NATIONAL QUALITY BOARD

For meeting on: 10 August 2018

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Paper for:

Decision	Discussion	Information
X	X	X

UPDATE ON THE LEARNING FROM DEATHS PROGRAMME

SUMMARY

This paper updates the NQB on progress made against the national Learning from Deaths (LfD) Programme and covers:

- Implementation by Trusts of the national policy framework;
- Publication of the NQB's *Guidance for NHS trusts on working with bereaved families and carers* in July;
- Publication of the annual report of the Learning Disabilities Mortality Review (LeDeR) Programme in May and the Government's planned response;
- Extending LfD policy to primary care and Ambulance trusts for inclusion in a planned second edition of *National Guidance on Learning from Deaths* from the NQB;
- Progress against all workstreams of the LfD programme and actions arising from a Learning from Deaths Programme Board meeting in May with bereaved families; and
- Alignment of LfD with the planned introduction of medical examiners.

PURPOSE

The NQB is asked to **provide a view** in relation to:

1) Plans for the NQB's second edition of *National Guidance on Learning from Deaths* (with publication assumed for early 2019) to include the application of LfD policy to primary care and Ambulance trusts.

2) The process for developing LfD policy to apply to primary care, including leadership on policy development from NHS England.

The NQB is asked to **note**:

1) Governance of actions arising from a families session at the Learning from Deaths Programme Board on 10 May, including that the CQC's review of its assessment of trusts' implementation of the duty of candour and NHS Improvement's review of the Serious Incident Framework will report regularly to the Programme Board but not form part of the Learning from Deaths Programme.

ALB Involvement in development and sign-off of paper:

NHS England	Care Quality Commission	NHS Improvement	NHS Health Education England
X	X	X	X

Public Health England	NICE National Institute for Health and Care Excellence	NHS Digital	Department of Health & Social Care
		X	X

UPDATE ON THE LEARNING FROM DEATHS PROGRAMME

Introduction

1. This month marks just over one and a half years since the Care Quality Commission (CQC) published the findings of its thematic review *Learning, candour and accountability* (December 2016). The review identified specific concerns about the way trusts were investigating and learning when patients in their care die and the extent to which they were engaging meaningfully with families and carers. Good progress has been made since that time including:

    - A *cross-system Learning from Deaths Programme Board* is overseeing plans and progress against all the CQC's seven recommendations;

    - Publication of the first edition of *National Guidance on Learning from Deaths* to support the NHS to standardise the approach to investigations, improve engagement with families and carers, and maximise learning from patient deaths (NQB, March 2017);

    - *Amended Regulations* require trusts to aggregate their quarterly avoidable mortality data and evidence their learning and improvements made to prevent deaths thought to be due to problems in care in their annual Quality Accounts from June 2018;

    - *Two national conferences in April and December 2017*: the second event was co-produced with families, helping DHSC and system partners to maintain a dialogue and better understand their perspectives a year after the CQC's report, and to explore trusts' good practice and lessons learned to disseminate to all trusts;

    - CQC strengthened its assessment of trusts' learning from deaths as part of its new annual well-led inspections of trusts from September 2017; and

    - Publication of *Guidance for NHS trusts on working with bereaved families and carers* (NQB, July 2018).

2. The NHS will need to deliver the full vision of a safer learning culture envisaged in the CQC's report in order that learning from deaths becomes an accepted part of practice that provides support and information for families, and delivers improvements in quality and safety of care. Case studies published by NHS Improvement in December 2017[1] show some of the important progress already underway since *National Guidance on Learning from Deaths* was published in 2017.

[1] *Learning from deaths: case studies from trusts*, December 2017; https://improvement.nhs.uk/resources/learning-deaths-nhs/#h2-case-studies

Trust Implementation

Updated policy

3. In accordance with national LfD policy, all 221 acute, mental health and community trusts have published a policy on how they respond to and learn from deaths.

Publication of mortality data, learning and actions

4. Amended Quality Accounts Regulations require trusts to set out in their annual Quality Accounts from June 2018:

    - the total number of their deaths in a 'reporting year' (1 April to 31 March);
    - the number of those deaths reviewed and/or investigated, and of those,
    - the number of deaths judged more likely than not to have been due to problems in healthcare.

5. The figures must be broken down by each quarter and may be taken from trusts' quarterly data publications which began from Q3 of 2017-18 in response to *National Guidance on Learning from Deaths*. Trusts must also report in their Quality Accounts what they have learnt from reviews and investigations of deaths, actions they have taken in a reporting year (and propose to take) and an assessment of the impact of actions taken.

6. By July 2018, all trusts were publishing some or all of their quarterly data since Q3, with 85% reporting all the required information.

7. Trusts were required to publish their Quality Accounts for 2017-18 by 30 June. NHS Improvement will check all Quality Accounts to identify any trusts that have not reported any deaths due to problems in care over a whole year. NHS Improvement will also review a sample of Quality Accounts (around 80) to identify the themes emerging and to inform thinking about what further support for trusts is required. NHS Improvement will present recommendations for consideration by the Learning from Deaths Programme Board later this year.

New Guidance to support Bereaved Families and Carers

8. On 11 July 2018, the NQB responded to another CQC recommendations when it published *Guidance for NHS trusts on working with bereaved families and carers*[2].

9. Guidance production has been led by NHS England since summer 2017. The guidance was co-produced with a Steering Group (including family members) along with a larger group of over 70 family members. It aims to improve how trusts engage with families and carers and learn when things go wrong. An 'Information for Bereaved Families' leaflet accompanies the guidance, which trusts are able to share with families following

[2] https://www.england.nhs.uk/ourwork/part-rel/nqb/national-guidance-for-nhs-trusts-engaging-with-bereaved-families/

bereavement as a supplement to their own information and resources. Further work is needed to explore offers around advocacy and training to support implementation of the guidance.

10. NHS Improvement is supporting the CQC to work through how the new guidance can inform the approach to inspection on this important issue.

11. The guidance has been well-received. However, families have also cautioned the Learning from Deaths Programme Board that there are wider system issues which they feel are important to the success of the programme but which are beyond the scope of the new guidance. These include implementation of the duty of candour and the quality and independence of investigations. These issues are being considered by the relevant Arms Length Bodies as part of their planned programmes of work (see paragraph 26).

Learning Disabilities Mortality Review (LeDeR) Programme

12. The CQC recommended that there should be greater scrutiny of the care provided to individuals with learning disabilities in all healthcare settings and learning from their deaths.

13. The Learning Disabilities Mortality Review (LeDeR) programme was established in June 2015. The aim is to help reduce premature mortality and health inequalities for individuals with learning disabilities by ensuring that local reviews of their deaths lead to learning and improved health and social care services.

14. The second annual report of the LeDeR Programme for 2016-17 was published by the University of Bristol on 4 May 2018. The report findings were disturbing, showing life expectancy of people with a learning disability lagging significantly behind the rest of the population. In 1 in 8 of the deaths reviewed, the person's health had been adversely affected by one or more of the following; neglect, abuse, delays in treatment or gaps in service provision. Further, only 8% of the 1,311 deaths reported to the LeDeR Programme had been reviewed.

15. As outlined in a Written Ministerial Statement by the Minister of State for Care on 23 July[3], DHSC is working with NHS England and other system partners to agree actions for each of the nine recommendations of the LeDeR report to help address the inequality in life expectancy between people with learning disabilities and the wider population. The Government's response will be published after summer recess as indicated in the Ministerial Statement.

16. Implementation of the LeDeR programme will continue to be reported to the Learning from Deaths Programme Board. Additional funding of £1.4m from NHS England for the fourth year of the programme (2018-19) is aimed at accelerating the timeliness and the number of completed reviews. Simon Stevens has also indicated that '*the differential life expectancy of*

[3] https://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2018-07-23/HCWS906/

people with learning disabilities" will be a priority area to address in the 10 year NHS Plan due to be released this autumn.

Extending Learning from Deaths to Primary Care and Ambulance trusts & Second Edition of the National Guidance

17. On 11th June, the Government announced that DHSC will look at how to extend the learning from deaths policy to GPs and Ambulance trusts so that more areas of the NHS can be made safer by generating learning, including between local health organisations.

18. The learning from deaths policy will need to be tailored for delivery in both sectors. For example, NHS Improvement will consider with stakeholder organisations (e.g. the Association of Ambulance Chief Executives) if policy extension to Ambulance trusts should consider issues such as extension to non-emergency work and the availability of bereavement support.

19. Translating the policy to primary care will require careful consideration. For example, considerations for general practice will include the feasibility of delivering the policy across a large number of independent practices, which deaths should be in scope and the implications on workload.

20. Exploring how to extend LfD policy to primary care will begin with a round table discussion over Summer to include the BMA, RCGP, NHS England, NHS Improvement, CQC and DHSC. The discussion will explore key aspects of the policy, including mortality governance, data transparency and engaging bereaved families, and the potential opportunities, challenges and risks for primary care.

21. There is an opportunity to learn from the process of implementing the first edition of *National Guidance on Learning from Deaths* to understand how policy extension to primary care and Ambulance trusts can prioritise activities in a way that focusses on learning and making tangible improvements in care. Given the differences in scale, organisational complexity and resources, we cannot assume much of the learning in secondary care can be applied to primary care.

22. As different Arm's Length Bodies (including NHS England) are responsible for taking forward policy development and implementing workstreams under the LfD Programme (see paragraph 25), the assumption is that NHS England is suited to lead on the process of policy development for primary care as it can provide the clinical and system leadership necessary to deliver the best chance of success. This is supported by David Geddes, NHS England's Director of Primary Care Commissioning.

23. There will need to be a process of policy development over the coming months to support the development of the second edition of *National Guidance on Learning from Deaths*. DHSC officials will need to ensure that the new Secretary of State has an opportunity to

consider plans for extending the programme however our proposal is to work to a timescale of early 2019 for the publication.

24. There is an opportunity through the planned publication of the second edition of *National Guidance on Learning from Deaths* to update guidance where there have been further policy developments or where further clarification on the expectations on trusts would be helpful. It is proposed to establish a small working group of officials from DHSC, NHS England, NHS Improvement and the CQC (with input from other Arm's-Length Bodies) to develop the second edition guidance.

Workstreams of the Learning from Deaths Programme

25. The recommendations from the CQC in *Learning, candour and accountability* translate into eight national workstreams:

- **Workstream 1:** *Establish learning from deaths as a national priority and coordinate delivery of the CQC's recommendations (Secretary of State for Health and Social Care, DHSC and partner organisations*); This is being addressed by the Learning from Deaths Programme Board (including two family members) which met on nine occasions.

- **Workstream 2:** *Deliver a new, single national policy framework (guidance) for the NHS on learning from deaths (NQB);* A second edition of *National Guidance on Learning from Deaths* is planned for publication later in 2018-19 (paragraph 23).

- **Workstream 3:** *Improve how trusts engage with and support bereaved families and carers (NHS England)*; A key milestone was delivered when the NQB published *Guidance for NHS trusts on working with bereaved families and carers* on 11 July (paragraphs 8 to 11);

- **Workstream 4** is split into three parts:

  - **Workstream 4a:** *Improve learning from deaths of service users with learning disabilities (NHS England)*: The recent publication of the LeDeR annual report prompted significant interest and debate. The National Clinical Director for Learning Disabilities has given a commitment to the LeDeR process in relation to the quality and timeliness of reviews, where the findings go, and the effectiveness of the actions taken;
  - **Workstream 4b:** *Improve learning from deaths of service users with serious mental health issues (NHS England)*: NHS England commissioned the Royal College of Psychiatrists (RCPsych) to develop a methodology and guidance to help review or investigate these deaths and understand key learning for mental health and community trusts. The tool and guidance are being piloted in 14 Mental Health Trusts from May to August 2018. RCPsych will refine both products to take account of the feedback and publish them later this year. RCPsych is keen to explore how the opportunity offered by the richness of the information gained from these reviews can be utilised through local and national analysis.

- **Workstream 4c:** *Improve learning from child death reviews (NHS England and DHSC)*: Statutory and operational guidance will be issued later this year to Clinical Commissioning Groups and local authorities ('Child Death Review Partners' under statute) and all practitioners involved in the child death review process. The guidance is intended to support local agencies to work together and share information effectively so that learning can be promoted and embedded and the bereaved are kept fully informed. Additional guidance entitled *When a Child Dies - a guide for families and carers* about the child death review process and support for the bereaved will be issued by NHS England. This guidance has been developed by bereaved parents, support organisations and professionals.

- **Workstream 5**: *Facilitate the development of provider systems and processes to help alert trusts to the deaths of all individuals who have recently been under the organisation's care (NHS Digital);* LfD policy states that over time, acute, mental health and community trusts may wish to consider including case record reviews of people who had died within a certain timeframe after discharge from the trust. In a small number of cases, deaths of patients after discharge may be linked to the care that they received within the trust, however often the trust is not aware that the patient has died and does not review the death. Whilst some national services are available, these are not always available to the correct people and do not contain all the information required to determine whether a case record review is required. The additional information may only be available for trusts via a chargeable service and in accordance with strict governance arrangements on access and use. NHS Digital are working to establish a free of charge service for trusts in late 2018, subject to funding and information governance approvals.

- **Workstream 6**: *Support providers to ensure that staff have the capability and capacity to carry out good investigations of deaths, with a focus on these leading to improvements in care (Health Education England and the Healthcare Safety Investigations Branch);* Health Education England (HEE) has scoped out what training for reviews and investigations is currently available in the NHS and recently published an e-Learning package for clinicians and reviewers[4]. The expectation is that eventually the Healthcare Safety Investigation Branch will play an important role in considering its approach to supporting investigation training for reviewers in line with the CQC recommendation, potentially through bespoke accredited training for investigators, face-to-face visits or development of national standards.

- **Workstream 7**: *Support trust boards to implement the new national policy framework on learning from deaths (NHS Improvement*); NHS Improvement continues to support trusts to implement the LfD policy framework, for example training in case record review methodology, providing detailed guidance, sharing case studies and other

[4] https://www.skillsplatform.org/courses/5193-learning-from-deaths

best practice resources, and supporting events and seminars. Support includes a webpage which includes advice, guidance and links to further resources, available at https://improvement.nhs.uk/resources/learning-deaths-nhs/

- **Workstream 8**: *Improve how the Care Quality Commission assesses how trusts learn from deaths of patients under their management and care*. In September 2017, the CQC changed its monitoring and inspection regime of how acute, mental health and community health services are learning from, reviewing and investigating deaths (to reflect the NQB's first edition of *National Guidance on Learning from Deaths* and will be updated to reflect the NQB's *Guidance for NHS trusts on working with bereaved families and carers*). The change is part of CQC's new approach to assessing how well-led Trusts are. The CQC has committed to sharing findings identified from its assessment of how trusts learn from deaths of patients.

26. On 10th May, bereaved families presented to the Learning from Deaths Programme Board about wider system issues which they feel can disempower families in relation to failings in care. Following that meeting:

- NHS Improvement is considering feedback from families as part of the process to review and revise the Serious Incident Framework;
- The CQC is reviewing its assessment of trusts' implementation of the Duty of Candour;
- DHSC is undertaking a stocktake of the effectiveness of organisational systems when families seek to address their concerns; and
- DHSC officials will consider with Ministers whether and how historical grievances by families might be considered.

27. Although work such as the CQC's review of the duty of candour and NHS Improvement's review of the Serious Incident Framework sit outside of the Learning from Deaths Programme, progress made against such areas will continue to be reported to Learning from Deaths Programme.

Introduction of Medical Examiners

28. On 11th June 2018, the Government announced the publication of its response to consultation on the introduction of Medical Examiners and Reforms to Death Certification in England and Wales. The anouncement confirmed the Government's intention to introduce a system of medical examiners in England, as a phased roll out from April 2019. The Welsh Government published their consultation separately in Wales.

29. The Medical Examiner and death certification reforms are intended to:

- Increase safeguards for the public by providing robust and independent scrutiny of the medical circumstances and causes of all deaths whether the deceased is buried or cremated, and also ensuring that the right deaths are notified or referred to a coroner;

- Improve the quality and accuracy of death certification by providing expert advice to doctors based on a review of relevant health records; and
- Ensure engagement with bereaved families in order to avoid unnecessary distress resulting from unanswered questions about the certified cause of death.

30. The new non-statutory scheme will require a doctor's certification of cause of death to be scrutinised and confirmed by an independent medical examiner, taking into account concerns raised by the bereaved, and could cover the care the deceased received prior to death.

31. Medical examiners will be employed in the NHS system, ensuring lines of accountability are separate from acute Trusts but allowing for access to information in the sensitive and urgent timescales to register a death. Safeguards will be enhanced in the process to enable medical examiners to report matters of a clinical governance nature to support local learning and changes to practice and procedures.

32. Initially, medical examiners will be funded through the existing fee for completing medical cremation forms, in combination with central government funding for medical examiner work not covered by those fees. When parliamentary time allows, funding of the system will then be placed on a statutory footing and will be revisited. With the statutory system, registration of the death will only be permitted once the death has been scrutinised by a medical examiner or a coroner. The Government also proposed that all child deaths (up to the age of 18) will be exempt from the costs associated with the medical examiner system.

33. There are two Medical Examiner pilots at Sheffield and Gloucester, both of which have been running for around 10 years. Benefits recorded by both sites demonstrate that the new system will serve as a crucial enabler to implementing learning from deaths policy by clarifying which non-coronial deaths should undergo a mortality review, collecting and reporting information on clinical governance, and giving a mandated role for medical examiners' offices to engage with bereaved families to understand any concerns.

Next Steps

34. The Learning from Deaths Programme Board invites feedback on any points presented in this paper and specifically would be grateful to know if the NQB;

- Is content for the Programme Board to plan on the basis of delivering a second edition of *National Guidance on Learning from Deaths* in early 2019 (paragraph 23); and
- Agrees that NHS England is suited to take forward policy development for the application of LfD to primary care with support from stakeholder organisations (paragraph 22).

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