![Care Quality Commission logo]

Learning, candour and accountability

A review of the way NHS trusts review and investigate the deaths of patients in England

DECEMBER 2016

Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England. We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation
Caring – treating everyone with dignity and respect
Integrity – doing the right thing
Teamwork – learning from each other to be the best we can

Contents

Foreword from CQC

The NHS is a universal healthcare system, caring for millions of people every year. As a result, it is not surprising that a large percentage of the nearly 500,000 people who die in England every year will have received care from an NHS trust in the days, weeks or months preceding their death.

Death is inevitable and a natural event for all of us, and not all deaths will represent a medical failing or problem in the way the person has been supported during their life. However, like any other human system, the NHS is fallible. It does not always respond when needed, its healthcare staff sometimes make mistakes and the component parts of the system do not always work together well.

This means that, when things go wrong, the cost can be a death that may have been prevented, and investigations need to be carried out to learn, explain to families and carers what went wrong or make sure accountability is clear when failure is found.

Two of the behaviours that underpin the vision and purpose of the NHS in England – openness and learning in order to improve – are never needed more than when a patient dies whose care may have been delivered differently and whose death might have been prevented.

All healthcare professionals have a duty, set out in their codes of conduct, to explain to those who are close to the patient what has happened and what will be done to reduce the likelihood of the same thing happening again, regardless of the emotions they may experience when someone dies. This includes being an active participant in any reviews that follow, whether they are leading the investigations or asked to provide information.

As well as being a professional duty, this is what families and carers expect and have a right to expect. The NHS 'system' must enable this transparency and learning.

This report describes what CQC found when it reviewed how NHS trusts identify, investigate and learn from the deaths of people under their care. It concludes that many carers and families do not experience the NHS as being open and transparent and that opportunities are missed to learn across the system from deaths that may have been prevented. Many of the NHS staff we heard from shared this view, together with a commitment for this to change.

We found that the level of acceptance and sense of inevitability when people with a learning disability or mental illness die early is too common. This may often be due to unidentified or unsupported health needs that, in many cases, will offer even greater opportunity for learning. There can be no tolerance of their deaths being treated with any less importance than other patients.

There is a real opportunity for the NHS to become world leaders in the way learning and investigations are completed and changes are made when a person dies.

The report makes recommendations for the improvements that need to be made if the NHS, as a leader for the wider social and healthcare system, is to be more open about these events, and improves how it learns and acts on them. The recommendations consider the contribution made by the whole of the system. They address the culture of the NHS, national policy and guidance, information flows, the capability and capacity of staff to review deaths and how quality assurance and regulation can promote good practice.

We call on everyone working in and with the NHS to play their part in making the changes needed, with a focus on pace, transparency and consistency being achieved in 2017.

Professor Sir Mike Richards
Chief Inspector of Hospitals

Dr Paul Lelliott
Deputy Chief Inspector of Hospitals
(Mental Health)

Professor Ted Baker
Deputy Chief Inspector of Hospitals
(Acute)

Foreword from CQC's Special Advisor on Family and Carer Experience

This review was carried out in response to the very low numbers of investigations or reviews of deaths at Southern Health NHS Foundation Trust. Over a four-year period, fewer than 1% of deaths in Southern Health's learning disability services and 0.3% of deaths in their mental health services for older people were investigated as a serious incident requiring investigation.

These figures and the lack of interest in patient safety and learning from deaths reflected the reality as described by families of patients at Southern Health. This review has set out to understand the picture across the rest of England, of how NHS trusts identify, investigate and learn from the deaths of people who are under their care.

We have known for decades that people with a learning disability and those with mental health problems are dying prematurely. Reports into failings at Ely Hospital, Mid Staffordshire, Morecambe Bay and Southern Health have all called for a change in culture, a focus on patient safety and the need to do better.

When a loved one dies in care, knowing how and why they died is the very least a family should be able to expect. Yet throughout this review process we have heard from families who had to go to great lengths themselves to get answers to these questions, who were subjected to poor treatment from across the healthcare system, and who had their experiences denied and their motives questioned.

Those working in health and social care have a moral responsibility, and a legal duty, to be open and honest with patients, and following their death, with their families and carers. Some families described incredibly kind and compassionate care by individual members of healthcare staff. Yet the same families also reported being ignored by others and feeling that their questions were left unanswered.

The work carried out by CQC, and this report, would not have been possible without the substantial contribution of bereaved families and relatives, who generously contributed their time and thoughts, in the hope that their experiences would be used to improve things for others.

We must learn from these families. Their trust, honesty and candour are an example to us all. We owe it to them, their loved ones, and to ourselves to stop talking about learning lessons, to move beyond writing action plans, and to actually make change happen.

Dr George Julian
Special Advisor on Family and Carer Experience

Summary

Last year 495,309 deaths were registered in England. Of these, 232,442 (47%) people died in hospital, with even more dying while receiving services provided by NHS trusts as an outpatient or from community services provided by the trust. In a small number of cases, NHS trusts will report these as needing a review of the care provided. Three key reasons why a trust may decide to investigate the care provided before a patient's death include:

- **Learning** to improve and change the way care is provided.
- **Candour** to support sharing information with others, including families.
- **Accountability** if failures are found.

However, in recent years it has become clear that there are problems with the way that trusts identify the need for investigation into the care provided and the way in which investigations are carried out. One of the most high profile examples of this is the death of 18-year-old Connor Sparrowhawk.

Connor, who had a learning disability and epilepsy, died in 2013 while receiving care at an assessment and treatment centre run by Southern Health NHS Trust. Initially the trust classified Connor's death as a result of natural causes, and his family had concerns about the way they planned to investigate Connor's death. Following campaigns by Connor's family, an independent investigation was commissioned by the trust that found his death was entirely preventable, and the coroner in 2015 concluded that there had been failures in his care and neglect had contributed to his death

In response to the concerns of Connor's family, NHS England commissioned a review of all mental health and learning disability deaths at Southern Health NHS Foundation Trust from April 2011 to March 2015. The report, published in December 2015, identified a number of failings in the way the trust recorded and investigated deaths and highlighted that certain groups of patients including people with a learning disability and older people receiving mental health care were far less likely to have their deaths investigated by the trust. This meant fewer than 1% of deaths reported in learning disability services and 0.3% of all deaths in mental health services for older people had been investigated.

Following its publication, the Secretary of State for Health asked CQC to look at how acute, community and mental health NHS trusts across the country investigate and learn from deaths to find out whether opportunities for prevention of death have been missed, and identify any improvements that are needed.

What we did

In order to understand what problems exist and what improvements are needed, we looked at the processes and systems NHS trusts (acute, mental health and community trusts) need to have in place to learn from problems in care before the death of a patient. As people with a mental health problem or learning disability are likely to experience a much earlier death than the general population, a key focus for the review was to look closely how trusts investigate the deaths of people in these population groups.

To gather the evidence for the review we:

- Carried out an information request with all NHS acute, community and mental health providers, and visited a sample of 12 acute, community health care and mental health NHS trusts.

- Involved more than 100 families through the public online questionnaire and social media, and held 1:1 interviews and listening events.

- Gathered evidence from charities, NHS professionals and other organisations.

What we found

Throughout our review, families and carers have told us that they often have a poor experience of investigations and are not always treated with kindness, respect and honesty. This was particularly the case for families and carers of people with a mental health problem or learning disability.

However, there is currently no single framework for NHS trusts that sets out what they need to do to maximise the learning from deaths that may be the result of problems in care. This means that there are a range of systems and processes in place, and that practice varies widely across providers. As a result, learning from deaths is not being given enough consideration in the NHS and opportunities to improve care for future patients are being missed.

Across our review, we were unable to identify any trust that could demonstrate good practice across all aspects of identifying, reviewing and investigating deaths and ensuring that learning is implemented. However, we have identified trusts that demonstrate elements of promising practice at individual steps in the investigation pathway. Specific findings from each of the key questions are outlined below.

1. Involvement of families and carers

- Families and carers told us they often have a poor experience of investigations and are not consistently treated with respect and sensitivity and honesty. This is despite many trusts stating that they value family

involvement and have policies and procedures in place to support it.

> "I was put in a room. I shall never forget what the nurse in the room told me. She said, 'You have got to accept that his time has come', bearing in mind my son was just 34 years old."
>
> **CQC family listening day, 2016**

- Families and carers are not routinely told what their rights are when a relative dies, what will happen or how they can access support or advocacy.

- The extent to which families and carers are involved in reviews and investigations of their relatives varies considerably. Families are not always informed or kept up to date about investigations – something that often caused further distress and undermined trust in investigations.

- Families and carers told us they are frequently not listened to. In some cases, family and carer involvement is tokenistic and the views of families and carers are not given the same weight as that of clinical staff.

- The NHS underestimates the role that families and carers can play in helping to fully understand what happened to a patient. They offer a vital perspective because they see the whole pathway of care that their relative experienced.

2. Identification and reporting

- There is variation and inconsistency in the way organisations become aware of the deaths of people in their care across the NHS. This was found to be an issue for acute, community and mental health trusts equally with organisations relying on information being shared by others to identify when a death occurs outside their inpatient services.

- Many patients who die have received care from multiple providers in the months before death, including GPs, acute hospitals, community health services, and mental health services. At present, there are no clear lines of responsibility or systems for the provider who

identifies a death to inform other providers or commissioners.

- There is no consistent process or method for NHS trusts to record when recent patients die after they have been discharged from the care of the service, either from an inpatient service or from receiving services in the community. This includes the way trusts are able to record when people with mental health conditions or a learning disability die in NHS hospitals or while receiving care from the community services of NHS trusts.

> "As soon as we started asking questions it was like we were interfering and that they were the professionals, not us. They became antagonistic."
>
> **CQC family listening day**

- Electronic systems do not support the sharing of information between NHS trusts or with others who have been involved in a patient's care before their death, for example primary care services or services run by independent health providers or adult social care.

3. Decision to review or investigate

- Healthcare staff understand the expectation to report patient safety incidents and are using the Serious Incident Framework as the process to support decisions to review and/or investigate when deaths occur. However, this means that investigations will only happen if the care provided to the patient has led to a serious incident being reported.

- Criteria for deciding to report as an incident and application of the framework varied across trusts, particularly the range of information that needs to be considered by individual clinicians and staff to identify any problems in care and escalate for further review or investigation. Decision making is inconsistently applied and recorded across the NHS trusts we visited.

- In the absence of a single national framework that specifically supports the review and decisions needed for deaths, recognising them as a significant event that may need a different response to patient safety

incidents, clinicians and staff are using different methods to record their decisions. This is leading to variation across NHS trusts, including within the same sectors, limiting the ability to monitor, audit or regulate decision making process in relation to reviewing deaths across the NHS.

- There is confusion and inconsistency in the methods and definitions used across the NHS to identify and report deaths leading to decisions being taken differently across NHS trusts.

- Decision making must be informed by timely access to information by clinicians and staff, but providers reported difficulties in getting clinical information about the patient from others involved in delivering care including from primary care services.

4. Reviews and investigations

- Most NHS trusts report that they follow the Serious Incident Framework when carrying out investigations. Despite this, the quality of investigations is variable and staff are applying the methods identified in the framework inconsistently. This acts as a barrier to identifying the opportunities for learning, with the focus being too closely on individual errors rather than system analysis.

- Specialised training and support is not universally provided to staff completing investigations. Many staff completing reviews and investigations do not have protected time in which to carry out investigations. This reduces consistency in approach, even within the same services.

- There are significant issues with the timeliness of investigations and confusion about the standards and timelines stated in guidance – this affects the robustness of investigations, including the ability to meaningfully involve families.

- A multi-agency approach to investigating is restricted by a lack of clarity on identifying the responsible agency for leading investigations or expectations to look across pathways of care. Organisations work in isolation, only reviewing the care individual

trusts have provided prior to death. This is a missed opportunity for identifying improvements in services and commissioning, particularly for patients with specific needs such as mental health or learning disability.

5. Governance and learning

- There are no consistent frameworks or guidance in place across the NHS that require boards to keep all deaths in care under review or effectively share learning with other organisations or individuals.

- Trust boards only receive limited information about the deaths of people using their services other than those that have been reported as serious incidents.

- When boards receive information about deaths, board members often do not interrogate or challenge the data effectively. Most board members have no specific training in this issue or time that is dedicated to focus on it.

- Where investigations have taken place, there are no consistent systems in place to make sure recommendations are acted on or learning is being shared with others who could support the improvements needed.

- Robust mechanisms to disseminate learning from investigations or benchmarking beyond a single trust do not exist. This means that mistakes may be repeated.

Recommendations

Learning from deaths needs to be a much greater priority for all working within health and social care. Without significant change at local and national levels, opportunities to improve care for future patients will continue to be missed. Below we outline a summary of our recommendations for change. Detailed recommendations with coordinating organisations are on page 59.

- **Recommendation 1:** We urge the Secretary of State for Health, and all within the health and social care system, to make this a national priority. We suggest that the Department of Health, supported by the National Quality Board – in partnership with families and carers, professional bodies, Royal Colleges and the third-sector – work together to review the findings and recommendations from our report and publish a full response. Action should then be taken to begin coordinating improvement work across multiple organisations.

- **Recommendation 2:** The Department of Health and the National Quality Board working with Royal Colleges and families should develop a new single framework on learning from death. This should define good practice in relation to identifying, reporting, investigating and learning from deaths in care and provide guidance for when an independent investigation may be appropriate. This should complement the Serious Incident Framework and clearly define roles and responsibilities.

Specifically the framework should:

- **Recommendation 3:** Define what families and carers can expect from healthcare providers when they are involved in the investigation process following a death of a family member or somebody they care for. This should be developed in partnership with families and carers.

- **Recommendation 4:** Provide solutions to the range of issues we set out for people with mental health conditions or a learning disability across national bodies, including the Royal Colleges. This should aim to improve

consistency, definitions and practices that support the reduction of the increased risk of premature death.

- **Recommendation 5:** NHS Digital and NHS Improvement should assess how they can facilitate the development of reliable and timely systems, so that information about a death is available to all providers who have recently been involved in that patient's care. They should also provide guidance on a standard set of information to be collected by providers on all patients who have died.

- **Recommendation 6:** Health Education England should work with the Healthcare Safety Investigation Branch (HSIB) and providers to develop approaches to ensuring that staff have the capability and capacity to carry out good investigations of deaths and write good reports, with a focus on these leading to improvements in care.

- **Recommendation 7:** Provider organisations and commissioners must work together to review and improve their local approach following the death of people receiving care from their services. Provider boards should ensure that national guidance is implemented at a local level, so that deaths are identified, screened and investigated, when appropriate and that learning from deaths is shared and acted on. Emphasis must be given to engaging families and carers.

What CQC will do

CQC will continue to be actively involved in translating these recommendations into actions through our involvement in the National Quality Board, and through the recommendations noted above. Specifically, we plan to:

- Strengthen CQC's assessment of learning from deaths to cover the process by which providers identify patients who have died and decide which reviews or investigations are needed, with particular emphasis on:
  - patients with a learning disability or mental health problem
  - quality of investigations carried out by trusts
  - reports to trust boards on learning from death
  - action taken in response to learning from death
  - how trusts have involved families and carers in reviews and investigations.

CQC will also review how learning from death is documented in inspection reports.

Introduction

Last year 495,309 deaths were registered in England. [a,1] Of these, 232,442 (47%) people died in hospital with even more dying while receiving services provided by NHS trusts as an outpatient or from community services provided by the trust. [2]

When a person dies, there is an action and decision that is then taken by someone working in the NHS, whether a doctor, nurse or paramedic. Actions are often routine, for example a doctor confirming the death of a patient.

However, a much smaller number of cases are reported by NHS trusts as needing a review of the care provided. From the information we received from trusts, we were told that in 2015/16 around 5,500 investigations into the deaths of patients receiving care were completed, with the intention of supporting learning and improvements through changes being made to the services provided for future patients. [b]

There are three, sometimes conflicting, reasons for NHS trusts to investigate a patient's death – identifying what care had been provided to offer **learning** to improve and change the way care is provided to others in future, supporting **candour** to share information with others including families, and making sure **accountability** is identified if failures are found.

The purpose of an investigation is to understand the care that was provided to the patient before they died and highlight any potential problems. The trust will carry out this investigation to make sure that both it and the patient's family understand what happened, and that staff can learn and changes can be made.

In a smaller number of cases, where there have been failings that could have been avoided, investigations can, if done well, help to identify issues that require holding organisations or individuals to account, through other systems such as disciplinary action, or regulatory action by CQC.

In recent years, it has become clear that there are problems with the way that deaths are identified as needing investigation and with the way in which they are investigated. One of the most high profile examples of this is the death of 18-year-old Connor Sparrowhawk. Connor, who had a learning disability and epilepsy, died in 2013 while receiving care at an assessment and treatment centre run by Southern Health NHS Foundation Trust.

Initially the trust classified Connor's death as a result of natural causes, and his family had concerns about the way they planned to investigate Connor's death. Following campaigns by Connor's family, an independent investigation was commissioned by the trust that found his

---

a   495,309 is the total number of deaths registered in England in 2015. The 232,442 deaths in hospital is also for 2015 and based on the date the death was registered.

b   Response rate of approximately eight in 10 trusts across acute, community and mental health sectors and investigation types.

death was entirely preventable, and the coroner in 2015 concluded that there had been failures in his care and neglect had contributed to his death.

In response to the concerns of Connor's family, NHS England commissioned a review of all mental health and learning disability deaths at Southern Health NHS Foundation Trust from April 2011 to March 2015. The report, published in December 2015, identified a number of failings in the way the trust recorded and investigated deaths including a lack of leadership, poor quality investigations, a lack of family involvement in investigations, and opportunities for learning being missed.

The report also highlighted that certain groups of patients including people with a learning disability and older people receiving mental health care were far less likely to have their deaths investigated by the trust. This meant fewer than 1% of deaths reported in learning disability services and 0.3% of all deaths in mental health services for older people had been investigated.

Following its publication, the government asked CQC to look at how acute, community and mental health NHS trusts across the country investigate and learn from deaths to find out whether similar problems exist elsewhere.

The focus for our review

In order to understand what problems exist and what improvements are needed, we looked at five different aspects of the processes and systems that NHS trusts need to have in place in order to learn from the death of a patient.

- **Involvement of families and carers:** How are families and carers treated? Are they meaningfully involved and how do organisations learn from their experiences?
- **Identification and reporting:** How are the deaths of people who use services identified and reported, including to other organisations involved in a patient's care, by NHS clinicians and staff, particularly when people die but are not an inpatient at the time of death?
- **Decision to review or investigate:** Are there clear responsibilities and expectations to support the decision to review or investigate?
- **Reviews and investigations:** Is there evidence that investigations are carried out properly and in a way that is likely to identify missed opportunities for preventing death and improving services?
- **Governance and learning:** Do NHS trust boards have effective governance arrangements to drive quality and learning from the deaths of patients?

As part of our review, we placed a spotlight on the particular issues for people with mental health conditions or a learning disability, in order to consider the learning from the report on Southern Health for these patient groups and identify any additional challenges and barriers that exist elsewhere in NHS trusts.

SCOPE OF REVIEW

The Secretary of State asked CQC to look only at **NHS trusts providing acute, community or mental health services**. This means that this review identified the way these providers investigate and learn from deaths. Other organisations, including ambulance trusts, GP practices, independent healthcare providers and adult social care services, will also carry out their own reviews when someone in their care dies.

Our review has identified the importance of reviews and investigations in providing both health and social care providers with an understanding of circumstances leading to deaths from a variety of perspectives. We expect commissioners of all NHS-funded care, and other services and organisations, to use this report to review their own practices and individual professional responsibilities, and identify the improvements needed against our findings.

WHAT DO WE MEAN BY A DEATH IN CARE?

We use this term throughout the report to refer to any person who is currently receiving, or has recently received, care from an acute, mental health or community NHS trust.

Where the person is an inpatient at the time of death they are clearly 'receiving treatment'. However, when someone dies outside hospital there are no national guidelines that define how long ago someone was 'recently in receipt of services'.

We wanted to understand the system for all deaths – inpatients, people receiving community services, and outpatients – so we looked at any deaths that occurred within six months of the person's last contact with any service at the trust or their last date of discharge from an inpatient setting.

WHAT DO WE MEAN BY TRUSTS?

Throughout this report we refer to NHS trusts. By this, we mean all NHS acute, mental health and community trusts, including both inpatient services in hospitals and community services. We did not review ambulance trusts or other NHS-funded care settings such as independent healthcare providers, primary care services or nursing homes.

The terms used by the NHS and in this report can be found at: **www.nhs.uk/NHSEngland/ thenhs/about/Pages/authoritiesandtrusts. aspx**

WHAT DO WE MEAN BY SYSTEM?

We use the term system throughout the report, but this has two different applications:

- The healthcare processes and systems that exist within NHS trusts, for example policies, procedures and electronic systems.
- The wider health and social care landscape, including national agencies responsible for regulation, guidance or oversight, local health and social care providers or commissioners, and other agencies and organisations that work to support or advise patients, carers and professionals.

WHAT DO WE MEAN BY FAMILIES AND CARERS?

We use this term in the report to refer to a relative or carer (paid and unpaid) of a person who has died following the care from an acute, mental health or community NHS trust. While, in most cases, family members will have the greatest knowledge of the person who has died, we recognise that where there is no family present, friends or advocates may know the person best and should therefore be considered in the review and/or investigation process.

Methodology

Our approach

Throughout the review, we sought the help and advice of experts, individuals and organisations to make sure we heard from everyone affected by the current approach following a death in care. This includes families with experience of reviews and investigations by the NHS, people working in the NHS, and national stakeholders from all sectors.

In particular, we have worked closely with our expert advisory group (EAG) to understand what evidence would be the most useful to inform a review in this area. Members of the EAG included representatives from family and patient groups, national organisations, NHS trusts and voluntary sector organisations. Appendix C shows a full list of member organisations.

Families and carers

Listening to the experiences, concerns and ideas for change has been a core focus of our review. Over the course of the review, we heard from more than 100 families with direct experience of an NHS review or investigation. Engagement activity included:

- **Online questionnaire** – in July 2016, we asked families and carers to tell us, through an online form, about their experiences of NHS investigations following the death of a relative. The questionnaire was hosted on our website and was promoted via different social media channels. This was delivered as an open consultation and respondents were self-selecting volunteers. Given the challenges of identifying a robust sample of individuals who have experienced NHS death investigations, this method was more appropriate than

using surveying or sampling tools within the available timeframe. In total, we had 66 responses to the questionnaire.

- **1:1 conversations with families** – we followed up the online questionnaire by inviting eight families to attend a family listening day (below) and contacted an additional four people, who could not attend the event, to ask them directly about the information they had provided about their experience.

- **Family listening day** – we commissioned the voluntary organisation INQUEST, working with our Special Advisor on Family and Carer Experience, to host an event to listen to the experiences of families and ask for their views on what needs to change. The event was attended by 30 family members, and a full report from the day will be available on the INQUEST website.

- **Making Families Count** – we held a separate engagement event with Making Families Count, a group of experts by experience who work with NHS trusts to promote the status of families during investigations.

People working in the NHS and system reviews

To understand the current system and processes in place, we carried out a number of activities with NHS providers and staff:

- **Provider information request** – in June 2016, we sent all 228 NHS acute, community and mental health trusts an information request. This asked trusts about the systems and processes for recording, reporting and investigating deaths (see annexes 3 to 9). We received responses from 212 trusts (93%).

This consisted of 143 (93%) acute trusts, 53 (96%) mental health trusts and 16 (84%) community trusts.

- **Site visits** – in July and August 2016, we visited a sample of 12 NHS trusts, comprising four acute, four mental health and four community trusts. We interviewed staff at different levels, including members of the board, operational leads and governance leads. Overall, we spoke with 137 different staff members: 44 in acute, 47 in community and 46 in mental health trusts. Appendix B shows a list of the trusts we visited.

- **Records review** – on the site visits, we reviewed 146 records of investigations, mortality reviews and notifications of death, and various supporting policy or procedural documents. This included reports on serious incidents , statutory notifications to CQC about patients detained under the Mental Health Act 1983, and complaints relating to the death of a person in their care. In addition to the serious incidents we reviewed on site, we conducted an in-depth review of 27 investigation reports from 10 of the trusts.

- **Review of board papers** – we analysed trust board papers and minutes from a sample of 48 NHS acute and community trusts covering the period December 2015 to March 2016.

We also reviewed findings of a separate analysis of 56 mental health trust board papers, carried out by our Special Advisor on Family and Carer Experience, Dr George Julian, covering the period December 2015 to February 2016. We carried out this activity to understand what information was provided to, and discussed by, boards in relation to deaths.

- **Analysis of national data** – we analysed national datasets, including Office for National Statistics (ONS), NHS Digital's Hospital Episode Statistics (HES), Strategic Executive Information System (STEIS), National Reporting and Learning System (NRLS), NHS staff surveys and Dr Fosters Intelligence.

- **Live Twitter chat** – as part of our spotlight on mental health and learning disability, we held a live Twitter chat with mental health and learning disability nurses on the #WeCommunity platform. In total, 170 people took part in the conversation.

We are grateful to everyone who has supported us in undertaking this review. We are especially grateful to those individuals who told us what it is like to lose a relative when the NHS was involved in their care and their experiences of the responses and processes that followed.

1. How are families and carers involved and treated?

KEY FINDINGS

- Families and carers told us that they have a poor experience of investigations and are not consistently treated with respect, sensitivity and honesty. This is despite many trusts stating that they value family involvement and have policies and procedures in place to support it.

- Families are not routinely told what their rights are when a relative dies, what will happen or how they can access support or advocacy.

- The extent to which families and carers told us they are involved in reviews and investigations of their relative's death varies considerably. Families are not always informed or kept up to date about investigations – something that often causes further distress and undermines trust in investigations.

- Families and carers are often not listened to, their involvement is tokenistic and the views of families and carers are not given the same weight as that of clinical staff.

- The NHS underestimates the role that families and carers can play in helping to fully understand what happened to a patient. They offer a vital perspective because they see the whole pathway of care that their relative experienced.

This section of the report focuses on how NHS trusts involve families and carers. It looks at how families and carers are treated, whether they are meaningfully involved and how organisations learn from their experiences.

Listening to, and understanding, the experience of families and carers has been a crucial part of this review. We have reviewed the publicly available evidence from healthcare inquiries, including Mid-Staffordshire, Winterbourne View and Morecambe Bay. We have also analysed information from other reports, such as the Public Health Service Ombudsman report on their review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged; and heard directly from a range of bereaved relatives and carers to understand what is working well, and what needs to change.[3]

Families told us that what they want most from an investigation is to know what has happened, why their relative has died, and to help prevent this from happening to anyone else. One family member summed it up. "All I want is the truth – the worst has already happened."

Some trusts report struggling to balance completing investigations to the standards they should within required timetables and involving families. This is despite many saying that they valued family involvement in investigations and that they had policies and procedures to make this happen. Having a policy in place does not guarantee the effective involvement of families.

Finally, staff working in NHS trusts do not feel confident enough to effectively involve families in investigations, with too few having the skills, expertise and experience needed to do this well.

Initial contact and notification of death

The way in which families and carers are treated, including from the very beginning when they are told about the death of a relative and the initial discussions that take place, is extremely important. It will often set the tone for their experience of the investigation process.

> "The most toxic, damaging, compounding, devastating thing that happens is they drip feed you information, they give you a tiny closed off answer. Letters are sent Friday so they arrive Saturday morning, you've nowhere to go, nothing to do with it. Every single time a piece of information came through it raised another question, and another question, and another question."
>
> **CQC interview, 2016**

NHS clinicians and staff should treat all bereaved relatives and carers with great sensitivity and compassion. Feedback from our share your experience questionnaire showed that when this is done well, NHS staff are helping individuals to understand what has happened, and to grieve.

> "They invited us (my sister and I) to meet with them, including the surgeon who operated on mum. The face-to-face meeting was extremely difficult but very valuable to us in understanding what happened and hearing things direct from a human being."
>
> **Family experience, online questionnaire**

However, families and carers told us that this opportunity is often missed and, in the case of people with a mental health problem or learning disability, that trusts seem ambivalent to the death of their relative.

> "I was put in a room. I shall never forget what the nurse in the room told me. She said, 'You have got to accept that his time has come.' Bearing in mind my son was just 34 years old."
>
> **CQC interview, 2016**

Families also described how trusts did not provide basic information around the death of their relatives, and how they were not routinely asked whether they had any questions or concerns. Families also reported that they had to apply to access information and care records. This can lead to mistrust and the feeling that trusts are hiding behind patient confidentiality to prevent information being disclosed.

> "The trust wouldn't release records without going through the access to information process; my daughter didn't make a will so I had to get letters of administration, that felt unnecessary... Once I got it, I felt hopeful that 40 days on I should get all of the records but how naïve can you be. We waited 40 days and nothing arrived, I pursued it and was told it was a longer job than they thought."
>
> **CQC interview, 2016**

In addition, we heard a number of accounts of NHS lawyers being present, even in the first meeting that relatives had with trusts after their relative died. Relatives described this as being intimidating and at odds with wanting to create a sense of openness and trust, which they themselves tried to protect.

> "All the way through people said that we should get solicitors, I thought if we got a solicitor involved the hospital would stop talking to us, I didn't want a solicitor."
>
> **CQC interview, 2016**

Lack of information about the forthcoming investigation process was also a concern, with only eight out of 42 respondents (19%) to our questionnaire saying they were clear about what would happen. Families also described feeling left out of decisions, including the initial decision about whether or not to investigate a death.

> "There is no formal process. No one comes to you and says, 'This is what is going to happen'."
>
> **Making Families Count meeting, 2016**

Involvement in the investigation process

Relatives and carers offer a vital perspective in helping to fully understand what happened to a patient as, unlike most clinicians and staff, they see the whole pathway of care that their relative experienced. Family involvement is particularly important when investigating the death of a person with complex needs, including people with a mental health problem or a learning disability. Without the meaningful involvement of families, it is likely that investigations will not identify what happened, the learning needed or the changes that need to be put into place.

> "When the investigation happened, we were invited up to the hospital, it was one of the most uncomfortable experiences we've ever had as a family.

> They said he wasn't given pain relief, I know he was, but they never recorded it. As a family it was awful, we didn't feel anybody took us seriously."
>
> **CQC interview, 2016**

Just four out of 42 respondents to our questionnaire (10%) said they were treated with as much care and respect as they would have liked during investigations. Others commonly described insensitive actions by staff, which added to their distress. Families also described being poorly informed about what is going on.

> "[We] were only told an investigation was happening when they responded to our complaint. However, it seems that an investigation was started, or considered at least, pretty much as soon as the consultant heard about mum's death. We think we should have been contacted sooner, although they did say they waited so that they had something meaningful to say to us rather than 'holding' responses."
>
> **Family experience, online questionnaire**

Some trusts reported feeling nervous about involving families, in some cases deciding not to involve families in an attempt to avoid adding to their distress. This is at odds with the duty of candour that legally requires health and care providers to be open and transparent with family and carers in these situations.[c] Other trusts referred to the difficulty of balancing starting the investigation quickly while following best practice around involving families.

A number of trusts said that they felt uncomfortable contacting families at the point of an investigation starting, which could be before or very soon after their relative's funeral. Yet only

---

c   The Duty of Candour is a legal duty on hospital, community and mental health trusts to inform and apologise to patients if there have been mistakes in their care that have led to significant harm. It aims to help patients receive accurate, truthful information from health providers.

one mental health trust said they had received feedback from relatives to say they had been contacted too soon in terms of informing them of an investigation.

DUTY OF CANDOUR

The duty of candour requires all health and social care providers, including NHS trusts, to be open and transparent with the people who use their services when there are notifiable safety incidents. This means incidents that are categorised as death, moderate harm, severe harm or prolonged psychological harm. This is a statutory requirement under regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

In order to meet the duty of candour, the person representing the provider is required to tell the relevant person face-to-face as soon as possible, give an account of the known facts and offer appropriate support to them. They must also notify the Care Quality Commission.

Where the incident has led to the death of a patient, the duty of candour applies to the patient's family member(s) or carer(s).

The person representing the provider must advise family members or carers about any more enquiries that are planned and must apologise on behalf of the provider. This means that the provider is admitting fault and expressing regret for harm caused is not the same as admitting liability. This means the risk of legal action should never prevent an apology.

If the provider is not sure if a notifiable safety incident has occurred, CQC urges providers to err on the side of caution and exercise the duty of candour.

Failure to comply with regulation 20 can lead to CQC issuing requirement notices or taking enforcement action.

Families told us that the decision about whether to be involved, and to what extent, should lie with them. People will be ready to get involved at entirely different stages, so trusts need to take a person-centred approach to engagement.

> "You should be able to have the level of involvement you want…families don't always know at the beginning how much they want…you need time to breathe."
>
> **CQC family listening day**

When families were involved, they told us that they were not happy with the level of involvement. Only three out of 42 (7%) respondents to our questionnaire said that they had had the right level of involvement. In these cases, positive examples included families being offered a family liaison officer or a named point of contact, and being invited to comment on or check the factual accuracy of the report.

Others, however, told us that their involvement felt tokenistic, that trusts seemed unwilling or reluctant to listen to them, and that their views were not given the same weight as that of clinical staff.

> "As soon as we started asking questions it was like we were interfering and that they were the professionals, not us. They became antagonistic."
>
> **CQC family listening day**

There was a sense that trusts were immediately on the defensive, with families describing an attitude of 'trust before patient', and seeing trusts as more interested in self-preservation.

> "You are viewed, I have a feeling that you're viewed as a pain in the neck really, it's a bit like if you keep complaining about the washing machine but the machine is out of warranty. I've had more courtesy at the supermarket checkout than I've had at the trust."
>
> **CQC interview, 2016**

This is another example of the tensions that exist and the lack of confidence in using the investigation process to support learning and candour, rather than an exercise in accountability from the outset. The tensions will be heightened when NHS trusts involve lawyers, which families found to be intimidating and counter-productive.

Both families and trusts described concerns around the skills and suitability of those conducting the investigation, including whether staff were experienced enough or too close to the incident.

> "The person who did the investigation did not have any experience or qualification. The main people who were in charge of my son's care were not interviewed, they sent us minutes with great chunks missing or selectively minuted what we said to improve their side of the discussion. They promised to update us but never did."
>
> **CQC interview, 2016**

Some families had dealt with individual investigators who were unable or unwilling to involve families, leading them to believe that trusts do not want to learn lessons. This reflected trusts' concerns that some staff lack the skills to involve families effectively in investigations and need specific training around this.

> "In a recent investigation, listening to the family gave the investigators vital clues about what had gone wrong and these included actions of other providers. We may not have picked up on some of the additional problems without speaking to the family, which has helped us provide a more joined-up level of care across the health economy."
>
> **Provider information request – mental health trust**

CASE STUDY: FAMILY INVOLVEMENT IN TRAINING VIDEOS

During our visits, we viewed a video made for a trust that featured the husband of a patient who had died while in the trust's care. The video was one of several featuring families of people who use services who had died and was being used for training purposes. The trust felt that there was great value for their staff in watching these videos, and that for people involved in making the experience could be cathartic.

Trusts told us that they value family involvement in investigations and have policies and procedures in place to support it. Examples included inviting family members to help draw up the terms of reference, asking them to sit on investigation panels, and offering them the opportunity to make a video sharing their experiences to be used in staff training. They also described ensuring that family members had the opportunity to comment on draft investigation reports, and sharing the final versions with them.

However, these practices were inconsistent across the NHS and the extent to which families were involved varied between trusts. In addition, despite the existence of such policies, families were not consistently treated with respect, sensitivity and honesty.

> "The report reads as though it's an investigation into us as parents, rather than an investigation into his care."
>
> **CQC interview, 2016**

There are trusts who are trying to address the poor involvement of families in investigations, but national support, for example an accredited training programme for investigators, would help reduce the problems we found.

Reporting and learning

Families expressed concern that their experiences of the investigation process, and the quality of reporting, gave them no confidence that lessons are being learned from investigations. In our online questionnaire, 73% of respondents said it was not clear what had been learned from the investigation and 83% felt that the investigation had not made a positive difference.

Families who completed our online questionnaire reported long delays to investigations being concluded, or delays to them being informed of the findings, sometimes with no explanation of why the delay had occurred:

> "The trust said it would be completed before Christmas, but it wasn't finished until the end of January. We were not shown the report until NHS England released it in May 2015. The trust said the reason for delay was that NHS England had it – no further explanation. NHS did not communicate with us at all regarding the report".
>
> **CQC family listening day**

While some trusts said they believed they were responsive to families' needs and preferences, they felt that this sometimes created a tension in terms of them meeting their reporting deadlines.

> "It is important that we are able to 'leave the door open' for families to contact us when they feel able to; however this does not sit easily with the timeframes for concluding serious incidents."
>
> **Provider information request – mental health trust**

As with the investigation itself, most families felt that either they were not involved or consulted on the writing of the report, or they were partially consulted and then ignored.

> "We were promised involvement and were invited to a meeting. We were very knowledgeable and were asking very pertinent questions, asking for copies of minutes, etc. We wrote a narrative version of what happened, which was a very long document. The author of the report did not read it, they totally ignored all the points we had raised. They ignored us, lied to us and refused to send us minutes. During that stage independent advocates or an organisation like INQUEST would have been very beneficial."
>
> **CQC family listening day**

There was a frustration that their comments were not included in the findings, and some families questioned how the reports can contribute to learning when vital information is missing or ignored.

> "Reading the report, they do accept these things happened, presumably from doctor's notes not what we said. Everything we told them was completely ignored or completely glossed over with statements like 'yes suboptimal care, but also good care'. Anything the hospital said they accepted as true, without any challenge."
>
> **CQC interview, 2016**

Some trusts told us that they offered families the opportunity to read and comment on the final report, but our review of the quality of investigations showed that there was a lack of clarity or recording of whether this had been done in several of the final reports reviewed.

"We trusted her, she said she'd make our changes to the report in May. In October we finally got our redacted copy and our changes hadn't been made."

CQC family listening day

When reports were published, families and carers told us that they contained factual inaccuracies, missing information, spelling and grammatical mistakes.

There was also feedback that the reports were full of jargon. This was supported by findings from our site visits, where inspectors felt that reports were not always written clearly enough, with some containing medical terminology that families might not understand. Following analysis of 27 investigation reports, we found that only two (7%) of the reports contained responses that we felt provided a satisfactory response to the family or carers of the person who died. Furthermore, 16 (59%) of reports clearly left important questions that had not been identified and/or explored.

On our site visits, we did find some examples of how, with the active involvement of families, trusts were learning from investigations and putting recommendations into place, but this is an area that needs significant improvement.

2. How are the deaths of people receiving care identified and reported?

KEY FINDINGS

- There is variation and inconsistency in the way organisations become aware of the deaths of people in their care across the NHS. This was found to be an issue for acute, community and mental health trusts equally with organisations relying on information being shared by others to identify when a death occurs outside their inpatient services.

- Many patients who die have received care from multiple providers in the months before death. These include GPs, acute hospitals, community health services, mental health services, ambulance services, NHS 111 services, out-of-hours doctors services, and urgent care centres. At present there are no clear lines of responsibility or systems for the provider who identifies a death to inform other providers or commissioners.

- There is no consistent process or method for NHS trusts to record when recent patients die after they have been discharged from the care of the service, either from an inpatient service or from receiving services in the community. This includes the way trusts are able to record when people with mental health conditions or a learning disability die in NHS hospitals or while receiving care from the community services of NHS trusts.

- Electronic systems do not support the sharing of information between NHS trusts or with others outside the service who have been involved in a patient's care before their death, for example primary care services or services run by independent health providers or adult social care.

This section of the report looks at how the deaths of people who use services are identified and reported by NHS trusts – in other words, how the death becomes 'known' or identified by clinicians and staff working in services, and how this may be captured or reported to others, or reported on electronic systems.

This is a key aspect of the process: any errors or omissions will have a critical and detrimental effect on the decisions, reviews and learning that may follow. Without being able to clearly identify deaths in care or after care has been provided, it will be impossible for NHS trusts to make decisions about whether or not the care they provided needs to be reviewed or investigated to support learning and make sure action takes place.

Overall, we found that there is not a clear or consistent picture of what good looks like for

identifying and reporting deaths, unless the person dies while receiving care on a hospital ward. This was particularly the case for people who use mental health services and those with a learning disability.

It is well known that people with a learning disability or mental health condition will, on average, experience much earlier death than the general population[d]. Capturing information about the deaths of these patients is critical to informing improvements and reducing the health inequalities, routine discrimination and

d   For example: Confidential Inquiry into premature deaths of people with learning disabilities (2012), Death by Indifference. Mencap (2007). Rethink Mental Illness (2013) Lethal discrimination. Why people with mental illness are dying needlessly and what needs to change. London: Rethink Mental Illness. Thornicroft G (2011) Physical health disparities and mental illness: the scandal of premature mortality. The British Journal of Psychiatry 199: 441-2.

premature mortality of this group of people. However, we found particular issues in the way NHS trusts identify and recognise when people with learning disabilities and people with mental health conditions have died in both community and hospital settings. This is not being captured in local reporting systems in a systematic way.

There are programmes in place to try and address this. For example, the NHS England learning disability mortality review and National Confidential Inquiry into Suicide and Homicide are learning programmes that review and analyse deaths at a national level to improve overall learning and improvements. However, they rely on services reporting accurate and timely information to support the use of the national databases to identify relevant deaths.

Many people who die will have received care from several different providers of NHS-funded care and social care. These may include primary care services, an acute general hospital, a mental health trust, a community health trust or a tertiary centre providing complex surgery or other treatments, for example for cancer or heart disease. Through our provider information request and on our site visits, we found that information about a person's death is not being passed between providers consistently and that this leads to problems in the way services identify a death has occurred.

We were told there are a number of reasons for this, including no national standard guidance available that would require people to share information, electronic systems not automatically sharing information between providers, difficulties over information governance (knowing what can be shared and how), and a lack of clarity about responsibilities for making sure that information is shared. This means that there is either a delay in finding out a patient has died or no knowledge of their death. As a result, there may be no review of care, no liaison or late liaison with families, and a limited understanding of the number and rate of post-care deaths.

Another barrier to identifying and sharing information highlighted during our review is the definitions that are used to capture if the death is 'unexpected', 'avoidable' or 'preventable'.

We explore this in more detail in chapter 3, but if a GP or NHS trust do not decide that there have been problems in the care received before death, by their service or other care providers, it is unlikely they will take additional steps to identify which other organisations need to be informed. This means that any review is limited to an individual provider's episode of care, and that there may not be a holistic review of the care by the NHS, which is what the patient and their family will have experienced.

Without a clear or consistent picture of 'what good looks like' for identifying and reporting deaths across organisations, it is not possible for there to be consistent practice across all parts of the NHS. There is a significant opportunity to improve how hospitals, and the wider system, share information about deaths.

Sharing information between organisations when a death occurs

Through our review we found that staff do not know what to do when a person dies while receiving care from more than one organisation. For example, if a person receiving care from a community mental health team dies on the ward of an acute hospital, how does the mental health trust come to hear of this death? If a person attending an outpatient clinic managed by an acute trust dies at home under the care of their GP, what role should staff in the acute trust play in any subsequent investigation?

Our site visits and provider information request highlighted that, unless a death is defined as a serious incident by a trust, there are no clear national guidelines on what to do when multiple organisations are involved.[e] This means, for example, that when a patient dies in the community and the death is identified by the GP, it is not clear whether they need to report or inform the other organisations providing additional care. There is also no single perspective on the length of time after a patient has been

---

e   If the death is defined as a serious incident, the Serious Incident Framework provides guidance on the processes and protocols to follow.

discharged from a service or services, that any providers should be informed of their death.

The 'need to know' will vary for different patients, services and causes of death. For example, it may be less relevant if a patient had been treated for a minor injury in an acute hospital but later dies from an unrelated cause in another hospital setting. However, it may be more relevant for a patient admitted to hospital and who dies from an undiagnosed illness related to their previous care.

There needs to be a standard expectation and guidance available so that hospitals and primary care services are clear on when to identify and share information about deaths that may need to be reviewed by other services. It should also be expected that information is routinely shared with families and carers.

Recording of deaths following discharge

As there is no standard or agreed length of time for what is meant by 'recently' discharged from a service, for the purpose of our review we agreed to look at all deaths occurring within six months of the patient's last contact with the provider[f]. Our provider information request and site visits showed that trusts' ability to identify when someone receiving care or treatment from one of their services, or who has recently (within the last six months) received care from their services, has died is variable.

While, on the whole, trusts were able to give us a number of deaths of people who they believed were receiving care from their service when they died, this was not consistent. Trusts, particularly

---

f   This is in line with the time period guidelines for homicide reviews, as stated in the NHS Serious Incident Framework. This included anyone who had had an inpatient spell (up to the date of discharge), attended outpatient appointment, A&E attendance, care given by the provider in a patient's own home, care home or any other location, any face-to-face contact between provider and patient, telephone appointment and contact with any of the providers of mental health support teams (including crisis support, substance misuse, mother and baby services, assertive outreach teams). This did not include telephone calls to discuss appointments only.

acute trusts, may know when people have died within 30 days of discharge from inpatient admissions, but a significant number of trusts told us they did not know how many patients died within six months of their last contact with them.

- All acute trusts who responded to our provider information request (143) could provide the number of people recorded in their systems who had died while an inpatient or an A&E patient in their trusts. However, 31% (45) told us they did not know how many of their patients had died within six months of their last point of contact with the service.

- All community trusts that responded (16) could report their total deaths of patients currently receiving care, but 25% (4) said they did not know the number of people who had died within six months of last receiving care from the trust.

- All but one mental health trust who responded (53) told us how many people in inpatient care had died. Twenty-one per cent (11) reported not knowing how many patients died post-discharge from both inpatient and community services.

- Across all the different types of trusts, a small proportion – 2% acute, 6% mental health and 19% community – reported that no deaths had occurred in the six months post-discharge.

Reporting on electronic systems

Effective reporting is important at a local level to support cross-organisational working, drive improvements in commissioning services based on learning from deaths, and improve the ability of providers to compare themselves against other, similar services. At a national level, it improves understanding about the number of deaths and informs policy changes.

Difficulties with reporting deaths, and which organisations should be involved, are made worse by the different electronic systems in use across the NHS. These all collect different pieces of data about a person and their care, and have different purposes for capturing information.

Many of the current electronic record systems do not readily support information sharing

between services within a trust, or with other organisations involved in the care provided to a person before their death. In the trusts we visited, there are a number of different systems in place including, for example, a patient record system for recording clinical information about patients, and a separate local risk management system used to record incidents in the service including those relating to individual patients. Risk management systems record patient safety data that should be used to inform service improvement or report incidents to the National Reporting and Learning System (NRLS).
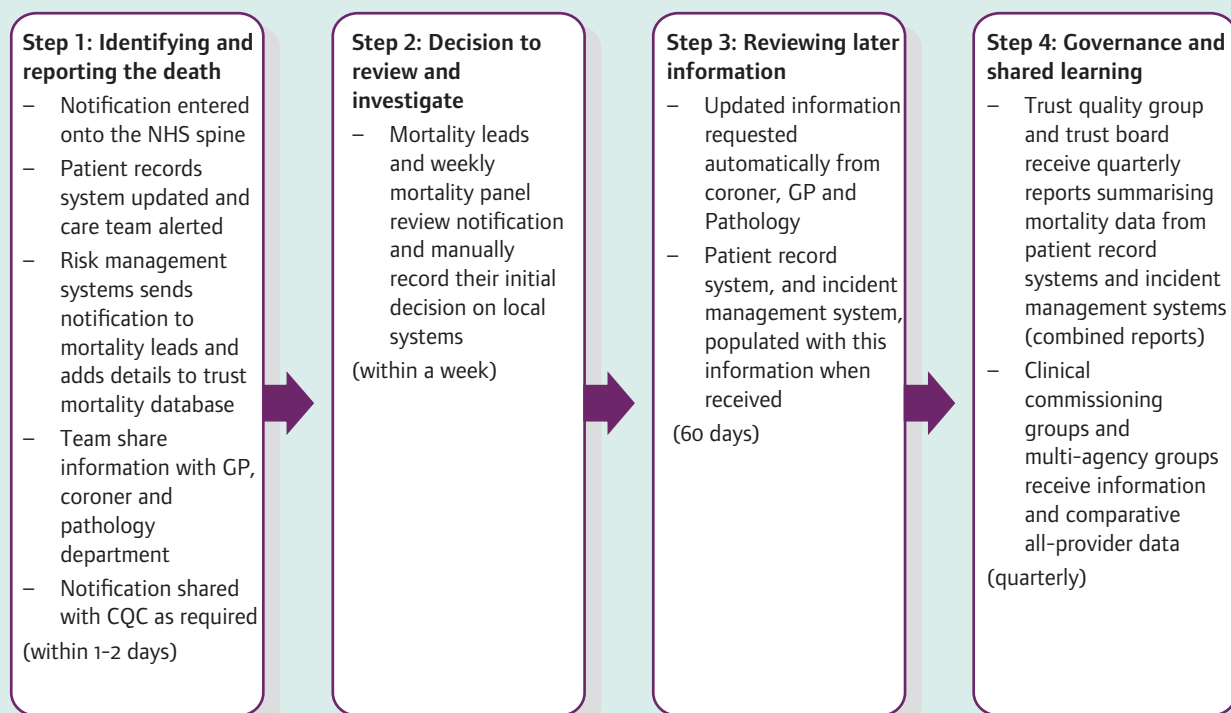
Across trusts, we found different systems in use. For example, on our site visits three out of four of the mental health trusts we visited used different patient record and incident management systems, which were local to the trust and not linked to

other organisations. There is no requirement for trust systems to be linked to national databases such as the 'NHS Spine', a collection of national databases that hold key information about patients' health and care. This includes a 'Personal Demographics Service', which records mortality information about the deaths of people who use services.[g] This will be updated by NHS trusts and GPs at the time of death and then by the registrar for deaths who will confirm the record. Any NHS organisation with access to the NHS Spine will have a way of updating their own records although we heard of examples where this was being done 'automatically' or manually by staff.

---

g   NHS Spine connects clinicians, patients and local service providers throughout England to a number of essential national services, including the Electronic Prescription Service, Summary Care Record, e-Referral Service and Demographics.

USING ELECTRONIC SYSTEMS TO IMPROVE OUR UNDERSTANDING OF PATIENT MORTALITY

Understanding the patterns of mortality within a trust can inform clinicians, patients and carers in ways that are helpful to improving care. Automatically updating electronic systems can make sure clinicians, staff and organisations have an accurate understanding of mortality rates in their patient populations and develop approaches to collecting data to identify themes and areas for potential improvement. The following example from the Royal College of Psychiatrists describes the way information could be collected, updated and shared within an organisation.

Step 1: Identifying and reporting the death
– Notification entered onto the NHS spine
– Patient records system updated and care team alerted
– Risk management systems sends notification to mortality leads and adds details to trust mortality database
– Team share information with GP, coroner and pathology department
– Notification shared with CQC as required

(within 1-2 days)

Step 2: Decision to review and investigate
– Mortality leads and weekly mortality panel review notification and manually record their initial decision on local systems

(within a week)

Step 3: Reviewing later information
– Updated information requested automatically from coroner, GP and Pathology
– Patient record system, and incident management system, populated with this information when received

(60 days)

Step 4: Governance and shared learning
– Trust quality group and trust board receive quarterly reports summarising mortality data from patient record systems and incident management systems (combined reports)
– Clinical commissioning groups and multi-agency groups receive information and comparative all-provider data

(quarterly)

Once known to clinicians and staff, many of the deaths in care will be recorded on the patient management system, so the services know the patient has died. However, unless there is a serious incident identified or problems with the care are flagged, these deaths will not be entered on to the incident management system. Some systems are linked across organisations, meaning that information can be shared, but our site visits and provider information request showed that systems are not consistently linked within a trust or between trusts.

In addition, staff reporting deaths did not always understand the coding system for reporting deaths. We were told this was because their managers had not given them clear guidance or training. As a result, there is inconsistency between trusts, and between staff within trusts.

As well as different local incident reporting systems, trusts have a number of different national databases that they are required to report to depending on the incident being reported. For example, all serious incidents must be recorded on the incident management system – STEIS (the STrategic Executive Information System) – as well as the National Reporting and Learning System (NRLS), a system used by the NHS to capture learning and information about patient safety incidents.

The NRLS is a voluntary system for all incidents except for serious incidents, including those that result in death and never events[h] that NHS providers are required to report via NRLS as part of their CQC registration. The criteria for what needs to be recorded on these systems is open to interpretation, and the guidance that does exist differs because they were set up with different purposes in mind. However, figures obtained for this review from March 2015 to April 2016 show that only 4,134 incidents resulting in death were reported to the NRLS, compared with 4,832 reported to STEIS during the same period.

The requirement to report deaths that are considered to be an incident on a number of different local and national systems makes it difficult for staff to know what to report and where. This results in them reporting some deaths multiple times and others not at all. Together with a lack of support and guidance for the staff making the decisions about whether they consider a death should be recorded as an incident, this shows the pitfalls of not sharing information and suggests that opportunities to learn from incidents are being missed.

This has been recognised and NHS Improvement had begun commissioning of a new Patient Safety Incident Management System in 2014.[4] The development of this system is urgently needed and our review findings, including the additional detail of the specific challenges for provider types and staff, should be used to inform the development and support the pace at which this work needs to progress.

Spotlight on mental health and learning disabilities

We found that staff in acute and community trusts often do not know or record whether people had a mental health problem or a learning disability. This meant that they could not report which of the people who died while under their care had a mental health problem or a learning disability.

These groups of patients will often be receiving care from multiple organisations, who would need to be aware of their death to be in a position to consider whether the care they had provided may need a review to identify problems. However, if services are not aware of the person's diagnosis then it is unlikely that information will be shared and the ability to identify problems in care that may have led to a premature death will be missed.

---

h   Never Events are serious incidents that are wholly preventable as guidance or safety recommendations that provide strong systemic protective barriers are available at a national level and should have been implemented by all healthcare providers

"We have no reliable way of identifying those with mental health team involvement at present, although this is to be added to our definition of 'vulnerable patient' shortly. In addition, the information we have regarding those with a learning disability substantially depends on the personal knowledge of our LD coordinator (Matron). The recognition of deaths in the NRLS upload depends on the coding within our local risk management system."

CQC provider information request – acute trust return

We asked all acute, mental health and community providers to tell us which of the patients who had died under their care had been in receipt of care from secondary mental health services or had a learning disability diagnosis. Acute trusts told us that they do not always record this information or know whether they are receiving care from other trusts. Similarly, the community trusts we visited did not always have a robust and reliable method to identify patients with mental health conditions or a learning disability. The incident recording systems we looked at on our site visits did not have a function that enabled trusts to flag patients with mental health problems or a learning disability.

Mental health trusts by their very nature record the mental health diagnosis of their patients, but struggled to identify deaths relating to people using their services who had a learning disability. In terms of specifically identifying whether a person had a learning disability, of the providers that responded to our provider information request:

- 25% (36) of acute trusts reported that they did not know how many of their inpatient/ A&E deaths related to patients with a learning disability. A further 13% (18) reported they did not have any deaths of patients with any learning disability recorded.
- 19% (3) of community trusts reported that they did not know how many of the deaths

of patients in their service had a learning disability. A further 50% (8) reported they did not have any deaths of patients with any learning disability recorded.

- 19% (10) of mental health trusts reported that they did not know how many of their inpatient deaths related to people with a learning disability diagnosis. Additionally 21% (11) reported that they did not know how many patients with a learning disability had died while receiving care in the community. A further 62% (33) and 8% (4) reported that they did not have any deaths of patients with any learning disability recorded for inpatient and community services respectively.
- The majority of acute trusts (69%) and a large proportion of community trusts (38%) reported that they did not know how many patients currently receiving care in their service were accessing secondary mental health services. A further 20% of acute trusts and 38% of community trusts reported that they did not have any deaths of people using secondary mental health services recorded.

In our provider information request, we asked NHS trusts to report on the data held in local systems only. It should be noted that the report on Southern Health described difficulties in identifying a clear picture of the total number of patients who had died while receiving services from the trust over the four-year period reviewed. The audit team looked at local databases and compared local system data to other local and national datasets, including the Office for National Statistics, coroner information, NRLS and information held by CQC relating to deaths.

3. Making the decision to review or investigate

KEY FINDINGS

- Healthcare staff understand the expectation to report patient safety incidents and are using the Serious Incident Framework as the process to support decisions to review and/or investigate when deaths occur. However, this means that investigations will only happen if the care provided to the patient has led to a serious incident being reported.

- Criteria for deciding to report as an incident and application of the framework varied across trusts, particularly the range of information that needs to be considered by individual staff to identify any problems in care and escalate for further review or investigation. Decision making is inconsistently applied and recorded across the NHS trusts we visited.

- In the absence of a single national framework that specifically supports the review and decisions needed for deaths, recognising them as a significant event that may need a different response to patient safety incidents, clinicians and staff are using different methods to record their decisions. This is leading to variation across NHS trusts, including within the same sectors, and limiting the ability to monitor, audit or regulate the decision-making process in relation to reviewing deaths across the NHS.

- There is confusion and inconsistency in the methods and definitions we use across the NHS to identify and report deaths leading to decisions being taken differently across NHS trusts.

- Decision making must be informed by timely access to information by clinicians and staff, but we found difficulties in getting clinical information about the patient from others involved in delivering care including from primary care services.

This section of the report focuses on the way that staff and trusts decide when the death of a patient may be due to problems in care and refer the death for investigation or action. Decisions at this stage will include the level of investigation needed, who is responsible for leading it, and whether there are clear responsibilities and expectations to support decision making.

Overall, we found that staff across the NHS understand that they are expected to report patient safety incidents, and we are seeing incident reporting increasing across the NHS. This includes the expectation for deciding if a serious incident may have occurred.

Serious incidents are defined in the Serious Incident Framework as "adverse events, where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is so great, that a heightened level of response is justified".[5]

However, the decision to review or investigate relies on clinicians and staff seeing potential problems in the care provided to the patient before their death as an opportunity for learning, and deciding that this needs to be reported as an incident, using the Serious Incident Framework.

The Serious Incident Framework provides guidance and standards for all providers of NHS-funded care (including NHS trusts, GPs and independent health care) on the process for reporting the death of a patient when it is clear that there has been a serious incident. The Serious Incident Framework also sets out a number of standards and expectations for clinical commissioning groups, who have an important role in the local management, oversight and assurance of learning when serious incidents are reported by providers. However, the framework is not designed to support decision making and the potential for wider learning when a death occurs. Many deaths will not be associated initially with problems in care; the care given in the days, weeks or months before the death may have been of a high standard. Where there are no immediately obvious or potential problems in care, and without an incident being recorded, there is no other clear and consistent process for screening, reviewing or investigating deaths.

Because there is no single national framework for reporting and reviewing deaths, staff take different approaches. This results in differences in practice between trusts and between clinicians and staff in the same trust. It makes it difficult for the NHS as a whole to monitor, audit or regulate how the decision-making process is completed.

For example, if the decision is not recorded and no action has been taken to refer the case for an investigation, then there is no way for regulators such as CQC to question who made the decision, what information was captured, or whether families were involved. It also limits the extent to which the NHS learns or identifies themes from the investigations of deaths.

Tools and methodology for making decisions to investigate

Healthcare staff providing care to the patient will often be responsible for the initial decision to report and escalate a death for further review. This means that the system relies on individual clinicians and staff feeling confident in highlighting potential failures to more senior

staff, and not fearing any possible retribution from doing this.

The Serious Incident Framework provides guidance and support for a just culture that helps clinicians and staff to report and learn from problems in care and, if failure is found, for this to be clearly identified and appropriate mechanisms used to take action. How effectively this works depends on how well leaders and managers support good local cultures of patient safety reporting, openness and learning.

The Department of Health's consultation on providing 'safe spaces' aims to reduce the likelihood of people fearing retribution or blame for speaking out when they are part of particular types of safety investigations, with the focus being on learning and not blaming individuals. This proposes introducing new legal protection so that any details shared by individuals will not be able to be disclosed without a court order or an overriding public interest.[6] This is intended to help create greater openness when mistakes occur, making sure families get the truth faster and clinicians are supported in speaking out. Although the final details of how this will work will not be known until the consultation response has been completed, protection for individuals will only exist where no malicious or criminal activity has occurred. Individual details shared with investigations will not be shared beyond the investigation team, although the findings, learning and actions for change as a result of the investigation would still be public.

Across trusts, there are considerable differences in how the decision is made as to whether or not to investigate a death, and who makes it. There will also be barriers and difficulties if the service caring for the person when they die needs to understand earlier contacts with other services, to identify whether there may have been problems in care. For example, a person with a learning disability may die of a heart attack while receiving care in an acute hospital. This may not require investigation of the acute care provided, but a review of the whole care pathway may identify issues and highlight problems at an earlier point in the patient's care from other

services, including opportunities to reduce the risk of heart attack.

In addition, information sharing about the deaths of people receiving services outside of hospitals is often lacking. The processes for investigating these deaths are far less clearly defined than those in inpatient settings. There is inconsistency in the definitions used across the NHS to identify and report deaths, with no nationally agreed terminology. We found that there were multiple definitions in use for deciding whether a death needed to be reported, including 'preventable', 'avoidable', 'expected', 'unexpected', 'natural' and 'unnatural'.

National bodies, such as CQC, use the terms 'unexpected' and 'avoidable' for reporting purposes, but we found that staff understanding of these terms varied both within and between trusts.

The lack of clarity around terminology makes it very difficult for providers, families and regulators to be clear on what should happen in the period after the person dies. Usually, the decision to review or investigate relies on the early assessment by members of staff as to whether the death may be 'unexpected' or 'avoidable', based on their knowledge of the patient's illness and care, and whether there needs to be further investigation to establish this.

Many people we spoke to during the review felt that the terms 'unexpected' and 'avoidable', which are used throughout national guidance, regulation and data collection, can be misleading and unscientific. It was suggested that improving the standard definitions should be a key part of the work programmes that follow this review. Families and carers should be involved in these discussions, to ensure that there is a holistic view of the person's care. This is even more important for people with a learning disability whose death, because of personal or collective prejudices or discrimination, may be considered 'expected' or inevitable, even if it would be a cause for concern in other patients.

In many cases, the decision about whether a death was 'unexpected' or 'avoidable' can only

be made after a review or investigation has been completed. In our provider information request, some smaller trusts told us that they screened all the deaths for people in their care to decide whether an investigation was needed, regardless of whether a death had been identified as 'unexpected' or 'avoidable', or whether an incident had been reported. This included patients receiving end of life care – to assess whether there had been any problems in the delivery of care, for example highlighting a late diagnosis of a physical health condition for people with mental health needs or a learning disability. We highlighted this issue in our thematic review on end of life care *A different ending*, which we published in 2016.[7]

However, in larger trusts where there could be more than 3,500 deaths a year, only 'unexpected' deaths (and perhaps a sample of other deaths) were routinely being screened. This highlights the importance of achieving greater consistency in the definitions and factors to consider when carrying out an initial assessment. There is a need for a system that clearly sets out expectations for screening all deaths, capturing the decision as to whether or not to refer the death for further review, and documenting the factors that must be considered in that decision-making process, for example:

a) the person being in ongoing and regular receipt of care in the period before death, including any open referrals to services.

b) clear or obvious (to staff, families or others) factors that indicate service failure.

c) the vulnerability of the patient – for example the death of a child or person with a learning disability should make it more likely that an investigation takes place.

d) the legal status of the patient, for example detained under the Mental Health Act.

e) certain types of death, for example suicide, unexplained, sudden or illness as a result of medical treatment.

Supporting protocols would help to create consistency in decision making. These should outline clear expectations for clinical staff,

such as asking families and carers if they had concerns.

In some trusts, we found that standard definitions or 'trigger lists' were available to support decision making, but this was not consistent across the sites we visited. There was also a common misperception that there are 'mandatory' types of deaths in the NHS. For example, we were told that all suicides in mental health settings must be investigated or maternity deaths in acute settings. However, there is no requirement for any specific types of death or group of patients to be investigated by the NHS in the Serious Incident Framework or elsewhere in guidance. There is a risk that this misperception could lead to organisations failing to explore other causes of death in depth while focusing on the 'must do's'. This means that potentially valuable quality improvement and opportunities to improve future care in other areas may be lost.

Recording of the decision to report or not was also inconsistently applied in the trusts we visited, and there is no expectation that NHS staff should record this initial decision in either the patient records or local risk management systems.

We were told of local processes being put in place that reported all known deaths in care as either an 'incident' or a 'significant event', with local guidance to support the decision, recording and reporting. However, these are not common or expected practices across NHS trusts, so national guidance does not exist to support or monitor their use.

Once an incident has been reported, it is likely that a more senior member of staff, who may be independent of the care provided, will make the decision about whether further review or investigation is needed. This is typically a decision made by a director. The information they have to help them assess and understand any potential problems in care will be critical, but there is currently no standard approach to the level of detail or factors to consider at this stage in decision making.

CASE EXAMPLE

One NHS trust has introduced a triage system for all deaths known to their mental health and community services (around 1,200 a year). It is led by a Mortality Surveillance panel. All deaths are reported and considered weekly by divisional teams.

A death will be reviewed if any of the following criteria are involved:

- anti-psychotic medication
- drug and alcohol related
- unexpected death
- stepped-up care engaged
- inpatient at the time of death and within two weeks of discharge
- self-harming behaviour involved.

Once the panel has reviewed the death, they will identify if mental health care could have contributed and report it as an incident with further investigation to be completed.

The nature, severity and complexity of serious incidents vary on a case-by-case basis and therefore the level of response should be dependent on and proportionate to the circumstances of each specific incident. The appropriate level of investigation should be proposed by the provider as informed by the initial review. The investigations team and, where applicable, other stakeholders will use the information obtained through the initial review to inform the level of investigation. The level of investigation may need to be reviewed and changed as new information or evidence emerges as part of the investigation process.

Serious Incident Framework guidance – agreeing the level/type of investigation (page 39)

Clinical commissioning groups (CCGs)[i] will offer a level of independence from the trust once the decision is made to report a serious incident relating to a death in care. The Serious Incident Framework requires CCGs to be notified whenever a death has occurred and the trust has made the decision that problems in care may have led to the death.

The expectations and standards of reporting of deaths to CCGs is variable. It is even more variable in trusts whose services are commissioned by a number of different CCGs. These trusts often have to work with a number of different protocols and systems for deciding to investigate a death. This leaves staff unsure about which policies and procedures they should be following, and as a result means that some decisions and discussions with CCGs may not be taking place.

However, the Serious Incident Framework says that trusts should be clear on their 'lead commissioner' for investigations into serious incidents. This would mean a single commissioner should be identified for providers who will set the expectations for serious incidents in individual cases or taking a lead on the processes in place overall. Therefore, this should not be a barrier to trust leadership teams identifying when problems or inconsistencies are occurring and raising this with their CCGs to identify a solution and agree a single lead.

The process for deciding whether to carry out a review or investigation is even more complicated and variable for patients who die in the community. This is because the GP will typically be seen as the 'lead NHS provider' for the patient, and so may complete their own review of care. For example, a desk-based examination of the clinical records may not lead to a GP to report the death to a trust, if a problem is not identified. GPs have access to the Serious Incident Framework, but it is not used as standard guidance in the same way as it is by NHS trusts (who are expected to follow

the Serious Incident Framework as part of NHS standard contracts).

This difference in approach, and expectations of information sharing, may be a key factor why investigations are less likely to be carried out for patients who die out of a hospital setting – see **FIGURE 1**, which shows the number of deaths and rates of incidents, reviews and investigations in different settings. But this should not be a barrier or reason for hospital providers to not carry out their own reviews for learning from the care they provided. Other factors identified in both our provider information request and on our site visits included a lack of coordination and information sharing within and between trusts.

Medical examiners

There are plans already in place to implement the medical examiner role across England.[8] This is expected to be implemented nationally from April 2018; the date will be confirmed after the Department of Health has reviewed responses to its recent consultation on the role.

Once in place, an independent clinical review of all deaths that occur in England (that are not being investigated by a coroner) will be required before the death can be registered. Medical examiners will be senior doctors who report to local authorities. They will be independent of the NHS, and have access to medical records, clinicians and staff and at least one of the relatives or carers of the person who has died. This will introduce a new system and additional role, to the NHS, for making decisions and identifying or defining the causes of deaths in England, and examiners will be well placed to identify non-malicious problems with the quality of health care, including problems that did not necessarily contribute to a death but which should still lead to change or action from services. The medical examiner will seek to identify cases that should be referred to the coroner, and pilots have also shown that they can identify cases that are likely to be informative if NHS organisations carry out more detailed reviews.

---

i   Clinical commissioning groups are responsible for commissioning (purchasing) most health and care services for people in a local area.

There have been some delays in implementing the medical examiner role since identifying the value and need for it. Our review shows the importance of all parts of the system working together to ensure it is introduced without further delay.

The medical examiner pilots to date have not been fully operational and have not included all community patients. However, they have shown that the independent 'check' with families and carers, including a clinical explanation of the cause of death and events preceding death, can help to support people during the grieving process, while enabling the experience and views of families to be captured and any concerns identified quickly.

The medical examiner role has the potential to offer a new important safeguard in England. However, it should be seen as an additional check for the NHS and not something to replace the important role of individual clinicians and staff and services being interested in identifying problems in care, and speaking directly with families and carers to offer explanations or invite concerns to be raised.

Learning Disabilities Mortality Review

Another important initiative is the Learning Disabilities Mortality Review (LeDeR) programme. All deaths of people with a learning disability are expected to be notified to the programme as it rolls out across England in 2017. All deaths of people with a learning disability, that meet the programme criteria, will receive an initial review by a trained reviewer. Where it is felt that further learning about a death could contribute to improved service provision, that death will receive a full multi-agency review.

The main purpose of the LeDeR reviews is to identify any potentially avoidable factors that may have contributed to the person's death, and to then develop action plans that, either individually or in combination, will guide changes needed in health and social care services to reduce premature deaths of people with a learning disability.[j]

National Mortality Case Record Review Programme

Another programme, the Royal College of Physicians' National Mortality Case Record Review Programme, aims to develop and implement a standardised way of reviewing the case records of adults who have died in acute hospitals across England and Scotland, thereby improving understanding and learning about problems and processes in health care associated with mortality, and to share best practice.

The standardised approach referred to as a Structured Judgement Review assesses separate phases of care including:

- admission and initial care – first 24 hours
- ongoing care
- care during a procedure
- perioperative/procedure care
- end of life care or discharge care
- assessment of care overall.

A judgement is made on each relevant phase of care, which are also scored from excellent (score 5) to poor (score 1). This approach has also been adapted for use by some mental health trusts although it is recognised that further national work will be needed to make sure mental health services are supported in implementing this approach, with particular focus on how problems with physical healthcare needs can be confidently identified by mental health staff.

---

j   Further information about the programme can be found at: **www.bristol.ac.uk/sps/leder**.

FIGURE 1: AVERAGE REVIEW AND INVESTIGATION RATE BY SECTOR AND CARE SETTING
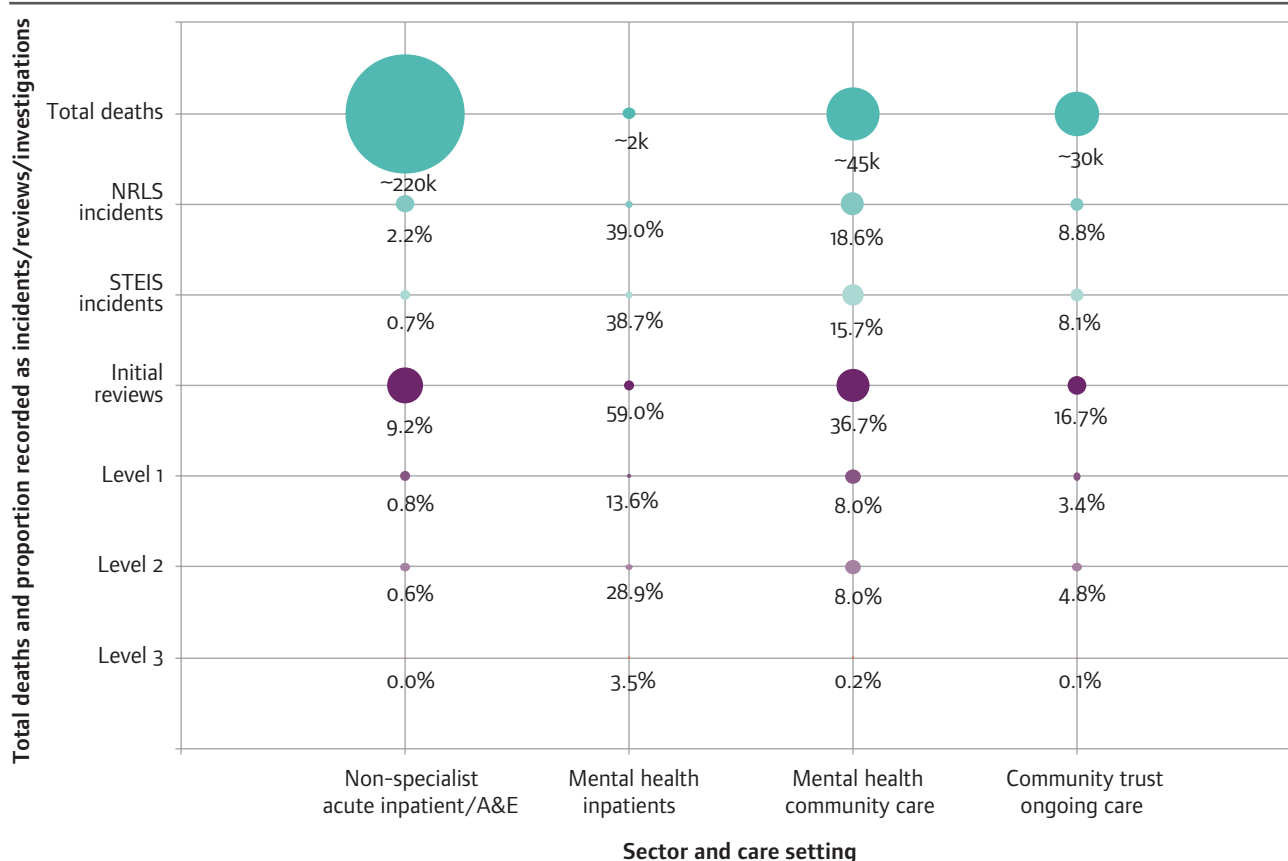
Source: CQC provider information request

The graph should be read vertically. Each column represents a sector and care setting. The top row shows the total deaths recorded, extrapolated to reflect the approximate total deaths we would have seen had all trusts responded to our information request. The rows below represent the different levels of incident reporting, reviews and investigations. The percentage given is the mean of the responses we received; the number represented by the size of the bubble is derived from that mean being applied to the extrapolated total deaths. While the overall response rate was 93%, not all trusts responded to every question, and therefore some of the average levels of investigation are based on responses from a smaller number of trusts. It should also be noted that there was considerable variation reported to CQC from trusts, even from within the same care setting regarding the proportion of deaths that were reviewed or investigated. For example, while nearly six in 10 acute trusts told us that they had carried out initial reviews on under 1% of inpatient deaths, approximately one in 10 acute trusts said that they had carried out initial reviews on more than half of their inpatient deaths. This variation does not relate to the number of deaths happening in trusts, the size of trusts or their location. Full details are available at annexes 5 and 9.

LEVEL OF REVIEW OR INVESTIGATION – SERIOUS INCIDENT FRAMEWORK DEFINITIONS

Once a decision to review or investigate is made, NHS trusts use the Serious Incident Framework to decide which level of review or investigation to carry out, with input and agreement from the lead CCG. Current definitions for the different levels and what they mean are outlined below. They will include individual reviews of patient safety incidents that result in death, and multi-incident reviews where multiple deaths may have occurred that need reviewing to identify cross-cutting issues. For example, three suicides of people receiving care from a hospital service may lead to a collective review of the care provided.

INITIAL MANAGEMENT REVIEW

A review, carried out by the identifying NHS trust and commissioner in the first 72 hours following the reported incident, to make the decision to investigate or not investigate. The information submitted as part of the initial review should be reviewed by the appropriate stakeholders and the investigation team (once in operation), to inform the subsequent investigation.

CONCISE INTERNAL INVESTIGATION (LEVEL 1)

A concise or compact investigation, which includes the essentials of a credible investigation. This is suited to less complex incidents that can be managed by individuals or a small group at a local level. A level 1

investigation must be completed within 60 working days of the incident being reported to the relevant commissioner.

COMPREHENSIVE INTERNAL INVESTIGATION (LEVEL 2)

A comprehensive investigation used to review complex issues. It should be managed by a multidisciplinary team involving experts and/or specialist investigators where applicable. The standard for completing a level 2 investigation is within 60 working days of the incident being reported to the relevant commissioner.

INDEPENDENT INVESTIGATION (LEVEL 3)

Required where the integrity of the investigation is likely to be challenged, or where it will be difficult for an organisation to conduct an objective investigation internally due to the size of organisation or the capacity/capability of the individuals available, and/or the number of organisations involved. The investigator and all members of the investigation team must be independent of the provider. The investigation must be commissioned and carried out entirely independently of the organisation whose actions and processes are being investigated. Level 3 investigations should be completed within six months of the date that the investigation is commissioned.

Multi-agency information to support decision making

Timely sharing of information between trusts and other organisations is key to good decision making, but we found that there are difficulties in routinely getting clinical information about the patient from others involved in delivering care. As each trust has their own patient record and incident management system (see chapter 1),

trusts often told us that that information was not readily shared, or not shared in timely way.

This was highlighted in our provider information request, where on average 28% of all types of trust did not know how many people had died within six months of being discharged from their service. Patient confidentiality was cited by NHS staff during our review as one reason why the medical records of patients who had died were

not exchanged. Yet families reported feeling that the system was not keen on sharing information.

> "It would help if trusts worked on the premise that they would have to release notes to someone in the family. There might be extenuating circumstances, but they work on the basis that they release nothing unless forced to legally."
>
> **CQC interview, 2016**

There is a consensus among national bodies, including the Department of Health, the General Medical Council and the British Medical Association, that patient confidentiality should continue after the death of a patient. However, Department of Health guidance permits the sharing of patient information if this is necessary, proportionate and justified in the public interest.[9] There is a clear public interest to be served by sharing clinical information to support learning and improvement following a death in care. Investigation leads should seek the advice of their Caldicott Guardian, information governance leads and legal team on a case by case basis, and follow guidance on making public interest disclosures.[10]

When patients who die in the community are identified by trusts, but multiple providers are involved, there is guidance in the Serious Incident Framework about who is responsible for leading a review of any problems in care that may have led to their death. If there are any disagreements, the CCG or NHS England can be asked to identify a single provider, or they may carry out the investigation themselves in some complex cases. Local protocols should support the identification of the lead provider, or escalation to the CCG where this cannot be determined, but we heard examples of where both providers and families had been left confused about who should be accountable for coordinating the review or investigation.

> "It is not clear, nor is there a multi-agency agreement in place, as to who then takes the lead in declaring a death [using electronic reporting systems to commissioners] or completing an investigation, and ultimately then sharing the learning."
>
> **Mental health trust – provider information request**

> "I was told, 'He was not in hospital so there will not be an investigation.' I stumbled over the fact that my son was in their 'care' and so there should have been an investigation. I asked again but they would not agree."
>
> **Family member – share your experience questionnaire**

Without timely access to information, trusts may be making decisions on whether to review or investigate a death without all of the relevant information available. This is particularly crucial for the initial management review stage. Key information could be held by another organisation, which would affect the decision to review or investigate. Without this an investigation may not take place, when there is a clear need for one if all the facts are taken into account.

Spotlight on mental health and learning disabilities

As noted in chapter 2, acute and community trusts often do not record whether a patient also has a mental health problem or a learning disability. Mental health trusts are similarly poor at identifying people with a learning disability.

Without reliable and effective recording of whether people receiving care have a mental health problem or a learning disability, it is impossible to know with any degree of certainty how many investigations are taking place into the deaths of patients in these groups.

Mental health trusts are reporting significantly larger proportions of total deaths as incidents, compared with acute or community trusts. However, how staff in mental health trusts decide whether to review or investigate a death varies widely between different trusts. While a third of mental health trusts told us that they report all deaths of inpatients as an incident and carry out at an 'initial management review', some trusts are reporting far fewer deaths as incidents and carrying 'initial reviews' on only a small proportion of their total deaths. This variation does not relate to the number of deaths happening in these trusts.

The proportion of initial management reviews and investigations carried out by trusts for patients with a mental health or learning disability diagnosis also varies. **FIGURE 2** shows the number of initial management reviews and investigations conducted by trusts in relation to patients with a mental health or learning disability diagnosis who have died whilst receiving services. Of the 1,070 deaths of patients with a learning disability diagnosis who die as inpatients or in A&E settings in an acute trust, 8.7% had an initial management review, in comparison to 17.9% of initial reviews carried out by mental health trusts for patients with a learning disability who died whilst receiving services as an inpatient.

FIGURE 2: TOTAL COUNT AND MEAN RATE OF INITIAL MANAGEMENT REVIEWS AND INVESTIGATIONS INTO DEATHS OF PATIENTS WITH A MENTAL HEALTH AND LEARNING DISABILITY DIAGNOSIS RECEIVING SERVICES AT TIME OF DEATH

		Acute non-specialist inpatient/A&E		MH trust inpatient		Mental health community care		Community trust ongoing care	
		Mental health	Learning disability	Mental health	Learning disability	Mental health	Learning disability	Mental health	Learning disability
Total deaths	**Total count**	2,946	1,070	704	25	25,600	823	534	42
	Response count	45	107	50	43	50	42	10	13
Initial management reviews	**Total count**	64	90	364	19	5,162	174	17	0
	Response count	63	91	52	42	51	42	10	11
	Mean rate	4.8%	8.7%	61.6%	17.9%	36.1%	25.0%	0.8%	0.0%
Level 1 investigations	**Total count**	32	28	75	3	770	29	17	1
	Response count	93	107	52	48	52	47	12	12
	Mean rate	1.6%	1.9%	14.1%	4.3%	7.6%	8.0%	0.7%	2.3%
Level 2 investigations	**Total count**	9	10	152	1	1,137	10	33	2
	Response count	78	99	52	43	51	44	15	15
	Mean rate	0.6%	0.7%	31.2%	2.3%	8.9%	3.6%	1.7%	1.4%
Level 3 investigations	**Total count**	5	1	9	1	7	3	0	0
	Response count	122	126	51	50	51	51	13	13
	Mean rate	0.0%	0.3%	3.8%	1.0%	0.1%	0.5%	0.0%	0.0%

There is less variation between sectors in the proportion of investigation carried out by trusts for patients with a learning disability diagnosis. **FIGURE 2** shows the mean proportion of investigations between the different sectors for patients with either a mental health or learning disability diagnosis. Further information can be found in annexes 6 to 8.

For mental health trusts, the legal status of a patient, and whether or not the patient is subject to the Mental Health Act 1983 (MHA) at the time of their death, will be relevant when making a decision to review or investigate. There were 266 deaths of people detained under the MHA reported in 2015/16, including those in independent healthcare settings. The Serious Incident Framework requires trusts to consider whether an independent review would be appropriate when someone who is subject to the MHA dies, and when the cause of death is unknown or where their "death may have been avoidable or unexpected".[11]

However, we found there was a lack of understanding about what is expected when someone who is detained under the MHA dies. We also found examples of where internal notifications and procedures were unclear or relied on the knowledge of experienced staff to make sure additional actions are completed – for example reporting the death directly to CQC[12] and the coroner, or reviewing care against national best practice in human rights such as the Equality and Human Rights Commission's Human Rights Framework.[13]

4. Reviews and investigations

KEY FINDINGS

- Most NHS trusts follow the Serious Incident Framework when carrying out investigations. Despite this, the quality of investigations is variable and staff are applying the methods identified in the framework inconsistently. This acts as a barrier to identifying the opportunities for learning, with the focus being too closely on individual errors rather than system analysis.

- Specialised training and support is not universally provided to staff completing investigations; many staff completing reviews and investigations do not have protected time in which to carry out investigations. This reduces consistency in approach, even within the same services.

- There are significant issues with the timeliness of investigations and confusion about the standards and timelines stated in guidance – this affects the robustness of investigations, including the ability to meaningfully involve families.

- A multi-agency approach to investigating is restricted by a lack of clarity on identifying the responsible organisation for leading investigations or expectations to look across pathways of care. Organisations work in isolation, only reviewing the care individual trusts have provided prior to death. This is a missed opportunity for identifying improvements in services and commissioning, particularly for patients with mental health or learning disability needs.

This section of the report focuses on how reviews and investigations are carried out, the quality of the investigations, and whether opportunities for preventing death and improving services have been missed.

Overall, we found that trusts have systems in place, based on the current national guidance, for carrying out investigations once a death is identified as a serious incident, but the methods are not well understood at a local level. People told us that the lack of understanding and consistency in application creates confusion, for staff, families and others, about the purpose of the reviews and investigations and they are not focused on learning but used as management tools or reports to coroners. This is wrong, and limits the quality of the reviews and investigations being carried out and the learning that can take place across the NHS.

If a death is investigated under the Serious Incident Framework, there should be a consistent approach to the process of investigation. However, our findings indicate that there is a lack of understanding and skilful application of the guidance available in the Serious Incident Framework about the Root Cause Analysis methodology that is used for investigations. We found that analysis was often superficial, focusing on the acts or omissions of staff with little evidence of systems analysis.

Barriers to learning are most notable where care is provided outside of hospital settings and where multiple providers are involved. A greater level of resource in time, training and expertise would give a platform for increasing the quality and output of investigations.

Context and approach

To understand the context in which reviews and investigations are carried out, in our provider information request we asked trusts to tell us about the total number of deaths for their services from April 2015 to March 2016, and how many initial management reviews, and level 1, 2 and 3 investigations they had completed using the criteria set out in the Serious Incident Framework (**FIGURE 3**). These figures obviously rely on trusts accurately identifying deaths. A more detailed summary of the provider information request are in annexes 6 to 8.

FIGURE 3: TOTAL NUMBER OF DEATHS BY TRUST SETTING AND SECTOR COMPARED WITH THE NUMBER OF INITIAL REVIEWS AND LEVEL 1, 2 AND 3 INVESTIGATIONS

		Acute non-specialist		Mental health			Community	
		Inpatient /A&E	Six-months post-discharge	Inpatient	Community	Six-months post-discharge	Ongoing care	Six-months post-discharge
Total deaths	Total*	207,633 (128 trusts)	233,942 (85 trusts)	1,987 (51 trusts)	40,635 (51 trusts)	19,343 (39 trusts)	25,842 (16 trusts)	8,517 (9 trusts)
Initial reviews	Total**	15,539 (120 trusts)	2,104 (62 trusts)	466 (53 trusts)	6,069 (53 trusts)	768 (41 trusts)	383 (15 trusts)	8 (10 trusts)
	Mean	9.2%	6.1%	59.0%	36.7%	30.4%	16.7%	11.1%
	Median	0.8%	0.0%	62.5%	16.3%	6.1%	2.2%	0.0%
Level 1 investigations	Total**	1,498 (118 trusts)	75 (64 trusts)	87 (53 trusts)	860 (53 trusts)	151 (42 trusts)	105 (16 trusts)	5 (10 trust)
	Mean	0.8%	3.5%	13.6%	8.0%	10.1%	3.4%	0.0%
	Median	0.1%	0.0%	0.0%	1.0%	0.1%	0.6%	0.0%
Level 2 investigations	Total**	1,163 (125 trusts)	111 (66 trusts)	175 (53 trusts)	1,204 (52 trusts)	232 (41 trusts)	109 (16 trusts)	14 (11 trusts)
	Mean	0.6%	0.2%	28.9%	8.0%	14.4%	4.8%	7.4%
	Median	0.5%	0.0%	24.6%	2.6%	0.8%	0.0%	0.0%
Level 3 investigations	Total**	23 (117 trusts)	5 (77 trusts)	14 (52 trusts)	10 (51 trusts)	4 (46 trusts)	17 (15 trusts)	1 (10 trusts)
	Mean	0.0%	0.0%	3.5%	0.2%	0.0%	0.1%	3.3%
	Median	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%

* Excludes 0 and 'not known' responses   ** Excludes 'not known' responses

Source: CQC provider information request

On our site visits we found that, once the decision to carry out a review or investigation has been made, most trusts have processes to support the minimum expectations of the Serious Incident Framework. This includes guidance and expectations for:

- setting up an investigation team
- involving stakeholders, including families and carers
- the appropriate level of investigation
- action planning
- submitting the report to commissioners.

It also outlines the seven underlying principles for managing serious incidents, which we expect should be applied to all reviews and investigations (**FIGURE 4**).[14] However, on our site visits we found that staff do not always fully understand the guidance or know how to apply it, and that they have not always had training on how to do so. In addition, we were frequently told that staff do not have dedicated time to be able to conduct investigations. This reduces the consistency of approach, even within the same services.

FIGURE 4: PRINCIPLES OF SERIOUS INCIDENT MANAGEMENT
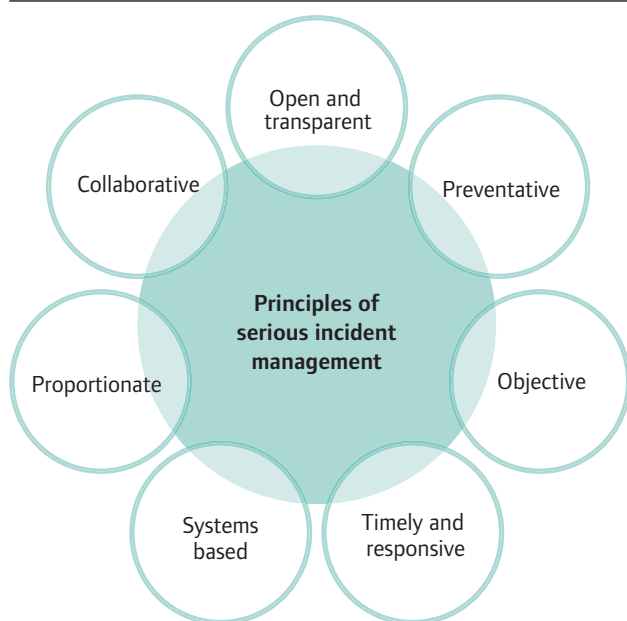
Quality of investigations

To assess the quality of investigations, we looked at 27 investigation reports from 10 different trusts. Of these, 26 were level 2 investigations. There was little evidence in the reports that the depth of investigation and analysis met the requirements of a level 2 investigation.

The reports we reviewed highlighted that there was no consistent approach to involving staff and families, or how investigators seek to establish facts (what happened) or offer opinions (cause of death and standard of care). In one case, only one member of staff was interviewed when the information provided in the report suggested that more than one person would have needed to give facts and offer opinions to give a full picture. Of the 27 reports, only three evidenced consideration of the family's perspective. Many reports included information about the family, but did not show that they had invited the family to contribute to the investigation.

The initial terms of reference should be a key factor in ensuring a quality investigation is completed. The Serious Incident Framework expects terms of references to be developed for all investigations and the objectives agreed with commissioners, and this is an opportunity for the involvement of families and carers.[15] It is particularly important to ask families and carers, who will often want to know what happened up to the time of death, rather than up to the last contact with the service investigating the death.

By addressing this at an early stage in the investigation, there will be a common origin to start from and a greater likelihood of the final report being satisfactory from a family perspective. Some families and carers may not want to engage at the start, and in these instances the Serious Incident Framework expects that the terms of reference will be provided to them and their views invited.

However, most of the investigations that we reviewed used the standard example terms of reference that are set out in the Serious Incident Framework. Only one report showed any evidence that questions from the family were included in the terms of reference.

The development of clear, effective terms of reference is directly within the control of providers and commissioners, and should be used to make sure there is clarity for any investigation team on the areas that should be reviewed. Strengthening this would also identify where the input of other organisations would be critical to meeting the review's objectives. Including families from the start could improve the transparency, relevance and accuracy of the investigation, and is highly likely to lead to a more open and credible investigation for families.

> "I don't apportion any blame for his death at all, it's one of those things that happened. But we're still not quite sure whether he did fall or not. So many different stories there, some of them just didn't make sense. There was no blame involved but the way it was handled was dreadful, it was quite embarrassing to be a nurse at that period of time."
>
> **CQC interview, 2016**

Training and support for investigators

Evidence from our site visits and provider information request showed that staff do not always receive specialised training and support in conducting an investigation. Previous reports, including the Parliamentary and Health Service Ombudsman's review of the quality of NHS complaints investigations, have equally highlighted the lack of a national, accredited training programme to support local investigators in the NHS.[16] This means that, even within the same services, there is not a consistent approach.

The Serious Incident Framework requires all investigations to use a recognised systems-based methodology that identifies:

- what the problems were
- how the various factors, including environmental and human factors, led to the incident

- why it happened and the fundamental issues that need to be addressed.

It identifies the Root Cause Analysis (RCA) approach as the most common methodology to use. Although we found that all the trusts included in our site visits were using the RCA methodology, not all of them were providing RCA training to people undertaking investigations, nor were they clear on which members of staff needed training or how they could make sure this was completed.

> "There needs to be some standard framework for investigators. They keep saying they've done the Root Cause Analysis course. So what is wrong with that course, if this is the quality of what's being written?"
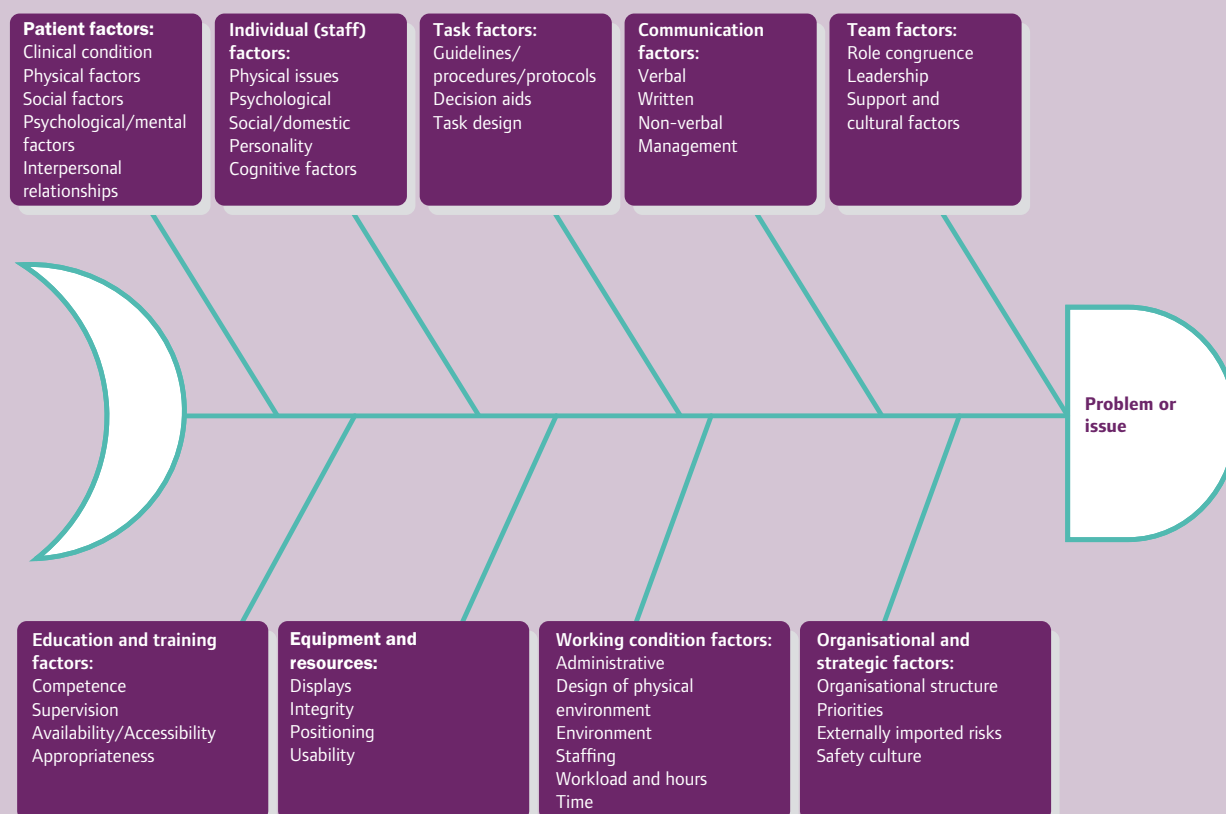>
> **CQC interview, 2016**

We found examples of misinterpretation of the RCA approach, with some trusts not understanding how it can be implemented in a variety of settings. Some mental health trusts told us they felt the methodology is better suited to acute trusts where there may be a greater likelihood of a single failure or 'root cause' – for example, a missed diagnosis or wrong site surgery. However, this showed a lack of understanding of the techniques, which rarely conclude with a single failure or root cause and which can be applied to most incidents in any setting. This supports the view that investigators need to be trained in how to apply the methods effectively to different scenarios.

EXAMPLE: ROOT CAUSE ANALYSIS INVESTIGATIONS

The following diagram is taken from the guidance for NHS staff on how to analyse contributory factors and root causes when reviewing patient safety.[17] This tool is called a 'fishbone diagram' and prompts investigation teams to look at a range of different information about the issue, event or incident they are investigating.

ROOT CAUSE ANALYSIS INVESTIGATION FISHBONE DIAGRAM – TOOL

Patient factors:
Clinical condition
Physical factors
Social factors
Psychological/mental factors
Interpersonal relationships

Individual (staff) factors:
Physical issues
Psychological
Social/domestic
Personality
Cognitive factors

Task factors:
Guidelines/ procedures/protocols
Decision aids
Task design

Communication factors:
Verbal
Written
Non-verbal
Management

Team factors:
Role congruence
Leadership
Support and cultural factors

Problem or issue

Education and training factors:
Competence
Supervision
Availability/Accessibility
Appropriateness

Equipment and resources:
Displays
Integrity
Positioning
Usability

Working condition factors:
Administrative
Design of physical environment
Environment
Staffing
Workload and hours
Time

Organisational and strategic factors:
Organisational structure
Priorities
Externally imported risks
Safety culture

Source: National Patient Safety Agency

"The Root Cause Analysis process may not be the most appropriate methodology for investigating some incidents. It is very difficult for a single RCA investigation report to satisfy the needs of all stakeholders, that is the trust (so that it learns), the family, commissioners, coroner, CQC, other involved organisations, and so on."

Provider information request, mental health trust

Lack of support was also identified as an issue, with staff telling us that the quality of reviews and investigations are often compromised by a lack of time and dedicated resources.

When clinicians and staff have to lead on the investigation and report writing, this is often not factored into their job plans, meaning that they have to fit investigations alongside other responsibilities. As a result, investigations can be rushed, with families not being meaningfully involved, or not completed on time, which affects the quality of reports.

Some trusts have specialist teams that are designated to carry out or oversee investigations.

In our provider information request, trusts told us that specialist investigators drew on clinical expertise as needed to carry out an investigation. In some trusts, we were told of concerns that having a team of specialist investigators removed from clinical settings would not allow the investigators to stay in touch with the context and pressures under which clinicians and staff work. Although this may not be necessary to identify the facts in investigations, trusts believed this clinical knowledge can often support identification of changes needed and help embed the learning in different clinical services.

It is important to recognise the need for support networks to be in place for staff following incidents, as being closely involved can have a significant emotional impact on the staff involved. This may be a negative or positive experience for staff but should be appropriately acknowledged and support offered by all care providers.

Independence of investigations

Many families and organisations external to the NHS raised concerns with us about the independence of investigations carried out within the NHS. The definition and understanding of 'independent' can mean multiple things in relation to the investigation of deaths in care, but the three main definitions are:

- Independence from the care team – this means trusts may identify investigators who work for the trust but who have not been involved in the care provided to the patient.

- The Serious Incident Framework sets out criteria for a level 3 Independent Investigation as "both commissioned and undertaken independently of those directly responsible for and directly involved in the delivery of the elements that the investigation is considering".[18] This will mean the investigation team is external to any organisation that has been responsible for care and treatment. This may look at specific provider level issues or more widely at commissioning systems or service configurations.

- Article 2 of the Human Rights Act – this requires an investigation to be completed that is independent of those implicated by the events under investigations, including NHS trusts as a public body or the NHS overall. Case law established that the role of the coroners and their inquiry into how the person died will satisfy the requirement for independence.[19] For example, in the case of a suicide of a patient subject to the MHA, the need for Article 2 would be triggered as the person is 'detained by the state' and a referral to the coroner will always be required.

The Serious Incident Framework requires that all investigations be completed by "teams that are sufficiently removed from the incident to be able to provide an objective view". We were told during the site visits and in our provider information request that it was quite common for some acute trusts to use people working in the same clinical area or team, where understanding of the specialty involved in the incident would be seen as preferable to someone from a different service type leading the investigation.

There is not currently a way to capture the number of level 1 and 2 investigations that are being completed independently of the clinical team in the different settings, but we did ask how many level 3 investigations occur (independent of the trust). Providers who responded reported 74 completed in 2015/16, out of about 5,500 investigations that they told us about. Trusts, working with commissioners, will typically be responsible for commissioning and covering the costs of any independent investigations, unless they are carried out on behalf of other organisations. For example NHS England may decide, as they did at Southern Health, to commission a specific separate investigation into a single death or multiple problems.

Coroners

Coroners have a statutory duty to investigate all deaths, including those in state detention, if the cause is unknown. However, there are no statutory or other clear criteria for medical practitioners reporting deaths to coroners. It has

been noted that this creates uncertainty and inconsistency in reporting deaths to coroners.[20] The Chief Coroner has urgently called for there to be clear statutory guidance for doctors, providing a clear framework and the basis for better education and training.

Of the 495,309 deaths registered in England in 2015, 222,174 (45%) were reported to the coroner, and there were 31,036 inquests.[21] Where reports are made, the coroner will be responsible for establishing the 'why and when' of death. However, they are not required to review a broad range of issues relating to the whole care and treatment provided to the person, so investigations would not be a substitute for the reviews for learning in the NHS.

Coroners also have the power to issue 'Reports Preventing Future Deaths', which highlight concerns and require action from organisations such as the NHS, other care providers or national bodies if they find problems in the care provided to the person or failings from services. In 2015, coroners in England and Wales issued 571 reports, which are all publicly available but will include deaths that are not related to NHS care delivery. These reports can be used to encourage local, regional or national learning in the NHS. For example, NHS England (London Region) has used this resource to identify learning from the deaths of vulnerable adults and children in healthcare settings across London.[22]

People who die while subject to the Mental Health Act or the Mental Capacity Act Deprivation of Liberty Safeguards are considered to be 'in state detention', so will always need to be referred to a Coroner, even if the cause of death is known and the person's death had been expected by the services delivering care and the family or carers. Last year, there were around 6,500 inquests for people subject to the Deprivation of Liberty Safeguards, but changes planned to the Coroners and Justice Act 2009 in 2017 will amend the meaning of state detention in the Act and only require an inquest for a person subject to the Deprivation of Liberty Safeguards if there are any unusual circumstances.

The requirement for all people who die when they are subject to the Mental Health Act to receive an inquest will continue. This involves between 200 and 300 cases a year.[23] A court judgment found that there is no obligation to have a separate independent investigation if an inquest is taking place.[24]

Other independent investigations

It should be noted that other independent investigations may take place when someone dies, including Child Death Overview Panels, police investigations, homicide investigations or local safeguarding board investigations.[25] This can be particularly challenging for bereaved relatives and carers.

> "In an ideal world I'd like just one to two people to coordinate things. From the death to when you go to see bereavement officer to get paperwork, that bit worked quite well. They told you to go to the registrar and register death, but there was no real link between ward, bereavement office, coroner and investigatory team. Actually someone explaining this is the investigation, this is what happened, so you weren't having to ring six different places to find out what's going on, that would be good."
>
> **CQC interview, 2016**

Although there will always be a need for different investigations to work together, it is likely that each will have a different purpose and scope. The existence of a separate investigation should not act as a barrier or reason for NHS trusts not to consider whether they should conduct a local investigation or review (depending on the circumstances of the individual case) to identify learning for their services.

The variation in the way independent investigations are identified as being needed (unless required by statute) was a significant problem for stakeholders during the review.

A consistent national approach is needed, acknowledging the different degrees of independence that will come with different problems, and identifying lead organisations to offer professional expertise when required.

Any new models should improve the capacity and capability of services to see independent investigations not as only for the 'most complex', but the potential to maximise opportunities for greater reflection and shared learning. During the review, it was suggested that this may include local trusts establishing joint investigation approaches – for example, where they have particular specialisms so that investigators are independent from the service but still clinically knowledgeable.

Another option that should be explored is for the Royal Colleges to consider offering clinical leadership and guidance for investigators to support local services. This would potentially reduce the high costs associated with external investigation teams (approximately £100,000 per investigation) or the likelihood of large independent public inquiries (around £22 million spent in the NHS over 10 years[k]) being required.

Timeliness of reporting

There are significant issues with the timeliness of investigations, and confusion about the standards and timeframes outlined in the Serious Incident Framework.

The Framework states that, once a death is categorised as requiring investigation, the trust has 60 days in which to produce a report and action plan.[l] NHS Improvement advises that

this is a guideline only and can be changed in negotiation between providers and clinical commissioning groups. However, at a local level we were told that timelines for completing investigations can be interpreted as targets and used as a measure of quality and performance by some trusts or commissioners.

This can compromise the effectiveness of an investigation, especially in complex cases, with staff more focused on timescales than producing a quality review with involvement from others including family members. In some cases, the tight timelines for conducting the investigation were used as an example of why families were not involved.
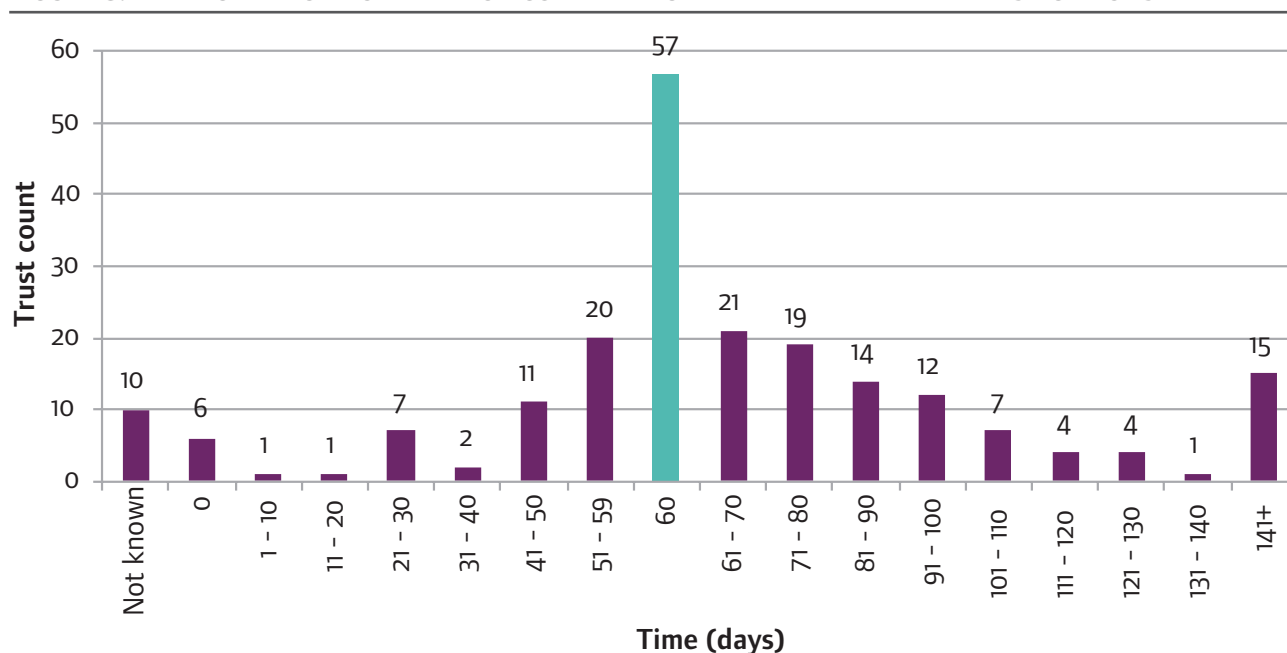
In our provider information request, we asked trusts to tell us how long, on average, they were taking to complete their investigations and reports. Overall, the length of an investigation reported by trusts ranged from 0 (or same day) to 264 days, with 57 (27%) reporting that their average length of investigation is exactly 60 days (**FIGURE 5**).

It is unlikely that so many are completing investigations on the 60-day target. It is more likely that trusts are not recording this data. One trust confirmed this in their feedback to our provider information request, telling us the average length of time recorded "is an estimate only".

---

k   Cost and averages based on the information shared by Department of Health teams establishing the Healthcare Safety Investigation Branch (HSIB).

l   The Serious Incident Framework states that serious incident reports and action plans must be submitted to the relevant commissioner within 60 working days of the incident being reported to the relevant commissioner, unless an independent investigation is needed, in which case the deadline is six months from the date the investigation began. However, there is a recognition that circumstances will not always allow for the timely submission of reports and permits for alternative timeframes to be agreed between the commissioner and investigation team.

FIGURE 5: AVERAGE LENGTH OF TIME FOR COMPLETING LEVEL 1 AND LEVEL 2 INVESTIGATIONS

Source: CQC provider information request

Some trusts told us that balancing completing investigations to the standard they should within the required timescales, and treating families with sensitivity, can be a challenge. Families told us that there were long delays to investigations being concluded, or delays to being informed of the findings, sometimes with no explanation from the trust of why the delay had occurred.

"They were supposed to send us monthly updates, they also told us they'd come back to us for clarification if people raised things where they wanted to hear our side of the story, but basically we waited and waited. After about seven weeks we didn't have an update, a pattern that we wouldn't hear, I'd think I don't want to chase them and look difficult."

One-to-one conversation with family and carers

A multi-agency approach to investigations

As identified throughout this report, there will often be more than one organisation involved when investigations take place. The organisation that first identifies a problem in care will be responsible for informing other providers, commissioners or partner organisations to begin discussions about further review or action.

The Serious Incident Framework is clear that organisations must work collaboratively and there should be a multi-agency approach to conducting investigations, supported by jointly agreed policies or procedures for multi-agency working. This includes requirements for providers and commissioners to liaise with other organisations, such as primary care or local authority safeguarding leads, and to work in partnership to support learning and avoid duplication or confusion in the investigation and how they work, and share information, with families.

However, during our site visits we found that trusts and other organisations are not routinely working together to at the point of identifying problems in care, or when conducting

investigations. This was a view reinforced by families.

> "I was phoning the location inspector. CQC put the care home under special measures after my brother died, but I had been contacting them when he was alive and telling them how bad it was there but no one was taking any notice. If a relative rings and reports serious concern, what happens? When you ring and they don't act, they don't visit the place? And someone dies, then what?"
>
> **CQC family listening day**

The Serious Incident Framework is clear that needing to involve multiple providers or commissioners should not be a barrier to completing a single investigation. However, local implementation of the guidance means that organisations tend to work separately, and if reviews are carried out this only looks at individual care they have provided before the person has died, rather than the totality of the care the person received before death. Coordination is particularly poor when an investigation involves two or more providers, and there is a lack of clarity about which organisation should or is taking the lead. This is a missed opportunity for identifying improvements in services and commissioning, particularly for patients with specific needs such as those with mental health problems or a learning disability.

Although some trusts make the effort to work with other providers and organisations as part of the investigation process, the local frameworks to support how this should be done are lacking. This is particularly the case for services outside of hospital settings, where processes are often unclear and much less well developed than for inpatients. Commissioners should be working collaboratively to agree how best to manage serious incidents for their services and make sure local protocols for reporting and escalating any complex or multi-agency issues exist.

Spotlight on mental health and learning disabilities

We have already highlighted in the report that many people with a mental health problem or a learning disability are not being correctly identified within NHS systems.

While this is sometimes the result of the policies and processes, or the configuration of IT systems, staff and organisational attitudes are also an important factor. Many trusts we visited did not consider people in these groups as needing specific attention, while others felt their normal systems covered everyone well. This means that many people are being 'lost in the system' and their deaths may not be investigated when they should be.

5. Do trust boards have effective governance arrangements to drive quality and learning from the deaths of patients in receipt of care?

KEY FINDINGS

- There are no consistent frameworks or guidance in place across the NHS that require boards to keep all deaths in care under review or effectively share learning with other organisations or individuals.

- Trust boards generally only receive limited information about the deaths of people using their services other than those that have been reported as serious incidents.

- When boards receive information about deaths, board members often do not interrogate or challenge the data effectively. Most board members have no specific training in this issue or time that is dedicated to focus on it.

- Where investigations have taken place, there are no consistent systems in place to make sure recommendations are acted on or learning is being shared with others who could support the improvements needed.

- Robust mechanisms to disseminate learning from investigations or benchmarking beyond a single trust do not exist. This means that mistakes may be repeated.

This section of the report focuses on whether NHS trust boards have effective governance arrangements to drive quality and learning from the deaths of patients in their care.

Overall, although we found governance systems in place, there is too little focus on the specific responses following the death of patients. The current approach across NHS trusts is not comprehensive enough to provide timely or detailed learning and improvements.

Based on the current guidance available, there are clinical and corporate governance systems in place for NHS trusts to monitor, review and improve systems following patient safety reviews and investigations. However, we found overall information about the deaths of patients is not routinely asked for or reviewed by trust boards, especially in the case of people receiving care outside hospitals.

There are opportunities to improve information and enhance the system's ability to learn and improve. This will need all parts of the system to recognise the importance of such information – regulators, commissioners, supervisors and boards.

Monitoring the deaths of patients

NHS trust boards are responsible for overseeing the quality and safety of their services, and for creating strong safety cultures that support learning. Across the NHS, trusts should have clear systems for sharing information and learning from patient outcomes to prevent harm to others.

As the regulator, CQC is responsible for checking that trusts' leadership teams are supporting a culture of learning. This includes the ability to identify learning, be open to challenge, and share information about safety issues to improve care. CQC also look at the systems in place to

make sure learning is shared across services and with external organisations, families, carers and patients. There are many improvements to be made to the way that CQC will regulate this in future, based on the learning from this review.

Guidance from NHS England and NHS Improvement requires trusts to have clinical and corporate governance systems in place to monitor, report, review and improve systems following patient safety reviews and investigations.[m] However, there is no guidance that specifically requires boards to keep all deaths in their care under review, corroborate information from a mix of data relevant to mortality (for example, looking at information from complaints, coroners or near-misses to get a complete picture), or effectively share any learning with other organisations or individuals.

We found that the governance of, and learning from, deaths of patients varied widely between trusts, meaning that trusts are not able to respond appropriately and in turn protect future patients.

> "If trusts spent more time on dealing with recommendations rather than on cover ups, we would not be here. They should put more effort in saving people's lives. It is always people at the bottom, nurses, agency staff etc., people at the bottom get all the blame, it is never the people at the top, the managers, the decision makers."
>
> **CQC family listening day**

From our review of board papers it was clear that most trust boards are provided with information about the deaths of people using their services. However, this is not always the case and the information provided is often limited, especially in the case of people receiving care outside of hospital. This particularly affects people with a mental health problem or a learning disability,

as they use community services and multiple providers. The level of detail that boards received again varied from trust to trust, ranging from boards being provided with information about overall mortality rates to those who held discussions about individual cases. This variability could result in valuable learning opportunities being missed and for relevant actions not being developed or shared within and across the NHS.

Board members did not always challenge trusts' assertions that there were strong systems and processes in place for identifying and reporting deaths, or monitoring whether reviews and investigations were completed fully. For example, at one trust we visited, the board were assured that the systems in place accurately captured the deaths of all patients. However, following a request by NHS England to carry out a retrospective case record review, the trust uncovered that they had missed a significant number of patient deaths in the previous year.

Evidence from board meeting minutes showed that some boards actively reviewed their policies in the light of national issues or findings from national publications, such as the *Report of the Morecambe Bay investigation* and the report on Southern Health. One acute trust told us that they had used the report into Southern Health to make sure they had appropriate mortality review processes in place, and the staff we spoke with at the trust appeared to understand its implications.

Most boards believed that their policies were appropriate and that the trusts were not making the same mistakes as those found at Southern Health. While some trusts did go on to recommend further actions to ensure that policies were appropriate and practice reflected the policies, others did not think that they needed to make changes. In trusts that did make changes, there was no shared framework for them to follow and ensure that their improvements were robust. In addition, while some of these boards set clear targets, objectives and measures to achieve improvement in their death review processes, this was not always evident in other trusts.

---

m   For example, the standard NHS contracts for hospitals requires services to have systems in place to report deaths to CQC or any other body and to have measures in place for the prevention of serious incidents

Reviewing mortality and investigations

The ability of boards to seek and review or interrogate the information they are given on mortality reviews and investigations can be limited because of the issues with current recording practices. Because patient management systems and incident management systems are not linked, some trusts told us that they find it difficult to identify deaths and related investigations.

This needs to be addressed locally and prioritised by services. Without being able to accurately identify when a patient in their care dies, boards will not have a full picture of the circumstances and will be unable to sufficiently challenge or interrogate the information they are presented with. This means that the potential for learning will be limited both within trusts and between trusts.

Where information is presented to boards, again data is not always sufficiently challenged or interrogated by board members. Reasons for this may include a lack of dedicated time to focus on deaths, and a lack of training for board members. In addition, there is considerable variability in reviewing the quality of investigations that take place, or making sure that recommendations are acted on and learning is shared with others who could support improvements and prevent it happening again.

Even where difficulties in running reports from electronic systems exist, additional information from the experience of families and carers, views from advocates or local support services can also be used by boards who want to understand how their staff are responding following a death in care. We identified some trusts who used examples and case studies from investigations and complaints. This type of user story and focus on individual experiences method should be considered on a wider scale, and in addition to the plans for developing mortality data, locally and nationally.

Focus on quality and learning

Across our inspections of NHS trusts, we often find concerns around safety culture. Problems include support for reporting and learning from incidents, insufficient record keeping, poor data sharing and systems that are not fit for purpose.[26] This review has found the same issues when we place a spotlight on deaths.

In trusts rated as good and outstanding, we have seen how boards prioritise quality and safety issues. During the review, a number of trusts also told us that they were trying to cultivate a culture of learning. We saw this on some of our site visits, where trusts were trying to embed a just staff culture, in which learning, transparency and openness are valued, encouraged and supported. However, trusts said that trying to change organisational culture was challenging, particularly engaging staff and being able to spend enough time on learning when resources are already stretched.

Over the last decade we have seen a change in attitude towards patient safety culture, and in turn positive changes in practice, but there has not been a clear approach that looks specifically at deaths and what happens when the patient can no longer be involved. For example, although CQC will always look at whether services are safe and people are being protected from harm, our inspection handbook for mental health providers does not include any specific reference to mortality or death.

This will be changed in our next phase of inspections for all services, with a new specific reference to learning from mortality reviews and deaths in the key lines of enquiry that we use when we look at how 'well-led' an organisation is.[n] However, the current lack of oversight and support means that the systems currently in place are not identifying failings or learning, and trusts are not communicating with bereaved families in effective or meaningful ways.

---

n   We are consulting on our next phase of inspection approach in December 2016. Key lines of enquiry refer to the questions we ask of providers during an inspection or informing the information we collect during our monitoring of services.

Findings from our provider information request suggest that learning is not always comprehensively embedded. Trusts often rely on written communication, such as newsletters and reports posted on the intranet, as the primary way to share learning with staff. However, staff felt that the pressures of clinical responsibilities mean they are not always fully considering information when shared in this way. Another challenge when sharing across the trust and between providers is making the content accessible and relevant to all staff from all specialisms.

Our site visits and provider information requests highlighted a variety of approaches that trust boards are taking to improve the way learning is shared with staff, to overcome these challenges. In some trusts, little follow-up, assigned time or support to embed learning was evident. In others, learning was more embedded with specific communication and learning strategies, where messages were tailored to suit specific audiences using a variety of channels. These trusts tended to make sure that staff had dedicated time (for example, monthly learning sessions) and designated roles to do with learning (such as learning groups).

"We have used staff reflective groups to promote a culture of reflection and compassionate practice. These groups emphasise learning from each other in the here and now, in a completely confidential space. Specific workshops using a 'forum theatre' approach have focused on particular themes from external feedback complaints and serious incidents."

Provider information request – mental health trust

The Serious Incident Framework promotes information sharing and encourages providers to share lessons learned at local and national levels to prevent incidents from happening again. However, our provider information request and site visits showed little evidence that learning was effectively shared within and between trusts, even though they recognised how valuable this would be.

PUBLISHING INFORMATION ON LEARNING FROM DEATHS

During the review, we asked providers what type of information they believed could be shared publicly, for example in their Quality Accounts or board reports, to support transparency and improve consistency in the information available to the public. A proposed summary was developed by NHS trusts through our NHS Co-production group and included:

- A summary description of the governance framework that guides how deaths are reported, reviewed and investigated within organisations.

- An explanation of how leadership teams seek assurance that processes after a person dies result in appropriate action and involve families and carers. This should include an outline of what recent changes (if any) have been made to improve local processes and take into account the findings and recommendations made by this review.

- An overview of how leadership teams make sure the views of families and carers are included in investigations and reviews, including any actions taken to improve and support meaningful family involvement in the reporting period.

- A summary of the themes identified from across the reviews and investigations completed in the organisation. This should include a statement of how the themes have been used to inform the selection of any quality priorities for the year ahead and plans for improvements.

This has been shared with the Department of Health to inform future development of the NHS Quality Account.

A key reason for this is the lack of robust local mechanisms to disseminate learning from investigations between trusts and within the wider health economy. These need to be developed so that mistakes are not repeated within trusts, and so that other providers do not have to make the same errors in order to learn from them. While we heard examples of clinical commissioning groups holding mortality review events for trusts to share learning from incidents, this is not common practice.

The National Reporting and Learning System (NRLS) should support national learning. Following the review of individual patient safety incidents that result in severe harm or death, it issues patient safety alerts, which offers the opportunity for cross-organisational learning.

SHARING LEARNING FROM PATIENT SAFETY INCIDENTS: THE NATIONAL REPORTING AND LEARNING SYSTEM (NRLS)

When an error occurs, even if no harm comes from it, any member of NHS staff should use their local reporting system to capture the information so that changes can be made to reduce the risk of it happening again. Local reporting systems also feed into the NHS National Reporting and Learning System (NRLS). This contains around 15 million records of patient safety incidents, including errors that have led to severe harm or the death of a patient.

The National Patient Safety team at NHS Improvement analyse each incident reported as leading to severe harm or death, to identify wider patient safety issues. When a new or under-recognised risk is identified, the team also review incidents reported as no, low or moderate harm, to better understand how to reduce the risks. The team then provides advice and guidance about how to take action by issuing a Patient Safety Alert. Healthcare providers are required to share the alert with the relevant teams in their organisation and put any relevant actions into practice.

There are three types of alerts, all of which are published online:[27]

- **Warning alerts**: typically used to quickly raise awareness of a risk that may be under-recognised and where healthcare providers could take action to reduce the risk of harm. Warning alerts ask healthcare providers to agree and coordinate an action plan, rather than simply distributing the alerts to frontline staff.

- **Resource alerts:** used to ensure healthcare providers are aware of any substantial new resources – typically guidance or toolkits – that will help to improve patient safety, and to ask healthcare providers to plan implementation in a way that ensures sustainable improvement.

- **Directive alerts**: typically issued because a specific, defined action to reduce harm has been developed and tested to the point where it can be universally adopted, or when an improvement to patient safety relies on standardisation (all healthcare providers changing practice or equipment to be consistent with each other) by a set date.

Providers told us that there was a greater emphasis on conducting investigations and completing investigation reports within a set timeframe, over ensuring that the learning from investigations was disseminated and embedded into practice. This was reflected in our provider information request, where one trust said they felt the focus was on getting through the "numbers" rather than learning and improvement. This was echoed by other trusts, suggesting that there needs to be a change with learning and understanding the improvements made or needed. This should be the priority for provider boards, rather than a focus on the numerical measures that will only give part of the picture and can limit the learning achieved about what is and is not working well across services.

"There is a risk in creating an investigative culture with the right balance between enough investigations to ensure good responsive learning culture, and an overbearing culture where the investigation itself takes precedence over the needs of the family and the patient."

Provider information request – mental health trust

Costs and benefits of reviewing and investigating deaths

To help us to understand the current costs of reviews and investigations and how these may vary, we worked with two mental health trusts, one acute trust and one community trust to estimate the costs of the activities they carry out for reviews and investigation when someone in their care dies. We looked at their activities in 2015/16 (**FIGURE 6**).

FIGURE 6: ESTIMATED ANNUAL COSTS TO TRUSTS OF UNDERTAKING DEATH REVIEWS AND INVESTIGATIONS IN 2015/16

		Mental health trust 1*	Mental health trust 2	Community health trust	Acute trust
Estimated total cost		£240,000– £280,000	£640,000	£62,000	£484,000
Total cost as a percentage of trust income		0.16%	0.18%	0.06%	0.05%
Total number of	**Deaths recorded of people who had contact with the trust**	948	948	225	2744
	Provider initial management reviews	218	137	3	100
	Level 1 investigations	32	68	3	100
	Level 2 investigations	10	56	3	7

*Mental health trust 1 also provides community services

FIGURE 7 provides a breakdown of the costs for each trust by the key activities they carry out when reviewing and investigating deaths. The activities that each trust described for the different activities varied. For example, involving family and carers included:

- Going out to visit the family and carers to discuss the incident and to explain that the trust is planning to carry out an investigation.

- Speaking with the family and carers to describe what the investigations will cover and to get their views on the terms of reference for investigation.

- Sharing the findings and recommendations of the report with the family and carers and asking for their comments before publication.

In addition to staff costs on the activities above, it included other costs such as translating the report into different languages for the family and carers, and staff travel costs. The costs are mainly the cost of staff time spent on the different activities carried out during reviews and investigations. Some trusts described the non-staff costs, such as IT software licenses, but these were small in comparison to staffing. The variation in costs, particularly for full investigations, reflects the different methods and levels of staff that trusts use when carrying out an investigation. For example, while mental health trust 1 uses a central team of trained incident investigators to carry out investigations, mental health trust 2 uses senior clinical staff. In contrast to these approaches, the acute provider has a dedicated team of four medical examiners that review the deaths in their trust.

It should be noted that the costs apply to the resources for the current systems in place. Any future developments to improving and strengthening the effectiveness of the reviews and investigations will need to be factored into changes. However, common themes cited by all four trusts around the benefits of carrying out investigations included providing closure and reassurance to those close to the deceased, and learning from incidents to ensure care is improved.

FIGURE 7: ANNUAL COST TO TRUSTS OF CARRYING OUT ACTIVITIES IN REVIEWING AND INVESTIGATING DEATHS (TO NEAREST £000)

	Mental health trust 1*	Mental health trust 2	Community health trust	Acute trust
Identifying and recording deaths	£9,000	£26,000	£24,000	£176,000
Decision making	£32,000	£204,000	£2,000	£43,000
Review and investigation	£51,000	£292,000	£12,000	£237,000
Governance and assurance	£107,000	£32,000	<£1,000	£1,000
Involving family and carers	£63,000	£19,000	£1,000	£10,000
IT costs	Not known	£67,000	£21,000	£16,000

*Mental health trust also provides community services

The cost of litigation

While some trusts may find the costs of conducting an investigation prohibitive, the costs of legal claims to the NHS overall can be even higher. Information from the NHS Litigation Authority (NHS LA) shows that, in the period from 2013/14 to 2015/16, they received 4,110 claims involving the death of a patient. Over the same period, £317 million was paid out on successful clinical claims where someone had died.[o] Many of these claims would have been received in previous years because of the time it takes to settle claims.

Of this £317 million, £164 million was paid to the bereaved in terms of damages, £118 million was paid to cover their legal expenses and £35 million was the cost of legal defence for the NHS.[p] The lower total cost of legal expenses to the NHS may be the result of different factors, for example only 2% of claims will be subject to a court case and require legal representation from the NHS LA, but people making a claim may have had legal representation from the start.[28]

The NHS LA always encourages trusts to say sorry to those who have suffered harm when things go wrong. Saying sorry is not an admission of legal liability; it is the right thing to do. This supports the findings throughout this review, from families, clinicians and staff, that when trusts support a culture that starts with a meaningful apology for any harm or the loss of life, it promotes open communication between services and families and is less likely to lead to families feeling they need to escalate or make legal claims to get the answers they need.

The NHS LA expects local policies to be in place that set out the process of communication and raise awareness of expectations to support openness during the investigation process. There was consensus among Expert Advisory Group members that if trusts are more open and honest about what has happened and apologise for the death of their relative, the bereaved may not feel they need to make a legal claim.

---

o   Claims can also be settled on many factors, and we are unable to distinguish what percentage of the damages related purely to the fatality aspect of the claim.

p   Please note that the NHS Litigation Authority database was designed primarily as a claims management tool rather than for research purposes. A claim may be multi-factorial and/or settled on a number of bases. The fatality figures provided here reflect the total numbers of all claims received annually and the cost to the NHS annually as the claims are closed with damages paid or not. They are not directly related to each other due to the timelines of receipt and investigation. They should not be relied on as a basis for audit or research.

Conclusion, next steps and recommendations

This review set out to discover how NHS trusts in England identify, investigate and learn from the deaths of people who are receiving their care. We conclude that opportunities to improve care for future patients are being missed, because learning from deaths is not currently being given enough consideration in the NHS.

Throughout our review, families and carers have told us they often have a poor experience of investigations and are not consistently treated as equals with kindness, respect and honesty, even though many trusts state that they value family involvement. This was particularly the case for families and carers of people with a mental health problem or learning disability.

We have found a lack of consistency in the way the NHS responds when deaths do occur and how problems in care may have contributed to premature deaths for people. There is currently no single mortality framework that recognises deaths as significant events, and outlines what NHS trusts need to do to maximise learning from these events.

There are a wide range of systems and processes in place, meaning that the way NHS trusts identify, share information and report the deaths of patients varies. This particularly applies to people with a learning disability or mental health problem, who often receive care from multiple organisations, as well as those who die in the community. If trusts are not made aware of a patient's death soon after the death has occurred, opportunities for learning, and opportunities to take action to improve care for future patients, are lost.

Where problems in care will require deaths to be subjected to further reviews or investigations, there needs to be training, support and education on the process for everyone working in the NHS, informed and developed by families and carers. This needs to highlight the importance of getting conversations right, from the first point of contact following the death of a patient and through all ongoing involvement.

Our evidence clearly shows that the quality of investigations varies both between trusts and within trusts. A lack of specialised training and support for staff means that the methods in the Serious Incident Framework are applied inconsistently, and a lack of protected time for staff to complete the review or investigation can affect the timeliness and robustness of the investigation. Trust boards have a major role in ensuring that there is a just learning culture within their organisations, and that opportunities to learn are maximised with improvements in care clearly evidenced. In addition, they need to make sure they keep all deaths in care under review, share learning and act on recommendations both within and beyond their trust.

Across our review we were unable to identify any trust that was able to demonstrate good practice across all aspects of identifying, reviewing and investigating deaths and ensuring that learning is implemented – although we did identify trusts that demonstrated good practice at individual steps in the investigation pathway.

Change is needed to make sure there is learning from the deaths of patients, and that this quickly translates into improved care for other patients. Although the remit of our review was limited to NHS trusts only, our findings and recommendations are applicable to all commissioning or providing NHS-funded care, and should be used to inform changes in the mortality processes and learning from death across local health and care economies. For this to happen there needs to be a change in culture across health care, and a change in approach from all parts of the system.

There is a real opportunity for the NHS to become world leaders in the way learning and investigations are completed and changes are made when a person dies.

We recommend that the Department of Health, supported by the National Quality Board – in partnership with families, clinicians, staff, professional bodies, colleges and the third-sector – do the following:

- Review CQC's findings and recommendations.
- Publish a full response to the review, setting out any progress already made that is starting to address the problems identified and stating how clarity will be provided for families and everyone working in the NHS on 'what good must look like'. This will state timeframes for improvement work and lead organisations, and note how families will be actively involved in developments (April 2017).
- Coordinate improvement work across multiple organisations and publish a full progress report on at least a six-monthly basis.

Next steps

Change is needed to make sure there is learning from the deaths of patients, and that this quickly translates into improved care for other patients. For this to happen health professionals need support from local boards and the wider system to reflect and improve the way they provide care; trust boards, leadership teams and commissioners need to be able to quickly respond to identified needs; and relatives and carers need to be actively involved and to always be treated equally, with honesty, compassion and respect. This will take a change in culture across health care, and a change in approach from all parts of the system.

This report sets out the problems found, the challenges and barriers that exist across healthcare and how – in some areas – families and organisations that support them are trying to overcome these. To support the change that is needed we make specific recommendations below However, these need to be considered, challenged and refined by all, developing and agreeing the best solutions, together.

Accountable bodies must be identified to ensure progress is made and clearly communicated. Importantly, this work must set the tone for how we expect cultures to truly involve families – at all levels of the system. In particular, we need to see honest, open conversations with families when things go wrong, as part of a genuine commitment to reflect, learn and make sure that things are different in the future.

Recommendations

Learning from deaths needs to be a much greater priority for all working within health and social care. Without significant change at local and national levels, opportunities to improve care for future patients will continue to be missed.

Clinicians and healthcare professionals will need to make changes to their practice to improve learning from deaths. They will need to be supported by trust boards and clinical commissioning groups.

National organisations must support local changes, including those for families, carers and others. To do this, national oversight bodies should develop specific guidance related to learning from death. These include the Department of Health, CQC, NHS England, NHS Improvement and Health Education England. Work will need to focus on agreeing definitions of what good looks like in relation to the areas highlighted in this report. For this work to be effective, it must be carried out in partnership with families and carers, and with clinical leadership from the Royal Colleges.

Below we outline the areas that need to improve, with our recommendations for changes to support this.

Learning from deaths needs much greater priority across the health and social care system. Without this, opportunities to improve care for future patients will continue to be missed.

Recommendation 1:

We urge the Secretary of State for Health and all within the health and social care system, to make this a national priority. We suggest that the Department of Health, supported by the National Quality Board – in partnership with families and carers, professional bodies, Royal Colleges and third-sector organisations – undertake the following:

- Review CQC's findings and recommendations.
- Publish a full response to this review, setting out the timeframes for improvement work, identifying lead organisations, and noting how families will be actively involved in the developments (April 2017).
- Coordinate improvement work across multiple organisations and publish a full progress report annually.

Coordinating organisations: Department of Health, CQC, NHS England and NHS Improvement and Royal Colleges.

Healthcare providers should have a consistent approach to identifying and reporting, investigating and learning from the deaths of people using their services, and when appropriate, sharing this information with other services involved in a patient's care before their death.

Recommendation 2:

Leaders of national oversight bodies (NHS Improvement, NHS England and CQC) and Royal Colleges, work together with families to develop a new single framework on learning from deaths. This should define good practice in relation to identifying, reporting, investigating and learning from deaths in care and should complement the Serious Incident Framework. Roles and responsibilities should be clearly defined.

The framework should consider cross-systems processes, leadership and oversight. For example:

- Describe arrangements between primary and secondary healthcare providers and between health and social care organisations and the role of clinical commissioning groups in coordinating investigations involving multiple organisations.

- Describe the roles of regional patient safety teams and Quality Surveillance Groups working in NHS England and NHS Improvement.

- Describe the additional scrutiny to be placed on deaths of individuals with learning disability or mental illness.

- Offer guidance on the role of boards to supporting improvements, how this will be resourced and how this will be regulated.

- Provide guidance on the expectation that the involvement of lawyers should be limited. Where lawyers are involved, there should be a focus on advising in the context of NHS values, the duty of candour, and the principles of patient partnership/involvement.

- Provide guidance for when an independent investigation may be appropriate.

To support the development of the single framework, we also recommend that a single lead for deaths in care in each national organisation is identified so there is a clear and accountable person for escalated issues and consistent involvement in the improvement work we have proposed.

Coordinating organisation: NHS Improvement, NHS England and CQC

Bereaved relatives and carers must always be treated as equal partners and receive an honest and caring response from health and social care providers. Families and carers should be supported to the extent that they wish to be involved, with particular importance and priority given to the first discussion and explanation of the processes that will follow, offering a full and accurate explanation of the reasons the person died and a response to all concerns they have raised about care provided.

Recommendation 3:

NHS Improvement and NHS England, with support from CQC, should lead work to define what families and carers can expect from healthcare providers when they are involved in the investigation process.

This guidance should be developed in partnership with families who have experienced the investigation process and should include how families can be offered access to timely independent advice and understand what resources are available to support them during the process. The guidance should set standards for local services on the information to be offered – for example, how and when families may be contacted about investigations, what local support is available, 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, and how this will be communicated, nationally and locally.

The guidance should ensure that:

- Families' views are proactively sought and used to inform decisions around whether a review or investigation is needed.

- When a decision is made that an investigation should be carried out, families and carers should be involved to the extent that they wish and treated as equal partners in this alongside NHS staff.

- Families and carers are involved in setting terms of reference, are kept fully informed of the progress of an investigation and offered an opportunity to shape the report, as well as updated on how this leads to improvements in care (if they wish).

Coordinating organisations: NHS Improvement and NHS England supported by CQC

The deaths of people with a learning disability or severe mental illness are not consistently receiving the attention they need – both from healthcare professionals locally and at national level. NHS England's work to review the deaths of individuals with a learning disability is a significant step forward, but more is needed

Recommendation 4:

NHS England and NHS Improvement should coordinate solutions to the range of issues we set out for people with mental health conditions or a learning disability across national bodies, including the Royal Colleges. This should aim to improve consistency, definitions and practices that support the reduction of the increased risk of premature death.

Coordinating organisations: NHS England and NHS Improvement

Systems and processes need to be developed and implemented to ensure that all relevant providers are aware when a patient dies and that information from reviews and investigations is collected in a standardised way

Recommendation 5:

NHS Digital and NHS Improvement assess how they can facilitate the development of:

- Reliable and timely systems, so information about a death is available to all providers who have recently been involved in that patient's care.

- A standard set of information to be collected on all patients who have died. In addition to demographic information, this should include information on whether the patient had a learning disability or mental health diagnosis and the outcome of screening for concerns in care. This should include concerns from the family as well as clinical staff.

- Processes to collate information about patient deaths that can be analysed by patient characteristics, such as diagnoses or services used. This information, combined with the findings from reviews and investigations should form the basis of audits to be presented to trust boards.

Coordinating organisations: NHS Digital and NHS Improvement

Reviews and investigations need to be carried out to a high quality, with a focus on system analysis rather than individual errors. Staff require specialist training and protected time to carry out investigations to help ensure that these identify missed opportunities for prevention of death and to improve care.

Recommendation 6:

Health Education England should work with the Healthcare Safety Investigation Branch (HSIB) and providers to develop approaches to ensuring that staff have the capability and capacity to carry out good investigations of deaths and write good reports, with a focus on these leading to improvements in care. This work needs to be factored into job descriptions and work plans. Investigation teams must be comprised of staff who have mental health and learning disability expertise, where relevant, as well as the skills to apply the Duty of Candour compassionately, and the skills to support individuals at a time of complex bereavement. Within this, we propose that an accredited training programme for people undertaking hospital-led investigations needs to be considered.

Coordinating organisation: Health Education England.

To ensure that learning from deaths is given sufficient priority at a local level, provider boards and clinical commissioning groups must take action without delay on this report and implement national guidance when this becomes available.

Recommendation 7:

Provider organisations and commissioners must work together to review and improve their local approach following the death of people receiving care from their services. Provider boards should ensure that national guidance is implemented at a local level, so that deaths are identified, screened and investigated, when appropriate and that learning from deaths is shared and acted on. Emphasis must be given to engaging families and carers.

Provider boards should ensure:

- Patients who have died under their care are properly identified.
- Case records of all patients who have died are screened to identify concerns and possible areas for improvement and the outcome documented.
- Staff and families/carers are proactively supported to express concerns about the care given to patients who have died.
- Appropriately trained staff are employed to conduct investigations.
- Where serious concerns about a death are expressed, a low threshold should be set for commissioning an external investigation.
- Investigations are conducted in a timely fashion, recognising that complex cases may require longer than 60 days.
- Families and carers are involved in investigations to the extent that they wish.
- Learning from reviews and investigations is effectively disseminated across their organisation, and with other organisations where appropriate.

- Information on deaths, investigations and learning is regularly reviewed at board level, acted upon and reported in annual Quality Accounts.
- That particular attention is paid to patients with a learning disability or mental health condition.

We also recommend that provider Boards strongly consider nominating a non-executive director to lead on mortality and learning from deaths.

Lead organisations: Boards in NHS trusts and other healthcare organisations.

What CQC will do:

CQC will continue to be actively involved in translating these recommendations into actions through our involvement in the National Quality Board, and through the recommendations noted above. Specifically we plan to:

1. Strengthen CQC's assessment of learning from deaths to cover the process by which providers identify patients who have died and decide which reviews or investigations are needed, with particular emphasis on:

- patients with a learning disability or mental health problem
- quality of investigations carried out by trusts
- reports to trust boards on learning from death
- action taken in response to learning from death
- how trusts have involved families and carers in reviews and investigations

CQC will also review how learning from death is documented in impact reports.

2. In addition to our involvement in the wider changes needed, we will use our independent voice to:

- Share our findings and insight about the quality of systems and processes in place across health and social care, including for people with mental health conditions or a learning disability, to encourage improvement at a local and national level.
- Encourage our inspection teams to report and identify good practice examples that emerge from the local development work that is taking place across the country, sharing examples in our national reports or in other communications as needed.

Appendix A: Deaths of NHS patients – roles and responsibilities

In this section we describe some of the main organisations that have direct or indirect roles or responsibilities in relation to incidents resulting in the death of an NHS patient. Almost all of the organisations listed have other roles and responsibilities too.

Organisation	Roles and responsibilities
Academy of Medical Royal Colleges	• Coordinates sharing of information between its 23 member colleges and faculties to help ensure consistent learning from deaths (and other sources) across all specialities.
Care Quality Commission (CQC)	• Receives National Reporting and Learning System (NRLS) data on deaths for NHS trusts, and uses this and other intelligence to prioritise and focus inspections. • Lead health and safety enforcement body when patients die/are harmed in registered health and social care services. • Receives direct notifications of all deaths of people detained under the Mental Health Act. Shares this information with national oversight systems including the Ministerial Board on Deaths in Custody. • Investigates complaints from/on behalf of people subject to the Mental Health Act, including in relation to deaths in detention (no powers to investigate other complaints).
Clinical commissioning groups (CCGs)	• Coordinate and disseminate learning from local deaths and near misses. • May commission or participate in some reviews or investigations.
Crown Prosecution Service (CPS)	• Decides which cases of death should result in prosecution. • Determines the charges in serious or complex cases. • Prepares cases and presents them at court. • Provides information, assistance and support to victims and prosecution witnesses.
Department of Health	• Leads on creation of national policies and legislation, which may be influenced by learning from deaths. • Accountable to UK Parliament for the performance of the NHS.
Fire and Rescue Service	• Investigates deaths that may have resulted from fire, gas, chemical or radiation incidents. • Has power to prosecute.

Organisation	Roles and responsibilities
Healthcare providers	• Verify death (or arranges for verification).
	• Notify family/carers.
	• Notify coroner if criteria met.
	• Notify police/fire service/other organisations if criteria met.
	• Comply with internal reporting requirements.
	• Comply with national reporting requirements.
	• Liaise with other relevant providers involved in the patient's care.
	• Decide whether review or investigation criteria are met.
	• Liaise with family/carers.
	• Conduct review or investigation if criteria met.
	• Involve and support family/carers if they wish.
	• Report on review or investigation.
	• Disseminate any learning internally.
	• Liaise with CCG/other relevant bodies to disseminate learning externally.
	• Prepare and implement action plan if required.
	• Monitor and review action plan progress.
	• Respond to any complaints arising from the death.
Healthcare Safety Investigation Branch (HSIB)	• Carries out independent safety investigations led by experts.
	• Identifies causes of harm and publishes reports with recommendations.
Health Education England (HEE)	• Ensures the health workforce has the right number of staff with the right skills, values and behaviours, so embeds learning from deaths (and other sources) in education and training outcomes.
Local authorities	• Register deaths.
	• Arrange public health funerals and disposal of assets if no next of kin.
	• Are involved in safeguarding investigations.
	• Have public health duties if death attributable to public health incident.
Local coroner	• Statutory duty to investigate all unnatural deaths, including those in state detention. Limited role in investigating unknown causes of death which turn out to be natural. Highlights concerns to prevent future deaths.
Local independent advocacy services	• May represent a deceased patient during review or investigation using a non-instructed rights-based approach if the patient's human rights or rights under the Equality Act 2010 may have been infringed.
	• Involvement post-death will depend on local commissioning arrangements.

Organisation	Roles and responsibilities

Local Safeguarding Boards – adults and children	• Safeguarding Children Boards have a statutory duty to undertake reviews if abuse or neglect of a child is known or suspected; and the child has died.
	
	• Safeguarding Adults Boards will become involved in investigations if the deceased patient had support needs, to
	  – help coordinate a response
	  – ensure agencies and individuals respond appropriately when abuse or neglect have occurred
	  – use lessons learned to improve support to other adults who may be vulnerable.

Medicines and Healthcare products Regulatory Agency (MHRA)	• Investigates medicines and medical devices if they are implicated in a death and a manufacturing defect is suspected; issues alerts and recalls when appropriate. • Operates a system for clinicians to report adverse incidents (including deaths) involving medicines, medical devices, blood and counterfeit products.
NHS Digital	• The national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care, including production of national data sets such as Hospital Episode Statistics (HES) and the Mental Health Services Data Set (MHSDS), and the publication of statistics including the Summary Hospital-level Mortality Indicator (SHMI).
NHS England (NHSE)	• Investigates homicides committed by patients being treated for mental illness.
NHS Improvement (NHSI)	In 2016, NHSI took over the statutory functions of the National Patient Safety Agency including: • operation of the National Reporting and Learning System (NRLS) • the Strategic Executive Information System (STEIS) • development of advice and guidance for the NHS on reducing risks to patients.
NHS Litigation Authority	• Offers indemnity cover to NHS providers (and independent providers of NHS-funded care) and manages claims against them. • Shares lessons from claims and other legal and professional cases. • Resolves concerns about professional practice through the National Clinical Assessment Service (NCAS).
National Institute for Health Research	• Manages Patient Safety Translational Research Centres which conduct and support research to improve safety, quality and effectiveness of services within the NHS.
National Quality Board	• Ensures the alignment of the systems for managing and improving quality to prevent avoidable deaths and other adverse incidents.

Organisation	Roles and responsibilities
Office for National Statistics	• Produces an annual report on deaths in England and Wales broken down by age, sex, area and cause of death. • Produces annual reports on specific types of death, for example, infants aged under one year or suicides.
Parliamentary and Health Service Ombudsman	• Makes final decisions on complaints in relation to deaths and other matters that have not been resolved by the NHS (and some other organisations); this includes NHS-funded care and treatment that takes place in independent healthcare settings.
Police	• Investigate deaths when criminal activity is suspected.
Professional regulatory bodies	Includes the General Medical Council, the General Pharmaceutical Council, the Health and Care Professions Council and the Nursing and Midwifery Council. • Maintain professional standards of conduct. • Resolve complaints against their registered practitioners.
Public Health England (PHE)	• Supports the management of deaths and other serious incidents within health services when there is potential for the wider population to be adversely affected.

Appendix B: Trusts visited

Trust type	Trust name
Acute	• Homerton University Hospital NHS Foundation Trust
	• Norfolk and Norwich University Hospitals NHS Foundation Trust
	• Royal Devon and Exeter NHS Foundation Trust
	• Sheffield Teaching Hospitals NHS Foundation Trust
Community	• Gloucestershire Care Services NHS Trust
	• Hounslow and Richmond Community Healthcare NHS Trust
	• Leeds Community Healthcare NHS Trust
	• Staffordshire and Stoke on Trent Partnership NHS Trust
Mental Health	• Cumbria Partnership NHS Foundation Trust
	• Dorset Healthcare University NHS Foundation Trust
	• North Essex Partnership NHS Foundation Trust
	• West London Mental Health NHS Trust

Appendix C: Expert advisory group membership

We worked with an expert advisory group (EAG) who provided advice and guidance throughout the review. The EAG was made up of representatives from family and patient groups, national agencies, NHS trusts and voluntary sector organisations.

- Action Against Medical Accidents
- Action on Elder Abuse
- Bindmans LLP Civil Liberties & Social Welfare
- Challenging Behaviour Foundation
- Consequence UK
- Coroners' Society
- Council For Disabled Children
- Department of Health
- Disability Rights UK
- Equality and Human Rights Commission
- Foundation of People with Learning Disabilities
- Generate (Opportunities Ltd)
- Healthwatch England
- HundredFamilies
- INQUEST
- Mazars
- Mental Health Foundation
- Mental Health Network
- Mental Welfare Commission for Scotland
- National Children's Bureau
- National Development Team for Inclusion
- NHS Confederation
- NHS Commissioners Confederation
- NHS Digital
- NHS England
- NHS Improvement
- NHS Litigation Authority
- NHS Providers
- Parliamentary and Health Service Ombudsman
- Prison Probation Ombudsman
- Race Equality Foundation
- Regulation and Quality Improvement Authority
- Rethink Mental Illness
- Scope
- Solent NHS Trust
- Southerns Law
- Sussex Partnership Foundation Trust
- The Royal College of Pathologists
- University of Bristol (Learning Disabilities Mortality Review Programme)
- Yorkshire and Humber Academic Health Science Network

References

1. Office for National Statistics, Death registrations summary tables – England and Wales for 2015

2. Public Health England, National End of Life Care Intelligence Network, Place of Death for 2015

3. Parliamentary and Health Service Ombudsman, **A review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged**, December2015

4. NHS England, **Development of the Patient Safety Incident Management System (DPSIMS)**

5. NHS England, *Serious Incident Framework*, March 2015, page 7

6. Department of Health, *Providing a 'safe space' in healthcare safety investigations* – Consultation, October 2016

7. Care Quality Commission, **A different ending: Addressing inequalities in end of life care**, May 2016

8. Department of Health, **Guidance: An overview of the death certificate reforms**, May 2016

9. Department of Health, **Guidance for access to health record requests**, February 2010

10. Department of Health, **Confidentiality: NHS Code of Practice Supplementary Guidance: Public Interest Disclosures**, November 2010

11. NHS England, *Serious Incident Framework*, March 2015, pages 61–62

12. Regulation 17, Care Quality Commission, (Registration) Regulations 2009, **www. cqc.org.uk/content/regulation-17-notification-death-or-unauthorised-absence-service-user-who-detained-or-liable**

13. Equality and Human Rights Commission, **Preventing deaths in detention of adults with mental health conditions**, February 2015

14. NHS England, *Serious Incident Framework*, March 2015, page 21

15. NHS England, *Serious Incident Framework*, March 2015, pages 37–38

16. Parliamentary and Health Service Ombudsman, **A review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged**, December 2015

17. NHS England, **Root Cause Analysis (RCA) tools: analysing to identify contributory factors and root causes**, August 2010

18. NHS England, *Serious Incident Framework*, March 2015, pages 60-68

19. R. (Dr Michael Antoniou) v (1) Central and Northwest London NHS Foundation Trust; (2) Secretary of State for Health; (3) NHS England, July 2013, **www.judiciary.gov. uk/wp-content/uploads/2015/12/r-antoniou-v-central-and-northwest-london-nhs-foundation-trust-2013-ewhc-3055-admin.pdf**

20. Ministry of Justice, **Report of the Chief Coroner to the Lord Chancellor. Third annual report: 2015–2016**, September 2016. Issues of concern number 120-128

21. Office for National Statistics, Death registrations summary tables – England and Wales for 2015

22. Ministry of Justice, **Report of the Chief Coroner to the Lord Chancellor. Third annual report: 2015–2016**. September 2016.

23. Care Quality Commission, **Monitoring the Mental Health Act in 2015/16**, November 2016, page 16

24. R. (Dr Michael Antoniou) v (1) Central and Northwest London NHS Foundation Trust; (2) Secretary of State for Health; (3) NHS England, July 2013, **www.judiciary.gov. uk/wp-content/uploads/2015/12/r-antoniou-v-central-and-northwest-london-nhs-foundation-trust-2013-ewhc-3055-admin.pdf**

25. Department for Education, **Guidance: Child death overview panels: contacts**, October 2016

26. Care Quality Commission, **The state of health care and adult social care in England 2015/16**, October 2016

27. NHS Improvement, Patient Safety Alerts, **https://improvement.nhs.uk/news-alerts/?articletype=patient-safety-alert**

28. NHS Litigation Authority, How we handle claims, **www.nhsla.com/Claims/Pages/Handling.aspx**

How to contact us

Call us on ❯ 03000 616161

Email us at ❯ enquiries@cqc.org.uk

Look at our website ❯ www.cqc.org.uk

Write to us at

Care Quality Commission
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

Follow us on Twitter
@CareQualityComm

Please contact us if you would like a summary
of this report in another language or format.

Corporate member of
Plain English Campaign
Committed to clearer
communication

459

CQC–356–122016