If death is unexpected- submit a Datix, to facilitate a learning from deaths review
- If death is expected – no Datix should be completed

9.3 There were 10 unexpected deaths, with 7 of these recorded on Datix as the child or young person was known to a CCS service. As per the policy these are reviewed at the Weekly Safety Huddle and a review is undertaken if CCS services were involved in the care. There were no detailed reviews under the Patient Safety Framework required in this quarter.

9.4 During this quarter all child deaths have been reviewed on SystmOne, and some good practice has been identified regarding the child death process being evident in all the child death cases. Neonatal cases continue to be incorrectly recorded on Datix; however, this is less this quarter.

10.0 LeDer Update

- There has been an increase in autism only referrals to LeDeR.
- Epilepsy and cancer were reported as a concern in reviews.
- Advocacy services are not being utilised as they should.
- Inappropriate learning disability support during admissions or hospital passport not being used.
- No advanced care planning (ACP).
- Lack of professional support and onward referrals.
- Poor quality of care in either placement, community or acute settings.
- Increase of physical disability identified within the reviews.

Work is being undertaken on hospital transfer of care forms and learning disability and autism are to be included.

11.0 Coroner

11.1 There was one inquest within the quarter which the trust previously provided a patient safety incident response report and action plan for. The cause of death in this sad case was unrelated to trust care. However, the incident review and action plan highlighted improvements that have been made. This has been shared with the family.

12.0 National and Regional Updates

12.1 **National Child Mortality Database (NCMD) Infant and Child Mortality – NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board**

A summary of the National Child Mortality Database (NCMD) was shared with the group and discussed. This is an NHS-funded program that collects and analyses data on all deaths of children in England, aged between birth and their 18th birthday. It's operated by the University of Bristol and aims to improve and save children's lives by learning from past deaths and sharing that knowledge. The NCMD works with local Child Death Overview Panels (CDOPs) to gather information from various agencies involved in a child's life and death

12.2 **NHS England Report themes in relation to Valdo Calocane**

Background to this case from Nottingham was shared in slides and discussed. The findings have come up in previous national and local reports and key learning that the Trust will take forward are:

- Being curious about non-compliance with treatment
- MCA assessment issues and staff skills and escalation routes for support and guidance
- Communication between our services and partners (GP's, Local Authority and Police)

12.3 **Sanctioned suicide websites and forums**
These were highlighted for awareness and communication has been shared about what to look out for and how to escalate concerns.

13.0 Next steps as a Group Learning from deaths meeting

13.1 Learning from Deaths Policy Review is underway with a plan to look at a Trust Group wide one.

13.2 A bimonthly joint meeting will commence in June. Terms of reference and agendas are being developed.

13.3 Feedback on the workshop on March was overwhelmingly positive, with another planned in the autumn.

14.0 Summary and escalation points to the Quality Committee and Board

14.1 There were no items requiring escalation, but the following will be highlighted:

- Continuing to improve our Datix reporting for unexpected deaths.
- Improving and working through the Child Death Overview Panel (CDOP) templates used on SystmOne.
- Looking to formulate a group Terms of Reference, agenda, report templates and a standard operating process (SOP).