

# National Guidance on Learning from Deaths

A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care

**National Quality Board**



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# National Guidance on Learning from Deaths

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# Foreword

Following events in Mid Staffordshire, a review of 14 hospitals with the highest mortality noted that the focus on aggregate mortality rates was distracting Trust boards “from the very practical steps that can be taken to reduce genuinely avoidable deaths in our hospitals”.

This was reinforced by the recent findings of the Care Quality Commission (CQC) report *Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England*. It found that learning from deaths was not being given sufficient priority in some organisations and consequently valuable opportunities for improvements were being missed. The report also pointed out that there is more we can do to engage families and carers and to recognise their insights as a vital source of learning.

Understanding and tackling this issue will not be easy, but it is the right thing to do. There will be legitimate debates about deciding which deaths to review, how the reviews are conducted, the time and team resource required to do it properly, the degree of avoidability and how executive teams and boards should use the findings.

This first edition of *National Guidance on Learning from Deaths* aims to kickstart a national endeavour on this front. Its purpose is to help initiate a standardised approach, which will evolve as we learn. Following the Learning from Deaths conference on 21<sup>st</sup> March 2017 we will update this guidance to reflect the collective views of individuals and organisations to whom this guidance will apply to ensure that it is helpful.



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On behalf of the National Quality Board.

# Executive Summary

## Introduction

1. For many people death under the care of the NHS is an inevitable outcome and they experience excellent care from the NHS in the months or years leading up to their death. However some patients experience poor quality provision resulting from multiple contributory factors, which often include poor leadership and system-wide failures. NHS staff work tirelessly under increasing pressures to deliver safe, high-quality healthcare. When mistakes happen, providers working with their partners need to do more to understand the causes. The purpose of reviews and investigations of deaths which problems in care might have contributed to is to learn in order to prevent recurrence. Reviews and investigations are only useful for learning purposes if their findings are shared and acted upon.
2. The following definitions apply for the purposes of this guidance:

- (i) Case record review:** The application of a case record/note review to determine whether there were any problems in the care provided to the patient who died in order to learn from what happened, for example Structured Judgement Review delivered by the Royal College of Physicians.
- (ii) Investigation:** The act or process of investigating; a systematic analysis of what happened, how it happened and why. This draws on evidence, including physical evidence, witness accounts, policies, procedures, guidance, good practice and observation - in order to identify the problems in care or service delivery that preceded an incident to understand how and why it occurred. The process aims to identify what may need to change in service provision in order to reduce the risk of future occurrence of similar events.
- (iii) Death due to a problem in care:** A death that has been clinically assessed using a recognised methodology of case record/note review and determined more likely than not to have resulted from problems in healthcare and therefore to have been potentially avoidable.

## Governance and Capability

3. Learning from a review of the care provided to patients who die should be integral to a provider's clinical governance and quality improvement work. To fulfil the standards and new reporting set out in this guidance for **acute, mental health and community NHS Trusts and Foundation Trusts**, Trusts should ensure their **governance arrangements**

**and processes** include, facilitate and give due focus to the review, investigation and reporting of deaths, including those deaths that are determined more likely than not to have resulted from problems in care. Trusts should also ensure that they share and act upon any learning derived from these processes. The standards expected of Trust boards are set out at [Annex A](#) including having an existing **executive director** take responsibility for the learning from deaths agenda and an existing **non-executive director** take responsibility for oversight of progress. Guidance for non-executive directors is at [Annex B](#).

4. Providers should review and, if necessary, enhance **skills and training** to support this agenda. Providers need to ensure that staff reporting deaths have appropriate skills through specialist training and protected time under their contracted hours to review and investigate deaths to a high standard.
5. Providers should have a **clear policy for engagement with bereaved families and carers**, including giving them the opportunity to raise questions or share concerns in relation to the quality of care received by their loved one. Providers should make it a priority to work more closely with bereaved families and carers and ensure that a consistent level of timely, meaningful and compassionate support and engagement is delivered and assured at every stage, from notification of the death to an investigation report and its lessons learned and actions taken.

#### Improved Data Collection and Reporting

6. The following minimum requirements are being introduced to complement providers' current approaches in relation to reporting and reviewing deaths:

##### A. POLICY ON RESPONDING TO DEATHS

- Each Trust should publish an **updated policy** by September 2017 on how it responds to, and learns from, deaths of patients who die under its management and care, including:
  - i. How its processes respond to the death of an individual with a **learning disability** ([Annex D](#)) or **mental health needs** ([Annex E](#)), **an infant or child death** ([Annex F](#)) and a **stillbirth or maternal death** ([Annex G](#)).
  - ii. **The Trust's approach to undertaking case record reviews.** Acute Trusts should use an evidence-based methodology for reviewing the quality of care provided to those patients who die. The Structured Judgement Review (SJR)

case note methodology is one such approach and a programme to provide training in this methodology for acute Trusts will be delivered by the Royal College of Physicians over the coming year (the current version of the SJR approach is available at <https://www.rcplondon.ac.uk/projects/outputs/national-mortality-case-record-review-nmcrr-programme-resources>). Other approaches also exist, such as those based on the PRISM methodology. Methods like SJR were not developed for mental health and community Trusts but can be used as a starting point and adapted by these providers to reflect their individual service user and clinical circumstances. Annex J provides a case study of how SJR is being adapted for mental health Trusts. Case record reviews of deaths of people with learning disabilities by acute, mental health and community Trusts should adopt the methodology developed by the Learning Disabilities Mortality Review (LeDeR) programme in those regions where the programme is available (details of the programme are available from Annex D).

- iii. **Categories and selection of deaths in scope for case record review:** As a minimum and from the outset, Trusts should focus reviews on in-patient deaths in line with the criteria specified at paragraph 14(ii). In particular contexts, and as these processes become more established, Trusts should include cases of people who had been an in-patient but had died within 30 days of leaving hospital. Mental Health Trusts and Community Trusts will want to carefully consider which categories of outpatient and/or community patient are within scope for review taking a proportionate approach. The rationale for the scope selected by Trusts will need to be published and open to scrutiny.

#### B. DATA COLLECTION AND REPORTING

- **From April 2017, Trusts will be required to collect and publish on a quarterly basis specified information on deaths. This should be through a paper and an agenda item to a public Board meeting in each quarter to set out the Trust's policy and approach (by the end of Q2) and publication of the data and learning points (from Q3 onwards).** This data should include the total number of the Trust's in-patient deaths (including Emergency Department deaths for acute Trusts) and those deaths that the Trust has subjected to case record review. Of these deaths subjected to review, Trusts will need to provide estimates of how many deaths were judged more likely than not to have been due to problems in care. The dashboard provided with this guidance shows what data needs to be collected and a suggested format for publishing the information,

accompanied by relevant qualitative information and interpretation.

- **Changes to the Quality Accounts regulations will require that the data providers publish be summarised in Quality Accounts from June 2018 ([Annex L](#)), including evidence of learning and action as a result of this information and an assessment of the impact of actions that a provider has taken.**

#### Further Developments

7. In 2017-18, further developments will include:

- **The Care Quality Commission will strengthen its assessment of providers learning from deaths** including the management and processes to review and investigate deaths and engage families and carers in relation to these processes.
- **NHS England, led by the Chief Nursing Officer, will develop guidance for bereaved families and carers.** This will support standards already set for local services within the Duty of Candour<sup>1</sup> and the *Serious Incident Framework*<sup>2</sup> and cover how families should be engaged in investigations. Health Education England will review training of doctors and nurses on engaging with bereaved families and carers.
- **Acute Trusts will receive training to use the Royal College of Physicians' Structured Judgement Review case note methodology.** Health Education England and the Healthcare Safety Investigation Branch ([Annex L](#)) will engage with system partners, families and carers and staff to understand broader training needs and to develop approaches so that NHS staff can undertake good quality investigations of deaths.
- **NHS Digital is assessing how to facilitate the development of provider systems and processes** so that providers know when a patient dies and information from reviews and investigations can be collected in standardised way.
- **The Department of Health is exploring proposals to improve the way complaints involving serious incidents are handled** particularly how providers and the wider care system may better capture necessary learning from these incidents<sup>3</sup>.

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<sup>1</sup> Further information is available from:

[http://www.cqc.org.uk/sites/default/files/20141120\\_doc\\_fppf\\_final\\_nhs\\_provider\\_guidance\\_v1-0.pdf](http://www.cqc.org.uk/sites/default/files/20141120_doc_fppf_final_nhs_provider_guidance_v1-0.pdf)

<sup>2</sup> <https://improvement.nhs.uk/resources/serious-incident-framework/>

<sup>3</sup> This follows the Parliamentary and Health Service Ombudsman's report *Learning from Mistakes* (July 2016) and the Public Administration and Constitutional Affairs Committee hearings on this report.

# Chapter 1 - Mortality Governance

## Context

8. In December 2016, the Care Quality Commission (CQC) published its review *Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England*. The CQC found that none of the Trusts they contacted were able to demonstrate best practice across every aspect of identifying, reviewing and investigating deaths and ensuring that learning is implemented.
9. The Secretary of State for Health accepted the report's recommendations and in a Parliamentary statement<sup>4</sup> made a range of commitments to improve how Trusts learn from reviewing the care provided to patients who die. This includes regular publication of specified information on deaths, including those that are assessed as more likely than not to have been due to problems in care, and evidence of learning and action that is happening as a consequence of that information in Quality Accounts from June 2018.

## Accountability

10. Mortality governance should be a key priority for Trust boards. Executives and non-executive directors should have the capability and capacity to understand the issues affecting mortality in their Trust and provide necessary challenge.
11. This *National Guidance on Learning from Deaths* should be read alongside the *Serious Incident Framework*. Trust boards are accountable for ensuring compliance with both these frameworks. They should work towards achieving the highest standards in mortality governance. However, different organisations will have different starting points in relation to this agenda and it will take time for all Trusts to meet such standards. Over time this guidance is likely to be updated to include wider providers of NHS care and whole healthcare systems.

## Responding to Deaths

12. Each Trust should have a policy in place that sets out how it responds to the deaths of patients who die under its management and care. The standards expected of Trusts are set out at Annex C.
13. Boards should take a systematic approach to the issue of potentially avoidable mortality and have robust mortality governance processes. This will allow them to identify any areas of

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<sup>4</sup> <https://www.gov.uk/government/speeches/cqc-review-of-deaths-of-nhs-patients>

failure of clinical care and ensure the delivery of safe care. This should include a mortality surveillance group with multi-disciplinary and multi-professional membership, regular mortality reporting to the Board at the public section of the meeting with data suitably anonymised, and outputs of the mortality governance process including investigations of deaths being communicated to frontline clinical staff.

#### Death Certification, Case Record Review and Investigation

14. There are three levels of scrutiny that a provider can apply to the care provided to someone who dies; (i) death certification; (ii) case record review; and (iii) investigation. They do not need to be initiated sequentially and an investigation may be initiated at any point, whether or not a case record review has been undertaken (though a case record review will inform the information gathering phase of an investigation together with interviews, observations and evidence from other sources). For example, the apparent suicide of an in-patient would lead to a Serious Incident investigation being immediately instigated in advance of death certification or any case record review. The three processes are summarised below:

**(i) Death Certification:** In the existing system of death certification in England, deaths by natural causes are certified by the attending doctor. Doctors are encouraged to report any death to the coroner that they cannot readily certify as being due to natural causes. Reforms to death certification, when implemented in England (and Wales), will result in all deaths being either scrutinised by a Medical Examiner or investigated by the Coroner in prescribed circumstances. Additionally, Medical examiners will be mandated to give bereaved relatives a chance to express any concerns and to refer to the coroner any deaths appearing to involve serious lapses in clinical governance or patient safety.

**(ii) Case Record Review:** Some deaths should be subject to further review by the provider, looking at the care provided to the deceased as recorded in their case records in order to identify any learning. At a minimum, providers should require reviews of:

- i. all deaths where **bereaved families and carers, or staff, have raised a significant concern about the quality of care provision;**
- ii. all in-patient, out-patient and community patient deaths of those with **learning disabilities** (the LeDeR review process outlined at [Annex D](#) should be adopted in those regions where the programme is available otherwise Structured Judgement Review or another robust and evidence-based methodology should be used) and

- with **severe mental illness**;
- iii. all deaths in a **service specialty, particular diagnosis or treatment group where an ‘alarm’ has been raised** with the provider through whatever means (for example via a Summary Hospital-level Mortality Indicator or other elevated mortality alert, concerns raised by audit work, concerns raised by the CQC or another regulator);
  - iv. all deaths in areas where people are **not expected to die**, for example in relevant elective procedures;
  - v. deaths where **learning will inform the provider’s existing or planned improvement work**, for example if work is planned on improving sepsis care, relevant deaths should be reviewed, as determined by the provider. To maximise learning, such deaths could be reviewed thematically;
  - vi. **a further sample of other deaths** that do not fit the identified categories so that providers can take an overview of where learning and improvement is needed most overall. This does not have to be a random sample, and could use practical sampling strategies such as taking a selection of deaths from each weekday.

The above minimum requirements are additional to existing requirements for providers to undertake specific routes of reporting, review or investigations for specific groups of patient deaths, such as deaths of patients detained under the Mental Health Act 1983 ([Annex E](#)).

Providers should review a case record review following any linked inquest and issue of a “Regulation 28 Report on Action to Prevent Future Deaths” in order to examine the effectiveness of their own review process.

Providers should apply rigorous judgement to the need for deaths to be subject to a Serious Incident reporting and investigation. For example, there may be instances where deaths clearly meet Serious Incident criteria and should be reported as such (whether or not a case record review has already been undertaken). Equally, problems identified in case record review may lead to the need for investigation whether this is an investigation under the Serious Incident Framework or other framework/procedure (see section iii)

**(iii) Investigation:** Providers may decide that some deaths warrant an investigation and should be guided by the circumstances for investigation in the Serious Incident Framework.

Some deaths will be investigated by other agents, notably the coroner. Indeed, the coroner has a duty to investigate any death where there are grounds to suspect that the death may have been avoidable. While care should be taken not to compromise such investigations, equally waiting until other investigations are completed may cause unacceptable delay. A good working relationship and close communication are needed to avoid problems.

Providers should review an investigation they undertake following any linked inquest and issue of a “Regulation 28 Report to Prevent Future Deaths” in order to examine the effectiveness of their own investigation process. If an inquest identifies problems in healthcare, providers may need to undertake additional investigation and improvement action, regardless of the coroner’s verdict.

#### Consistency and Judgement in Case Record Review

15. All Trusts currently undertake some form of mortality review. However there is considerable variation in terms of methodology, scope, data capture and analysis, and contribution to learning and improvement. To generate learning for improvement in healthcare, clinicians and staff should engage in robust processes of retrospective case record review to help identify if a death was more likely than not to have been contributed to by problems of care.
16. The Structured Judgement Review (SJR) case note methodology is an approach being rolled out by the Royal College of Physicians. Other methodologies exist and Trusts may already be using them. Trusts need to be assured that the methodology they are using is robust and evidence-based, that it will generate the information they are now being required to publish and that their staff are trained and given sufficient time and resources to undertake case record reviews and act on what they learn.
17. Case record review assessment is finely balanced and subject to significant inter-reviewer variation. It does not support comparison between organisations and should not be used to make external judgements about the quality of care provided.
18. The judgement of whether a problem may have contributed to a death requires careful review of the care that was provided against the care that would have been expected at the time of death. Research has shown that when case record review identifies a death that may have been caused by problems in care, that death tends to be due to a series of problems none of which would be likely to have caused the death in isolation but which in

combination can contribute to the death of a patient<sup>56</sup>. Some of these elements of care are likely to have occurred prior to the admission and providers should support other organisations, for example in primary care, to understand and act on areas where care could be improved.

19. Trusts should acknowledge and cooperate with separate arrangements for the review (and where appropriate investigation) of certain categories of deaths, for example suicides, homicides, and child and maternal deaths.

#### Objectivity in Case Record Review

20. To ensure objectivity, case record reviews should wherever possible be conducted by clinicians other than those directly involved in the care of the deceased. If the specific clinical expertise required only resides with those who were involved in the care of the deceased, the review process should still involve clinicians who were not involved in order to provide peer challenge. Objectivity of reviews should be a component of clinical governance processes. Providers may wish to consider if their review processes should additionally be the responsibility of a designated non-executive director who could do this by chairing the relevant clinical governance committee.

#### Investigations

21. This *National Guidance on Learning from Deaths* and the *Serious Incident Framework* are complementary. This guidance sets out what deaths should be subject to case record review (paragraph 14(ii)), which is inevitably a wider definition than deaths that constitute Serious Incidents. Equally, when a death meets Serious Incident criteria there is no need to delay the onset of investigation until case record review has been undertaken. A review of records will inevitably be undertaken as part of an investigation process. However, immediate action to secure additional information and evidence to support full investigation should not be lost due an inappropriate requirement for all deaths (regardless of nature) to first undergo a case record review.

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<sup>5</sup> Hogan et al. Preventable deaths due to problems in care in English acute hospitals: a retrospective case record review study. *BMJ Qual Saf* 2012; 21: 737-45.

<sup>6</sup> Hogan et al. Avoidability of hospital deaths and association with hospital-wide mortality ratios: a retrospective case record *BMJ* 2015; 351:h3239.

22. Inquiries by the coroner<sup>7</sup> and investigations by providers are conducted to understand the cause of death and contributing factors. However provider investigations are not conducted to hold any individual or organisation to account. Other processes exist for that purpose including criminal or civil proceedings, disciplinary procedures, employment law and systems of service and professional regulation, including the General Medical Council and the Care Quality Commission. In circumstances where the actions of other agencies are required then those agencies must be appropriately informed and relevant protocols must be followed.

### Medical Examiners

23. The introduction of the Medical Examiner role will provide further clarity about which deaths should be reviewed. Medical Examiners will be able to refer the death of any patient for review by the most appropriate provider organisation(s) and this new mechanism should ensure a systematic approach to selecting deaths for review, regardless of the setting or type of care provided in the period before a patient's death. NHS Improvement and the Department of Health are commissioning research to explore whether Medical Examiners are best placed to select which deaths need further review and ensure they do not inadvertently miss or over-refer certain types of cases. Prior to the implementation of the Medical Examiner system, Trusts are advised to allow for any doctors undertaking the certification of death to refer cases for case record review to the most relevant organisation.

### Learning

24. Providers should have systems for deriving learning from reviews and investigations and acting on this learning. The learning should be shared with other services across the wider health economy where they believe this would benefit future patients, including independent healthcare services and social care services. Recommendations within any "Regulation 28 Report on Action to Prevent Future Deaths" from the coroner should also be integral to a provider's systems to support learning within and across their organisation and local system partners.

25. Regardless of whether the care provided to a patient who dies is examined using case record review or an investigation, the findings should be part of, and feed into, robust clinical governance processes and structures. The findings should be considered alongside

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<sup>7</sup> Coroner investigations, A short guide (February 2014) is available from:  
<https://www.gov.uk/government/publications/guide-to-coroner-services-and-coroner-investigations-a-short-guide>

other information and data including complaints, clinical audit information, mortality data, patient safety incident reports and data and outcomes measures etc. to inform the Trust's wider strategic plans and safety priorities.

26. Where case record review identifies a problem in care that meets the definition of a patient safety incident (any unintended or unexpected incident which could have or did lead to harm to one or more patients receiving NHS care) then this should be reported via local risk management systems to the National Reporting and Learning System (NRLS).
27. All patient safety incidents reported as resulting in death or severe harm to a patient are clinically reviewed by the National Patient Safety Team at NHS Improvement to determine if there are implications for national learning and if a response is appropriate. Any deaths that are identified via case record review as due to problems in healthcare would meet the criteria for NRLS reporting. More information on the national process is available at <https://improvement.nhs.uk/resources/patient-safety-alerts>. All serious incidents that relate to patients should be reported to the NRLS for the same reason.

#### Cross-system Reviews and Investigations

28. In many circumstances more than one organisation is involved in the care of any patient who dies. Guidance in relation to cross-system reviews and investigations is at Annex H.

#### Roles and Responsibilities of National Bodies and Commissioners

29. Guidance is provided at Annex I. The lead roles with overall responsibility for the learning from deaths programme at each of the relevant national organisation are provided at Annex K.

# Chapter 2 - Bereaved Families and Carers

## Key Principles

30. Providers should engage meaningfully and compassionately with bereaved families and carers in relation to all stages of responding to a death and operate according to the following key principles below.

### BEREAVED FAMILIES AND CARERS - KEY PRINCIPLES:

- bereaved families and carers should be treated as **equal partners** following a bereavement;
- bereaved families and carers must always **receive a clear, honest, compassionate and sensitive response** in a sympathetic environment;
- bereaved families and carers should receive a **high standard of bereavement care** which respects confidentiality, values, culture and beliefs, including being offered appropriate support. This includes providing, offering or directing people to specialist suicide bereavement support;
- bereaved families and carers should be informed of their **right to raise concerns about the quality of care** provided to their loved one;
- bereaved families' and carers' views should **help to inform decisions about whether a review or investigation is needed**;
- bereaved families and carers should receive **timely, responsive contact and support in all aspects of an investigation process**, with a single point of contact and liaison;
- bereaved families and carers should be **partners in an investigation** to the extent, and at whichever stages, that they wish to be involved, as they offer a unique and equally valid source of information and evidence that can better inform investigations;
- bereaved families and carers who have experienced the investigation process should be supported to work in partnership with Trusts in **delivering training for staff in supporting family and carer involvement** where they want to.

## Context

31. Dealing respectfully, sensitively and compassionately with families and carers of dying or deceased patients within the NHS is crucially important. The principles of openness, honesty, and transparency as set out in the Duty of Candour should also be applied by

providers in all their dealings with bereaved families and carers. Yet the Care Quality Commission's report *Learning, candour and accountability* identified that NHS providers are continuing to fail too many bereaved families and carers of those who die whilst in their care.

32. When a patient dies under the management and care of a Trust, bereaved families and carers should be informed immediately after the death. People who are bereaved need others to recognise and acknowledge their loss. Recognition by professionals, appropriately expressed, may be particularly valued. Communication at the time of a death, and afterwards, should be clear, sensitive and honest. Bereaved families and carers should be given as much information as possible in line with the Duty of Candour for providers. Every effort should be made to hold these discussions in a private, sympathetic environment, without interruptions. Providers should ensure that their staff, including family liaison officers where available, have the necessary skills, expertise and knowledge to engage with bereaved families and carers. This includes recognising and dealing with common issues such as family members feeling guilty about their loss.
33. All too often the terms of the conversation people have with the NHS about a concern or complaint are set by the organisation. Organisations can often be too quick to dismiss or explain away concerns, compounding the grief of bereaved families and carers with obfuscation and a lack of openness. Paying close attention to what bereaved families and carers say can offer an invaluable source of insight to improve clinical practice. Listening to them goes hand in hand with the Duty of Candour. In particular, bereaved families and carers should be asked if they had concerns about the quality of care received by the deceased to inform decisions about the need to undertake a case record review or investigation.
34. When reviewing or investigating possible problems with care, involvement of bereaved families and carers begins with a genuine apology. Saying sorry is not an admission of liability and is the right thing to do. The appropriate staff member should be identified for each case, including to explain what went wrong promptly, fully and compassionately. This may include clinicians involved in the case but this may not always be appropriate and should be considered on a case by case basis.
35. Depending on the nature of the death, it may be necessary for several organisations to make contact with those affected. This should be discussed with the bereaved families and carers and a co-ordinated approach should be agreed with them and the

organisations involved. If other patients and service users are involved or affected by the death they should be offered the appropriate level of support and involvement.

36. The provider should ensure that the deceased person's General Practitioner is informed of the death and provided with details of the death as stated in the medical certificate at the same time as the family or carers. The GP should be informed of the outcome of any investigation.

### Bereavement Support

37. Bereavement can influence every aspect of well-being. Providers should offer a bereavement service for families and carers of people who die under their management and care (including offering or directing people to suicide bereavement support) that offers a caring and empathetic service at a time of great distress and sadness. This includes offering support, information and guidance. This should include bereavement advisors to help families and carers through the practical aspects following the death of a loved one such as:

- arranging completion of all documentation, including medical certificates;
- the collection of personal belongings;
- post mortem advice and counselling;
- deaths referred to the coroner;
- emotional support, including counselling;
- collection of the doctor's Medical Certificate of Cause of Death and information about registering a death at the Registrar's Office;
- details of the doctor's Medical Certificate of Case of Death (this is needed to register a death at the Registrar's Office).

38. The following should also be considered:

- timely access to an advocate (independent of the Trust) with necessary skills for working with bereaved and traumatised individuals;
- support with transport, disability, and language needs;
- support during and following an investigation. This may include counselling or signposting to suitable organisations that can provide bereavement or post-traumatic stress counselling, with attention paid to the needs of young family members, especially siblings;

- further meetings with the organisations involved or support in liaising with other agencies such as the police.

### Review

39. If the care of a patient who has died is selected for case record review providers should:

- have formed that decision based on the views of the family and carers. Providers should require reviews in cases where family and carers have raised a significant concern about the quality of care provision (paragraph 14 (ii)(i));
- communicate to the family and carers the findings of the review if any problems with care are identified and any lessons the review has contributed for the future.

### Investigations

40. If a provider feels that an investigation into a death is needed, early contact should have been made with bereaved families and carers so that their views helped to inform the decision.

41. Bereaved families and carers will expect to know: what happened; how; to the extent possible at the time, why it happened; and what can be done to stop it happening again to someone else. If a provider proceeds with an investigation, skilled and trained investigators need to be able to explain to bereaved families and carers the purpose of the investigation which is to understand what happened. If problems are identified, the investigation should be clear why and how these happened so that action can be taken to prevent the same mistakes from occurring again.

42. Provided the family or carer is willing to be engaged with regarding the investigation, an early meeting should be held to explain the process, how they can be informed of progress, what support processes have been put in place and what they can expect from the investigation. This should set out realistic timescales and outcomes. There should be a named person as a consistent link for the families and carers throughout the investigation, for example a family liaison officer.

43. Bereaved families and carers should:

- be made aware, in person and in writing, as soon as possible of the purpose, rationale and process of the investigation to be held;

- be asked for their preferences as to how and when they contribute to the process of the investigation and be kept fully and regularly informed, in a way that they have agreed, of the process of the investigation;
- have the opportunity to express any further concerns and questions and be offered a response where possible, with information about when further responses will be provided;
- have a single point of contact to provide timely updates, including any delays, the findings of the investigation and factual interim findings. This may disclose confidential personal information for which consent has been obtained, or where patient confidentiality is overridden in the public interest. This should be considered by the organisation's Caldicott Guardian and confirmed by legal advice in relation to each case;
- have an opportunity to be involved in setting any terms of reference for the investigation which describe what will be included in the process and be given expectations about the timescales for the investigation including the likely completion date;
- be provided with any terms of reference to ensure their questions can be reflected and be given a clear explanation if they feel this is not the case;
- have an opportunity to respond on the findings and recommendations outlined in any final report; and,
- be informed not only of the outcome of the investigation but what processes have changed and what other lessons the investigation has contributed for the future.

### Guidance

44. NHS England will develop guidance for bereaved families and carers, identifying good practice for local services on the information that families say they would find helpful. It will cover what families can expect by way of local support in relation to investigations and what to expect when services have identified the death as complex or needing an independent investigation so potentially involving longer timeframes and multiple agency involvement.

45. Public Health England has published guidance which provides advice to local authorities and the NHS on developing and providing suicide bereavement support<sup>8</sup>.

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[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/590838/support\\_after\\_a\\_suicide.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/590838/support_after_a_suicide.pdf)

# **Annexes**

# Annex A - Board Leadership

## BOARD LEADERSHIP - KEY POINTS

The board should ensure that their organisation:

- has an existing board-level leader acting as **patient safety director** to take responsibility for the learning from deaths agenda and an existing **non-executive director** to take oversight of progress;
- pays particular attention to the care of patients with a **learning disability or mental health needs**;
- has a systematic approach to **identifying those deaths requiring review** and selecting other patients whose care they will review;
- adopts a robust and **effective methodology for case record reviews** of all selected deaths (including engagement with the LeDeR programme) to identify any concerns or lapses in care likely to have contributed to, or caused, a death and possible areas for improvement, with the outcome documented;
- ensures **case record reviews and investigations are carried out to a high quality**, acknowledging the primary role of system factors within or beyond the organisation rather than individual errors in the problems that generally occur;
- ensures that **mortality reporting in relation to deaths, reviews, investigations and learning is regularly provided to the board** in order that the executives remain aware and non-executives can provide appropriate challenge. The reporting should be discussed at the public section of the board level with data suitably anonymised;
- ensures that learning from reviews and investigations is **acted on** to sustainably change clinical and organisational practice and improve care, and **reported in annual Quality Accounts**;
- **shares relevant learning** across the organisation and with other services where the insight gained could be useful;
- ensures sufficient numbers of **nominated staff have appropriate skills** through specialist training and protected time as part of their contracted hours to review and investigate deaths;
- **offers timely, compassionate and meaningful engagement with bereaved families and carers** in relation to all stages of responding to a death;
- acknowledges that an **independent investigation** (commissioned and delivered entirely separately from the organisation(s) involved in caring for the patient) may in

some circumstances be warranted, for example, in cases where it will be difficult for an organisation to conduct an objective investigation due to its size or the capacity and capability of the individuals involved; and,

- **works with commissioners to review and improve their respective local approaches** following the death of people receiving care from their services.

Commissioners should use information from providers from across all deaths, including serious incidents, mortality reviews and other monitoring, to inform their commissioning of services. This should include looking at approaches by providers to involving bereaved families and carers and using information from the actions identified following reviews and investigations to inform quality improvement and contracts etc.

# Annex B - Non-Executive Directors

## Context

1. The board of directors of an NHS Trust or Foundation Trust is collectively responsible for ensuring the quality and safety of healthcare services delivered by the Trust, and in the case of a Foundation Trust taking into consideration the views of the board of governors.
2. Boards must ensure robust systems are in place for recognising, reporting, reviewing or investigating deaths and learning from avoidable deaths that are contributed to by lapses in care. Providers should ensure such activities are adequately resourced.  
Commissioners are accountable for quality assuring the robustness of providers' systems so that providers develop and implement effective actions to reduce the risk of avoidable deaths, including improvements when problems in the delivery of care within and between providers are identified.
3. All Trust directors, executive and non-executive, have a responsibility to constructively challenge the decisions of the board and help develop proposals on strategy. Non-executive directors, in particular, have a duty to ensure that such challenge is made. They play a crucial role in bringing an independent perspective to the boardroom and should scrutinise the performance of the provider's management in meeting agreed goals and objectives and monitor the reporting of performance. Non-executive directors should satisfy themselves as to the integrity of financial, clinical and other information, and that clinical quality controls and systems of risk management, for example, are robust and defensible.

## Learning from Deaths

4. Executive and non-executive directors have a key role in ensuring their provider is learning from problems in healthcare identified through reviewing or investigating deaths by ensuring that:
  - the processes their organisation have in place are robust, focus on learning and can withstand external scrutiny, by providing challenge and support;
  - quality improvement becomes and remains the purpose of the exercise, by championing and supporting learning, leading to meaningful and effective actions that improve patient safety and experience, and supporting cultural change; and

- the information the provider publishes is a fair and accurate reflection of its achievements and challenges.
5. From April 2017, providers will start to collect and publish new data to monitor trends in deaths. Alongside this, they will need to establish an ongoing learning process. Board oversight of this process is as important as board oversight of the data itself. As a critical friend, non-executive directors should hold their organisation to account for its approach and attitude to patient safety and experience, and learning from all deaths, particularly those assessed as having been avoidable. The roles and responsibilities of non-executive directors include:

**i. Understand the process: ensure the processes in place are robust and can withstand external scrutiny, by providing challenge and support. For example:**

- be curious about the accuracy of data and understand how it is generated; who is generating it, how are they doing this, is the approach consistent across the Trust, are they sufficiently senior/experienced/trained?
- seek similar data and trend information from peer providers, to help challenge potential for improvements in your own organisation's processes, but understand limitations of any direct comparisons;
- ensure timely reviews/investigations (what is the interval between death and review or investigation?), calibre of reviewer/investigator and quality of the review or investigation;
- is the Care Record Review process objective, conducted by clinicians not directly involved in the care of the deceased?
- how was the case-record review selection done? For example, does selection reflect the evidence base which suggests older patients who die or those where death may be expected are no less likely to have experienced problems in healthcare that are associated with potentially preventable death? Does it ensure all vulnerable patient groups (not just those with learning disabilities or mental health needs) are not disadvantaged?
- are deaths of people with learning disabilities reviewed according to the LeDeR methodology?
- for coordination of responses to reviews/investigations through the provider's clinical governance processes, who is responsible for preparing the report, do problems in care identified as being likely to have contributed to a death feed into the organisation's Serious Incident processes?

ii. **Champion and support learning and quality improvement such as:**

- ensuring the organisation has a long-term vision and strategy for learning and improvement and is actively working towards this;
- understanding the learning being generated, including from where deaths may be expected but the quality of care could have been better;
- understanding how the learning from things going wrong is translated into sustainable effective action that measurably reduces the risks to patients - ensuring that learning and improvements are reported to the board and relevant providers;
- supporting any changes in clinical practice that are needed to improve care resulting from this learning;
- ensuring families and carers are involved reviews and investigations, and that nominated staff have adequate training and protected time to undertake these processes;
- paying attention to the provision of best practice and how the learning from this can be more broadly implemented.

iii. **Assure published information; ensure that information published is a fair and accurate reflection of the provider's achievements and challenges, such as:**

- ensuring that information presented in board papers is fit for publication i.e. it is meaningful, accurate, timely, proportionate and supports improvement;
- checking that relevant team are working towards a timely quarterly publication, in line with the Quality Accounts regulations and guidance;
- checking that arrangements are in place to invite, gather and act on stakeholder feedback on a quarter by quarter basis;
- ensuring the organisation can demonstrate to stakeholders that "this is what we said we would do, and this is what we did" (learning and action), and explain the impact of the quality improvement actions.

# Annex C - Responding to Deaths

Trusts should have a policy in place that sets out how they respond to the deaths of patients who die under their management and care.

## POLICY FOR RESPONDING TO DEATHS - KEY POINTS

The policy should include how providers:

- **determine which patients are considered to be under their care and included for case record review if they die** (it should also state which patients are specifically excluded);
- **report the death within the organisation and to other organisations who may have an interest** (including the deceased person's GP), including how they determine which other organisations should be informed;
- **respond to the death of an individual with a learning disability ([Annex D](#)) or mental health needs ([Annex E](#)), an infant or child death ([Annex F](#)) and a stillbirth or maternal death ([Annex G](#))** and the provider's processes to support such deaths;
- **review the care provided to patients who they do not consider to have been under their care at the time of death but where another organisation suggests that the Trust should review the care provided to the patient in the past;**
- **review the care provided to patients whose death may have been expected**, for example those receiving end of life care;
- **record the outcome of their decision whether or not to review or investigate the death**, which should have been informed by the views of bereaved families and carers;
- **engage meaningfully and compassionately with bereaved families and carers** - this should include informing the family/carers if the provider intends to review or investigate the care provided to the patient. In the case of an investigation, this should include details of how families/carers will be involved to the extent that they wish to be involved. Initial contact with families/carers are often managed by the clinicians responsible for the care of the patient. Given that providers must offer families/carers the opportunity to express concerns about the care given to patients who have died, then the involvement of clinicians who cared for the patient may be considered a barrier to raising concerns. Providers should therefore offer other routes for doing this;
- **offer guidance, where appropriate, on obtaining legal advice for families,**

**carers or staff.** This should include clear expectations that the reasons, purpose and involvement of any lawyers by providers will be communicated clearly from the outset, preferably by the clinical team, so families and carers understand the reasons and are also offered an opportunity to have their own advocates.

# Annex D - Learning Disabilities

## Context

1. Since the 1990s, there have been a number of reports and case studies which have consistently highlighted, that in England, people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry of 2010-2013 into premature deaths of people with learning disabilities (CIPOLD) reported that for every one person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so<sup>9</sup>. Overall, people with learning disabilities currently have a life expectancy at least 15 to 20 years shorter than other people<sup>10</sup>.
2. A concerning finding from CIPOLD was that assumptions were sometimes made that the death of a person with learning disabilities was 'expected' or even inevitable, because that person had learning disabilities. As with the CQC report of 2016<sup>11</sup>, CIPOLD also identified deaths that should have been, but were not, reported to mandatory review processes, including safeguarding reviews and to the coroner.
3. The lives of people with learning disabilities often involve a complex array of service provision with multiple care and support staff. If we are to improve service provision for people with learning disabilities and their families, and reduce premature deaths, we need to look wider than NHS-related circumstances leading to a person's death, in order to identify the wider range of potentially avoidable contributory factors to their death. A cross-sector approach to reviewing deaths of people with learning disabilities is imperative; one that includes families, primary and secondary healthcare, and social and third sector care providers. Such a balanced approach across acute and other settings is needed from the outset of a review process, in order to accurately determine if there are any concerns about the death, or to identify examples of best practice that could lead to service improvement.

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<sup>9</sup> Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Needleman D, Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities. Bristol: University of Bristol.

<sup>10</sup> Glover G, et al, 2017. Williams R. Heslop P, Oyinola J, Grey J. (2016) Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disabilities Research*, 61, 1, 62-74; *Health and Care of People with Learning Disabilities, 2014-15*, NHS Digital, 9 December 2016.

<sup>11</sup> *Learning, candour and accountability: A review of the way NHS Trusts review and investigate the deaths of patients in England*, Care Quality Commission December 2016.

4. There is unequivocal evidence that demands additional scrutiny be placed on the deaths of people with learning disabilities across all settings. This work has already been started by the Learning Disabilities Mortality Review (LeDeR) programme, commissioned by Healthcare Quality Improvement Partnership (HQIP) for NHS England. Once fully rolled out, the programme will receive notification of all deaths of people with learning disabilities, and support local areas to conduct standardised, independent reviews following the deaths of people with learning disabilities aged 4 to 74 years of age. These will be conducted by trained reviewers.
5. The purpose of the local reviews of death is to identify any potentially avoidable factors that may have contributed to the person's death and to develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

### Scope

6. A conceptual definition of learning disabilities is used in the Learning Disabilities White Paper 'Valuing People'<sup>12</sup> (2001).
7. At present, NHS England is working with NHS Digital to explore the options and potential of 'flagging' the records of people with learning disabilities on the NHS Spine<sup>13</sup>. Over time, this could provide an access point for identifying that a person who has died had learning disabilities.
8. The LeDeR programme currently supports local reviews of deaths of people with learning disabilities aged 4 years and over. The lower age limit is set at 4 years of age because before that age, it can be difficult to be sure that a child has learning disabilities as defined above.

### Operationalising Mortality Reviews of People with Learning Disabilities

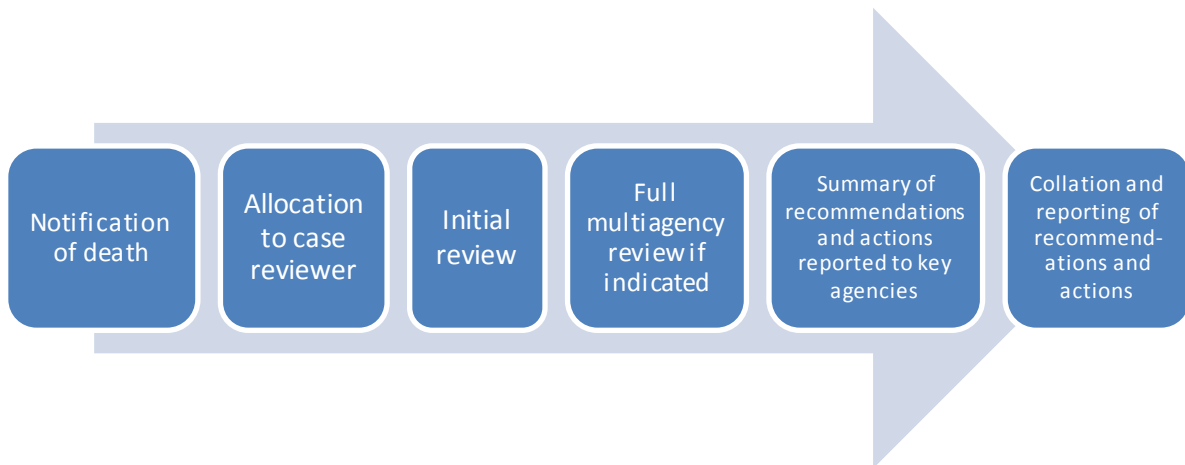
9. The LeDeR programme has an established and well-tested methodology for reviewing the deaths of people with learning disabilities.

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<sup>12</sup> Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health, 2001. LeDeR briefing paper.

<sup>13</sup> Spine supports the IT infrastructure for health and social care in England, joining together over 23,000 healthcare IT systems in 20,500 organisations.

### Current process



10. All deaths of people with learning disabilities are notified to the programme. Those meeting the inclusion criteria for mortality review receive an initial review of their death by an independent, trained reviewer.
11. The standardised review process involves discussing the circumstances leading up to the person's death with someone who knew them well (including family members wherever possible), and scrutinising at least one set of relevant case notes. Taking a cross-agency approach, the reviewer develops a pen portrait of the individual and a comprehensive timeline of the circumstances leading to their death, identifies any best practice or potential areas of concern, and makes a decision, in conjunction with others if necessary, about whether a multi-agency review is indicated.
12. A full multi-agency review is required if the criteria for the current themed priority review are met (death of a person from a Black and Minority Ethnic background or aged 18-24), or where an assessment of the care received by the person indicates deficiencies in one or more significant areas. A full multi-agency review is recommended if there have been any concerns raised about the death, if any 'red flag alerts'<sup>14</sup> have been identified in the initial review, or if the reviewer thinks that a full multi-agency review would be appropriate. The purpose of the multi-agency review is to gain further learning which will contribute to improving practice and service provision for people with learning disabilities, so the review process concludes with an agreed action plan and recommendations that are fed back to the regional governance structures for the programme.

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<sup>14</sup> 'Red flag' alerts are those identified in the initial review that may suggest potential problems with the provision of care e.g. no evidence that an assessment of mental capacity has been considered when this would have been appropriate; delays in the person's care or treatment that adversely affected their health.

13. The LeDeR programme currently operates independently of, but communicates and cooperates with, other review and investigatory processes. This enables an integrated approach to initial reviews of deaths of people with learning disabilities to be taken whenever possible, so as to avoid unnecessary duplication but ensure that the specific focus of the different review or investigation processes is maintained.
14. Alignment of LeDeR with SJR for example will enable a balanced approach to be taken to reviewing deaths of people with learning disabilities that draws on contributions from across acute and other settings. Deaths of people with learning disabilities that occur in hospital settings should be subject to the LeDeR review process in order that insights from families, primary and secondary healthcare, and social and third sector care providers are all included in the mortality review.
15. The LeDeR programme provide annual reports on its findings, collating learning and recommendations at the regional and national level on how best to take forward the learnings across the NHS.
16. Because of the different methodology adopted by the LeDeR programme, it would not be appropriate to use the same definition of 'avoidable death' as used by the SJR, nor to compare rates of avoidable deaths across and between the two review processes. The LeDeR programme will continue to use the Child Death Review Process terminology of 'potentially avoidable contributory causes of death' and the Office for National Statistics definition of avoidable deaths using ICD-10 coding of the underlying cause of death<sup>15</sup>.

#### Integration of the LeDeR Process into National Level Mortality Review Structures

17. When a death of a person with learning disabilities occurs, mandatory review processes need to take precedence, working with the LeDeR programme reviewers to ensure that a coordinated approach is taken to the review of the death in order to minimise duplication and bring in the learning disabilities expertise of the LeDeR reviewers, whilst recognising that some investigatory processes will be more focused than that of LeDeR which is cross-agency in nature and may require the provision of additional information.

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<sup>15</sup> Office for National Statistics (2016) Revised Definition of Avoidable Mortality and New Definition for Children and Young People.

<https://www.ons.gov.uk/aboutus/whatwedo/statistics/consultationsandsurveys/allconsultationsandsurveys/reviewofavoidablemortalitydefinition>

18. Learning and recommendations from LeDeR reviews will identify opportunities for improvement at the local, regional and national level. Governance structures that can support the cross-agency implementation of recommendations from mortality reviews are required at all levels, but in particular for the reviews of deaths of people with learning disabilities. Such structures exist in the form of regional steering groups for the LeDeR programme, and these are usually best placed within the safeguarding framework. Not all deaths of people with learning disabilities are safeguarding issues; however the existing multi-agency framework and statutory responsibility mean that this is a natural 'home' for governance of mortality reviews.

#### Guidance for Providers

19. Key points to note are:

- All deaths of people with learning disabilities aged four years and older are subject to review using LeDeR methodology;
- The LeDeR programme is currently being rolled out across England. Full coverage is anticipated in all Regions by the end of 2017. If there is a death of a person with learning disabilities in an acute setting in an area that is not yet covered by the LeDeR programme, Trusts are recommended to use the SJR process or a methodology of equivalent quality that meets the requirements for the data that must be collected as an interim measure;
- If a Trust wishes to complete its own internal mortality review, it is recommended that it uses the LeDeR initial review process and documentation available at:  
<http://www.bristol.ac.uk/media-library/sites/sps/leder/Initial%20Review%20Template%20version%201.2.pdf> The provider can then submit that as an attachment to the LeDeR notification web-based platform once their internal review is completed;
- Once the LeDeR review has been completed, a copy will be sent to the relevant governance body at the Trust where the death occurred;
- Trusts are encouraged to identify appropriate personnel to undertake LeDeR training and review processes. Reviewers would be expected to conduct reviews independent of the Trust in which they work.

# Annex E - Mental Health

1. Physical and mental health are closely linked. People with severe and prolonged mental illness are at risk of dying on average 15 to 20 years earlier than other people<sup>16</sup>. In addition, people with long term physical illnesses suffer more complications if they also develop mental health problems.
2. Reporting and reviewing of any death of a patient with mental health problems should consider these factors i.e. premature death of those with a mental disorder and the increased risk of complications for those with physical and mental health difficulties.

## Inpatients detained under Mental Health Act

3. Regulations<sup>17</sup> require mental health providers to ensure that any death of a patient detained under the Mental Health Act (1983) is reported to the Care Quality Commission without delay. In 2015, the Care Quality Commission reported concern that providers were failing to make this notification in 45% of cases. The Commission has since updated its notifications protocols to ensure that providers ensure they report in a timely way.
4. Under the Coroners and Justice Act 2009, coroners must conduct an inquest into a death that has taken place in state detention, and this includes deaths of people subject to the Mental Health Act. Providers are also required to ensure that there is an appropriate investigation into the death of a patient in state detention under the Mental Health Act (1983).
5. In circumstances where there is reason to believe the death may have been due, or in part due to, to problems in care - including suspected self-inflicted death - then the death must be reported to the provider's commissioner(s) as a serious incident and investigated appropriately. Consideration should also be given to commissioning an independent investigation as detailed in the *Serious Incident Framework*.

## People with Mental Health Disorders in Prisons

6. Evidence shows that there is a high incidence of mental health problems in prisons: 72% of adult male and 71% of female prisoners may have 2 or more mental disorders (e.g.

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<sup>16</sup> *The Five Year Forward View For Mental Health* (NHS England, 2016) is available at: <https://www.england.nhs.uk/wp-content/uploads/2016/05/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>17</sup> Regulation 17, Care Quality Commission (Registration) Regulations 2009

personality disorder, psychosis, anxiety and depression, substance misuse); 20% have 4 or more mental disorders.

7. There have been large increases in the number of natural and non-natural deaths in prisons over the most recent five-year reporting period. The increase in recent years in non-natural deaths in prisons are due to a number of factors. Prisons contain a high proportion of vulnerable individuals, many of whom have experienced negative life events that increase the likelihood of suicide or self-harm. Issues that increase risk include drug/alcohol abuse, family background, social disadvantage or isolation, previous sexual or physical abuse, and mental health problems. The increase in part reflects an ageing prison population. Prisons are also very challenging environments particularly so for those prisoners who have a learning disability. Average estimates of prevalence of learning disabilities amongst adult offenders in the UK is thought to be between 2-10%. This figure is much higher for children who offend<sup>18</sup>. Prisoners with learning disabilities are also more likely than other prisoners to suffer mental ill health. As such, the mental wellbeing of prisoners with learning disabilities should be a key consideration for healthcare staff of NHS providers along with all other prison staff.
8. The *Serious Incident Framework* states that in prison and police custody, any death will be referred (by the relevant organisation) to the Prison and Probation Ombudsman (PPO) or the Independent Police Complaints Commission (IPCC) who are responsible for carrying out the relevant investigations. Healthcare providers must fully support these investigations where required to do so. The PPO has clear expectations in relation to health involvement in PPO investigations into death in custody. Guidance published by the PPO<sup>19</sup> must be followed by those involved in the delivery and commissioning of NHS funded care within settings covered by the PPO.

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<sup>18</sup> *Equal Access Equal Care*, Guidance for Prison Healthcare Staff treating Patients with Learning Disabilities (2015) available at <https://www.england.nhs.uk/.../equal-access-equal-care-guidance-patients-ld.pdf>

<sup>19</sup> Guidance is available online: <http://www.ppo.gov.uk/updated-guidance-for-clinical-reviews/>

# Annex F - Children and Young People

## Infant and Child Mortality

1. Over the last 20 years, the UK has gone from having one of the lowest mortality rates for 0 to 14 year olds in Europe to one of the highest<sup>1</sup>. In 2014, 4, 419 children and young people aged 0 to 18 years old died in England and Wales. 24% of deaths in children and young people are thought to be preventable<sup>2</sup>. In the year ending March 2016, 68% of all deaths occurred in hospital, 22% in the home, 4% in a public place, and 4% in a hospice. In the year ending March 2016, 32% of all deaths occurred following a perinatal or neonatal event, 26% in children with chromosomal, genetic and congenital anomalies, 8% in children with 'sudden unexpected and unexplained' death, 7% in children with malignancy, 6% in children with acute medical or surgical illnesses, 6% in children with infection, 5% in children suffering trauma, 3% in young people taking their life, and 2% following deliberately inflicted injury, abuse or neglect<sup>2</sup>.
2. In child mortality review, professionals have moved away from defining 'avoidability' to instead using the language of 'a preventable death' where the latter is defined as a death in which 'modifiable factors may have contributed to the death and which, by means of nationally or locally achievable interventions, could be modified to reduce the risk of future child deaths'<sup>3</sup>. In the year ending March 2016, 54% of deaths in hospital and 31% of death in the home were identified as having modifiable factors. Most modifiable factors are found in children dying from perinatal/neonatal events, followed by trauma, followed by those with chromosomal, genetic and congenital anomalies<sup>2</sup>.

## National Data on Causes of Death and International Comparisons<sup>4</sup>

3. The UK ranks 15 out of 19 Western European countries on infant (under one year of age) mortality and has one of the highest rates for children and young people in Western Europe<sup>5</sup>. There is a strong association between deprivation and mortality; for example infant mortality is more than twice as high in the lowest compared with the highest socio-economic groups<sup>6</sup>.

## Infants (under 1 year)

4. Around 60% of deaths during childhood occur in infancy. Infant mortality can be split into neonatal mortality (deaths 0–27 days) and post-neonatal mortality (28–365 days). Births without signs of life (stillbirths if after 24 weeks of pregnancy) do not contribute to infant mortality but are also an important indicator of maternal and child health. The Infant

Mortality Rate (IMR) is an indicator of both population health and the quality of healthcare service. It is also a key international indicator in the United Nation's Sustainable Development Goals and in UNICEF international comparisons.

5. Neonatal mortality accounts for between 70% and 80% of infant deaths. The great majority of neonatal deaths are due to perinatal causes, particularly preterm birth, and are strongly related to maternal health, as well as congenital malformations. The remainder of infant deaths are post-neonatal and are due to a broad range of causes including sudden infant death syndrome (SIDS). Stillbirths (defined in the UK as a baby born without signs of life after 24 completed weeks of pregnancy) account for half of all deaths during the perinatal period. In 2014, the IMR across the UK was 3.9 deaths per 1,000 live births. Although there has been an overall decline in the IMR across the UK over the past 45 years, in recent years the reduction in infant mortality in the UK has not equalled the gains observed in comparable countries. An international study of mortality in the UK compared with similar wealthy countries in Europe and elsewhere showed the UK to have IMR in 1970 similar to the average of the group, but that the UK had become among the worst performing 10% by 2008<sup>7</sup>.
6. Social inequalities play a role in almost all the leading causes of infant death. The mechanisms underlying this social gradient are related to increased risk of preterm delivery in more deprived groups, as well as to maternal health during pregnancy (for example, smoking, poor nutrition, substance abuse) and uptake of recommended practices such as breastfeeding and safe infant sleeping positions<sup>8</sup>. Maternal age is also associated with infant mortality<sup>6</sup>. Many of the causes of infant mortality are preventable and necessitate actions at both a population and individual level<sup>9</sup>:
  - maximising the health and wellbeing of women before conception and during pregnancy (smoking cessation programmes, promotion of breastfeeding and promoting healthy weight in women of childbearing age)
  - protecting and supporting health promotion and early intervention services (universal midwifery and health visiting services for new mothers)
  - promoting evidence-based research into maternal and infant health, and translating findings into improved practice, standards of care, and ultimately policy
  - identifying best practice and reducing variations in outcomes across health care services

### Children (1-9 years)

7. The main factors that contribute to death during childhood are different to those that contribute to death during infancy or adolescence. The common causes of death amongst 1 to 9 year-olds are cancer, injuries and poisonings, congenital conditions and neurological and developmental disorders. Injuries and poisonings from external causes are the leading cause of death in boys aged one to four years, whilst cancer is the leading cause of death in girls of the same age<sup>5</sup>. For both girls and boys five to nine years of age, cancer is the leading cause of death. Very early life also still has an impact on mortality in later childhood; children who were born preterm remain more likely to die before age 10 years compared to children born at term.
8. In the period 2012-2014, the mortality rate in children aged 1-9 years in the U.K. was 12.1 per 100,000 population. Although the mortality rate has declined across the UK since the 1970s, the UK's recent progress has been significantly lower than in other wealthy European countries, and concerning the incidence of death due to diseases such as asthma and diabetes is higher than equivalent high-income countries. The scale of difference between the UK child mortality rate and the average suggests there are around 130 excess deaths of 1- to 9-year-olds each year in the UK<sup>10</sup>.
9. Many childhood deaths are preventable. As with infants there is a strong association between deprivation, social inequality, and mortality. Causes amenable to interventions include environmental and social factors as well as health service factors and key actions include the following<sup>9</sup>:
  - creating safe environments, including access to information and safety equipment schemes to promote safety in the home;
  - reduce road speed limits in built-up areas to 20mph;
  - ensuring that clinical teams looking after children with long-term conditions such as asthma, epilepsy and diabetes deliver care to the highest standards, incorporating good communication, open access for patients and families, use of established tools such as the epilepsy passport and asthma plan, adherence to the components prevalent in the best practice tariff for diabetes, and address early the optimal conditions for safe transition to adult services. Implicit in this is teaching self-management and ownership of the condition;
  - increasing the provision of high-quality end-of-life care and access to appropriate palliative care;

- delivering integrated health systems across primary and secondary care; whilst providing the optimal configuration of specialist services for children with complex conditions needing tertiary care, such as cardiac, renal conditions and children's cancer.

### Young People (10-19 years)

10. After the first year of life, adolescence is the life stage when children are most likely to die. The factors leading to death in adolescence are different to those in earlier childhood, and differ between males and females. The most common causes of death in this age group are injuries, violence and suicide, followed by cancer, substance misuse disorders and nervous system and developmental disorders.
11. Although the mortality rate in young people has decreased across the UK since the 1970s, progress recently has been slower than that seen in other wealthy countries<sup>10</sup>. The UK's 'average' adolescent overall mortality today is a mixed picture. Whilst our injury mortality rate is amongst the lowest, we have a higher rate of deaths due to 'non communicable diseases' such as asthma than other equivalent wealthy countries. Social inequalities are important since injury and illness are associated with poor environmental conditions and hazards such as smoking, alcohol, and drug use<sup>8</sup>.
12. Many deaths are preventable and key actions include<sup>9</sup>:
  - reducing deaths from traffic injuries through the introduction of graduated licensing schemes;
  - improving adolescent mental health services;
  - improving services for children with long term conditions, and especially those transitioning to adult care;
  - increasing the involvement of young people and their families with rare and common long-term conditions in developing guidelines, measuring outcomes, service design and research trials.
13. Underpinning all efforts to reduce child mortality in England lies an urgent need to collect high-quality data to better understand the reasons why children die, to allow accurate international comparisons, and to inform health policy. This requires a national system for the analysis of child mortality data, as well as improved child death review processes.

### Historical Background to the Process of Child Mortality Review

14. Since 1<sup>st</sup> April 2008, Local Safeguarding Children's Boards in England have had a statutory responsibility for Child Death Review (CDR) processes. The relevant legislation underpinning such responsibility is enshrined in the Children's Act 2004 and applies to all children under 18 years of age. The processes to be followed when a child dies are described in Chapter 5 of the statutory guidance document, *Working Together to Safeguard Children*<sup>11</sup>. The overarching purpose of child death review is to understand how and why children die, to put in place interventions to protect other children, and to prevent future deaths. *Working Together* describes two interrelated processes:

- i. a "Rapid Response" multi-professional investigation of an individual unexpected death; and,
- ii. a Child Death Overview Panel (CDOP) review of all deaths in a defined geographical area. The purpose of the CDOP is to establish the exact cause of death, identify patterns of death in community and remedial factors, and to contribute to improved forensic intelligence in suspicious deaths. The family should be kept central to the process.

### Drivers for Change including new Legislation

15. The review of child deaths has been, to date, far more comprehensive than that for adults. However the following drivers for change exist:

- i. *Variation in process*. There is significant variation across the system in how child deaths are reviewed, which deaths are reviewed, and the quality of the review. Specifically:
  - 'unexpected' deaths in the community are generally reviewed as per the Sudden Unexpected Deaths in Infancy (SUDI) process. However there is variation in when a death is considered "unexpected" and in the timing of triggering investigations.
  - hospital deaths are usually reviewed at a Mortality and Morbidity (M&M) meeting. However there is wide variation, across the NHS, in how these meetings are convened, no standardisation on terminology, and a confused array of investigations (root cause analysis, serious incident inquiry, mortality review) that follow certain types of deaths.

- there is wide variation in CDOP processes (size, structure and functioning) and many CDOP panels are dislocated from governance processes within their local children's hospital.
- ii. *The Wood Review*<sup>12</sup>. In 2016, Alan Wood recommended that national responsibility for child death reviews should move from the Department for Education to the Department of Health, that DH should re-consider how CDOPs should best be supported within the new arrangements of the NHS, and that DH should determine how CDOPs might be better configured on a regional basis with sub-regional structures to promote learning. He also recommended that child deaths be reviewed over a population size that allowed a sufficient number of deaths to be analysed for patterns and themes. He went further to recommend that the NHS consider the role CDOPs should play in the process for achieving a common national standard for high quality serious incident investigations. Finally, he supported the intention to introduce a national child mortality database, and urged DH to expedite its introduction.
  - iii. *The National Adult Case Review programme*<sup>13</sup>. This programme uses a very different structured judgment review (SJR) methodology to that used in child mortality review. It focuses on problems in health care processes within an organization rather than trying to understand the cause of death. Cases in which care is judged to be poor are scored according to an 'Avoidability of Death' scale. It is important to recognise that many 16 and 17 year olds die in adult ITU's and therefore it is important to understand what processes should take precedence in the review of such patients.
  - iv. *Medical Examiner process*. The Medical Examiner will be introduced across England. This appointee will link with bereaved families as well as the Coroner and their involvement will affect all mortality review processes.
  - v. *CQC report: Learning, Candour, and Accountability*<sup>14</sup>. This report identified inconsistencies in: the involvement of families and carers; the process of identifying and reporting the death; how decisions to review or investigate a death was made; variation in the quality of reviews and investigations; and variation in the governance around processes and questionable demonstration of learning and actions.
  - vi. *Legislative change (Children and Social Work Bill 2017)*. The Wood Review recommendation that national responsibility for child death reviews should move from the Department for Education to the Department of Health is being enacted through

the Children and Social Work Bill 2017. Under the new legislation, local authorities and clinical commissioning groups are named as 'child death review partners' and must make arrangements for the review of each death of a child normally resident in the local authority area. They may also, if they consider it appropriate, make arrangements for the review of a death in their area of a child not normally resident there. The proposed legislation also states that the 'child death review partners' must make arrangements for the analysis of information about deaths reviewed and identify any matters relating to the death or deaths in that area a) relevant to the welfare of children in the area or to public health and safety and b) to consider whether it would be appropriate for anyone to take action in relation to any matters identified.

#### National Child Mortality Programme

16. NHS England is undertaking a national review of child mortality review processes both in the hospital and community. A key aim is to make the process easier for families to navigate at a very difficult time in their life. Central to the programme is the creation of a National Child Mortality Database, which is currently being commissioned. The effective functioning of the national database requires high-quality, standardised data arising from simplified and standardised local mortality and CDOP review processes. NHS England have therefore established 3 work streams:

- the simplification and standardisation of mortality review processes in the community and hospital;
- a review of the governance arrangements and standardisation of CDOP processes;
- the creation of the national child mortality database.

17. The goals of the NHS England's child mortality review programme are to:

- establish, as far as possible, the cause or causes of each child's death;
- identify any potential contributory or modifiable factors;
- provide on-going support to the family;
- ensure that all statutory obligations are met;
- learn lessons in order to reduce the risk of future child deaths;
- establish a robust evidence base to inform national policy across government to reduce avoidable child mortality across the UK nations.

18. NHS England, the Department of Health and the Department for Education are working together to produce new statutory guidance for child death review. This guidance will cover the processes which should take place following the death of a child, and in particular how the death should be reviewed at local mortality meeting and child death overview panel. This new guidance will be published in late 2017.

### Reporting

19. The definitions used within the adult Case Review programme for record review and to identify problems in care are not recognised within *Working Together*. NHS England's work programme intends to identify best practice and standardise processes across deaths in hospital and the community, to improve the experience of families and professionals. The deaths of children who are treated in acute, mental health and community NHS Trusts should be included by Trusts in quarterly reporting from April 2017. The information should come from child death review processes, and should include reporting problems related to service delivery.

### Board Leadership

20. Hospital Trust, Local Authority, Community Trust, Mental Health Trusts, and CCG boards should ensure that learning is derived from the care provided to children who die, by the appropriate application of the child mortality review process, and that learning is shared and acted on.
21. Many of the points around board leadership relating to adult deaths (set out in the main body of this guidance) also apply for child deaths. For example, providers must ensure that they have a board-level leader designated as patient safety director to take responsibility for the learning from deaths agenda (Annex A) and he or she should also have specific responsibility for the learning from child mortality processes. The director should ensure that the reviews are delivered to a high quality, with sufficient numbers of trained staff to lead the child mortality review process.
22. Particular attention should be paid to the deaths of children and young people with learning disabilities or mental health conditions, as these present with frequent co-morbidities and are often a more vulnerable group.
23. Providers should acknowledge that an independent investigation (one commissioned and delivered entirely separately from the organisation(s) involved in caring for the patient) may be required where the integrity of the investigation is likely to be challenged.

### Best Practice in responding to Death of a Child who dies under a Trust's Care

24. All Trusts should have a policy in place that sets out how they respond to the deaths of children who die under their care. In doing this they should be mindful of current expectations described within *Working Together to Safeguard Children* (2015) and of NHS England's current review of child mortality review processes. New statutory guidance on child death review will be published in late 2017.

25. That policy should also set out how Trusts:

- communicate with bereaved parents and carers. This should include providing an honest and compassionate account of the reasons for death and knowledge of any potential problems in care that may need further review, ensuring initial contacts are managed by clinicians responsible for the care of the patient, and offering support to express concerns about the care given to patients who have died;
- achieve independence (where relevant) and objectivity in the child mortality review process, as well as lay membership within wider clinical governance systems.

### Cross-system Reviews and Investigations

26. When the death of a child involves treatment across the health care pathway (primary: secondary: tertiary care) it is expected that child mortality review processes will not be duplicated and that a single overarching meeting will be convened. Child mortality review processes should interface with existing organisational governance systems. The NHS England child death review programme is mindful of expectations arising from the Serious Incident Framework, which sets out the circumstances in which further investigation is warranted in certain situations. It is therefore anticipated that when a review identifies a problem in care that meets the definition of a patient safety incident (any unintended or unexpected incident which could have or did lead to harm to one or more patients receiving NHS care) then this is reported via local risk management systems to the National Reporting and Learning System (NRLS). Regardless of the type of review, its findings must form an integral part of and feed into the organisation's clinical governance processes and structures. Review findings should be considered alongside other information and data including complaints, clinical audit information, patient safety incident reports and other outcomes measures to inform the Trust's wider strategic plans and safety priorities.

### Bereaved Families and Carers

27. *Working Together* places the family at the heart of its processes. However it is recognised that the multitude of investigations that may unfold following a child's death can cause great confusion and distress to parents. The national bereavement group and bereavement charities are closely involved with developing NHS England's child death review programme – both in the co-design of systems and public guidance that explains processes.

28. The national Child Death Review programme recognises the following principles:

- bereaved families and carers should be treated as equal partners both in the delivery of care and following a bereavement;
- bereaved families and carers should receive a high standard of bereavement care, including being offered appropriate support;
- bereaved families and carers must always receive an honest, caring and sensitive response;
- bereaved families and carers should receive timely, responsive contact and support in all aspects of any review process, with a single point of contact and liaison.

### Learning Disabilities and Mental Illness

29. NHS England's National Child Mortality Review programme fully recognises the unique challenge in reviewing the deaths of children with learning disabilities and mental health disorders. The Programme is working closely with the Learning and Disabilities Mortality Review (LeDeR) programme, and also aims to align itself with the Children and Young People's (CYP) Mental Health Programme and Specialised Commissioning particularly with regard to deaths in Tier 4 inpatient CAMHS Units. It will also work closely with the National Programme on Suicide in Young People. Going forward, the programme will ensure that there are appropriate mechanisms in place to allow data flows to occur unencumbered between all these systems and the national Child Mortality Database.

### Conclusion

30. This section highlights the very different circumstances that pertain to the death of a child in acute, mental health and community organisations. Although infant and child mortality has declined in the UK, these improvements have not been sustained in comparison to other European countries. While poverty and inequality have a major impact on child mortality, we can nonetheless do much in front line service delivery to improve outcomes

for children, and experiences for both bereaved parents and the professionals who deliver care. Sadly, deaths in childhood are often an inevitable consequence of congenital malformations, birth events, and long-term conditions or chronic illness. Many, however, have preventable factors, and there is therefore an absolute imperative to scrutinise all deaths both locally and nationally to ensure that learning always occurs.

31. NHS England is seeking to address this by establishing a National Child Mortality Database to allow analysis and interpretation of child mortality data. The programme will also seek to improve, standardise and simplify the processes that follow the death of a child. This is predominantly to improve the experience of bereaved parents at such an overwhelming time, but also to enable uniformly robust data collection, to ultimately lead to a reduction in infant and child mortality in this country.

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# Annex G - Maternity

1. In England, maternity care is generally safe and for the majority of women and their babies there is a good outcome. However, when things go wrong, the impact is devastating and has a profound effect on the parents, partners, siblings and extended family members.
2. Dr Bill Kirkup was tasked by the Secretary of State for Health to investigate and report on maternity services at Morecambe Bay NHS trust. The Report of the Morecambe Bay Investigation in 2015<sup>20</sup> highlighted a number of failures over a number of years at the Trust which resulted in poor care and the tragic deaths of mothers and babies. The report makes recommendations for mandatory reporting and investigation of serious incidents of maternal deaths, late and intrapartum stillbirths and unexpected neonatal deaths. It recommends a requirement that investigation of these incidents be subject to a standardised process, which includes input from and feedback to families, and independent, multidisciplinary peer review. In *Learning not Blaming*<sup>21</sup> the Government accepted this recommendation.
3. In October 2016, *Safer maternity care: next steps towards the national maternity ambition* was published setting out an action plan for the Government's vision for making NHS maternity services some of the safest in the world, by achieving the national ambition to halve the rates of stillbirths, neonatal deaths, brain injuries that occur during or soon after birth and maternal deaths, by 2030 with an interim measure of 20% by 2020. The plan details the actions needed at national and local level that build on the progress already made to improve the safety of maternity services.
4. Currently MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquires across the UK)<sup>22</sup>, appointed by Health Quality Improvement Partnership and funded by NHS England, run the national Maternal, Newborn and Infant

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<sup>20</sup> The report of the Morecambe Bay Investigation (March 2015):

<https://www.gov.uk/government/news/morecambe-bay-investigation-report-published>

<sup>21</sup> The government response to the Freedom to Speak Up consultation, the Public Administration Select Committee report 'Investigating Clinical Incidents in the NHS', and the Morecambe Bay Investigation (July 2015).

<sup>22</sup> 'MBRRACE-UK' is the collaboration appointed by the Healthcare Quality Improvement Partnership (HQIP) to continue the national programme of work investigating maternal deaths, stillbirths and infant deaths, including the Confidential Enquiry into Maternal Deaths (CEMD). The aim of the MBRRACE-UK programme is to provide robust information to support the delivery of safe, equitable, high quality, patient-centred maternal, newborn and infant health services.

Clinical Outcomes Review to conduct surveillance of all late fetal losses, stillbirths and neonatal deaths, biennial topic-specific confidential enquiries into aspects of stillbirth and neonatal death or serious neonatal morbidity and surveillance and confidential enquiries of all maternal deaths.

5. Surveillance reports on stillbirths and neonatal deaths are published annually. Reports on maternal deaths are published on a triennial basis, because the number of maternal deaths from individual causes is small, and thus three years' worth of data is required to identify consistent lessons learned for future care and to maintain anonymity and confidentiality.
6. A maternal death is defined internationally as a death of a woman during or up to six weeks (42 days) after the end of pregnancy (whether the pregnancy ended by termination, miscarriage or a birth, or was an ectopic pregnancy) through causes associated with, or exacerbated by, pregnancy. Deaths are subdivided on the basis of cause into: direct deaths, from pregnancy-specific causes such as preeclampsia; indirect deaths, from other medical conditions made worse by pregnancy such as cardiac disease; or coincidental deaths, where the cause is considered to be unrelated to pregnancy, such as road traffic accidents. Maternal deaths are very rare. The MBRRACE-UK report 'Saving Lives, Improving Mothers Care highlights that for 2012-14, the maternal death rate was 8.5 per 100,000 women. Overall, 241<sup>23</sup> women among 2,341,745 maternities in 2012–14 died during or within 42 days of the end of pregnancy in the UK.
7. Better Births (2016)<sup>24</sup>, the report of the NHS England commissioned National Maternity Review, set out a five year forward view for improving outcomes of maternity services in England. The report highlighted the lack of a standard approach to investigating when things wrong during before, during or after labour: Reviews and investigation are currently undertaken using different protocols and processes by different organisations. The Report recommended there should be a national standardised investigation process for when things go wrong, to get to the bottom of what went wrong and why and how future services can be improved as a consequence. Work has now begun on the development of a Standardised Perinatal Mortality Review Tool that will enable maternity

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<sup>23</sup> Of these 41 deaths were classified as coincidental

<sup>24</sup> <https://www.england.nhs.uk/wp-content/.../02/national-maternity-review-report.pdf>

and neonatal services to systematically review and learn from every stillbirth and neonatal death in a standardised way.

8. Maternal deaths, neonatal deaths and stillbirths occurring in acute, mental health and community Trusts should be included by Trusts in quarterly reporting from April 2017.
9. It should be borne in mind that in addition to hospital obstetric units, maternal deaths can occur in a local midwifery facility (for example, a local midwifery unit or birth centre) or during home births. The definition also covers up to 42 days after the end of pregnancy.

# Annex H - Cross-system Reviews & Investigations

1. In many circumstances more than one organisation is involved in the care of any patient who dies, with the most common combinations being primary care and acute care, ambulances services and acute care, or mental health services combined with any of these. Case record reviews typically have to rely on the records held by a single organisation, but even these records can provide indications of possible problems in earlier stages of the patient pathway.
2. Where possible problems are identified relating to other organisations, it is important the relevant organisation is informed, so they can undertake any necessary investigation or improvement. Most trusts already have effective systems to notify other organisations when concerns are raised via incident reports, and are likely to be able to adapt these to address potential problems identified in case record review.
3. Trusts should consider whether they can routinely arrange joint case record reviews or investigations for groups of patients where more than one organisation is routinely providing care at the time of death - for example, for older people with dementia and frailty receiving frequent input from their GP and from community mental health nurses. Commissioners have a role in encouraging appropriate routine collaboration on case record review.
4. Where the provision of care by multiple providers, and particularly the coordination of that care, is thought to have potentially contributed to the death of a patient, investing the significant resources required to coordinate major and complex investigations must be considered. For example, the Serious Incident Framework outlines the principles which underpin a serious incident investigation process and the relevant content is set out in paragraphs 5 to 10 below.
5. The organisation that declares the serious incident is responsible for recognising the need to alert other providers, commissioners and partner organisations as required in order to initiate discussions about subsequent action.

6. All organisations and agencies involved should work together to undertake one single investigation wherever this is possible and appropriate. Commissioners should help to facilitate discussions relating to who is the most appropriate organisation to take responsibility for co-ordinating the investigation process. Commissioners themselves should provide support in complex circumstances. For example, where no one provider organisation is best placed to assume responsibility for co-ordinating an investigation, the commissioner may lead this process. If commissioners do not have the capability or capacity to manage this type of activity this should be escalated to ensure appropriate resources are identified. This may be something to consider escalating through the relevant Quality Surveillance Group or through specific review panels and clinical networks. This should ensure the cumulative impact of problems with care can be resolved.
7. In some circumstances the local authority or another external body may be responsible for managing and co-ordinating an investigation process. Where this is the case, providers and commissioners must contribute appropriately and assure themselves that problems identified will be addressed.
8. Often in complex circumstances, separate investigations are completed by the different provider organisations. Where this is the case, organisations (providers and commissioners and external partners as required) must agree to consider cross boundary issues, such as gaps in the services that may lead to problems in care. The contributing factors and root causes of any problems identified must be fully explored in order to develop effective solutions to prevent recurrence. Those responsible for coordinating the investigation must ensure this takes place. This activity should culminate in the development of a single investigation report.
9. To determine oversight of an investigation, the RASCI (Responsible, Accountable, Supporting, Consulted, Informed) model supports the identification of a single 'lead commissioner' with responsibility for managing oversight of serious incidents within a particular provider. This means that a provider reports and engages with one single commissioning organisation who can then liaise with other commissioners as required. This approach is particularly useful where the 'accountable commissioner' is geographically remote from the provider (and therefore removed from other local systems and intelligence networks) and/or where multiple commissioners' commission services from the same provider. It facilitates continuity in the management of serious incidents, removes ambiguity and therefore the risk of serious incidents being

overlooked and reduces the likelihood of duplication where there is confusion regarding accountability and/or responsibility and general management of the serious incident process.

#### Healthcare Safety Investigation Branch

10. The Healthcare Safety Investigation Branch (HSIB) will provide capability at national level to offer support and guidance to NHS organisations on investigations, and to carry out up to 30 investigations itself per year where there is a deeper learning opportunity for the NHS. Through a combination of setting exemplary practice and structured support to others, the HSIB is expected to make a decisive difference to the NHS, promoting a culture of learning and a more supportive relationship with patients, families and staff.
11. Providers will benefit from the HSIB, and their expert advice on safety improvement. It should mean timely investigations, with a genuine commitment to openness, transparency and engagement with staff and patients and their families and carers that adopt an ethic of learning and continuous improvement. The HSIB will contribute strongly to the culture change that is needed in the NHS.

# Annex I - Roles and Responsibilities of National Bodies and Commissioners

1. Each national organisation will have a single lead at executive level who has accountability, internally and externally for that organisation's support of delivering against the national programme on learning from deaths. This will include ensuring progress is reported to the National Quality Board and ensuring that learning from deaths remains a priority area in future developments. A list of the lead roles for each national organisation is at [Annex K](#) and will be made available on each organisation's website.
2. As the independent regulator of health and social care, the **Care Quality Commission** will use this national guidance on learning from deaths to guide its monitoring, inspections and regulation of services. Inspectors will use new key lines of enquiry in relation to safety and governance, set out in the Care Quality Commission's assessment framework, to assess learning from deaths, collect evidence and identify good practice. Where specific concerns are identified, the Care Quality Commission can use its powers to take action with individual providers and will report its findings of good and poor progress in individual inspection reports or national publications to help encourage improvement.
3. **NHS Improvement** will continue to provide national guidance for managing serious incidents. Local processes setting out what deaths should be subject to case record review will inevitably use a wider definition than deaths that constitute Serious Incidents. Equally, when a death clearly meets Serious Incident criteria there is no need for an initial stage of case record review to be completed before work to initiate and support a full investigation is undertaken. Serious Incident guidance provides the framework upon which the Care Quality Commission and commissioners (including CCGs and NHS England) will assess the quality of investigations undertaken across the NHS. NHS Improvement will, alongside the Healthcare Safety Investigation Branch and others, support implementation of best practice in investigations by Trusts.
4. As the revised inspection regime of the Care Quality Commission will assess providers' ability to learn from deaths as a key component of high quality care, work to address this will be factored into NHS Improvement's work to support providers in achieving good or outstanding Care Quality Commission care ratings. Regional teams will work with

providers, their commissioners and NHS England to identify areas where improvements can be made and the strategies which can help deliver the change required.

5. Nationally, NHS Improvement commissions (via the Healthcare Quality Improvement Partnership) the work of the Royal College of Physicians to develop and roll-out the Structured Judgement Review methodology, which will be providing a national training programme for acute Trusts to support them to carry out the methodology for adult inpatient deaths.
6. **NHS England** has a direct commissioning role as well as a role in leading and enabling the commissioning system. This national guidance on learning from deaths will guide its practice in both of these areas.
7. The **National Institute for Health and Care Excellence (NICE)** has produced best practice guidelines on the care of the dying, covering adults and children. These guidelines are supported by measurable quality standards that help Trusts demonstrate high quality care, and by information for the public describing the care that should be expected in the last days of life.

# Annex J - Structured Judgement Review in Mental Health Trusts

## Background

1. Some mental health providers have seen a missed opportunity in not learning more widely from deaths by reviewing the safety and quality of care of a wider group of people. This is despite research showing that people with mental health problems have greater health care needs than the general population and may suffer unnecessarily with untreated or poorly managed long-term conditions.

## Where Next - Making a Decision on the Review Method

2. Since 2014 hospitals in Yorkshire and the Humber have been working together with the AHSN Improvement Academy to refine a mortality review method called Structured Mortality Review (SJR), a method proposed for all acute hospitals in England. The acute sector methodology reviews phases of care appropriate to their settings, such as initial assessment and first 24 hours, care during a procedure, discharge/end of life care and assessment of care overall. Written explicit judgements of care and phase of care scores form the basis of the reviews. This now forms the basis of the national acute hospitals mortality review programme.
3. This methodology and review format was seen as potentially valuable by three regional Mental Health trusts and they have individually worked to create phase of care headings more appropriate to mental health care, with the support of the Improvement Academy and Professor Allen Hutchinson. These three trusts are at different stages of implementation. In the early adopter trust the tool was also adapted to include a pen picture to enable the reviewer to understand both the life and death of the person, considering this fundamental to understanding areas for learning that may include review of physical health and lifestyle choices. In the same trust this approach was used within Learning Disability services prior to the introduction of the Learning Disability Review of Deaths (LeDeR) programme. In another trust both the mental health care and community care facilities have been using the methods.

## Introducing the Review Process

4. Just as with the acute services, future reviewers require initial training in how to make explicit judgements of the quality and safety of care and how to assess care scores for

each phase of care. Assessments are made of both poor and good care and it is common to find that good care is far more frequent than poor care.

5. One of the findings from introducing the methods into mental health care is that many of the reviewers naturally have a focus on the mental health care component of the services. But review teams have found that using this review method they also identify common long-term conditions such as diabetes and heart disease that do not appear to have been well managed. For example, in one hospital it became evident that many people had a number of co-existing comorbid/long term conditions, yet it was unclear from the records whether or not the person was receiving support and or review from primary care and or secondary care services for their physical health. There is value, therefore, in also training up review staff who have an understanding of what good care looks like in long-term conditions within the context of mental health facilities.
6. Scoring of the phases of care is a new approach for many clinical staff in mental health care (just as has been the case in acute care) and scoring was initially felt to be very daunting by some reviewers. Nevertheless, as staff become more confident with its use, scoring can often be seen as a natural outcome of their judgements on the level of care provided. Some of the hospital teams have set up a mortality-reviewers support group to provide peer review and guidance. Feedback of the good care may be shared with both the individual staff and the wider teams - this is often well received. Of course, concerns also have to be discussed with services to identify areas for improvement.

### Where Next

7. The use of the structured judgement method often receives very positive feedback from staff trained in this methodology and so in one centre SJR is being rolled out for wider use to review the quality of care being received whilst people are currently receiving services. Looking forward, it has been recognised that whilst services can learn from each case, more can be learnt from the aggregation of cases, where patterns of poor care and good care emerge. In one case study that has sought for such patterns it is of note that where patterns exist of poorer care, these have been in the main linked to the management of physical ill health within mental health and learning disability services.
8. For further details please contact Allyson Kent [allyson.kent@nhs.net](mailto:allyson.kent@nhs.net) , or Professor Allen Hutchinson [allen.hutchinson@sheffield.ac.uk](mailto:allen.hutchinson@sheffield.ac.uk) Yorkshire and The Humber AHSN Improvement Academy.

# Annex K - National Leads

The list below provides the lead role with overall responsibility for the learning from deaths programme at relevant national organisations:

- NHS Improvement - Executive Medical Director
- Care Quality Commission - Chief Inspector of Hospitals
- Department of Health - Director of Acute Care and Workforce
- NHS England - National Medical Director

# Annex L - Background and Links

## Learning Disabilities Mortality Review (LeDeR) programme

Background is available at <http://www.bristol.ac.uk/sps/leder>

## Quality Accounts

Background is available at:

<http://www.nhs.uk/aboutNHSChoices/professionals/healthandcareprofessionals/quality-accounts/Pages/about-quality-accounts.aspx>

## Healthcare Safety Investigation Branch

The new Healthcare Investigation Branch (HSIB) will offer support and guidance to NHS organisations on investigations, and carry out certain investigations itself. It is envisaged that the HSIB will be established to:

- i. generate investigation findings and recommendations which drive action on the reduction or prevention of incident recurrence;
- ii. conduct investigations and produce reports that patients, families, carers and staff value, trust and respect; and,
- iii. champion good quality investigation across the NHS, and lead on approaches to enhance local capability in investigation.

The HSIB will be hosted by NHS Improvement and will undertake a small number of investigations annually. It will focus on incident types that signal systemic or apparently intractable risks in local healthcare systems. The HSIB and the role of Chief Investigator will play a crucial part in developing the culture of safety, learning and improvement in the NHS that will be one of the key elements of national policy and cross-system action in the years ahead.