

Learning, candour and accountability

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

SUMMARY



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

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.

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