NATIONAL QUALITY BOARD

For meeting on: 06 September 2017

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Paper for:

Decision	Discussion	Information
X	X	

UPDATE ON LEARNING FROM DEATHS PROGRAMME, INCLUDING ALIGNMENT WITH CHILD DEATH REVIEW WORK

SUMMARY

This paper:

1) Learning from Deaths (LfD) Programme: Updates the NQB on progress made against the LfD Programme (further context is at Annex A), including new Regulations to underpin the new Trust reporting arrangements (paragraph 2). We are also seeking agreement from the NQB for the second edition of *National Guidance on Learning from Deaths* to be published in summer 2018 (paragraph 1(ii)).

2) Child Death Review: Updates the NQB on NHS England and the Department of Health's (DH) work on child death review, and how this links with the LfD Programme. A draft of the new comprehensive child death review guidance will be circulated to the NQB for comment in due course.

PURPOSE

The NQB is asked to:

1) **Note** progress made against the LfD Programme;

2) **Agree** for the second edition of *National Guidance on Learning from Deaths* to be published in summer 2018; and

3) **Note** the work on child death review, and how this links with the LfD 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
		X	X

UPDATE ON LEARNING FROM DEATHS PROGRAMME, INCLUDING ALIGNMENT WITH CHILD DEATH REVIEW WORK

A. LEARNING FROM DEATHS PROGRAMME

1. Good progress has been made since publication of the first edition of *National Guidance on Learning from Deaths* and the national Learning from Deaths conference in March 2017. This is summarised below within the context of the CQC's recommendations in its report *Learning, candour and accountability* of December 2016;

   i. **CQC Recommendation 1 - Secretary of State and system partners to make LfD a national priority:** DH has established programme management arrangements as well as a Learning from Deaths Programme Board, chaired by William Vineall[1] and comprising senior representatives of Arms-Length Bodies, to oversee plans and progress against all the CQC recommendations. The Board has met three times[2] and the next meeting is scheduled to take place on 13 September. The Board will include family representatives for its future meetings.

   ii. **CQC Recommendation 2 - To develop a new national Learning from Deaths framework:** The NQB delivered this recommendation when it published the first edition of *National Guidance on Learning from Deaths* for Trusts on 15 March. The guidance outlines expectations of the health system so that Trusts identify, analyse and learn from deaths that could have been avoided had care been better. It calls for good leadership to drive radical change in culture and approach from Trusts so that there can be consistency of approach across the health service. The guidance was presented at the Learning from Deaths conference in March which was attended by executives and non-executives from a large number of Trusts. The LfD Programme Board believes that the guidance should be allowed to bed-in during 2017-18 and that a second edition, which is expected to address wider providers of NHS care and reflect other developments such as new guidance for bereaved families and carers (point (iii)) and a planned update to the Serious Incident Framework, should be published in summer 2018. Are NQB members content with the Board's recommendation?

   iii. **CQC Recommendation 3 - To improve how providers engage with and support bereaved families and carers:** An NHS England-led steering group comprising of families, advocates and NHS Improvement (NHSI) is advising on, and will co-produce, national guidance for bereaved families and carers, and providers. It is scheduled for publication in early 2018. A two-day event is planned with families, advocates, relevant experts, CQC, providers, Skills for Health and NHS Improvement (NHSI) to agree the principles of the guidance.

[1] Director of Acute Care and Quality, Department of Health
[2] 25 April 2017, 14 June 2017 and 11 July 2017.

Links are also being made with the Child Death review work (Section B) and other developments. The steering group will soon nominate family representatives to sit on the Learning from Deaths Programme Board (point (i)). A formal process has been in process to recruit these members objectively.

iv. **CQC Recommendation 4 - To improve learning from deaths of service users with learning disabilities or serious mental illness:** Implementation of NHS England's Learning Disabilities Mortality Review Programme (LeDeR) is being rolled out nationally and will be active in all areas by the end of 2017. LeDeR has an established and well-tested methodology for reviewing the deaths of people with learning disabilities and is supporting local and regional areas to conduct such reviews and implement recommendations. So far, 38 steering groups have been established across the country, more than 400 learning disability death notifications have been recorded and over 120 trained reviewers are engaged in reviewing these deaths. In relation to mental health, NHS England and NHSI, supported by the Royal College of Psychiatrists, have agreed an initial set of diagnoses that Trusts should use as a minimum for the Learning from Deaths policy framework. They will continue to work together to develop a suitable methodology for the review of the care of people who die and who have a severe mental illness.

v. **CQC Recommendation 5 - NHS Digital to assess how to facilitate the development of provider systems and processes to help alert providers to all their deaths, and provide guidance on a standard set of information to be collected by providers on all patients who have died:** *National Guidance on Learning from Deaths* states that the starting point for reviews of deaths in acute Trusts should be inpatients but that Mental Health Trusts and Community Trusts in particular will want to consider carefully which other categories of patients are within scope from the outset, which may include individuals who had died within a certain timeframe after leaving the Trust. Feedback from Trusts indicates that in many cases they are not aware that patients have died outside of their care, particularly in the case of Mental Health Trusts and Community Trusts. NHS Digital has developed guidance outlining existing services to support the identification of such patients which will be issued following review by several Trusts. It is working to identify different options, and their associated costs, to enable Trusts to access a richer set of information in order to support the identification and investigation of deaths. This data is currently only available via a chargeable service and in accordance with strict governance arrangements on access and use. The LfD Programme Board will discuss this issue further on 13 September. The Board accepts that if, nationally, the LfD Programme could clarify the legal and policy position around the provision of data relating to those who had died to support reviews and investigations into their death, this would reduce the risk of variation through differential application of information governance rules. The Board also

accepts that Trusts should not be expected to pay individually for receiving data they require in order to implement a national policy initiative.

vi. **CQC Recommendation 6 - Health Education England (HEE) to work with the Healthcare Safety Investigation Branch (HSIB) and providers to develop approaches to ensuring that staff have the capability and capacity to carry out good investigations of deaths and write good reports, with a focus on these leading to improvements in care:** Although there has been a delay in support from HSIB in light of its newness and capacity constraints, HEE has continued to deliver the elements agreed with the LfD Programme Board, notably scoping of training already in place and development of e-learning. The e-learning will build on and not duplicate current training, reflecting the key principles of good investigations and reviews. The scoping has been completed and the e-learning will be developed with ongoing support from NHSI and CQC by March 2018. However, mandating completion of the e-learning and any further plans to develop more bespoke accredited training and standards will require HSIB involvement and additional resource. The involvement of HSIB to progress the CQC recommendation will be discussed by the LfD Programme Board on 13 September.

vii. **CQC Recommendation 7 - To support provider boards to implement *National Guidance on Learning from Deaths* locally:** NHSI and its regional teams are working to ensure a consistent and pragmatic approach to supporting implementation of the new LfD policy framework. This includes the requirement for each Trust to publish by the end of September 2017 an updated policy on how it responds to and learns from deaths. NHSI has so far supported six regional and national events to spread understanding amongst providers and developed a webpage with resources, including further guidance[3] to supplement *National Guidance on Learning from Deaths*. NHSI is also working with the Royal College of Physicians to offer training in the structured judgement review (SJR) methodology to two representatives from each Trust using the 'train the trainer' approach. This is in accordance with NQB guidance which recommends that all providers take a consistent and evidence-based approach to reviewing case records of adults who have died in acute hospitals. 900 individuals have been trained so far in SJR. NHSI has also set up its own Mortality Surveillance and Learning from Deaths Board, chaired by Dr Kathy McClean[4], and will have ongoing routine engagement with Trusts.

viii. **CQC is also improving how it assesses Trusts' learning from deaths:** CQC has been working with partners, including NHSI and NHS England, to develop its approach to assessing how Trusts are learning from deaths. Families and carers

[3] *Implementing the Learning from Deaths framework: key requirements for trust boards* (July 2017), available at https://improvement.nhs.uk/resources/learning-deaths-nhs/

[4] Executive Medical Director, NHS Improvement

have been given the opportunity to comment on and influence the assessment tool. CQC has undertaken three pilots as part of its new approach to assessing how well-led a Trust is. The findings are being reviewed and the assessment tool is being amended for roll-out in October. The tool will be updated to reflect guidance published for community and mental health services.

2. **Quality Accounts Regulations** have been amended to specify Trusts' new reporting arrangements. They will come into force on 1 November. The Regulations will require Trusts to set out in annual Quality Accounts the total number of their deaths in a 'reporting year' (1 April to 31 March), the number of those deaths reviewed or investigated, and of those, the number of deaths judged more likely than not to have been due to problems in healthcare. The figures will need to be broken down by each quarter and this may be taken from Trusts' quarterly data publications (which will begin from Q3 of 2017-18) they produced in response to *National Guidance on Learning from Deaths*. Trusts will also be required to report in their Quality Accounts what they have learnt from reviews and investigations of deaths, the actions they have taken in the reporting year (and propose to take) and an assessment of the impact of the actions taken. The Regulations cover 2017-18 and therefore impact Quality Accounts from June 2018 onwards. The Regulations and Explanatory Memorandum are available at http://www.legislation.gov.uk/id/uksi/2017/744.

3. Also connected to the LfD Programme is the planned death certification reform and the introduction of **medical examiners**. This will result in all deaths either being scrutinised by a medical examiner or investigated by a coroner in prescribed circumstances, with a mandated role for medical examiners offices to engage with the bereaved to understand any concerns. The new system would provide an opportunity to join up the NHS acute sector with local authorities and coroners offices, and further clarify which deaths should be reviewed under the LfD policy framework.

B. CHILD DEATH REVIEW

4. *National Guidance on Learning from Deaths* requires Trusts to collect and publish quarterly information on deaths in their care (paragraph 2). Deaths of both adults and children are expected to be reported, however, every child's death must be reviewed, and different review processes apply for adults and children. However, due to legislative and other changes, child death review processes are currently themselves being reviewed. NHS England is leading this work, working closely with DH and the Department for Education (DfE). There are some complex interactions between the Learning from Deaths Programme and the Child Death Review work, which this section briefly sets out.

5. The key differences between child death review requirements and those for adult deaths are that:
   - every child's death must be reviewed; and,
   - the focus is on understanding why the child died, rather than focussing the review of the quality of care (although this is included).

Statutory Background on Child Death Review

6. Since 2008, Local Safeguarding Children Boards (LSCBs) in England have had statutory responsibility for reviewing every child's death. This has been undertaken by Child Death Overview Panels (CDOPs) in line with statutory guidance, *Working Together to Safeguard Children*.

7. **The Wood Review:** In December 2015, following a number of inadequate Ofsted ratings, the Government asked Alan Wood to undertake a review of the role and functions of LSCBs. He concluded that LSCBs were ineffective and recommended a number of changes. On child death review, Alan Wood recommended that policy responsibility should move from DfE to DH, given that 80% of child deaths have medical or public health (rather than safeguarding) causation. He also recommended that CDOPs be reconfigured to review deaths over a larger population size, and the establishment of a National Child Mortality Database.

8. **Legislative Change:** The Government accepted Alan Wood's recommendations. This has led to legislative change through the Children and Social Work Act 2017. Policy responsibility for child death review will move from DfE to DH later this year.

NHS England's Child Death Review Programme

9. NHS England's work on child death review has two main aims:
   i. **To reduce preventable child mortality** in response to the UK falling behind comparable countries on rates of infant and child mortality over the last 20 years; and
   ii. **To improve the experience of bereaved families, and staff**, in the period following the death of a child. Currently, the processes that follow a child's death can be very difficult for families to navigate at an acutely difficult time in their lives.

10. To achieve these aims, there are three strands to NHS England's work on child death review:
    i. **National Child Mortality Database:** Since CDOPs were created in 2008, practitioners and academics have called for the establishment of a National Child Mortality Database (NCMD) to identify preventable deaths and share learning. NHS England has secured funding to establish this and the NCMD is currently being procured through the Healthcare Quality Improvement Partnership (HQIP);

ii. **National review of child death review processes** (in hospital and in the community), to inform new national guidance to standardise and simplify processes around the death of a child in England. This is important both to ensure robust data collection of high-quality, standardised data for the national database and to improve the experience of bereaved parents and staff; and,
iii. **Develop new guidance for families** on child death review to help parents understand and navigate the processes that follow a child's death.

11. NHS England's programme has significant stakeholder engagement. Between November 2016 and March 2017, NHS England held a series of meetings, large stakeholder events and expert groups, involving families, clinicians, police, social workers, bereavement teams, CDOP chairs, the National Network of CDOPs, the Chief Coroner's office, DH, NHSI, PHE, medical examiners and others. This included a dedicated event with bereaved parents. Some of the parents involved in this programme are also involved in the Learning from Deaths Programme.

12. Building on this work, two national guidance documents relating to child death review are currently being developed:
    i. ***Working Together* Chapter 5:** To maintain the link with wider safeguarding arrangements, DfE plan to keep a short chapter on child death review in the revised edition of *Working Together* being developed following the Children and Social Work Act 2017. NHS England and DH are working closely with DfE to develop this. DfE are aiming to put *Working Together 2018* out for public consultation in November.
    ii. **Comprehensive child death review guidance:** To ensure that child death review processes are adequately simplified and standardised, more detailed guidance is needed. This is being developed by NHS England and DH, with the drafting process led by clinical advisers and parents. *Working Together* will direct readers to this guidance. DH and NHE England plan to publish this alongside the revised edition of *Working Together*. A copy of the draft comprehensive child death review guidance will be provided to the NQB for comment.

<u>Learning from Deaths and Child Death Review: alignment</u>

13. **Clarity on different processes and requirements for children and adults:** Trusts have said that there is currently confusion over requirements for child death review within the Learning from Deaths framework. In particular, whether the structured judgment review (SJR) methodology should be used for children. NHSI is clarifying to Trusts that SJR only applies to adult inpatients, and that a different review process applies to child deaths. However, these messages are complicated by the current changes to child death review. More communications work may be needed over coming months.

14. **Governance and aligning scope:** The new comprehensive child death review guidance will cover principles and best practice for involving families. This interacts with the planned NHS England guidance for bereaved families and carers, and providers (paragraph 1(iii)). We will need to ensure that these are aligned and published in a way that makes sense to families. Dr Jackie Cornish[5] will join the Learning from Deaths Programme Board from September to ensure that the appropriate links are made at programme level.

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ANNEX A LEARNING FROM DEATHS PROGRAMME

1. The CQC report *Learning, candour and accountability: A review of the way NHS trusts review and investigate deaths of patients in England*[6] was published on 13 December 2016. The review found that Trusts were not giving sufficient priority to learning from deaths and need to do more to engage bereaved families meaningfully.

2. The ambition of the national programme being taken forward by the Department of Health and its Arms-Length Bodies to implement the CQC's seven recommendations is to:

   - ensure that avoidable mortality remains clearly in view by NHS Trusts and Foundation Trusts so that avoidable deaths in England due to problems in care are significantly reduced;
   - improve investigative capability in Trusts.
   - improve engagement by Trusts with bereaved families and carers;
   - ensure greater scrutiny of the care provided to individuals with learning disabilities and mental health needs, in all healthcare settings.

3. On the day the CQC report was published, the Secretary of State (SofS) delivered a statement in Parliament in which he accepted all the CQC's recommendations for improvement. SofS also made a series of commitments to improve the way the NHS learns from deaths, including a requirement for Trusts to publish specified information on deaths from 2017-18 on a quarterly basis, including the number of deaths reviewed or investigated, and of those, the number judged more likely than not to have been due to problems in care (to begin from Q3 of 2017-18).

4. Trusts will also be required to summarise their quarterly data and provide evidence of learning and improvements arising from this data in annual Quality Accounts from June 2018 (these requirements have recently been included in amendments to the Quality Accounts Regulations which were laid in Parliament on 13 July to come into force on 1 November and published on the Legislation website: http://www.legislation.gov.uk/id/uksi/2017/744)

5. On 15 March 2017, the National Quality Board responded to a key recommendation within the CQC's report by publishing the first edition of *National Guidance on Learning from Deaths*[7]. The guidance provides a national framework for NHS Trusts and Foundation Trusts (acute, MH and community) on identifying, reporting, investigating and learning from deaths of people in their care. The guidance was presented at a national conference for Trusts and family representatives on 21 March 2017.

[6] http://www.cqc.org.uk/content/learning-candour-and-accountability
[7] https://improvement.nhs.uk/resources/learning-deaths-nhs-national-guidance/

6. Further to the national guidance and conference, a Learning from Deaths Programme Board, comprising senior officials from DH and ALBs, is overseeing plans and progress against all the CQC recommendations being progressed over this financial year (2017-18). In effect, the remaining recommendations are:

    - NHS England to deliver guidance for bereaved families and carers;
    - NHS England to build on existing work to reduce premature mortality for patients with a Learning Disability or severe Mental Illness;
    - NHS Digital to assess how to facilitate the development of provider systems and processes to help alert providers to all their deaths including when patients die outside their services;
    - NHS Improvement to support Trust boards to implement the national learning from deaths framework.
    - Health Education England to work with the Healthcare Safety Investigation Branch (HSIB) and providers to improve investigations conducted at Trusts through training and capacity building.

7. The CQC is also working to strengthen its assessment of Trusts' learning from deaths in line with the new *National Guidance on Learning from Deaths*.

8. Improving patient safety across the NHS is a key priority for the government. The government wants to continue improving how the NHS investigates and learns from mistakes when things go wrong as its keeps working towards making the NHS one of the safest healthcare systems in the world. It is why NHS Trusts and Foundation Trusts are being required to publish how many deaths they could have avoided had care been better, along with the lessons that they have learned as a result of those incidents (paragraph 4 above).

9. The government also established the Healthcare Safety Investigation Branch in 2016 to conduct major safety investigations into the most serious risks for patients. The government has announced its intention to publish a Bill in draft later this year to establish HSIB as a fully independent body to take its work forward and embed a culture of learning within the NHS.