

LEARNING, CANDOUR AND ACCOUNTABILITY: A REVIEW OF THE WAY NHS TRUSTS REVIEW AND INVESTIGATE THE DEATHS OF PATIENTS IN ENGLAND

INTRODUCTION AND SUMMARY

The Care Quality Commission has today published a review of how NHS acute, mental health and community trusts and foundation trusts review and investigate deaths of patients in care. The [report](#) provides helpful insight into the system-level and local challenges to effective investigations, greater candour and transparency, and learning from deaths across the NHS. Overall, the review found that:

- Families and carers often reported a poor experience of investigations and felt they were not always treated with kindness, respect and honesty, especially for people in mental health or learning disabilities services.
- There is no single framework for NHS trusts that sets out the approach to learning from deaths, which means there is wide variation in systems and processes in place locally. As a result, learning from deaths is not being considered appropriately in the NHS and opportunities to improve care for future patients are being missed.
- There are trusts that demonstrate elements of promising practice at individual steps in the investigation pathway, but none that could demonstrate good practice across all aspects of identifying, reviewing and investigating deaths and ensuring that learning is implemented.

The CQC makes seven recommendations that require action across the health system. The Secretary of State [responded today](#) in Parliament to the recommendations, with a range of measures for all acute, mental health, community and learning disabilities providers that will require new regulations, to come into effect on 31 March 2017, including:

- New reporting requirements on a standardised set of information to be collected and published quarterly by providers on all deaths and serious incidents, including estimates of avoidable death at the trust and action plans setting out what action must be taken;
- A new single framework will be developed for identifying, reporting, investigating and learning from deaths in care that defines what families and carers can expect from providers during investigations, and addresses the specific challenges affecting persons with mental health or learning disabilities needs;
- Trusts must identify a board-level leader as patient safety director to take responsibility for this agenda and ensure it is prioritised and resourced, and appoint a non-executive director to take oversight of progress;
- Specific measures undertaken by providers and commissioners to address the identified shortcomings in governance, assurance, family and carer involvement, and learning at organisational level, to which boards will be expected to respond in due course and in alignment with the system-level response;
- A focus on the mortality of people with mental health and learning disabilities, especially in acute settings.

This briefing summarises the key findings main points from each of the thematic chapters in the report, the recommendations, the response from the Secretary of State, and NHS Providers [media statement](#). We recommend that members review the full content of the report, particularly the sections examining board governance of the quality and outcome of mortality reviews and investigations. CQC will embed its review of this work into the 'well led' domain of its inspection framework for all acute, mental health, community and learning disabilities services providers going forward.

OVERVIEW OF REPORT

Introduction and methodology

In December 2015, as a response to the findings of the NHS England-commissioned review into the deaths of people receiving learning disability and mental health services from Southern Health NHS Foundation Trust, the Secretary of State commissioned the CQC to assess:

- how trusts identify, review, investigate and learn from deaths of people in receipt of their care;
- whether opportunities for improving care have been missed especially for people using mental health or learning disability services; and
- recommend changes in policy and process to drive improvements in learning, candour and quality of care

CQC's review examined the 'death in care' of any person receiving, or who had recently received, care from an acute, mental health or community NHS trust, whose death occurred within six months of the person's last contact with any service at a trust, or their last date of discharge from an inpatient setting. The methodology encompassed:

- site visits at 12 acute, community healthcare and mental health NHS trusts with in-depth reviews of processes, patient records, mortality review case notes, investigations and staff interviews;
- data analyses encompassing a survey completed by 212 NHS provider trusts and foundation trusts, national statistics datasets, and the NHS staff survey;
- analysis of board papers and minutes of 48 trusts covering meetings held December 2015 - February 2016;
- interviews and feedback from families, carers and charities;
- stakeholder engagement through monthly Expert Advisory Group meetings (which NHS Providers attended).

The review was guided by five 'key questions' around which the CQC's report is structured:

Theme	Key Question
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 undertaken properly and in a way that is likely to identify missed opportunities for prevention of 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 in receipt of care?

1. How families and carers are involved and treated

The first chapter reviews the family and carer involvement and experience of their engagement with the NHS including how they are informed of a death, their involvement in the investigation process, and their access to information, reporting and learning. It reports the feedback from CQC's family and carer engagement activities.

Key findings:

- 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 involvement of families and carers in reviews and investigations of their relative's death varies considerably and they are not always informed or kept up to date about investigations, which 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 because they see the whole pathway of care that their relative experienced.
- Trusts reported experiencing challenges balancing the requirement to keep families involved and informed and to complete investigations within the required 60-day timeframe
- NHS staff reported feeling inexperienced and lacking in necessary skill to involve families in investigations without adding to their distress. Involving lawyers early on tended to exacerbate the distrust felt by families.

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

This chapter explores the processes by which trusts currently identify and report the deaths of people who are in their care, what systems are used and how deaths are categorised as warranting further review or investigation. It examines the way in which the system, as currently organised, prevents the effective sharing of information to ensure that deaths are notified to all relevant providers and that the assessment of care quality prior to a person's death considers care beyond the settings of the lead provider conducting the investigation.

Key findings:

- There is no clear and consistent picture of what constitutes good practice in identifying and reporting deaths, unless a person dies while they are receiving care in an inpatient setting.
- As a consequence, there is variation and inconsistency across the NHS in the way organisations become aware of the deaths of people in their care, with organisations being reliant on information shared by others to be notified when a death occurs outside their inpatient services.
- Many patients who die have received care from multiple NHS providers in the months before death. In such circumstances, 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 learning disabilities die in NHS hospitals or while receiving care from the community services of NHS trusts.
- Electronic systems do not support information being shared between NHS trusts or with others outside the service that have been involved in a patients' care before their death, and create confusion for staff about what should be recorded as an incident.
- Electronic systems do not support the effective identification of people with a mental health or learning disability who die while receiving care.

3. Making the decision to review or investigate

This chapter 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. It reviews the tools and methodology for making decisions to investigate, the level of investigation needed, who is responsible for leading it, and whether there are clear responsibilities and expectations to support decision making.

Key findings:

- NHS staff understand the expectation to report patient safety incidents and are using the Serious Incident Framework 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 a death 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.
- In the absence of a single national framework that specifically supports the review and decisions needed for deaths, which may warrant 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 used to identify and report deaths, leading to decisions across trusts based on local procedures and reported in different ways to CCGs.
- Timely access to information by clinicians and staff is constrained by difficulties experienced in getting clinical information about the patient from others involved in delivering care, including from primary care services.

4. Reviews and investigations

This section of the report focuses on how reviews and investigations are carried out, the quality of the investigations, the training and support available to investigators, independence of investigations, involvement of coroners, timeliness of reporting and whether opportunities for preventing death and improving services have been missed.

Key findings:

- Most 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 that affect the robustness of investigations, including meaningful involvement of 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 needs such as mental health or learning disability.

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

This section focuses on whether NHS trust boards have effective governance arrangements to drive quality and learning from the deaths of patients in their care. It explores how boards monitor the deaths of patients in their care, support a culture of learning and share information about safety challenges.

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.

Conclusions, next steps and recommendations

The final section reviews the key findings and areas for improvement discussed in the previous sections, and sets out recommendations with coordinating organisations (mainly national bodies) to lead on the response:

Recommendation 1: to make learning from deaths a national priority the Department of Health, supported by the National Quality Board – in partnership with families and carers, professional bodies, Royal Colleges and third-sector organisations – to:

- 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.

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. 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 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.

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 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).

Recommendation 4: NHS England and NHS Improvement should coordinate solutions to the range of issues identified for people with mental health conditions or a learning disability across national bodies. 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 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.

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. An accredited training programme for people undertaking hospital-led investigations needs to be considered.

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 care given to patients who 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 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.
- provider Boards should strongly consider nominating a non-executive director to lead on mortality and learning from deaths.

CQC will strengthen its 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 and encourage inspection teams to report and identify good practice examples that emerge from local development work in response to this review.

RESPONSE BY THE SECRETARY OF STATE

The Secretary of State's statement to the House of Commons announced a range of measures to address the recommendations. For trusts, these will include:

- From March 31 2017 the boards of all NHS Trusts and Foundation Trusts will be required to:
 - Collect and report to NHS Improvement a range of specified information, to be published quarterly (this requirement will be confirmed in new regulations), on deaths that were potentially avoidable and serious incidents and consider what lessons need to be learned on a regular basis.
 - This will include estimates of how many deaths could have been prevented in their own organisation and an assessment of why this might vary positively or negatively from the national average, based on methodology adapted by the Royal College of Physicians from work by Professor Nick Black and Dr Helen Hogan.
 - Publish evidence of learning and action that is happening as a consequence of that information.
 - Identify a board-level leader (likely the medical director) as patient safety director to take responsibility for this agenda and ensure it is prioritised and resourced within their organisation.
 - Appoint a non-executive director to take oversight of progress.

- Follow a new, standardised national framework to be developed for identifying potentially avoidable deaths, reviewing the care provided, and learning from mistakes.
- Government will ensure that investigations of any deaths that may be the result of problems in care are more thorough and genuinely involve families and carers.
- The NHS National Quality Board will draw up guidance on reviewing and learning from the care provided to people who die, in consultation with the new Chief Investigator of Healthcare Safety. These guidelines will be published before the end of March 2017, for implementation by all Trusts in the year starting April 2017.
- Health Education England will review the training for all doctors and nurses with respect both to engaging with patients and families after a tragedy and maintaining their own mental health and resilience in extremely challenging situations.

To address particular challenges for the investigations of deaths of people with learning disabilities:

- The Government will ensure that the NHS reviews and learns from all deaths of people with learning disabilities, in all settings.
- The Learning Disabilities Mortality Review Programme will provide support to both families and local NHS areas to enable reporting and independent, standardised review of all learning disability deaths between the ages of 4 to 74.
- There will be coverage in all regions by the end of 2017 and full national roll out by 2019.
- As the programme develops, all learnings will be transferred to the national avoidable mortality programme.
- The LeDeR programme has been asked to provide annual reports to the Department of Health on its findings and how best to take forward the learnings across the NHS.
- In acute trusts: particular priority will need to be given to identifying patients with a mental health problem or a learning disability to make sure their care responds to their needs; and that special effort is made during any mortality investigations to ensure wrong assumptions are not made about the inevitability of death for these patients.

The Secretary of State also emphasised that he will not be setting any target for reducing reported avoidable deaths, as does not believe it will be valid to compare numbers between hospitals because the data depends on clinical views which may change or vary. However, he expects to see an increase in the number of reported avoidable deaths as a likely result of hospitals getting "better at spotting and reporting them, than because care is deteriorating."

MEDIA STATEMENT

Vital to work with trusts to improve inconsistencies in investigating patient deaths

- CQC release report following review of investigation processes into patient deaths by NHS trusts
- Regulator expresses concerns that opportunities to learn from deaths are missed
- We welcome important report which exposes inconsistencies in practice. It's vital that circumstances around a patient's death are well understood, and if warranted, investigated to ensure lessons are learnt to improve quality of care

Today, the Care Quality Commission released its report following a national review about the quality of investigation processes led by NHS trusts into patient deaths.

The quality regulator has raised significant concerns about the processes undertaken by many trusts and the failure to prioritise learning from deaths so that action can be taken to improve care for future patients and their families.

The CQC's review was carried out at the request of the Secretary of State for Health following the findings of the NHS England commissioned report into the deaths of people with a learning disability or mental health problem who were being cared for by Southern Health NHS Foundation Trust.

Responding to the CQC's report on the way trusts review and investigate the deaths of patients, the chief executive of NHS Providers, Chris Hopson, said:

"When a person dies under NHS care, bereaved families and carers must be treated with honesty, respect and compassion. It is also vital that the circumstances surrounding the person's death are well understood and, if warranted, investigated to ensure that the NHS learns lessons that can improve the quality of care. Families need to know that the NHS will recognise and act on any failings in care to prevent them happening again.

"We welcome this important report from the Care Quality Commission. It exposes inconsistencies and variations in practice across the NHS and within trusts which mean opportunities to learn from deaths and improve care are being missed.

"There are particular problems identifying and investigating the deaths of people who were being helped by a number of different services at the same time for a range of often-complex conditions, and who died out of hospital. This is frequently the case for those receiving NHS mental health or learning disability services, reinforcing health inequalities.

"We need significant change at local and national levels to resolve this.

"The CQC has identified some areas of good practice by trusts that can serve as examples for others to follow. The CQC has also recognised the commitment of NHS staff to making change happen.

"We look forward to supporting our members in working with the Department of Health and national bodies to develop the CQC's recommendations into clear improvement in care and to ensure families feel they have always been treated with kindness and candour."

NHS Providers

13 December 2016