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Family involvement in, and experience of, death investigations by the NHS

13 December 2016

This review presents an overview of how families currently experience NHS death investigation processes. It explores the purpose of investigations for families and how they are involved in the process. A number of problems are identified with existing processes, alongside some things that help. These experiences are illustrated with direct quotes from family members, taken from a small number of structured one-to-one conversations, from personal testimony shared in the media, and through published literature.

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What A review looking at evidence collected from four sources including personal testimony and conversations with family members who had experience of NHS death investigations. Experiences relating to over 20 families are included.

Why To collect family experiences of NHS death investigations together in one place; as a companion to the CQC Deaths Review report.

Overall findings The picture painted is of a chaotic and confusing process, with little concern or care for bereaved relatives, and little focus on answering families questions about what happened in the care of their loved one.

When families experience compassion, honesty and humanity it helps. However, bereaved relatives are frequently dismissed and their concerns are deflected or diminished. 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 an appropriate way, and are subjected to multiple investigations from different agencies. Families are expected to cope with little help, coordination or support.

Implication It is clear that there is a huge gulf between rhetoric and reality when someone dies in NHS care. This needs to change.

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1. Introduction

Robert Powell died in 1990
Krista Ocloo died in 1996
Elizabeth Dixon died in 2001

Will and Diane Powell, Josephine Ocloo and Anne and Graeme Dixon deserve particular recognition at the outset of this report for their efforts over many years to get answers in relation to the deaths of their loved ones.

Their experiences are not the focus of this review, in part due to the time passed since they occurred, however we owe a debt to them, and other parents, for their efforts to improve patient safety.

‘These parents are truly remarkable for the tenacity with which they have fought to get honest explanations of how and why their children died. Each case has taken years of campaigning, corresponding, emailing, complaining, complaining again, hunting for evidence, getting independent reports, legal action, more legal action, and commissioning of inquiries before anything like a proper answer was forthcoming’ (Shale, 2016).

The evidence that follows in this report suggests to date we have learned little about how to treat bereaved relatives, how to investigate deaths, and most importantly how to improve care and prevent further deaths.

1.1 Purpose of this review

This review was written with the explicit purpose of collating in one document, existing

family experiences and testimony relating to NHS investigations following a patient’s death.

It was written to coincide with the release of the Care Quality Commission’s report into the way NHS trusts review and investigate deaths of patients. That report provides a detailed picture of current NHS death investigation processes and practice.

1.2 Methodology

This review draws on the experience of more than twenty families. It contains testimony and evidence collected from four main sources:

- 1) Reports that collate experiences of families and/or complainants following deaths in NHS care
- 2) Personal testimony shared on social media, in print and television media coverage, in films and patient stories
- 3) Parliamentary and Health Services Ombudsman (PHSO) complaints and related rulings
- 4) One-to-one conversations with four bereaved families.

The media reports that are contained within this document have not been verified by the family members to which they relate, the one-to-one conversation quotes have.

These families were asked four questions:

1. How were you treated and what is your experience of NHS death investigation processes?
2. Were there any problems with the process?
3. Was there anything that worked well or helped?
4. What would have made the most difference to your experience?

2. What do families want from the investigation process?

When someone dies in NHS care, knowing how and why they died is the very least a family should be able to expect. A number of reasons for engaging with an NHS investigation were offered. These, perhaps unsurprisingly, focus on wanting to know why and how their loved one died:

‘When things go wrong with NHS care, it can have devastating consequences for patients and their families. People want answers, to understand what happened and why, and to know that action is being taken to prevent the same thing happening again to others’ (PHSO, 2015, 2).

Despite lengthy campaigns for transparency and answers about the events and circumstances of the death of a loved one, all too often accountability remains an elusive end goal.

2.1 How and why someone died

First and foremost families want to know how and why someone died (Salman, 2014). Many report that they place great trust in the investigation system, believing that everyone would want to know the same things as they do:

‘When our son Sam died suddenly and unexpectedly we trusted that no stone would be left unturned in trying to understand what had happened and why’ (The Morrishes in Morris, 2016).

Families often complain because they do not want the same thing to happen to another family (PHSO, 2015). They report being driven by a need to protect other people, patients and families (HJA, 2015).

2.2 To know there will be change

Many families report that they want to know that learning will happen as a result of any mistakes that are made:

‘The family who brought this complaint to us have told us that they have pursued their complaints for over 5 years to encourage NHS organisations to get the first step right so that they can learn and improve safety when mistakes are acknowledged and learnt from. They want staff to understand what happened and why and be able to learn so that services can be made safer. They want the learning from this case to be used by other health service providers and the NHS as a whole as a catalyst for wider improvement’ (PHSO, 2016, 4).

Families clearly articulate the desire to focus on learning:

‘So much good could come from openness and honesty and a willingness to learn from the two trusts. So much learning could be shared. I could finally feel free of this weight on my shoulders of feeling I have to get Justice in the form of truth for my girl’ (Hughes, 2015).

Additionally, some families articulate a wish to secure change and improvements in their relatives memory:

‘For Caplan, a law to boost family rights and support learning disabled people would mean her sister did not die in vain: “It would mean that her suffering and her death had achieved something of lasting value.” She adds: “I just feel as if her life didn’t matter. She had a life worth living – she was comprehensively failed” (Salman, 2016).

2.3 Clarity, truth and accountability

An argument can often be observed in conversations on social media, or the comments sections of media stories, that families want someone to blame when things go wrong. Time and again families are at pain to point out that blame is not their motivation:

“I don’t apportion any blame for his death at all, its one of those things that happened but we’re still not quite sure about whether he did fall or not. So many different stories there, some of them just didn’t make sense. There was no blame involved but the way it was handled was dreadful, it was quite embarrassing to be a nurse at that period of time” (1-1 conversation).

Family members rarely seek to complain, yet the system forces them to do so to try and access information or answers:

‘Mr Morrish said: “The irony is we never wanted to lodge a formal complaint. We only did because we were advised to by the Patients Association in response to the NHS completely getting it wrong, not once, but twice. We didn't want it to be about blame, we wanted it to result in good learning” (BBC, 2014).

Families want clarity and they want their questions answered. They need to hear the truth, which requires them to have access to detail and facts, not softened versions or fuzzy half truths (Donnelly, 2015). Some people may try to ‘soften’ the facts for honourable and compassionate reasons; some may choose to do so for more deliberate means; whatever the reason if a family is seeking detail, it is not helpful. Melissa Mead sums up her need, and search for answers, in the following extract from her blog:

‘In the immediate aftermath of losing William before we really understood the true consequences of how and why he died, I searched everywhere for the answers. When I received William’s post-mortem report a paediatrician came to visit me to explain the content. At best this was a summary – it didn’t really tell me what I wanted to know... I wanted to understand. I didn’t want to be placated with answers that were formed in such a way that they caused less hurt’ (Mead, 2016).

While families are driven by a desire to prevent errors reoccurring, this is not mutually exclusive from a desire for accountability. For

many families this is a relentless quest, with failure after failure recorded in the literature.

The parents of Kate Stanton-Davies have had to complain repeatedly to try and ascertain what happened to their daughter, and to establish accountability. An independent reviewer found:

‘Shrewsbury and Telford Hospitals NHS Trust failed to fulfil its responsibility to establish the facts of this case and to establish accountability. Rather the Trust abdicated its responsibility to the Local Supervising Authority, an organisation with no accountability to the Trust and whose investigation was subsequently found not fit for purpose’ (Graham, 2015, 44).

In recent years there has been a policy-shift towards establishing a ‘no-blame’ culture in the NHS. There is not universal agreement for this change though, as for some this appears to be a convenient shift to avoid accountability even further. Following the publication of the second investigation into his son’s death, and the flawed investigation that followed it, Scott Morrish said:

“He added that he did not agree with the notion of a “no blame” culture in the NHS, but instead wanted to see “a just culture” with staff properly held to account for negligent behaviour and others supported when mistakes happen” (Scott Morrish in Lintern, 2016).

3. Family experience of the investigation process

The picture painted of family experiences of investigation processes is a bleak one. Relatives report being excluded and not listened to, their questions and concerns dismissed. Forced to complain by the system, they are often left having to campaign for answers, complaining time and again. The elusiveness of candour and the relentless demands placed on family members to oversee and ‘police’ the investigations puts untold stress and pressure on bereaved relatives.

3.1 Families are not heard

One of the most common themes in relation to how families experience the investigation process is that they are not listened to, or heard.

‘I tried contacting the midwives, no one would speak or return my calls’ (1-1 conversation).

This can perhaps be explained by a culture of trusts failing to keep families at the centre of the investigation process:

‘Culture also appears to play a part in the responses received by Ms Davies and Mr Stanton to their formal letters of complaint. The Reviewer found that the Trust did not put Kate or her parents at the centre of their response, failed to address all the issues raised by Ms Davies and Mr Stanton and contained factual inaccuracies’ (Graham, 2015, 4).

Much of the personal testimony gathered from bereaved relatives in the course of this review

leads to the conclusion that there is an attitude that families should be seen and not heard, indeed one blog post states as much:

‘What I have learnt is that there is a pervasive culture in health and social care that prefers families to be seen and not heard’ (Anonymous, 2014a).

Zoe Bojelian’s son Adam lived with complex health needs and physical disabilities. Adam died in 2015, despite him and his parents stating for months he had an infection. This was left untreated and his symptoms were incorrectly put down to his cerebral palsy, something known as diagnostic overshadowing:

‘For months, as Adam became sicker and sicker, our concerns were dismissed as irrational. We were told Adam’s symptoms were due to his cerebral palsy; we were shouted out by consultants when we asked that doctors seek a second opinion or Adam be admitted to PICU....

Too often we read after the event of particularly vulnerable patients dying from poor care. Patients with learning disabilities, frail elderly and children, like Adam, with severe physical impairments. Too often deaths are followed by enquiries and we are told lessons will be learnt. Too often enquiries show family members and other staff were jumping up and down and doing all they could to highlight genuine concerns, but were being

ignored, just as happened in Adam’s case’ (Bojelian, 2015).

There were similarities across the experiences of families with many reporting that they were not listened to when their relatives were alive, and still not listened to once they died.

3.2 Families forced to complain

Families do not want to fight for answers, but often find themselves forced into a corner by a system that requires them to become a ‘complainant’. Sara Ryan, in her blog latterly documenting the investigations into her son, Connor Sparrowhawk’s death, has this to say about being labelled a complainant:

‘Worth pointing out we’re not ‘complaining’ about NHS actions. We tried that back in March/April in a vacuous, pointless exercise. We’re focusing on the abusive, exploitative, bullying and careless treatment of learning disabled people. On systemic disregard and indifference. On the breaching of the right of learning disabled people to be – to go to the cinema, or live in the community – and their families to be with them.

And, in LB’s case, his right to life’ (Ryan, 2013).

Families are simultaneously ignored and not listened to, while also being caricatured as vexatious and unreasonable:

‘I am seen as ‘challenging’ because I want to see the reports written within the investigations into my brother’s

death. My behaviour and communication with professionals is consistently compassionate, yet everything I say becomes further evidence that I am ‘challenging’ (and should not see the reports). Am I actually ‘difficult and a pain’? Or does brandishing me a ‘trouble-maker’ conveniently absolve responsibility to fulfil the ‘duty of candour’?

Too often professionals hold families at arm’s length. Families are dismissed and their distress is compounded. Can professionals not bear to connect with families’ internal worlds and emotional experiences? Or does blaming families protect services from acknowledging their own inadequacies?’ (Anonymous, 2014b).

3.3 Confusion and lack of clarity

Many families articulate how confusing, and confused the investigation process is, relying on advice offered by others who have faced similar experiences, or pro-bono legal support.

‘For Ryan, a key turning point was being contacted by a barrister in the days after Connor’s death. The barrister advised her to request all of her son’s medical records and told her to contact Inquest, a charity that provides support to bereaved families.

Without the barrister’s advice, says Ryan, the family “wouldn’t have had a clue” what to do and it’s likely that the initial finding that Connor died of ‘natural causes’ would have been the

final word on her son’s death’ (Sara Ryan in McNicoll, 2015a).

This confusion and lack of reliability is acknowledged by the PHSO:

‘The process of investigating is not consistent, reliable or good enough – no shared principles, no national guidance on investigations’ (PHSO, 2015, 4).

Family members sometimes mention needing support to ask the ‘right kind of questions’ (Bowen, 2014). Even then, concerns and questions raised by family members were repeatedly deflected, ignored or dismissed (e.g. Farrier, 2015; Shropshire Star 2016b).

One family described being misled by NHS staff about the need for an inquest:

‘He said in law it only goes to the coroner if the place or cause of death isn’t known. Well the thing is the law is quite logical, and that’s not logical. I asked an expert in that area of law who said it’s standard NHS practice to tell families that if cause of death is known they shouldn’t go to the coroner, standard’ (1-1 conversation).

The PHSO, in their 2015 review of the quality of complaints investigations where serious or avoidable harm had been alleged, acknowledged this failure to involve families, or answer their questions:

‘Organisations that provide care should not lose sight that it is patients, carers and families who are often at the

heart of these investigations. They need to be involved in a meaningful way if investigations are to answer their questions' (PHSO, 2015, 4).

Not only are families required to become complainants, the poor quality of many investigations requires them to enter into a perpetual battle; to complain multiple times to trusts and to the PHSO.

'In the time that has passed since Jasmine died, we have spoken to countless parents, who after the death of their child, wanted openness, honesty, to have their concerns heard and dealt with appropriately, to be told the whole truth about the circumstances leading up to the death of their child, and to have sincere apologies and a promise all possible measures would be taken to ensure the same tragedy could not reoccur. Very sadly, few of them have been able to get what they need without a lengthy, distressing 'battle'' (Mothers Instinct).

In several instances, for example that of Sam Morrish and Kate Stanton-Davies, repeated failings were eventually publicly recognised, and the work of their families involved in reaching that point acknowledged. However, the relentless struggle adds to the distress these families have already faced (PHSO, 2015; Sawyer and Donnelly, 2014).

3.4 Lack of information and convenience narratives

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).

When families did succeed in securing information and some sort of investigation, narratives of convenience often emerge. Farrier in his review into Jonnie Meek's death concludes with *A Sort of Ending* and highlights the conveniences at play:

'Throughout the story there is another narrative. It is one of convenience. The finding of pneumonia by the pathologist was convenient. It meant the professionals involved not needing to consider other issues. It was accepted by all those involved other than Jonnie's family (Farrier, 2015, 24).

Families of people with a learning disability, such as Connor Sparrowhawk, Richard Handley and Robin Kitt Callender, report their struggles to overturn the *convenience* of a death

being classed as ‘natural causes’. There often seems to be a general acceptance some people die prematurely and routine discrimination when it comes to disabled patients:

‘The whole tone is parents were completely unreasonable. At one point they use words to the effect of what do we expect he had complex needs, what did they expect to happen. Whole tone is he’s disabled why should he have good care’ (1-1 conversation).

Others felt that a similar level of discrimination was at play in mental health services:

‘One of the philosophies in mental health is you cant save them all, there seems to be a quota and questions aren’t asked until you’re over quota’ (1-1 conversation),

Other *conveniences* include loss of paperwork and key medical records:

‘Worryingly, medical records, statement and interviews were missing from almost a fifth of investigations making it even harder for trusts to arrive at what went wrong and why... Our results show that in 41% of cases, complainants were given inadequate explanations for what went wrong and why’ (PHSO, 2015, 4).

Another common narrative from NHS staff is that of ‘not wanting to make it worse for families’ or wanting to avoid further distress. This is never acceptable given families desire for the truth. The desire to not want to make it

worse often seems to conveniently coincide with legal teams wishing to avoid a focus on failure (e.g. Campbell, 2013).

The narratives of convenience include bad luck and ‘one offs’ despite considerable evidence that there is little or no change.

“We need to shift away from a culture that perceives people like Sam as unlucky, and the bereaved as a problem to be managed. It shouldn’t be left to patients, or grieving families to drive the process for learning” (The Morrishes in Morris, 2016).

3.5 Absence of candour

There has been much talk of candour over the past five years as preparations were made for the implementation of the duty of candour. A recent AvMA report (Blythe, 2016) highlighted the lack of standardised guidance or approach to the issue of candour within CQC inspections, and perhaps more worryingly the lack of recommendations to improve, even when poor implementation or non-compliance were noted. The report concludes with a number of recommendations including the need for a system to log breaches of the duty of candour reported by members of the public or other bodies, and the requirement that CQC should be more consistent and robust in identifying, recording and demanding improvement in line with the duty of candour.

Candour seems elusive, despite the many and multiple failings, across the NHS. In his independent review into Jonnie Meek’s death,

Martin Farrier, drew a number of conclusions, including:

'5. The response of Mid Staffordshire NHS Foundation Trust to the complaints of Jonnie's family was poor. There is little evidence of the open culture that is aspired to by the NHS. Our contact with a separate NHS Trust during the review suggests this is not isolated.

- I consider that problems of a closed culture within the NHS continue to exist. Expectation of blame leads to defensive behaviours. There should be an expectation within NHS organisations that they will openly cooperate with reviews of care performed within the NHS' (Farrier, 2015, 25-26).

This legally enshrining of the right to be open and honest, seems far removed from many families' experiences:

'We are told there is a Duty of Candour and that all trusts are open and honest...

My legal guys used to work for 'the other side'. They tell me that the clinicians involved will not willingly admit to their mistakes, and that I am dealing with one of the most famous children hospitals in the world, they will want to protect their reputation at all costs rather than admit any liability here. They tell me they would expect the other side to 'slightly alter' witness statements in an effort to make their

actions look more acceptable if we just gave them all the damning evidence without receiving their clinicians accounts of what they did and why first. What about the Duty of Candour I ask? Pah! They say. Hmmmmm' (Hughes, 2015).

The family of Joshua Titcombe experienced similar challenges, as criticised by the coroner at his inquest:

'Mr Titcombe's complaint prompted concern by the Trust Chief Executive, Tony Halsall, who ordered an external review of the case. This review, by an obstetrician, a midwife and a paediatrician was based on the clinical records and the midwives' accounts to the internal investigation. The content of the report was shared with Mr Titcombe, who challenged several aspects, and it became clear that there were significant discrepancies between the accounts given by midwives and the record made by the Titcombe family shortly before Joshua died. When an inquest was eventually held, the coroner was critical that the midwives had collaborated on the accounts given in court and of the loss of the observation chart, as well as the clinical care' (Kirkup, 2015, 17).

The behaviour of legal teams and trust solicitors has been called into question many times. Indeed, the inquiry into what went wrong at Mid Staffordshire NHS Trust heard

from the head of legal services that as her client was the trust, it was her responsibility to act in their best interests, not in the interests of truth or candour (Campbell, 2015).

For families candour is a basic expectation that is unrealised and far removed from their current experiences.

3.6 The emotional, physical and administrative work

There is very little support available to recently bereaved families. Many do not know what their rights are, what will happen or what is expected of them:

‘When she died I was really lost obviously, all of this was just pushing me further and further away, was like living in a constant nightmare, terrified of what would come in the post, we were having to manage and deal with it all by ourselves really’ (1-1 conversation).

The NHS death investigation process has a devastating impact, with families describing ‘suspended grief’, and the physical and emotional impact that such prolonged processes has on them.

‘The most toxic, damaging, compounding, devastating thing that happens is they drip feed you information, they give you a tiny closed off answer. Letters are sent Friday so they arrive Saturday morning, you’ve nowhere to go, nothing to do with it. Every single time a piece of information

came through it raised another question, and another question, and another question’ (1-1 conversation).

Getting answers and improvements take a phenomenal amount of tenacity by families:

‘The lessons learnt and subsequent changes made to improve the quality of care were not all directly developed from Kate’s death. Many resulted from the findings from external reviews of the case instigated by Ms Davies and Mr Stanton. Without their tenacity in seeking the truth of the circumstances surrounding Kate’s death vital lessons would not have been learnt’ (Graham, 2015, 44).

The current approach to investigation by the NHS requires families to try and make sense of chaotic processes, often with little or no reward:

‘Finally, at a time when most people with learning disabilities may expect to live longer lives than previous generations, the death of a 33 year old man is shocking. James’ [*real name Richard, see Section 4.5*] family has sought to make sense of the traumatic circumstances of their loss by asking questions of all agencies which have had roles in supporting him. The contingent and variable responses of agencies to the urgency of their search for answers have left them far from consoled’ (Flynn and Eley, 2015, 51).

Families are forced to undertake extensive research, develop new skills and specialist

knowledge; familiarise themselves with the language and process of the investigation system; compile reports and dossiers of information about failures:

‘They just fob you off and fob you off and fob you off. You have to do so much research about everything before you can even challenge them.

You do have to be a person who has analytical skills and research skills – how many families do? Not everyone can challenge and is mentally robust enough to challenge in the most awful circumstances that are so distressing, even a normally assertive person may not be. It shouldn’t rely on being able to fight after the death of a loved one’ (1-1 conversation).

Families also have to engage in a continual oversight and quality assurance role:

‘Sam’s mother Susannah Morrish said: “The report looks the way it does because of our constant intervention. The fact there had to be two draft reports, both of which looked radically different to this final report, says something. Our involvement included providing information, pointing out omissions, correcting factual errors. Our thoughts were if we didn’t do this, who would?” (BBC, 2014).

The *Report of the Independent Review of Children’s Cardiac Services in Bristol*, observed that the immense emotional and physical labour of

families was not always welcomed by unsupported and under-resourced clinical staff:

‘In the course of the Review, we saw examples of the enormous efforts made by families to set their account of events before Trust staff, seeking to ensure that their perspectives were fully reflected in the reports produced and challenging inaccuracies or statements that they disagreed with. Clinical and family expectations about the level of detail needed were frequently at odds. This process led to multiple drafts of documents such as CDRs and RCAs being exchanged between families and Trust staff, with no clear mechanism for resolving disputes or calling an end to the re-drafting process’ (Grey and Kennedy, 2016, 208).

There is a clear need for a more effective and efficient process, and a shared understanding between families and investigators.

In addition to the frequent demands placed on families and the poor quality of investigations, there is a sense that families’ grief becomes public currency. There is a power imbalance clearly reflected in the experiences that families recount; of being called upon to attend meetings at short notice or to feel grateful for the communication or invite. For example, Sara Ryan describes their experience:

‘We’ve been racking up some toe curling and often parasitic meetings since LB died. Pretty much all involve travel (at our expense), time (unfunded)

and no apparent change or tangible outcome...

What really stinks about all of this is that families engage with these meetings because we want change. For what happened to our relatives not to happen to anyone else. Instead, we are engaged with (momentarily), at a time and place dictated by the NHS, or related organisation/charity, offered a fake whiff of change, have a bit more life sucked out of us and then spat out until the next time' (Ryan, 2016).

Similarly, relatives such as Karen Caplan, are forced into a space where they feel they have no option but to become campaigners:

'Caplan says bereaved relatives must become campaigners, pursuing answers from disparate agencies. At her Essex home, boxes of carefully labelled files include material from a myriad of organisations involved, from the local council that commissioned the care, to the care provider, hospital trust, and regulator, the Care Quality Commission (CQC). How are families treated? Caplan says: "You feel dismissed, you feel ignored ... you have to gird your loins, you have to be ready to be bullish and persistent.'" (Karen Caplan in Salman, 2016).

All of this emotional and physical effort that is required by families, is often made harder still by the lack of care shown to them by those they are dealing with:

"You are viewed, I have a feeling that you're viewed as a pain in the neck really, it's a bit like if you keep complaining about the washing machine but the machine is out of warranty, I've had more courtesy at the supermarket checkout than I've had at the trust' (1-1 conversation).

This family member attributes this to the core focus of the NHS being lives not deaths:

'It's about deaths being a bit of a nuisance, deaths aren't what the trust is about, its back to running out of warranty on your washing machine – they're only interested while they have to be, once it's run out, once patients are dead its quite annoying, irritating, takes up lots of resources and not really interested' (1-1 conversation).

It is certainly an explanation worthy of further consideration.

4. Problems identified with the current process

Family experiences share a number of common themes of what urgently needs improving in existing investigation processes.

4.1 Defensiveness and hiding

Perhaps the most common complaint is that families felt that NHS staff were immediately, and repeatedly defensive.

‘So many of these parents has suffered immeasurable extra emotional pain and suffering; caused not by the unintentional act of making a mistake, but the absolutely conscious decision of those tasked with providing information about any mistakes not to give the family the whole truth, or to engage with the family as part of the investigation process.

This, despite every hospital in the country having a “being open” policy, many having ‘being open’ as a core value, and all claiming that they are open and honest with patients and their families when things go wrong’ (Mothers Instinct).

This defensiveness starts as soon as someone has died:

‘We asked for a copy of Beth’s notes. She said she’d have to check with the lawyers. Why do you need to check with the lawyers? Why do you need to be defensive? Automatically as a parent and an outsider your automatic

response is you’re being defensive for a reason and therefore you’ve got something to hide’ (Clare Bowen).

Some families experience defensiveness and denial:

‘We really wanted to hear from these people, what did they think went wrong and they were not prepared... it was this whole institutional denial that things can go wrong. What we got was absurd, the fobbing off of a lifetime, pure denial to the level that I wanted to actually go and shake them’ (Beatrix Futák-Campbell).

Melissa Mead, commenting on the second PHSO investigation into Sam Morrish’s death, observes:

‘With the medical establishment, whenever you suggest that there has been any kind of wrong doing the shutters come down’ (BBC, 2016).

This hiding and defensiveness is well documented in official reports. The annual report of Each Baby Counts, looks at local reviews of stillbirths, neonatal deaths and brain injuries occurring in labour. They found:

‘In a quarter of instances (25%), parents were not made aware that a local review was taking place. Just under half the time (47%), parents were made aware that the review was happening and informed of the outcome but were not invited to contribute. In just over a quarter of local reviews (28%) the

parents were invited to contribute evidence if they wished to' (RCOG, 2016a, 16).

The same number of parents were unaware a review was taking place, as were invited to provide evidence.

4.2 Poor quality of investigations

Even when an investigation takes place, there is no guarantee the investigation will be of a high quality, get answers for families, or secure learning and improve care.

People have the right to know their complaint is taken seriously and investigated thoroughly, yet the PHSO find NHS trusts regularly fail to identify patient safety incidents and when investigations happen they're inconsistent, often failing to understand what has gone wrong or ensure any lessons are learned (PHSO, 2015). Investigations often fail to provide the information or answers sought.

'The report reads as though it's an investigation into us as parents, rather than an investigation into his care...they do find the things we raised concerns about; they do acknowledge those things happened and shouldn't have happened... they acknowledge all sorts of really awful things that happened but what they say is there were episodes of sub optimal care but also episodes of good care so that's ok' (1-1 conversation).

Documents go missing and families are excluded, resulting in inadequate explanations

for what went wrong and why in 41% of cases (PHSO, 2015).

'It raises doubts over the ability of trusts to reliably identify when something has gone seriously wrong and why. Without this capability, trusts will continue to miss opportunities to learn and make service improvements' (PHSO, 2015, 11).

The PHSO intention that families and patients are at the centre of the investigation process, is far removed from the reality that many experience, such as Kate Stanton-Davies family:

"We took our case to the parliamentary and health service ombudsman and they upheld it, detailing that the hospital trust was guilty of Kate's avoidable death and of maladministration."

She said the original 2009 investigation was carried out by a colleague of one of the midwives involved and was deemed by NHS England last year as "not fit for purpose", leading to this year's independent report which harshly criticised the first for containing errors and omissions' (Rhiannon Davies in Shropshire Star, 2016a).

If families were central to the investigation process there may be a greater chance that the conclusions and findings of investigations would match the evidence provided, another area highlighted as fraught with problems:

'We found that one third of investigations did not have reasonable conclusions that were based on

evidence, and did not reliably identify when something had gone wrong. Equally we found that, even when investigations did identify failings, the trusts did not always try to find out why something had gone wrong, or take remedial action' (PHSO, 2015, 18).

It is somewhat perplexing that investigators would go through the motions of 'investigating' deaths if the conclusions then drawn are not backed up by the available evidence. This was also a problem identified in the Serious Case Review into Richard Handley's death (where he is referred to as James):

'The rationale for Ipswich Hospital NHS Trust's assertion that there was no diagnostic overshadowing in James' case is not known. As their independent review states that there is a need for it to be everyone's responsibility to meet needs of patients with a learning disability and support for family members/carers with need [sic] for all hospital staff to be aware of the complexities and needs of people with learning disabilities and other vulnerable adult's patients' (Flynn and Eley, 2015, 51).

Family involvement in a review is no guarantee that the conclusions will match the evidence, as demonstrated by the second investigation into Connor Sparrowhawk's death by Verita. It had two lay representatives, including one to represent the family (myself). Despite oversight and engagement throughout the process:

'A couple of months ago the first draft of the report was shared with us. I was lost for words... I've seen the interview transcripts, had sat in meetings with the project group and just could not understand how the evidence they have amounted to the conclusions they have drawn. I discussed my concerns with Sara and Rich, who had a very similar response. We agreed that there was little point to my further involvement with the process, the simple fact is that no-one could explain how these conclusions were reached... There comes a point where 'going along' with something (even if you fundamentally challenge the findings) gets wrapped up into an acknowledgement of support for it, a risk we were not prepared to take' (Julian, 2015).

Families are expected to engage, as and when it suits, in ways that work for the investigators. If their input and challenge is so readily ignored, then the value of their participation must be questioned.

Given the poor quality of investigations and conclusions not relating to the evidence collected, it is perhaps inevitable that family members consider staff are going through the motions, and are not really invested in learning lessons from the investigation process.

'Surely it's time to admit that the "learning lessons" ship has sailed? In fact the "learning lessons" ship has sunk and everyone on it has drowned.

Senior people from involved organisations attend numerous meetings and compile reports whilst nothing changes. My family is clinging desperately to a life raft that the involved agencies seem more intent to sink every time we dare to ask a question' (Anonymous, 2014a).

The evidence suggests that people are 'performing' the investigation process, following a tick box of requirements. This approach seems to lead to a worrying expectation that action is being taken, while the risks that need investigation remain untouched.

Bill Kirkup in his review of maternity services at Morecambe Bay provides support for this view:

'We believe that the Trust needs to consider carefully how it interacts with patients and families through complaints. It cannot see them as administrative tasks, but rather as insights into the working of the organisation. Complaints can be an essential route to tackling systemic and individual failings within an organisation. The approach during the period of the Investigation does not demonstrate that anything changed as a result of the lessons learnt by the failures in service. The Board needs to be vigilant and to challenge its officers about the complaints it receives, and not be satisfied with number-based reports' (Kirkup, 2015, 77).

Similarly, the Each Baby Counts annual report looked at 921 babies during its 2015 programme (RCOG, 2016b). One in three investigations were of too poor quality to assess the care provided. Of those that were deemed to be of reasonable quality, almost two in five made no recommendations, or recommendations that solely focused on individuals, not reviewing systems or processes. It is hard to conclude anything other than learning is not truly the focus in many of the instances where investigations happen.

The lack of meaningful investigations could be linked to the lack of specialist expertise and an overreliance on generalists. Melissa Mead shares her concerns about the generalist paediatrician brought to her son's inquest by the NHS:

'To assist with answering these questions they bring in a paediatrician. Not a specialised one, a general one. So, immediately I was concerned. How can a general paediatrician who has no experience of empyema and pleural effusions confidently ascertain and answer questions in relation to William's death. Simply put – he couldn't. An expert in his field, but an expert in the areas that contributed to William's death he was not' (Mead, 2016).

It is unclear why a generalist without specific knowledge would be brought to an inquest, if the aim is to identify why someone died.

The Serious Case Review into Richard Handley's death also called into question the expertise and knowledge of those who completed the SIRI report:

'The external reviewer noted that the SIRI report demonstrates limitation with regards to embedding a person-centred approach...the investigators...needed to demonstrate more appreciation of James' learning disability and expertise from learning disability, safeguarding and mental capacity/DoLS hospital leads; there was an over reliance and unrealistic expectation of the learning disability liaison nurse role' (Flynn and Eley, 2015, 29).

Not only did the investigator lack expertise in relation to learning disability, they clearly lacked investigation skills more generally:

'The lead investigator of the SIRI had not attended training on Root Cause Analysis or any Serious Incident related training and this was the first SIRI they had undertaken; the family members were not interviewed as part of the SIRI; the terms of reference...are not explicit within the SIRI report...the inclusion of aims and objectives...would have been helpful; the final report was submitted on 01/02/2013 – this exceeded the 45 day reporting requirement; at the initial... junior doctors who had made clinical judgements were not interviewed as part of the SIRI' (Flynn and Eley, 2015, 29).

The poor quality of investigations is no surprise if investigators do not have the appropriate training, support or skills to investigate.

4.3 Poor communication

There is much evidence of poor communication with families. Families report: they are not routinely told things had gone wrong, delays in communication, infrequent contact and that they are not regularly kept updated.

'NHS England said had to be independent not an internal investigation. We were told this would happen, we waited. It must have been about April. We heard nothing, then in September we contacted them because we'd not heard anything and were told they'd appointed a chair, I think before summer they'd appointed a chair who was appointing people to the panel.... We were told that the Terms of Reference would be agreed with us, but we didn't hear anything' (1-1 conversation).

Given family experiences of not being listened to, perhaps this poor communication is inevitable. It in turn leads to a lack of trust, as observed in the *Report of the Independent Review of Children's Cardiac Services in Bristol*:

'Clinicians and the Trust's leadership had struggled to take consistent and effective account of families' perspectives in the investigation of serious incidents. We have no doubt that this had a detrimental effect not just on communication with the families

involved, but on their trust in the integrity of the process and of the Trust's general approach' (Grey and Kennedy, 2016, 207).

Issues of communication must be considered holistically, not just what is said, and how, but also when. A consequence of the non-involvement of families in investigations in a meaningful way is that they are then placed under unreasonable and inhuman levels of stress, and expected to conform, perform and submit to others' processes, to ensure bureaucratic deadlines or measures are met.

One such example is reported in the first PHSO report into Sam Morrish's death, where his parents describe being presented with the draft report for the first time:

'On 30 August Mr and Mrs Morrish met the independent investigators to discuss their draft investigation report before it was sent to the Chair the following day. They were given a copy at the meeting. This was the first time Mr and Mrs Morrish had seen the report. The meeting lasted for about eight hours... Mr and Mrs Morrish told us that it appeared the investigation had an immovable deadline of 31 August and the report was going to be signed off then regardless of whether it was correct. They felt like they were being asked to 'rubber stamp' a report without having sufficient time to read it, and said the report should have been shared with them before the meeting. Mrs Morrish told us that she had to

temporarily leave the meeting in tears when she heard how Sam died, but she then returned. Mr and Mrs Morrish told us that the terms of reference set out that the investigation would identify the root causes of what went wrong. However, when they were presented with the report, there were no root causes for what had happened' (PHSO, 2014, 76).

Even though The Morrishes had concerns about the quality of the report, insufficient time to read it or feed into the process, and despite their protestations, the report was still signed off by the Chair the next day. This disregard for the thoughts or feelings of bereaved relatives is not restricted to the way Sam's family were treated.

This poor communication, and expectation that families should make themselves available at short notice to meet reporting deadlines, is in stark contrast to the perpetual waiting that families are expected to endure. They wait for investigations to be completed, for disciplinary procedures, for NMC or GMC referrals, for inquests, for legal developments, for more investigations, for Police investigations, for HSE investigations and more. All of these processes crawl along, hitting delays time and time again.

Families are left in a state of limbo with few organisations or individuals, if any, meeting their own promised timescales, and reasonable (any) explanations for delays rarely offered. This is not just disrespectful, but is also indicative of the lack of urgency to actually

learn or improve before further poor care or avoidable deaths.

4.4 Lack of independence, impartiality or scrutiny

Families repeatedly identify concerns that investigations are not independent enough to identify what actually happened.

The first PHSO investigation into Sam Morrish's death documents his father's concern about the lack of independence (PHSO, 2014); concerns that were shown to be justified in the second investigation into his son's death:

'Mr and Mrs Morrish complained that the NHS investigation processes are not fit for purpose, believing that they are not sufficiently independent, inquisitive, open or transparent, properly focused on learning, or able to span organisational and hierarchical barriers, and that they exclude patients, their families, and junior staff in the process. In relation to the investigations undertaken after Sam's death, we agree' (PHSO, 2016, 5).

The PHSO upheld complaints about every organisation that investigated Sam death, including their own. They found that investigations were not always suitably independent, a finding replicated elsewhere such as in the case of Kate Stanton-Davies whose death was initially investigated by a colleague of one of the midwives involved and deemed not fit-for-purpose.

The Each Baby Counts report advocates for the

role of independent clinicians, yet in 2015 it found only 7% of panels included an external expert (RCOG, 2016). The aforementioned review into children's cardiac care in Bristol highlighted yet more failings in this area, and the scale of this problem:

'It appeared to the Review that the Trust, perhaps in common with other NHS organisations, could not meet the criterion of 'independent element' in an investigative process (whether of a complaint, an incident or the review by the Trust's staff of a child's death), save by making exceptional arrangements' (Grey and Kennedy, 2016, 209).

The report goes on to discuss the challenges in securing independent chairs, the lack of process for doing so, and it also directly challenges the scepticism of some clinicians about the value of an independent chair.

Related to a lack of independence is a lack of impartiality. Families frequently ask the question of whether the NHS is fit to investigate itself:

'What would have made a difference to the investigation itself? The investigation has been flawed from day one so in terms of what could have been done better, there is no point asking an NHS trust to investigate itself. It just cant do it' (Nic Hart).

The investigation into Nic Hart's daughter Averil's death has been fraught with issues, it has not run to time and relevant expertise was

not made available. Nic Hart describes the SIRI report as 'half baked' and the lack of impartiality was also reflected in a separate 'independent' inquiry undertaken by a clinician who had trained under the lead clinician where his daughter had died, Cambridge and Peterborough Foundation Trust.

The absence of independence and impartiality is further compounded by the absence of any meaningful scrutiny, as highlighted in Farrier's conclusions into the Child Death Overview Panel:

'3. The Child Death Overview Panel (CDOP) failed to notice any discrepancy between the cause of death and the information available during life despite Jonnie's parents' concerns. There is an opportunity missed by CDOP to provide an impartial overview. The system is designed such that CDOP is the final step. If it were to maintain a view throughout the process and hear the voice of the child through their parents, then its role could be greater than it currently is. There is no reason to consider that this is an issue specific to an individual CDOP.

> I consider that CDOP processes should be reviewed. There are opportunities for the Panel to give an independent view and act as an "ombudsman" for families that are not currently taken (Farrier, 2015, 25).

4.5 Anonymity

A further problem easily solved, is the issue of anonymity and the use of aliases. Ostensibly these are used to protect the parties involved when someone dies, yet several families have shared that they find it an offensive practice. Families who have been bereaved should not be denied the request for their relative to be named, especially when the information is already in the public domain.

Anonymity feels like another narrative of convenience, this time to hide failings and protect the reputations of those who should be held accountable.

'The serious case review referred to Richard by the alias 'James' for 'reasons of anonymity' but his family have shared his identity and said they'd asked for his real name to be used in the report' (McNicoll, 2015b).

A comment left on this article by Richard's mother clearly sums up how she feels about this practice:

'As the mother of the 33 year old man I can assure you that Richard was not referred to as James to protect HIS anonymity. We begged for the report to be published in his name. We said "he was denied dignity in life so please give it to him in death." We were overruled!' (Sheila Handley on McNicoll, 2015b).

Not only is this practice offensive to family members, it is also awkward and confusing for anyone who may be interested. In Richard

Handley's Serious Case Review not only was his identity anonymised, so too was the identity of the supported living provision run by United Response who were his care provider. It would seem that protecting reputation was the foremost concern on this occasion

4.6 Parliamentary and Health Services Ombudsman

While reviewing the evidence and testimony of families in relation to NHS investigations, there has been repeated reference to the problems with the Parliamentary and Health Services Ombudsman, the PHSO. These are wide ranging and relate to issues of competence, capability, and the lack of accountability.

In the two years it took the PHSO to investigate The Morrishes complaint, they failed to meet with any of the staff involved, or conduct an acceptable investigation:

'In March 2012 Mr and Mrs Morrish complained to the Ombudsman, the highest authority on NHS complaints, which agreed to investigate. However the couple were shocked that the officials repeatedly failed to understand the information they were given about the events leading up to and following Sam's death, forcing them to relive "the life-shattering death" of their child.

Furthermore the Ombudsman's investigation turned out to be largely a paper based exercise – with no face-to-face meetings held with any of the healthcare staff involved – and which

the family felt failed to examine the incident properly.

As a result the Ombudsman produced several inaccurate draft reports which had to be corrected by Mr and Mrs Morrish which led to long delays in the investigation...

Mr Morrish added: "We have had plenty of expressions of regret over what happened to Sam, but they don't go anywhere. Our experience of the NHS complaints procedure and the Parliamentary and Health Service Ombudsman is that, when challenged, it is a closed and unaccountable system that seems to protect assets and reputations, not people like my son, the patients.'" (Sawer and Donnelly, 2014).

Nic Hart offers a similar experience, with the PHSO not meeting its own deadline and poor quality reports being produced. He describes them as inept (Nic Hart). Another family described PHSO as in 'meltdown'.

There are many other experiences of failures documented in the Patients Association (2014) publication *Parliamentary and Health Service Ombudsman; The 'Peoples' Ombudsman – How it failed us*. The introduction describes these families as having been 'let down by the very organisation established to throw them a life line'. When asked to respond to criticism levelled at the PHSO:

'Outgoing ombudsman Dame Julie Mellor said: "We hope that this case acts as a wake-up call to drive through much

needed improvements in how the NHS investigates complaints about potential avoidable harm or death” (Lintern, 2016).

How many wake-up calls can one organisation require?

4.7 Care Quality Commission

The Care Quality Commission (CQC) also featured in people’s accounts of what had happened and why. The lack of consideration and focus on bureaucratic processes were highlighted:

‘I wrote to the CQC, got no response, so I rang up to try to get them in on the case. You just try to get people to see what you can see. The call centre said we don’t write back to people... CQC have done f*ck all. To write these letters takes a piece out of you every single time, but CQC don’t even reply’ (1-1 conversation).

4.8 Inquest tactics

A number of unwelcome practices and tactics are discussed in family testimony about their experiences of inquests. These include only finding out at their relative’s inquest that an investigation had taken place:

‘The doctor’s surgery who had ‘treated’ William had opened and closed a Serious Event Audit. Which we hadn’t been informed of until we were sat in the inquest. How can the general practitioners have a meeting and close an audit when they have not even

discussed William’s care and concerns with us, his parents?’ (Mead, 2016).

Others knew investigations had taken place but did not have reports disclosed to them (Campbell, 2013), and others report contradictory reports, or changes of severity within the reports shared at inquests, as the report from Luke Jenkins inquest documents:

‘In a report published last year, an investigative team at the trust said errors had been made. But before the inquest another report was produced that appeared to row back from that, to the frustration of the boy’s parents’ (Morris, 2013).

Many families also describe the late arrival of information and documentation for inquests, and some find out deeply disturbing and relevant information within the inquest process, that should have come to light before:

‘One of the various devastating moments during LB’s inquest was the revelation that another patient had died in the same bath in 2006. *Can you imagine?*

As difficult as it is to believe, the same psychiatrist, Dr J, who rang me at work the morning LB died in a pretty lackadaisical way, signed the patient’s death certificate in June 2006’ (Ryan, 2015).

Clare Bowen describes her daughter Beth’s inquest and its impact:

Family involvement in, and experience of, death investigations by the NHS

'We did not receive an apology before or after the inquest. The hospital admitted they had failed in their duty of care and they were sorry that they had failed to prevent Beth's death. They didn't fail to prevent Beth's death – they caused it.

The three-day inquest took place 18 months after Beth died. Unfortunately, the only way we could afford a solicitor was to take legal action against the hospital, which is something we never really wanted to do. For us it was never about money; it was about answers.

The only way I can describe the inquest from a parent's point of view is that it's like being tortured and you can't escape. We had to listen to different stories about Beth's last hours, while trying to fit it all together in our heads – it was horrible. Information that came out in the inquest was contrary to what the hospital had been telling us in the months previously...

The striking thing during the inquest was the arrogance and complete disregard by the medical professionals in the room for our feelings, and for the part that they played in Beth's death.

In the months after the inquest, Richard suffered a massive heart attack and died – he was only 31 years old' (Bowen, 2014).

Additionally some families have to contend with the prospect of further investigations as a

result of information being withheld at an inquest, such as Sally Mays family who are awaiting the outcome of a Police investigation into allegations three members of staff at Humber NHS Foundation Trust withheld evidence at Sally's original inquest (Coggan, 2016).

The behaviour and conduct of NHS staff and Barristers commissioned by the NHS was also commented on by bereaved families:

'The inquest process was harrowing and it was made very difficult by midwives sitting there with packed lunches, like a day out at a picnic, sobbing and hugging each other when they came off the stand, while the family had to sit dignified right by the jury. There were four barristers and they were disgusting too' (1-1 conversation).

and

'Trust staff showed no respect for coronial system, behaved like they were on a night out in the corridor. No respect for the system, no respect for our family. You never would have thought it was a Coroners court' (1-1 conversation).

The picture painted of families' experiences of inquests involving the NHS is far removed from the inquisitorial stance often claimed.

5. Who or what helps

Many of the suggestions families make about improvements replicate what is already known, such as the key points made in the *Review of the NHS Hospitals Complaints System* (2013).

That report suggested that patients, relatives, friends and carers wanted to see the following improvements:

- 1) Information and accessibility – patients want clear and simple information about how to complain and the process should be easy to navigate.
- 2) Freedom from fear – patients do not want to feel that if they complain their care will be worse in future.
- 3) Sensitivity – patients want their complaint dealt with sensitively.
- 4) Responsiveness – patients want a response that is properly tailored to the issue they are complaining about.
- 5) Prompt and clear process – patients want their complaint handled as quickly as possible.
- 6) Seamless service – patients do not want to have to complain to multiple organisations in order to get answers.
- 7) Support – patients want someone on their side to help them through the process of complaining.
- 8) Effectiveness – patients want their complaints to make a difference to help prevent others suffering in the future.
- 9) Independence – patients want to know the complaints process is independent, particularly when they are complaining about a serious failing in care (Clywd and Hart, 2013, 19).

It is hard to understand why these failings need to be continually pointed out and why so little action follows.

5.1 Compassion and humanity

The compassion, humanity and kindness of staff who get it right stays with families, much as the opposite is also true:

‘When William died at home, we were taken to hospital by ambulance. An ambulance that had blocked our one car road. Traffic was queueing, but the paramedics didn’t move their ambulance. They did not rush us. They went at our pace... The paramedic sat in the ambulance and cried with me. A man, a father, a real person, how did he feel? The worst, most tragic part of his job. When we arrived at hospital they waited until I was ready to carry my baby into resus. They stayed with us until we were ready for them to go. We weren’t a ‘job’ to them. William was carefully cradled by them, and treated with the dignity he deserved. Their demeanour our only solace of feeling secure in a situation that had completely shattered our world. They allowed me the space to lay next to William on his nursery floor and scream, beg and plead with him to wake up, knowing full well that he never would. They were human. They cared and their compassion will never be forgotten’ (Mead, 2016).

Clinical staff who acknowledge the need for truth also help:

‘What has made a difference is where, on a very rare occasion you’ll find a clinician will actually says to you, you

know what I have a daughter or I have a son, and we need to do something about this, we need to get to the truth (Nic Hart).

5.2 Honesty and detail

Closely related to families searching for the truth and not wanting half answers, many suggest that honesty and detail helps.

‘She came to see us, the kindest thing anyone ever did for us. She was exceptional, spent the day with us and went through the post mortem’ (1-1 conversation).

There is a clear message here that nothing you can say will make things better, or worse:

‘Tasked with a job that no one would envy, what those who were in direct contact with me didn’t realise is that there is nothing you, or any report could ever say that could ever lessen the hurt. Carefully constructed sentences, they don’t work. Summarised reports, also don’t work. They do nothing to satisfy my desire to truly understand’ (Mead, 2016).

While the degree of detail is likely to depend on the family, the option for some families, or indeed some members within a family, to access the detail, is essential.

5.3 Support and family liaison

A number of families contrasted the support available to them by different public sector bodies.

Len Hodkin, in the Making Families Count film, compares and contrasts the experience his family had of the police and the NHS following his mother’s death:

‘When I compare how we were treated by the Police and how we’ve been treated by the NHS, there’s no comparison really. The Police were open, honest, provided information when we requested it and we genuinely feel they were on our side... Contrast that with the NHS, there’s no comparison. It feels like they didn’t really want to deal with us, they’re not really prepared to share their report with us. It feels like they’ve got something to hide, it feels like they’re not telling us because they’ve got something to hide’.

Whether the NHS has anything to hide or not, time and again families experience them as hiding. Sara Ryan addressed the lack of support, and the role of family liaison in a post on her blog:

‘If LB had been murdered, died in a road death, mass fatality, or any other ‘critical incident’, we would have had a Family Liaison Officer.

The National Policing Improvement Agency states;

“Family liaison is, without a doubt, one of the most demanding roles performed by the Police Service. It is also one of the most important because it is one of the the most

significant relationships that we develop with the families of victims, at one of the most difficult times in their lives”.

The Family Liaison Officer role involves conducting appropriate investigation and the human rights of the family. Acting as “a channel for welfare, occupational health and support”.

...When your child/relative dies a preventable death in the NHS you aren't a 'family of the victim' for several months or years (or ever). Until that 'preventability' is established. You ain't really anything. Even though you've experienced the same brutality as any of the criteria above. A brutality that is arguably worse because you thought your child was in a safe space. With people who cared' (Ryan, 2014a).

It is not difficult to imagine the support that Family Liaison Officers could provide to relatives after an unexpected death. Currently the support available to families is totally ad-hoc and requires an awareness and sophistication of communication that seems lacking in most areas.

While there is a lack of support offered to bereaved relatives, there is often much talk of the support offered to, and required by staff, seemingly with little awareness of the disparity:

“We have fought to get the truth and to get the hospital trust to accept that truth – we've done that now, we've done it for Kate. It's all we could ever do for her

and we had to do it. Any parent who found themselves in our position would surely do the same. What happens now? Of course we hope change will come from it”

It has not been an easy road for the couple. Richard said hospital bosses initially took their continued questioning as “an attack on them personally”.

“Much was written about staff needing support,” he said. “No one ever thought to offer us support when all we were doing was seeking answers about how and why Kate came to die’ (Shropshire Star, 2016b).

It is reasonable to expect a considerate employer will provide staff with support, as required. However it is not clear why organisations need to reference that publicly. Additionally, supporting staff does not negate the need to support bereaved relatives. When independent bereavement support is offered families report it as being of some use. Sadly it seems few families are offered support, and it is often unclear who is to provide or pay for it.

5.4 Actually involving families

If trusts wish to truly understand what happened to a patient they are likely to need to involve families in their investigations.

‘The advisory group felt that the patient and family that had made the complaint should be involved at every stage to manage expectations and to

provide information for the investigation. They also felt that the patient and/or family should be able to have access to a source of independent advice and support' (PHSO, 2015, 29).

The Each Baby Counts report includes a similar recommendation for parental involvement in any investigation (RCOG, 2016). The CQC Briefing *Learning from serious incidents in NHS acute hospitals* reviewed 74 investigation reports from 24 NHS acute hospital trusts. It found:

'Only nine (12%) of the reports in the sample included clear evidence that the patient or their family had been involved in the investigation' (CQC, 2016, 3).

The Bristol Children's Cardiac review acknowledged the challenge of effectively involving families in improving services, but it took the view that actions as a result of complaints should be clearly visible to all parties:

'The Trust's mechanisms for involving parents or complainants in the changes that took place as a result of their complaint or of an investigation were weak...

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, particularly when an offer has previously been made' (Grey and Kennedy, 2016, 210-211).

Report after report has concluded that family members should be:

- a) involved in investigations
- b) aware of the findings, and
- c) clear about the improvements and changes as a result.

Despite all of these conclusions, practice is incredibly slow to change. While searching literature and media reports for this review only one example of family members being effectively involved in an investigation was identified. In this case its impact was clearly transformative:

'The conclusions of the report by NHS England are far-reaching, and we welcome improved patient safety as a result of implementation of the recommendations. 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).

The Root Cause Analysis report into William Mead's death describes his family's involvement as happening at all stages and ensuring the perspective of his parents was central throughout (NHS England, 2016).

5.5 Ethical practice

Candour needs to go hand in hand with ethical practice, a subject discussed by the Chair of AvMA Suzanne Shale:

'Dealing compassionately with healthcare harm is about more than good governance. If we are really going to get this right, we need to think long and hard and humanly about what it takes to rebuild trust and make amends.

Managing the aftermath of adverse events is about very much more than investigations and action plans. A broader view of ethical practice is required. Organisations need to understand, but also see beyond, how they currently get it wrong. They also need a credible vision of 'what good looks like' (Shale, 2016).

5.6 A focus on change and removing risk

Families repeatedly report the excruciating lengths of time it takes to get any answers or make any progress. In no small part this is due to concerns that it takes to make any changes or remove risks. Anonymous makes a plea for people to move faster:

'Haven't we reached the point that the "lessons" are there and we actually need to get out there and do something differently? Isn't it time for radical change? Isn't it time to translate these goddamn 'lessons learnt' into

significant, meaningful and tangible changes in practice?

When patients are seriously harmed we need to sit up fast and take action immediately. Immediate, honest analysis, immediate changes and wide dissemination so that improvements are implemented nationally, for the benefit of all. Immediate, immediate, immediate...not months and years of navel gazing with no action and more bodies on the pile!

We need swat teams, going into services fast to help them pull their socks up. To understand the problems, make the necessary changes and stop it happening again! Surely this would be better for patients, staff and families? Not a 'blame' culture but a 'change' culture.

The changes needed in responses to serious incidents aren't actually all that radical. But they do require a willingness to do something differently, which is possibly where it all falls down.' (Anonymous, 2014a).

Sara Ryan has blogged about an ideal imaginary process in which the focus is on establishing answers and apologising for fault:

'They instead turn a critical lens on how a fit and healthy 18 year old young man could die in their care. They contact the family and say how desperately sorry they are that this has happened. They'll do everything they possibly can to find

out how it happened and make sure it will never happen again. They will work with the family and keep them informed of all developments.

A key person is designated to make sure this happens (the Southern Caped Crusader in this instance). S/he knocks up a newly designated work station (with clear plastic ER type 'white' boards and brightly coloured whiteboard pens) and knuckles down. With resources. The police are investigating but that doesn't stop the planning and organising of the investigation team. The caped one pulls together a robust investigation team and provides them with the records to start doing meticulous preparatory work. An external advisory set of experts, including an epilepsy expert, is created.

As soon as the police pass the baton, the investigation team are off. Leaving no stone unturned in their quest to establish how such a catastrophic incident could have happened. At the centre of their investigation, always, is LB. The dude. Not a hollow set of initials. Disconnected from anything other than NHS speak. The team regularly update the family with their progress (checking, of course, in advance how regularly they want to be updated). The investigation is timetabled to take 60 days...

Sixty days later the report is finished (bang on time). It doesn't look good for

Southern Health (obviously). But that's cool. They're willing to hold their hands up, admit appalling practice, operate the shiny, new duty of candour and spell out how they are going to change. Slamming and locking the door on the traditional/historic 'sweep it under the carpet brigade' is a bit niggling/challenging but no, the Caped Crusader is firm. It's time to face the public. And the family.

"We got it so completely wrong. We are so sorry. LB should never have died." (Ryan, 2014b).

Rhiannon Davies and Richard Stanton have produced a document proposing the establishment of a Fatal Incident Task Force:

'The body of first recourse following an unexpected death resulting from a sudden untoward incident in a healthcare setting: the objectives of which are truth, learning and accountability' (Davies and Stanton, 2015).

Davies and Stanton have been obliged to engage with at least 22 different organisations since their daughter Kate died. It has taken them six years (to the date of publication, now seven) to try and obtain answers, highlight learning requirements and pursue justice.

The Fatal Incident Task Force is their proposal to ease the time, effort and burden placed on bereaved families. At a glance it is structured as follows:

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- 1) Unlike the Parliamentary and Health Service Ombudsman which is a body of final resort, the Fatal Incident Task Force is a body of first recourse.
- 2) The Task Force is activated immediately that a qualifying case arises.
- 3) A qualifying case is an unexpected death that occurs in a healthcare environment as a result of a sudden untoward incident.
- 4) The Task Force drives an investigation forward by ensuring the concurrent assessment of cases by all the relevant bodies and organisations.
- 5) It exists to hold to account, require action and ensure positive change.
- 6) The aim of the Task Force is to assist family members left behind and to ensure a reduction in untimely and avoidable deaths.
- 7) The Task Force has the power to make recommendations including to the coroner and CPS in respect of investigation. It also has the power to obtain answers through its own investigations and demand action to prevent future harm.

Their proposal has been shared with Jeremy Hunt and health service officials, however it is unclear that any of their suggestions have been taken on board.

What is common to all these family suggestions is a desire to move swiftly and decisively to prevent further harm.

The lengths to which families have gone to document their experiences, and invest their own time, thought and grief in trying to improve the status quo is worth remarking upon. The staggering commitment of bereaved families has yet to be matched by most NHS trusts and providers.

6. Conclusion

There is a wealth of evidence, information and personal testimony available online that describes in great detail families experiences of the NHS investigation process following a relative's death.

This review reflects the experience of more than twenty separate families whose relatives died in England in the last ten years, as well as drawing on public reports collating the experiences of many more families. It does not begin to capture what happens to an individual who dies without active family involvement. Too often when things go wrong narratives emerge of 'bad luck' or 'one offs', yet many of these families have had similar experiences.

The picture painted is of a chaotic and confusing process, with little concern or care for the bereaved relatives themselves, and little focus on answering families questions about what happened in the care of their loved one. When families experience compassion, honesty and humanity it helps. However, bereaved relatives are frequently dismissed and their concerns are deflected or diminished.

Even 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.

It is clear that there is a huge gulf between rhetoric and reality when someone dies in NHS care. Improvements are long overdue.

Acknowledgements

I have had the privilege over the past few years to witness first hand what I can only describe as the truly remarkable tenacity, commitment and love of Connor Sparrowhawk's family. They have battled to ensure that Connor's death was not simply swept aside by the NHS, and that his life counts. This report, and much of the associated work on NHS death investigation processes, would not have happened without them. I, and we all, owe them a great debt.

I have spoken to many other bereaved relatives who I will not name here, but to whom I also owe my thanks and gratitude. I am always somewhat humbled when family members share their experiences with me, good and bad. The fact they are willing to offer such personal, and for many painful, memories in an effort to improve things for others, is noteworthy.

I'm going to end this report with a quote from Don Berwick's keynote at the Institute for Healthcare Improvement National Forum 2016. It is one fight that I think we should all be fighting:

'Justice is love and love breeds love.

Let's fight for that.

Let's fight hard'

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