


Aims/ambitions

 The patient will be at the heart of everything the NHS does.


Department of Health, 2015. The NHS Constitution. Page 3.

<http://pexlib.net/?211849>

 Engage, empower, and hear patients and carers at all times.

National Advisory Group on the Safety of Patients in England, 2013. A promise to learn - a commitment to act. Improving the Safety of Patients in England. Page 4.

<http://pexlib.net/?8158>

 All organisations should seek out the patient and carer voice as an essential asset in monitoring the safety and quality of care.

National Advisory Group on the Safety of Patients in England, 2013. A promise to learn - a commitment to act. Improving the Safety of Patients in England. Page 5.

<http://pexlib.net/?8158>

 Hear the patient voice, at every level, even when that voice is a whisper.

National Advisory Group on the Safety of Patients in England, 2013. A promise to learn - a commitment to act. Improving the Safety of Patients in England. Page 17.

<http://pexlib.net/?8158>

 Incorrect priorities do damage: other goals are important, but the central focus must always be on patients.


National Advisory Group on the Safety of Patients in England, 2013. A promise to learn - a commitment to act. Improving the Safety of Patients in England. Page 4.

<http://pexlib.net/?8158>

 The patient must be first in everything that is done.


Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013. Executive summary, Page 66.

<http://pexlib.net/?195069>

 If quality is to be at the heart of everything we do, it must be understood from the perspective of patients.

High Quality Care For All. NHS Next Stage Review Final Report. 2008. Page 47.

<http://pexlib.net/?182438>

 Good patient experience is an essential indicator of high-quality health care and should be central to national performance measures.

Healthwatch England, 2020. What matters to people using A&E. A report for the NHS Clinical Review of Standards. Page 4.

<http://pexlib.net/?210883>

The Patient Experience Library

Quote Selector



...when patients describe issues that may reflect a lack of safety, they must be heard, and appropriate action initiated.

Independent Neurology Inquiry, June 2022. Page 46.

<https://pexlib.net/?236098>

No hospital can run well with poorly led medical staff who do not or cannot focus on the care of the patients as being their first concern.

Kark, T. and Russell, J., November 2018. A review of the Fit and Proper Person Test. The Kark Review. Page 3

<https://pexlib.net/?192797>

Barriers to feedback

People "often worry that raising a concern or making complaints will adversely affect the care they receive"
Healthwatch England, October 2014. *Suffering in silence. Listening to consumer experiences of the health and social care complaints system.* Page 23
<http://pexlib.net/?424>

...it has been observed that fear of retribution inhibits many patients from voicing concerns
Clwyd, A., Hart, P., October 2013. *A Review of the NHS Hospitals Complaints System. Putting Patients Back in the Picture.* Page 9.
<http://pexlib.net/?8011>

Although patients desire safe care, they are reluctant to perform safety-related behaviors when they worry it could harm the relationships they have with clinicians
Mishra et al. Undated. *Must We Bust the Trust?: Understanding How the Clinician-Patient Relationship Influences Patient Engagement in Safety.*
<http://pexlib.net/?191828>

[Patients] exhibited a desire to protect their clinician's emotional or professional needs that at times interfered with their desire to engage with their own safety.
Mishra et al. Undated. *Must We Bust the Trust?: Understanding How the Clinician-Patient Relationship Influences Patient Engagement in Safety.*
<http://pexlib.net/?191828>

[Patients] were reluctant to report undesirable events because of their concern over repercussions to hospital staff
Mishra et al. Undated. *Must We Bust the Trust?: Understanding How the Clinician-Patient Relationship Influences Patient Engagement in Safety.*
<http://pexlib.net/?191828>

Patients are often reluctant to assert their interests in the presence of clinicians, whom they see as experts. The higher the stakes of a health decision, the more entrenched the socially sanctioned roles of patient and clinician can become. As a result, many patients are susceptible to "hostage bargaining syndrome" (HBS), whereby they behave as if negotiating for their health from a position of fear and confusion. It may manifest as understating a concern, asking for less than what is desired or needed, or even remaining silent against one's better judgment. When HBS persists and escalates, a patient may succumb to learned helplessness, making his or her authentic involvement in shared decision making almost impossible.
Berry, L. et al. 2017. *When Patients and Their Families Feel Like Hostages to Health Care.* Mayo Clinic Proceedings. doi.org/10.1016
<http://pexlib.net/?162999>

The Patient Experience Library

Quote Selector

Medical care has recently become more focused on serving patients as consumers, but some distinctions are important. Most commercial services are "want" services... Medical care is a "need" service that consumers turned-patients often dread and may delay receiving. In using most commercial services, the consumer is in charge, deciding what service to buy and where to buy it; in a medical clinic or hospital, clinicians (and health care management) typically have the greater authority.

Berry, L. et al. 2017. When Patients and Their Families Feel Like Hostages to Health Care. Mayo Clinic Proceedings. doi.org/10.1016
<http://pexlib.net/?162999>

...50%-70% of patients and families "expressed hesitancy to voice concerns in real time about some common care situations with safety implications, including a possible mistake or mismatched goals related to aggressiveness of care".

Bell SK et al. 2018. Speaking up about care concerns in the ICU: patient and family experiences, attitudes and perceived barriers. BMJ Qual Saf doi:10.1136/ bmjqs-2017-007525
<http://pexlib.net/?180465>

People often refrain from complaining because it is effortful, time-consuming, and sometimes perceived as futile.

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). Page 532.
<http://pexlib.net/?182740>

I was tired of being contacted and being told that my complaint had been passed on, and it became obvious that a well organised system was in place making things difficult for someone like myself to get a simple answer. I realised that there was a huge industry dedicated to making sure nothing would be done, and I would just be passed around until I gave up. So I decided I would give up.

Healthwatch England, 2014. Suffering in Silence. Page 20.
<http://pexlib.net/?424>

...professionals see patient anonymity as a barrier to effective use of feedback, and a risk to the reputation of individual practitioners or organisations, given that anyone can say anything, no matter how unfair or damaging. Meanwhile patients fear that being identifiable may compromise the care they receive if they make critical remarks. This constitutes an 'anonymity paradox', whereby patients see anonymity as a prerequisite but professionals see it as a barrier.

Locock, L. et al, 2020. Anonymity, veracity and power in online patient feedback : A quantitative and qualitative analysis of staff responses to patient comments on the 'Care Opinion' platform in Scotland. Digital Health Volume 6: 1-13.
<http://pexlib.net/?210200>

“ If you are ill enough to be detained, you do not have the mental energy to start formulating complaints and pursuing a complaints procedure.

Berzins, K. et al., 2019. A qualitative exploration of mental health service user and carer perspectives on safety issues in UK mental health services. *Health Expectations*, 2020, 00:1 1-12.

<http://pexlib.net/?210639>

“ ...medical staff in both primary and secondary care were strongly supportive in principle of incorporating patient feedback into quality improvement work. Yet they also expressed a simultaneous view questioning the credibility of survey findings and patients' motivations and competence in providing feedback.

Locock, L., et al., 2020. Anonymity, veracity and power in online patient feedback: A quantitative and qualitative analysis of staff responses to patient comments on the “Care Opinion” platform in Scotland. *Digital Health Volume 6*: 1-13.

<http://pexlib.net/?210200>

“ ...the purpose of providing feedback was not clear to most patients. The lack of organisational response to their survey feedback meant they perceived it as a “tick box exercise” and they thought that their comments would not be used.

NIHR, 2019. Themed review: Improving care by using patient feedback.

<http://pexlib.net/?209510>

“ A fear of reprisals, fear of impact on clinical care and fear of sometimes petty and sometimes more serious retaliation from staff members were cited by both patients and carers as some of the main reasons why feedback would not be shared outside a trusting relationship with staff and only under certain conditions.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 65

<http://pexlib.net/?216782>

“ When it was difficult to establish trusting relationships, such as when there was a shortage of permanent staff or when the quality of care was poor, patients and carers were less likely to give honest feedback about their experience.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 65

<http://pexlib.net/?216782>

“ Patients and carers reported a fear of retaliation from staff if they provided feedback, suggesting a lack of recognition by staff of the impact of power differences on patients and carers and a lack of accountability of staff for their actions. When poor cultures of care exist, it is less likely that honest feedback from patients or carers will be obtained.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 66

<http://pexlib.net/?216782>

Our thematic analysis uncovered the importance of carers, patients and staff seeing changes and staff being able to make changes in response to feedback... When change was not observed, it disincentivised patients and carers from giving feedback and staff from collecting it, as they felt that there was nothing they could do about actioning it.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 61

<http://pexlib.net/?216782>

Positive feedback is seen as superficial and not useful and so staff tend to deflect it, which is disempowering for the patients and carers giving the feedback and a missed opportunity to identify what is working.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 74

<http://pexlib.net/?216782>

When staff were over stretched, demoralised because they felt that they did not have the agency or resource to provide good-quality care, and frustrated at the lack of change that resulted from patient experience feedback, they stopped attempting to collect the feedback.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21). Page 106

<http://pexlib.net/?216782>

...the healthcare system...is disjointed, siloed, unresponsive and defensive. It does not adequately recognise that patients are its raison d'etre. It has failed to listen to their concerns and when, belatedly, it has decided to act it has too often moved glacially

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page i

<http://pexlib.net/?223550>

When patients and families are not met with openness and transparency when something has gone wrong, they face a complex landscape of possible actions. Their priorities are most often to discover the truth and to prevent the same thing happening to others, but they may also understandably seek accountability for individual or corporate actions, or compensation. The landscape they have to navigate includes internal and external safety investigations, inquests, the Patient Advice and Liaison Services, Healthwatch, complaints, civil litigation, professional regulators such as the Nursing and Midwifery Council and General Medical Council, the Care Quality Commission, the Parliamentary and Health Services Ombudsman, and criminal investigation by police services. It is hardly surprising that families may feel bewildered about the approach best fitted to give them the answers and actions they seek. At the least, this landscape requires clear signposting.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 17

<http://pexlib.net/?227756>

There have also been cases where women and their families raised concerns about their care and were dismissed or not listened to at all.

Ockenden Report, 2020. Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page 11.

<http://pexlib.net/?228088>

There are limited, absent, and confusing aims that are rarely, if ever, logically linked to the proposed process of involvement. There are unclear rationales for involvement and no attempts to reflect on the influence of structural, positional, and political power.

Matthews, R. et al., 20-19. How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

<http://pexlib.net/?207501>

Dense language has to be unpacked to gain an understanding of aspiration and direction. The documents differed in accessibility of language and content. Some were closer to Plain English and clearly explained NHS or organisational structures. Managerial and technical language with jargon and acronyms dominated the sample.

Matthews, R. et al., 20-19. How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

<http://pexlib.net/?207501>

.....for all the fine words printed and spoken about candour, and willingness to remedy wrongs, there lurks within the system an institutional instinct which, under pressure, will prefer concealment, formulaic responses and avoidance of public criticism.

The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 1: Analysis of evidence and lessons learned (part 1). Page 184.

<http://pexlib.net/?76249>

.....when relatives complained about the safety of patients and the appropriateness of their care, they were consistently let down by those in authority - both individuals and institutions. These included the senior management of the hospital, healthcare organisations, Hampshire Constabulary, local politicians, the coronial system, the Crown Prosecution Service, the General Medical Council and the Nursing and Midwifery Council. All failed to act in ways that would have better protected patients and relatives, whose interests some subordinated to the reputation of the hospital and the professions involved.

Gosport War Memorial Hospital. The Report of the Gosport Independent Panel. June 2018. Page viii

<https://pexlib.net/?177680>

...the litigation process is lengthy, adversarial and fails to address the wider emotional and psychological needs of patients and families. The approach to clinical negligence in the United Kingdom has cultivated a culture of defensiveness and blame, preventing families getting the transparency and accountability they need and deserve.

House of Commons Health and Social Care Committee, 2021. The safety of maternity services in England. Fourth Report of Session 2021-22. Page 27

<https://pexlib.net/?231192>

There are several different platforms available to patients to provide feedback. However, not all of these platforms are equally regarded by healthcare organisations. Often organisations limit their attention to sources which are sanctioned, solicited and sought by the organisation. Social media platforms and blogs may be used by patients to give feedback, but these are often disregarded.

Berry, E. et al, 2022. Using humanity to change systems - understanding the work of online feedback moderation: A case study of Care Opinion Scotland. Digital Health Volume 8: 1-13.

<http://pexlib.net/?234754>

People and their families still tell us that it is not always easy to raise and escalate concerns to providers or commissioners. Where they do, they can feel labelled as difficult or persistent complainers and are concerned that it will have a negative impact on how providers see and treat them or their loved one.

Care Quality Commission, March 2022. Out of sight - who cares? Restraint, segregation and seclusion review. Progress report.

<https://pexlib.net/?235180>

There is currently no requirement for PALS teams to collect data or any guidance for them on how this might be done.

Shepard, K. et al. 2021. How do National Health Service (NHS) organisations respond to patient concerns? A qualitative interview study of the Patient Advice and Liaison Service (PALS) BMJ Open 2021

<https://pexlib.net/?236980>

...those responsible for the services too often provided clinical care that was suboptimal and led to significant harm, failed to listen to the families involved, and acted in ways which made the experience of families unacceptably and distressingly poor.

Reading the signals. Maternity and neonatal services in East Kent - the Report of the Independent Investigation. October 2022. Page 1

<https://pexlib.net/?237419>

We have found a worrying recurring tendency among midwives and doctors to disregard the views of women and other family members. In fact, in a significant number of cases, the Panel has found compelling evidence that women and their partners were simply not listened to when they expressed concern about their treatment in the days and hours leading up to the birth of their babies, when they questioned their care, and when they challenged the decisions that were made. Too often, their well-founded concerns were dismissed or ignored altogether.

Reading the signals. Maternity and neonatal services in East Kent - the Report of the Independent Investigation. October 2022. Page 21

<https://pexlib.net/?237419>

Complaints

“ 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, Volume 1, Chapter 3 pp 245

<http://pexlib.net/?76249>

“ ...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

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).

<http://pexlib.net/?182740>

“ ...it was rare for complaints to be used as grounds for making improvements". The focus was on "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".

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).

<http://pexlib.net/?182740>

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

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.

<http://pexlib.net/?162412>

“ ...there was 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

Sheard L, Peacock R, Marsh C, Lawton R. 2018. 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

<http://pexlib.net/?181784>

“ ...the daily work of 'putting out fires' and ... simply placating patients and resolving complaints as quickly as possible... may in effect suppress the patient voice.

Liu JJ, Rotteau L, Bell CM, et al. 2019. BMJ Qual Saf doi:10.1136/

<http://pexlib.net/?197012>

The Patient Experience Library

Quote Selector

...the major categories of complaints remained unchanged year after year [which] in itself attests to difficulties in developing effective improvements from past complaints.

Liu JJ, Rotteau L, Bell CM, et al. 2019 BMJ Qual Saf doi:10.1136/

<http://pexlib.net/?197012>

The use of health care complaints to improve quality and safety has been limited by a lack of reliable analysis tools and uncertainty about the insights that can be obtained.

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).

<http://pexlib.net/?182740>

...health care complaints provide added value because they are patient-centred, focus on problematic care episodes, and provide an end-to-end account of care that includes concrete details not captured in incident reports or case reviews

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).

<http://pexlib.net/?182740>

Complaints occur when a threshold of dissatisfaction has been breached, with dominant motivations being to correct an ongoing problem or prevent recurrence.

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). Page 532.

<http://pexlib.net/?182740>

People often refrain from complaining because it is effortful, time-consuming, and sometimes perceived as futile.

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). Page 532.

<http://pexlib.net/?182740>

First, there is a blind spot for events that occur outside the institution, either before admission or after discharge. For example, a case review study found that nearly 8% of adverse incidents related to discharge, none of which were picked up by incident reporting. Health care complaints may address this blind spot because patients can report on events occurring before and after staff are involved. Second, there is a blind spot for problems that are systemic across the patient journey. Serious medical errors often involve a culmination of multiple problems (eg, misdiagnosis and communication failure) spread across stages (eg, examination and discharge); these issues are difficult to capture without the vantage point of multiple agents. A study on incident reporting in anesthesia found a tendency to capture isolated incidents (eg, medication errors) but not cascades of problems leading to incidents. Complaints may address this limitation because they often narrate the entire sequence of events as the patient moved through the health care system. Third, there is a blind spot for errors of omission. An error of omission is an action that is not performed, whereas an error of commission is an action that is performed incorrectly. Errors of omission are widespread in health care, and estimates of

preventable harm would increase dramatically if errors of omission could be assessed reliably. Detecting errors of omission is difficult, because people rarely observe or take responsibility for what has not happened. Moreover, if the omission was deliberate, it is unlikely to be self-reported. Health care complaints may provide data on omissions because patients usually experience their consequences.

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). Page 535.

<http://pexlib.net/?182740>

Ensuring that instances of speaking up are acted on and that complaint data are turned into actionable insights are low-cost, and potentially high-validity, forms of patient involvement.

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). Page 557.

<http://pexlib.net/?182740>

I was tired of being contacted and being told that my complaint had been passed on, and it became obvious that a well organised system was in place making things difficult for someone like myself to get a simple answer. I realised that there was a huge industry dedicated to making sure nothing would be done, and I would just be passed around until I gave up. So I decided I would give up.

Healthwatch England, 2014. Suffering in Silence. Page 20.

<http://pexlib.net/?424>

If you are ill enough to be detained, you do not have the mental energy to start formulating complaints and pursuing a complaints procedure.

Berzins, K. et al., 2019. A qualitative exploration of mental health service user and carer perspectives on safety issues in UK mental health services. Health Expectations, 2020, 00:1 1-12.

<http://pexlib.net/?210639>

This is a recurring feature of health services complaints: instead of serving as a valuable warning of problems, they are seen as something to be fended off with limited, closed and defensive responses, which is deeply unsatisfactory for all concerned.


Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 16

<http://pexlib.net/?227756>

.....the descriptions most effective at establishing failures in care were those that allowed public scrutiny


Goodwin, D. 2020. Describing failures of healthcare: a study in the sociology of knowledge.

<http://pexlib.net/?228169>

 The failure to learn from complaints was one of the more disturbing aspects of the investigation conducted by this Inquiry. Time after time, information was raised in a patient complaint, which needed to be independently investigated. Consistently the answer given to the complainant was obtuse and unhelpful.


Independent Neurology Inquiry, June 2022. Page 17.

<https://pexlib.net/?236098>

 Instead of recognising that a well-run complaints system can be perhaps the most effective way of identifying aberrancy, the approach was focused on responding within stipulated time periods and 'resolving' complaints... the opportunity for learning from complaints often seems to have been missed.

Independent Neurology Inquiry, June 2022. Page 19.

<https://pexlib.net/?236098>

 The complaints system as currently constructed is excessively complex and can be confusing for members of the public to navigate.

Parliamentary and Health Service Ombudsman, April 2022. Written evidence from the Parliamentary and Health Service Ombudsman to the Joint Committee on Human Rightsâ€™ inquiry on Protecting Human Rights in Care Settings.


<https://pexlib.net/?236332>

Culture

 A culture focused on doing the system's business-not that of the patients.


Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013. Executive summary, Page 4.

<http://pexlib.net/?195069>

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


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.

<http://pexlib.net/?162412>

 Patient experience is often viewed as 'nice to have' rather than critical to enhancing the quality of service provision.


University of Birmingham, October 2019. Evaluating the Use of Patient Experience Data to Improve the Quality of Inpatient Mental Health Care (Euripides).

<http://pexlib.net/?201827>

 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.

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

<http://pexlib.net/?192501>

 ...there is no one factor that guarantees good practice, with enablers and barriers to implementing the guidance being interrelated. However... the existing culture of an organisation can be a key factor in trusts' implementation of guidance

Care Quality Commission, 2019. Learning from deaths. A review of the first year of NHS trusts implementing the national guidance. Page 15.

<http://pexlib.net/?192501>

 Cultural change is not easy and will take time. However, the current pace of change is not fast enough

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

<http://pexlib.net/?192501>

...a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection

Parliamentary and Health Service Ombudsman, December 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 11.

<http://pexlib.net/?171461>

The current requirement to collect patient feedback so infrequently (once every five years) sends the message, whether intentional or not, that patient feedback is unimportant.

Baines, Rebecca; Donovan, John; Regan de Bere, Samantha; Archer, Julian; and Jones, Ray (2019) "Comparing psychiatric care experiences shared online with validated questionnaires; do they include the same content?," Patient Experience Journal: Vol. 6 : Iss. 1 , Article 12.

<http://pexlib.net/?194109>

While there are many strong partnerships between service users and NHS services, there was also evidence of profound differences in perspective on what is important and even, at times, outright hostility and distrust between the two sides.

King's Fund, 2019. Outcomes for mental health services. What really matters? Page 4.

<http://pexlib.net/?192887>

...people with mental health problems are among the 'problem patients' of modern health care - those that seem to rub the system up the wrong way and wear professionals down with their stubborn refusal to be cured

King's Fund, 2019. Outcomes for mental health services. What really matters? Page 5.

<http://pexlib.net/?192887>

The outcomes prioritised, and those discounted, inevitably reveal the degree of influence of different voices in the discussion - those around the table and those outside the room.

King's Fund, 2019. Outcomes for mental health services. What really matters? Page 6.

<http://pexlib.net/?192887>

...we cannot usefully direct mental health services to the dogged pursuit of particular outcomes until there is a broader consensus on which outcomes really matter

King's Fund, 2019. Outcomes for mental health services. What really matters? Page 6.

<http://pexlib.net/?192887>

Where service users, professionals and different professions already appear to be pulling in different directions... It is also clear that some sort of reconciliation is urgently needed.

King's Fund, 2019. Outcomes for mental health services. What really matters? Page 6.

<http://pexlib.net/?192887>

The Patient Experience Library

Quote Selector

☞ All feedback collected ideally needs to have the ability to be meaningfully used by those providing frontline care. Otherwise, it becomes unethical to ask patients to provide feedback which will never be taken into account.

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

☞ Patient experience was sometimes said to be the poor relation of patient safety and finance with a lesser emphasis and priority placed on it

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

☞ Medical care has recently become more focused on serving patients as consumers, but some distinctions are important. Most commercial services are "want" services... Medical care is a "need" service that consumers turned-patients often dread and may delay receiving. In using most commercial services, the consumer is in charge, deciding what service to buy and where to buy it; in a medical clinic or hospital, clinicians (and health care management) typically have the greater authority.

Berry, L. et al. 2017. When Patients and Their Families Feel Like Hostages to Health Care. Mayo Clinic Proceedings. doi.org/10.1016

<http://pexlib.net/?162999>

☞ ...patients are invited to fill in questionnaires, attend focus groups or tell their stories (if they are lucky) at board meetings or the like. The focus is what happened to them in the past, mostly about their experience of services (rather than living with a condition, or about their lives beyond the institutional scope of interest), and the meaning of their data is left to professionals to assess

Gilbert, D. 2018. Rethinking engagement. BJPsych Bulletin (2018) doi:10.1192/bjb.2018.55

<http://pexlib.net/?181123>

☞ ...almost everything we do in the clinic sends clear signals to patients that we are the people who make and apply the rules, and they are the ones who are obliged to comply

Launer, J., 2012. Waiting rooms and the unconscious. Postgrad Med J June 2012 Vol 88 No 1040 Page 361.

<http://pexlib.net/?173392>

☞ Some doctors regularly finish an hour or two late, yet their patients are still stacked up for appointments every session without the remotest chance they will ever be seen on time.

Launer, J., 2012. Waiting rooms and the unconscious. Postgrad Med J June 2012 Vol 88 No 1040 Page 361.

<http://pexlib.net/?173392>

The Patient Experience Library

Quote Selector

...we identified powerful cultures of containment and restraint, with... work in the ward driven by the organisational demands of delivering care within fixed routines and timetables that do not meet the needs of people living with dementia... These approaches created damaging cycles of stress for patients, families and ward staff.

Featherstone, K. et al., 2019. Refusal and resistance to care by people living with dementia being cared for within acute hospital wards: an ethnographic study. Health Services and Delivery Research Volume 7 Issue 11 March 2019 Page xv
<http://pexlib.net/?198668>

The system is not good enough at spotting trends in practice and outcomes that give rise to safety concerns. Listening to patients is pivotal to that.

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page ii
<http://pexlib.net/?223550>

We must acknowledge that the response to these issues from those in positions of authority has not always been good enough. Sometimes the reaction has felt too focussed on defending the status quo, rather than addressing the needs of patients and, as a result, patients and their families have spent too long feeling that they were not being listened to...

Secretary of State for Health's statement to the House of Commons, 21st February 2018.
<https://hansard.parliament.uk/commons/2018-02-21/debates>

It became all too clear that those who have been affected have been dismissed, overlooked, and ignored for far too long. The issue here is not one of a single or a few rogue medical practitioners, or differences in regional practice. It is system-wide.

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page 3
<http://pexlib.net/?223550>

We heard about the failure of the system to acknowledge when things go wrong for fear of blame and litigation. There is an institutional and professional resistance to changing practice even in the face of mounting safety concerns. There can be a culture of dismissive and arrogant attitudes that only serve to intimidate and confuse. For women there is an added dimension - the widespread and wholly unacceptable labelling of so many symptoms as "normal" and attributable to "women's problems".

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page 7
<http://pexlib.net/?223550>

Patients often know when something has gone wrong with their treatment. All too often they are the first to know. Their experience must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine.

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page 10
<http://pexlib.net/?223550>

...there is one simple core theme that runs through all of this, and it goes to the heart of our work on patient safety. It comprises just two words: listening and humility. So much of the frustration and anger from patients and families stem from what they see as an unwillingness to listen

Statement to the House of Commons by Nadine Dorries MP, Minister for Patient Safety, Mental Health and Suicide Prevention. July 9th 2020. Hansard Vol. 678, Column 1147.

<https://hansard.parliament.uk/commons/2020-07-09/debates/5190E4DD-1319-4187-B1A2-13E9ACC3098D/Indepe...>

Elizabeth Dixon... was let down by every organisation that should have cared for her, and at every stage of her short life there were failures to avert its sad course. Following her death, her parents were met with indifference, rejection and outright deception instead of openness and honesty. It is vital that what happened acts as a catalyst for the significant changes that are necessary to ensure that this does not happen again.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 1

<http://pexlib.net/?227756>

Following any death, particularly under such harrowing and worrying circumstances as Elizabeth's, the very least that a bereaved family deserves is a truthful and complete account of what happened and why. This was denied to the Dixon family from the outset, a situation that unforgivably has been allowed to fester for almost twenty years. With full knowledge of events that none of the later investigations managed to uncover, it is manifestly obvious that concealment of what happened began on the day of Elizabeth's death, and has continued ever since. That a cover up so rapidly and simply instigated could be so influential and persistent has significant implications for all of us, and for how public services react when things go wrong.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 13

<http://pexlib.net/?227756>

...it is inescapably clear that some individuals have consistently concealed the truth and fabricated alternatives. This was fundamental to the cover up in the first few months, but it has been sustained since, including in written statements and in evidence.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 13

<http://pexlib.net/?227756>

The initial spark which kindled what became a twenty year cover up was the deep and widespread reluctance of clinicians to admit that something had gone very badly wrong with Elizabeth's care.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 17

<http://pexlib.net/?227756>

Almost all PALSs who participated in the study did not have clear policies or guidance within their trusts defining the scope of their role and responsibilities of the team. As a result, a majority of PALS staff questioned their individual role and wished for some written guidelines.

Shepard, K. et al. 2021. How do National Health Service (NHS) organisations respond to patient concerns? A qualitative interview study of the Patient Advice and Liaison Service (PALS) BMJ Open 2021

<https://pexlib.net/?236980>

The Trust not only failed in its duty to provide safe and effective services, it concealed this from external bodies. Both patients and staff suffered harm for too long as a result.

Report of the Liverpool Community Health Independent Review Dr Bill Kirkup CBE January 2018 Page 7

<https://pexlib.net/?237017>

The incidence of patient harm incidents subject to mandatory reporting nationally rose, including pressure ulcers and falls. Other incidents, some serious, should also have been reported and investigated, but we heard repeated accounts that reporting was discouraged, investigation was poor, incidents were regularly downgraded in importance, and action planning for improvement was absent or invisible.

Report of the Liverpool Community Health Independent Review Dr Bill Kirkup CBE January 2018 Page 5

<https://pexlib.net/?237017>

The sense of constant demands from above, including from politicians, creates an institutional instinct, particularly in the healthcare sector, to look upwards to furnish the needs of the hierarchy rather than downwards to the needs of the service-user. These pressures inevitably have an impact on behaviours in the workplace, and we have encountered too many reports to ignore of poor behavioural cultures and incidences of discrimination, bullying, blame cultures and responsibility avoidance. We experienced very little dissent on this characterisation

Department of Health and Social Care, June 2022. Leadership for a collaborative and inclusive future. The Messenger review.

<https://pexlib.net/?237026>

Equality and inclusion

Some groups may have good reason to feel distrustful of the health and social care system and be inherently concerned that data about them could be used to target or discriminate against them

Understanding Patient Data, 2019. Understanding public expectations of the use of health and care data. Page2.

<http://pexlib.net/?198376>

Despite efforts on multiple fronts, substantial morbidity and mortality differences persist between white and black patients, regardless of their socioeconomic status and level of education.

Drybye, L. et al. 2019. Association of Racial Bias With Burnout Among Resident Physicians. JAMA Network Open. 2019;2(7):e197457. doi:10.1001

<http://pexlib.net/?201189>

...physicians with higher implicit bias toward black people demonstrate fewer patient-centered behaviors during clinical interactions with black patients; in turn, their black patients have greater distrust, have lower level of adherence to treatment recommendations, and are less likely to follow up

Drybye, L. et al. 2019. Association of Racial Bias With Burnout Among Resident Physicians. JAMA Network Open. 2019;2(7):e197457. doi:10.1001

<http://pexlib.net/?201189>

For many of the rarer neurological conditions - which we estimate represent over 150,000 neurological cases - there is little or no data collected at all, meaning this group of patients is virtually invisible to the health system.

Neurological Alliance, 2019. Neuro Numbers 2019. Page 3.

<http://pexlib.net/?192134>

...the broader research mandate about rare diseases must move beyond diagnostics and treatment to address the very real and pressing issues that arise from the patient - and by extension family - experience in navigating healthcare systems

Baumbusch et al, 2018. Alone in a Crowd? Parents of Children with Rare Diseases' Experiences of Navigating the Healthcare System.

<http://pexlib.net/?181286>

Patient experience surveys also find that patients from minority ethnic groups report more negative experiences, and this may be a contributing factor to differences in the satisfaction levels reported in the BSA survey

King's Fund and Nuffield Trust, 2018. Public satisfaction with the NHS and social care in 2017 Results and trends from the British Social Attitudes survey. Page 7.

<http://pexlib.net/?171668>

The Patient Experience Library

Quote Selector

...when BME staff thought their role makes a difference to patients, and when they were more able to contribute toward improvements at work, overall patient satisfaction was higher.

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 19.
<http://pexlib.net/?171667>

...the extent to which an organisation values its minority staff is a good barometer of how well patients are likely to feel cared for

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 7.
<http://pexlib.net/?171667>

...too many people have received no help at all, leading to hundreds of thousands of lives put on hold or ruined, and thousands of tragic and unnecessary deaths

The Five Year Forward View for Mental Health, 2016. Page 3.
<http://pexlib.net/?90084>

...many people... seeking support with one condition are also living with other conditions and too often experience siloed, condition-based, care and support. The point at which each person goes from one to many health conditions... seems to track issues of deprivation, culture, lifestyle and place.

Taskforce on Multiple Conditions, 2018. "Just one thing after another". Living with multiple conditions. Page 2.
<http://pexlib.net/?181797>

There is now clear evidence that The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2017 are deterring vulnerable groups from accessing NHS treatment, threatening public health, and taking vital clinical time away from patient care.

British Medical Association, 2019. Delayed, deterred, and distressed: The impact of NHS overseas charging regulations on patients and the doctors who care for them. Page 1.
<http://pexlib.net/?194115>

Too often medical professionals focus on sexual health rather than broader health needs and differences when supporting LGBT people.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.
<http://pexlib.net/?203433>

Too few health and social care providers are actively thinking about LGBT people when they plan their services.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.
<http://pexlib.net/?203433>

Senior leaders are not doing enough to ensure that LGBT-inclusion is hardwired into commissioning strategies. This problem filters all the way down to training, where medics of the future are not taught how to provide LGBT-inclusive treatment.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.

<http://pexlib.net/?203433>

Training currently sends the message that sexual orientation and gender identity are not relevant to providing 'person-centred care'.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.

<http://pexlib.net/?203433>

Too often medical professionals focus on sexual health rather than broader health needs and differences when supporting LGBT people.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.

<http://pexlib.net/?210883>

We have found that too few health and social care providers are actively thinking about LGBT people when they plan their services and that senior leaders are not doing enough to ensure that LGBT-inclusion is hardwired into commissioning strategies. This problem filters all the way down to training, where medics of the future are not taught how to provide LGBT-inclusive treatment.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.

<http://pexlib.net/?203433>

Very few documents stated any meaningful detail about who was to be involved, for example by offering data about the local community or demographic information about the patient population across services. This was especially concerning when considering issues of inclusivity, equity and equality.

Matthews, R. et al., 2019. How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

<http://pexlib.net/?207501>

Evidence suggests more assertive patients gain access to services in primary care, but in mental health services, assertiveness can hinder access to services with participants being seen as difficult.

Berzins, K. et al., 2019. A qualitative exploration of mental health service user and carer perspectives on safety issues in UK mental health services. Health Expectations, 2020, 00:1 1-12.

<http://pexlib.net/?210639>

In other care settings, patients have the right to choose between care providers and can avoid certain individuals or services. For mental health service users however, this autonomy often cannot be exercised due to lack of treatment providers and threat of compulsory treatment.

Berzins, K. et al., 2019. A qualitative exploration of mental health service user and carer perspectives on safety issues in UK mental health services. *Health Expectations*, 2020, 00:1 1-12.

<http://pexlib.net/?210639>

A tension emerges between public involvement premised on broadbased representation of an entire public (whether "citizens", "potential patients", "local community" or "users of a service") and one which draws on the knowledge of a select few within it.

Martin, G. 2007. "Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health*

<http://pexlib.net/?176250>

Through a combination of self-selection by those wishing to be involved and selection of the kind of people by those managing the process, public-participation initiatives are seen to represent some subgroups of the public better than others.

Martin, G. 2007. "Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health*

<http://pexlib.net/?176250>

There is no fundamental reason why the descriptive representation of shared characteristics, such as ethnicity or class... should translate into accurate representation on the level of expressed opinions. Efforts to ensure inclusion of groups defined by particular demographic characteristics prioritise these assumed bonds over other, less socially prominent, boundaries of commonality and difference, with potentially insidious effects.

Martin, G. 2007. "Ordinary people only": knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health*

<http://pexlib.net/?176250>

Inequalities in maternal and neonatal outcomes have been well documented for many years, but we heard that there has been little progress in closing the gap. A recent report by the Joint Committee on Human Rights concluded that 'the NHS acknowledge and regret this disparity but have no target to end it'.

House of Commons Health and Social Care Committee, 2021. The safety of maternity services in England. Fourth Report of Session 2021-22. Page 34

<https://pexlib.net/?231192>

Investigations

...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

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

<https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/patient-safety-strategy/us...>

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.

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

<http://pexlib.net/?133751>

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.

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

<http://pexlib.net/?133751>

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.

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

<http://pexlib.net/?133751>

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.

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

<http://pexlib.net/?133751>

[There is] evidence of poor quality serious incident investigations at a local level - The patient and family were only involved in 40% of investigations.

NHS Resolution, September 2017. Five years of cerebral palsy claims. A thematic review of NHS Resolution data. Page 9.

<http://pexlib.net/?163547>

...an ad hoc and inadequate approach to involving families and carers in investigations

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.

<http://pexlib.net/?80610>

...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

Royal College of Obstetricians and Gynaecologists, June 2016. Each Baby Counts. Key messages from 2015. Page 16.

<http://pexlib.net/?113312>

...local NHS investigation processes were not fit for purpose... and they excluded the family

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.

<http://pexlib.net/?118564>

Women repeatedly stated they were not listened to and their concerns were not taken seriously or valued... they were ignored or patronised, and no action was taken, with tragic outcomes including stillbirth and neonatal death of their babies.

Broderick, C. 2019. Listening to women and families about Maternity Care in Cwm Taf. Page 6.

<http://pexlib.net/?194265>

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.

Parliamentary and Health Service Ombudsman 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 17.

<http://pexlib.net/?171057>

...local NHS investigation processes were not fit for purpose, they were not sufficiently independent, inquisitive, open or transparent, properly focused on learning, or able to span organisational and hierarchical barriers, and they excluded the family and junior staff in the process

Parliamentary and Health Service Ombudsman, 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.

<http://pexlib.net/?118564>

Patients were further let down when they complained to regulators and believed themselves frequently treated with disdain.

Report of the Independent Inquiry into the Issues raised by Paterson. 2020. Page 2.

<http://pexlib.net/?210376>

This report is primarily about poor behaviour and a culture of avoidance and denial.

Report of the Independent Inquiry into the Issues raised by Paterson. 2020. Page 1.

<http://pexlib.net/?210376>

Following any death, particularly under such harrowing and worrying circumstances as Elizabeth's, the very least that a bereaved family deserves is a truthful and complete account of what happened and why. This was denied to the Dixon family from the outset, a situation that unforgivably has been allowed to fester for almost twenty years. With full knowledge of events that none of the later investigations managed to uncover, it is manifestly obvious that concealment of what happened began on the day of Elizabeth's death, and has continued ever since. That a cover up so rapidly and simply instigated could be so influential and persistent has significant implications for all of us, and for how public services react when things go wrong.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 13

<http://pexlib.net/?227756>

...it was very clear that something had gone badly amiss with Elizabeth's care. It is profoundly unsatisfactory that this remained unexplored and inadequately investigated from the outset, by the coronial service, the health authority, and the private healthcare provider. This may have appeared at first to be simply a startling lack of curiosity, but it clearly progressed to the point that facts were wilfully ignored and alternatives fabricated. That this resulted in a cover up of significant facts that stood for so long is greatly disturbing.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 16

<http://pexlib.net/?227756>

Having listened to families we state that there must be an end to investigations, reviews and reports that do not lead to lasting meaningful change.

Ockenden Report, 2020. Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page 2.

<http://pexlib.net/?228088>

Involving families in a compassionate manner is a crucial part of the investigation process. Too often, maternity investigations have failed to do this in a meaningful way. Families must be confident that their voices are heard and that lessons have been learnt

House of Commons Health and Social Care Committee, 2021. The safety of maternity services in England. Fourth Report of Session 2021-22. Page 21

<https://pexlib.net/?231192>

The review team found evidence of poor investigation... as well as a lack of transparency and dialogue with families. This resulted in missed opportunities for learning, and a lost opportunity to prevent further baby deaths from occurring at the Trust.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page ix

<https://pexlib.net/?235216>

The Patient Experience Library

Quote Selector

...internal investigations frequently did not, recognise system and service-wide failings to follow appropriate procedures and guidance... and in some incidents women themselves were also held responsible for the outcomes.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page ix

<https://pexlib.net/?235216>

...the maternity governance team inappropriately downgraded serious incidents to a local investigation methodology in order to avoid external scrutiny, so that the true scale of serious incidents at the Trust went unknown until this review was undertaken.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page xi

<https://pexlib.net/?235216>

It took numerous investigations, inspections and inquests before the Trust started making measurable improvements, and this began only after it was merged with another Trust under new leadership. We found the Trust failed to investigate one of the deaths adequately, and this was a breach of human rights. This tells a story of the complex and difficult journey the families had to endure to get answers about what happened to their loved ones.

Parliamentary and Health Service Ombudsman, April 2022. Written evidence from the Parliamentary and Health Service Ombudsman to the Joint Committee on Human Rightsâ€™ inquiry on Protecting Human Rights in Care Settings.

<https://pexlib.net/?236332>

Serious incidents causing patient harm were not reported, not investigated and lessons not learned. The result was unnecessary harm to patients.

Report of the Liverpool Community Health Independent Review Dr Bill Kirkup CBE January 2018 Page 7

<https://pexlib.net/?237017>

The incidence of patient harm incidents subject to mandatory reporting nationally rose, including pressure ulcers and falls. Other incidents, some serious, should also have been reported and investigated, but we heard repeated accounts that reporting was discouraged, investigation was poor, incidents were regularly downgraded in importance, and action planning for improvement was absent or invisible.

Report of the Liverpool Community Health Independent Review Dr Bill Kirkup CBE January 2018

<https://pexlib.net/?237017>

Where things went wrong, clinical staff, managers and senior managers often failed to communicate openly with families about what had happened. Safety investigations were often conducted narrowly and defensively, if at all, and not in a way designed to achieve learning. The instinct was to minimise what had happened and to provide false reassurance, rather than to acknowledge errors openly and to learn from them.

Reading the signals. Maternity and neonatal services in East Kent - the Report of the Independent Investigation. October 2022. Page 6

<https://pexlib.net/?237419>

Learning from deaths

...the story it tells is first and foremost of appalling suffering of many patients. This was primarily caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients.

Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry House of Commons, 2013. Executive Summary, Page 3.

<http://pexlib.net/?195069>

...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

Care Quality Commission, December 2016. Learning, Candour and Accountability. Page 4.

<http://pexlib.net/?133751>

It is vital that the lessons, now plain to see, are learnt and acted upon, not least by other Trusts, which must not believe that "it could not happen here". If those lessons are not acted upon, we are destined sooner or later to add again to the roll of names.

Dr Bill Kirkup CBE, March 2015. The Report of the Morecambe Bay Investigation. Page 5.

<http://pexlib.net/?10203>

We owe it to [bereaved families] to stop talking about learning lessons, to move beyond writing action plans, and to actually make change happen.

Care Quality Commission, December 2016. Learning, Candour and Accountability. Page 4.

<http://pexlib.net/?133751>

...an underlying institutionalised reluctance to admit major shortcomings

The Inquiry into Hyponatraemia-related Deaths, 2018. Page 111.

<http://pexlib.net/?171239>

...there was no acknowledgement of any of the very many failings in care.

The Inquiry into Hyponatraemia-related Deaths, 2018. Page 210.

<http://pexlib.net/?171239>

...defensiveness, deceit and a strong inclination... to close ranks.

The Inquiry into Hyponatraemia-related Deaths, 2018. Page 119.

<http://pexlib.net/?171239>

I am compelled to the view that clinicians did not admit to error for the obvious reasons of self-protection and that this defensiveness amounted to concealment and deceit.

The Inquiry into Hyponatraemia-related Deaths, 2018. Page 222.

<http://pexlib.net/?171239>

...most of the NHS organisations which dealt with Mr Hart's complaint failed to respond to his concerns in a sensitive, transparent and helpful way.

Parliamentary and Health Service Ombudsman, 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 4.
<http://pexlib.net/?171057>

The responses to Mr Hart's requests for information were delayed and appeared evasive, and information he requested was often not provided. The responses to his complaints were equally unsatisfactory, and often appeared defensive or protective of the organisation concerned.

Parliamentary and Health Service Ombudsman, 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 11.
<http://pexlib.net/?171057>

...a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection.

Parliamentary and Health Service Ombudsman, 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 11.
<http://pexlib.net/?171057>

The death of Averil Hart was an avoidable tragedy. Every NHS organisation involved in her care missed significant opportunities to prevent the tragedy unfolding at every stage of her illness from August 2012 to her death on 15 December 2012. The subsequent responses to Averil's family were inadequate and served only to compound their distress. The NHS must learn from these events, for the sake of future patients.

Parliamentary and Health Service Ombudsman, 2017. Ignoring the alarms: How NHS eating disorder services are failing patients. Page 12.
<http://pexlib.net/?171057>

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.

Care Quality Commission, 2019. Learning from deaths. A review of the first year of NHS trusts implementing the national guidance. Page 4.
<http://pexlib.net/?192501>

This Report details... avoidable harm to mothers and babies, including tragic and unnecessary deaths. What followed was a pattern of failure to recognise the nature and severity of the problem, with, in some cases, denial that any problem existed, and a series of missed opportunities to intervene that involved almost every level of the NHS.

Dr Bill Kirkup CBE, March 2015. The Report of the Morecambe Bay Investigation. Page 5.
<http://pexlib.net/?10203>

.....there has been a lack of leadership, focus and sufficient time spent on reporting and investigating unexpected deaths of Mental Health and Learning Disability service users at all levels of the Trust including at the Trust Board... There are a number of facets to this poor leadership [including] an ad hoc and inadequate approach to involving families and carers in investigations

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.

<http://pexlib.net/?80610>

Had the investigations been proper at the start, it would not have been necessary for the family to pursue a complaint. Rather, they would, and should, have been provided with clear and honest answers at the outset for the failures in care and would have been spared the hugely difficult process that they have gone through in order to obtain the answers they deserved.

Parliamentary and Health Service Ombudsman, 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.

<http://pexlib.net/?118564>

I was surprised at how difficult it was to persuade some witnesses to be open and frank with the work of the Inquiry. All too often, concessions and admissions were extracted only with disproportionate time and effort. The reticence of some clinicians and healthcare professionals to concede error or identify the underperformance of colleagues was frustrating and depressing, most especially for the families of the dead children.

The Inquiry into Hyponatraemia-related Deaths, 2018. Page 25.

<http://pexlib.net/?171239>

Over the many years during which the families have sought answers to their legitimate questions and concerns, they have been repeatedly frustrated by senior figures... The obfuscation by those in authority has often made the relatives of those who died angry and disillusioned... It further shatters your confidence when you summon up the courage to complain and then sense that you are being treated as some sort of troublemaker.

Gosport War Memorial Hospital. The Report of the Gosport Independent Panel, June 2018. Page vii.

<http://pexlib.net/?177680>

This report is...the story of a healthcare system which proved itself dysfunctional at almost every level when it came to keeping patients safe, and where those who were the victims of Paterson's malpractice were let down time and time again.

Report of the Independent Inquiry into the Issues raised by Paterson. February 2020. Page 1.

<http://pexlib.net/?210376>

There were failures of care by every organisation that looked after her, none of which was admitted at the time, nor properly investigated then or later. Instead, a cover up began on the day that she died, propped up by denial and deception, which has proved extremely hard to dislodge over the years. The fabrication became so embedded that it has taken a sustained effort, correlating documents from many sources and interviewing key participants, to demolish it. The most troubling aspect of compiling this report has been the clear evidence that some individuals have been persistently dishonest, both by omission and by commission, and that this extended to formal statements to police and regulatory bodies.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page vii

<http://pexlib.net/?227756>

Following any death, particularly under such harrowing and worrying circumstances as Elizabeth's, the very least that a bereaved family deserves is a truthful and complete account of what happened and why. This was denied to the Dixon family from the outset, a situation that unforgivably has been allowed to fester for almost twenty years. With full knowledge of events that none of the later investigations managed to uncover, it is manifestly obvious that concealment of what happened began on the day of Elizabeth's death, and has continued ever since. That a cover up so rapidly and simply instigated could be so influential and persistent has significant implications for all of us, and for how public services react when things go wrong.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 13

<http://pexlib.net/?227756>

As a result of the concealment of key facts about [Elizabeth's] death from the outset, her parents have been left for far too long without a complete, true account of what happened. This was a needless and cruel burden for a mother and father already grieving the loss of their child. It must not happen again.

Kirkup, B. November 2020. The Life and Death of Elizabeth Dixon: A Catalyst for Change. Report of the Independent Investigation. House of Commons HC 1025. Page 15

<http://pexlib.net/?227756>

...the litigation process is lengthy, adversarial and fails to address the wider emotional and psychological needs of patients and families. The approach to clinical negligence in the United Kingdom has cultivated a culture of defensiveness and blame, preventing families getting the transparency and accountability they need and deserve.

House of Commons Health and Social Care Committee, 2021. The safety of maternity services in England. Fourth Report of Session 2021-22. Page 27

<https://pexlib.net/?231192>

...for far too long women and families who accessed maternity care at the Trust were denied the opportunity to voice their concerns about the quality of care they had received.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page ii

<https://pexlib.net/?235216>

So many families have explained to me that for more than two decades they have tried to raise concerns but were brushed aside, ignored and not listened to.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page iii

<https://pexlib.net/?235216>

Never again should families be left to grieve or suffer in isolation, with the additional pain of feeling their legitimate concerns are being ignored.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page iii

<https://pexlib.net/?235216>

In the final weeks leading up to publication of the report, a number of staff withdrew their cooperation from the report and therefore their content (or 'voice') was lost from the report. The main reason for withdrawing from the report as cited by staff was fear of being identified.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page viii

<https://pexlib.net/?235216>

...for far too long women and families who accessed maternity care at the Trust were denied the opportunity to voice their concerns about the quality of care they had received

Ockenden Report - Final Findings, Conclusions And Essential Actions from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust. March 2022. Page ii.

<https://pexlib.net/?235216>

So many families have explained to me that for more than two decades they have tried to raise concerns but were brushed aside, ignored and not listened to.

Ockenden Report - Final Findings, Conclusions And Essential Actions from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust. March 2022. Page iii.

<https://pexlib.net/?235216>

Never again should families be left to grieve or suffer in isolation, with the additional pain of feeling their legitimate concerns are being ignored.

Ockenden Report - Final Findings, Conclusions And Essential Actions from the Independent Review of Maternity Services at The Shrewsbury and Telford Hospital NHS Trust. March 2022. Page iii.

<https://pexlib.net/?235216>

It took numerous investigations, inspections and inquests before the Trust started making measurable improvements, and this began only after it was merged with another Trust under new leadership. We found the Trust failed to investigate one of the deaths adequately, and this was a breach of human rights. This tells a story of the complex and difficult journey the families had to endure to get answers about what happened to their loved ones.

Parliamentary and Health Service Ombudsman, April 2022. Written evidence from the Parliamentary and Health Service Ombudsman to the Joint Committee on Human Rights's inquiry on Protecting Human Rights in Care Settings.

<https://pexlib.net/?236332>

Where issues have been brought into public focus by the efforts of families or through the media, too often the Trust has focused on reputation management, reducing liability through litigation and a 'them and us' approach. Again, this has got in the way of patient safety and learning.

Reading the signals. Maternity and neonatal services in East Kent - the Report of the Independent Investigation. October 2022. Page 9

<https://pexlib.net/?237419>

The default response of almost every organisation subject to public scrutiny or criticism is to think first of managing its reputation... the experience of many NHS organisational failures shows that it is the whole basis of the response in many cases. Further, it has clearly led to denial, deflection, concealment and aggressive responses to challenge... Not only does this prevent learning and improvement, it is no way to treat families, who are heartlessly denied the truth about what has happened when something has obviously gone wrong, compounding the harm that they have already suffered.

Reading the signals. Maternity and neonatal services in East Kent - the Report of the Independent Investigation. October 2022. Page 162

<https://pexlib.net/?237419>

Failings in health and social care services are often reported first by patients and families. It has often been patients and families who have identified the issues and 'raised the red flag'.

RQIA, 2022. Report on the Expert Review of Records of Deceased Patients (Neurology). Page 2

<https://pexlib.net/?237907>

Making sense of patient experience evidence

Our scoping review identified 37 different types of PE feedback 'on offer' to staff within UK hospitals... within these types, there are currently no 'ready to use' data sets for informing and monitoring improvements to [patient experience], apart from mandated data relating to high level organizational trends.

Marsh, C. et al., 2019. Patient experience feedback in UK hospitals: What types are available and what are their potential roles in quality improvement (QI)? Wiley Health Expectations.

<http://pexlib.net/?198366>

Indeed, the distinction between different uses of data within improvement is not a new one and in 1997, "The 3 Faces of Performance Measurement" were outlined: data used for accountability (outcome measurements of interest to external parties, eg, funders and regulators), data for improvement process (detailed information to aid identification of problems, opportunities for change and monitoring of success) and data for research (generating universal knowledge)

Marsh, C. et al., 2019. Patient experience feedback in UK hospitals: What types are available and what are their potential roles in quality improvement (QI)? Wiley Health Expectations.

<http://pexlib.net/?198366>

...quantitative surveys [are] the most frequently collected type of patient experience data (often mandated) but the least acceptable to healthcare teams with respect to use within quality improvement". On the other hand, there is "an apparent sense of nervousness amongst hospital teams surrounding the use of qualitative data as it is regarded as time-consuming to collect and difficult to interpret without bias".

Marsh, C. et al., 2019. Patient experience feedback in UK hospitals: What types are available and what are their potential roles in quality improvement (QI)? Wiley Health Expectations.

<http://pexlib.net/?198366>

If feedback is to be used more frequently within quality improvement, more attention must be paid to obtaining and making available the most appropriate types.

Marsh, C. et al., 2019. Patient experience feedback in UK hospitals: What types are available and what are their potential roles in quality improvement (QI)? Wiley Health Expectations.

<http://pexlib.net/?198366>

Patient feedback is a potentially useful source of information which could be used to drive improvement [however] enthusiasm for its collection is not quite matched by the capacity to turn data into insight... the eagerness for collecting [data] dissipates into confusion as busy staff struggle to transform reams of patient comments into useful information. The inevitable result is that, despite the best efforts of staff, information which patients share in good faith is wasted.

Gibbons, C., Greaves, F., 2017. Lending a hand: could machine learning help hospital staff make better use of patient feedback? BMJ Quality and Safety.

<http://pexlib.net/?168288>

- Previous research has highlighted the disconnect between the collection of patient feedback, a relatively straightforward endeavour and its subsequent use to drive improvement activity - a far more elusive task
Gibbons, C., Greaves, F., 2017. Lending a hand: could machine learning help hospital staff make better use of patient feedback? BMJ Quality and Safety.
<http://pexlib.net/?168288>
- Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it... In order for patient-reported feedback to be an effective improvement tool, and avoid the ethical grey zone around soliciting patient input and not acting on it, feedback programs need to make efforts to facilitate data comprehension and use.
Flott, K. et al., 2018. Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study. Journal of Medical Internet Research Volume 20, Issue 4
<http://pexlib.net/?174569>
- The value of data for organizational quality improvement is not commensurate to the volume of data the system supplies. This misalignment is... in many ways, the consequence of national survey programs being set up to satisfy a national agenda rather than being designed with respect to local circumstances.
Flott, K. et al., 2018. Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study. Journal of Medical Internet Research Volume 20, Issue 4
<http://pexlib.net/?174569>
- ...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.
Flott, K. et al., 2018. Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study. Journal of Medical Internet Research Volume 20, Issue 4
<http://pexlib.net/?174569>
- The paradigm regarding patient experience feedback is heavily rooted in large national initiatives... which are accompanied by a sluggish bureaucracy and political concerns. It is likely that these initiatives are neither capturing, nor producing, what is most useful to the organizations trying to use patient feedback to improve care.
Flott, K. et al., 2018. Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study. Journal of Medical Internet Research Volume 20, Issue 4
<http://pexlib.net/?174569>
- Considering the data set as a whole, possibly 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.
Sheard, L. et al., 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study. Wiley Health Expectations.
<http://pexlib.net/?181784>

The Patient Experience Library

Quote Selector

...only around one-quarter [of patient experience leads] were able to collect, analyse and use patient experience data in inpatient settings to support change.

University of Birmingham, October 2019. Evaluating the Use of Patient Experience Data to Improve the Quality of Inpatient Mental Health Care (Euripides).

<http://pexlib.net/?201827>

...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 Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

...you're flying blind with your service and you're just picking out bits of data from everywhere

MES and InHealth Associates, June 2015. Making Sense and Making Use of Patient Experience Data. Page 15.

<http://pexlib.net/?49012>

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

MES and InHealth Associates, June 2015. Making Sense and Making Use of Patient Experience Data. Page 15.

<http://pexlib.net/?49012>

...staff find interpretation of [patient experience] data sets difficult or impossible... but there was no strategy in place or forthcoming at any of the three organizations we studied to address this issue

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

...timeliness was seen as one of the main concerns with it being difficult to engage ward staff with data that are not real time. A specific example of this is the NHS Inpatient Survey where patient feedback is viewed months after it has been collected

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

Despite many countries employing the use of national and large scale regional surveys to explore women's experiences of their maternity care, with the results informing national maternity policy and practice, the concept itself is ambiguous and ill-defined having not been subject of a structured concept development endeavour.

Beecher, C. et al., 2019. Women's experiences of their maternity care: A principle- based concept analysis. Women and Birth.

<http://pexlib.net/?207968>

“ We found that meaningful and sustained change occurred only when patient experience feedback was analysed alongside other performance data. In almost all case sites, different types of data were being held in silos. The triangulation of patient experience feedback with other data such as patient safety data, clinical outcomes data and complaints helped staff to spot trends or hotspots. Cause-and-effect relationships as regards serious incidents were much easier to link, and staff were more engaged in using data to understand and innovate within their services.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 74

<http://pexlib.net/?216782>

“ Without the triangulation of data, quality improvement risks were being driven by targets alone. If a trust centralises its patient experience recording and reporting system and allows its quality improvement to be driven by external drivers, such as the CQC, complaints and serious incidents, staff disengage from collecting feedback and develop a siege mentality motivated by fear.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 74

<http://pexlib.net/?216782>

“services need more systematic ways of using learning from patient experience data to translate this intelligence into effective action plans

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 74

<http://pexlib.net/?216782>

“ NHS trusts are required to collect experience data from patients. Currently, there is little understanding of what data are most important, what processes are in place to collect them and whether such data make any difference to the quality of patient experience. There are no widely established principles of data collection and analysis, and there is variability in how such data are used to inform and improve services.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 89

<http://pexlib.net/?216782>

“ Moreover, there is no systematic nationwide policy in place or standard measure to collect people's experience of health care in the NHS. The methodologies used to aggregate patients' complaints are often inconsistent or do not aggregate data sufficiently to give optimal depth to complaints. Data thus remains at a raw and experimental level, unstandardized and difficult to compare.

Dalingwater, I. 2019. Right to Reply: Using Patient Complaints and Testimonials to Improve Performance in the NHS . Revue Française de Civilisation Britannique [Online], XXIV-3 DOI : 10.4000/rfcb.4422

<https://pexlib.net/?229105>

The Patient Experience Library

Quote Selector

Across our sample, participants emphasised the difficulties for senior managers and leaders of forming an accurate picture of the quality of care delivered at the sharp end... participants recognized that well intentioned efforts to expand metrics of quality could be counterproductive

Martin, G. et al. July 2015. Beyond metrics? Utilizing 'soft intelligence' for healthcare quality and safety.






<https://pexlib.net/?177154>

Generally, the inability of the systems then in place to identify a pattern of concern was a conspicuous problem. Information was essentially retained in silos.

Independent Neurology Inquiry, June 2022. Page 9.

<https://pexlib.net/?236098>

Making use of patient experience evidence

-  The most commonly cited barrier to using patient experience data was a lack of staff time to examine the data (75%), followed by cost (35%), lack of staff interest/support (21%) and too many data (21%).
Locock L, Graham C, King J, Parkin S, Chisholm A, Montgomery C, et al. Understanding how front-line staff use patient experience data for service improvement: an exploratory case study evaluation. *Health Serv Deliv Res* 2020;8(13). Page vii.
<http://pexlib.net/?211161>
-  The importance of listening and responding to the voices of patients and carers as a means of supporting high quality and safe care in hospital settings has been strongly advocated. The use of patient experience (PE) feedback as a data tool within quality improvement (QI) is a seemingly logical step as evidenced by a systematic review into how different types of feedback have been used in QI, and a more discursive piece on PE feedback as measurement data. Both reveal an immature field of study providing more questions than answers, relating to what feedback to collect, and how and when, and then how to use feedback to inform and measure QI. This lack of certainty has not prevented its collection: we know that much feedback is collected but is not used.
Marsh, C. et al., 2019. Patient experience feedback in UK hospitals: What types are available and what are their potential roles in quality improvement (QI)? *Wiley Health Expectations*.
<http://pexlib.net/?198366>
-  For patient experience processes to be cost-effective for NHS providers, they need to find ways of collecting and analysing patient experience feedback and then using it to drive change
University of Birmingham 2019. Evaluating the Use of Patient Experience Data to Improve the Quality of Inpatient Mental Health Care (EURIPIDES)
<http://pexlib.net/?201827>
-  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
Sheard L, et al, 2018. 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
<http://pexlib.net/?181784>
-  In the NHS, patient experience and satisfaction is recorded in primary care using the General Practice Patient Survey (GPPS) and the Friends and Family Test (FFT). However, the FFT has been criticised for its invitation and response biases, and because it has resulted in a significant amount of staff time spent collecting, collating and reporting on the data, rather than devoting this time to quality improvement.
Boylan, A. et al 2020. Online patient feedback as a measure of quality in primary care: a multimethod study using correlation and qualitative analysis. *BMJ Open* 2020;10:e031820.
<https://bmjopen.bmj.com/content/bmjopen/10/2/e031820.full.pdf>

Boards spend substantial amounts of time reviewing patient satisfaction, listening to patients' stories and discussing quality and safety. But, despite the discussion of the survey results, none of the managers and none of the trust's directors we interviewed explicitly stated in interview that the board itself used feedback as assurance. None of the minutes of board meetings and nobody who spoke at board meetings explicitly stated that patient feedback provided assurance of the quality of care. The discussion at board meetings about patient surveys did not translate into explicit statements of assurance about quality.

Lee R, et al, 2017. The use of patient feedback by hospital boards of directors: a qualitative study of two NHS hospitals in England BMJ Qual Saf. doi: 10.1136/bmjqs-2016-006312 Pages 1 and 4.

<http://pexlib.net/?160166>

Patients are increasingly being asked for feedback about their healthcare experiences. However, healthcare staff often find it difficult to act on this feedback in order to make improvements to services.

Sheard et al, 2017. The Patient Feedback Response Framework - Understanding why UK hospital staff find it difficult to make improvements based on patient feedback: A qualitative study. Social Science and Medicine Journal.

<http://pexlib.net/?156183>

...teams, whilst on the surface seemingly engaged in the moral imperative to respond to patient feedback, often discussed the report in a 'clinician knows best' manner. For both teams, responses to the patient data were firmly entrenched in a rhetoric of 'managing patient expectations' rather than seeking to tackle the underlying issue at hand which patients had raised.

Lee R, et al, 2017. The use of patient feedback by hospital boards of directors: a qualitative study of two NHS hospitals in England BMJ Qual Saf. doi: 10.1136/bmjqs-2016-006312

<http://pexlib.net/?160166>

...in an effort to do something rather than nothing, [patient experience staff] reach for simple and inexpensive responses.

Liu JJ, Rotteau L, Bell CM, et al. 2019. BMJ Qual Saf doi:10.1136/

<http://pexlib.net/?197011>

...surveys are a valuable resource for monitoring national trends in quality of care. However, surveys may be insufficient in themselves to fully capture patient feedback, and in practice GPs rarely used the results of surveys for quality improvement.

Burt J et al, 2017. Improving patient experience in primary care: a multimethod programme of research on the measurement and improvement of patient experience. Programme Grants Appl Res 2017; 5(9). Page vii.

<http://pexlib.net/?157550>

While the GP Patient Survey data for any given practice is used as part of its CQC inspection record, there is no standard requirement for practices to review that data or act upon them. As a result there are wide variations in the use of the data and the value that can be derived from them.

<https://www.dc.nihr.ac.uk/highlights/patient-experience/using-survey-data-to-improve-patient-experie...>

...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...

Flott K, et al, 2018. Improving the Usefulness and Use of Patient Survey Programs: National Health Service Interview Study J Med Internet Res 2018; 20(4):e141

<http://pexlib.net/?174569>

...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

Sheard L, et al, 2018. 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

<http://pexlib.net/?181784>

Staff and patient experience teams are sometimes so busy gathering data and compiling reports, that less time is available to do something with the data - efforts to improve services are in danger of being squeezed out

MES and InHealth Associates, June 2015. Making Sense and Making Use of Patient Experience Data. Page 15.

<http://pexlib.net/?49012>

The use of health care complaints to improve quality and safety has been limited by a lack of reliable analysis tools and uncertainty about the insights that can be obtained.

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). Page 530.

<http://pexlib.net/?182740>

All feedback collected ideally needs to have the ability to be meaningfully used by those providing frontline care. Otherwise, it becomes unethical to ask patients to provide feedback which will never be taken into account.

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

...timeliness was seen as one of the main concerns with it being difficult to engage ward staff with data that are not real time. A specific example of this is the NHS Inpatient Survey where patient feedback is viewed months after it has been collected

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

💬 Patient experience was sometimes said to be the poor relation of patient safety and finance with a lesser emphasis and priority placed on it

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

💬 Patients are increasingly being asked for feedback about their healthcare experiences. However, healthcare staff often find it difficult to act on this feedback in order to make improvements to services.

Sheard et al, 2017. The Patient Feedback Response Framework - Understanding why UK hospital staff find it difficult to make improvements based on patient feedback: A qualitative study.

<http://pexlib.net/?156183>

💬 Simply providing hospitals with patient feedback does not automatically have a positive effect on quality standards.

Sheard et al, 2017. The Patient Feedback Response Framework - Understanding why UK hospital staff find it difficult to make improvements based on patient feedback: A qualitative study.

<http://pexlib.net/?156183>

💬 ...there is currently a huge gap between the upstream measurement of patient experience, which is increasingly sophisticated and insightful, and the downstream actions being taken as a result.

Burt, J. 2017. What should we do about patient experience in primary care? Cambridge Centre for Health Services research online article.

<https://www.cchsr.iph.cam.ac.uk/2985>

💬 ...the major question for the future is how we are going to take the wealth of data on patient experience and make experiences better, rather than simply better understood

Burt, J. 2017. What should we do about patient experience in primary care? Cambridge Centre for Health Services research online article.

<https://www.cchsr.iph.cam.ac.uk/2985>

💬 ...senior hospital managers recognise the potential value of so-called 'soft intelligence', but struggle to work out 'how to process such a detailed, frustrating, rich, and irreducibly complex resource'

Locock, L. et al, 2020. Anonymity, veracity and power in online patient feedback : A quantitative and qualitative analysis of staff responses to patient comments on the 'Care Opinion' platform in Scotland. Digital Health Volume 6: 1-13.

<http://pexlib.net/?210200>

💬 Online patient feedback was found to express the extremes of experience, the very positive and the very negative, as demonstrated by the U-shaped distribution of the frequencies of different ratings (figure 4). The majority of the ratings were positive with few middle-ground experiences being reported. This also suggests that it is not appropriate to take an arithmetic average (mean) score from these data, given the skewed distribution towards each end of the spectrum.

Boylan, A. et al 2020. Online patient feedback as a measure of quality in primary care: a multimethod study using correlation and

qualitative analysis. BMJ Open 2020;10:e031820.

<https://bmjopen.bmj.com/content/bmjopen/10/2/e031820.full.pdf>

☞ All the [data] we collect feels like a huge task and nothing happens to it... we're told we have to collect it, but [we're] not aware that it goes anywhere else.

Al-Zaidy, S., et al., 2019. Briefing: The Measurement Maze. Health Foundation.

<http://pexlib.net/?207753>

☞ Any approach to enabling greater use of data for local improvement will need to consider the lack of analytical capacity within NHS organisations.

Al-Zaidy, S., et al., 2019. Briefing: The Measurement Maze. Health Foundation.

<http://pexlib.net/?207753>

☞ ...existing health care quality frameworks do not cover all aspects that patients want to feedback and... procedure-driven, standardised approaches such as surveys and checklists are too narrow.

NIHR, 2019. Themed review: Improving care by using patient feedback.

<http://pexlib.net/?209510>

☞ In general, only sanctioned channels get monitored and responded to with feedback from other channels ignored.

NIHR, 2019. Themed review: Improving care by using patient feedback.

<http://pexlib.net/?209510>

☞ ...the purpose of providing feedback was not clear to most patients. The lack of organisational response to their survey feedback meant they perceived it as a "tick box exercise" and they thought that their comments would not be used.

NIHR, 2019. Themed review: Improving care by using patient feedback.

<http://pexlib.net/?209510>

☞ Patients, carers and staff said that feedback was valuable and important in relation to trying to improve services. Experiences from patients, carers and staff were valued. However, our data suggest that positive feedback was not used constructively in inpatient mental health services.

Weich S, Fenton S-J, Staniszevska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 60

<http://pexlib.net/?216782>

☞positive feedback was often treated in an (unintentionally) dismissive way by staff. Positive feedback really existed only in the informal sphere and was not fed into formal processes for patient experience data collection or analysis. In some cases, positive comments were recorded in patient records. Change was driven across the six sites largely by complaints or crisis, rather than by experiences of competent care.

Weich S, Fenton S-J, Staniszevska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 61

The Patient Experience Library

Quote Selector

<http://pexlib.net/?216782>

Much of the data from staff related to the relationship between corporate and clinical staff and who owned and was empowered to use patient experience data. There was a lack of connection between data collected on wards and their use by wards in the majority of the case sites. The analysis of the data collected was not received by wards in a timely way

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 63

<http://pexlib.net/?216782>

Ratings-based patient experience feedback (such as the FFT) offers little useful information to trusts on why or what elements of service are working or not. This means that wards cannot plan actions or improve quality based on these data alone.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 72

<http://pexlib.net/?216782>

Almost all sites had some sort of display for patient experience feedback (e.g. You said, We did boards or posters). These were frequently suboptimally implemented (e.g. placed in inaccessible locations or not updated) and served little use.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 92

<http://pexlib.net/?216782>

.....patient experience work was universally regarded as a positive influence but was rarely embedded in the core business of mental health trusts...We found that most trusts collect patient experience data (albeit in varying ways and at different intervals across wards), but few analyse or use it


Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 106

<http://pexlib.net/?216782>

.....ward staff (who rarely see the results of feedback, let alone actions that might arise from its use) often perceived patient experience data as serving corporate purposes (e.g. the obligation to report these data outside the organisation) rather than as leading to service improvement.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 107

<http://pexlib.net/?216782>

 Patient feedback data, despite vast amounts of data collection, have arguably had little impact on improving services. Barriers include patient feedback lacking legitimacy, organisational inertia, unclear pathways, defensiveness to critical feedback and lack of established procedures for analysing unstructured textual feedback.

Gillespie A, Reader TW, 2020, Identifying and encouraging high quality healthcare: an analysis of the content and aims of patient letters of compliment. BMJ Qual Saf 2020

<http://pexlib.net/?226307>

Motivations for feedback and involvement

☞ The seven identified motivations that explain 65% of the total variance in engagement were named: Self-fulfillment, Improving Healthcare, Compensation, Influence, Learning New Things, Conditional and Perks. McCarron, T. et al. 2019. Understanding the motivations of patients: A co-designed project to understand the factors behind patient engagement. Health Expectations. 2019;22: 709-720.
<http://pexlib.net/?203450>

☞ ...motivations for engaging in research were oriented primarily towards benefiting others, including a desire to improve patients' lives and to support effective healthcare interventions. Hemphill, R. et al. 2019. What motivates patients and caregivers to engage in health research and how engagement affects their lives: Qualitative survey findings. Health Expectations. 2019;00: 1-9.
<http://pexlib.net/?208375>

☞ Patients want to know that their complaints make a difference.... the reassurance that lessons will be learned. Clwyd, Hart 2013. A Review of the NHS Hospitals Complaints System. Putting Patients Back in the Picture. Page 23.
<http://pexlib.net/?8011>

☞ Complaints occur when a threshold of dissatisfaction has been breached, with dominant motivations being to correct an ongoing problem or prevent recurrence. 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). Page 532.
<http://pexlib.net/?182740>

☞ ...most people who make a complaint don't do it in search of compensation or retribution. People are motivated by a desire to make sure health and social care improves for others. Healthwatch England 2020. Shifting the mindset. A closer look at hospital complaints.
<http://pexlib.net/?209509>

☞ ...staff often characterised complainants as 'inexpert, distressed or advantage seeking' Adams M, Maben J and Robert G. 'It's sometimes hard to tell what patients are playing at': How healthcare professionals make sense of why patients and families complain about care. Health 2018; 22: 603-623.
<http://pexlib.net/?162412>

☞ NHS Resolution commissioned The Behavioural Insights Team (BIT) to research the motivation of patients making legal claims for compensation for clinical negligence ("claims"). Personal or 'intrinsic' motivations [were]: Wanting to prevent similar things happening to others. Wanting to receive an apology or an explanation for the incident, or to trigger a detailed investigation of the incident. Wanting the clinicians involved to be held to account. Cognitive biases: sunk costs, loss aversion, optimism bias. Emotional responses (e.g. frustration and anger) brought about by poor incident or complaint handling. Financial compensation. NHS Resolution, 2018. Behavioural insights into patient motivation to make a claim for clinical negligence Final report by the Behavioural

The Patient Experience Library

Quote Selector

Insights Team. Page 6.
<http://pexlib.net/?194567>

...people's reasons for posting online reviews or comments are often more positive than assumed. The top three reasons for posting were to provide information for other patients (39%); to praise a service received (36%); and to improve standards of care in the NHS (15%). Providing praise was thus considerably more common than wanting to complain about a service (6%), treatment (5%) or professional (4%). This is confirmed by qualitative interview findings from INQUIRE, suggesting that online feedback is seen by those posting as primarily a means of expressing care for the NHS as a valued institution.

Locock, L. et al, 2020. Anonymity, veracity and power in online patient feedback : A quantitative and qualitative analysis of staff responses to patient comments on the 'Care Opinion' platform in Scotland. Digital Health Volume 6: 1-13.
<http://pexlib.net/?210200>

Repeatedly, families have told us of two key wishes. Firstly, they want questions answered in order that they understand what happened during their maternity care. Secondly, they want the system to learn, so as to ensure that any identified failings from their care are not repeated at the Trust or occur at any other maternity service in England.

Ockenden Report, 2020. Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page 3.
<http://pexlib.net/?228088>

While legal redress provides families with financial compensation, that is not the only or primary reason for pursuing litigation. Important motivations for families are the desire to prevent similar incidents in the future

House of Commons Health and Social Care Committee, 2021. The safety of maternity services in England. Fourth Report of Session 2021-22. Page 27
<https://pexlib.net/?231192>

Over and over, families have expressed their two key wishes for this review. They want answers so that they can understand what happened during the care they received and why. Secondly, they want the system to learn.

March 2022. Findings, conclusions and essential actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Page 3
<https://pexlib.net/?235216>

The Inquiry Panel was struck by the determination of the patients of Dr Watt to ensure that issues were properly investigated and that lessons will be learned from this Inquiry.

Independent Neurology Inquiry, June 2022. Page 72.
<https://pexlib.net/?236098>

Patient and public involvement

There is no single formula for co-production. Some definitions of co-production include: - Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them. Think Local Act Personal (2011) Making it real: Marking progress towards personalised, community based support, London: TLAP. - A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all. The approach is value driven and built on the principle that those who use a service are best placed to help design it. National Occupational Standards (undated) SFHMH63: Work with people and significant others to develop services to improve their mental health. - A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities. National Co-production Critical Friends Group (undated).

Social Care Institute for Excellence (SCIE) website (Posted 2013)

<https://www.scie.org.uk/publications/guides/guide51/what-is-coproduction/defining-coproduction.asp>

There is not one definition of co-production that everyone agrees on because the approach is still developing and changing.

<https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/In-more-d...>

Co-production is a term increasingly 'claimed' by researchers and research funders. However its application in health and social care research varies, revealing a lack of consensus around the concept.

<https://www.invo.org.uk/current-work/co-production/>

Patient and public engagement, as traditionally conceived, buffers power by distancing patients from decision-making

Gilbert, D. 2018. Rethinking engagement. BJPsych Bulletin (2018) doi:10.1192/bjb.2018.55

<http://pxlib.net/?181123>

Citizens, patient/service user representatives, carers, third-sector organisations and local community groups were more likely to believe that decommissioning is driven by financial and political concerns than by considerations of service quality and efficiency, and to distrust and/or resent decision-makers.

Williams I, Harlock J, Robert G, Mannion R, Brearley S, Hall K. Decommissioning health care: identifying best practice through primary and secondary research - a prospective mixed-methods study. Health Serv Deliv Res 2017;5(22). Page v.

<http://pexlib.net/?197952>

Political conflict is an inherent, and potentially beneficial, part of healthcare planning. Thought should be given to reframing the conflict in large scale change as positive, and how it can be incorporated into meaningful methods of public involvement

Djellouli et al <https://doi.org/10.1016/j.healthpol.2019.05.006>

<http://pexlib.net/?196802>

...there is limited agreement about how, when, and why [PPI] should best be done

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 1.

<http://pexlib.net/?197943>

Some have assumed the more PPI, the better, suggesting that co-production - the most involved of PPI approaches - is the 'gold standard'. Others reject the idea of 'the more, the better', raising concerns that it may lead to tokenistic practice or work against meaningful involvement

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 11.

<http://pexlib.net/?197943>

...with careful consideration of when to do PPI... all sides can benefit from bringing real-world understandings into research about healthcare

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 11.

<http://pexlib.net/?197943>

It is worth noting that distinctions are sometimes made between 'involvement', 'engagement' and 'participation' in research (eg by the National Institute for Health Research's (NIHR) INVOLVE advisory group). However, these distinctions are often blurred in the literature

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 1.

<http://pexlib.net/?197943>

Few studies evaluated the fidelity of their PPI approaches, making it difficult to know whether the approaches discussed were implemented as intended.

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 2.

<http://pexlib.net/?197943>

There are also concerns that what is advocated as good PPI practice isn't always feasible, and that PPI can sometimes become a tick-box exercise.

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 1.

<http://pexlib.net/?197943>

💬 PPI lacks standard terminology.

Marjanovic, S. et al. 2019. Involving patients and the public in research. THIS Institute. Page 1.

<http://pexlib.net/?197943>

💬 Lack of clarity on what PPI is (or might be) has given rise to a poorly monitored, complex field of activity

Madden, M., Speed, E., 2017. Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context

<http://pexlib.net/?156649>

💬 ...there is a lack of consensus about what effective PPI in research processes might look like and... little conclusive evidence about the best (or worst) ways to invoke PPI in research design, research practice, or research commissioning

Madden, M., Speed, E., 2017. Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context

<http://pexlib.net/?156649>

💬 Different models of PPI carry distinctive and sometimes contradictory assumptions about the types of public to be involved, the knowledge those publics might bring to bear, and their degree of involvement in decision-making processes.

Madden, M., Speed, E., 2017. Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context

<http://pexlib.net/?156649>

💬 ...formal PPI can be seen as a ghastly composite of a zombie policy that continually pops up, offering (but never providing) a solution to purported deficits in democratic engagement, despite being useless in the last policy round, and a unicorn policy, a mythical beast, prevalent, and much discussed but never discovered in replicable form in any health-care system. This zombie/unicorn hybrid creates PPI as a form of busywork in which the politics of social movements are entirely displaced by technocratic discourses of managerialism".

Madden, M., Speed, E., 2017. Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context

<http://pexlib.net/?156649>

💬 ...a lack of a common language to share PPI practice... the term PPI is not universal in its application or definition.

Baines, R. Regan De Bere, S. 2017. Optimizing patient and public involvement (PPI): Identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology. Health Expectations. 2018;21:327-335.

<http://pexlib.net/?170266>

Despite the proliferation of evidence, policy, guidance and toolkits about PPI in healthcare and research, published literature offers a complex and confusing picture about the underlying rationale for involvement practice.

Matthews, R. et al., 20-19. How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

<http://pexlib.net/?207501>

Very few documents stated any meaningful detail about who was to be involved, for example by offering data about the local community or demographic information about the patient population across services. This was especially concerning when considering issues of inclusivity, equity and equality.

Matthews, R. et al., 20-19. How helpful are Patient and Public Involvement strategic documents - Results of a framework analysis using 4Pi National Involvement Standards. Research Involvement and Engagement. 2019 5:31.

<http://pexlib.net/?207501>

There is a great deal of information being collected already that can be used before procuring something new or that can be used to ensure any new research is based on what we already know.

NHS England, 2016. Bite-size Guide to patient insight: Insight - what is already available?

<http://pexlib.net/?136652>

Public contributors established their legitimacy by using nine distinct roles: (1) lived experience, as a patient or carer; (2) occupational knowledge, offering job-related expertise; (3) occupational skills, offering aptitude developed through employment; (4) patient advocate, promoting the interests of patients; (5) keeper of the public purse, encouraging wise spending; (6) intuitive public, piloting materials suitable for the general public; (7) fresh-eyed reviewer, critiquing materials; (8) critical friend, critiquing progress and proposing new initiatives and (9) boundary spanner, urging professionals to work across organisations. Individual public contributors occupied many, but not all, of the roles.

Barker J, Moule P, Evans D, et al. Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network. BMJ Open 2020

<http://pexlib.net/?221419>

Public contributors can experience challenges to the legitimacy of their lived experience. Some professionals do not believe in the value of experiential knowledge, or consider it legitimate only when public contributors are either representative of or connected to their particular patient group. However, there is no guarantee that public contributors will identify with a patient group, nor do groups necessarily share a broad set of interests. PPI places public contributors in a legitimacy double bind where the involvement admits a few individuals whom professionals are able to denigrate as "unrepresentative" when they speak for a group, and as "anecdotal" when they offer their own stories.

Barker J, Moule P, Evans D, et al. Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network. BMJ Open 2020

<http://pexlib.net/?221419>

Identifying PPI solely with lived experience presents difficulties. One is the limit placed on the ambition of public contributors and the government to see the public involved in decision making at all levels of the English National Health Service (NHS). To be involved at the higher levels public contributors need to take on more strategic roles in determining healthcare agendas and directions. In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand. There are difficulties for organisations too. PPI based on lived experience tends to work better in areas such as rheumatology where professionals and public contributors can build long-term relationships. Health delivery organisations serving acute rather than chronic conditions, and those working in fields such as implementation and antimicrobial medicines research all report challenges to involving public contributors on the basis of their lived experience.

Barker J, Moule P, Evans D, et al. Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network. BMJ Open 2020

<http://pexlib.net/?221419>

The conflation of PPI with lived experience presented a challenge for public contributors and involving organisations alike... the lost opportunity represented by an exclusive focus on a single role suggests that all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles.

Barker J, Moule P, Evans D, et al. Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network. BMJ Open 2020

<http://pexlib.net/?221419>

The patient groups, some of whom have campaigned for decades, have been invaluable to us, well informed, knowledgeable, and research based. They never failed to ensure we learnt from them and were up to date with emerging developments. They are outstanding communicators and expert in the subject matter.

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020 Page i

<http://pexlib.net/?223550>

There is currently no systematic way of knowing which children and young people are involved in health research in England, let alone assessing what form that involvement may have taken or any impacts from involvement.

Brady, L.-M. and Preston, J. (2020) "How do we know what works? Evaluating data on the extent and impact of young people's involvement in English health research". Research for All, 4 (2), 194-206. Online. <https://doi.org/10.14324/RFA.04.2.05>

<http://pexlib.net/?226463>

First, well over 60 frameworks already exist, many though not all of which have been robustly developed using both theoretical principles and extensive patient and lay involvement. Second, we have developed a new taxonomy of these frameworks - power-focused, priority-setting, study-focused, report-focused and partnership-focused - based on their primary focus and intended purpose. Third, we have ascertained that most published frameworks have been little used beyond the groups that developed them (with the exception of frameworks oriented to a particular clinical field and disseminated via networks within that field).

Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: Systematic review and codesign pilot. Health Expect. 2019

<http://pexlib.net/?200927>

...we have ascertained that most published frameworks have been little used beyond the groups that developed them (with the exception of frameworks oriented to a particular clinical field and disseminated via networks within that field).

Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: Systematic review and codesign pilot. Health Expect. 2019

<http://pexlib.net/?200927>

.....the descriptions most effective at establishing failures in care were those that allowed public scrutiny

Goodwin, D. 2020. Describing failures of healthcare: a study in the sociology of knowledge.

<http://pexlib.net/?228169>

Measures of public involvement which are easy to count, such as numbers of people involved, tend to be favoured. However, this tells us little about how patients and the public have changed the course of research studies. Certain kinds of impact, such as how do public involvement activities change power relations and empower the public, are largely not being captured.

Russell et al. 2020. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Research Involvement and Engagement (2020) 6:63 <https://doi.org/10.1186/s40900-020-00239-w>

<https://pexlib.net/?227052>

Critical academics, prompted by the inclusion of impact in the Research Excellence Framework (a system for assessing research quality in UK universities), have argued against measuring impact. Formal measurement of impact may distort practice and draws us into the mindset and practices of performativity. As Fielding put it, 'it valorises what is short-term, readily visible and easily measurable... it has difficulty comprehending and valuing what is complex and problematic'. Reports tend to emphasise positive impacts and to under-report or neglect what might be construed as negative. Rarely considered - perhaps because they are hard to measure - are long-term but potentially far-reaching influences (positive and negative) on the culture of research itself. Impacts may get overblown in an attempt to secure further funding - a phenomenon referred to as "impact sensationalism".

Russell et al. 2020. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Research Involvement and Engagement (2020) 6:63 <https://doi.org/10.1186/s40900-020-00239-w>

<https://pexlib.net/?227052>

Public involvement is conceptualised as a means to the end of achieving better research - or, to put it in philosophical terms, public involvement is seen through a "consequentialist", or "benefits-based" lens. In line with the norms of evidence-based medicine, which is seen as the gold standard for measuring effectiveness in health research, public involvement is positioned as an intervention that has a potentially fixed and measurable effect size. This conceptualisation of public involvement has appeal and persuasive power to researchers - it focuses on what is familiar to them in terms of scientific method, and what is likely to matter to them most: the question of whether public involvement leads to better research. However, the risk is that other, equally important, conceptualisations of public involvement are obscured... An alternative "democratic" or "rights-based" framing of public involvement draws on philosophies of justice, human rights and empowerment, and sees public involvement not so much as a means to an end (better research) but as an end in itself.

The Patient Experience Library

Quote Selector

Russell et al. 2020. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Research Involvement and Engagement (2020) 6:63 <https://doi.org/10.1186/s40900-020-00239-w>
<https://pexlib.net/?227052>

Service users have not fought for a voice at the table merely to help improve the research process, but because they have a right to be there.

Russell et al. 2020. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Research Involvement and Engagement (2020) 6:63 <https://doi.org/10.1186/s40900-020-00239-w>
<https://pexlib.net/?227052>

We still know very little about whether and how public involvement changes power relations between researchers and the public, because this is rarely the focus of impact research.

Russell et al. 2020. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? Research Involvement and Engagement (2020) 6:63 <https://doi.org/10.1186/s40900-020-00239-w>
<https://pexlib.net/?227052>

...we have identified eight barriers to compensating patient partners... lack of awareness about patient partnership, institutional inflexibility, policy guidance from funders, compensation not prioritized in research budgets, leadership hesitancy to create a new system, culture of research teams, preconceived beliefs about the skills and abilities of patient partners, and expectations placed on patient partners.

Richards, . P. et al, 2022. Identifying potential barriers and solutions to patient partner compensation (payment) in research. Research Involvement and Engagement (2022) 8:7
<http://pexlib.net/?234753>

...there were also many barriers to meaningful involvement. These included time and financial constraints

Baines, R et al, 2022. Meaningful patient and public involvement in digital health innovation, implementation and evaluation: A systematic review.
<https://pexlib.net/?235655>

The paradox of representation in public involvement in research is well recognized, whereby public contributors are seen as either too naïve to meaningfully contribute or too knowledgeable to represent the average patient™.

Knowles, S. et al., 2022. Contributors are representative, as long as they agree: How confirmation logic overrides effort to achieve synthesis in applied health research. Health Expectations. 2022
<https://pexlib.net/?236778>

Patient experience and staff experience

When the pressure is higher, and when staff are less satisfied with the resources and support available, patients clearly notice and have a less satisfactory experience.

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 18.
<http://pexlib.net/?171667>

In organisations where employees feel that there are not equal opportunities for career progression or promotion, or when staff experience discrimination, or when staff suffer physical violence at the hands of colleagues, patients are less happy.

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 18.
<http://pexlib.net/?171667>

...when BME staff thought their role makes a difference to patients, and when they were more able to contribute toward improvements at work, overall patient satisfaction was higher.

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 19.
<http://pexlib.net/?171667>

...the extent to which an organisation values its minority staff is a good barometer of how well patients are likely to feel cared for

NHS England, 2018. Links between NHS staff experience and patient satisfaction: Analysis of surveys from 2014 and 2015. Page 7.
<http://pexlib.net/?171667>

The complaints we have included in this report demonstrate how patient care and safety is jeopardised by... workforce challenges. They show clinical staff ill-equipped with the skills to manage potentially violent situations, being expected to work double shifts leading to exhaustion, and clinicians having to treat conditions they have no experience of. Unless these workforce challenges are addressed it is difficult to see how the transformation of mental health care, envisioned in the Five Year Forward View for Mental Health, can be realised.

Parliamentary and Health Service Ombudsman, 2018. Maintaining momentum: driving improvements in mental health care. Page 7.
<http://pexlib.net/?173363>

Personalised and impersonal care

One of the "five major, practical, changes to the NHS service model" is that "People will get more control over their own health, and more personalised care when they need it".

The NHS Long Term Plan, January 2019. Page 12.

<http://pexlib.net/?189259>

Personalised care represents a new relationship between people, professionals and the health and care system. It provides a positive shift in power and decision making that enables people to have a voice. NHS England definition of personalisation: <https://www.england.nhs.uk/personalisedcare/what-is-personalised-care/> People tend not to care about organisational boundaries, but about how services can work better for them and their families

Patient and public participation in commissioning health and care: Statutory guidance for clinical commissioning groups and NHS England. Page 5. Undated.

<http://pexlib.net/?157136>

A fundamental principle of any systematic evaluation is clarity of definition... Given that we observe few clear definitions in use, then how can organisations evaluate person-centredness?

Dewing, J. and McCormack, B, 2016. Tell me, how do you define person-centredness? Journal of Clinical Nursing, 26, 2509-2510, doi: 10.1111/jocn.13681

<http://pexlib.net/?161180>

...publishing incomplete and poorly considered definitions of person-centredness promotes the view that person-centredness is less complex than it is and that it is easier to implement than it is. This can lead to unnecessary burden or even guilt for many in our profession as to why we are not achieving it better than we do or even a collective false consciousness that we have already achieved it and should be moving on to the next fad or miracle improvement/innovation

Dewing, J. and McCormack, B, 2016. Tell me, how do you define person-centredness? Journal of Clinical Nursing, 26, 2509-2510, doi: 10.1111/jocn.13681

<http://pexlib.net/?161180>

The benefits of writing directly to the patient rather than sending them a copy of a letter written to their GP have long been recognised... Doctors who have adopted the practice say their communication style has become more patient-centred. GPs find the letters easier to understand and spend less time interpreting the contents for the patient.

Academy of Medical Royal Colleges, 2018. Please, write to me. Writing outpatient clinic letters to patients. Guidance. Page 4.

<http://pexlib.net/?180919>

...hospital gowns might contribute towards patients experiencing an increased sense of exposure, discomfort, disempowerment, and embarrassment at a time of potential vulnerability while undergoing medical intervention, emphasising the importance of challenging cultural norms in health care. Dehumanising aspects of care, as symbolically represented by the hospital gown, might adversely affect patient wellbeing and increase distress. Cogan et al, 2019. Exploring the effect of the hospital gown on wellbeing: a mixed methods study
The Lancet Meeting abstracts, Volume 394, special issue s32. Page 32.

<http://pexlib.net/?209391>

I was tired of being contacted and being told that my complaint had been passed on, and it became obvious that a well organised system was in place making things difficult for someone like myself to get a simple answer. I realised that there was a huge industry dedicated to making sure nothing would be done, and I would just be passed around until I gave up. So I decided I would give up.

Healthwatch England, 2014. Suffering in Silence. Page 20.

<http://pexlib.net/?424>

As a former cancer patient I fear getting sick again, but it's not the disease I fear, it's being lost in the system that scares me.

Rachael Bull, 2019. Down the rabbit hole. Patient Experience magazine, Summer 2019, page 3.

<http://pexlib.net/?197130>

...the broader research mandate about rare diseases must move beyond diagnostics and treatment to address the very real and pressing issues that arise from the patient - and by extension family - experience in navigating healthcare systems

Baumbusch et al, 2018. Alone in a Crowd? Parents of Children with Rare Diseases' Experiences of Navigating the Healthcare System.

<http://pexlib.net/?181286>

...there's a risk that the public could experience [artificial intelligence] more as a barrier than an open door, blocking access to care, offering opaque advice and dehumanising healthcare in every sense.

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 4.

<http://pexlib.net/?176402>

Page 7 of this report sets out "principles that apply to any form of healthcare that aims to be humane and person-centred". However, they "are not presently being applied to the design, development and implementation of AI".

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 7.

<http://pexlib.net/?176402>

...training currently sends the message that sexual orientation and gender identity are not relevant to providing person-centred care.

House of Commons Women and Equalities Committee, 2019. Health and Social Care and LGBT Communities. First Report of Session 2019-20. Page 3.

<http://pexlib.net/?203433>

For many of the public, patient experience feedback is about being heard as a unique individual and not just as part of a group. This requires their experience to be considered as a whole, rather than reduced to a series of categories.

NIHR, 2019. Themed review: Improving care by using patient feedback.

<http://pexlib.net/?209510>

In other care settings, patients have the right to choose between care providers and can avoid certain individuals or services. For mental health service users however, this autonomy often cannot be exercised due to lack of treatment providers and threat of compulsory treatment.

Berzins, K. et al., 2019. A qualitative exploration of mental health service user and carer perspectives on safety issues in UK mental health services. Health Expectations, 2020, 00:1 1-12.

<http://pexlib.net/?210639>

.....on many of the wards visited in the study, there was no demonstrable culture of including carers in care-planning other than in a tokenistic way. The result was that carers often felt excluded or thought of themselves as annoying the staff... Carers reported being particularly aggrieved when they felt that staff did not prioritise listening to them, particularly when the feedback about the patient they were close to could have helped inform the staff in caring for them better...Our analysis suggests that when staff proactively engage with carers, they can provide intelligence about how best to provide care for the person they care for and about the quality of the care being provided.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 63

<http://pexlib.net/?216782>

Technology and online

...there's a risk that the public could experience [artificial intelligence] more as a barrier than an open door, blocking access to care, offering opaque advice and dehumanising healthcare in every sense.

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 4.

<http://pexlib.net/?176402>

...the path towards AI replacing humans is not solely determined by technical capability. Technology implementation will need to address trust, accountability and similar factors.

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 4.

<http://pexlib.net/?176402>

Page 7 of this report sets out "principles that apply to any form of healthcare that aims to be humane and person-centred". However, they "are not presently being applied to the design, development and implementation of AI".

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 7.

<http://pexlib.net/?176402>

Policymakers should set rules for AI and ownership of public data that ensure the public gets not only value for any data it decides to share, and privacy elsewhere, but also AI products that deliver maximum public benefit.

Loder, J. and Nicholas May, L., 2018. Confronting Dr Robot: Creating a people powered future for AI in health. Page 8.

<http://pexlib.net/?176402>

...the systems and processes that lead to the adoption of technology tend to marginalise the voice of most patients and the public

Dumper, H. Undated. Patient & Public Involvement (PPI) in a Digital Age An overview of AHSN activity and learning. Page 6.

<http://pexlib.net/?175075>

...projects are nervous about involving the public, and are worried about adverse publicity, particularly in the wake of the Care.data scandal

Dumper, H. Undated. Patient & Public Involvement (PPI) in a Digital Age An overview of AHSN activity and learning. Page 7.

<http://pexlib.net/?175075>

Some groups may have good reason to feel distrustful of the health and social care system and be inherently concerned that data about them could be used to target or discriminate against them

Understanding Patient Data, 2019. Understanding public expectations of the use of health and care data. Page 2.

<http://pexlib.net/?198376>

It is incumbent upon those managing and using data to describe a clear trajectory from the collection of data to delivery of benefits. Without this, the public will have every reason to question whether the case for using data beyond individual care really stacks up

Understanding Patient Data, 2019. Understanding public expectations of the use of health and care data. Page 2.

<http://pexlib.net/?198376>

The near real-time, automated collection and aggregation of multiple sources of patient feedback should be used to help prioritise inspections

Griffiths, A., Leaver, M. 2017. Wisdom of patients: predicting the quality of care using aggregated patient feedback. BMJ Qual Saf 2017;0:1-9

<http://pexlib.net/?164293>

Online patient feedback was found to express the extremes of experience, the very positive and the very negative, as demonstrated by the U-shaped distribution of the frequencies of different ratings (figure 4). The majority of the ratings were positive with few middle-ground experiences being reported. This also suggests that it is not appropriate to take an arithmetic average (mean) score from these data, given the skewed distribution towards each end of the spectrum.

Boylan, A. et al 2020. Online patient feedback as a measure of quality in primary care: a multimethod study using correlation and qualitative analysis. BMJ Open 2020;10:e031820.

<https://bmjopen.bmj.com/content/bmjopen/10/2/e031820.full.pdf>

Value of feedback and involvement

A related benefit of greater transparency about 'safety gaps' in our care systems is the potential for patients and families to act as 'knowledge brokers'. Knowledge brokers fill 'structural holes' between otherwise interconnected parts of a network.

O'Hara JK, Aase K, Waring J., 2018 BMJ Qual Saf doi: 10.1136/ bmjqs-2018-008216
<http://pexlib.net/?182051>

Patients and families have unique insight and tacit knowledge that can support safe progression through our imperfect healthcare systems. For example, their movement across and between system boundaries means that they are uniquely positioned to understand how different system components work, often in ways that eludes the understanding of professionals working within these component departments, wards or hospitals.

O'Hara JK, Aase K, Waring J., 2018 BMJ Qual Saf doi: 10.1136/ bmjqs-2018-008216
<http://pexlib.net/?182051>

...we should seek to understand the ways that patients and families might be involved over time to help manage the inconsistencies and unwanted variability in the care system.

O'Hara JK, Aase K, Waring J., 2018 BMJ Qual Saf doi: 10.1136/ bmjqs-2018-008216
<http://pexlib.net/?182051>

...fostering comfort for patients and families to voice concerns is central to patient-centred care, including understanding the risks and benefits of care and participating in shared decision-making and informed consent. In addition, speaking up about care concerns may contribute to patient safety as part of an overall safety culture. For example, families-vigilant stakeholders-may be the first to detect a change in a patient's clinical status. Also, as the 'common thread' uniting care encounters, patients and families may improve continuity of care among team members, or convey key information that clinicians may have overlooked. Finally, patients and families can detect errors, even those not apparent to clinicians.

Bell SK et al. 2018. Speaking up about care concerns in the ICU: patient and family experiences, attitudes and perceived barriers. BMJ Qual Saf doi: 10.1136/ bmjqs-2017-007525
<http://pexlib.net/?180465>

Families and carers can offer a vital perspective in helping to fully understand what happened to a patient as they see the whole pathway of care the patient experienced, which clinicians conducting the investigation may not have seen.

Independent review of gross negligence manslaughter and culpable homicide. 2019. Page 24.
<https://www.gmc-uk.org/-/media/documents/independent-review-of-gross-negligence-manslaughter-and-cul...>

The Patient Experience Library

Quote Selector

☞ [Patients'] movement across... boundaries means that they are uniquely positioned to understand how different system components work, often in ways that elude the understanding of professionals.

O'Hara JK, Aase K, Waring J. BMJ Qual Saf, 2018. Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience.

<http://pexlib.net/?182051>

☞ What is needed is to provide everyday opportunities for [patients] 'reaching in' to healthcare systems.

O'Hara JK, Aase K, Waring J. BMJ Qual Saf, 2018. Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience.

<http://pexlib.net/?182051>

☞ 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, Volume 1, Chapter 3 pp 245

<http://pexlib.net/?76249>

☞ The sharing of healthcare experiences online could help create desirable and dynamic transparency to the benefit of both current and future patients.

Baines, Rebecca; Donovan, John; Regan de Bere, Samantha; Archer, Julian; and Jones, Ray (2019) "Comparing psychiatric care experiences shared online with validated questionnaires; do they include the same content?," Patient Experience Journal: Vol. 6 : Iss. 1 , Article 12.

<http://pexlib.net/?194109>

☞ Without good data it is difficult to know whether services and treatments are leading to improved outcomes.

Neurological Alliance, 2019. Neuro Numbers 2019. Page 2.

<http://pexlib.net/?192134>

☞ ...with careful consideration of when to do PPI... all sides can benefit from bringing real-world understandings into research about healthcare

THIS Institute, 2019. Involving patients and the public in research. Page 11.

<http://pexlib.net/?197943>

☞ ...health care complaints provide added value because they are patient-centred, focus on problematic care episodes, and provide an end-to-end account of care that includes concrete details not captured in incident reports or case reviews

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).

<http://pexlib.net/?182740>

💬 A flexible approach to embracing the presence of carers has led to improving the overall experience of care, changing the atmosphere in wards and services, and helping to make best use of current resources. It has also led to better communication, fewer complaints, reduction in falls, violence, delirium, length of stay, improvement in hydration and nutrition, acceptance of therapy and medication, generally improved well-being and maintenance of function

Chief Nursing Officer for England, 2018.

<https://www.england.nhs.uk/blog/lets-be-open-all-hours-for-carers/>

💬 The participants interviewed for this study nearly all saw an immense value in patient experience feedback, and most believed it should receive a high priority at a strategic and Trust board level

Sheard et al, 2018. What's the problem with patient experience feedback? A macro and micro understanding, based on findings from a three-site UK qualitative study.

<http://pexlib.net/?181784>

💬 ...how are patients, the vast majority of whom will have no clinical training, able to predict the outcome of comprehensive quality inspections? There are several possible non-exclusive explanations. A growing volume of research suggests that, in addition to the more service-orientated aspects of care such as dignity and respect, cleanliness and timeliness, patients are able to accurately assess some of the more clinical aspects of their care. This insight may be enhanced by the 'wisdom of crowds' phenomenon which states that, under the right circumstances, groups can be remarkably insightful, even if the majority of people within a group are not especially well informed. While individuals seldom have all the necessary facts to make an accurate assessment, and are subject to numerous heuristics and biases, when their assessments are aggregated in the right way, the collective assessment is often highly accurate.

Griffiths, A., Leaver, M. 2017. Wisdom of patients: predicting the quality of care using aggregated patient feedback. BMJ Qual Saf 2017;0:1-9

<http://pexlib.net/?164293>

💬 ...online feedback found on NHS Choices is significantly correlated with established measures of quality in primary care. This suggests it has a potential use in understanding patient experience and satisfaction, and a potential use in quality improvement and patient safety.

Boylan, A. et al 2020. Online patient feedback as a measure of quality in primary care: a multimethod study using correlation and qualitative analysis. BMJ Open 2020;10:e031820.

<https://bmjopen.bmj.com/content/bmjopen/10/2/e031820.full.pdf>

💬 While many interviewees acknowledged that [the Friends and Family Test] is a fairly limited tool, it was still seen as a valuable resource, without which there would be a considerable gap in measuring patient experience. Positive patient feedback, from the Friends and Family Test and other patient experience indicators, was thought to have significant value in terms of improving staff morale.

Al-Zaidy, S., et al., 2019. Briefing: The Measurement Maze. Health Foundation.

<http://pexlib.net/?207753>

The Patient Experience Library

Quote Selector

.....staff also struggled to articulate the amount of time spent on patient experience data, with many simply resorting to terms such as: "a lot", "varies hugely", "informally throughout the day", "a massive part", "hard to quantify - once per week", "not much", "every day", "limited" and "smallest amount of time". These terms did not permit the costing of time spent on collecting, analysing and feeding back patient experience data. This was further hindered in instances in which it was not clear what type of patient experience work they were referring to.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 102

<http://pexlib.net/?216782>

.....Patient Experience Lead posts were subject to high rates of turnover and many were insecurely funded and hence acutely vulnerable to cost improvement pressures.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 106

<http://pexlib.net/?216782>

.....patient experience data were often either treated as necessary only for regulatory compliance (in the form of the minimally informative results from the FFT) or viewed as "nice to have" rather than as essential to the delivery of trusts' core objectives.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 110

<http://pexlib.net/?216782>

.....when safety and outcomes data indicate a service hot spot, patient experience data can be crucial in providing evidence of the ways in which services need to change. Whereas outcomes and safety data can show what is happening (as well as trends), patient experience data often hold explanatory power and help explain the reasons why something is happening.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020;8(21). Page 111

<http://pexlib.net/?216782>

Our analysis suggests that when staff proactively engage with carers, they can provide intelligence about how best to provide care for the person they care for and about the quality of the care being provided.

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. Health Serv Deliv Res 2020

<http://pexlib.net/?216782>

The Patient Experience Library

Quote Selector

“ The gap between feedback collection and use not only represents a costly misuse of resources, as national surveys cost upwards of £640,000 per survey per year, but it also raises ethical concerns around not acting on critical patient information.

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

<http://pexlib.net/?174569>

“ Reported benefits of co-production were rarely formally evaluated

Co-Production Collective, October 2022. The Value of Co-Production Research Project: A Rapid Critical Review of the Evidence. Page 6.

<https://pexlib.net/?237510>