



# How can we assess how well providers review, investigate and learn from deaths?

A response to a Care Quality Commission consultation

Patient Experience Library  
June 2017

## Introduction

In June 2017, the Care Quality Commission's website invited "*views on how we can strengthen the way we look at whether NHS trusts learn from deaths to improve the care they provide*".

The CQC's consultation refers to its 2016 "Learning, Candour and Accountability" report. Page 4 of that report says "*throughout this review process we have heard from families who had to go to great lengths themselves to get answers..., who were subjected to poor treatment from across the healthcare system, and who had their experiences denied and their motives questioned*".

Our views, set out below, focus principally on these repeated systemic failures to listen and learn from bereaved families.

The CQC invited interested parties to give their views via a survey form on its website. In the notes below, we have tried, wherever possible, to fit our answers to the survey questions. However, we have also taken the opportunity to address other issues which we believe lie behind NHS difficulties in learning from deaths.

Our observations are based on our experience in collating, cataloguing and analysing the UK's collective intelligence on patient experience. They also come from conversations with NHS patient experience leads about their need for - and barriers to - the kinds of learning tools and insights we can offer.

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## Summary

The CQC invited interested parties to contribute to the consultation via a survey form on its website. This summary offers our best attempt to fit our replies to the survey questions.

The more detailed notes in the rest of this consultation response offer further insights and evidence that would not fit within the online survey format.

### Q. What do you think the most important information we should be monitoring is?

The most important information is that supplied by patients and families. As the CQC itself acknowledges, "*The NHS underestimates the role that families and carers can play*". Nearly five years on from the publication of the Francis report, it is time for feedback from patients and families to be given due prominence.

Feedback from families also matters because conventional sources of information (performance measures and statistics) are not always reliable. "Uses & Abuses of Performance Data in Healthcare" (Dr Foster, April 2015) states that "*Examples of adverse impacts of measures in healthcare include... Bullying culture within the NHS, Gaming waiting time and mortality data in English hospitals... Arguments about data quality diverting attention from poor care*". (The underline is ours).

### Q. When we inspect care providers, who should we talk to?

#### Q. What questions should we ask?

##### a) Trust Boards and management

Can you show us how you have made change happen, by acting on relevant recommendations from:

- The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, February 2013
- Putting Patients Back in the Picture. Clwyd/Hart October 2013
- The Report of the Morecambe Bay Investigation. Dr Bill Kirkup CBE March 2015
- Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. Mazars LLP 2015
- Each Baby Counts: key messages from 2015. Royal College of Obstetricians and Gynaecologists, June 2016
- Learning from Mistakes. Parliamentary and Health Service Ombudsman, July 2016

b) Patient Experience Leads

- In terms of influence on Trust policy and practice, do you have parity with clinicians and managers?
- Do you have access to professional knowledge (the UK literature on patient experience and patient/public involvement) to help you contextualise and make sense of what is happening in your Trust?
- Does your Trust learn well from deaths?

c) Patients and families who have recently complained

- Are complaints systems easy to understand and use?
- Were you well treated during the course of your complaint?
- Were your concerns answered promptly? If not, were any delays explained and were you kept informed of progress?
- Are you satisfied with the outcome of your complaint?

d) Patient representatives

- Is your role clear in terms of purpose and your ability to influence Trust policy and practice?
- Do you have access to training to help you carry out your role well?
- Do you have access to professional knowledge (the UK literature on patient experience and patient/public involvement) to help you contextualise and make sense of what is happening in your Trust?
- Does the Trust learn well from deaths?

**Q. What else should we consider when assessing whether the trust has an open and learning culture?**

The CQC should consider whether patient experience leads are adequately supported for their learning.

A series of reports from 2013 onwards have concluded that avoidable deaths are more likely to occur when the patient voice goes unheard. They have also found that a key reason for the failure of the NHS to learn from mistakes is that carers and families are not adequately involved in investigations.

Patient experience leads within Trusts are the key to hearing the patient voice, and learning from patient feedback. So in the context of "learning from deaths" the starting point should be whether patient experience leads themselves operate within a learning culture. Our observation is that they do not.

## 1. The essential foundation for learning: a learning culture

We start our detailed response to the CQC's consultation with the online survey form's penultimate question: "*What else should we consider when assessing whether the trust has an open and learning culture?*" Our answer is that the CQC should consider whether patient experience leads are adequately supported for their learning.

A series of reports from the Francis Inquiry (2013) through to Learning, Candour and Accountability (2016) have concluded that avoidable deaths are more likely to occur when the patient voice goes unheard. They have also found that a key reason for the failure of the NHS to learn from mistakes is that carers and families are not adequately involved in investigations.

Patient experience leads within Trusts are the key to hearing the patient voice, and learning from patient feedback. So in the context of "learning from deaths" the starting point should be whether patient experience leads themselves operate within a learning culture. Our experience is that they do not.

It is worth noting that NHS clinicians work in a culture that takes their practice and professional development seriously. So they have access to comprehensive professional databases as a matter of course. Patient experience leads have a similar need for access to knowledge. And yet they are expected to resort to Google. That, in our view, is not sensible, and is not safe.

To be a truly learning organisation, the NHS must learn from patient experience. So patient experience leads must have ready access to reports produced by the whole of the Healthwatch network (mentioned in the CQC's 2017 "Driving Improvement" report as a valued source of evidence). They also need access to patient experience literature emanating from government bodies, health charities, academics and think tanks.

We have created the Patient Experience Library to help the NHS learn. One year on from the launch of the Library, we have 2,000 newsletter recipients and 6,000 visits per quarter to parts of the website offering free materials.

There is a clear need and appetite for the knowledge we hold, and yet patient experience leads within Trusts tell us that subscription to the Library (giving full access to the content and learning potential) is beyond their budgets and authority levels. They are locked out of the UK's collective intelligence on patient experience.

It is inconceivable that clinicians would accept being blocked from knowledge databases that support their practice and professional development. Patient experience leads seem to have to put up with it.

The NHS struggles to learn from deaths because it struggles to hear from patients, and to understand their experience. As long as patient experience leads are not properly supported for their learning, the NHS will continue to find it hard to learn from mistakes.

## 2. Making change happen

*The suffering of the patients and those close to them ... requires a fully effective response and not merely expressions of regret, apology and promises of remedial action. They have already been at the receiving end of too many unfulfilled assurances.*  
Public Inquiry into the Mid Staffordshire NHS Foundation Trust 2013, Executive Summary, Page 18

*To hear that this (mistake) has happened before - it's just another blow. I've had an apology from the hospital, and assurances that this won't happen again. But other families have had those assurances and those apologies and if those were followed up, in the way that they said that they would, then ... I would have my daughter.*  
A mother whose baby died in the care of the Shrewsbury and Telford Hospital Trust, 2017

*We owe it to [bereaved families] to stop talking about learning lessons, to move beyond writing action plans, and to actually make change happen.*  
Learning, Accountability and Candour. Care Quality Commission, December 2016

The CQC's "Learning, Candour and Accountability" report adds to the pile of literature on unexpected deaths within NHS services, how deaths are investigated, and how the NHS learns from them.

A common feature of all of those reports has been recognition of a failure to hear from patients and families. And every report makes recommendations - for strengthening the patient voice, or overhauling complaints systems, or giving families a more prominent role in investigations.

The recommendations in Learning, Accountability and Candour are of course welcome. But so were all the other recommendations in all the preceding reports. The CQC correctly states that the important thing now is to make change happen.

One of the questions in the CQC's survey is "*What questions should we ask?*" We suggest that this question should be put to Trusts:

Can you show us how you have made change happen, by acting on relevant recommendations from:

- The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013
- Putting Patients Back in the Picture. Clwyd/Hart, 2013
- The Report of the Morecambe Bay Investigation. Dr Bill Kirkup CBE, 2015
- Independent review of deaths of people with a Learning Disability or Mental Health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. Mazars LLP 2015
- Each Baby Counts: key messages from 2015. RCOG, 2016
- Learning from Mistakes. Parliamentary and Health Service Ombudsman, 2016

### 3. Hearing from patients and families

*A health service that does not listen to complaints is unlikely to reflect its patients' needs. One that does will be more likely to detect the early warning signs that something requires correction, to address such issues and to protect others from harmful treatment.*

Public Inquiry into the Mid Staffordshire NHS Foundation Trust 2013, Volume 1, Page 245

*The NHS underestimates the role that families and carers can play in helping to fully understand what happened to a patient. They offer a vital perspective because they see the whole pathway of care that their relative experienced.*

Learning, Candour and Accountability. Care Quality Commission, December 2016. Page 6

One of the CQC's survey questions is, "*What do you think the most important information we should be monitoring is?*" Our answer is that the most important information is that supplied by patients and families. That is for two reasons:

Firstly, as the CQC itself acknowledges, "*The NHS underestimates the role that families and carers can play*". Nearly five years on from the publication of the Francis report, it is time for feedback from patients and families to be given due prominence.

Secondly, it is because conventional sources of information - performance measures and statistics - are not always reliable. "Uses & Abuses of Performance Data in Healthcare" (Dr Foster, April 2015) states that "*Examples of adverse impacts of measures in healthcare include... Bullying culture within the NHS, Gaming waiting time and mortality data in English hospitals... Arguments about data quality diverting attention from poor care*". (The underline is ours).

Patient feedback is sometimes (even now) dismissed as "anecdotal evidence". But perhaps the most important learning point from the Francis Inquiry is that statistics never tell the whole story.

Health professionals (clinicians and managers) are people of dedication and integrity. But health institutions, with an eye to funding, contracts and reputation, have vested interests. That is why there is "gaming" of mortality data.

Bereaved families generally have just one interest - finding out why a loved one died. Their "vital perspective" across the whole pathway of care must come first.

#### 4. Conversations with patient experience leads

*We are data rich, but we don't bring it all together (national surveys scores and comments). It's a nightmare to see what's going on. Trying to triangulate between 12 different data sources coming from different angles, presented differently...*

Making Sense and Making Use of Patient Experience Data. Membership Engagement Services and InHealth Associates, June 2015

*It's mad. We need to rationalise what we ask.*

Ibid.

These quotes amply illustrate the plight of people tasked with trying to understand patient experience within the NHS. Those based within NHS Trusts may describe their role as complaints management, or patient liaison or patient engagement. But they all have one thing in common.

They are grappling with patient feedback from multiple sources, and in multiple formats - quantitative and qualitative. Much of it is not comparable and some of it may not be reliable. And yet patient experience leads are expected to use it to help health services with risk management and quality improvement.

That is not a realistic expectation. "Making Sense and Making Use..." (the report cited above) also said "*Staff and patient experience teams are sometimes so busy gathering data and compiling reports, that less time is available to doing something with the data - efforts to improve services are in danger of being squeezed out*".

Our own discussions with patient experience leads confirm this observation. They tell us that:

- They are kept busy filing "update reports" that do little to support risk management or service improvement.
- Their skills are seen as "soft" skills, as against the "hard" skills of clinicians and management.
- They would like access to the Patient Experience Library, but have little or no budget for continuing professional development.

The CQC survey asks, "*When we inspect care providers, who should we talk to?*" Our view is that a conversation with the patient experience lead(s) is crucial. As to "*What questions should we ask?*", we would suggest the following:

- In terms of influence on Trust policy and practice, do you have parity with clinicians and managers?
- Do you have access to professional knowledge (the UK literature on patient experience and patient/public involvement) to help you contextualise and make sense of what is happening in your Trust?
- Does your Trust learn well from deaths?

## 5. Conversations with patients, families and patient representatives

*"I had a meeting with a trust member and the analogy he used was that they were a bit like British Airways and it was like losing baggage. I really couldn't believe what the person was saying to me. It was harrowing."*

Parent of a patient who died in the care of the Southern Health Trust. December 2015

*"Previously [our complaints system] was meticulous in terms of following an auditable process, but it lacked any sense of humanity. The process has been completely overhauled. The moment something goes wrong a patient or carer can contact a matron by a bleep and we tackle the issue there and then. We get far fewer complaints now."*

Driving Improvement: Case Studies from Eight NHS Trusts. Care Quality Commission, June 2017. Page 21

The CQC survey asks, "*When we inspect care providers, who should we talk to?*" and "*What questions should we ask?*" We would suggest that the list of people to talk to should include patients and families who have recently complained (about anything, no matter how trivial), and patient representatives from engagement committees, patient and public involvement forums etc. Questions should be as follows:

Patients and families who have recently complained:

- Are complaints systems easy to understand and use?
- Were you well treated during the course of your complaint?
- Were your concerns answered promptly? If not, were any delays explained and were you kept informed of progress?
- Are you satisfied with the outcome of your complaint?

Patient representatives:

- Is your role clear in terms of purpose and your ability to influence Trust policy and practice?
- Do you have access to training to help you carry out your role well?
- Do you have access to professional knowledge (the UK literature on patient experience and patient/public involvement) to help you contextualise and make sense of what is happening in your Trust?
- Does the Trust learn well from deaths?

## 6. Conclusion

We are grateful for the opportunity to contribute to this important consultation. We offer our comments in a spirit of constructive support for the CQC's proposals. We are happy to offer further information or clarification if required:

[info@patientlibrary.net](mailto:info@patientlibrary.net)

02827 662273

07759 112 428

[www.patientlibrary.net](http://www.patientlibrary.net)