



INADMISSIBLE EVIDENCE

The double standard in evidence-based practice, and how it harms patients

**Patient
Experience
Library**



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Library

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FIRST...

...do no harm

In July 2020, the Independent Medicines and Medical Devices Safety Review published a report entitled “First Do No Harm”.

Also known as the Cumberlege Review, the report set out extensive evidence of avoidable harm in healthcare. It described “heart wrenching stories of acute suffering, families fractured, children harmed”. The suffering had occurred over years, even decades.

The harm was avoidable because patients and families had repeatedly spoken out about the ill effects of the treatments they had received. But no-one had wanted to hear them.

In a letter to the Secretary of State, Baroness Cumberlege said “The healthcare system... does not adequately recognise that patients are its raison d’etre. It has failed to listen to their concerns... and has too often moved glacially”.

The words “healthcare system” are important.

The NHS is full of dedicated staff who, at a one-to-one level with patients, offer deeply personal and compassionate care. But too often the system as a whole seems institutionally deaf to the patient voice.

In this report, we explore the reasons for that. We show how the NHS – at an institutional and cultural level – fails to take patient experience evidence seriously enough. And we call for a few simple and entirely feasible steps that would strengthen evidence-based practice and ensure that the patient voice is better heard.



1. EVIDENCE

Evidence based?

Medicine prides itself on being evidence-based.

The National Health Service (NHS) makes this explicit: the opening chapter of the NHS Long Term Plan says that the service has “a strong scientific tradition of evidence-based decisions about care”.¹

A quick look at medical culture and practice seems to confirm this. Clinicians have access to huge databases of medical research. Their training and professional development are informed by research, and their clinical guidelines, practice protocols and diagnostic aids are evidence-based. Conferences and journals help busy practitioners keep abreast of a non-stop flow of new findings.

Medical research is progressing all the time, but even when older evidence becomes outdated, it is not abandoned. Clinicians understand the importance of organisational memory, so historical evidence is cherished and preserved in well-maintained archives.

Medicine respects evidence.

Or rather, it respects medical evidence.

Evidence biased?


There is another strand of evidence in healthcare that is less well respected. It comes from patient feedback, and it describes people's experiences of care.

The NHS works to a principle established by the 2008 Darzi review²: that high quality healthcare is built on three pillars – clinical effectiveness, patient safety and patient experience.

The report does not set out a hierarchy – all three are of equal importance.

In spite of this, the NHS repeatedly fails to accord the same respect to patient feedback as it does to other forms of evidence.





2. LANGUAGE REVEALS CULTURE

I report. You complain.

The terms that healthcare systems use to describe different types of evidence can be revealing. We can start with the language of complaints.

When a health professional flags up something that has gone wrong, it is called an incident report. But when a patient does the same, it is called a complaint. The word “complaint” is synonymous with words like “objection”, “grievance,” and “criticism”. In contrast with the calm objectivity of “incident report”, the term “complaint” sets a negative tone.

It is perhaps unsurprising, then, that research finds health professionals having difficulty in seeing complaints as evidence.

Some see complaints as “a breach in fundamental relationships involving patients’ trust or patients’ recognition of their work efforts”³. Consequently, it is “rare for [professionals] to describe complaints raised by patients as grounds for improving the quality of care”⁴.



We're hard. You're soft.

A similar language problem affects wider patient feedback—from the Friends and Family Test⁵, patient surveys, focus groups, social media posts, and so on. This is frequently described as “anecdotal evidence.”

The term indicates a tendency to see patient feedback as subjective, irrational, and potentially unreliable. The phrase “soft evidence” is also used to distinguish patient feedback from the “hard evidence” of statistics.

Research, however, has shown that healthcare statistics are easily manipulated—for example through intimidating staff to achieve performance targets, or by distorting the process of care to misrepresent actual performance⁶.

This was amply illustrated during the 2020 Covid-19 crisis, with the UK government's release of questionable statistics⁷ on the quantities of personal protective equipment distributed, on the scale and effectiveness of “test and trace”, and on infection and death rates.

“Hard data” is sometimes not hard at all. It can be flexible, slippery, elusive.



My records. Your stories.

In yet another verbal twist, comments from patients and service users are often described as “patient stories”. But health professionals who give their own accounts of care processes are never described as “telling stories”. They are credited with the much more serious work of “keeping records”.

The difficulty here is that record-keeping, too, can be abused.

Numerous avoidable harm inquiries have shown how dysfunctional professional and organisational cultures can put reputation before truth. At Gosport⁸, Mid Staffordshire⁹, Morecambe Bay¹⁰ and elsewhere, defensiveness, collusion and cover-up were common factors.

Inquiry reports describe “denial that any problem existed”¹¹, and tell of families who “had their experiences denied and their motives questioned”¹². Investigators have stated that the “reticence of some clinicians and healthcare professionals to concede error or identify the underperformance of colleagues was frustrating and depressing”¹³ and that “The obfuscation by those in authority has often made the relatives of those who died angry and disillusioned”¹⁴.

Patient stories may indeed be unreliable at times. But, sometimes, the same can apply to professionals’ stories.




The double standard

These terms – “incident reports” versus “complaints”, “hard” evidence versus “soft” or “anecdotal” evidence, professional “records” versus patient “stories” reveal a culture in which some forms of evidence are seen as more equal than others.

When it comes to “evidence-based decisions about care”, there seems to be a double standard.





**3. IF YOU
CANNOT FIND
THE EVIDENCE
YOU CANNOT
USE IT**

37 varieties

On the clinical side, the NHS is well supplied with medical research databases. Evidence is extensively catalogued and archived, ensuring that healthcare has ready access to the raw material it needs for policymaking, professional training and clinical guidance. In patient experience, the situation is somewhat different.

Patient experience evidence gathering is carried out via the Friends and Family Test, the CQC national patient surveys (adult inpatients, children and young people, community mental health services, maternity services, and urgent and emergency care) and the NHS England national patient surveys (cancer services and GPs).

Alongside these are thousands of reports emanating from 150 local Healthwatch organisations, as well as from health charities and other patient voice organisations.

Academic studies add to the mountain of literature, while NHS Trusts and Clinical Commissioning Groups carry out their own surveys and focus group work.

One recent study¹⁵ identified no fewer than 37 different types of patient feedback on offer to staff within UK hospitals.



Flying blind

The output from this welter of activity is published across hundreds of different websites.

Some are poorly maintained, so links get broken, pages go out of date, and evidence gets lost.

Even dedicated patient experience staff can find it hard to know where all the evidence is held. One is reported as saying “...you’re flying blind with your service and you’re just picking out bits of data from everywhere”¹⁶.

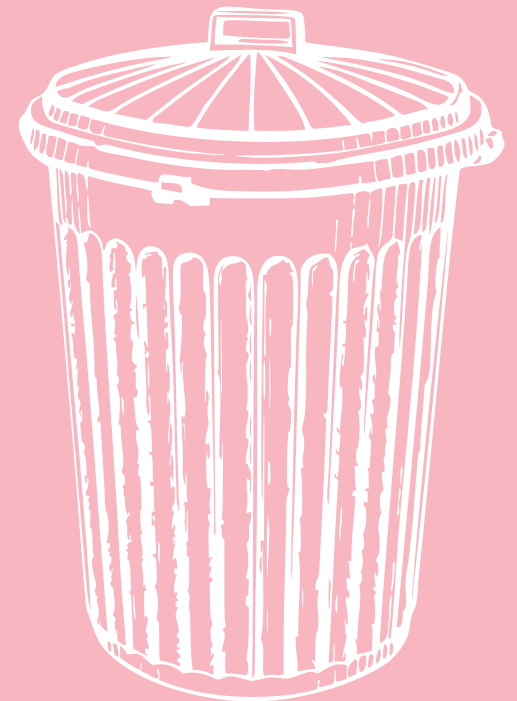
Another said, “We are data rich, but we don’t bring it all together... It’s a nightmare to see what’s going on”¹⁷.

Waste

The loss of evidence has been relentless. Government has invested heavily in “patient voice” initiatives, starting with the establishment of Community Health Councils in the 1970s. Those were succeeded by Patient and Public Involvement Forums, then by Local Involvement Networks and latterly by Healthwatch.

All gathered large volumes of evidence on patient experience, but it was never properly archived. So as each initiative shut down, its entire body of knowledge went with it.

While medical evidence is cherished, patient experience evidence has been treated as disposable.



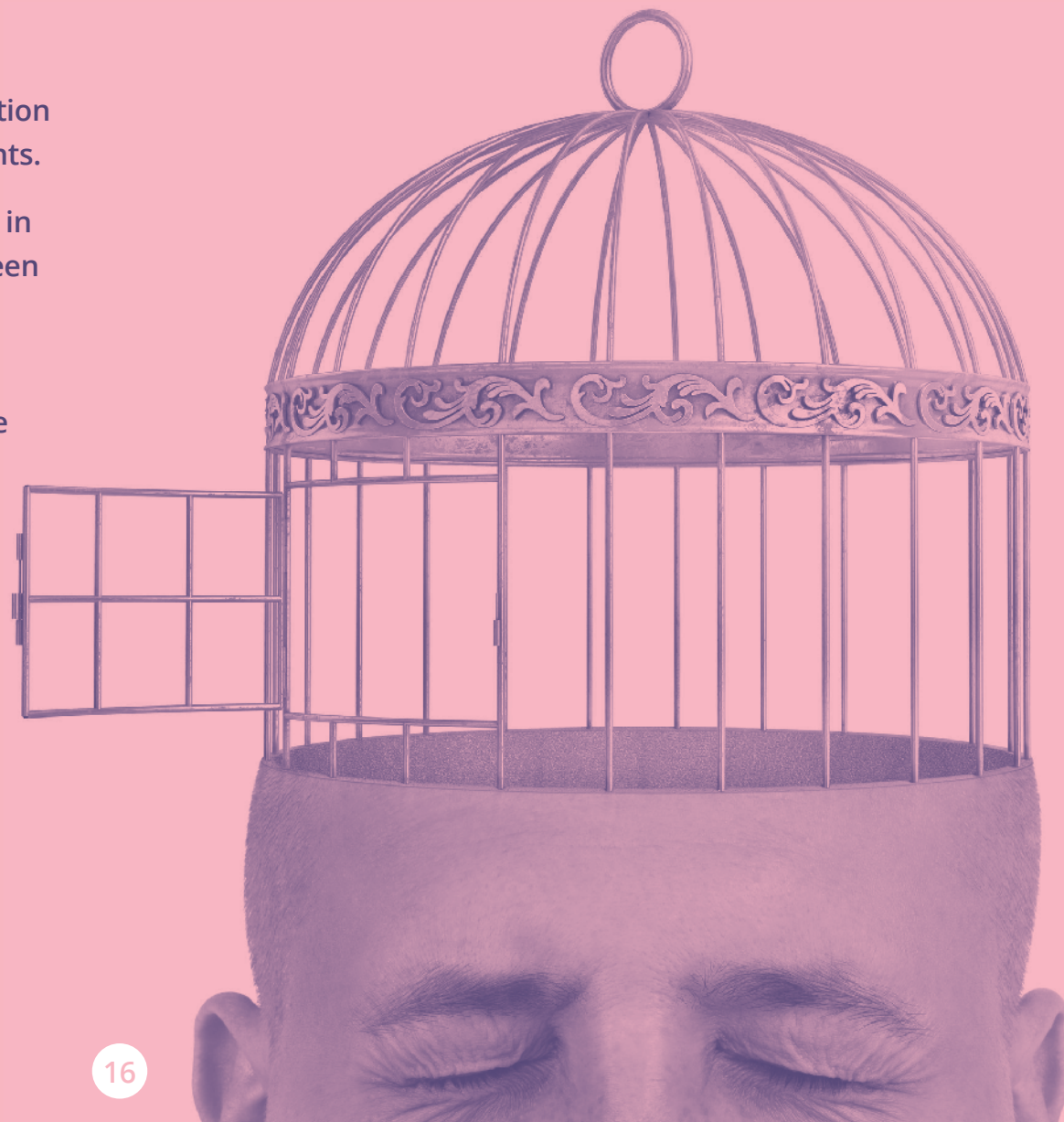
Amnesia


In 2000, the Department of Health published “An organisation with a memory”¹⁸ – a report on learning from adverse events.

In the foreword, the then Health Secretary said “Too often in the past we have witnessed tragedies which could have been avoided had the lessons of past experience been properly learned”.

But twenty years on, with its continuing failure to preserve testimony from patients, the NHS remains unable to learn from past experience.

It is an organisation with an incomplete memory.





4. THE EVIDENCE PRACTICE GAP

Quantity vs quality

Evidence on patient experience is gathered in large volume by many different organisations.

The Friends and Family Test alone can bring in over one million comments per month¹⁹. The 2020 GP patient survey had nearly three quarters of a million respondents²⁰. Other national surveys have tens of thousands of respondents.

Unfortunately, the evidence is not always well used.

“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.”²¹

“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.”²²

“...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.”²³

Skills

So what are the barriers to making sense and making use of patient experience evidence?

We have seen that some barriers are cultural, as revealed by use of language. Some arise from the difficulty in tracking down patient experience evidence in the first place, and from the failure to preserve it. But some relate to a lack of skills and capacity among patient experience staff.

"...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."²⁴

"...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."²⁵

"...only around one-quarter [of patient experience leads] were able to collect, analyse and use patient experience data in inpatient settings to support change."²⁶

Muddle

Once again, we can see a difference between the use of medical evidence as against the use of patient experience evidence.

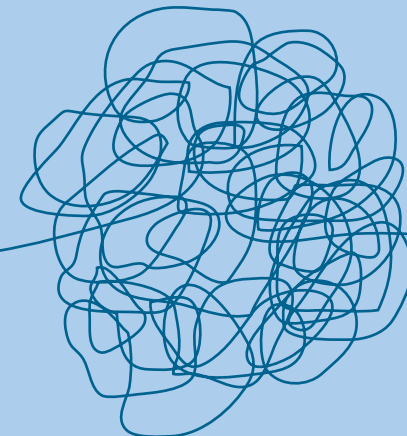
Clinicians are faced with vast quantities of medical evidence. It would be entirely unreasonable to expect them to read and assimilate it unaided. So medical evidence is embedded in clinical practice via professional training, clinical guidelines and diagnostic aids.

The work of knowledge translation is done for clinicians so that they do not have to do it for themselves.

There is, by contrast, no standard training for patient experience staff, and no professional development pathway. The Parliamentary and Health Service Ombudsman has recently commented that complaints managers, for example, “often receive limited access to training and are asked to address serious and complex issues with little assistance”²⁷.

Analytical tools are few and far between and there was, until very recently, no professional journal for patient experience staff. The one that now exists²⁸ is run on a voluntary basis, with no funding support.

While clinicians are actively helped to deliver evidence-based practice, patient experience staff are expected to muddle through.





5. WHEN THE PATIENT VOICE GOES UNHEARD, PEOPLE DIE

Early warning

Patient feedback is sometimes seen as trivial – involving grumbles about appointments, car parking and hospital food. It is seen as less important than clinical care, where mistakes could lead to the death of a patient.

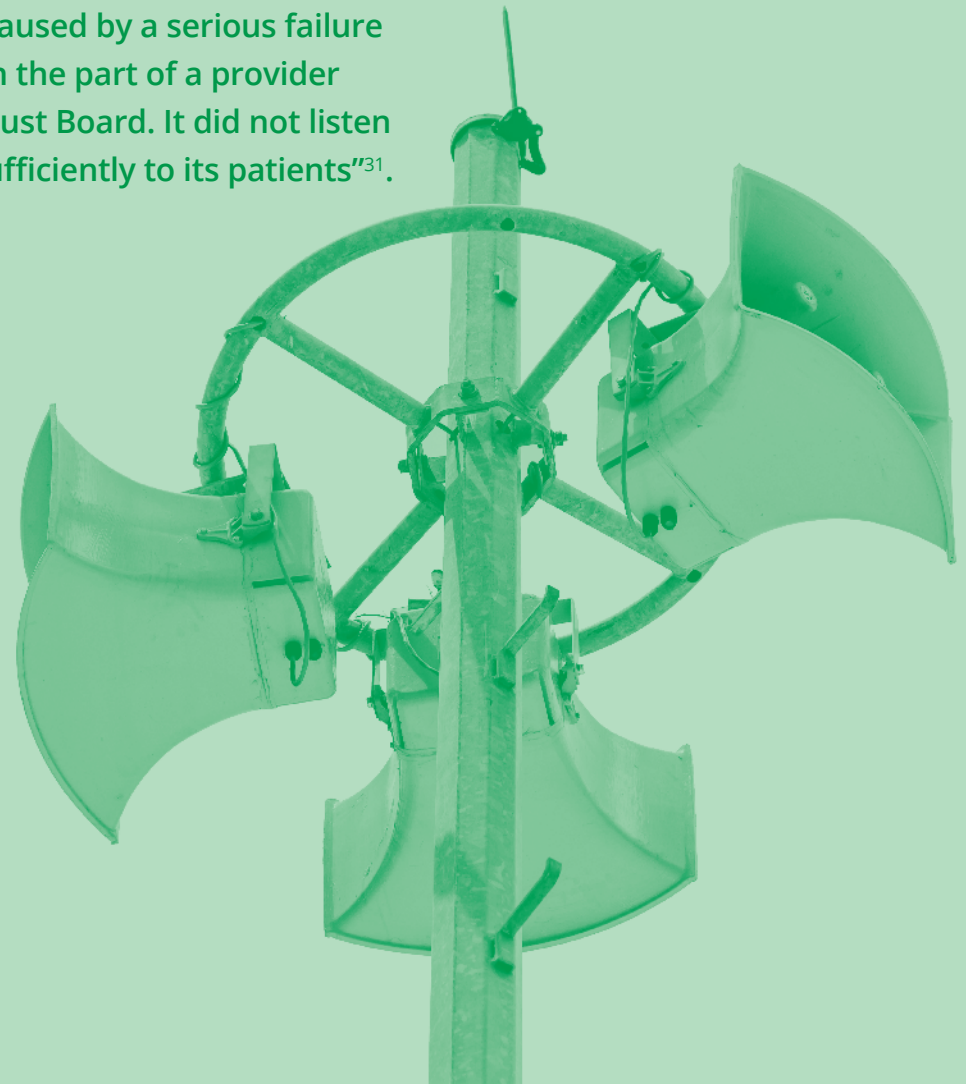
But ask any GP about their caseload and they too will describe the minor complaints – headaches, earaches, stomach aches – that they have to deal with day in and day out.

Doctors know that attending to apparently trivial matters is important, because minor complaints could be the first signs of much more serious illness.

The same is true in patient experience work.

The routine gripes of dissatisfied patients are what Sir Robert Francis called “the early warning signs that something requires correction”²⁹. It was the failure to take patient feedback seriously that led, at the Mid Staffordshire NHS Foundation Trust, to what Francis described as the “appalling suffering of many patients”³⁰.

Their suffering was, he said, “caused by a serious failure on the part of a provider Trust Board. It did not listen sufficiently to its patients”³¹.



Ignoring the alarms

Two years after Francis, the Kirkup report into avoidable harm and death at the Morecambe Bay Trust described “repeated failures to be honest and open with patients, relatives and others raising concerns”³².

Since then, reports with similar observations have been coming in at the rate of more than one per year – from Southern Health³³, Gosport³⁴, the Northern Ireland Hyponatraemia Inquiry³⁵, and Cwm Taf in Wales³⁶.

Ombudsman’s reports such as Learning from Mistakes³⁷, Ignoring the Alarms³⁸ and Missed Opportunities³⁹ have added to the pile, as has the independent inquiry into Paterson⁴⁰.

The most recent is the Cumberlege review, which had this to say: “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.”⁴¹

Different times, different places, different providers and services. But running all the way through is a failure to take seriously the concerns raised by patients and relatives.

Their testimony is not seen as evidence. It is not deemed worthy of serious investigation. It is not taken as a prompt for action. It is swept aside – met with disdain or outright denial.

So patients suffer and die – needlessly, and in large numbers.





6. IT IS NOT A
CONSPIRACY,
IT IS A
CULTURE

The evidence blind spot

There is an evidence blind spot in healthcare. Medical evidence is taken seriously and embedded in policy and practice. Patient experience evidence – meant to have equal standing – is looked at askance.

The disparity is not accidental. But neither is it deliberate, in a conscious or conspiratorial kind of way.

It is cultural.

The Care Quality Commission spotted this in 2019, when it reported on take-up of Learning from Deaths guidance.

In his foreword, the Chief Inspector of Hospitals said, “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”⁴².

A year later, Cumberlege described “a culture of dismissive and arrogant attitudes that only serve to intimidate and confuse”⁴³.



There are no bad apples

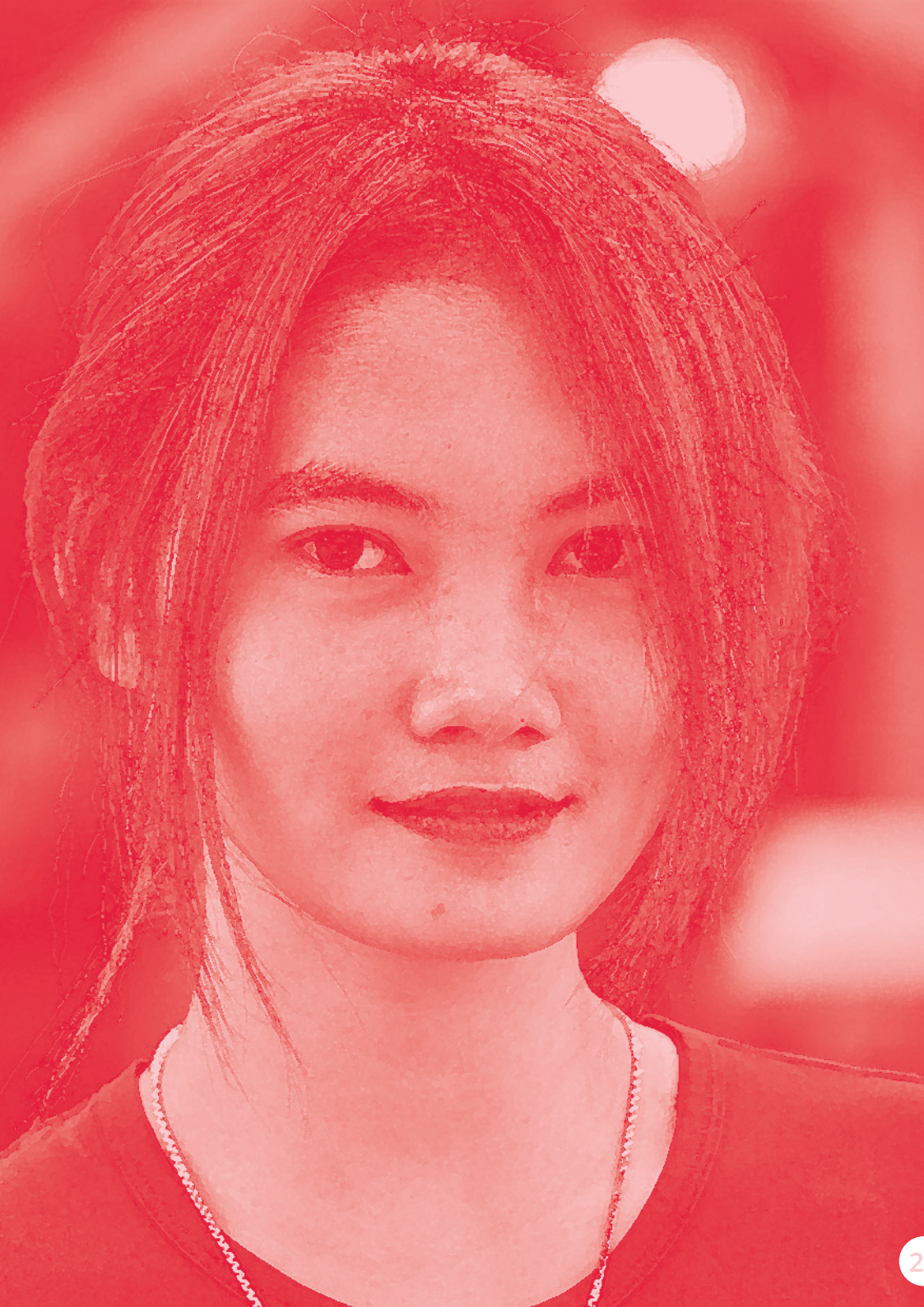
Culture is hard to change – not least because when some practices are just “the way we do things around here”, staff can become oblivious to the impact of their own behaviour and attitudes.

Hence the evidence blind spot: if you don’t see patient feedback as evidence, you won’t use it as evidence. If you see it as a lesser form of evidence, you’ll pay less heed to it. If you don’t consider it worth preserving, you won’t learn from past mistakes.

But organisational culture does not arise in isolation. So it is not enough to set up inquiry after inquiry, looking at culpable organisations one after another, and pursuing a never-ending “bad apple” theory.

NHS Trusts operate within an overarching national culture which – for all the reasons set out above – gives implicit messages that patient experience evidence is not all that important.

And this is why every single year in healthcare, we relive the Groundhog Day of Mid Staffs and Morecambe Bay and Southern Health and Gosport – and every single report tells the same story of patient experience evidence being ignored or suppressed.



7. REMOVING THE BLIND SPOT

Breaking through the double standard

In 2015, frustrated by the lack of a national evidence base for patient experience, we – the Patient Experience Library⁴⁴ – decided to build one.

When we asked for help, we were told by national health bodies that the task would be too difficult or too expensive. We were not convinced. Big medical research databases are deemed both feasible and affordable, so why should a research database for patient experience be any different?

The answer, of course, is the double standard.

Undeterred, we pressed on, and now the Library holds over 60,000 documents on patient experience and patient/public involvement.

For the first time ever, the NHS has a national evidence base for patient experience. It has all the raw materials it needs for policymaking, training, guidelines and analytical tools – and they are all in one place.

All we need to do now is start using them.

Tactics

Determined to stem the loss of historical evidence, we have created an archive. Among its contents are 12,000 reports from the Healthwatch network⁴⁵, dating back to its inception in 2013. Next time government decides it needs a new patient voice initiative, we will not see the legacy of the current one being scrapped.

We know that NHS staff struggle to keep track of the many sources of patient feedback. So we have given every NHS Trust in England a “one-click” access point⁴⁶ for their key patient experience datasets.

New surveys and studies are published all the time, and it can be hard to keep up with the flow of information. So we produce a series of publications⁴⁷ including weekly summaries of new research, along with a quarterly journal and an annual “Patient Experience in England” overview.

It is not difficult to do these things. In the world of medical evidence, they are taken for granted. In patient experience work, we need to move to a similar position – one where it goes without saying that evidence will be taken seriously and used well.

Strategy

In 2019, there were around 70,000 visits to the Patient Experience Library and 100,000 document downloads. There is clearly – among individuals at least – an appetite for patient experience evidence.

But we need to get a similar enthusiasm embedded at the system level. That means taking further steps to put patient experience work on the same kind of evidence-based footing as clinical work. We want to...

END THE WASTE. No-one in the NHS has a strategic overview of strengths and weaknesses in the patient experience evidence base. So there are hundreds of duplicate reports on issues such as access to GP appointments, and huge gaps in matters such as disadvantaged communities' experience of services. We are desperately keen to get an independent assessment of the evidence base, so that research effort can be better targeted.

BUILD THE TOOLS. It is well known that patient experience teams lack analytical capability. We have built basic tools into the Patient Experience Library, but we dream of more and better analytics, to get the evidence better understood.

PROFESSIONALISE THE PRACTICE. Patient experience staff and patient representatives lack systematic, evidence-based training. Our library contains essential building blocks for courses and curricula. We hope that someone will seize the opportunity to build a professional learning infrastructure.

Mission

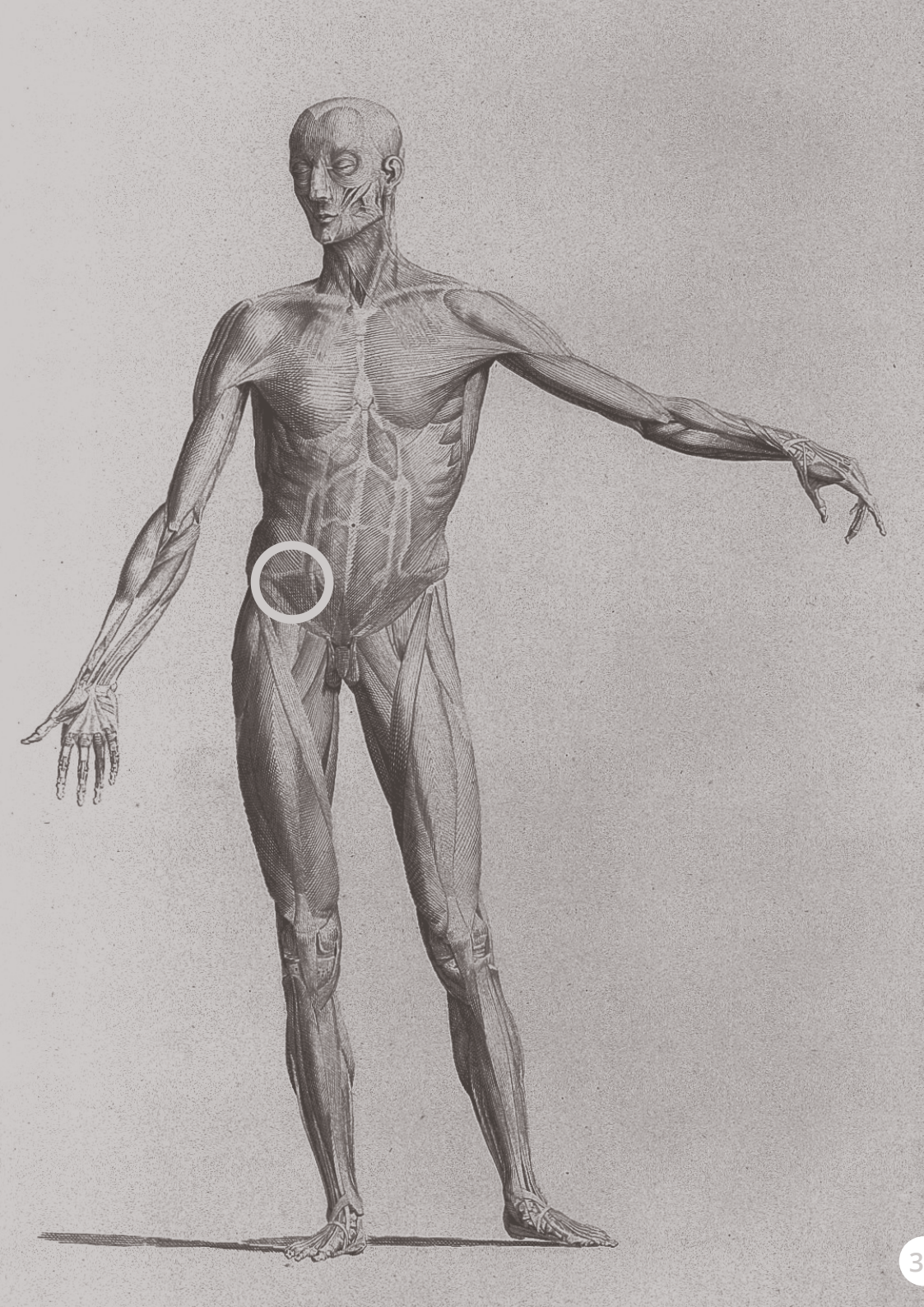
We are on a mission to get patient experience evidence taken as seriously as medical evidence.

We believe that the culture in medicine is already starting to shift. There are many, many health professionals who understand the value of patient feedback – not just as “stories” or “complaints”, but as evidence. Sooner or later, the NHS – at the institutional and system level – will begin to catch up.

In the meantime, we are propelled by comments like this, from the Cumberlege review:

“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.”⁴⁸





APPENDIX: WHY THIS MATTERS

2013 Mid Staffordshire

...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.

2015 Morecambe Bay & Southern Health

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.

...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.

2016 Learning from Mistakes and Learning, Candour and Accountability

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.

...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... 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.

2017 Ignoring the Alarms

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... 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.

2018 Hyponatraemia and Gosport

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.

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.

2019 Cwm Taf, Learning from Deaths and Missed Opportunities

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.

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.

Overall the investigations into Matthew's death were not adequate. [The report] lacks credibility because it was written by a member of staff who was later found to have been involved in the falsification of Matthew's care plan... Matthew's family was not as involved in the investigation as they should have been.

Parliamentary and Health Service Ombudsman, 2019. Missed opportunities: What lessons can be learned from failings at the North Essex Partnership University NHS Foundation Trust. Pages 18, 20.

2020 Paterson and Cumberlege

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. 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. February 2020. Page 1.

...the healthcare system...is disjointed, siloed, unresponsive and defensive. It does not adequately recognise that patients are its raison d'être. 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

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