Learning from deaths

A review of the first year of NHS trusts implementing the national guidance

Care Quality Commission

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- We use our legal powers to take action where we identify poor care.
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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

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Foreword

In December 2016, our report *Learning, candour and accountability* detailed our concerns about the way NHS trusts investigate and learn from the deaths of people in their care, and the extent to which families and carers are involved in the investigations process.

Guidance issued by the National Quality Board in March 2017, the specific guidance for NHS trusts on working with families and carers, published in July 2018, and the announcement of the new arrangements for introducing medical examiners are welcome developments. This report, through examples and case studies, shows that we are beginning to see the start of progress in NHS trusts in terms of implementing this guidance.

However, we are concerned that we are still seeing the same issues persist in some NHS trusts more than two years on. In particular, involvement and engagement with bereaved families and carers is an area with which some trusts continue to struggle. Issues such as fear of engaging with bereaved families, lack of staff training, and concerns about repercussions on professional careers, suggest that problems with the culture of organisations may be holding people back from making the progress needed.

In our recent report *Opening the door to change: NHS safety culture and the need for change*, we called for transformation of safety, leadership and culture. Our findings in this report emphasise the necessity of this. While there is no one factor that guarantees good practice, the report highlights the need for having an open and honest culture in place where people feel they can speak up. This also needs to happen at a system-wide level, where organisations need to engage with families and carers, be open with each other and share information and learning to improve the care they provide, rather than perpetuating a culture of blame.

Cultural change is not easy and will take time. However, the current pace of change is not fast enough. NHS trusts need to use the findings of this report to remind themselves of the key drivers to improve learning from deaths, to build on progress made so far and to accelerate the changes needed.

Our report acknowledges that to make these changes, there needs to be continued support from the centre, including support for behaviours that encourage more openness and learning across the NHS. CQC also has a role in supporting this change, and we will continue to strengthen how we look at and assess the issues identified in our report as part of our focused well-led inspections.

Professor Ted Baker

Chief Inspector of Hospitals

Introduction

Since September 2017, we have been assessing NHS trusts' implementation of national guidance on learning from deaths as part of our new well-led inspections. Now that most of these reviews have been completed, we are reporting back as part of our commitment to the Learning from Deaths Programme Board. It is very early stages, both in the implementation of the guidance and of our well-led inspections. This report provides a very first look at observations from our inspection teams, as well as an indication of the types of enablers and barriers that we have seen trusts face in implementing the guidance, and is not necessarily representative of all trusts' experiences.[1] The report acknowledges that it is early days for trusts and that it will take time to change attitudes and culture in the NHS, including how the NHS engages with families. To help encourage improvement we have included examples of good practice to inspire NHS trust staff to continue to improve how they review and learn from deaths.

Background

In December 2015, the Secretary of State for Health commissioned CQC to carry out a review of how acute, community and mental health trusts across the country investigate and learn from deaths to find out whether opportunities for preventing deaths have been missed, and identify any improvements needed. This followed the publication of NHS England's report into Southern Health NHS Foundation Trust's investigation of deaths, and in particular its handling of the investigation into the death of Connor Sparrowhawk, who had a learning disability and epilepsy, and died while under the care of the trust in 2013.[1,2] As a result, a key focus of CQC's review was how trusts investigate the deaths of people with a mental health problem or learning disability.

We published the findings from this review in December 2016. Our report, *Learning, candour and accountability* highlighted that there were generally poor experiences for families and carers in how deaths were identified and reported, in the quality of reviews and investigations, and how they were engaged in the process, with no consistent frameworks used by NHS trusts providing acute, community or mental health services.[3,4]

Following the publication of the report, the Department of Health and Social Care established the Learning from Deaths Programme Board, overseen by the National Quality Board, to implement the report's recommendations. In March 2017, the National Quality Board issued national guidance for NHS trusts on learning from deaths.[5] The purpose of the national guidance was to initiate a standardised approach on learning from deaths in NHS trusts providing acute, mental health and community health services. It included:

- the need to have processes that identify those deaths that result from problems in care
- the appointment of an executive director and non-executive director to take responsibility for oversight of progress
- having a clear policy in place for engaging with bereaved families and carers

[1] See appendix for more details on the methodology

- ensuring staff reporting deaths have appropriate skills and protected time to review and investigate deaths to a high standard
- minimum requirements on collecting data and reporting, with NHS trusts expected to collect, and publish on a quarterly basis, information on deaths of people in their care, effective from April 2017. Trusts were expected to publish their policy and approach by summer 2017, and then publish data and learning points by autumn 2017.[6]

The national guidance was followed in July 2018 with specific guidance for NHS trusts on working with families and carers.[7] This was co-produced with families and carers to provide trusts with advice on how they should support, communicate and engage with families following the death of someone in their care. This guidance expanded on the principles in the national guidance to provide more details to reflect the feedback and experiences of families and carers. It set expectations for what families can expect from NHS trusts.

Since the publication of our report, there have been a number of other reports and developments that support the findings of our review and aim to address the issues highlighted. For example, the government's response to the Gosport Independent Panel Report, published in November 2018, emphasised the importance of NHS staff, patients and families speaking up with concerns about care. This followed the government's response to a consultation in June 2018 for the introduction of medical examiners from April 2019.[8] The aim of introducing this new system is to make sure that all deaths not investigated through the coronial process are subject to a degree of independent scrutiny, with increased transparency for the bereaved and an opportunity for them to raise any concerns.

CQC's report *Opening the door to change: NHS safety culture and the need for change*, which published in December 2018, similarly called for a change in culture in the NHS to reduce the number of patients who experience avoidable harm.[9] As referenced in the report, the National Patient Safety Strategy, which is being developed by NHS Improvement, will provide another important opportunity to support NHS trusts to embed safety as a top priority.

What we did

This report is based on a qualitative analysis of interviews and focus groups with inspection staff and specialist advisors involved in well-led inspections between September 2017 and June 2018. We interviewed eight inspection staff, two CQC specialist advisors and held four focus groups with a total of 12 inspection staff. These interviews and focus groups focused specifically on understanding how well trusts have been implementing the national guidance, and the enablers of and barriers to good practice. We also used these discussions to identify examples of good practice. Some of these examples are included in this report, with text drawn from our published inspection reports. Where possible, we have engaged through trusts with local patient, family and carer groups to comment on these, and verify that they reflect their experiences.

We also carried out a case study analysis of three trusts that were rated as outstanding for well-led between September 2017 and June 2018. This focused specifically on the quality of their processes for learning from deaths and the factors that had supported good practice in learning from deaths. More details about our methods are available in appendix A.

In support of the qualitative analysis, we held a discussion with NHS trusts at our NHS co-production meeting in November 2018.

Findings have been corroborated and in some cases supplemented with expert input from our external NHS co-production group, which includes representatives of families, carers and trusts, and other stakeholders, including voluntary sector organisations, to make sure that the report represents what we are seeing in our inspections.

How well are trusts implementing the guidance?

During our first year of inspecting how trusts are learning from deaths, we have seen that how they are implementing the learning from deaths guidance varies. Trusts are at different stages of implementing the guidance, with some finding it more difficult than others to make the changes needed.

Analysis of our interviews and focus groups with inspection staff suggests that awareness of the national guidance is high, and we have seen some trusts taking action to revise policies and establish oversight of learning from deaths.

However, there is some, albeit limited, evidence to suggest that the guidance is better suited to acute trusts rather than mental health or community services. For example, people we spoke with at Norfolk Community Health and Care NHS Trust told us that they felt the guidance and surrounding frameworks are "*always acute-focused*", while a member of West Suffolk NHS Foundation Trust felt that implementation of the guidance was more challenging for community services as it "*isn't clear and prescriptive for those different [non-acute] settings.*"

This sentiment was supported by attendees at our co-production meeting who gave some examples of difficulties with applying the learning from deaths guidance in community services. These included the high number of deaths and the fact that these may not be serious incidents, for example deaths of people at the end of their lives in the normal course of events. The co-production group also suggested that it is sometimes difficult for a community-based service or mental health service to find out about the death if it occurs in the community in the first place.

These comments, and other feedback, can be used to help inform any of the ongoing development work of guidance planned by the Programme Board, for example for ambulance trusts.

Enablers and barriers to good practice

This chapter looks at the themes that we found were supporting or inhibiting trusts' ability to improve. Overall, we found that the following factors can help support trusts to implement the guidance well:

- **values and behaviours that encourage engagement with families and carers** and support for staff
- **clear and consistent leadership** and governance by a specific person who is at a reasonably high level in a trust's hierarchy
- **a positive, open and learning culture** that encourages staff to speak up about safety issues and has a focus on improving the care of patients
- **staff with the resources, training and support** to carry out reviews and investigations
- **positive working relationships with other organisations** also providing care for the person who has died, to enable the sharing of information and learning from any investigation.

These factors are not new and reinforce the findings of our original report. Where we found examples of good practice, trusts were able to build on existing strengths, such as having an open and learning culture, that the national guidance could be integrated within. This also echoes the findings of our thematic review of Never Events, *Opening the door to change*, which found that the culture of an organisation could affect how well an organisation was able to implement safety guidance.[10]

We explore the above themes in more detail in this chapter. Other contributing factors we identified included existing capabilities, and good governance and oversight, as well as the financial resources of a trust.

However, it is important to note that our analysis suggests that these enablers and barriers are interrelated and that there is not one factor on its own that guarantees good practice. All these factors need to be tackled in a coherent approach.

Values and behaviours that encourage engagement with families and carers and support for staff

In March 2017, the national guidance on learning from deaths set clear expectations for how NHS trusts should engage meaningfully and compassionately with bereaved families and carers at all stages of responding to a death. It also described trust board's responsibilities for ensuring this happened.

In July 2018, additional guidance for NHS trusts on working with bereaved families and carers was published by the National Quality Board. It was developed by NHS England in collaboration with families who have experienced the death of someone in NHS care and have been involved in NHS investigations, as well as with voluntary sector organisations. It has also been informed by feedback from trusts and other NHS organisations. It advises trusts on how they should support, communicate and engage with families following the death of someone in their care. It consolidates existing guidance and provides a perspective from many family members who have experienced a bereavement in the NHS. The guidance is complemented by *Information for*

families following a bereavement in the annex, which should supplement a trust's own information and resources for bereavement support for families.[11]

There are eight guiding principles that set out what bereaved families and carers can expect. These include:

1. Being treated as equal partners
2. Receiving clear, honest, compassionate and sensitive response in a sympathetic environment
3. Receiving a high standard of bereavement care including being offered appropriate support
4. Being informed of their rights to raise concerns
5. Receiving help inform decisions about whether a review or investigation is needed
6. Receiving timely, responsive contact and support in all aspects of an investigation process, with a single point of contact and liaison
7. Being partners in an investigation as they offer a unique and equally valid source of information and evidence
8. Being supported to work in partnership with trusts in delivering training for staff in supporting family and carer involvement where they want to.

However, as the above guidance only came out in July 2018 we would not expect this to have been fully reflected in what our inspection staff saw in trusts.

Analysis of our interviews and focus groups with inspection staff showed that there was variation in how well trusts are engaging meaningfully with bereaved families and carers. For example, in some trusts we saw ad hoc engagement with families and carers, where contact with families and carers had only taken place after a serious incident or complaint. More needs to be done to make sure that bereaved families and carers are involved from the start.

Inspection staff found that staff can sometimes be fearful of engaging with bereaved families and carers. Reasons for this could be linked to a lack of skills or confidence to contact bereaved families, a fear of adding to families' distress and grief, a culture of blame and concerns about potential repercussions on their professional career. Creating a culture where people feel able to speak up without retribution was one of the key findings of our thematic review on Never Events, published in December 2018. *Opening the door to change* highlighted that to achieve a 'just culture' there both needed to be transparency for staff, patients and leaders, and when something goes wrong, patients and families should be involved in the investigation process from an early stage.[12] Trusts need to invest and support their staff so they have the appropriate skills and resources to engage with bereaved families and carers in a meaningful and compassionate way.

However, we have also seen some examples of positive engagement with families and carers, where trusts had clear pathways of contact, an open and transparent approach to engagement, and showed compassionate communication with families. For example, at Greater Manchester Mental Health NHS Foundation Trust, the trust had clear processes in place for how families are initially contacted, how they are given condolences and support, and how they are involved in investigations. The Director of Nursing and Governance at the trust recognised that families and carers react differently to bereavement, and described how communication needed to be

open and flexible, with support offered at multiple points over the course of any review or investigation.

Greater Manchester also showed evidence of an open, honest and person-centred culture, which was one of the factors that we found influenced good practice. Availability of specialist resource and training, and the existing capabilities of a trust were also related to good practice. For example, at West Suffolk NHS Foundation Trust we saw evidence that the way the trust engages with bereaved families and carers was well developed. However, a representative of the trust told us that it is continuing to develop its communication with families, and that it was organising Cruse training for the learning from deaths team on the best ways to support recently-bereaved people.[13]

Berkshire Healthcare NHS Foundation Trust

Berkshire Healthcare was rated as good overall in October 2018. On our inspection, we looked at five serious incidents and five deaths investigations to assess the quality of the investigation and how the trust applied the duty of candour. We found that the investigations had been completed to a high standard. In all cases, families and carers had been contacted and were given an explanation of what had happened and, where appropriate, an apology. Families and carers had contributed to deciding the scope of the incident investigation, and the trust had shared the outcome of the investigations with them.

Nottinghamshire Healthcare NHS Foundation Trust

Nottinghamshire Healthcare NHS Foundation Trust was rated as good overall in February 2018. We found that the trust had clear pathways of support for families and carers. The trust showed a sensitive approach to ensuring meaningful involvement of families and carers that was supported by a clear understanding of, and empathy for, the needs of people experiencing bereavement. The Nottinghamshire Healthcare investigation teams were able to link to existing support structures led by the family support service in the trust.

"The inspection team saw good processes in place for engaging with the family and carers of deceased patients. Communication was through a single point of contact. Initial condolences and duty of candour were applied at first point of contact. Families were seen at a place of their choosing, this could be in the home, on site, or at another site where the incident did not occur. Targets were set to make contact within three days or up to a maximum of five days. Families received choice about how they would like to be given information on the investigation process and outcome. Letters sent to families we found to be open, honest and a kind tone was used to offer condolences and explain the process clearly. There were good links with external bodies, including local authorities, clinical commissioning groups, other trusts and the local coroner, for supporting engagement with families and offering the opportunity to ask questions and gain further information. The trust offered leaflets, bereavement signposting, and provided pastoral care in the trust."

Sussex Partnership NHS Foundation Trust

Sussex Partnership NHS Foundation Trust was rated as good overall in January 2018. The trust was one of the first in England to be involved with Making Families Count, an approach developed by the charity 100Families and NHS England.[2] Through this work, the trust was one of the first in the country to implement a team of dedicated family liaison leads, which was introduced in August 2016. This team led on the investigation of serious incidents and worked with bereaved families during the process of investigating the death of their family members. There were three dedicated family liaison leads, with a further 13 staff trained to provide family liaison services. The family liaison leads were part of the serious incident team and provided root cause analysis training to senior staff who carried out reviews, which were based on a strong ethos of enabling strong engagement with families and carers. This included, as part of serious incident reports, details of family meetings and the views of the family, as well as ensuring that duty of candour requirements had been met.

[2] 100Families is a charity that supports people who have lost loved ones as a result of suicide, homicides by NHS patients or relative had died as a result of a NHS serious incident of avoidable harm. www.hundredfamilies.org

Derbyshire Healthcare NHS Foundation Trust

Although Derbyshire Healthcare NHS Foundation Trust was rated as requires improvement overall in September 2018, it had strong processes in place for engaging with bereaved families and carers. Feedback from families about support received from the family liaison team was overwhelmingly positive.

The family liaison role has evolved in line with learning from the national learning from deaths guidance. The family liaison team works with families where there has been a serious incident or unexpected death as reported through the trust's reporting system. They also work with families on referral through the process for learning from deaths, serious incident process and the complaints process where concerns have been highlighted about care.

The team start engaging with families after the death of their loved one has been identified. A single point of contact is established, initial condolences are given and the duty of candour, where applicable, is applied at the first point of contact, which can include providing the clinical team with advice.

Engagement with families is individualised and person-centred, and families are invited to contribute to the investigation's terms of reference and outline any specific questions they want answered about their relative's care and treatment. Monitoring of these actions is done through the Serious Incident Group (SIG) and the family liaison team who can review and see if the report answers the family's questions.

Families are invited to feedback on the care and treatment of their family member, and the family liaison worker meets with the family at the end of the investigation process to explain the outcome of the investigation. The family liaison team will support the family for as long as they need them up until the inquest, then work towards closure. Any additional needs are met through arranging activities such as referral to independent advocacy or psychological services.

There is also a range of information shared with families including details about the Samaritans, Public Health England's 'Help is at Hand' booklet, WAY Widowed and Young (if under 50), details of local support groups, and The Compassionate Friends leaflet. The information that is sent to families depends on the circumstances around the death of their loved one.

Clear and consistent leadership and governance

Our comprehensive inspections of NHS trusts have identified the importance of good leadership and governance in providing high-quality care.[14,15] This is echoed in our early findings on the quality of the processes for learning from deaths, which highlighted that clear leadership and governance processes can play an important role in driving forward improvements in learning from deaths.

Our first year of inspecting trusts' implementation of the guidance suggests that having a specific person, at a reasonably high level in the trust, is key to driving the work forwards. For example, at Berkshire Healthcare NHS Trust, which was rated as outstanding for well-led, the medical director was the operational trust lead on learning from deaths, with a lead non-

executive having oversight (see case study below). However, it has not always been clear if learning from deaths was a top priority for trusts.

Clarity over who is responsible and 'churn' in the leadership team were also potential influences on trusts' ability to implement the national guidance. This echoes the findings of *Opening the door to change*, which noted high turnover of staff as a challenge to implementing safety guidance.[16]

Linked to this, support from the board also influenced how well trusts are implementing the learning from deaths guidance. For example, at West Suffolk NHS Foundation Trust the board have made learning from deaths a priority, and appointed a public health consultant who was given the time and resources to consider and implement the guidance. The trust representative described to us how executive and non-executive directors had been "*very, very enthusiastic [and] very, very supportive*" of the work towards implementing the guidance.

At West Suffolk, and elsewhere, we saw evidence that strong existing governance and processes, such as review groups and systems for learning from deaths, was also a factor. For example, at Norfolk Community Health and Care NHS Trust, we saw evidence of how the trust had carried out work to expand on their existing processes for learning from deaths to make sure that the correct deaths are identified for review. However, we have also seen that challenge and interest at board level are important to make sure that these governance arrangements are robust and well adhered to. Good governance, we found, is also important in ensuring that the lessons learned from reviews are shared and acted on.

Berkshire Healthcare NHS Foundation Trust

Berkshire Healthcare NHS Foundation Trust was rated as good overall and as outstanding for well-led in October 2018. Inspection staff found that the trust had embedded its work on learning from deaths well. The trust had an executive group for learning from deaths, which was attended by the medical director, director of nursing and governance, lead clinical director, deputy director of nursing for patient safety and quality, and the head of clinical effectiveness and audit. This met on a weekly basis to review all deaths reported in the trust incident reporting system.

The medical director was the operational trust lead on learning from deaths. A lead non-executive director provided oversight. The level of investigation for deaths was considered in the weekly Executive Mortality Group, and monthly Mortality Group when the death did not meet the threshold for a serious incident. Where the threshold for reporting of a death as a serious incident on StEIS (Strategic Executive Information System) was met, this followed the usual trust serious incident processes. This committee also reviewed those deaths not reported as an incident to make sure that they were also investigated if needed.

Open and learning culture

In our State of Care 2017/18 report, we commented on the link between the culture and the performance of an organisation, and how leaders are integral to setting a good culture, with capable, high-quality leaders creating workplace cultures that are conducive to providing high-quality care.[17,18] A culture that is open and transparent, and in which staff feel able to speak up and speak out, was also previously noted as one of the most valuable aspects of driving improvement in trusts.[19]

Analysis of our interviews and focus groups with inspection staff for this review suggests that the existing culture of an organisation can be a key factor in trusts' ability to implement the guidance on learning from deaths, with inspection staff observing a difference between an open, transparent no-blame culture that is focused on learning, and an inward-looking, fearful culture, which can manifest in defensiveness and blame. As highlighted in the section on engagement with families and carers, negative cultural factors can include a fear of litigation, public perception, or confrontation with families, and a failure to engage staff with the trust's cultural values or empower them to raise concerns.

This supports the findings of our review of Never Events, *Opening the door to change,* which found that organisational and individual cultural issues could prevent the effective implementation of safety guidance.[20] In that review, we also heard from other industries that it is culture that drives the reporting of and learning from incidents.[21] To truly learn from serious incidents in the NHS, there needs be a culture where staff, patients and leaders all feel able to speak up and work collaboratively to learn. This need for cultural change was highlighted in the foreword of our Never Events thematic review and in our recommendation for "*leaders with a responsibility for patient safety to make sure that the trust reviews its safety culture on an ongoing basis, so that it meets the highest possible standards and is centred on learning and improvement*."[22]

Positive cultural factors we observed for this report included staff at all levels feeling able to speak up, a working environment that feels like "*a collaborative team, rather than a directional board downwards team*", strong patient focus, engagement of medical staff (particularly consultants), and a desire to learn as a central value of the organisation. It can also have an effect on how quickly processes are put in place and how likely any learning from reviews of deaths is shared. For example at the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust, inspection staff found that the trust's learning culture acted as an enabler to developing their processes for learning from deaths, and that trust leaders were open and accountable in their approach, engaging with stakeholders in a transparent and collaborative way.

We also found that culture can also influence other factors in learning from deaths, including how a trust works with partner organisations who share the responsibilities for caring for that person, and how a trust involves bereaved families in the review, investigation and learning process.

Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust was rated as good overall and outstanding for well-led in June 2018. Since its last inspection in 2015, the trust had improved the culture of the organisation. Inspection staff found that the trust had a learning culture, which acted as an enabler to developing their processes for learning from deaths and was indicative of their outstanding rating. Trust leaders were open and accountable in their approach, engaging with stakeholders in a transparent and collaborative way. Quality improvement was deeply embedded in the everyday workings of the trust through the development of team coaching, change champions and wide-reaching quality improvement training.

Staff in all areas felt empowered and had access to the right tools to drive improvements and innovate, resulting in a firmly established culture of continuous improvement. The trust had developed an innovative reporting system that enabled staff to report incidents, share improvement ideas, raise a concern or highlight good practice. When incidents did occur, investigations were timely, thorough, person-centred and led to improvements in patient safety and experience. The role of the freedom to speak up guardian (FTSG) was well embedded at the trust. Staff knew how to access the FTSG, including through the online reporting system. The FTSG made sure that any trends, themes or concerns were escalated to the trust board.

The trust produced a quarterly newsletter for all staff, which captured key learning from deaths from across the directorates. Clinical staff interviewed across the trust were aware of the newsletter and could give examples of learning from death reviews.

Providing staff with resources, training and support

Having sufficient resource (in terms of staff capacity and capability, support and training) is an important factor in a trust's ability to deliver effective reviews and investigations. Not all trusts are in an equally good position to allocate resource to learning from deaths. We have seen that trusts can face challenges in providing support and training, allowing staff time away from clinical duties and protecting time to carry out reviews. This echoes the findings of our recent report *Opening the door to change,* which also found that staff had limited time and space to attend relevant training for patient safety.[23]

Factors that influence trusts' ability to allocate resourcing include funding and commissioning, competing priorities, such as those brought about by organisational restructures, and the willingness of the board to provide adequate resources to learning from deaths. For example, at West Suffolk NHS Foundation Trust, which was rated as outstanding for well-led in November 2017, there was evidence that the board had a coherent approach to addressing the key drivers for improvement, including appointing dedicated personnel to implement the guidance.

Analysis of the feedback from our inspection teams showed that where we have seen good practice, this has been related to freeing people up from clinical commitments to take responsibility; protected time for reviews and training; and support from board and clinical commissioning groups (CCGs) for resource, such as a medical examiner or mortality technician.

City Hospital Sunderland NHS Foundation Trust

City Hospital Sunderland NHS Foundation Trust was rated as good overall in August 2018. The trust had a well-established process for reviewing and learning from deaths, which had been in place for four years. At the time of inspection, the trust was developing a process to move all information related to deaths onto a new electronic system, so that information could be obtained more effectively and to reduce the chance of transcribing errors.

The trust had a mortality review panel (MRP), which reported through the clinical governance steering group. The panel measured 'Hogan avoidability' (looking at the scale and scope of preventable deaths), Hogan quality, and national confidential enquiry into patient outcome and death (NCEPOD). The panel met on a weekly basis and comprised senior doctors and other clinical staff who critically reviewed all in-hospital deaths. The meeting excluded child and maternal deaths as they had their own statutory process; it included deaths of patients with a learning disability.

At the conclusion of each case review, the MRP provided a judgement using the review outcomes. Where there were any unexplained variations in care the reviews were referred for speciality reviews. Quarterly reports on the outcomes from the MRP reviews were presented to the mortality review group and to the clinical governance steering group. The report included articles on any reviews of deaths where there was evidence of preventability, poor care, or room for improvement, for example in death certification.

The MRP process incorporated a separate end of life review. In this process, all patients who had received either specialist palliative care or general end of life care the subject of a structured review of their death, which enabled the trust to assess the quality of end of life care. The specific reviews were based on the five core elements of care from the national implementation of care of the dying patient documentation. The outcomes of the reviews were used to target staff awareness and training sessions in care of the dying. The outcomes of these reviews were fed back to wards on a quarterly basis.

Engaging with partner organisations delivering care

Some deaths involve people whose care was provided by a number of different organisations. In these circumstances, any review or investigation needs to involve communication, information sharing and learning across these different organisations. The national guidance focuses on what individual NHS trusts need to do to review and investigate deaths. There is less information on how organisations need to work together on common issues such as engaging with families and carers or working with other non-NHS services such as the police and coroners. In addition to this, while it is usually clear whose care the person was under when they died, many trusts do not routinely record information about which other organisations were involved and what care they provided.

There was some evidence that the quality of existing relationships between organisations can affect how well trusts are working with partners on investigations into deaths. For example, our inspection staff have described how a lack of incentive or support for building relationships between system partners can be a barrier to collaborative investigations into deaths.

Difficulties in sharing information can also be a barrier. This was mentioned about obtaining information from GPs, a lack of established systems or routes for sharing information, and working across multiple CCGs. Inspection staff felt that CCGs could play a bigger role in

encouraging sharing learning and collaboration but noted that differences in approach and levels of support can be a problem, particularly for trusts that work with multiple CCGs.

We also heard that concerns about data protection when sharing information could be a barrier. This is similar to the finding of our local systems review that poor information governance, or a lack of understanding of rules and regulations for sharing information, can prevent joined-up care and support.[24] Trusts need to be confident that they understand the data protection rules and regulations, and that these are being appropriately applied when implementing the national guidance on learning from deaths.

However, we have seen pockets of good practice, for example one trust that had begun to build relationships with primary care colleagues, which included starting to work with GPs about the standard judgement framework. Other inspection staff we spoke with felt that CCGs were in a position to enable relationships between trusts and primary care, but felt that this would only be possible where they covered the hospital and the GP practice.

Case studies

In this section, we explore in more depth three trusts' overarching experiences of implementing the learning from deaths guidance. To inform these case studies, we spoke to the inspection manager who led the well-led inspection and representatives of the trust. At West Suffolk, we also spoke to a family representative to better understand their experiences, including what has helped or hindered them when putting the recommendations in place.

West Suffolk NHS Foundation Trust

West Suffolk NHS Foundation Trust is a combined acute and community trust, with a district general hospital, a community hospital and other community-based services. The trust, which serves a population of around 280,000 people across rural areas and market towns in the county, was rated as outstanding in December 2017.

Inspection staff felt that the trust has done well with implementing the guidance, with high-quality processes and systems in place to make sure that they are putting the guidance on learning from deaths into action. This was echoed by comments from the trust representative who felt that the national guidance was broadly positive and easy to implement, particularly for acute services. However, they also felt that implementation of the guidance was more challenging for community services as it *"isn't clear and prescriptive for those different [non-acute] settings."*

Strong leadership and governance played a large role in implementing the guidance at West Suffolk. A substantial, dedicated financial and human resource was given to the programme, which has been driven by the board and a medical director who is passionate about the programme.

In particular, the appointment of a public health consultant, with dedicated time and resources to consider and implement the guidance, was seen by the trust as key to driving improvement in learning from deaths. This included the appointment of administrative support for the consultant role:

> *"I have a full-time coordinator and there is no way this could work without her… I genuinely do not know how trusts have done it if they haven't been able to invest in protected time for people, and we are fortunate that our financial position meant that we could. I calculated… [we spent] £130,000… specifically for this, and without that… we wouldn't be doing a comprehensive job."*

Inspection staff also praised the trust's existing culture and practices – including an openness to learning, good staff engagement and a desire to provide high-quality care – as important factors in its ability to implement the learning from deaths guidance.

While the trust had good processes in place for learning from deaths, and was already reviewing all inpatient deaths before the guidance was published, it recognised that there was more to do in terms of identifying and reviewing deaths in the community and of people with a diagnosed mental health condition or learning disability.

The trust has built on these existing processes and continues to make improvements to comply with the requirements of the guidance. For example, the trust representative we spoke with described how they had attended the Royal College of Physicians' training on Structured Judgement Reviews (SJRs), then cascaded this learning to the medical reviewers during a full

day session on learning from deaths. They also described the steps the trust has taken to improve its quality improvement processes and learning from deaths:

> *"…we didn't at that time have a quality improvement framework, we weren't using quality improvement [QI] methods for our approach to QI… so knowing the learning was going to turn into a reliable, sustainable action was a bit of a gap…I've… introduced a quality improvement framework, we've got a head of quality improvement in post now, [and] we're training quality improvement coaches, all of that is necessary to…make change happen."*

However, the trust representative also acknowledged there needs to be further improvement to be more effective in sharing the learning, both in the trust and with other providers. One step the trust has taken to overcome these barriers is to become a member of their regional academic health sciences network, which a member of the trust described as providing "*a lot of support*".

The trust representative described the role of families and carers, and how the trust viewed this as highly important. They also stated how valuable they see the role of the family representative in helping with the implementation of the national guidance:

> *"I can't celebrate enough the help that we have had from our family representative and if trusts can find somebody who is, without being patronising, the right kind of person,… someone who can be… [an] advocate for families, for the inputs of patient experience and family experience, and hold the professionals, the senior leaders to account very effectively, then that is extremely powerful."*

While the trust has a good approach to involving families and carers, the trust representative described how the trust is continuing to develop its communication with bereaved families:

> *"…we are iterating as we go the best way to communicate, the best way to invite people to be involved, the best way to integrate all of this with the PALS service, and make sure we have a clearly joined-up approach so families don't end up with loads of different points of contact in the hospital*."

The importance and value that the trust places on family involvement was supported by the trust's family and carer representative who was positive about their role, and described how they felt that the way families are engaged with has changed for the better since their own experience following the death of a family member. As part of their role, the family and carer representative is working with the patient experience team to identify more opportunities for bereaved families and carers to be involved:

> *"… we are actively looking to… involve more families in the process. We might, for instance, think of having more than one family representative sitting on the learning from deaths group, but whether we do that or not, the main point is that we do need to get more information about how families are interacting in the process…"*.

Greater Manchester Mental Health NHS Foundation Trust

Greater Manchester Mental Health NHS Foundation Trust provides community-based and inpatient mental health care and treatment to a population of 1.2 million people living in Salford, Bolton, Trafford and Manchester. It provides a wide range of more specialised mental health and substance misuse services, as well as in-reach services to prisons in the North of England. The trust, which was formed in January 2017 after a merger with Manchester Mental

Health Social Care Trust, was rated as good overall and outstanding for well-led in February 2018.

From the trust's perspective, the National Quality Board (NQB) guidance on learning from deaths guidance has been of limited use to them. The trust representative we spoke with felt that it was too acute focused, and that much of it was not relevant to mental health and community services. In particular, they felt that the language and methodology set out in the guidance were not always applicable to mental health settings:

> *"So for example,…there can be a very different view taken if someone has died of a surgical procedure, which can be measurable, to someone who's taken their own life in a community setting."*

However, as our inspection staff highlighted, the trust already had good existing governance and processes in place for learning from deaths in the trust, with well-established systems for investigating deaths, so had not needed to make significant changes to processes following the introduction of the guidance.

Inspection staff found that overall leadership of the trust was strong, with a leadership team who had passion and drive, which filtered down through the organisation and was reflected in their practices on learning from deaths. The inspection team described the leadership as visible, outward looking and joined-up.

Closely linked to this, the culture of the organisation was also cited as an enabler of good practice, with evidence that the trust is open, honest and person-centred. This was reflected in conversations with the person we spoke with at the trust who described the importance of the user voice and how having a strong user voice in the trust changed the thinking of the organisation and helped them to provide services that were more person-centred:

> *"…we have a number of service user forums, we have service users presenting at board, they co-produce our recovery academy… they're at the heart of what we do and they're very involved in the organisation…"*

While the culture of the organisation was described as open and honest, and the importance of a no blame culture was emphasized by the trust representative, they had concerns about the culture of the coronial system and the challenges this could create in terms of good practice in learning from deaths:

> *"It's about making sure we maintain a culture where there isn't finger pointing going on, because 90% of the time, sadly, it's [a] system failure not an individual failure. However, when it gets to the coronial system, that's when the finger pointing can be pretty horrible for clinicians."*

The person we spoke with at the trust also explained the trust's approach to identifying and reviewing deaths. They explained how the trust is known for having a high rate of reporting of incidents, including low level incidents, that broaden the cases from which to learn. All deaths in the trust, excluding expected deaths, are subject to a three-day review. The trust also carries out 'deep dives' to look at underlying themes and improve the trust's understanding of particular issues:

> *"…a year ago, we had a deep dive review on the mortality rate in our substance misuse services, there was no sort of underlying trend or theme discovered but nonetheless it gave us a greater understanding of the vulnerability of someone who's accessing such services… as well as the complexity… of the physical issues that they can have."*

The trust representative also felt that they had a robust policy in place to make sure that there was parity in reviewing the deaths of people with a learning disability, and that all deaths are reviewed in the same way.

However, resourcing of reviews for learning from deaths was identified as a challenge. Even though the trust had appropriately trained people assigned to carry out the reviews, demands on time and resource were identified as barriers to leading a high-quality review. Linked to this, the timescales of the review were also seen as problematic, with the trust sometimes having to ask for an extension:

> *"I think often timescales can be a bit challenging and that doesn't mean you want things to go on forever, but often there are very good reasons why things take time, and… having to ask for extensions… can be a bit of a bind…"*

Our inspection staff found evidence that the trust was actively using the learning from these reviews to improve quality. This was supported by feedback from the trust representative, who described how learning from deaths contributes to quality improvement at the trust. They explained how coordinated learning events are organised within two months of the report being signed off, and gave an example of quality improvement after sharing the lessons learned from one review:

> *"…in January of this year [2018], there was a homicide that had taken place very sadly in one of our areas. There was an external review… [with] both [Supported Housing Management Team] SHMT and substance misuse teams [involved in] the person's care… we had what we called a joint learning event… so we could review the whole pathway… One of the learning points… was access to probation services and information from probation services so as a result of that… [the] amount of information has improved…"*

This quote also highlights some of the good practice that we found about the trust's approach to working collaboratively. We found some evidence that the trust is collaborating well with system partners, but it was identified by the trust representative as an area for improvement. They described how it could be difficult to engage some partners for joint reviews, particularly in primary care. It was felt that learning from deaths was not a priority for some GP practices, and believed that this could be why they seemed reluctant to be involved in joint investigations.

One of the strongest areas for the trust was engagement with families, which inspection staff felt was meaningful and sensitive. They found that the trust had clear processes in place for how families and carers were initially contacted, how they were offered condolences and support, and how families were engaged in reviews. These processes make sure that families are contacted by the most appropriate person, and that staff who engaged bereaved families have the right training and support. The person we spoke with at the trust explained that these processes had been in place before the introduction of the guidance. However, since the guidance they had introduced sending a letter to families at the end of the investigations from the medical director and director of nursing and governance. Again, the trust showed a person-centred approach, with the letter drafted for each individual case rather than a standard format being used.

The trust representative described how the trust recognised that families and carers react differently to bereavement and may feel different at different times, and how communication should be open and flexible, with support offered at multiple points across any review or investigation. This supported the evidence that we found that the trust provided responsive contact and support in all aspects of investigations, in line with the national guidance.

Norfolk Community Health and Care NHS Trust

Norfolk Community Health and Care NHS Trust provides a range of services including district nursing, community services and inpatient units. The trust serves the population of Norfolk, excluding Great Yarmouth, and was rated as outstanding in June 2018.

We found evidence that Norfolk Community Health and Care NHS Trust was working to expand on their existing processes for learning from deaths, despite facing a number of challenges. At the time the guidance was published the trust already had a process in place for learning from deaths, and was reviewing all inpatient deaths. This put it in a strong position for implementing the guidance, with a trust representative describing how a 'gap analysis' of existing processes had found that it wasn't "*a million miles away*" from the new requirements. However, they acknowledged that some changes were needed, and that there were also challenges in implementing the guidance itself as it was too "*acute-focused*".

As with other trusts, leadership of the organisation was an important factor in Norfolk's implementation of the guidance. There was some evidence that the board had prioritised learning from deaths, and that the leadership team were engaged with learning from deaths. The inspector we interviewed described how "*key individuals [were] identified to lead the project*", and that this was a key factor in their implementation of the guidance. This was supported by feedback from a trust representative, who told us:

> *"I think it's really been key that our directors have supported the work… and invested in leadership, in terms of owning the agenda and taking it forward… strategic leadership and encouragement, and… dedicated resource… is really, really key."*

The trust representatives also told us that the executive team had driven developments in processes for learning from deaths, and we found evidence that Norfolk had carried out work to expand on their existing processes to make sure that the correct deaths were identified for review. While the trust was already carrying out reviews of many deaths, following the publication of the guidance it had expanded its policy to include details on how the trust makes sure that the deaths of people with a learning disability or mental health condition are treated with parity:

> *"The first thing we did in the policy when we refreshed that last year was to define which deaths we were going to review. And currently that includes all inpatient deaths…; community deaths where there are concerns raised…; learning disability deaths of anyone that's been under our service in the last year; and… anyone that would have had a known mental health diagnosis…"*

However, the trust found defining which deaths to review challenging due to the perceived focus of the national guidance on acute trusts. For example, while the national guidance states that, "*Mental health trusts and community trusts will want to carefully consider which categories of outpatient and/or community patient are within scope for review taking a proportionate approach*", it does not offer further advice, creating more work for these types of trusts in defining which deaths to review.

When reviews of inpatient deaths are carried out, the trust told us that it had a two-stage approach. Stage one involves the doctor, that covered the inpatient unit where the person died, conducting a review with the senior nurse. Stage two is more in-depth and takes place if concerns are raised in stage one, and occurs in approximately 2% of deaths. This proportion is driven by the findings from the stage one reviews. The trust carries out a thematic review of stage one reviews quarterly to see if there is any further learning or review needed, as well as

recognise any good practice. The trust is currently considering whether the threshold it applies for conducting stage two in-depth reviews produces enough cases to generate learning. Stage 2 reviews are carried out by a consultant who is independent of the unit or department where the death occurred. A person we spoke with at the trust told us that the trust is encouraging multidisciplinary team reviews, which it has trialled in palliative care and found effective:

> *"…our palliative care team [will do] a multidisciplinary team review, so they will sit down each month and look at all of their deaths, and do their reviews together, and they'll have more in-depth discussions of any cases that are of interest."*

Sharing lessons learned, both inside and outside the trust, was also important, with a trust representative describing how there was *"a real keenness to share the work…"*. At a trust level, we saw how it uses technology and a range of channels to communicate learning for staff. These included, for example, weekly messages to all staff, sharing via the medical director, and a grand round focusing on the learning from deaths process.

At a regional and local level, we heard from trust representatives that the trust was a member of at least two local and regional groups that have a focus on learning from deaths. For example, they described how the trust's links with the local sustainability and transformation partnership meant that the trust could "*take a systems approach to learning*", and that the trust has found it reassuring that other trusts seem to be facing similar problems:

> *"…the learning that's coming out of other trusts that they're sharing with us… is very similar. We're all having the same kind of issues. So that's really useful…"*

However, we also found that collaborating on reviews is complex for the trust and that work is ongoing.

Another area that the trust needed to improve was its engagement with families and carers. A trust representative described this as their "*biggest challenge*" for learning from deaths. Since the introduction of the guidance, the trust had taken steps to address this including updating their policy and action plan:

> *"So what we've put in our policy and in our action plan is that obviously being open, duty of candour, the complaints and PALS process are still available for all families, and patients that are at end of life and going through that process."*

The trust also explained how they use the FAMCARE scale to assess how satisfied families are with their experience, following the death of a loved one, where the patient was in palliative care leading up to their death:[3]

> *"…so all palliative care patients go through FAMCARE survey, and we've just got the results of that. That pulls out a lot of experience of families, of how they felt going through that process, what it was like for them, so we get a lot of learning from that."*

Despite the challenges that the trust has faced in implementing this aspect of the guidance, the trust told us that they are keen to get family engagement right to avoid adding to families and carers' distress, and to this end were looking at having a patient or family representative on their mortality review group.

[3] The FAMCARE Scale is a tool to measure family satisfaction with the care of patients with advanced cancer. The tool was originally developed for use on inpatient units, measuring different areas of care such as availability of care, physical patient care, psychosocial care and information giving.

Learning, next steps and recommendations

As we set out in the introduction, we are at the beginning of the implementation of the learning from deaths guidance, but a first look at this early stage suggests that how well trusts are implementing the guidance is variable.

Our findings have highlighted a lot of the same issues that were raised in the original report, and have shone a light on the need for NHS trusts to act now to build on the key drivers for change, including:

- encouraging values and behaviours that enable engagement with families and carers as well as support for staff
- providing clear and consistent leadership at a senior level with challenge and oversight from non-executives
- creating a positive, open and learning culture where people who use services, and staff, feel confident to speak out
- providing staff with the time, support and training to carry out robust reviews and investigations of deaths
- developing positive working relationships with partner organisations to share information and learning following the deaths of people for whom they have provided care.

This review has reinforced that there is no one factor that guarantees good practice, with enablers and barriers to implementing the guidance being interrelated. However, as we found in our report *Opening the door to change*, the existing culture of an organisation can be a key factor in trusts' implementation of guidance, and could be preventing trusts from making the progress needed. To be able to learn from serious incidents in the NHS, there needs to be a culture where staff, patients and leaders all feel able to speak up and work collaboratively to learn.

Where we have seen examples of good practice in implementing the national guidance in this first year, trusts have built on existing processes, cultures and expertise in reviewing, investigating and learning from sources of feedback, such as the investigation of serious incidents, concerns and complaints. This means that when trusts do not have these characteristics in place at the start, they need to take a long-term view to start to invest and build the necessary capabilities and capacities over the next few years.

There are also actions that others, including the Learning from Deaths Programme Board and CQC, need to take to provide further support to NHS trusts and families and carers in developing their approach to learning from deaths.

The DHSC-led Learning from Deaths programme has shone a light on the importance of learning from deaths, and provided NHS trusts with a benchmark for trusts to measure themselves against. However, there has also been comment about what the programme needs to do next to continue to support implementation, and to make sure that learning from deaths remains a priority for the NHS so there is the necessary investment made by trusts. These challenges include:

- how to align the work with related policy initiatives on introducing medical examiners, safety improvement, complaints and concerns so there is coherence and consistency in the approach

- the need to further develop a system-wide view on learning from deaths that includes clarity on which organisation leads on a death that occurs outside of a hospital, and how to encourage information sharing across NHS providers (including GPs), when investigating the death of a person who receives care from different NHS or other organisations
- the need for a focused assessment of the progress made on reviews and investigations of deaths of people with mental health problems or a learning disability (working with partners such as the Learning Disabilities Mortality Review (LeDeR) programme)
- improved support from a single set of consistent guidance for staff that is agreed across national bodies, including NHS Improvement and Healthcare Safety Investigation Branch, that helps them to carry out robust reviews and investigations of deaths and serious incidents. This should include children, people with a learning disability, people with mental ill-health and mothers.
- the need to analyse and monitor the investment made by NHS trusts in resources in learning from deaths, in terms of training and support and dedicated staff time to carry out reviews and investigations.

As part of developing our relationship management and monitoring functions, we are committed to provide further support and training for CQC inspection and other staff in understanding what good reviews and investigations look like, as well as how to engage sensitively with bereaved families and carers to hear the learning from their experiences of care. CQC will continue to monitor progress by NHS trusts through its monitoring and inspection processes.

Appendix: what we did

All of the analysis used to inform this report is generated by CQC and is qualitative in nature. Specifically, the report is based on qualitative analysis of inspection colleagues' accounts of their experiences of overseeing and/or involvement in well-led inspections at NHS trusts since September 2017. To inform this analysis, we conducted eight interviews with inspection staff, two interviews with CQC specialist advisors and four focus groups with a total of 12 inspection staff. These interviews and focus groups focused specifically on understanding the quality of trust implementation of national guidance on learning from deaths and the enablers of and barriers to good practice. All those invited to interview had led or been involved in at least two well-led inspections. All those invited to the focus groups had led or been involved in at least one well-led inspection. All interviews and focus groups were conducted between June and August 2018.

It is important to note that the findings of this analysis represent an early indication of the quality of trust implementation of national guidance on learning from deaths as described by a sample of CQC inspection staff involved in well-led inspections conducted between September 2017 and June 2018. There are several limitations to the findings, which should be acknowledged when reading this report.

- The sample is composed of CQC inspection staff with differing levels of experience of overseeing and/or involvement in well-led inspections and learning from deaths. As such, depth of knowledge and understanding among participants varied.
- Participants were asked to recount their experiences of trusts inspected since September 2017. As such, trusts discussed as part of this work have had differing lengths of time to implement the national guidance. This was not considered as a factor in the analysis.
- Findings are based on 10 interviews and four focus groups, with a total of 12 inspection staff. No claim is being made as to the extent to which these findings are representative of the overall picture across England.
- We were in the first year of implementing the learning from deaths inspection methodology when this analysis was conducted. As a result, depth of CQC organisational knowledge is limited. In addition, our analysis suggests that inspection teams may have faced some capacity and capability challenges in implementing the learning from deaths inspection methodology. In response CQC is developing its relationship management and monitoring functions, and is committed to provide further support and training for CQC inspection and other staff in understanding what a good review and investigation look like, as well as how to engage sensitively with bereaved families and carers to hear the learning from their experiences of care.

We also carried out a case study analysis of three trusts that had been awarded an outstanding rating in well-led since September 2017. This analysis focused specifically on the quality of processes for learning from deaths and the factors that had supported good practice in this area. To inform these case studies, we spoke to the inspection manager who led the well-led inspection and a representative of the trust. For the West Suffolk case study, we also spoke to a family representative who has been working with the trust to develop processes for learning from deaths. All interviews were conducted between July and October 2018. Findings are trust-specific and no claim is being made as to whether they are representative of other trusts in England.

We have attempted to corroborate these findings about individual NHS trusts with other intelligence on them that is publicly available and used by CQC and NHS Improvement.

We discussed the early findings of this work with CQC's NHS co-production group at a meeting on 8 November. This group includes representatives of families, carers and trusts, and other stakeholders including voluntary sector organisations. Where possible, we have also engaged through trusts with local patient, family and carer groups to comment on these, and verify that they reflect their experiences. We used the points raised in discussion to help inform our interpretation of the findings.

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