

# INQUEST's report on the CQC Family Listening Day

October 2016

**POLICY • ADVICE • CAMPAIGNS**

# Introduction



The events took place on the 22<sup>nd</sup> September 2016 and involved family members discussing their experiences of deaths involving relatives...

INQUEST was invited by the Care Quality Commission (CQC) to hold a family listening day to gather evidence to inform its review of how NHS trusts investigate and learn from deaths. A link to the terms of reference can be found below.<sup>1</sup>

The events took place on the 22<sup>nd</sup> September 2016 and involved family members discussing their experiences of deaths involving relatives who had used learning disability or mental health services.

The structure of the day saw feedback from families outlining the process and systems that frame the investigation and inquest process with a particular emphasis on family recommendations for improving current practice. This was followed by an opportunity to feedback on the CQC review's current thinking and provisional recommendations to date.

## Methodology

The family listening day model is a tried and tested methodology for seeking participant feedback and uses the following framework:

- planned – in conjunction with the review team, families and INQUEST staff;
- facilitated – by experienced INQUEST staff, briefed and knowledgeable on the key issues, and with an understanding of the families' particular cases;
- thematic – to provide focus and to avoid the event becoming too wide reaching and broad based;
- discursive – by encouraging participants to discuss the issues in a safe and understanding environment, allowing a free flow of ideas and thoughts surrounding the review's themes;
- inclusive – ensuring as wide a range of families affected by the issues under scrutiny felt able to attend and speak;
- confidential – information shared during listening days is honest and heartfelt, and families recognise that what is shared within the group should not be disclosed outside the group;
- compassionate – as an INQUEST caseworker pointed out, "families find it difficult and painful to talk through these things". The importance of

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<sup>1</sup> 2016, C.Q.C. (2016) *Get involved*. Available at: <http://www.cqc.org.uk/content/review-how-nhs-trusts-investigate-and-learn-deaths> (Accessed: 26 September 2016).

compassion and understanding is crucial to the success of the process and families should not feel isolated by judgemental attitudes;

- reflective – offering a chance to re-balance power structures and give participants the chance to reflect on the impact of events;
- archived – the families’ contributions are recorded and placed in the public domain.

INQUEST has run six of these events in the past for organisations including the Independent Advisory Panel on Deaths in Custody, the Independent Police Complaints Commission, the Equality and Human Rights Commission, for Lord Toby Harris as part of his Independent Review into Self Inflicted Deaths in Custody of 18-24 year olds and for Dame Elish Angiolini’s Independent review into deaths and serious incidents in police custody.

This report draws out the thematic issues that arose in conversation and uses family quotes to illustrate the evidence and ideas. There are a series of family recommendations for consideration, initially included at the end of sections as they arose, and consolidated in the final section of the report.

## 1 Initial contact and provision of advice and support

Families described varying approaches of being informed of a relative’s death. Discussion focused both on how they were informed of the death and what information they were given. 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.

Informing families of a death was often initiated via a telephone call, with very little or no information other than a brief explanation or an invitation to attend the hospital, or in other rarer cases, a police station.

Some explained the lack of sensitivity displayed by those involved in the initial contact;

***“We were left on our own in a room on arrival [at the hospital]. The ward manager came in in tears. We were given [our daughter’s] glasses, rings,***

***phone and a police incident number. There was no cup of tea, can we ring anyone for you, taxi home”.***

***“When I arrived in the hospital I was totally ignored. His dad lived nearer so he was already there. It was him who told me that our son had died”.***

***“The police officer informed his sister in the police station through a Perspex screen in the reception of the station that [he] had died. There should have been an area to deal with the family. The approach of officers and other professionals makes a major difference, they need to deal with families differently”.***

Families want empathy, dignity and sensitivity from the first point of contact and for that to continue throughout.

One parent suggested what would have helped was ***“if we could have had someone who instantly empathised and understood the complexity of the situation”***. Another felt the response from the hospital was so impersonal it was ***“like they were reading from a prepared script”***.

Others spoke of encountering staff who seemed ***“off”*** with them. In one case, a family member met a ***“nurse who shouted at us”***.

One family was given incorrect information about the way their relative had died, and only discovered the correct information by chance;

***“We received a phone call and were told that [their son] had had a heart attack. The hospital gave us the wrong hospital details and we only discovered the correct hospital when that hospital called our home”.***

**Written submission from a non-attendee**

Families also reported that they felt confidentiality was unfairly used as a way of barring them from any involvement. In one case the hospital rejected the family’s request for details as to what was happening as their daughter was estranged from them;

***“We have no idea where the [idea that] ‘[she] wants nothing to do with her family’ came from. Mental health staff in the hospital demonised us. The receptionist refused to give our details so we could be told she was in hospital [following suicide attempt]”.***

Another family outlined their concerns that the clinical team withheld information on treatment for their daughter, resulting in decisions that they felt were not in her best interest;

***“We would never have allowed her to move to an acute unit, we weren’t told consent had been withdrawn, even though we continued to go to meetings with the team treating her”.***

Other families echoed this concern that family experience and understanding was ignored by the professionals.

## 1.1 Lack of information about the death

Initial contact and communication with families was described as lacking clarity, there being no framework for explaining what had actually happened and what would happen next. Families wanted detail about how their relative had died but were often denied even basic information on the cause of death;

***“Six days after [she] died, we still didn’t know what type of cable she’d used”.***

***“Finally the coroner’s officer told us that [our son] died following swallowing an aerosol top after the autopsy was provided to the coroner. The coroner’s officer was shocked we had not already been told.”***

### Written submission from a non-attendee

Families described the sense that by failing to provide even the basic information surrounding the death or answer specific questions, the hospital/trust were denying them an opportunity to ask the right questions and offer background information that may prove useful in understanding what had taken place. In what was to become a recurring theme of the day, information wasn’t given to families until the hospital was pressed. It further exacerbated the sense that the hospital/trust were already **“covering their backs”** and added to the families’ sense of isolation;

***“They then changed their account, first they said he was hanging from the back of the door then they changed this and said that he was hanging from the handles of the wardrobe. I thought why they could not get one fact right. They found him, they saw where he was hanging from, why couldn’t they just say? I was offered nothing”.***

Families also described the lack of compassion and humanity that framed the initial contact and how upsetting that felt at a time of huge grief;

***“When I received a phone call they told me that [my son] had been found hanging and he did not look good but he had been dead over an hour when that phone call was made. When I arrived, there was a group of people standing and as I walked in, I heard them saying ‘she is here’. I was not allowed to touch him as it was a crime scene; just look but don’t touch”.***

## 1.2 Lack of information about the process

Families consistently made reference to the information vacuum in the immediate aftermath of a death and the way in which this felt like a denial of their rights. As one person pointed out, **“it was like being put into the world of the unknown.”** Central to the discussion was a desire to see the

hospital/trust provide information about what would happen next and for information to be made available about independent sources of support and guidance which should include legal support.

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.



In the absence of information families felt they were being put on the “back foot” from the beginning.

***“I should have been given my rights, they should have said these are your rights, you can have a doctor present at the post mortem etc. and give me information about what to do. I had to do everything myself”.***

Where families were contacted there appears to have been mixed or inconsistent approaches. For example where meetings were set up, families were not given guidance on the meeting’s purpose or agenda, but left in the **“lurch”** and ill-equipped to properly engage. In one case a meeting was arranged at the family home and those attending arrived early and the family felt unprepared.

***“At the first meeting, no condolences were offered, they arrived 15 minutes early which threw us, there was confusion in what they told us about the process and they couldn’t give us a timeframe”.***

Another family experienced a more sympathetic approach initially but an acknowledgement that the investigation was unlikely to criticise the trust involved;

***“Our meeting with the trust was between 4:30-7:30pm on a Friday evening. The lady from trust, who we’d met before, told us ‘I come to this table as a mother’. She told us how unprofessional her colleagues had been but said we couldn’t expect her to sell her colleagues down the river”.***

There was significant evidence of first contact failing to address or engage with the questions that families had;

***“No one asked me about my concerns and what questions I needed answered. For nine months, we had no information. Since I contacted INQUEST I have been getting all the information”.***

One family suggested that the first meeting following a death should be organised around an established agenda and accompanying information establishing the next stages of the process. It was felt that families were attempting to fill in the gaps anyway and the trusts should acknowledge that.

Families need information around the role of the coroner, the coroner’s officer and the role of the inquest. Hospitals/trusts should inform families of their rights,

including their right to information on the post mortem, their right to view the body, their right to a second post mortem and to funeral costs.

There was a consensus amongst families that they had to do all the research when information could and should be made freely available;

***“She should have come prepared, with a handbook, an agenda. We’d done all our research two days after our daughter’s funeral”.***

When families do eventually gain access to independent advice and guidance it comes as a huge relief;

***“Nothing except for a leaflet about bereavement services from the coroners officer. INQUEST provided information about the inquest process, funding and help with finding a solicitor. Talking to our case worker that first time put our minds at ease for the first time in months”.***

As has been noted above, 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”.***

### **1.3 Access to counselling and support following a death**

There would appear to be a dearth of bereavement counselling for families bereaved in this way, and accessing independent support is problematic. Some families sought support from the hospital/trust in which their relative had died, and in one case this was offered but subsequently the service appeared not to exist, highlighting initial confusion around what families were being offered and what was deliverable. One mother was told by her GP receptionist, ***“If you want bereavement counselling, you need to come and see a doctor like everyone else’. Which put me off”***. Some were directed towards counselling by the coroner’s office, but there is little or no consistency of approach.

However when families discussed the offer of counselling and support from the trust, it was pointed out that ***“a lack of trust in the trust”*** is the problem. Another family expanded on this;

***“In my experience, I was offered access to services, within the trust, which would have been the last thing I accepted given the circumstances. Perhaps it could be suggested that sign-posting should include alternative services, such as Just Be, or similar”.***

**Written evidence by an attendee**

Worryingly there was also evidence that those sharing information seemed to misunderstand the circumstances surrounding a death or had already made assumptions about those that had died, suggesting it was almost expected or inevitable;

***“A policeman said to us ‘mental health patients do kill themselves sometimes don’t they?’”.***

Another said:

***“I was put in a room. I shall never forget what the nurse in the room told me. She said, ‘You have got to accept that his time has come’ bearing in mind that my son was just 34 years old. They knew damn well that something was going to hit the fan hard, there was an atmosphere of fear in the room”.***

Families felt that these types of misconceptions were instrumental in defining the rigour, type and quality of ensuing investigations. One person provided an example;

***“The death of a 45 year old with a learning disability could be seen as ‘normal’ or ‘not unusual’ and is deemed less important for investigation or review and therefore chances could be missed to improve clinical care”.***

## **1.4 Recommendations**

Those tasked with informing families of a death should be trained, including in the use of appropriate language, and be empathetic and sensitive to the family’s needs and wishes. Training should be updated at regular intervals. Training should include an understanding of traumatic bereavement and the impact of the investigation and inquest process.

- Trusts/hospitals should have dedicated staff whose primary role is family liaison.
- Families should be treated with dignity and respect at all times.
- Initial contact with families should follow a consistent approach.
- Hospitals/trusts should have a handbook/information sheet outlining the various stages of the processes following a death: family liaison, a named contact within the trust, time frames, protocols for family engagement, the investigation aims and remit, complaints procedure and the chain of responsibility for overseeing the process. (See the INQUEST handbook as an example of good practice).
- Families should be given information around the role of the coroner, the coroner’s officers and the role of the inquest.
- Information should be made available around the post mortem and the family’s rights to view the body, right to a second post mortem, funeral costs etc.
- Independent advice should be made available on accessing specialist legal representation and their rights in the process.

- Trusts should have a handbook/information sheet which lists independent support agencies specialising in bereavement, counselling and support groups (if they exist in the given area).
- All information provided to families orally should be duplicated in writing.

## 2 The investigation process

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. This was most keenly expressed when discussing the failures to respond to warnings about deficiencies in care.

Families felt that their input was always trumped by the ‘experts’, a case of ***“professionals know best”***.

Families also described some of the meetings that took place with those tasked with initial family liaison and fact finding. For some these meetings were hostile or used as a means for gauging the families’ potential role. Some explained that as soon as they began to ask questions or query official versions of events they were met with hostility. Others felt threatened by the involvement of hospital/trust lawyers when they were unaware that they would either be present or required, placing them at a disadvantage from the outset.

Families did want to engage with meetings, and they wanted them placed on a formal footing with an agenda and minutes etc. But they also acknowledged that these should be optional, and offered giving families the choice whether to attend. Families wanted the process to reflect their needs rather than the convenience of hospitals/trusts.

Other concerns centred on the quality and skillset of those investigating, the failure to explain what an investigation involves and the inability to grant simple courtesies; explanation for delays; factual inaccuracies when gathering and exploring evidence; failures in communicating progress; and the constant reliance on families to maintain the momentum of a process that they expect to illuminate truths and any potential failings.

***“The investigation was supposed to take 65 days but it took eight months. It was ‘published’ in draft form without asking me to be involved further since the initial meeting in June 2015”.***

There were examples of investigations being initiated only after complaints or prolonged requests by families, and of being initiated without the families' knowledge - and in a couple of extreme cases completed - without the family ever being informed at all.

These factors combined to **“wear us down”** as one man explained, with the experience also being described as a **“battle”** or a **“struggle”**. In many cases families felt that this could be easily avoided if the investigators were **“open and honest”**. Some felt this was an intentional tactic deployed by trusts who were more concerned with preserving reputation and defending their actions than seeking truth and learning lessons. For many it points towards an investigation system that lacks proper independence and functionally becomes more about defensiveness and obfuscation. The question was raised; if trust investigators aren't impartial, **“whose truth are they after”**?

Families were also critical about the quality of external investigations, especially involving the police. There was scepticism that the investigations of deaths of people using learning disability or mental health services was carried out to the same standard or with the same rigour as would normally be the case, echoing some of the attitudinal issues highlighted in Section 1.

## **2.1 Absence of an agreed investigation framework and time frame**

It was common for families to have been given little or no details about what an investigation involved. Families argued that without hearing directly from families, any investigation was rendered incomplete and biased in its approach. Families want and need a framework for the process which clearly outlines timescales, scope and role of those involved and clearly establishes how relatives can effectively engage with investigators to create an investigation and report that reflects the circumstances surrounding a death and reveals any failings in care that can prevent future deaths or “near miss” incidents. Families were unanimous in their belief that without this, lessons can never be properly learned. One family felt they were placed at a disadvantage when the initial meeting was convened earlier than scheduled and seemed to have no clear purpose;

**“At the first meeting, no condolences were offered, they arrived 15 minutes early which threw us, there was confusion in what they told us about the process and they couldn't give us a timeframe”.**

Another outlined the information deficit that surrounded their case;

**“After we identified the body, the police said no information could be given to us as there was an ongoing investigation. The trust would not speak to us because of the ongoing investigation either”.**

In other cases there was no communication about the investigation and the subsequent investigation was initiated after persistent complaints;

***“There was no investigation so we made a complaint. SIR began a year later, only after being persistent with the trust”.***

Some families were concerned that investigations were started without their knowledge, the discovery of which came about by chance;

***“We received a pile of documents from the Coroner and the trust’s SUI report was in there. This is when we found out that there had been an internal investigation, no one had told us about it before. The investigation was a shambles”.***

Another’s experience suggested this was not an isolated example and followed a complaint about the care of their relative;

***“My first contact with the trust was my letter of complaint. They followed up according to their complaints procedure. Everything was done on the deadline, never before, at every step. They said they’d instigated an investigation as soon as they heard about Mum’s death. I wasn’t told this until the meeting after my complaint”.***

A further example highlighted failings on the part of the hospital/trust to understand the impact of a death on families. This led them to implement a time frame for investigation that suited the trust, but not the family. This resulted in an initial investigation that was conducted without the family’s involvement at all;

***“We received a letter two days after [our son’s] funeral asking us to contact them [the trust] regarding our participation in the investigation process. A month or so later we responded as we were still in a state, another month after that the lady replied to say sorry for the delay, she’d been on holiday and the investigation had been completed. We didn’t even have a confirmed cause of death!”***

The wish of families to engage with the process should be acknowledged and the hospitals/trusts must recognise that conducting an investigation should be geared towards families’ needs wherever possible. The need for an agreed timeline is a two way process and those investigating need to keep families promptly informed, but families also sought ***“time to consider the information they were being given”.***

Another person elaborated;

***“You should be able to have the level of involvement you want...families don’t always know at the beginning how much they want...you need time to breathe”***

## **2.2 Competence of investigators – the need for training**

Some families believed there was evidence that failures could be attributed to the competence of those conducting investigations and the culture informing the

process. Families felt investigators were unable or unwilling to involve families and failed to engage with hugely important questions surrounding the quality of care and treatment and in doing so gave little impression of wanting to learn lessons from potential wrong doing or failings. In addition there were repeated examples of investigators failing to interview key members of staff, other witnesses, and by failing to consult the family, omitting evidence either by incompetence, or by design.



Families felt investigators were unable or unwilling to involve families and failed to engage with hugely important questions surrounding the quality of care and treatment...

Families were quick to question the basis on which investigators were chosen;

***“The quality of people and competency was low”.***

***“Some of the people weren’t very bright. They misunderstood what we told them and overpromised what they could deliver”.***

This sense of not delivering on promises also focused attention on the need for investigators to be properly trained for what was acknowledged to be a difficult job;

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

One family explained how the investigator in their case was undertaking the task whilst still carrying out her duties as a matron in the hospital;

***“We asked how she had time to do her main job as well as helping us. She said ‘most times I take it home and do it at the weekend over a bottle of wine’”.***

Others pointed to the pain of discovering information relating to the death which was uncovered during the investigation but not shared with families;

***“All these details were distressing to us and we had not heard any of this before, we only found out when the report arrived”.***

The failure to adequately share information and to keep families up to date is a failure of both process and system, and erodes families’ trust in the robustness of the investigation. It was felt by some that the solution lies with selection and training;

***“There should also be a training process, academic capabilities to analyse data should be important. What is the standard and threshold for their selection and training? It’s not clear”.***

### 2.3 Independent investigators

This raises further questions about the independence of investigations, and families were unanimously adamant that investigators need to be independent

and able to criticise where warranted. Families agreed that all investigations, and those carrying them out, must be independent of the hospital/trust in which care the death took place. There was a description of investigators in one case working freelance but being reliant on the trust for future work, a situation that families believe rendered independence unlikely at best;

***“People who carry out the investigations, I do not know how they are regulated, but they depend on getting further work, they want to get the next job so how critical can they be? They are not a registered professional so they can't be struck off; they are not regulated by the CQC. They might think ‘if I tell them too much I will not get the next gig’”.***

There was a suggestion that the skills set required was on a par with police work and should reflect that;

***“It's like a criminal investigation – the person leading it needs to be able to do that”.***

However some felt the process was ‘rigged’ from the start and was geared up to defend hospital/trust decision making and as such investigators are working within a defensive culture which refuses to acknowledge wrong doing or apportion blame;

***“It seems the internal investigators are putting their job in jeopardy if they produce a critical report. It seems there's a problem with the culture”.***

A concern was raised about the opportunity to find the truth when a criminal offence may have taken place. The lack of independence in these situations meant the whole process was open to abuse;

***“An independent investigation from the start is important. Trust is not required to request external investigation apart from the time when the patient has committed a criminal offence, what about manslaughter and criminal neglect committed by the trust itself”? As a family member we need to be treated with respect and have proper investigation, they can't investigate themselves, they are guilty, and why are they being asked to investigate themselves?”***

Another person believed the investigation was used to identify mistakes that allowed them to correct errors and inaccuracies and following the investigation, ***“staff went back and updated notes from eight weeks before”.***

The lack of proper family engagement was seen as a consequence of this ‘institutional resistance’. Families faced hostility and were made to feel their input was an irritant or inconvenient to the process;

***“As soon as we started asking questions it was like we were interfering and that they were the professionals, not us. They became antagonistic”.***

It was also pointed out that by resorting to a defensive approach from the start, families were forced into engaging with legal processes as other options for influencing learning and change were denied them;

***“The immediate focus on protecting the organisation, over engaging in a transparent and inclusive investigation, hampers the process and puts the family in a position where they have no option but to engage legal support (if indeed they are in a position to do so). This misses the opportunity for the NHS to genuinely learn, and also avoid the legal claims which are inevitable in the absence of any other avenues for change to be sought”.***

In those cases where there was police involvement families were critical of perceived failings with the quality of investigation.

***“Police said forensic examination was going to take place. I asked them what forensic examination, the room had already been cleaned and somebody else put in”.***

***“The police investigation was poor. They did not seal the scene, they just got an officer who was already in the hospital to have a look at the scene and tick the box to say that there was no third party involvement”.***

It is also worth noting that of the cases discussed during the event, not one involved an independent investigation by the Health and Safety Executive (HSE).

## **2.4 Family responsibility for maintaining investigation momentum**

Ultimately families want their knowledge and input to have influence and bearing, their voice to be heard during investigations and to help create reports that properly impact on future care, working practices and the quality of future investigations.

***“Valuing the input of family is completely lacking from the investigation process. Many family members have valuable insight into the care received by their loved ones, which should be taken into account in any SUI”.***

### **Subsequent written submission of an attendee**

Another 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”.***

Another suggested an independent, truthful investigation was the very least families deserve;

***“All we wanted was the truth – the worst had already happened. Independence is key”.***

It was also clear from discussions that families had to work very hard to maintain the momentum of the investigation process and constantly had to remind investigators regarding deadlines, make requests for minutes of meetings and challenge inaccuracies, all of which required skills, confidence and stamina. For many it was a terrible toll to pay for a fair investigation and families worried that those who could not maintain pressure on the hospitals/trusts would inevitably end up with an inadequate investigation and report.

***“Unless you have an understanding of the process, the sector and systems are hard to get through”.***

***“We had to tell them to stop every time they said something, which was not true and in the end he apologised but what about other people who might not be as articulate or knowledgeable as us, what about them? We found out that they did not bother to investigate properly”.***

Another suggested that professional experience was the only thing that got her through the process;

***“I’m quite used to chairing meetings as part of my job. If not, it would have been totally overwhelming”.***

The skills and perseverance to monitor investigations and seek truth and justice does have an impact on families. It places them under both physical and mental health pressures and requires time away from work and places a burden on families financially. One person explained how the ***“the investigation caused further trauma”*** whilst others described having to re-live the whole experience. Another person explained;

***“I was a healthy person but since the death I had to see my GP twice as I started having panic attacks. The emotional toll on families when something like this happens is immense, it completely changes your life”.***

Ultimately families are seeking answers and these should be available regardless of financial means, capacity or confidence.

## **2.5 Recommendations**

- Hospitals/trusts must provide families with the opportunity to shape the terms and reference of the investigation and enable them to play an effective part.

- Investigations must seek to include the “family voice” where possible; their experiences, evidence, information and concerns in order to ensure the investigation scope is as broad as possible.
- Hospitals/trusts need to be seen to value the contribution of families rather than manage families or regard it as a threat or inconvenience.
- Investigations need to be carried out by competent, trained specialists for whom the investigation is their primary function.
- Investigations must be independent, carried out by independent investigators.
- Hospitals/trusts must not investigate themselves or employ staff involved in the care and treatment of the relative. Anything other than independent investigations produces an inherent conflict of interest and does not inspire family confidence.
- Face to face meetings with investigators and hospital/trust staff must be minuted, and those minutes made available to families as would be the case with any other formal meeting. Minutes must be agreed as a true record with families.
- A process framework for the investigation must be provided for and agreed with families with realistic timeframes.
- Families should be consulted on how and when communication takes place, providing space for families to digest and analyse information.
- Families should be promptly informed of any delays in the investigation and provided with explanations of the cause.
- Any investigation involving the police needs to be conducted with the same rigour and professionalism as would be the case with any other criminal investigation.

### 3 Investigation reports

In many ways the families’ exposure to investigation reports chimed with what had gone before; delays, limited involvement, inadequate reporting, inaccuracies and secrecy. Experiences varied but these themes presented time and again. It led those present to ask a key question; who is the report for and what function does it serve?

As one person stated,

***“the aim of the report seems to be to go back and cover up rather than to prevent. I can’t see the point if this is the approach”.***

Families concerns about the quality of the investigation led them to believe the findings and recommendations must be of a poor quality as well, and as such the whole process required re-assessment. One contributor suggested that the lack of independence from the outset undermined the findings. Another was more direct in their assessment of the process;

***“The quality of reports was crap. Spelling mistakes, errors, inaccuracies. We had to push them back many times”.***

It was suggested that the way reports are written and structured appeared inconsistent and authors should rely on a template based on best practice.

As well as serious doubts as to the quality of investigations, families were also angered by the omissions. These extended to failures to include family evidence, missing information and data surrounding care and treatment, a failure to include the evidence of witnesses and crucially, the inability to see the broader picture. Concerns were raised as to why references to other serious incidents and deaths were rarely referred to and why concerns about the safety and standard of care, provided by families either independently, as part of the investigation or directly to the hospitals/trusts and the CQC were omitted from the final versions of reports?

Many families explained that until this happens, instinctively *“as a lay person you believe the professionals”* but going through the process that belief and trust is quickly and in many cases, terminally eroded. What results is a stand-off between sceptical relatives and defensive trusts which families believe does nothing to ensure these tragedies do not happen again.

There were some examples of families welcoming the report, regardless of quality as it was the first opportunity they had to read about what happened and the quality of care afforded their relatives, and confirmed their concerns and fears. However there was still anger that information had not been passed onto them as it became apparent during the course of the investigation.

### **3.1 Quality and accessibility of reports**

The families’ scepticism surrounding reports was based on the basic premise that the ***“report is only as good as the information it is based on”***. Many families were quick to provide examples of reporting that contained inaccuracies which may have been minor to those producing them, but were extremely upsetting for the relatives;

***“There were false problems and ongoing inaccuracies like the time of my daughter’s death, which mattered to us”.***

Others experienced something similar;

***“Factual inaccuracies were not corrected. The time on report given when family were notified of the death was 4 hours earlier”.***

These errors do much to undermine confidence in the accuracy of what was being reported. As one person said, ***“our investigation report- I could just throw it”.***

Families also highlighted their concerns at the omissions which meant key information was not recorded and thus altered the tone and tenor of the reports.

This seemed to be most common when alluding to specific details of care, treatment and clinical decision making;

***“In my report there was no mention of [a friend’s] son’s death. There was no indication whatsoever that other people died in the same way in the same unit. They withheld information, they lost information, staff gave no comment interviews and they were allowed to do so”.***



As is the case with other aspects of the investigation, families were faced with on-going unexplained delays in receiving information as to where the process had got to.

The inaccuracy of reporting places an even greater emphasis on families taking responsibility for scrutinising the details;

***“They’d changed the logs so we felt we had to forensically analyse the evidence”.***

Others were upset by language used in the report which appeared to belittle the seriousness of the situation;

***“The report said [their daughter] had ‘tailgated’ someone to get into the disabled toilet, we found that language offensive”***

There were also suggestions that the reports were filled with jargon, written in a style that was inaccessible to anyone other than those who shared a professional knowledge of the terminology and language. One family explained they would have ***“needed a committee of people to read the report and make sense of it”***. Others raised questions about the structure of reports, and whether there was an accepted template for producing good information that enabled families and trusts to understand and learn from what had happened;

***“All these reports come out and end up on the shelf. I told them ‘I want you to use Connor Sparrowhawk’s report structure and then write your own report’. Needs to be more institutional learning – don’t outsource this”!***

### 3.2 Delays in receiving the report

As is the case with other aspects of the investigation, families were faced with on-going unexplained delays in receiving information as to where the process had got to. This adds further stress to an already impossibly difficult experience and creates further layers of suspicion and anger. It is also avoidable with the introduction of a framework and guidelines for the process, and a named point of contact within the investigation team who can keep families up to date with progress. As things stand the families only felt frustration;

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

Often it was left to families to pursue the matter of delays and provide the impetus for action. One family explained that;

***“We had to pursue the trust – they didn’t share the report for around three months, we called to ask where the report was and two days later it was sent out”.***

This reluctance to disclose information on the part of trusts also extended to the coroner in one case;

***“I received the report at 7.00pm the night before the inquest and it was presented to the coroner five minutes before the inquest started”.***

### **3.3 Independence of reports**

As with the initial investigations families questioned the validity of a process that could not be considered transparent when there was a conflict of interest around independence. In a considerable numbers of cases, those tasked with producing reports had previous involvement with the care of their relatives or were employed by the hospital/trust under investigation. Examples given included staff who had treated relatives being asked to author investigation reports, and in one case there was a suggestion that the author of one report had been involved in false record keeping at an earlier stage;

***“Seven day incident report was completed, but it was meaningless as I was not even informed about it and only found out about it after receiving the SUI. Worse than that, the person who wrote this report was the same person who falsified the records”.***

Families felt any such conflicts of interest need to be disclosed

***“Families should know about conflicts of interest - when [trust] staff were then found out to be co-authors of our investigation report”***

And as was the case with the investigations families wish is for report authors to be entirely independent of the hospital/trusts under investigation.

### **3.4 Family input into reports**

Families felt they were either not involved in a collaborative sense or were partially consulted and then ignored. There was a deep sense of frustration expressed by many at the inability to have their comments included within the findings. It raised a key question about what impact on change reports could possibly engender when vital information was not included. Families had little confidence that the reports contributed enough to learning lessons and preventing future deaths.

As has been established in Section 2, families were given little or no opportunity to help negotiate the terms of reference of the report and those who were, felt undermined or angered that they had to push for inclusion;

***“We actually wrote the terms of reference and [the trust] handed it back to us asking ‘have you seen this’?”***

***“The lovely action plan shown to the coroner was because of us pushing them”.***

Some families had been offered a chance to comment and then found the report had not been amended;

***“We trusted her, she said she’d make our changes to the report in May, in Oct we finally got a redacted copy and our changes hadn’t been made”.***

While others simply had no chance to comment at all:

***“The report was made without family input. The trust wasn’t interested in our input”.***

One person had to accept that they would never actually see the official report following her son’s death as the trust blocked its release;

***“I was told that I will never get to see the original investigation report. Three people prepared that report and then wrote to their solicitors. The NHS trust said that they only had the draft report. I asked to see the original report but couldn’t. What’s the point of it then? The report I have got, which was damning, was meaningless as I did not know what had been changed and I still don’t know now”.***

In one case it appeared that the meeting with the family to discuss the report’s findings was purely a matter of procedure as ***“the report had already been signed off and dated some months before we met”***. In other examples the lack of confidence and scepticism about the report’s impact was borne out by the lack of subsequent action;

***“When the final report came I took it to a lawyer friend of mine and we went through it line by line and commented on them. They did not change anything. No staff statements were ever produced. His care plan was falsified after his death, a total cover up”.***

Whilst another family explained;

***“The report said a lot but it didn’t tell us anything we didn’t already know. The trust has not followed up with us on any of their recommendations for change. The level of observations [he] was on at the hospital was not adequately addressed in the report and nor was the lack of appropriate search policies”.***

**Written submission from a non-attendee**

### 3.5 Inclusion of concerns raised by families prior to the death

The potential for **“trusts to become learning organisations”** as one person suggested is compromised by the failure to include evidence of concerns or complaints raised by families prior to the death of their relative. This was viewed as highly disadvantageous to proper reform of a flawed system.

Families could not understand why their observations, sometimes regarding what they believed to be a direct risk to life, were not placed on public record as part of the investigation and reporting process. They felt their contribution to a broader debate on patient care and safety had been ignored or overlooked;

***“My elder brother had a learning disability and autism. There were issues around the care home where he was. I had written to the CQC on many occasions highlighting all the issues, but I was ignored”.***

Another explained in detail their endeavour to prepare crucial questions regarding their relative’s care, and the resistance to using the information;

***“As a family we prepared a list of 20 questions for the Coroner. Our questions were then passed on to the hospital by the Coroner. We did not know that an investigation was going on and had not been asked to feed into it. We told them about the vital aspects of his care plan being missing, we raised the fact that they did not interview any witnesses, they had only sent a junior officer in who was not experienced, and we made complaints to 5 agencies. They ignored us, lied to us and refused to send us minutes, during that stage”.***

Another family described their anger and frustration at having their concerns firstly ignored when their relative was alive, and then again when the investigation was underway;

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

Without family scrutiny and resilience, inferior reports that do little to enhance future learning are accepted without question. This fails the relative and lets down future patients in the same settings;

***“Had I not been scrutinising [my relative’s] care and recorded the facts along with three social workers in the lead up to his death, and had I not been present during the final two days of my brother’s life we would have had to accept this report’s dishonest recording of the 48 hours leading up to his death as an honest account. It is nothing less than an attempt at a cover up”.***

#### **Written submission of an attendee**

Families want future investigations and reports to become more representative of their views, and to include evidence of their broader observations of care, treatment and patient safety.

***“There needs to be an opportunity to feedback on the experience – feels like they don’t want to know, the family isn’t a priority when producing a report. ‘Catastrophic incident’ seems to relate to the investigation not the death”.***

### **3.6 Further/independent reports and the impact on families**

Those families who had experienced multiple investigations/reports explained how the process became a drain on them. The need to focus and re-focus on traumatic information meant re-living the initial trauma and grief;

***“The pain of going through those reports again and again made me feel ill”***

However there were some advantages to be had as some felt the re-examination of cases had the potential to uncover fresh evidence and information, especially when undertaken independently and although tiring and draining for families, there was a sense that repeating the process allowed some truth to come out;

***“We had two reports, one internal, one independent. Trust got external expert to comment on the care my uncle received. A lot of failures were identified. They had no records for him; no list of medication, the fact that he was diabetic was not on the records”.***

Families also found they tended to be written in a more accessible fashion.

However there were still doubts about the efficiency of independent investigations and reports;

***“The coroner got an independent expert and there were 180 mistakes in his report which didn’t help”.***

***“Everyone took the psychiatrist’s report as gospel at the inquest. He came to our home after and admitted he’d been suckered in. We lambasted him for two hours, he apologised, and he’ll never do it again”.***

Flaws with the system for commissioning independent investigations/reports often rested with the same hospital/trust that had produced poor quality initial investigations;

***“The Ombudsman investigation was based on information given by the hospital. It’s taken at face value, still didn’t speak to those involved or the family”.***

Or a situation where;

***“The hospital commissioned an independent report, which made critical findings, but the hospital was able to hide this report. Any detrimental information was excluded from the hospital’s report”.***

Families described being confronted by resistance and defensiveness throughout the process, and question the competence and independence of the investigations and are unsurprised to find the reports reflect this. Apart from wanting a sensitive and honest account of the circumstances surrounding the death of their own relative, families also seek improvements and swift action to prevent future deaths. To this end families suggested there needs to be careful consideration of what constitutes the duty of candour during the investigation and its subsequent findings. To encourage an end to what were described variously as ***“cover ups”*** or a ***“pack of lies”*** some felt it was important to remind all staff of their duty of candour at the very beginning of the process, with another suggestion that before signing off on reports the CEO or senior investigator signed a statement of candour which was legally binding, something along the lines of;

***“We confirm that to the best of our abilities this is a full and honest version of event without omissions. We are aware that this statement is subject to potential fine or criminal prosecution under the duty of candour”.***

### **3.7 Recommendations**

- Investigation reports must be seen as a collaborative process involving the families.
- Families must be given draft reports and have an opportunity to comment.
- Attention must be given to the quality of investigation reports with particular emphasis on inconsistencies, inaccuracies, the use of insensitive language and spelling mistakes.
- Reports should try and use accessible language suitable for a mixed audience avoiding jargon (whilst acknowledging the need for some medical and technical detail).
- Reports must reflect more accurately the evidence and information provided by families.
- The reports must be written openly and honestly with attention to detail and end to the defensive culture of omission and secrecy.



One message that was clearly related throughout the day was the importance of families having quick access to independent advice about specialist legal representation.

- The reports must be broadened to include information relating to other deaths or near miss incidents which have a relevance to the hospital/trust being investigated.
- Reports must include evidence of any complaints/warnings made by families prior to the events leading to the death of a relative.
- Reports should adhere to a template outlining best practice for the author/s.
- There should be an on-going commitment to reminding all staff of their duty of candour from the beginning of the process.

(Some families supported a recommendation for every report to include a statement of legal responsibility stating **“this is a full and honest version of events without omissions etc.”** to be signed off by the trust CEO.)

## 4 The importance of legal representation and the role of lawyers

One message that was clearly relayed throughout the day was the importance of families having quick access to independent advice about specialist legal representation. Much is made of the apparent “straight forwardness” of investigations, and the inquest process not being adversarial but inquisitorial. However, families described being faced with a daunting and complex set of circumstances when a relative dies in the care of a hospital/trust. This can be complicated further when there are a number of bodies/organisations tasked with treatment and care, operating under different contracts overseen by one Care Commissioning Group (CCG).

Families suggested that without legal representation things would have been difficult at best and hopeless otherwise. As such they recommended that information on specialist legal advice be provided at the earliest opportunity. Without this families felt they were denied their **“rights”** and parity of arms in the struggle to find out what happened to their loved one. As one person observed, **“If we had not got legal representation, nothing would have happened”**.

The benefit of having early access to legal advice was described. At the time of being notified of a death families are struggling to make sense of what has happened, and by their own admission found decision making extremely difficult;

**“I felt angry that they even put that question to you [option of a post mortem]. You are the bereaved parent this was an unexpected death of a vulnerable person, why did they put you in a position of having to**

***make a choice? Luckily the decision was made to have a post mortem, but there was no support or advice available to us. We had to proactively search for help. It was only after we contacted INQUEST that we found a solicitor who helped us”.***

For those that didn't have legal representation from the start things were much more difficult and placed the responsibility on families to find and research suitable lawyers;

***“I should have been given my rights. They should have said ‘these are your rights; you can have a doctor present at the post mortem etc.’, and give me information about what to do. I had to do everything myself. I decided to get lawyers and went on line and found Bindmans Solicitors and they helped me”.***

It also became clear that legal expertise had a big impact on the quality of investigations and potential outcomes;

***“We did not know about INQUEST, when we found them and contacted [our caseworker] she helped us get legal representation. If we knew our rights or had someone independent on our side to speak to us, it would have been very helpful or if we knew about INQUEST earlier it would have saved us a lot of heartache”.***

Families suggested their lawyers had helped them establish the parameters of the inquest and in some cases this meant the adoption of an Article 2 inquest which has a broader remit to look into the wider circumstances and any systemic failings that might result in further deaths. In addition these inquests are often heard in the presence of a jury. Families felt this is the only way future deaths can be avoided. Legal representatives to argue the families' cases became crucial when faced with hospital/trust resistance;

***“We also had to fight for Article 2 and they tried to stop this but [the] Coroner is sympathetic. They would have said 'natural causes' if I did not put up a fight”.***

***“We had to fight for Article 2. The trust wanted to argue against it. So many failures in his care, there were no records or anything. After INQUEST got involved things got better, the Coroner started responding”.***

The importance of Article 2 inquests was recognised by another contributor;

***“It struck me that the CQC report could look at the option of recommending that community mental health deaths be treated in the same way as hospital deaths, in terms of increased likelihood of an Article 2 inquest”.***

**Written submission by an attendee**

Once into the investigation process families were relieved to have had representation to help navigate their way through the process and to counter

lawyers instructed by the trust, who families felt were there to make life as difficult for them as possible. The discussions highlighted how this was an issue from the outset, starting with initial meetings at which families were surprised by the presence of lawyers, a situation that some felt ***“limits information being shared from the start”***.

The conduct of hospital/trust lawyers was criticised as being aggressive and insensitive;

***“The State gets the most vicious dogs in the street, lawyers, against ordinary people”***.

***“They showed insensitive conduct at the inquest, why are they being instructed with this approach”?***

Another person explained;

***“Being told about the death was like an out of body experience, but the inquest almost matched it in its horror. The trust lawyers were very, very aggressive”***.

Families were also keen to question the inequality of the state paying for hospital/trust representation when accessing legal aid is hugely difficult for them;

***“There is no way we could not be represented at the inquest, we would be eaten alive, absolutely no way, but then the bill in the end all gets paid by us as the tax payers”***.

For one person the solution was a simple one;

***“They should put a blanket ban on trusts employing a lawyer and put things back on a level playing field”***.

There were examples provided that suggests that even with legal representation the families faced an up-hill struggle to gain advance disclosure of information that could illuminate what had happened to their relatives and have a bearing on the investigation or inquest;

***“With disclosure even lawyers have difficulty getting documents”***.

***“Initially the Trust were reluctant to provide disclosure”***.

## **4.1 Recommendations**

As noted in Section 1;

- Independent advice should be made available on families rights in the process and accessing specialist legal representation.

As noted in Section 6;

- Trusts must review the defensive conduct of lawyers they instruct and their involvement from early meetings with the family and during the investigation and inquest process.

## 5 The inquest process

There was a mixed response to the role of coroners; some families found them “sympathetic” and “sensitive” to the families’ with one saying the **“coroner’s officer was excellent”** with regard to providing information, support and regular communication. The family reported this made a real difference to them.

Others felt their dealings with the coroners smacked of arrogance and self-importance which informed the way in which the inquest was conducted;

**“The coroner was almost affronted that we asserted our rights”.**

And another suggested the view of the inquest as inquisitorial rather than adversarial proved naïve;

***I had anxiety at the thought of going up against the coroner, I hadn’t gone in with a view to it being combat”.***

One family described initial difficulty making contact with the coroner’s court in their case, and emphasised the importance of legal representation;

***“I had phoned and emailed the Coroner on many occasions but did not receive a reply. As soon as INQUEST was involved they started responding to me”.***

The family’s perceptions were subsequently re-enforced during the inquest;

***“Coroner was not bothered about anything; he just wanted to get on with it. He was all relaxed about the lying and he did not care about the impact this had on us”.***

However there was significant evidence given that the inquest can offer a more thorough, independent and accountable investigation of the circumstances surrounding a death and this was a comfort and relief for families even if the process was a daunting one.

***“The inquest added more than the investigation as it was based on fact”.***

***“Finally we found out the truth about how [our son] was treated”.***

***“The lack of care plan and risk assessments was worse than we knew from reading in the report. It makes you wonder if there were other kids who were treated like that”.***

That notwithstanding, it would appear that hospitals/trusts still felt defensive after the outcome, and this was a matter of some concern for families;

***“We struggled to get the trust to confirm what was said at the inquest which had gone beyond the findings of the report”***

***“NHS wants to put people off. The coroner found failings and they still argued about everything, on whose instructions are they acting”?***

One family revealed they had not been contacted by the trust after the inquest and had still not received an apology;

***“We’ve had no contact. The trust put out a press release following the conclusion of the inquest with an apology to the family but the trust have never directly apologised to us. The trust’s barrister shook our hand and apologised for our loss at the start and the end of the inquest but the trust have not”.***

## **5.1 Recommendations**

As noted in Section 1;

- Independent advice should be made available on accessing specialist legal representation and their rights in the process.
- Families should be given information around the role of the coroner, the coroner’s officers and the role of the inquest.

As noted in Section 6;

- Trusts must review the defensive conduct of lawyers they instruct and their involvement from early meetings with the family and during the investigation and inquest process.

## 6 Learning from investigations and implementing recommendations

Families were particularly concerned that any recommendations following an investigation are implemented, actions taken monitored, and that the failure to do so is picked up and sanctions brought and that learning is shared on a national level. Families viewed their role in the listening day as bringing their experiences to wider attention in the hope that future deaths (and near misses) could be avoided in the future. Crucial to this was their desire and commitment to turning the investigation process into one of learning and action and away from defensiveness and secrecy.

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”.***

***“Wardrobe handles were supposed to be flush to the door but nothing had changed, they just screwed the wardrobes to the walls, the handles stayed the same”.***

***“They told me that changes had been made but then in February and March two other people died so none of the changes were actually made”.***

***“They said they made changes since the death but they haven't”.***

***“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”.***

The role of the CQC was also raised as a serious issue that needed addressing;

***“I have been telling you [CQC] about changes which had to be done, you did not listen, my brother had to die before you took any notice. Sara Ryan needs an MBE in terms of bringing deaths of learning disabled people onto the public agenda, a lot more has to be done”.***

Another comment questioned the CQCs ability to act independently;

***“I can see a new investigative role for the CQC, but will loyalties override true independence”?***

A written submission received from an attendee after the event highlighted the failure to respond to inherent problems on a scale that must be under reported;



Trusts must become more learning organisations. There needs to be effective filtering down of information from investigations and inquests.

***“I also note that the remit of the CQC report extends to addressing whether opportunities to avoid unnecessary deaths have been missed due to inadequate reporting or [I assume] learning and systems being put in place. The number of situations almost identical to [our daughters] which were mentioned today suggests that there are hundreds, if not more, instances of patients or families expressing a direct risk to life and being ignored. [She] had pleaded for help and directly expressed her intentions due to how she felt prior to her death. To hear several other instance of this within such a small sample of people today really drove home that there must be a systemic risk assessment issue within mental health provision which is not being picked up”.***

For some, the only solution was the introduction of legislative powers to enforce implementation, whereas others felt this could be more effectively achieved by introducing an official body to oversee implementation with powers of enforcement and sanction.

There was also the sense that until senior staff within trusts recognised the importance of transparency, honesty and accountability, little would change;

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

Much of the discussion around recommendations and learning was heard as a Q and A response to the CQC presentation on their findings to date. As such they are included below as a list of family recommendations.

## **6.1 Recommendations**

- Trusts must become more learning organisations. There needs to be effective filtering down of information from investigations and inquests. Stakeholders referenced within reports must go beyond the hospital/trust and families and include coroners, coroner's officers, police and lawyers as they are all part of the learning process.
- Trusts must review the defensive conduct of lawyers they instruct and their involvement from early meetings with the family and during the investigation and inquest process.
- Families should have a role in the review of trust responses to serious incidents/deaths and future written information provided to families following a death.

- The duty, role and responsibility of the CQC needs to be clearly defined and made available to all families going through the investigation process and greater transparency about their inspection/regulation role.
- There needs to be greater clarity as to which body owns the report and recommendations. Is it the trust, CQC, CCG or NHS England that has ultimate responsibility for ensuring compliance with recommendations?
- Learning needs to be shared nationally with all trusts and this could be through the introduction of an alert system that is triggered when issues of concern are flagged up in other regions or areas.
- Trusts should have access to a “data dashboard” introduced to highlight issues relating to deaths, care, treatment etc. which can be accessed by families and the broader public.
- There needs to be greater emphasis placed on the learning from near miss incidents, also shared on a national level. It is clear that there must be many more of these incidents which are not uniformly collected and analysed.
- There needs to be a national body tasked with overseeing and monitoring the enactment of recommendations made in reports and following inquests with the power to compel compliance.

Perhaps the requirements for change are described up by a contribution from one of the attendees who reflected on the experience:

***“For me, the message which was raised a number of times is that the investigation process should provide hope to surviving family and reassurance that lessons will be learned, that the same thing won't happen to someone else's daughter, brother, mother or husband. The system as it stands today does exactly the opposite; it actually has a negative effect on relatives, causing mental and physical illness, work and financial pressures and is ultimately damaging for the NHS, leading to unnecessary legal claims resulting in financial penalties with no positive outcome”.***

## 7 Recommendations in full

- Those tasked with informing families of a death should be trained (and this includes the use of appropriate language), empathetic and sensitive to the family's needs and wishes.
- Families should be treated with dignity and respect at all times.
- Initial contact with families should follow a consistent approach.
- Hospitals/trusts should have a handbook/information sheet outlining the various stages of the processes following a death: family liaison, a named contact within the trust, time frames, protocols for family engagement, the investigation aims and remit, complaints procedure and the chain of responsibility for overseeing the process. (See the INQUEST handbook as an example of good practice).

- Trusts/hospitals should have dedicated staff whose primary role is family liaison.
- Families should be given information around the role of the coroner, the coroner's officers and the role of the inquest.
- Information should be made available around the post mortem, the family's rights to view the body, their right to a second post mortem, funeral costs etc.
- Independent advice should be made available on accessing specialist legal representation and their rights in the process.
- Trusts should have a handbook/information sheet which lists independent support agencies specialising in bereavement, counselling and support groups (if they exist in the given area).
- Hospitals/trusts must provide families with the opportunity to shape the terms and reference of the investigation and enable them to play an effective part.
- Investigations must seek to include the "family voice" where possible; their experiences, evidence, information and concerns in order to ensure the investigation scope is as broad as possible.
- Hospitals/trusts need to be seen to value the contribution of families rather than regard it as a threat or inconvenience.
- Investigations need to be carried out by competent, trained specialists for whom the investigation is their primary function.
- Investigations must be independent, carried out by independent investigators.
- Hospitals/trusts must not investigate themselves or employ staff involved in the care and treatment of the relative. Anything other than independent investigations produces an inherent conflict of interest and does not inspire family confidence.
- Face to face meetings with investigators and hospital/trust staff must be minuted, and those minutes made available to families as would be the case with any other formal meeting. Minutes must be agreed as a true record with families.
- A process framework for the investigation must be provided for and agreed with families with realistic timeframes.
- Families should be consulted on how and when communication takes place, providing space for families to digest and analyse information.
- Families should be promptly informed of any delays in the investigation and provided with explanations of the cause.
- Any investigation involving the police needs to be conducted with the same rigour and professionalism as would be the case with any other criminal investigation.
- Investigation reports must be seen as a collaborative process involving the families.
- Families must be given draft reports and have an opportunity to comment.
- Attention must be given to the quality of investigation reports with particular emphasis on inconsistencies, inaccuracies, the use of insensitive language and spelling mistakes.
- Reports should try and use accessible language suitable for a mixed audience avoiding jargon (whilst acknowledging the need for some medical and technical detail).

- Reports must reflect more accurately the evidence and information provided by families.
- The reports must be written openly and honestly with attention to detail and end to the defensive culture of omission and secrecy.
- The reports must be broadened to include information relating to other deaths or near miss incidents which have a relevance to the hospital/trust being investigated.
- Reports must include evidence of any complaints/warnings made by families prior to the events leading to the death of a relative.
- Reports should adhere to a template outlining best practice for the author/s.
- There should be an on-going commitment to reminding all staff of their duty of candour from the beginning of the process.

(Some families supported a recommendation for every report to include a statement of legal responsibility stating **“this is a full and honest version of events without omissions etc.”** to be signed off by the trust CEO.)

- Trusts must become more learning organisations. There needs to be effective filtering down of information from investigations and inquests. Stakeholders referenced within reports must go beyond the hospital/trust and families and include coroners, coroner’s officers, police and lawyers as they are all part of the learning process.
- Trusts must review the defensive conduct of lawyers they instruct and their involvement from early meetings with the family and during the investigation and inquest process.
- Families should have a role in the review of trust responses to serious incidents/deaths and future written information provided to families following a death.
- The duty, role and responsibility of the CQC needs to be clearly defined and made available to all families going through the investigation process and greater transparency about their inspection/regulation role.
- There needs to be greater clarity as to which body owns the report and recommendations. Is it the trust, CQC, CCG or NHS England that has ultimate responsibility for ensuring compliance with recommendations?
- Learning needs to be shared nationally with all trusts and this could be through the introduction of an alert system that is triggered when issues of concern are flagged up in other regions or areas.
- Trusts should have access to a “data dashboard” introduced to highlight issues relating to deaths, care, treatment etc. which can be accessed by families and the broader public.
- There needs to be greater emphasis placed on the learning from near miss incidents, also shared on a national level. It is clear that there must be many more of these incidents which are not uniformly collected and analysed.
- There needs to be a national body tasked with overseeing and monitoring the enactment of recommendations made in reports and following inquests with the power to compel compliance.

This report was written for INQUEST by independent consultant Chris Tully. He assisted in designing the Family Listening Day model. He has helped deliver Listening Day events and written reports arising from the day for the *Independent Advisory Panel on Deaths in Custody*, the *Independent Police Complaints Commission*, the *Equalities and Human Rights Commission* and the *Harris Review into Self-Inflicted Deaths in Custody of 18-24 year olds*. He designed the INQUEST Skills Toolkit for families and has delivered training for the organisation. He has 27 years experiences of working with voluntary sector organisations and has also conducted monitoring and evaluation projects for Clinks, Women in Prison and INQUEST.

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