The Patient Experience Library

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Developing a patient safety strategy for the NHS

Proposals for consultation December 2018

Response from the Patient Experience Library, January 2019

Introduction

NHS Improvement has invited comments on proposals for a patient safety strategy. The aim is to "*make sure people receive the safest care possible*"[i].

We are pleased to see reference to Gosport, Mid Staffordshire and Morecambe Bay at the very start of the consultation document. The fundamental learning point from those incidents is that when the patient voice goes unheard, people die.

Patients can sometimes spot risks and errors that have been missed by busy health professionals. And they can give voice to concerns that dysfunctional organisational cultures would prefer not to hear.

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*"[ii]. Our response, set out below, will focus on the need to put patient experience, and patient voice, at the centre of a patient safety strategy.

Our comments come from our unique experience in maintaining the UK's national evidence base on patient experience. That evidence base should itself be embedded within a systematic approach to patient safety across the NHS.

We are grateful for the opportunity to comment on the consultation proposals, and we offer the following response in a spirit of partnership.

1. Our starting point: Patient experience is integral to safety

The consultation proposals state that safety "*is one of three core components of quality in healthcare alongside clinical effectiveness and patient experience*"[iii]. It is important to remember that those components are not separate - they are closely intertwined. To ensure "the safest care possible", we need high quality clinical practice and robust safety management and careful attention to patient experience.

In this response, we will focus on patient experience and the vital part that patient feedback plays in helping to ensure safety.

2. The "just safety culture" principle: For patients as well as staff

The consultation proposals make repeated reference to a "just safety culture". It is good to see the acknowledgement that organisational culture has a profound influence on patient safety.

We support the idea that a just safety culture should "*abandon blame as a tool*"[iv]. Staff must feel free to speak up about honest errors, and must feel safe from unfairly punitive responses. But the "just culture" principle should extend beyond staff, taking in patients as well.

The NHS has a stated commitment to being patient-centred. So a just safety culture must offer justice to patients as well as to staff. It must make it safe for patients and their relatives and carers to voice concerns. It must treat patient stories with the same respect that is accorded to clinicians' written records.

The consultation proposals recognise the learning from "*the Gosport Inquiry and other inquiries such as those at Mid Staffordshire NHS Foundation Trust, and University Hospitals of Morecambe Bay NHS Foundation Trust*"[v]. Those inquiries found unsafe cultures on wards, in boardrooms, and in organisational processes such as complaints handling and communications. They also found that when patients and relatives tried to speak up about safety concerns, they encountered dismissiveness, defensiveness and outright denial.

It would be a mistake to think that such punitive action towards patients is confined to one or two rogue Trusts. Six headline-hitting inquiries in five years (from the Mid Staffs report in 2013, through Morecambe Bay, Southern Health, Hyponatraemia, and Gosport, to Shrewsbury and Telford in 2018) form a roll call of unjust treatment of patients, stretching across the NHS. It is no wonder that fear of retribution inhibits many patients from voicing concerns.[vi]

A just safety culture for patients would not allow punitive responses to legitimate concerns. The "just safety culture" principle proposed in the consultation document must result in justice for all.

3. Developing a just safety culture: Complaints

Patient complaints should be an embedded part of safety culture within healthcare organisations. But cultural attitudes towards complaints can inhibit their use for learning and quality improvement. These include the following:

3.1 Language

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. The word "complaint" is synonymous with words like "objection", "grievance" and "criticism". Culturally, it creates a tone of negativity.

Research has found that professionals perceive complaints as "*a breach in fundamental relationships involving patients' trust or patients' recognition of their work efforts*"[vii]. Consequently, "*it was rare for [professionals] to describe complaints raised by patients as grounds for improving the quality of care*"[viii].

Recommendation: Change the language. We need to be clear that patient complaints are not negative criticism, but are a form of incident reporting, complementary to that practised by staff.

3.2 Process

It is common to hear talk of "complaints handling" or "complaints management". The phrases point to a process-led reaction to patient feedback, focussed on moving the complaint through the system, rather than taking it as an opportunity to build a robust safety culture.

This is confirmed by research, which 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*"[ix].

One Trust employee commented "*Number of complaints is one thing, great, are they [complaints team] getting more or less? Less, great. Are they responding to them within our forty day timescale? Yeah, great. For me that's all nice and boxes we can count and tick, but actually what are the main complaints? What are the main themes? What are they doing about them? What's on their action plan?*"[x]

Recommendation: Abandon "process for its own sake". 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.

3.3 Competence

There is sometimes a problem with staff being inadequately trained and supported for the complex tasks involved in complaints management. A recent report by the Parliamentary and Health Service Ombudsman[xi] investigated the avoidable death of a young woman. It tracked her father'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.

A failure on this scale is not an unhappy accident, or the fault of one individual. It is systemic. It stems from organisational cultures that are both unsafe (causing the death of a patient) and unjust - failing to offer a grieving father a proper explanation of what went wrong. The ombudsman's findings also point to organisational cultures that fail to invest in the competence of staff and systems to respond well to complaints.

Recommendation: 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. Complaints handlers should be similarly supported.

3.4 Blind spots

A culture of safety can also be inhibited by people's failure to see beyond their own organisational or specialism boundaries. Research has shown that there are blind spots for "*events that occur outside the institution, either before admission or after discharge*", and for "*problems that are systemic across the patient journey*". Incident reporting by staff features "*a tendency to capture isolated incidents (eg, medication errors) but not cascades of problems leading to incidents*". Patient complaints, however, "*may address this limitation because they often narrate the entire sequence of events as the patient moved through the health care system*".

Recommendation: Use complaints to eliminate blind spots. Organisational cultures need to accord the same respect to incident reporting (ie complaints) by patients as they do to incident reporting by staff, recognising that patients can sometimes see things that staff cannot.

4. Developing a just safety culture: Other patient feedback

Formal complaints are one small part of the way that feedback is received from patients. Cultural attitudes within healthcare organisations can also mean that more general feedback is poorly exploited for learning and quality improvement. These include the following:

4.1 Language

Feedback other than formal complaints comes from many sources, including the Friends and Family Test, patient surveys, focus groups, social media posts, etc. This 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.

Research[xii], 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.

Even when statistics are reliable, professional and organisational fear can put reputation before truth. At Morecambe Bay and Southern Health, and in the Hyponatraemia inquiry, defensiveness, collusion and cover-up were common factors. Patient stories may indeed be unreliable at times. But, sometimes, the same can apply to professionals' stories.

Recommendation: 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 safety culture, and should not be tolerated.

4.2 Competence

Research[xiii] 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...*"

One Trust employee 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*"[xiv].

There is a serious problem with an NHS culture that describes patient experience as being a "core component"[xv] of quality in healthcare, but fails to give patient experience

staff a professional qualification, or well-structured continuing professional development, or good quality analytical tools.

Recommendation: 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.

4.3 Responsiveness

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*".[xvi] A just safety culture for all would make it clear to patients that their feedback was valued and would be acted on promptly. Unfortunately, that is often not the case.

Many PALS teams in Trusts and CCG's have their email addresses set permanently to autoreply, and carry messages such as these[xvii]:

- *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.*

These give the impression of organisational cultures that do not value patient feedback sufficiently to want to respond promptly. Or that are not especially interested in picking up Francis's "early warning signs".

Recommendation: Be responsive. PALS 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.

5. Developing a just safety culture: National culture

The consultation proposals note that "*Too many staff still fear blame, believing incident reporting is a punitive process*"[xviii]. Fear of blame, however, affects not just individuals, but whole organisations, leading to the closed ranks and institutional denials seen at Mid Staffs, Morecambe Bay, Southern Health and so on.

The point here is that just as individuals operate within, and are affected by, organisational culture, so healthcare organisations operate within, and are affected by, national NHS culture. And the national culture does not always seem to treat patient

feedback as a valued resource for safety learning and practice. Evidence of this is as follows:

5.1 Inadequate access to evidence . A mass of patient feedback is generated from national patient surveys, local Healthwatch reports, health charities, think tanks, academic research and more. However, it is published across hundreds of different organisational websites, all of which are designed and structured differently, and some of which are not well maintained. Even dedicated patient engagement professionals can find it hard to keep up with the flow of data and remember where everything is held. As one person said, *"...you're flying blind with your service and you're just picking out bits of data from everywhere*"[xix]. This leads to a serious difficulty: if healthcare providers cannot easily find the evidence, they cannot act on it.

Recommendation: Support easy access to the evidence. The Patient Experience Library has built a national evidence base for patient experience, with over 50,000 documents fully catalogued and indexed. Patient experience 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.

5.2 Poor preservation. Medicine respects evidence, so clinical research is cherished and preserved. There is a cultural recognition of the importance of organisational memory - understanding where current evidence comes from, and ensuring that old mistakes are not repeated. Patient experience evidence, by contrast, is treated as disposable. It has been collected for over forty years by Community Health Councils, Patient and Public Involvement Forums, Local Involvement Networks and now Healthwatch, but no archive was ever created. Knowledge accumulated over decades has been allowed to disappear.

Recommendation: Support maintenance of the archive. The Patient Experience Library holds the entire Healthwatch reports collection, plus materials from LINks and other sources, going back many years. It does not reflect well on NHS safety culture that such important materials are being preserved in spite of, not because of, any effort on the part of the NHS. Preservation of evidence that can contribute to development of a safety culture should be actively supported by the NHS.

6. Conclusion

To sum up: patient safety cannot be looked at in isolation from patient experience.

We have seen, at Mid Staffs and elsewhere, what happens when patient experience is poorly understood and/or the patient voice is ignored.

The patient safety strategy should include strategic development of patient experience work. In line with our recommendations above, this should include:

- Different language: Understanding patient complaints as another form of incident reporting, and rejecting the term "anecdotal evidence" to describe patient feedback.
- A focus on learning: Making learning, rather than process management, the key component of complaints handling.
- Investment in staff and systems: To improve analysis of patient feedback, and use it to help drive a better safety culture.
- Responsiveness: Ending the practice of PALS teams having their emails set permanently to autoreply.
- Access to evidence: Giving patient experience staff the same access to patient experience evidence as clinicians would expect for medical evidence. Working with the Patient Experience Library to continue building and sustaining the national evidence base for patient experience.

We are grateful for the opportunity to contribute to this important consultation and are happy to offer further information or clarification if required:

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References

[i] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 2.

[ii] Public Inquiry into the Mid Staffordshire NHS Foundation Trust, Volume 1, Chapter 3 pp 245-287

[iii] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 3.

[iv] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 7.

[v] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 2.

[vi] Healthwatch England,October 2014. Suffering in silence. Listening to consumer experiences of the health and social care complaints system. Page 24

[vii] 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.

[viii] Ibid.

[ix] 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

[x] 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

[xi] Parliamentary and Health Service Ombudsman, December 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Pages 11, 12.

[xii] Dr Foster, 2015. Uses & Abuses of Performance Data in Healthcare. page 4.

[xiii] 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

[xiv] 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

[xv] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 3.

[xvi] Public Inquiry into the Mid Staffordshire NHS Foundation Trust, Volume 1, Chapter 3 pp 245-287

[xvii] E-mail autoreplies received from PALS teams during December 2018

[xviii] NHS Improvement, December 2018. Developing a patient safety strategy for the NHS. Proposals for consultation. Page 5.

[xix] 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