Title:	Learning from Deaths Group – Quarter 2, 2023-24
Report to the:	Trust Board
Meeting date:	24th January 2024
Agenda item:	10
Report author:	Liz Webb
Executive sponsor:	Dr David Vickers

Assurance level:	Substantial ✓ Reasonable ☐ Partial ☐ Minimal ☐
Rationale:	- Evidence of reports across clinical services where people die under our care. - Evidence of discussion and analysis.
Assurance action:	N/A

1.0 Executive Summary

1.1 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. This report has been presented and discussed at the Quality Improvement and Safety Committee on 6 December 2023.

1.2 The National Guidance required Trusts to:

- Have a Learning from Deaths Policy approved and published by the end of September 2017 which reflects the guidance and sets out how the Trust responds to, and learns from, deaths of patients who die under its management and care. The policy should also include deaths of individuals with a learning disability and children.
- Publish information on deaths, reviews and investigations via an agenda item and paper to public Board meetings.
- Have a considered approach to the engagement of families and carers in the mortality review process.

- Publish evidence of learning and actions taken because of the mortality review and Learning from Deaths process in the Trust's Quality Account from June 2018.

2.0 Recommendation

2.1 The members are asked to:

- **discuss** the report.
- **approve** the Learning from Deaths Policy [Appendix A].

3.0 How the report supports achievement of the Strategic Objectives:

Provide outstanding care:	Report details learning and required activity relating to people who die under our care.
Be collaborative:	Identifies when collaboration has been undertaken.
Be an excellent employer:	Learning from the Learning from deaths supports staff safety and overall level of practice.
Be sustainable:	On-going learning and compliance with standards.

4.0 How the report supports tackling Health Inequalities

4.1 Within the Learning from Deaths Group memberships and any discussion around care at the end of life, consideration of anti-racist practice is considered.

4.2 The collection of demographic data for people who give feedback. This will be explored via the Patient experience and Safety team including the use of Datix to capture this information.

5.0 Links to Board Assurance Framework / Trust Risk Register

5.1 Risk 3166 – There is a risk that patients and service users do not receive outstanding care if services fail to remain compliant with Care Quality Commission Fundamentals of Care Standards (Risk rating 12).

6.0 Legal and Regulatory requirements

6.1 Not Applicable.

7.0 Previous report

7.1 September 2023, Learning from Deaths Group Quarter 1 Report.

8.0 Introduction

8.1 This Quarter 2 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). This report was reviewed and discussed as per the usual process at Quality Safety and Improvement committee on December 6, 2023.

8.2 This 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. The Learning from Deaths Group meets quarterly, and service leads provide individual reports and analysis which makes up the content of this report. The group were asked to agree the updated policy [**Appendix A**].

9.0 Luton Adults

9.1 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.

9.2 The NHS numbers in the list were used to access SystmOne 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.

9.3 This Electronic Palliative Care Coordinating Systems (EPaCCS) template gives a single place for staff to record conversations around advance care planning that can include:

- Preferred place of death (PPD).
- Any end-of-life planning that is in place.
- Actual place of death.
- Reason PPD not met.

9.4 **Overview**

In Q2 there were 95 patients who died under the care of Teams in Luton Adults. Of these, 48 had a preferred place of death (PPD) recorded and 26 subsequently died in their PPD. To support further learning a random selection of 8 patient's records was reviewed.

9.5 **Themes from these record reviews included:**

- Positive impact when the planning and care is achieved for both the patient and the family.
- Successful liaison between the acute hospital and community to enable someone to be discharged home for end-of-life care.
- The multi-disciplinary team working across hospital, community, hospice and GP when someone deteriorates quickly to enable them to remain at home. The impact of achieving this for a bereaved family.

- The ongoing work required to ensure all our services document where possible an individuals' preferred place of care, especially when they have a long-term condition such as heart failure, which can be unpredictable to predict the outcome.
- The reality of care when a person isn't wising to discuss their end-of-life care needs for whatever reason, often meaning a rushed admission to hospital.
- Recognising that if someone does not achieve their preferred place of care, that this not a failure in care. Needs can change rapidly and an alternative to home for end-of-life care is necessary and ensures comfort and support.

9.6 **Actions:**

- Ongoing support is required for the teams to have early advance/ future planning conversations and completion of EPaC template. Following discussion at the last BLMK working group an action has been set to update the hospitals SystmOne programme template (which currently doesn't show the EPaC template) to ensure collaborative and co-ordinated care from both the acute and primary care settings and therefore, allow the patients End of Life Care (EOLC) journey to be more robust enabling good quality of care.
- A rolling training programme is being developed by the specialist palliative care team to provide learning on EOLC, advance care planning conversations to roll out end of 2023 / beginning of 2024. Including syringe driver /EPaCS/ Last Days of Life template.
- There is currently a staff survey (based on the National Audit of Care at the End of Life (NACEL) being distributed to Luton adult services that asks staff their level of confidence in having future/ advance care planning. This will allow for the Service to look at the gap analysis of certain teams and where training needs to be focused on and look at other areas out of the box in provided different training resources.

**Ethnicity data is still being worked on for future inclusion in this report.*

10.0 Syringe Driver Audit- Luton Adults

10.1 An audit of 33 patients on syringe drivers between June – August 2023 was completed. The purpose was to explore appropriateness of prescribing of a driver. Syringe drivers are commonly used in palliative and end of life care to deliver subcutaneous drugs to control troublesome symptoms such as pain, nausea and agitation.

- All patients on syringe drivers in Luton Adults are discussed on the ward round with the Palliative Care Consultants.
- 22 were prescribed in community and 11 within hospital setting – all were required as this was the only way for treatment to be delivered.
- Two could have been discontinued earlier and started on new medication.

11.0 Safeguarding Q2 Report

11.1 Update given on the development of the Child Death Overview Panel (CDOP) SystmOne template. This has been developed and co-produced with Palliative Care Teams and other Services. It will go live in December 2023 and ensure consistency of completing CDOP process for Form B and enable monitoring of child deaths as we record them.

11.2 The process for reviewing child deaths and reporting via CDOP has been refined and Trust wide Standard Operating Procedure is being produced.

12.0 HIV Deaths – Integrated Contraceptive and Sexual Health Service (iCaSH)

12.1 **Summary of HIV patient deaths reported in quarter (financial years)**

2023/2024	Q1	Q2	Q3	Q4	YTD
Total Deaths	**11**	**3**			**14**
Deaths requiring RCA	**0**	**Awaiting 2 SJRs. 1 SJR completed. No RCAs expected.**			**0**

Year on Year Comparator of Reported HIV Patient Deaths (Financial Years)	
2022/ 2023	20
2021/ 2022	23
2020/ 2021	10

12.2 There have been 3 deaths reported during the quarter, of these 2 are still awaiting a Structured Judgement Review (SJR) within Norfolk and Suffolk. For the Norfolk patient there is no indication of cause of death – they were a regular patient and fully engaged in treatment.

12.3 The third death has had a SJR completed, and the individual died in February 2023 after stopping their HIV medication in 2022. They did have capacity to make this choice and there was a rapid deterioration. There was extensive multi-agency work to support this across iCaSH, acute and hospice.

12.4 Action from a previous serious incident update; Syphilis Recall Training has been added to the ESR mandatory training matrix. Across all iCaSH 90% plus have completed this training already.

13.0 Childrens Community Nursing (CCN)

13.1 **Bedfordshire and Luton CCN**

13.2 **Bedfordshire**

- No child deaths this quarter.
- A death of a 17-year-old reported in quarter one has been declared as a serious incident and a full review is underway. This relates to complications of constipation.

13.3 **Luton**

13.3.1 There was one child death this quarter. A 6-month-old boy with a complex congenital cardiac defect that was diagnosed antenatally, but baby was referred at 2 weeks old. He was a looked after child in short term foster care. He was expected to die in the first few weeks, but he lived for 6 months. The Foster Carers were making decisions alongside the Local Authority. The baby died in a hospice whilst on a respite day care session. The maternal mother was included and had supervised contact. All worked well together in the best decisions for the child. The learning from this case was around the understanding of palliative care by Social Care – it was a hard learning process for them.

13.4 **Cambridgeshire & Peterborough**

13.4.1 Five child deaths were recorded in the last quarter:

- Four of these children were known to the service and care was provided to support a good end of life. One child was unknown to the service.
- The meeting noted that all those in school died during the school holidays except one.
- The review of the cases didn't identify additional learning identified from these cases for us. But it was recognised the theme that 3 of the children were in the same school, which would have been impactful for the school community.

14.0 Learning From Unexpected Deaths Cases

14.1 There have been unexpected deaths within the last two quarters which is uncommon. These were discussed and care reflected on.

14.2 **Datix W74676**

14.2.1 **Patient cared for by our Brain Injury service:**

14.2.2 The service involved the adult safeguarding team in the case, as the patient had sustained a brain injury and had fluctuating capacity due to heavily drinking alcohol. When sober he made unwise decisions around his lifestyle and care needs and disengaged with his family and health services. The teams involved worked hard with him and his family, but he sadly died unexpectedly at home.

14.2.3 The reflections of the Brain injury service were around how we communicate with community services, acute, secondary and primary care and how we encourage responsibility with the patient. Excellent work by Kirsty Hughes, Safeguarding Adults Nurse, was commended.

14.2.4 It was noted in the discussion how the complexities for specialist services can be seen in this case, as maybe having all the solutions but not necessarily having the statutory responsibilities.

14.3 **Datix W73731**

14.3.1 A 14-year-old unexpected death following an involvement in a road traffic accident. The Trust was involved in his care, as he had a complicated health and social history. A rapid review of the case has taken place. This recognised the impact of the multifaceted and chaotic nature of this young person's life and our involvement through community paediatrics at different points for treatment for ADHD.

14.4 **Datix W73739**

14.4.1 A complex case involving a little boy under 1. It was an unexpected death, and the cause is currently not known but likely to be overlay (when baby is accidently smothered while sleeping in the same bed as another). The child did have other injuries, so a police investigation is ongoing, and the mother has been arrested.

There is quite a lot of learning from this case and looking at the following:

- The implications from lockdown – once restrictions were lifted CIN conference and meetings took place virtually but need to ensure you are seeing children in care.
- Information on the father not known and partner in prison.
- There were pressures around sickness and vacancies within the Team.
- There is a need for increased supervision across the 0-19 service.

- During the child's life they never saw a GP or received vaccinations.

14.4.2 There were good working arrangements around the transfer in and out as the family moved around a lot. Good documentation on the interaction between baby and mother but not encompassed across the whole period. This has all been shared across the 0-19 Team.

14.5. **W73460**

14.5.1 A serious incident review is being undertaken after the death of a 17-year-old with complex needs. He was supported by several of our services in Bedfordshire. This report will be shared in due course. This relates to constipation treatment and diagnosis. We are working with the coroner and supporting the staff and family involved.

15.0 LeDeR update

15.1 Common learning in the quarter includes:

- Hospital passports not in place for all.
- Advanced care planning not always completed.
- Mental Capacity Act not completed where appropriate.
- Constipation
- Delays in referrals and assessments, where there was known safeguarding and mental health concerns in 45% of the reviews within BLMK.
- There was no poor quality of care.
- There were no deaths referred to LeDeR that contained autism.

15.2 Child to Adult transition particularly for young people with complex needs remains vital and work is still required to ensure this takes place in a consistent and planned way. Our guidance for this is under review currently but resourcing is a challenge.

16.0 Learning From External Cases and Reviews

16.1 Chester/ Letby criminal case – next steps from a Learning from Deaths perspective

16.1.1 Aside from learning from deaths, a Trust Wide Working Group has started to consider the outcomes that have arisen following the conviction of Letby. Obvious themes with learning from deaths is about speaking up, how we think about deaths plus look at the variation in services. A question posed was how we would know if there was a change in what we expect within our services?

16.1.2 To facilitate looking at potential trends a standardised reporting template is being considered, being cognisant of the wide variety of services we have.

16.2 North East Ambulance Service NHS Foundation Trist Assurance Statement 12 – July 2023

16.2.1 The report lists the failures relating to patient safety and governance in the North East Ambulance Service. Within the recommendations:

- The need to ensure we are clear around encouraging people to speak up when things aren't going the way they should.
- Ensuring that the investigation and report writing process is reflective of the facts and not diluted in the process of review.

16.3 **Healthcare Safety Investigation Branch (HSIB) Variations in delivery of Palliative Care Services Report**

16.3.1 This report was published in July 2023 and came on the back of concerns raised by a family over palliative and end of life care of Dermott a 77-year-old man. This report highlighted that palliative care services still have a way to go in joining up care and pathways. There are valid and useful recommendations especially for the Integrated Care Board (ICB). The Trust is actively involved in the BLMK Group.

16.3.2 It is proposed that it would be timely to ask Internal Audit to review our Learning from Deaths processes.

17.0 Learning from Deaths Policy Revised

17.1 This has been reviewed and agreed by the Learning from Deaths Group and includes an update to sections updated as follows:

1.0 Introduction and purpose

4.2 Our involvement with CDOP

2.0 Medical examiners

6.2 Luton data capture

18.0 Summary

18.1 **Highlights are below:**

- The 4 unexpected death cases.
- The iCaSH analysis when patients decide not to engage/ continue with their treatment and how we respond to this.
- The ongoing work being done around training and support for staff on preferred place of death (PPD) in Luton.
- The EPACS challenges raised in the meeting and the frustrations this is causing to services. How can we make digital better? This will also be flagged as an issue with the Digital Team.