

Public Administration and Constitutional Affairs Committee: Inquiry to explore the findings of "Ignoring the Alarms" by the Parliamentary and Health Services Ombudsman.

Written evidence submitted by the Patient Experience Library, April 2019

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1. Introduction

- 1.1. The Public Administration and Constitutional Affairs Committee (PACAC) has invited written evidence on questions relating to the findings of the Parliamentary and Health Services Ombudsman's (PHSO) report Ignoring the Alarms.
- 1.2. We would like to open our response by offering our sympathy and respects to the family of Averil Hart.
- 1.3. Our submission will focus on the "Investigations and learning" section of Ignoring the Alarms, set out on page 17 of the report. We will respond to Question 4 from the inquiry's [Terms of Reference](#): "In which areas is there still a need for improvement? What steps need to be taken to achieve such improvement?"
- 1.4. Ignoring the Alarms refers to flaws in the investigation process, not least the fact that that Mr. Hart (Averil's father) had been in contact with six different organisations for more than a year and a half before turning to the PHSO. None of those organisations had worked together to conduct a co-ordinated investigation, or to provide a co-ordinated response to the family.
- 1.5. The report notes that "*This is something we see time and again in the cases we investigate; rather than organisations working together to understand what happened and why, and to learn and improve, the burden instead falls to families*".
- 1.6. We will draw on evidence to show that the failures of investigation and learning highlighted by the PHSO are not unique to Averil Hart's case. Nor are they unique to eating disorder services. They are systemic, and extend right across the NHS.
- 1.7. We will present further evidence to show that flaws in investigations and learning derive from an overarching NHS culture that does not always seem to treat patient feedback as a valued resource for learning. There is a double standard in the treatment of patient experience evidence as opposed to medical evidence.
- 1.8. We will show that the overarching culture plays out in practice via persistent and well documented weaknesses in investigations and learning.
- 1.9. Finally, we will recommend steps for improvement.

2. About the Patient Experience Library

- 2.1. Our comments come from our unique experience in maintaining the UK's national evidence base on patient experience. The Patient Experience Library contains over 50,000 documents on patient experience and involvement, from sources including government bodies, health charities, patient voice organisations and academic institutions.
- 2.2. This submission draws its evidence from those sources, and demonstrates the value of patient experience evidence as an aid to learning. NHS staff should have access to the library as a matter of course, just as they have access to databases of medical research.
- 2.3. The library was established in the absence of any support from national NHS bodies. We do not accept advertising or commercial sponsorship.
- 2.4. We are grateful for the opportunity to submit this response and are happy to provide further information or clarification, if required.

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3. Executive Summary

3.1 The question we are addressing

3.1.1 Our submission concentrates on the "Investigations and learning" section of Ignoring the Alarms (page 17 of the report). We have responded to Question 4 from the inquiry's [Terms of Reference](#): "In which areas is there still a need for improvement? What steps need to be taken to achieve such improvement?" Our main points are as follows:

3.2 Flaws in investigations and learning are widespread

3.2.1 Evidence shows that the failures of investigation and learning highlighted in Ignoring the Alarms are not unique to Averil Hart's case. Neither are they unique to eating disorder services. They are systemic, and extend right across the NHS. A common factor throughout is a failure to hear from patients and bereaved relatives, and to understand the patient experience.

3.2.2 Although national guidance has been issued, the Care Quality Commission has shown persistent problems in some NHS trusts, including fear of engaging with bereaved families. It has warned that the current pace of change is not fast enough.

3.3 NHS culture diminishes patient experience evidence

3.3.1 Flaws in investigations and learning derive from an overarching NHS culture that does not value patient feedback for learning. There is a double standard in the treatment of patient experience evidence as opposed to medical evidence.

- The language of reporting. When a health professional flags up something that has gone wrong, it is called an incident report. When a patient does the same, it is called a complaint. General patient feedback is described with the dismissive term "anecdotal evidence".
- Preservation of evidence. Medical research and evidence is preserved in well-maintained archives. Patient experience evidence is treated as disposable.
- Access to evidence. Medical research databases underpin training, professional development and evidence-based practice. The national evidence base for patient experience and involvement (the Patient Experience Library) is largely unused by healthcare organisations.

3.4 How the culture plays out in practice

3.4.1 The overarching NHS culture translates into specific weaknesses in investigations and learning. These manifest as follows:

- Fear of retribution. 1 in 4 prospective complainants keep quiet because of concerns about repercussions for their treatment or care.
- Professional sensitivity. Healthcare professionals can be inclined to see patient complaints more as a breach of trust than a basis for improving quality.
- Process before learning. Complaints managers often spend more time processing complaints than actively learning from them.
- Data overload. Patient feedback is produced from so many sources and in so many different formats that it can be hard to make sense of it all.
- Poor responsiveness. Many patient experience teams in Trusts and CCG's have their email addresses set permanently to autoreply.
- Lack of training and capacity. Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it.

3.5 Steps to achieve improvement

3.5.1 Change the language. Describing patient feedback as "anecdotal evidence" is indicative of a dismissive and disrespectful culture, and should not be tolerated.

3.5.2 End the double standard in preservation of evidence. The archive developed by the Patient Experience Library is preserving important materials in spite of, not because of, any effort on the part of the NHS. It should be actively supported.

3.5.3 End the double standard in access to evidence. Staff across the NHS should have automatic access to the national evidence base for patient experience, in the same way that clinicians are granted access to databases of medical research and evidence.

3.5.4 Get feedback out in the open. Patients and relatives keep quiet about their concerns for fear of retribution. Health professionals see negative feedback as a breach of trust. We need to confront these fears by bringing feedback and complaints processes out of the shadows and into the open, via platforms such as Care Opinion.

3.5.5 Abandon "process for its own sake". Satisfactory sign-off of a complaint is not the end of the journey. It should be the start of a search for understanding and wider corrective action.

3.5.6 Rationalise feedback systems. We need to review how and why patient experience evidence is gathered (from CQC patient surveys, NHS England patient surveys, Friends and Family Test, local Healthwatch reports and more), bearing in mind that the goal should be learning, not confusion.

3.5.7 Be responsive. Patient experience teams should not have e-mail autoreplies switched on as a matter of course.

3.5.8 Invest in staff and systems. People entrusted with the complex task of understanding patient feedback should be given training, qualifications and continuing professional development, as well as analytical tools.

4. Investigations and learning: the need for improvement

4.1 The question we are addressing

4.1.1 Question 4 from the PACAC inquiry's [Terms of Reference](#) asks: "In which areas is there still a need for improvement?" We would like to answer this question with reference to the section on "Investigations and learning" on page 17 of Ignoring the Alarms.

4.1.2 We will start with the following overview of current evidence on system-wide weaknesses in investigations and learning.

4.2 Flaws in investigations and learning are widespread

4.2.1 Investigations and learning are vitally important in the aftermath of avoidable harm and death. But NHS Improvement has recently noted "*providers' lack of capability and capacity to carry out good quality investigations; the tendency to use investigation for the wrong purposes; the generally poor approach to patient and family involvement*"ⁱ.

4.2.2 The "poor approach to patient and family involvement" has been confirmed by the Care Quality Commission, whose Learning, Candour and Accountabilityⁱⁱ report noted the following:

- Families and carers... often have a poor experience of investigations and are not consistently treated with respect and sensitivity and honesty. This is despite many trusts stating that they value family involvement and have policies and procedures in place to support it.
- Families and carers are not routinely told what their rights are when a relative dies, what will happen or how they can access support or advocacy.
- The extent to which families and carers are involved in reviews and investigations of their relatives varies considerably. Families are not always informed or kept up to date about investigations – something that often caused further distress and undermined trust in investigations.
- Families and carers told us they are frequently not listened to. In some cases, family and carer involvement is tokenistic and the views of families and carers are not given the same weight as that of clinical staff.

4.2.3 Ignoring the Alarms is subtitled "How NHS eating disorder services are failing patients". But when it comes to investigations and learning, the evidence shows that eating disorder services are by no means unique in their failings. Recent reports from other parts of the NHS have said the following:

Five Years of Cerebral Palsy Claims: "*[There is] evidence of poor quality serious incident investigations at a local level - The patient and family were only involved in 40% of investigations*"ⁱⁱⁱ.

- Southern Health NHS Foundation Trust: "*an ad hoc and inadequate approach to involving families and carers in investigations*"^{iv}.
- Each Baby Counts: "*in a quarter of instances [of death or brain injury] parents were not made aware that a local review was taking place. Just under half the time, parents were made aware ...but were not invited to contribute*"^v.
- Learning from Mistakes: "*local NHS investigation processes were not fit for purpose... and they excluded the family*"^{vi}.
- Learning, Candour and Accountability: "*we have heard from families who had to go to great lengths themselves to get answers... who had their experiences denied and their motives questioned*"^{vii}.

4.2.4 Similar failures have been documented in still more inquiries, taking in Mid Staffordshire^{viii}, Morecambe Bay^{ix}, Gosport^x and the Northern Ireland Hyponatraemia inquiry^{xi}. All of these found that when patients and relatives tried to voice their concerns, they encountered dismissiveness, defensiveness and outright denial. The current investigation at the Shrewsbury and Telford Hospital NHS Trust seems likely to add to the list^{xii}.

4.2.5 It is clear that the Hart family's experience, as outlined in Ignoring the Alarms, fits with a widespread pattern of flawed NHS investigations of serious incidents, and a persistent failure to learn.

4.3 Patient voice is the make or break for learning

4.3.1 The Care Quality Commission has said that "*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*"^{xiii}.

4.3.2 Other research supports this. A recent paper notes that "*the more stages and staff groups a patient trajectory entails, the more likely that the patient is the only person who was present for each encounter. Accordingly, health care complaints are particularly suited to providing insight into continuity of care issues*"^{xiv}.

4.3.3 Another paper describes patients and relatives as knowledge brokers, filling structural holes and helping to "*manage the inconsistencies and unwanted variability in the care system*"^{xv}.

4.3.4 Elsewhere, relatives of patients have been described as "vigilant stakeholders" who may spot things that clinicians have missed. Researchers recommend "*encouraging and supporting patients and families to voice concerns with clear steps and a genuine invitation, and preparing clinicians to respond meaningfully when patients speak up*"^{xvi}.

4.3.5 All of this has clear relevance for the experience of the Hart family. Had Mr. Hart not questioned the causes of his daughter's death, there would have been no recognition of failure. Had he not persisted, in the face of "*a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection*"^{xvii} there would have been no accountability and no possibility of learning.

4.3.6 As at Mid Staffordshire, Morecambe Bay, Southern Health, Gosport and so on, organisational policies and procedures were no guarantee of learning or accountability. Time and time again, it is the presence or absence of "patient voice" that is the make or break for learning.

4.4 Improvement is not fast enough

4.4.1 In 2017, against the background of known weaknesses in NHS investigations and learning, the National Quality Board issued guidance on learning from deaths^{xviii}. The purpose of the guidance was to initiate a standardised approach on learning from deaths in NHS trusts. It included having a clear policy in place for engaging with bereaved families and carers.

4.4.2 A recent report^{xix} from the Care Quality Commission has looked at how - and whether - NHS Trusts have been implementing the guidance.

4.4.3 It paints a mixed picture of good and bad practice. But a comment from the Chief Inspector of Hospitals stands out. He says, "... *we are concerned that we are still seeing the same issues persist in some NHS trusts more than two years on. Issues such as fear of engaging with bereaved families, lack of staff training, and concerns about repercussions on professional careers, suggest that problems with the culture of organisations may be holding people back from making the progress needed*"^{xx}.

4.4.4 The report goes on to make the point that "*the existing culture of an organisation can be a key factor in trusts' implementation of guidance*"^{xxi}.

4.4.5 This matters because getting investigations and learning right is not simply a matter of updating policies and procedures. Organisations have to be open to admitting the possibility of failure. They need to be ready to hear from patients and families. And they need to be willing to learn. These are cultural matters, and as the Chief Inspector of Hospitals says, "*Cultural change is not easy and will take time*"^{xxii}.

4.4.6 Worryingly, he also says that "*the current pace of change is not fast enough*"^{xxiii}.

5. Investigations and learning: The cultural context

5.1 NHS culture diminishes patient experience evidence

5.1.1 The evidence outlined above shows that the failures of investigation and learning highlighted in Ignoring the Alarms are not unique to Averil Hart's case. Neither are they unique to Eating Disorder services. They are systemic, and extend right across the NHS.

5.1.2 At the heart of the problem is a reluctance or inability to take patient experience seriously. That leads to deeply embedded professional, cultural and organisational deficiencies - particularly when it comes to hearing the voices of patients and relatives.

5.1.3 Sir Robert Francis tackled this head on in his report into the Mid Staffordshire disaster. He was unequivocal about the reason for "appalling suffering" and unnecessary death at the Mid Staffordshire NHS Foundation Trust: "*[it] was primarily caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients.*"^{xxxiv}

5.1.4 Referring to some Trusts' failure to act on national Learning from Deaths guidance, the Chief Inspector of Hospitals recently said that "*the existing culture of an organisation can be a key factor in trusts' implementation of guidance*"^{xxxv}.

5.1.5 An important point here is that the culture of individual healthcare organisations does not arise in isolation. It is part of, and to some extent derives from, an overarching NHS culture. And the national culture does not always seem to treat patient feedback as a valued resource for learning. Evidence of this is as follows:

5.2 Inappropriate language is used

5.2.1 Language reveals culture. And when we look at the language used to describe patient feedback, we can see some difficulties.

5.2.2 One example is that when a health professional flags up something that has gone wrong, it is called an incident report. However, when a patient does the same, it is called a complaint. The word "complaint" is synonymous with words like "objection", "grievance" and "criticism". Culturally, it creates a tone of negativity. It positions the patient or relative as "complainant" as opposed to "observer".

5.2.3 Another example is that more general feedback (from the Friends and Family Test, patient surveys, etc.) is still described in many parts of the healthcare system as "anecdotal evidence". The term indicates a cultural tendency to see patient feedback as subjective, irrational, and potentially unreliable. The term "soft evidence" is also used to distinguish patient feedback from the "hard evidence" of statistics - seen as objective, rational, and reliable.

5.2.4 Research^{xxvi}, however, has shown that healthcare statistics are easily manipulated - for example through intimidating staff to achieve performance targets or to adjust data, or by distorting the process of care to meet targets or misrepresent actual performance.

5.2.5 At other times, professional and organisational fear can put reputation before truth. At Morecambe Bay and Southern Health and Gosport, defensiveness, collusion and cover-up were common factors.

5.2.6 "Anecdotal evidence" from patients' stories may indeed be unreliable at times. But, sometimes, the same can apply to statistics and professional records.

5.3 There is a double standard in use of evidence

5.3.1 Medicine respects evidence. So clinicians have access to huge databases of medical research. Their training and professional development are informed by that research, and their clinical guidelines and practice protocols are evidence-based. There is recognition of the importance of organisational memory, and the need to understand where current knowledge comes from. So historical evidence is cherished and preserved in well-maintained archives.

5.3.2 Patient experience evidence, by contrast, has been treated as disposable.

5.3.3 Government has invested heavily in "patient voice" initiatives, starting with the establishment of Community Health Councils in the 1970's. Those were succeeded by Patient and Public Involvement Forums, then by Local Involvement Networks and latterly by Healthwatch. All gathered large volumes of evidence on patient experience, but none was ever archived. So as each initiative shut down, its entire body of knowledge went with it. Evidence collected over decades has been lost for ever.

5.3.4 In 2015, frustrated by the lack of a national evidence base for patient experience, we decided to build one. When we asked for help, we were told by national health sector organisations that the task would be too difficult or too expensive. It is hard to imagine clinicians being told that medical research databases are neither feasible nor affordable.

5.3.5 Undeterred, we pressed on, and now the Patient Experience Library holds tens of thousands of documents on patient experience and patient/public involvement. More are added every week - both from newly published research, and from older surveys and studies, for which we are developing an archive. It does not reflect well on NHS learning culture that such important materials are being preserved in spite of, not because of, any effort on the part of the NHS.

6. Investigations and learning: How the culture plays out in practice

6.1 A closer look

6.1.1 We have shown that the failures of investigation and learning highlighted in Ignoring the Alarms are not unique to Averil Hart's case - they extend right across the NHS. We have drawn on other evidence to reveal an NHS culture that does not value patient feedback as resource for learning, and which operates a double standard in the treatment of patient experience evidence as opposed to medical evidence.

6.1.2 In this section, we will dig deeper into the evidence, to look at how the overarching culture plays out in practice via specific and persistent weaknesses in investigations and learning.

6.2 How investigations and learning should happen

6.2.1 Ignoring the Alarms rightly recommends improvements in the way that investigations and learning are carried out. It refers to "*circumstances like the Hart's, where local bodies are failing to work together to establish what has happened and why*"^{xxvii}.

6.2.2 The process of establishing "what happened and why" should of course include consideration of clinical effectiveness and patient safety. But for thorough understanding, it should also look at the experience of the patient and the family. That would mean:

- Comparing what is known about the individual patient's experience with what is known about the experience of other service users - for example via Care Quality Commission or NHS England national patient surveys.
- Taking account of what the patient's relatives have said - through feedback, complaints and requests for information.
- Examining more general assessments of the service from the patient perspective - eg Healthwatch Enter and View visits^{xxviii}, Patient-Led Assessment of the Care Environment (PLACE) visits^{xxix} and 15 Steps visits^{xxx}.
- Comparing all of the above with evidence of patient experience in similar services across the country.

6.2.3 This would give a fully rounded view of "what has happened and why". It would help to establish whether the patient's or family's experience was a one-off anomaly, or whether it was part of a pattern of poor patient experience - either within the service in question, or within all such services across the country.

6.2.4 The patient/family experience could then be fully contextualised and understood. There would be a foundation for learning.

6.3 How investigations and learning actually happen

6.3.1 We have shown above (section 4.2) that there is, in practice, a common tendency for NHS investigations to exclude bereaved relatives. Protection of professional and organisational reputations (as described in official inquiries) is undoubtedly a motivating factor. But what else is at play? Here is what the evidence shows:

6.3.2 To begin with, it has been observed that fear of retribution inhibits many patients from voicing concerns^{xxxix}. People "*often worry that raising a concern or making complaints will adversely affect the care they receive*"^{xxxix}, and as many as 1 in 4 are concerned about repercussions on their treatment or care^{xxxix}. Straight away, that means that providers may be missing vital signals that all is not well with the service. And it means that if things go badly wrong, investigations may be weakened for lack of contextual evidence.

6.3.3 Healthcare professionals, for their part, can sometimes allow personal feelings to get in the way of careful listening. Research has found that professionals perceive complaints as "*a breach in fundamental relationships involving patients' trust or patients' recognition of their work efforts*"^{xxxix}. Consequently, "*it was rare for [professionals] to describe complaints raised by patients as grounds for improving the quality of care*"^{xxxix}.

6.3.4 Of course, complaints are not generally handled by clinicians - they are dealt with by complaints managers. But complaints managers often spend more time simply processing complaints than actively learning from them. Research has shown "*an overt focus on both the timeliness of response to complaints and on trying to reduce the volume of them rather than an understanding of what an effective response looked like*"^{xxxix}.

6.3.5 It is the same with more general feedback, coming from the Friends and Family Test, Care Quality Commission national patient surveys, NHS England national patient surveys, local Healthwatch reports, engagement exercises run by local Trusts and Clinical Commissioning Groups and so on. So much data is produced from so many sources and in so many different formats that it can be hard to make sense of it all: "*the most striking element is the overwhelming nature of the industry of patient experience feedback. Ward staff... reported feeling overwhelmed and fatigued by the volume and variety of data that the Trust collected*"^{xxxix}.

6.3.6 One person is reported as saying: "*...you're flying blind with your service and you're just picking out bits of data from everywhere*"^{xxxix}. Another said, "*We are data rich, but we don't bring it all together... It's a nightmare to see what's going on*"^{xxxix}. Yet another said, "*So we have got the Friends and Family Test, which produces, as I am sure that you are aware, reams and reams of information but nobody is really quite sure what to do with that information*"^{xli}.

6.3.7 Timeliness is another issue. Sir Robert Francis said that a healthcare system that listens to patients "*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*"^{xli}.

6.3.8 Effective early warning systems pick up alerts quickly and respond promptly. But many patient experience teams in Trusts and CCG's have their email addresses set permanently to autoreply, and carry messages such as these^{xlii}:

- *Please accept this email as an acknowledgment of your contact and if you have not heard from us within two working days please let us know.*
- *We aim to answer your enquiries as soon as possible but we will acknowledge within 3 working days as per NHS Complaint regulations.*
- *We are experiencing a high level of enquiries at the moment we may not be able to respond to you immediately.*

6.3.9 These give the impression of organisational cultures that are not alert to "early warning signs". Once again, it is possible that providers are losing opportunities to gather evidence that could, sooner or later, support investigations.

6.3.10 Sluggish handling of patient feedback is compounded by weaknesses in the way that staff are trained and supported for the complex tasks involved in analysing patient feedback and complaints. Ignoring the Alarms tracked Mr. Hart's complaint across multiple organisations, and had this to say:

- The Cambridgeshire and Peterborough Trust's handling of [the] complaint was so poor that it was maladministration.
- The GP practice's complaint handling was so poor that it was maladministration.
- The Norwich Acute Trust's complaint handling was so poor that it was maladministration.
- NHS England's approach... was so poor that it was maladministration.

6.3.11 A failure on this scale is not an unhappy accident, or the fault of one or two individuals. It is systemic. It points to organisational cultures that routinely fail to invest in the competence of staff and systems to respond well to complaints.

6.3.12 Other evidence confirms this. Research has shown that "*gleaning information from experience data requires the same analytical capability as interpreting clinical data; however, that capability is often unavailable. Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it...*"^{xliii} Another study stated that complaints managers, "*did not have the required skills to be able to perform sophisticated analytic tasks on the data they received*"^{xliv}.

6.3.13 Even when Trust management and Boards are aware of skills deficits, they may not act: "*it has been known about for some time that many members of ward staff find interpretation of [patient experience] data sets difficult or impossible as they have minimal or no training in analytics or quality improvement... but there was no strategy in place or forthcoming at any of the three organizations we studied to address this issue*"^{xlv}.

7. What steps need to be taken to achieve improvement

7.1 The question we are addressing

7.1.1 Question 4 from the PACAC inquiry's [Terms of Reference](#) asks: "What steps need to be taken to achieve improvement?"

7.1.2 In respect of improving investigations and learning, one thing is sure: we do not need more guidelines, frameworks, toolkits, policies or procedures. Every organisation responsible for the care of Averil Hart would have had access to all of these, and yet they were all found guilty of maladministration in the handling of Mr. Hart's complaints and requests for information.

7.1.3 The Care Quality Commission seems to understand that the answer does not lie in more rules and documentation. It points to cultural change as a necessity if healthcare providers are to learn from deaths. However, the Chief Inspector of Hospitals admits that "*Cultural change is not easy and will take time*"^{xlvi}.

7.1.4 So what are the practical steps that providers can take - right now - to start changing attitudes and practice? Our answer is as follows:

7.2 Recommendations

7.2.1 Change the language. We need to be clear that patient stories are valid evidence, having equal weight with clinicians' stories, as set down in their written notes. Referring to patient feedback with the term "anecdotal evidence" is indicative of a dismissive and disrespectful culture, and should not be tolerated.

7.2.2 End the double standard in preservation of evidence. We should stop treating patient experience evidence as disposable. The archive that has been developed by the Patient Experience Library holds important materials that are being preserved in spite of, not because of, any effort on the part of the NHS. It should be actively supported.

7.2.3 End the double standard in access to evidence. The Patient Experience Library is the national evidence base for patient experience and involvement, with over 50,000 documents fully catalogued and indexed. Staff across the NHS should have automatic access to it, in the same way that clinicians are granted access to databases of medical research and evidence.

7.2.4 Get feedback out in the open. Patients and relatives keep quiet about their concerns for fear of retribution. Health professionals see negative feedback as a breach of trust. We need to confront these fears by bringing feedback and complaints processes out of the shadows and into the open. The Care Opinion platform shows how open dialogue between patients and professionals can be conducted in a way that is honest, respectful and constructive - even when bad news needs to be shared.

Providers need to stop handling feedback behind closed doors. They should let the sunlight in to disinfect the culture of fear.

7.2.5 Abandon "process for its own sake". Complaints managers often spend more time processing complaints than learning from them. Response times to complaints matter, as does the ability to sign off complaints after their journey through the system. But a satisfactory sign-off is not the end of the journey. It should be the start of a search for understanding and wider corrective action.

7.2.6 Rationalise feedback systems. Staff cannot keep up with, or make sense of feedback coming at different times and in different formats from CQC patient surveys, NHS England patient surveys, Friends and Family Test, local Healthwatch reports and more. We need to review how and why patient experience evidence is gathered, bearing in mind that the goal should be learning, not confusion.

7.2.7 Be responsive. Patient experience teams should not have e-mail autoreplies switched on as a matter of course. They should have sufficient staff to enable same-day initial replies to patient queries and concerns. In the spirit of "person-centred care", those replies should be, at least to some extent, personalised.

7.2.8 Invest in staff and systems. We do not expect clinicians to practice without training, qualifications and continuing professional development, as well as analytical and diagnostic tools. So why do we expect patient experience staff and complaints managers to operate without similar support? People entrusted with the complex task of understanding patient feedback should be given training, qualifications and continuing professional development, as well as analytical tools.

8. Conclusion

8.1 The next major report on avoidable deaths within the NHS will be the Ockenden review^{xlvii} of events at the Shrewsbury and Telford Hospital NHS Trust. We fully anticipate that it will echo much of the evidence that we have presented in this submission, including:

- Poor complaints handling
- An organisational culture that did not take patient experience seriously enough
- A failure to investigate well and learn from deaths

8.2 In this context, our challenge to healthcare providers is this: If your clinical practice is soundly evidence-based, but your patient experience work is not, your whole provision and perspective is out of balance.

8.3 Our challenge to NHS England is this: If you treat patient experience evidence as disposable, and patient experience staff as not worthy of professional training and support, there will be more avoidable deaths, and a continuing failure to learn.

8.4 Our challenge to the Department of Health and Social Care is this: Work with us to put patient experience work on the same evidence-based footing as clinical work.

8.5 We are grateful for the opportunity to contribute to the PACAC inquiry, and are happy to provide further information or clarification, if required.

References

- ⁱ NHS Improvement, December 2018. Developing a patient safety strategy for the NHS Proposals for consultation. Page 5.
- ⁱⁱ Care Quality Commission, December 2016. Learning, Candour and Accountability. Page 6.
- ⁱⁱⁱ NHS Resolution, September 2017. Five years of cerebral palsy claims. A thematic review of NHS Resolution data. Page 9.
- ^{iv} Mazars LLP, December 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. Page 18.
- ^v Royal College of Obstetricians and Gynaecologists, June 2016. Each Baby Counts. Key message from 2015. Page 16.
- ^{vi} Parliamentary and Health Service Ombudsman, July 2016. Learning from mistakes. An investigation report by the Parliamentary and Health Service Ombudsman into how the NHS failed to properly investigate the death of a three-year old child. Page 2.
- ^{vii} Care Quality Commission, December 2016. Learning, Candour and Accountability. Page 4.
- ^{viii} Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013.
- ^{ix} Dr Bill Kirkup CBE, March 2015. The Report of the Morecambe Bay Investigation.
- ^x Gosport War Memorial Hospital The Report of the Gosport Independent Panel June 2018
- ^{xi} The Inquiry into Hyponatraemia-related Deaths. January 2018.
- ^{xii} <https://www.theguardian.com/society/2018/aug/31/deaths-feared-shrewsbury-telford-nhs-trust-maternity-unit-investigation>
- ^{xiii} Care Quality Commission, December 2016. Learning, Candour and Accountability. Page 6.
- ^{xiv} Gillespie. A., Reader. T., 2018. Patient-Centered Insights: Using Health Care Complaints to Reveal Hot Spots and Blind Spots in Quality and Safety. The Milbank Quarterly, Vol. 96, No. 3, 2018 (pp. 530-567).
- ^{xv} O'Hara JK, Aase K, Waring J., 2018 BMJ Qual Saf doi:10.1136/ bmjqs-2018-008216
- ^{xvi} Bell SK, Roche SD, Mueller A, et al. 2018. BMJ Qual Saf doi:10.1136/ bmjqs-2017-007525
- ^{xvii} Parliamentary and Health Service Ombudsman, December 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 11.
- ^{xviii} National Quality Board, July 2018. Learning from deaths: Guidance for NHS trusts on working with bereaved families and carers.
- ^{xix} Care Quality Commission, 2019. Learning from deaths. A review of the first year of NHS trusts implementing the national guidance.
- ^{xx} Ibid, page 4.
- ^{xxi} Ibid. Page 15.

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- ^{xxii} Ibid. Page 4.
- ^{xxiii} Ibid. Page 4.
- ^{xxiv} Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013.
- ^{xxv} Care Quality Commission, 2019. Learning from deaths A review of the first year of NHS trusts implementing the national guidance. Page 15.
- ^{xxvi} Dr Foster, 2015. Uses & Abuses of Performance Data in Healthcare. page 4.
- ^{xxvii} Parliamentary and Health Service Ombudsman, December 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 17.
- ^{xxviii} <https://www.patientlibrary.net/cgi-bin/library.cgi?page=EVMAP;prevref=>
- ^{xxix} <https://digital.nhs.uk/data-and-information/areas-of-interest/estates-and-facilities/patient-led-assessments-of-the-care-environment-place>
- ^{xxx} <https://www.england.nhs.uk/participation/resources/15-steps-challenge/>
- ^{xxxi} Clwyd, A., Hart, P., October 2013. A Review of the NHS Hospitals Complaints System. Putting Patients Back in the Picture. Page 9.
- ^{xxxii} Healthwatch England, October 2014. Suffering in silence. Listening to consumer experiences of the health and social care complaints system. Page 23
- ^{xxxiii} Ibid.
- ^{xxxiv} Adams et al, 2017. 'It's sometimes hard to tell what patients are playing at': How healthcare professionals make sense of why patients and families complain about care. Sage Journals: Health.
- ^{xxxv} Ibid.
- ^{xxxvi} Sheard L, Peacock R, Marsh C, Lawton R. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. Health Expect. 2018;00:1–8
- ^{xxxvii} Ibid.
- ^{xxxviii} Flott K, Darzi A, Gancarczyk S, Mayer E Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study J Med Internet Res 2018;20(4):e141
- ^{xxxix} MES and InHealth Associates, June 2015. Making Sense and Making Use of Patient Experience Data. Page 15.
- ^{xl} Sheard L, Peacock R, Marsh C, Lawton R. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. Health Expect. 2018;00:1–8
- ^{xli} Public Inquiry into the Mid Staffordshire NHS Foundation Trust, Volume 1, Chapter 3 pp 245-287
- ^{xlii} E-mail autoreplies received from patient experience teams during December 2018
- ^{xliii} Flott K, Darzi A, Gancarczyk S, Mayer E Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study J Med Internet Res 2018;20(4):e141

^{xliv} Gillespie. A., Reader. T., 2018. Patient-Centered Insights: Using Health Care Complaints to Reveal Hot Spots and Blind Spots in Quality and Safety. The Milbank Quarterly, Vol. 96, No. 3, 2018 (pp. 530-567).

^{xlv} Sheard L, Peacock R, Marsh C, Lawton R. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. Health Expect. 2018;00:1–8

^{xlvi} Care Quality Commission, 2019. Learning from deaths. A review of the first year of NHS trusts implementing the national guidance. Page 4.

^{xlvii} <https://www.theguardian.com/society/2018/aug/31/deaths-feared-shrewsbury-telford-nhs-trust-maternity-unit-investigation>