How does the NHS use patient experience data as a driver for service improvements?

Rapid literature review

Patient Experience Library

Contents

1.   Introduction

Every two years The Neurological Alliance runs the largest national neurological patient experience survey of its kind in the country – the My Neuro Survey. Data from the survey has been used to inform campaigning and influencing activities as well as supporting and informing service improvement in the health system.

This rapid literature review was carried out as part of preparations for the 2024 iteration of the My Neuro Survey. Undertaken during a four week period in May 2024, it supports the Neurological Alliance in deepening its understanding of how patient experience data and insights are used to inform service improvement in the NHS.

2. Key messages

2.1 Types of patient experience data

A basic difficulty in patient experience work is that there is a general lack of definition or agreement on what patient experience data actually is. One study found eight different types of feedback (of which two came directly from patients) while another found 37. Other studies have outlined other typologies. For this review therefore, we have avoided theoretical definitions, and simply tabulated the commonly collected datasets currently in use across the NHS.

2.2 Methodologies, approaches and best practices

There is little in the way of standardised approaches for translating patient experience data into service improvement. The literature describes various methods, and some studies make recommendations for improved practice. Within these, a common theme is that formulaic data processing is inadequate as a route to improvement. More effective methods involve multi-disciplinary work, with staff given dedicated time, facilitated support and safe spaces to critically reflect on what patient experience data might be revealing about strengths and weaknesses in their service provision.

2.3 Measuring impact

For all the time and effort put into patient experience data gathering, NHS bodies seem to have given little thought to impact. Studies from non-NHS bodies suggest that improvements arising from patient feedback are small-scale and local. National patient surveys indicate that at the strategic level, patient experience data is having little or no impact as a driver for larger scale service improvements.

2.4 Challenges

Challenges in making use of patient experience data are both practical and cultural. Practicalities include problems with patient-centredness and with a lack of clarity around definitions of both patient experience and of quality in healthcare. Further challenges arise from capability issues, and from the sheer amount of patient experience data that has to be processed. Cultural flaws have been observed in listening culture, reporting culture, responsiveness culture, governance culture, practitioner cultures and corporate cultures.

3. Method

3.1 Research question

Based on a brief from the Neurological Alliance, a research question was defined as follows:

"How does the NHS use patient experience data as a driver for service improvements?"

This was broken down to the following subsets:

- What types of patient experience data are commonly collected within the NHS?
- What methodologies, approaches and best practices are used to incorporate patient experience data into service improvement initiatives?
- How does the NHS measure the impact of patient experience data on service improvement?
- What challenges are associated with the use of patient experience data in the NHS?

3.2 Search strategy

SEARCH TERMS

The search was conducted using the following terms:

Feedback improvement
Complaints improvement
Focus group improvement
Friends and Family Test improvement
Survey improvement
Care Opinion improvement
Online improvement
Social media improvement
Co-production service improvement

Feedback impact
Complaints impact
Focus group impact
Friends and Family Test impact
Survey impact
Care Opinion impact
Online impact
Social media impact
Co-production service impact

EXCLUSIONS

PLACE: Evidence was taken primarily from UK sources. International literature was used only if it added insight that was not available from UK research.

TIME PERIOD: We reviewed literature up to ten years old – ie from April 2014 to March 2024.

SOURCES: Evidence was drawn from both formal literature (peer reviewed, journal published) and informal/grey literature. The search did not include documents that held behind journal paywalls, or other literature that would normally be for sale from booksellers.

RELEVANCE: Search results were filtered for relevance, narrowing the selection to documents that dealt exclusively or mainly with patient experience data as a driver for improvement, and excluding documents that mentioned the topic only in passing.

THEMES: The search concentrated on use of patient experience data in the context of service improvements. It excluded use of patient experience data for research, policymaking or any other purposes not related to service delivery.

LIMITATIONS

This was a rapid review, drawing on literature held by the Patient Experience Library, which specialises in literature on patient experience and engagement and acts as the UK evidence base for this kind of material.

SEARCH RESULTS AND CODING

After de-duplication and relevance filtering, search results consisted of exactly 300 documents. These were read manually, enabling further filtering (based on the exclusion criteria listed above) and bringing the total down to 87 documents. The documents were read again, with relevant themes and topics extracted and coded against headings relating to the main research question and each of its subsets (as per section 3.1 above).

4. Findings

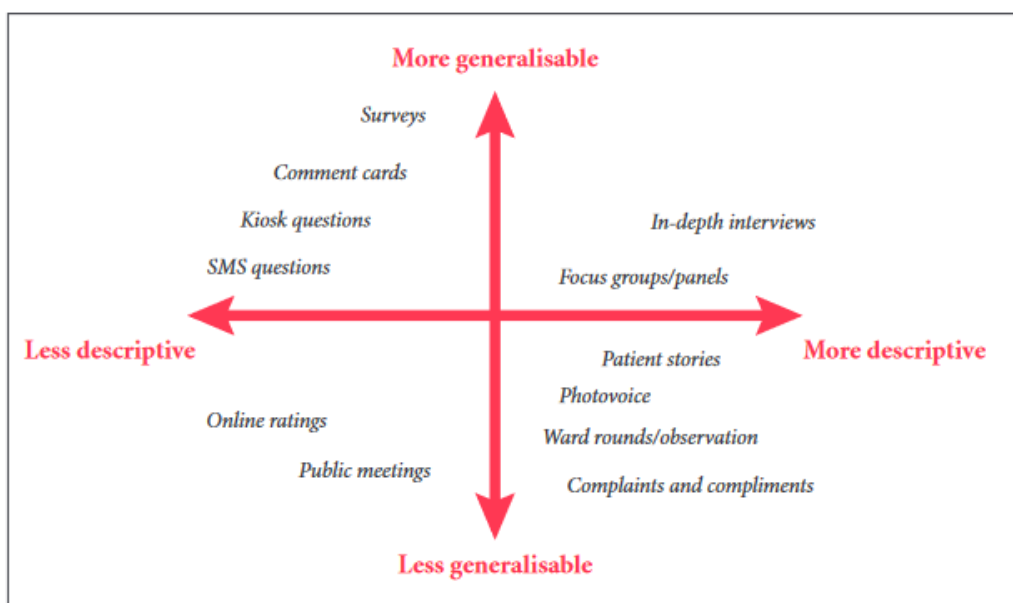## 4.1 What types of patient experience data are commonly collected within the NHS?

Various research studies have attempted to define types of patient experience data.

One, on the role of feedback in emergency ambulance services[1], described eight different types of feedback, of which two came directly from patients. The types were: patient outcome feedback, patient-experience feedback, peer-to-peer feedback, performance feedback, feedforward, on-scene advice, debriefing and investigations or coroners' reports.

Another study[2] looked at patient experience feedback in UK hospitals, and its role in quality improvement. The authors found 37 different types of feedback, which they grouped into four main categories: Hospital-initiated quantitative surveys (eg the NHS Adult Inpatient Survey); Patient-initiated qualitative feedback (eg complaints or twitter comments); Hospital-initiated qualitative feedback: (eg Experience Based Co-Design); Other: (eg Friends & Family Test).

A third attempt was made via an editorial in the Digital Health journal.[3] It described "SSS" feedback – that is, feedback that is "sanctioned" (ie obtained through a medium that is approved by the Trust as an official feedback channel), "solicited" (consistently asked for from patients or carers) and "sought" (actively searched for and used). Against this, it posited a different type of "UUU" feedback: "unsanctioned" (not officially approved), "unsolicited" (not asked for), and "unsought" (not searched for).

Alongside all of this, the Health Foundation have presented a graphical representation[4] of types of patient experience data:

These broad typologies indicate a key difficulty in patient experience work: a general lack of definition or agreement on what patient experience data actually is.

For this review, however, the question is about the types of data that are "commonly collected". We have sought to answer this question via the table below.

TABLE 1: COMMONLY COLLECTED DATASETS WITHIN THE NHS.

Type	Key features	Sources
1. Surveys	These gather mainly numerical data, often presented in spreadsheet format, and capable of statistical analysis. They involve large sample sizes (typically tens of thousands of respondents), with national overviews, broken down to local detail. CQC surveys also offer benchmarking reports, enabling NHS Trusts to compare their results with those of other similar Trusts. The surveys are rigorous in their methods and analysis. However, timeliness is an issue, with survey results often being published six months or more after commencement of fieldwork.	Care Quality Commission patient surveys for: Adult inpatients Children and young people (includes views from parents and carers) Community mental health services Maternity services Urgent and emergency care NHS England patient surveys for: GP practices Cancer services Under 16 cancer patient experience
2. Formal research	This takes the form of research papers formally published in academic and professional journals. The papers feature rigorous methodology, are often grounded in theory and are published following peer review. Timeliness is an issue, with lengthy research periods compounded by potential delays and revisions during peer review. Access is also an issue, as many papers are not available through open access publication.	Universities – sometimes in collaboration with health research bodies such as NIHR, HRA, NICE etc.

Type	Key features	Sources
3. Reports	Mainly qualitative evidence based on patient surveys and focus groups. They tend to feature small sample sizes, with a focus on specific named services and/or health conditions. The studies are open to criticism from academic researchers, who might see them as lacking rigour (eg not related to theory, or not peer-reviewed). They can also be seen as containing bias – particularly in the case of studies by health charities which can be linked to campaigning or fundraising goals. Strengths, on the other hand, can come from the fact that some studies are produced by organisations that are embedded in communities of place (eg Healthwatch) or of interest (eg charities linked to specific health conditions). Studies therefore can be based on trusted dialogue, and may reveal insights that are unavailable to more detached academic researchers.	"Patient voice" bodies including Healthwatch, National Voices, Patients' Association. Health charities and think tanks such as the King's Fund, Nuffield Trust, Health Foundation.
4. Real time feedback	These forms of patient experience data come directly from patients, service users, families and carers. They are not filtered through predetermined survey questions or mediated through the editing choices of report writers. So the people offering feedback can say exactly what matters to them. A potential disadvantage is that comments can lack detail – eg dates, places or even the service that is being commented on. Sometimes poor spelling and grammar can make the feedback hard to understand. A further problem with the Friends and Family Test is the sheer volume of data (nearly 2 million responses across England in the month of March 2024 alone).[5]	The NHS Friends and Family Test Care Opinion NHS.UK reviews

Type	Key features	Sources
5. Complaints and compliments	Complaints data is formally logged and reported via collection processes known as KO41a and KO41b. Returns are made annually.[6] Compliments come via thank you cards and letters, emails etc. We are not aware of any formalised or standardised mechanisms for collating and analysing compliments data.	Written communications from patients, families, carers and service users.
6. Other local evidence gathering	Healthcare providers and commissioners gather further patient experience data via standing forums such as Patient Participation Groups or patient engagement committees, and also via occasional local surveys, focus groups and public meetings. We are not aware of any formalised or standardised mechanisms for collating and analysing data from these sources.	Various local sources.

Note: Health service managers may also be looking at data from Patient Reported Outcome Measures (PROMs). These are not included in the table above, however, as they focus on clinical outcomes as opposed to being specifically about people's experiences of access to, and the quality of, care services.

4.2 What methodologies, approaches and best practices are used to incorporate patient experience data into service improvement initiatives?

4.2.1 A VARIED LANDSCAPE

There seems to be little in the way of standardised approaches for translating patient experience data into service improvement. NIHR makes the point that "Whilst most organisations have a standardised method for quality improvement, there is less clarity and consistency in relation to using patient experience data".[7] One recent study,[8] for example, compared approaches to using patient experience data generated by the online Care Opinion platform.[9] It described approaches across three different hospital trusts as follows:

- Site A: A focus on listening to individual patient concerns and getting answers quickly. The patient experience team saw their role as 'resolution providers'.

- Site B: The focus was on logging, counting, and reporting feedback routinely. The patient experience team saw their role as data processers and report generators, which often did not lead to improvement work.

- Site C: A focus on responding openly, continually improving, and inviting further involvement. The patient experience team saw their role as ensuring that listening and learning to patients was valued across the organisation, underpinned by many years of challenge and perseverance.

These differences perhaps highlight an underlying difficulty that has been described in terms of "communicative rationality" and "functional rationality". To summarise: communicative rationality allows for deliberation, constructive disagreement, and negotiated consensus. Functional rationality, on the other hand, "belongs in the domain of the System" and is focused towards organisational objectives that have already been established, and are not up for negotiation. In some cases, functional rationality means that humane and compassionate dialogue in pursuit of service improvements can sometimes be displaced by the logic of reporting formats, rigid data categorisation and deadlines.[10]

In spite of these difficulties, documented examples of approaches to quality improvement based on patient experience data include those shown below.

4.2.2 METHODS, APPROACHES AND BEST PRACTICE

LEARNING FROM THE FRIENDS AND FAMILY TEST

A 2019 paper[11] makes the point that qualitative data derived from the Friends and Family Test "are not so easily analysed nor is it easy to use to make quality improvement". It describes an approach within a GP practice that used Card Sorts and control charts to "lead to a deeper understanding of patient feedback and facilitate quality improvement without requiring advanced skills, thus making it suitable for lay staff and patient groups to use". The outcome was an "easy-to-understand visualisation" which was posted in the waiting room. This meant that "over time the patients and staff could monitor the changes; an increase in positive responses indicated an improvement in the delivery of healthcare that could be celebrated, a decrease outside of the range could be investigated".

LEARNING FROM COMPLAINTS

A report from the Parliamentary and Health Service Ombudsman looked at failings in imaging services (X-ray, CT, MRI). The failings came to light not because of provider vigilance but because the PHSO undertook a careful analysis of patient complaints. The report recommends an approach to improvement that would mean staff having time for meaningful learning and reflection, including triangulation of data from complaints, claims, serious untoward events, patient safety issues, Freedom to Speak Up Guardian data and candour learning.[12]

More detailed recommendations are set out in a paper[13] which comments that "healthcare complaints practice has not yet been successful at achieving the complex dual role of case- by-case handling and system-wide improvement". It suggests strengthening the complaint handling pathway through better access of information; collaboration with support and advocacy services; attention to staff attitude and signposting; bespoke responding; and public accountability. Simultaneously, the improvement pathway could be addressed via a reliable coding taxonomy; standardised training and guidelines; a centralised informatics system; appropriate data sampling; mixed-methods spotlight analysis; a focus on board priorities and leadership; and just culture.

LEARNING FROM COMPLIMENTS

A study on thank you letters from patients[14] makes the point that healthcare organisations often focus on breaches of procedure, and learning from mistakes. But more holistic approaches recognise safety and quality as something that emerges from organisational cultures, teamworking and personal relationships. This can be overlooked by staff, but patients who recognise and offer feedback on excellence can help "further the goal of understanding high-quality and resilient healthcare".

Analysis of compliment letters showed patients going beyond simply "acknowledging" excellent care, to "rewarding" or "promoting" examples of excellence. This would indicate compliments whose purpose was not simply gratitude, but an attempt to help improve services. The authors state that "Patient feedback data, despite vast amounts of data collection, have arguably had little impact on improving services". But, they say, "Compliments are credible, specific and narrative, and positive, which might make them a relatively effective route to improve quality".

LEARNING FROM STORIES

Research from America[15] notes that patient feedback can be "garbled, fragmented, or laden with multiple plausible inferences". Providers often respond by channelling patient feedback into formal surveys, where questions are predetermined, and designed to generate quantifiable results. But patients' stories convey what matters most to them so "their focus often extends beyond the domains of experience assessed by conventional closed-ended survey questions".

The authors suggest an approach based on the "actionable content" within patient stories – looking for "the who, what, when, and where of the event, as well as how the experience felt to the patient". This is more prevalent than might be imagined: "Overall, 80% of narratives contained actionable content. Fifty-six percent had multiple actionable events, and 17% contained four or more distinct actionable elements".

LEARNING FROM MULTI-DISCIPLINARY INVOLVEMENT

One study[16] noted bluntly that "The idea that current [patient experience] data can be effectively triangulated for the purpose of improvement is largely a fallacy". Researchers' observations of improvement efforts by ward staff led to the conclusion that "additional but more relational feedback had to be collected by patient representatives... to provide health-care staff with data that they could work with more easily". The paper recommends multidisciplinary involvement with dedicated time and sensitive management. Facilitation was essential, with the most important factors stated as "the development of relationships between people and the facilitator's ability to navigate organisational complexity". Improvement outcomes varied from "far-reaching plans" to "time-minimising quick wins".

LEARNING FROM CRITICAL FACTORS

An NIHR study[17] looked not so much at the types or sources of patient experience data, but at the critical factors that might lead to its use for quality improvement. It described three key factors:

- When patient experience data (even data that was not ideal) was given to skilled members of staff (often nurses) and when those staff had the power to act, it was very effective in leading to quality improvement.

- When patient experience data is given equal weighting with patient safety and clinical outcomes data, it can make a difference to staff understanding of its importance.

- When patient experience data becomes a visible part of quality improvement practices, it can increase awareness of the skills needed to collect, interpret and use the data.

The authors conclude that "for patient experience data to lead to improvements in quality of care, it is not sufficient to focus solely on improving, and/or maximising the number of, the data that NHS trusts collect. This effort yields limited benefits if attention is not also paid to the qualities (in particular autonomy, authority and contextualisation) that are needed... for the data to lead to care improvements".

Still on the topic of critical factors, another study[18] of providers' use of the Care Opinion platform described the following best practice features:

- The task of dealing with patient feedback was not confined to the patient experience team, but included other clinical and non-clinical staff distributed widely across the organisation.

- The involvement team appeared to be on a mission to spread the word about involving and learning from patients, encouraging staff at any level of the organisation to take ownership of feedback, and to take it seriously.

- The team helped to get over the "too busy to improve" attitude by providing middle management and frontline staff with permission for dedicated time and the facilities of physical space (conference rooms, meeting spaces etc.) to think about feedback with intention, what it meant and how it was going to inform improvement.

- The team met regularly with frontline staff, volunteers and/or senior management including the chief executive to discuss plans to move forward. There was a friendly, open atmosphere in which criticism was welcome throughout the hierarchy. The focus was on teamwork and reflection.

4.3   How does the NHS measure the impact of patient experience data on service improvement?

It is hard, from the literature, to know how the NHS measures the impact of patient experience data on service improvement. The NHS publishes guidance on how to collect patient feedback, and also publishes Friends and Family Test scores, along with the results of national patient surveys. But it seems to have little or nothing to say about the impact of any of this activity.

There has been some evaluation of impact by non-NHS organisations involved in patient experience work. One example is the Healthwatch network made up of 150 local Healthwatch across England. Independent evaluation[19] found that "Healthwatch overwhelmingly reported impacts that were local in nature". The most commonly reported impact was "Improved access to care and treatment for members of our community", followed by "Increased levels of participation in co-production of people who use a service". Just 10 local Healthwatch reported that they had influenced changes in national policy or specialist commissioning.

The online Care Opinion platform has published its own self-assessment of impact[20] which, as far as service improvements are concerned, also seems to point to relatively small-scale local changes. Out of 27,825 patient stories published on the site, just 353 (1.2%) are known to have led to service changes being planned or made. (The percentage figure needs to be treated with some caution, as many of the 27,825 stories will not have been asking for any changes. But the report does not present "changes made or planned" as a proportion of "changes requested".)

A third study[21], looking at use of patient experience survey data by out of hours services came to similar conclusions. It said that "changes to service provision… tended to be 'low-level', that is, things that were easily fixed, such as signage and the use of badges for identification of staff". However, "patient survey data was insufficient to instigate service-wide changes due to the lack of clear trends observed within it".

The lack of larger scale impact arising from patient experience data seems to be borne out by national survey results. For example:

- The 2022 Adult Inpatient Survey showed that people's experiences of inpatient care had worsened since 2020.[22]

- The 2023 Community Mental Health Survey reported that experiences of community mental health services are persistently poor. Only 39% of respondents were "definitely" given the help they needed the last time they saw someone. Half (50%) were not always given enough time to discuss their needs and treatment. Experiences of waiting to receive care are especially poor, with almost half (44%) reporting that their mental health got worse while they waited.[23]

- The 2023 GP Patient Survey states that the proportion of patients reporting a good overall experience of their GP practice decreased to its lowest level for six years.[24]

- The 2022 Urgent and Emergency Care Survey says that "Compared with earlier surveys (back to 2016), results show that people's experiences of urgent and emergency care are worse than in previous years".[25]

- The 2023 British Social Attitudes Survey says that overall satisfaction with the NHS is at the lowest level since the survey began in 1983.[26]

These survey results might seem to indicate that – at the national level at least – patient experience data is having little or no impact as a driver for service improvements.

Some researchers are also sceptical about patient experience data as a driver of change.

One study stated that "policy assumptions about the transformative capacity of patient feedback... were not consistently empirically demonstrated in studies that examined its impact at general practice or practitioner level". This paper concluded that "improvement efforts rarely resulted in improved patient experience survey scores".[27]

Another cast doubt on "the importance placed on patient feedback as a performance assessment methodology due to the implicit and often unclear assumptions made about its capacity to facilitate quality improvement". The authors commented that "current understanding of patient feedback as a catalyst for change remains limited".[28]

4.4   What challenges are associated with the use of patient experience data in the NHS?

There is widespread recognition of the challenges involved in making use of patient experience data. As long ago as 2014, NHS England was noting that "Improvements need to be made in how data on the experiences of patients and staff is collected and turned into useable intelligence, and how changes made as a result of this data are fed back to patients and staff".

Challenges to good data collection and use can be both practical and cultural, as follows:

4.4.1   PRACTICAL CHALLENGES

LACK OF PATIENT-CENTREDNESS

NHS England has questioned whether patient experience data collection is truly patient-centred: "It is unclear whether the data on experiences that is currently being collected truly reflects what is important to people. Also, current data and insight collected does not properly reflect the experiences of seldom-heard communities".[29]

Healthwatch England, looking at complaints processes, has said that data collection is hampered by the fact that "People are not given the information they need to complain" and that they "find the complaints system complex and confusing".[30]

LACK OF CLARITY

We have noted in the section on types of patient feedback (page 7 above) that there seems to be a lack of definition or agreement on what patient experience data actually is. This might be compounded by a similar lack of clarity over the meaning of "quality" in healthcare.

One paper[31] states that "There is no widely accepted definition of quality of care; rather, there is an understanding that it is multi-dimensional, with varying interpretations dependent on who is being asked". It goes on to say that "the terms 'satisfaction' and 'experience' are often used interchangeably despite their different meanings. Satisfaction is the gap between patient expectations and experience. Patients tend to overrate satisfaction, due to gratitude bias and other factors. Therefore, the validity and usefulness of satisfaction data is limited".

LACK OF CAPABILITY

The King's Fund and Picker have pointed to the need for skills and capacity in data analysis: "Patient survey data [is] hugely powerful – but requires skill & time for analysis". Their summary goes on to warn of "risks in misuse" of the data.[32] Their concerns are corroborated from a number of sources.

A 2018 paper made the point that "...gleaning information from experience data requires the same analytical capability as interpreting clinical data; however, that capability is often unavailable. Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it".[33]

Another pointed to the lack of any measure to improve capability: "...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".[34]

The Parliamentary and Health Service Ombudsman has also noted that complaints managers "often receive limited access to training and are asked to address serious and complex issues with little assistance".

The consequences can be profound. A further paper reported that "…only around one-quarter [of patient experience leads] were able to collect, analyse and use patient experience data in inpatient settings to support change".[35]

UNMANAGEABLE QUANTITIES

It can be seen from the section on types of patient feedback (pages 8-10 above) that the data comes from a wide variety of sources. One of the practical challenges for healthcare staff is simply keeping up with it all.

A 2018 paper looking at how staff dealt with patient feedback said that "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".[36]

Other researchers have found that "…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".[37]

A third study found that "What was perceived as an overwhelming quantity of feedback being received… also meant that collection and resolution of individual patient concerns was all-consuming, leaving no space to report, and to a lesser extent, learn".[38]

Ironically, one study found that general practice staff managed the workload arising from the Friends and Family test by simply ignoring it: " Interviewees did not describe the FFT as time consuming or a distraction, largely because of the low priority given to it. The FFT did not interfere with the receptionists' normal activities, as receptionists did not hand it out when they were busy".[39]

4.4.2   CULTURAL CHALLENGES

The task of collecting and making sense of patient experience data is partly about practicalities. But it is also about organisational and professional cultures. Cultural challenges identified in the literature are as follows:

LISTENING CULTURE

In 2008, a national review of healthcare quality said that high quality healthcare is built on three pillars – clinical effectiveness, patient safety and patient experience.[40] Six years later, in 2014, NHS England noted that "Patient experience is still not seen as an equal element of high-quality care, alongside clinical effectiveness and patient safety".[41]

Over the years since, problems with organisational cultures have persisted. A paper on "openness" in healthcare states that openness policies "focus primarily on organisations and staff. We found that patients and families were mainly bit-part players".[42]

For their part, the Parliamentary and Health Service Ombudsman has named "failure to listen to the concerns of patients or their families" as one of their "four broad themes of clinical failings leading to avoidable death".[43]

Numerous avoidable harm inquiries refer to dismissive attitudes towards patient feedback. The Francis Inquiry, for example, said that the "appalling suffering" of patients at the Mid Staffordshire Trust was "caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients".[44] Baroness Cumberlege, investigating harms from medicines and medical devices, said "It became all too clear that those who have been affected have been dismissed, overlooked, and ignored for far too long".[45]

Listening culture also depends on ideas about legitimacy. One study[46] on online feedback from patients noted that some NHS Trusts do not see online channels of communication as valid: "A significant finding from our work is that, varying by trust, different online channels are seen as 'sanctioned' or 'unsanctioned' by the organisation, and, in general, only the sanctioned channels get monitored and responded to".

Even when providers are keen to listen to patients, there is a risk that they are hearing only part of the conversation. Research from NIHR states that "Patients' intentions in giving feedback are sometimes misunderstood. Many want to give praise and support staff and to have two-way conversations about care, but the focus of healthcare providers can be on complaints and concerns, meaning they unwittingly disregard useful feedback".[47]

REPORTING CULTURE

There are questions over how and why healthcare organisations report on their patient experience data.

One paper on patient experience and quality improvement in UK hospitals[48] refers to the "3 Faces of Performance Measurement" which distinguish between data used for accountability (outcome measurements of interest to external parties, eg, funders and regulators), data for improvement processes (to aid identification of problems, opportunities for change and monitoring of success) and data for research (generating universal knowledge). It suggests that routinely collected NHS patient experience data is geared more to measuring accountability than to informing ward-based improvement.

Another study[49] observed a "patient feedback abyss" caused by an unthinking reporting culture. It described "risks that patient experience teams were working tirelessly to keep pace with the data being collected and reporting patient experience information, largely to themselves and other senior staff, mistaking activity for the end goal of improvement. Reporting was also often viewed as a neutral presentation of patient experiences, yet risked stripping the original context, displacing meaning and silencing patient experiences, subsequently reducing the opportunities to improve".

RESPONSIVENESS CULTURE

A key aspect of responsiveness is timeliness – the ability of providers to react quickly to patient experience evidence as it appears.

However, one paper[50] has described a "patient experience lag", stating that "Trusts were slow to adapt to patients' needs, preferences and technology". Writing in 2023, the authors noted that despite the online Care Opinion platform being founded in 2005, it was still considered "a relatively novel feedback mechanism" in the NHS Trusts that they had studied.

Responsiveness can also be hampered by bureaucratic processes. A paper on national policies for complaints handling[51] showed how "the design of national rules and policies functioned to undermine a patient-centric and improvement-focused approach to complaints". Problems included a "confusing landscape of routes for raising concerns", and a complaints data collection system built on categories that "did not describe the problems that complaints tend to report and were further insufficiently granular for actionable learning".

This ties in with findings from an avoidable harm inquiry, which described a focus on "resolution" of complaints rather than learning from them: "there was no consistent method of dealing with clinical complaints and the emphasis remains on timely resolution... the approach was focused on responding within stipulated time periods and 'resolving' complaints".[52]

Another saw a barrier to responsiveness in the "often tangled web of pathways for speaking up, reporting issues, raising grievances, commenting on care and complaining...Each pathway had its own procedures, policies and personnel, as well as timelines and terms of reference, all oriented towards its own, functionally rational objective".[53]

GOVERNANCE CULTURE

Boards of NHS Trusts are, ultimately, accountable for the quality of the Trust's services. So governance culture arguably has an influence on the extent to which patient experience data is used for quality improvement. However, one study found that "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".[54]

PRACTITIONER CULTURES

Health professionals can sometimes be inclined to take patient feedback personally. Research from 2017[55] found that some clinicians see 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".

A more recent study[56] has described patient experience staff trying to " consider feedback more meaningfully", but "encountering difficulties establishing relationships with clinical staff who held deeper concerns regarding threat to their professional position or reputation".

Research on doctors' engagement with patient experience surveys[57] found that they expressed "strong personal commitments to incorporating patient feedback in quality improvement efforts" but simultaneously held "strong negative views about the credibility of survey findings and patients' motivations and competence in providing feedback". The consequence was "contradictory views regarding the plausibility of patient surveys, leading to complex, varied and on balance negative engagements with patient feedback".

As far as online feedback is concerned, it has been reported[58] that "medical professionals are sceptical and cautious about the usefulness of online patient feedback" and "It is perhaps not surprising that very few patients report being encouraged to provide online feedback and few doctors or nurses ask their patients to do so".

CORPORATE CULTURES

A discussion paper from the Nuffield Trust[59] makes the point that "analytics teams are usually managed as corporate functions, with a primary focus on analysis for regulation and performance, rather than quality improvement and transformation". This, it says, creates "cultural barriers between clinical and informatics specialists... there is a deeply held view in the NHS that analytical and informatics work is low status, and belongs in the 'back office', rather than being critical for transformation and quality improvement". It concludes that "this is a significant challenge as methods used for robust analysis of large health datasets are not routinely undertaken in the NHS".

Policies and procedures can also present a challenge to the use of patient experience evidence for improvement. In one study,[60] researchers found that formal procedures in an NHS Trust were "predominantly structured to judge the 'well-foundedness' of complaints. The paper states that "The legitimacy of complaints was appraised by investigators through cross-validating raised issues with corresponding hospital documentation and staff statements, with internal evidence being regarded as superior". The consequence was that "Paradoxically therefore, complaints were only utilised for quality improvement in cases where they described the already known and managed".

About The Patient Experience Library

The Patient Experience Library acts as the national evidence base for patient experience and patient/ public involvement. Its open access online research database holds tens of thousands of reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

The Library has developed analytics to help healthcare staff and patient advocates make sense of patient experience data, and offers knowledge translation services via literature reviews and a quarterly journal.

We are inspired by Baroness Cumberlege whose First Do No Harm report said that patient experience "must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine".

www.patientlibrary.net

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Endnotes

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