

Family involvement in death investigations by the NHS: Existing practice and experience

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Context for this paper

In December 2016 the Care Quality Commission published [Learning, candour and accountability](#), a review of the way NHS trusts review and investigate patient deaths in England. It found that families and carers often have a poor experience of reviews and investigations, and that they are not always treated with kindness, respect and sensitivity. It also found that the extent of family involvement in reviews and investigations was variable and that families and carers are not always listened to. This is unacceptable and has to improve.

NHS England has been [asked by the Secretary of State for Health](#) to develop guidance for bereaved families and carers. This guidance will complement existing legal duties, requirements and standards within the Duty of Candour and the Serious Incident Framework.

There is a growing evidence base of family experience and testimony of NHS investigations. These experiences are captured in reports, media coverage, Parliamentary and Health Services Ombudsman complaints and rulings, and more recently in work associated with the CQC Deaths Review, including [Inquest's report on the CQC Family Listening Day](#) and a scoping review [Family involvement in, and experience of, death investigations by the NHS](#).

This paper will not recap all of this evidence (see references for more information) instead it will provide a brief overview of current experiences, highlighting where possible what families wish to see improved, changed or added. It will also highlight current guidance and resources that are available to bereaved family members and NHS trusts. Its purpose is to provide an overview as a starting point for discussions with bereaved families and carers and NHS staff about the guidance NHS England will develop. This is a working document, to which additional information or evidence will be added throughout the process of developing guidance for bereaved families and carers.

Ways in which families can inform the guidance being developed

Two family representatives with experience of NHS death investigations, Josephine Ocloo and Richard Huggins, have been appointed to the Programme Board. A virtual group of families will be established to inform their work, and that of those developing guidance.

Families have also been invited to an event taking place on Wednesday 1 November 2017. This day long event will gather family experience and input into guidance. Families can participate in person, or online.

Principles

The National Quality Board (CQC, Health Education England, NHS England, NHS Improvement, NICE, Public Health England with Department of Health) issued draft guidance in response to the CQC Deaths Review. This guidance [National Guidance on Learning from Deaths for Trusts](#) included a set of principles for engaging compassionately and meaningfully with bereaved families and carers. These principles are reproduced in full below:

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

These principles build on those within the Being Open Framework published by the Patient Safety Agency in 2009. These ten principles are:

- 1) Acknowledgement
- 2) Truthfulness, timeliness and clarity of communication
- 3) Apology
- 4) Recognising patient and carer expectations

- 5) Professional support
- 6) Risk management and systems improvement
- 7) Multidisciplinary responsibility
- 8) Clinical governance
- 9) Confidentiality
- 10) Continuity of care

Overview of current experiences

Families currently have a very varied experience of NHS death investigation processes. For many their experience is of a confused and chaotic process, with little opportunity for families to be heard or for their questions to be answered. When families experience compassion, honesty and humanity they report that it helps. When investigations do take place they are often of a poor quality, with conclusions that do not relate to the evidence collected, errors and omissions and little, if any, specialist input. Family members are rarely engaged in the investigation process in anything other than a tokenistic way, and families are often subjected to multiple investigations from different agencies. Families report that they are expected to cope with little help, coordination or support.

Say sorry

The requirement to say sorry should not need to be flagged, however many families report that NHS staff are reluctant to say sorry:

‘It is important to remember that saying sorry is not an admission of liability and is the right thing to do’ (NPSA, 2009, 2).

This guidance was issued eight years ago, and there is now also a legal Duty of Candour, yet many families are hurt as the absence of a human response to their bereavement:

‘Families were dismayed not to be offered condolences on first meeting, a basic human response. Others observed that the inability to say sorry for what had happened upset them a great deal, the “*sense that by saying sorry it’s an admission of guilt*”. Apologies seem to be hard won and often only offered after families had demanded them or as a procedural duty;

“*The trust apologised through the media, but we had to ask for a direct apology which took six weeks*”

“*We only received a written apology two minutes before going into court at the start of the inquest*” (Inquest, 2016, 7).

Family members and friends bereaved by suicide also report that people are uncomfortable acknowledging their bereavement, perhaps for fear that they do not have the right words:

'I needed people to say the same things they might have said if she had been a sister or had died in an accident: that they were sorry, that they would listen, that they were there for me. No-one did. I think they were – still are – scared to talk about suicide and thought it was best not to mention my friend. It's as if she is best forgotten – and she did die a long time ago. But I haven't forgotten her' Di, whose friend died (PHE, 2015, 50).

It is essential that NHS staff are not afraid to say sorry for someone's loss, and that they are provided with any necessary support to feel free to do so. In particular the way in which bereaved families are communicated with at the outset, can set the tone for what follows:

'There were concerns about the quality and tone of initial communication. Families detailed how the immediate impact of hearing about a death left them confused, traumatised, scared, desolate and isolated and how difficult they found it in the immediate aftermath to take in information and process what had happened. What they sought was kindness, sensitivity, empathy, openness, and most importantly, information. Many felt these qualities were in short supply and in their absence left a vacuum that was quickly filled by suspicion, mistrust, and defensiveness and in some cases hostility on the part of the hospital/trust. Families observed that this initial defensiveness set the tone for what was to follow' (Inquest, 2016, p3)

It is essential that all staff are confident in their communications about death, and clear about the processes that follow.

Develop clear information and compassionate communication

The CQC Deaths Review found that families were not routinely involved, or in some cases even informed, that an investigation was taking place:

'Families are not always informed or kept up to date about investigations – something that often caused further distress and undermined trust in investigations' (CQC, 2016, 6).

The Inquest Family Listening Day reported that this lack of clarity at the outset, unsurprisingly had a knock on effect in undermining trust in any investigation that followed:

'If families were unhappy with inadequate information at the outset, this theme continued in their experiences of the investigation process and subsequent reports. The dissatisfaction focused on a lack of information about the investigation process and what it entailed, a lack of involvement, both in setting the scope of the

investigation and little or no opportunity to feedback family insights and experience. In short those undertaking the investigation seemed unwilling or reluctant to listen to the family “voice” and as a result missed a vital opportunity to see the investigation in broad enough terms to make it thorough, inclusive and an opportunity for learning’ (Inquest, 2016, 9).

This paper is being produced in support of the NHS England task of developing guidance and information. It is suggested that this information outlines what processes follow a death; any family liaison on offer or a named point of contact; the purpose, aims and remit for any investigation or review of care; the complaints procedure and clarity around how families can raise any concerns about the investigation process.

‘In the absence of information families felt they were being put on the “back foot” from the beginning. Families were keen to point out that what they wanted was to know how they could engage with the process. They wanted that process to seek the truth, prevent this happening to others and help them to begin to seek support and comfort. Very few families reported receiving even basic information about what the hospitals/trusts would be doing following the death and the practical steps of the post mortem, investigation and inquests’ (Inquest, 2016, 6).

There are a number of information booklets available that may contain information relevant to families. These are listed in the resources and references section. Some trusts, such as Cumbria Partnership NHS FT, have also developed short information sheets to provide to recently bereaved family members following an unexpected death:

Unexpected death

Information and support for family and friends following an unexpected death



Our concern for you

This leaflet is designed to assist the families and friends of patients who have recently died by providing information about support that is available, and by explaining how the Cumbria Partnership NHS Foundation Trust responds to unexpected deaths.

You have been given this leaflet because you will have experienced an unexpected loss. It is normal to feel a range of emotions at this time; these might include shock, confusion, distress or anger about what has happened. We would like to offer our deepest sympathy and our support as you try to come to terms with your loss.

You may have questions about the care your relative/friend received which you would like to put to the Trust, and we will do our very best to provide you with answers and address any concerns you may have.

The Trust is committed to reviewing the care it has provided in an open, honest and transparent way.

The information that follows explains how this process occurs and how you might become involved as well as signposting you to support networks that you may find helpful.

Review of care

We appreciate that you will want to know that the care that was offered and given was appropriate, and that correct treatment was provided.

The investigation is conducted by senior staff from within the Trust, who will examine whether the level and quality of care was appropriate and whether the correct treatments were given and offered.

They will reflect on the decisions made by the care team and form an opinion on the care delivered to your relative/friend.

Your involvement

You will be invited to meet the senior clinical staff undertaking the review in order that you may present and discuss your views about the care given and to identify any questions that you would like to have answered in the report.

Once the investigators have completed their written report you will again be invited to a meeting where the content of the report will be shared and the findings discussed with you.

During the investigation:

If you have any concerns in relation to the process, please do not hesitate to contact the person below:

Name

Job title

Contact number

1

This information sheet also provides contact details for local and national support organisations.

Listen to families

It is essential that families are provided with an opportunity to share their perspectives. It is incredibly unlikely (impossible) that the NHS could build a full picture of the care provided without engaging with family members and carers.

'All too often the terms of the conversation people have with the NHS about a concern or complaint are set by the organisation. Organisations can often be too quick to dismiss or explain away concerns, compounding the grief of bereaved families and carers with obfuscation and a lack of openness. Paying close attention to what bereaved families and carers say can offer an invaluable source of insight to improve clinical practice. Listening to them goes hand in hand with the Duty of Candour. In particular, bereaved families and carers should be asked if they had concerns about the quality of care received by the deceased to inform decisions about the need to undertake a case record review or investigation' (NQB, 2017, 16).

The recent publication *Gathering feedback from families when a baby dies* (NHS London Clinical Networks, 2017) includes three stages to consider

when collecting feedback: preparing internal channels; developing the process; collecting feedback. This is followed by using feedback to drive improvements, and a recommendation to use the Always Event methodology to do so (see IHI, 2016 for more information).

A number of methodologies and approaches may be required to be developed at a local level to enable the NHS to listen to bereaved family members and carers.

Provide bereavement support

There is a wealth of guidance available to support NHS trusts to develop bereavement services and supports. The NQB framework states:

'Bereavement can influence every aspect of well-being. Providers should offer a bereavement service for families and carers of people who die under their management and care (including offering or directing people to suicide bereavement support) that offers a caring and empathetic service at a time of great distress and sadness. This includes offering support, information and guidance.

This should include bereavement advisors to help families and carers through the practical aspects following the death of a loved one such as:

- arranging completion of all documentation, including medical certificates;
- the collection of personal belongings;
- post mortem advice and counselling;
- deaths referred to the coroner;
- emotional support, including counselling;
- collection of the doctor's Medical Certificate of Cause of Death and information about registering a death at the Registrar's Office;
- details of the doctor's Medical Certificate of Case of Death (this is needed to register a death at the Registrar's Office)' (NQB, 2017, 17).

NHS trusts must arrange bereavement support, and should consider how best to provide it to families who may be mistrustful of their services following a poor experience. They may choose to commission support from an independent organisation, or agree a reciprocal arrangement with a neighbouring trust.

Provide access to independent advice, support and advocacy

The CQC Deaths Review found that families and carers are not routinely told what their rights are when a relative dies, what will happen or how they can access independent advice, support or advocacy.

Families also report that they face many barriers to engaging with the investigation process, and that independent advocates could be a useful aid:

'Another [family] summed up their frustration and feelings of impotence in the face of organisational resistance, highlighting the need for independent support and guidance as an aid to navigating the process; "We were promised involvement and were invited to a meeting. We were very knowledgeable and were asking very pertinent questions, asking for copies of minutes etc. We wrote a narrative version of what happened, which was a very long document. The author of the report did not read it, they totally ignored all the points we have raised. They ignored us, lied to us and refused to send us minutes. During that stage independent advocates or an organisation like INQUEST would have been very beneficial"' (Inquest, 2016, 14).

The NQB framework states that 'timely access to an advocate (independent of the Trust) with necessary skills for working with bereaved and traumatised individuals' should be considered (NQB, 2017, 17). It is suggested by the NQB that consideration should be given to providing 'timely access to an advocate independent advocate (independent of the Trust) with necessary skills for working with bereaved and traumatised individuals' (NQB, 2017, 17). This builds on the already mandatory guidance in the Duty of Candour and the Serious Incident Framework which states:

'It is important that appropriate treatment and support is provided for patient and victims and their families and carers. This should be considered on an individual basis. However, the following needs should be considered:

- The need for an independent advocate with necessary skills for working with bereaved and traumatised individuals;
- Support with transport, disability, and language needs;
- Support during and after the investigation. This may include counselling or signposting to suitable organisations that can provide bereavement or posttraumatic stress counselling;
- Further meetings with the organisation involved or support in liaising with other agencies such as the police' (NHS England, 2015, 38-39).

Advocacy After Fatal Domestic Abuse have a number of hints and tips for how to include families and loved ones properly. These include a number relating to raising the status of the family, the first of which is to 'use an independent advocate to help the family' See [their website](#) for more.

Offer a single point of contact

Some NHS trusts have Family Liaison Officers (FLOs) who work with bereaved family members and carers, to support them with the investigation process. Where FLOs are not available, a single point of contact should be provided to bereaved relatives, and where possible all communications should come through this person.

It would also help families if this person could support them to access their relative's medical records, notes and associated documents:

'Often one of the first barriers families face, is trying to access their relatives medical records or notes: 'The trust wouldn't release records without going through the access to information process, my daughter didn't make a will so I had to get letters of administration, that felt unnecessary, two trips to Leeds. Once I got it I felt hopeful that 40 days on should get all of the records but how naïve can you be. We waited 40 days and nothing arrived, I pursued it and was told it was a longer job than they thought' (1-1 conversation)' (Julian, 2017, 10).

A person who could help access, and provide regular updates of any delays or changes to an agreed plan, would help families enormously.

Working with bereaved family members

The NHS has a legal duty to involve and consult the public about the running of local health services and to ensure that patients are listened to and actions taken to remedy any concerns they may have (Health and Social Care Act, 2012). This duty extends to bereaved family members and carers.

The Bristol Children's Cardiac review acknowledged that staff may find it a challenge to effectively involve families in improving services, however there is no acceptable reason for not doing so:

Whilst the Review does not underestimate the challenges of so involving parents in situations where relationships are strained, this is not an adequate reason for not trying. (Grey and Kennedy, 2016, 211).

The experiences and feedback of bereaved family members are crucial if the NHS wishes to understand how it performs and if it has a genuine commitment to improvement. The only way to understand the experience of bereaved family members and carers is to ask them, and to listen to their response.

Where this has happened, such as the review of William Mead's care (NHS England, 2016), it results in as best an outcome as possible for the family, and increased learning for the NHS:

The involvement of William's parents in the investigation by NHS England has meant that their concerns and questions have been fully explored, and it is refreshing to see the benefits of care providers' compliance with the statutory Duty of Candour for those affected by substandard treatment (Treloar in HJA, 2016).

Most recently Sands, NHS England and the London Maternity Clinical Network have worked with bereaved parents to develop the Maternity Bereavement Experience Measure (MBEM) questionnaire and its supporting resource. They state:

Many parents who have experienced bereavement want to offer feedback to ensure lessons are learned and good practice is shared. This can be instrumental to inform improvements in care.... The questionnaire is designed to seek feedback from bereaved parents where a baby or babies have died during pregnancy or shortly after birth (NHS London Clinical Networks, 2017).

Leigh Kendall, one of the bereaved parents involved in developing the measure highlights why parents wish to be included in this work:

"Bereaved parents want to be involved in talking about the care they and their baby received. We want to give praise where it is due, and to help make improvements where needed for the benefit of other families. We also want to be involved so that we can talk about our babies, to say their name, to show that they matter." Leigh Kendall, mother of baby Hugo (NHS London Clinical Networks, 2017, 5).

Focus on change and removing risk and follow through on promises

Families report that they engage with NHS trusts through a desire and commitment to improve things for others. It is devastating for previously bereaved families, and newly bereaved ones, when it becomes clear that prior learning was not acted upon, resulting in yet further deaths or harm:

'Families regularly returned to the subject of failures to learn from previous mistakes and how failing to implement changes from the past had resulted in deaths that were now the focus of this event. In emotional evidence families placed the responsibility on the trusts and those that have responsibility for implementation of recommendations:

“If recommendations were seen through, my son would have been alive and there would not have been another seven people dead after him”

“I wouldn’t be here now if the trust followed CQC recommendations in 2006. My son died two and a half years later in 2008” (Inquest, 2016, 29).

It is essential that NHS trusts openly engage, welcome, and act on any learning that emerges from the investigation process. They must deliver on actions, follow through on recommendations from regulators, coroners, or local investigations. Failing to do so is not only disingenuous but is also likely to result in yet more harm.

Resources and references

Academy of Medical Royal Colleges (2010) A code of practice for the diagnosis and confirmation of death

<http://www.aomrc.org.uk/publications/reports-guidance/ukdec-reports-and-guidance/code-practice-diagnosis-confirmation-death/>

AvMA (2016) The duty of candour: the legal duty to be open and honest when things go wrong. What it means for patients and their families

https://www.avma.org.uk/?download_protected_attachment=Duty-of-Candour-2016.pdf

Blythe H (2016) Regulating the duty of candour: A report by Action against Medical Accidents on CQC inspection reports and regulation of the duty of candour

https://www.avma.org.uk/?download_protected_attachment=Regulating-the-duty-of-candour.pdf

CQC (2016) Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England

<http://www.cqc.org.uk/publications/themed-work/learning-candour-and-accountability>

Cruse (Undated) Has someone died? Restoring hope

https://www.cruse.org.uk/sites/default/files/default_images/pdf/Free-leaflets/Restoringhope.pdf

Cruse (Undated) Coping with trauma and loss

https://www.cruse.org.uk/sites/default/files/default_images/pdf/Free-leaflets/CopingTrauma.pdf

Cruse (Undated) Supporting children through grief

https://www.cruse.org.uk/sites/default/files/default_images/pdf/Free-leaflets/SupportChildGrief.pdf

Cruse (2004) After someone dies: A leaflet about death, bereavement and grief for young people

https://www.cruse.org.uk/sites/default/files/default_images/pdf/Free-leaflets/AfterSomeoneDies-forYoungPeople.pdf

Cumbria Partnership NHS Trust (2015) Unexpected death: Information and support for family and friends following an unexpected death

https://cdn.cumbriapartnership.nhs.uk/uploads/leaflets/TW013_Unexpected_death.pdf

Department of Health (2005) When a patient dies: Advice on developing bereavement services in the NHS

http://webarchive.nationalarchives.gov.uk/20130123205207/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4122191

Health and Social Care Act (2012)

http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf

Hundred families (2015) A practical guide for families after a mental health homicide http://www.hundredfamilies.org/wp/wp-content/uploads/2015/12/HF_informationBrochure-web.pdf

Inquest (2016) Inquest's report on the CQC Family Listening Day http://www.cqc.org.uk/sites/default/files/20161212_inquest_report_on_family_day.pdf

Inquest (2016) The Inquest Handbook: A guide for bereaved families, friends and advisors http://inquest.org.uk/pdf/inquest_handbook_third_edition_2016_web.pdf

Institute for Healthcare Improvement (2016) Always Events Toolkit <https://www.england.nhs.uk/wp-content/uploads/2016/12/always-events-toolkit-v6.pdf>

Julian G (2016) Family involvement in, and experience of, death investigations by the NHS <http://www.georgejulian.co.uk/wp-content/uploads/2016/12/FamilyInvolvementExperienceNHSDeathInvestigationsFinal.pdf>

National End of Life Care Programme (2011) When a person dies: guidance for professionals on developing bereavement services <http://bsauk.org/uploads/834766631.pdf>

National Patient Safety Agency (2009) Being open: Communicating patient safety incidents with patients, their families and carers <http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=65172&type=full&servicetype=Attachment>

National Quality Board (2017) National Guidance on Learning from Deaths: A Framework for NHS Trusts and NHS Foundation Trusts on Identifying, Reporting, Investigating and Learning from Deaths in Care <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf>

NHS England (2016) Root Cause Analysis Investigation Report 2014/41975 <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/03/root-cause-analysis-wm-report.pdf>

NHS London Clinical Networks (2017) Gathering feedback from families following the death of their baby: A resource to support professionals in maternity care <http://www.londonscn.nhs.uk/wp-content/uploads/2017/06/mat-bereavement-mbem-062017.pdf>

NICE (2016) End of life care for adults: Quality Standard [QS13] <https://www.nice.org.uk/guidance/qs13/chapter/quality-statement-14-care-after-death-bereavement-support>

Public Health England and National Suicide Prevention Alliance (2015) Health is at Hand: Support after someone may have died by suicide <http://www.nhs.uk/Livewell/Suicide/Documents/Help%20is%20at%20Hand.pdf>

Salisbury NHS Foundation Trust (2015) Information for families following the death of a person with a Deprivation of Liberty Safeguard (DoLS) authorised <http://www.icid.salisbury.nhs.uk/ClinicalManagement/MentalHealth/Documents/information%20-%20death%20of%20a%20person%20DoLS%20PI1355.pdf>

Southampton Children's Hospital (2014) When a child dies: Information for parents, families and carers <http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Childhealth/Whenachilddies-patientinformation.pdf>

SOBS (2004) Support after a suicide <http://uk-sobs.org.uk/wp-content/uploads/2014/02/SupportAfterASuicide.pdf>

Together for Short Lives (2012) A guide to end of life care: Care of children and young people before death, at the time of death and after death http://www.togetherforshortlives.org.uk/assets/0000/1855/TfSL_A_Guide_to_End_of_Life_Care_5_FINAL_VERSION.pdf

Williams M (2011) Coping with grief when someone you love dies suddenly <http://www.suddendeath.org/assets/docs/SUDDEN-CWG-2011.pdf>

Organisations

Action against Medical Accidents <https://www.avma.org.uk/>

Advocacy after fatal domestic abuse <http://aafda.org.uk/>

Bereavement Advice Centre <https://bereavementadvice.org/>

Bereavement Services Association <http://bsauk.org/>

Child Bereavement UK <https://childbereavementuk.org/>

Compassion in Dying <https://compassionindying.org.uk/>

Cruse Bereavement Care <https://www.cruse.org.uk/>

Hundred Families <http://www.hundredfamilies.org/>

Inquest <http://www.inquest.org.uk/>

Lullaby Trust <https://www.lullabytrust.org.uk/>

SAMM: Support after murder and manslaughter <http://samm.org.uk/>

SANDS: Stillbirth and neonatal death charity <https://www.sands.org.uk/>

SOBS: Survivors of bereavement by suicide <http://uk-sobs.org.uk/>

Sudden: Supporting people after sudden death
<http://www.suddendeath.org/>

Support around death <http://www.sad.scot.nhs.uk/>

The Patients Association <https://www.patients-association.org.uk/>

Together for Short Lives <http://www.togetherforshortlives.org.uk/>