

# Patient Experience in England



# Foreword



**S**haping services in response to customer feedback is essential in a competitive world. Insight into people's experience and what they value is crucial to survival in most industries. As a result we have become inured to invitations to push smiley and not so smiley faces at the exit of retail outlets and airports and fill in online surveys after accessing any form of service this way. The NHS, a massive service industry, is also an assiduous collector of feedback data, but as a near monopoly provider the rationale is rather different. The aim of collecting data is primarily to fuel a quest to provide more responsive and person centred care.

This report from the Patient Experience Library collates and catalogues NHS patient experience literature, looks at the nature and extent of the organisation's feedback enterprise, outlines major findings from recent quantitative and qualitative surveys, and raises critical questions about its value. It also illustrates the point that with the exception of *Care Opinion* the organisation remains largely wedded to yesterday's methods of getting feedback from service users, not least via the ubiquitous paper based NHS Friends and Family Test.

The most worrying of the report's headline conclusions is that little progress has been made in tackling the entrenched and widely acknowledged problem of a failure to systematically collate, analyse, and use the data to improve the quality of services. It states that "eagerness for collecting [data] dissipates into confusion as busy staff struggle to transform reams of patient comments into useful information." This in turn raises important questions around the ethics of collecting data and then failing to use it.

Among the most interesting observations is that crucial "whispers" from patients can be hidden in written feedback. The report also makes the important point that some staff are inclined to see critical comments from patients as complaints from "the inexpert, distressed and advantage seeking" rather than valuable insights into where the care they provide is less than optimum. There is also discussion of how staff experience tracks to patient experience. A topic of much current concern in a climate where staff morale is low and work pressure mounting.

The report stops short of suggesting major change to the patient experience feedback enterprise in the NHS, nor does it advocate for an evaluation of its methodologies. But it does suggest ways to improve the status quo, where its main advocacy is for greater investment in supporting the staff who are responsible for collecting, and promoting understanding of patient experience data, and handling public engagement and complaints.

Looking to the future the suggestion is made that machine learning may help providers track and appraise information, including the massive volume of unstructured comments that are being made about care on social media. But for now, it concludes "distilling messy patient data into clear and actionable insight" is best left to humans. And here it's clear that those in charge of decisions about what data to collect and how it is used need to do a better job.

Tessa Richards  
Senior Editor BMJ/Patient Partnership

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And last but not least, everyone who reads and comments on our newsletter and quarterly journal, and who engages with us via Twitter. Keep the feedback coming!

# Introduction



**A**t the heart of a patient-centred NHS is a solid understanding of patient experience. So we want to see an NHS that takes patient experience evidence as seriously as it takes clinical evidence.

We have already done the hard bit, by putting all of the UK's patient experience literature in one place. And this year, we reached an important milestone, with 50,000 documents on patient experience and patient/public involvement now fully catalogued within the Patient Experience Library. That's a huge body of evidence, and our commitment is to help NHS staff and Boards make sense of it. Here's how:

- **MONITOR.** We constantly look for new evidence on patient experience and patient/public involvement - from formal sources as well as from "grey literature". Every document is catalogued and preserved, then linked to powerful search functionality for fast and accurate retrieval.
- **HELP.** We help policymakers, commissioners and providers to make sense of the evidence, through *Knowledge Maps*, *Insight Reports*, a *quarterly journal* and a weekly *research-based blog*. And we're identifying overlaps and gaps in the evidence, to help researchers avoid duplication, and focus their efforts where they're really needed.
- **NORMALISE.** Patient experience work needs to be central within a patient-centred NHS. That means that patient experience staff should have the kind of access to knowledge and learning that clinicians take for granted. They should have a professional qualification, and continuing professional development. They should have analytical tools to help translate evidence into practice. And they should have access to the whole of the patient experience evidence base as a matter of course. We're looking for partners who can help us make these things happen.

This document is our annual "state of patient experience" report for the NHS in England. We hope you'll find it an interesting and useful read. If you'd like to get in touch with us, please do.

*Miles*

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# 1. Making sense of patient experience

The NHS wants to be patient-centred. We know this because all its key strategies say so.

To be patient-centred, it has to have a good understanding of patient experience. But successive studies have shown that healthcare commissioners and providers struggle to make sense of patient experience evidence. This creates an evidence-practice gap, as we reported last year (*Patient Experience in England, 2017 edition*).

Here, we explore these issues further, and put forward some solutions.

## 1.1 Too much data

Back in 2015, a report entitled *Making Sense and Making Use of Patient Experience Data* showed how patient experience staff can be overwhelmed by multiple datasets coming from national patient surveys, Friends and Family Test, local Healthwatch reports, NHS Choices, online feedback and more. It commented that *“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”*.

Three years on, not much has changed.

A 2017 paper entitled *Lending a hand* notes that *“Patient feedback is a potentially useful source of information which could be used to drive improvement”*. However, *“It appears as though enthusiasm for its collection is not quite matched by the capacity to turn data into insight”*. The authors find that *“the eagerness for collecting [data] dissipates into confusion as busy staff struggle to transform reams of patient comments into useful information”*.

In April 2018, *a paper on the “usefulness and use” of patient surveys* dug further into the topic. It said: *“Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it...”*. It added that *“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.”*

## 1.2 Too little investment

The NHS draft workforce strategy (*Facing the Facts, Shaping the Future*) was published in December 2017. We looked forward to reading about better support for NHS staff undertaking the vital tasks of understanding patient experience, managing public engagement and handling complaints. We were disappointed.

The draft workforce strategy had nothing to say about investment in patient experience work. It had nothing to say about training and continuing professional development for patient experience staff. It had nothing to say about offering easier access to patient experience evidence, or developing analytical tools to help make sense of it.

In an NHS that wants to be patient-centred, this seems odd. But it is not just within the NHS that patient experience workers get a raw deal.

Alongside the NHS, the biggest single source of qualitative evidence on patient experience is the local Healthwatch network.

In December 2017, Healthwatch England took the step of publishing a letter to the Secretary of State for Health, along with a *briefing note* describing a 37% reduction in funding since the network's first allocation in 2013/14. They said that the cut was "*putting at risk the ability of the network to deliver on its statutory obligations*".

Healthwatch was set up in the wake of the Francis Inquiry into "appalling suffering" and avoidable deaths at the Mid Staffordshire Trust. It was meant to be a stronger and more effective patient voice organisation than its predecessor, the Local Involvement Network. But it is hard to see how it can fulfil that expectation with the financial rug being pulled each and every year since its inception.

## 1.3 A better deal...

The evidence is clear: if staff have good experience of care, so do patients (see section 3.3 below). A workforce that is nurtured, developed and supported will have a better chance of giving patients the best possible care.

Patient experience staff are central to this. And they deserve better support.

During Experience of Care week (April 2018), we took to *BMJ Opinion* to make the case for a better deal for patient experience staff. We called for better professional recognition, and a structured learning pathway covering disciplines such as complaints handling, data analysis, risk management, and quality improvement. We said that patient experience staff should have analytical tools to help them make sense of the mass of data that comes their way. And we suggested that they should have automatic access to the UK evidence base on patient experience, in the same way that clinicians get automatic access to medical databases.

We hope that senior managers in Trusts, CCGs and NHS England are listening. But in the meantime, we're continuing to provide front line staff with tools to help them make sense and make use of patient experience evidence. Over the last year we have:

- Launched a series of *research-based blogs*, offering weekly updates on the latest patient experience evidence.
- Published the *Patient Experience in Trusts* map, putting all the key patient experience evidence for the English Trusts together in one place.
- Launched the *Patient Experience quarterly magazine* - the UK's first professional journal for patient experience work.

For the 70th anniversary of the NHS, we made available a specially commissioned set of *patient experience posters*, based on quotes from the Francis Inquiry, the Darzi review and the Berwick review. We hope that these will be on the walls of CEO's offices and Boardrooms, as well in wards and waiting rooms.

Last but not least, we reached the huge milestone of 50,000 documents on patient experience and patient/public involvement catalogued and preserved in the Library. Patient experience work needs to be central within a patient-centred NHS, in the same way that clinicians have access to large databases of medical research. We look forward to a dialogue with NHS England on this topic.

## 2. What we learned in the last year: Surveys

This year's crop of surveys offers useful insights into patient experience across a range of health services. Each provides valuable evidence in its own right. But looking back over a year's worth of survey findings, it is possible to join the dots, and see some underlying themes emerging.

The CQC national patient surveys, for example, shed light on the experiences of people with mental health conditions.

The Children and Young People's Survey, the Adult Inpatient Survey and the Emergency Department Survey all revealed poorer experiences of care for people with mental illness. A fourth survey - Women's Experiences of Maternity Care - found that *"Half of all women reported that they had questions or concerns about their mental wellbeing, which they were not able to raise"*. Finally, the Community Mental Health Survey showed little sign of improvement for *"substantial concerns"*, and stated that services *"have even declined slightly in key areas"*.

The findings make a nonsense of Prime Minister Theresa May's claim that mental illness is a *"hidden injustice"*. The injustices are in plain sight, and the evidence could not be clearer.

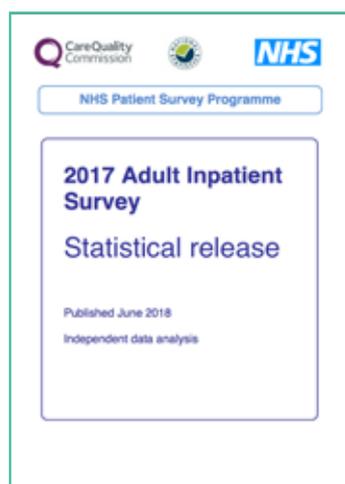
Another cause for concern is hospital discharge, which remains one of the weakest areas of patient experience. 19% of respondents to the Adult Inpatient survey thought hospital staff did not take their family or home situation in to account when planning their discharge, while a quarter (25%) of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital. This feedback is echoed in the Emergency Department survey, where nearly half of respondents (45%) reported being discharged without any account being taken of their family or home situation.

Problems with hospital discharge have also been repeatedly highlighted in local Healthwatch reports, going as far back as 2013. If patient experience of hospital discharge remains poor, it is not for want of evidence.

We have also included in this section a couple of surveys which give a wider sense of public attitudes to, and satisfaction with, the NHS. They reveal a continuing public commitment to the founding principles and values of the NHS, together with a sense that services are significantly underfunded.

Summaries of survey findings are below - for further detail, click on the report pictures.

## 2.1 Adult inpatient survey



The survey shows consistent improvements over time in how well doctors and nurses care for patients. 78% of patients said they “always” had confidence in nurses this year, compared with 72% in 2009. And fewer patients now say that doctors had spoken in front of them “as if they weren’t there” (23% compared with 29% in 2009).

Hospital discharge, however, remains one of the weakest areas of patient experience for adult inpatients.

19% of respondents thought hospital staff did not take their family or home situation into account when planning their discharge, while a quarter (25%) of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital.

Less than two-thirds of patients (62%) left hospital with written information telling them how to look after themselves post discharge, a figure which has deteriorated since 2013 (67%).

The problem is not just with hospital staff. 17% of survey respondents said they left hospital not knowing what would happen next with their care, and 22% said they did not receive enough help from health or social care professionals to help recovery or to manage their conditions.

## 2.2 British Social Attitudes



This report, using data from the British Social Attitudes survey, looks at general public satisfaction with the NHS.

The good news is that *“the NHS remains a treasured national institution that is a key part of the British national identity. The public is unwavering in its support for the underlying principles of the NHS and consistently prioritises the health service for extra government funding”*.

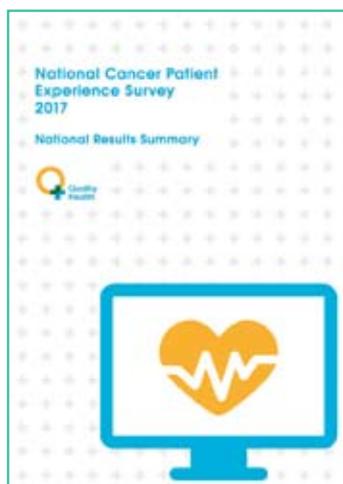
The bad news is that *“public dissatisfaction with the NHS grew to 29% in 2017 – the highest level of dissatisfaction with the NHS since 2007”*. Further, *“Dissatisfaction with the NHS has risen*

*rapidly over the past three years: between 2014 and 2017, the level of dissatisfaction almost doubled”*.

The top two reasons for satisfaction were *“quality of care”* and *“free at the point of use”*. The top two reasons for dissatisfaction were *“not enough staff”* and *“takes too long to get an appointment”*.

The conclusion to the briefing states that *“With an increase over the last few years in the proportion of survey respondents reporting lack of funding as a reason for their dissatisfaction, it seems the public is increasingly aware of the reality of funding pressures that the NHS has experienced”*.

## 2.3 Cancer patient experience



This year's Cancer Patient Experience Survey brought encouraging findings, with significant improvements across a range of indicators.

91% of respondents said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment. And 86% said that it had been 'quite easy' or 'very easy' to contact their Clinical Nurse Specialist.

Alongside that, 89% of respondents said that they were treated with respect and dignity in hospital, and 79% said they were definitely involved as much as they wanted to be in decisions

about their care and treatment.

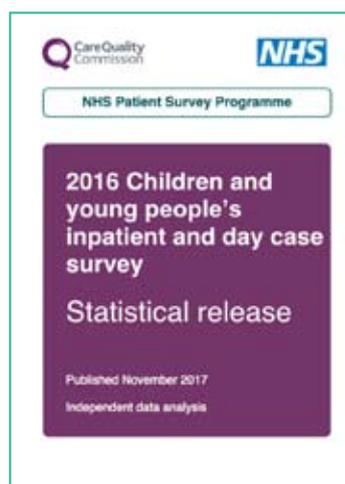
On information giving, the picture is less good, and a comparison with the Adult Inpatient Survey (2.1 above) is instructive.

In the Adult Inpatient Survey, a quarter (25%) of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital. In the cancer survey, only 59% of respondents said that the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home.

Additionally, the Adult Inpatient Survey found that less than two-thirds of patients (62%) left hospital with written information telling them how to look after themselves post discharge. For the cancer survey, patients were asked if they had a written care plan, but found that only one third (35%) said that they had been given one.

Since NHS strategies stress the importance of "self-management" for people with long term conditions (including living with and beyond cancer) the issue of information giving is crucial. Differences in the way questions are asked may mean that the Cancer Patient Experience Survey and Adult Inpatient Survey are not directly comparable. But the similarities are striking, and taken together, the surveys seem to be pointing to an area that suggests room for improvement.

## 2.4 Children and young people



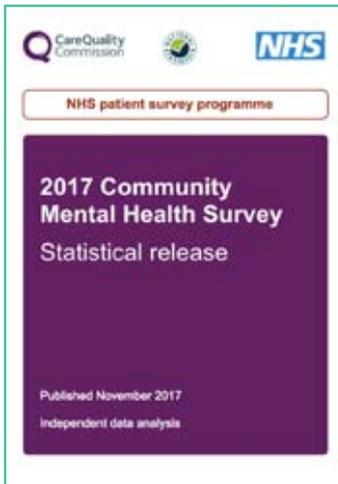
91% of children and young people said that they had been looked after 'very well' or 'quite well' while in hospital.

Communication was good - 86% reported that staff talked with them about how they would be cared for, and 90% were able to talk to a doctor or nurse without their parent or carer being there if they wanted to. However, 32% of children and young people said they did not always understand what staff said when they spoke to them, and 57% felt they were either not involved in making decisions about their care or treatment, or were involved 'a little'.

When asked about their child's overall experience in hospital, 81% of parents and carers rated it 'eight or above' out of 10. Most parents (92%) said they were given enough information about new medication prescribed to their child in hospital, and 91% said that staff agreed a plan for their child's care with them.

On the downside, over a third (36%) of parents and carers did not feel that staff were 'always' available when their child needed attention. More than a quarter (28%) felt that staff did not 'definitely' know how to care for their child's individual or special needs. Over a third of all parents and carers (38%) who wanted to prepare food while in hospital said they were unable to do so.

## 2.5 Community mental health services



In the 2016 survey of patient experience in community mental health services, the Care Quality Commission said that *“substantial concerns remain about the quality of care some people using community mental health services receive. There has been no notable improvement in survey results in the last year”*.

They suggested that there was *“scope for further improvements in a number of areas including: involvement in care, crisis care, care planning and reviews”*.

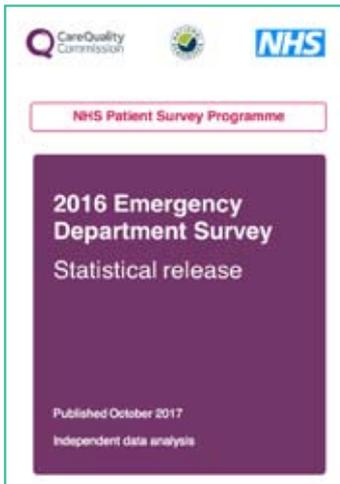
The 2017 survey results showed little sign of improvement. The CQC’s own headline was that *“patients’ experiences of these services across England have not improved and have even declined slightly in key areas”*.

The survey showed that:

- 26% of respondents said that they did not feel they got the help they needed from crisis care, compared to 21% in 2014.
- 25% of respondents reported they had not seen workers from their mental health services often enough to meet their needs in the last year - up from 21% in 2014.
- 68% of respondents felt listened to by their healthcare or social workers - down from 73% in 2014.

Especially troubling was *“a marked trend that the longer a person is in contact with mental health services, the worse the experience reported”*.

## 2.6 Emergency Departments

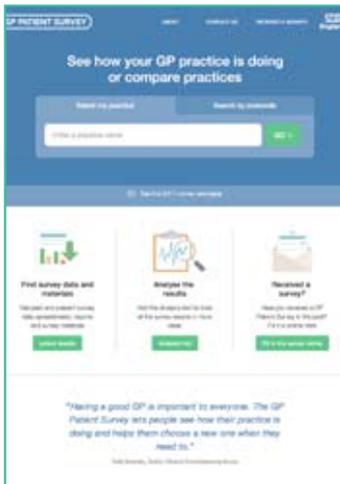


The CQC’s Emergency Department survey shed interesting light on the idea that many people misuse accident and emergency services. It found that 42% of respondents did not go to A&E as their first port of call - they used alternatives such as GPs, or the 111 and 999 numbers. But three-quarters ended up in A&E anyway because they were referred there by those other services.

Many patients - once in the Emergency Department - have a very favourable experience of the service. There are high levels of confidence in clinicians, and a significant majority feel listened to and respected (78%). Even more (82%) had enough privacy while being examined or treated.

On the other hand, less than half of those who were distressed felt that staff “definitely” reassured them. And nearly half (45%) reported being discharged without any account being taken of their family or home situation.

## 2.7 GP patient survey



The 2018 GP Patient Survey offers some good news, with generally high levels of satisfaction at the NHS’s front line of care. 93% of patients felt involved in decisions about their care and treatment. 87% felt their healthcare professional was good at treating them. And of everyone who wanted a same day appointment, 66% got one.

The survey method changed this year, so comparison with previous years’ results is problematic for most questions.

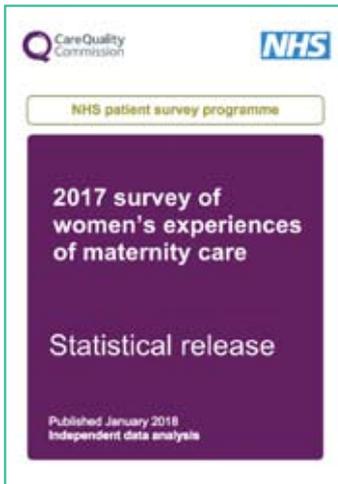
According to NHS England, the new method was necessary because the survey questions had not changed significantly since 2012 and so had not kept pace with changes in frontline general practice. Examples included the ways people make appointments, extended opening hours and the broader range of healthcare professionals now providing care at many surgeries.

The new survey allows for measurement of progress on commitments set out in the GP Forward View and the Five Year Forward View. It updates the terminology on some of the questions, includes additional questions and removes questions of limited use. It also, for the first time, included 16 and 17 year olds in the survey.

NHS England commented that “Evolution of national surveys is normal over time, along with the consequent loss of trend data from time to time, which is less important for us than measuring experience of the system as it is now”.

This year’s survey will now provide a baseline from which trends can be built over the coming years.

## 2.8 Maternity care



This survey showed “*small incremental improvements in results across almost every question that women were asked in the questionnaire*”, compared to the last survey in 2015.

Some of the key findings were that:

- More women in 2017 said they were offered the choice of giving birth in a midwife-led unit or birth centre than in 2013 (42% compared with 35%).
  - In 2017, 77% of respondents said they were never left alone during labour or birth if they were worried, compared with 74% in 2013.
- Various aspects of postnatal care showed significant improvement, although the fact remains that experience of postnatal care remains generally less positive than other aspects of the maternity pathway.
  - Women who said they did not see the same midwife throughout their antenatal care, and then did not see a consistent midwife during their postnatal care, felt their care was less compassionate than care for other women.

## 2.9 NHS at 70: public perceptions



The opener to this report indicates a gloomy outlook among the general public as to the long term future of the NHS. Only one in five people felt that the NHS would be free at the point of use in 70 years' time. 23% predicted that the NHS would not exist at all 70 years from now.

More than three quarters (79%) felt that the NHS is underfunded, and 54% are in favour of increasing taxation to fund greater NHS expenditure.

When it comes to staying healthy, the public are far more likely to put responsibility on the individual than on any other body or organisation. Almost all (97%) feel that individuals have a great deal or fair amount of responsibility for ensuring they stay healthy.

At the same time, most people support government interventions including limiting fast food outlets near schools (70%); restricting the advertising of unhealthy food and drink (68%); banning advertising of 'junk' foods before 9pm (67%); and imposing a 'sugar tax' on soft drinks containing added sugar (62%).

## 3. What we learned in the last year: Research

In this round-up, we look back over studies on patient experience and patient/public involvement, to get a sense of key learning points from the last twelve months. For full attributions, and copies of the original documents, click on the report pictures.

### 3.1 It's hard to hear the whisper

The Berwick Review (*A promise to learn - a commitment to act*) said that “*Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper*”. But hearing the whisper is easier said than done - as evidenced by this set of papers, published over the last year.



This paper from America’s Mayo Clinic describes how the patient voice can be reduced to a whisper when patients succumb to “hostage bargaining syndrome” (HBS), and start to behave as if negotiating for their health from a position of fear and confusion.

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. HBS is especially apparent when serious illness unfolds over the course of multiple, complex, emotionally laden interactions with clinicians. Cancer care and intensive care, for example, are characterised by a high degree of dependence and powerlessness for patients.

HBS can 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.



The problem may be compounded by a lack of capacity within patient experience teams: *“... 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...”*

The authors see a need for analytical tools to help hard-pressed staff separate the signal from the noise: *“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.”*

### 3.2 Our definitions are unclear



The phrase “person-centred” appears repeatedly in NHS strategies – but what does it actually mean? An editorial piece from the Journal of Clinical Nursing found that “person-centredness” is incompletely and poorly defined, leading to *“an unhelpful simplification of the concept”*.

One consequence is that evaluation is problematic: *“Given that we observe few clear definitions in use, then how can organisations evaluate person-centredness?”*

Furthermore, *“poorly considered definitions of person-centredness promote the view that person-centredness is... easier to implement than it is. This can lead to unnecessary burden or even guilt... 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”*.



The question of definitions is also picked up in a paper that looks at how we define patient and public involvement (PPI). It points to *“a lack of a common language to share PPI practice... the term PPI is not universal in its application or definition”*.

In spite of this, attempts to nail down a definition of PPI may not be helpful. They can lead to *“semantic intricacies”* and *“circular debates held primarily amongst academics”*.

The paper suggests aiming instead for a basic set of principles – clear enough to be commonly understood, but flexible enough to be applied across different PPI settings. It outlines a set of

“essential” and “desirable” PPI principles, assembled from the viewpoints of both patients and professionals.

Importantly, *“the principles suggested provide quality guidelines for best practice, not prescriptive rules... a ‘one size fits all’ approach to PPI would be inappropriate, as no single PPI initiative will work for all situations, individuals or agendas”.*

### 3.3 Staff experience affects patient experience

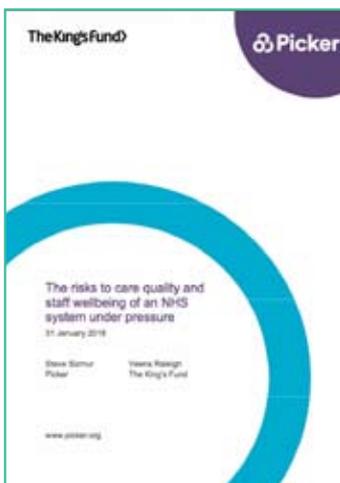
Through 2017 and into 2018, the NHS Workforce Strategy was being developed, consulted on and finalised. Over the same period a series of reports highlighted the connections between NHS staff experience and patient experience.



A study published in BMJ Open stated that *“when nurses have high patient loads... necessary nursing care can be missed because of lack of time”.* No surprises there perhaps.

But the study then looked at the types of tasks that get missed. It found that 7% of nurses reported that they lacked time to complete necessary pain management, and 11% missed treatments and procedures. But a staggering 52% reported lacking the time to educate patients and their families, and two out of three (65%) were unable to comfort or talk with their patients.

So when the pressure is on, some clinical care may suffer. But what really gets hit is the kind of person-centred care that is meant to be the bedrock of good patient experience.

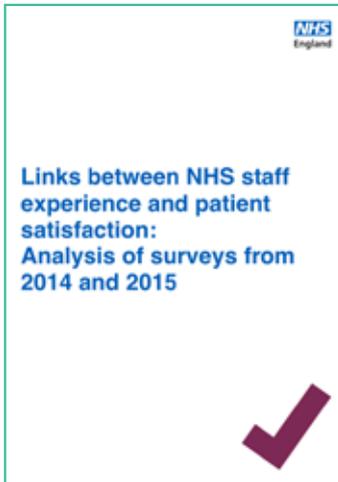


The Kings Fund and Picker Institute confirmed links between workforce pressures and patient experience. On busy wards with high bed occupancy, patient feedback was more negative, particularly in respect of getting comprehensible answers from nurses, and timeliness of response to call buttons.

Conversely, patients at trusts with more nurses per bed reported a more positive experience.

Patient experience was also negatively associated with higher spend on agency staff. The authors comment that *“The main focus of concern for spend on agency staff has been on financial savings; our analysis suggests that there are quality issues at stake as well”.*

The report states that *“work pressures and staff shortages in the NHS are escalating, and likely to worsen”*. In these circumstances, *“the risks to patient care are self-evident and it is important to monitor staff wellbeing and how it is impacting on patients”*.



This report took evidence from NHS staff experience surveys and considered how staff experience (good or bad) can be a predictor of good or bad patient experience. It found that *“there are some clear and strong associations between staff experience and how satisfied patients are... 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.”*

The report goes beyond quantitative matters such as staffing levels, to look at more qualitative aspects of staff experience. It found that organisational culture matters: *“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.”*

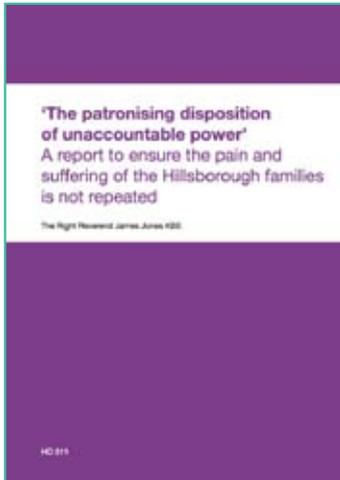


The Parliamentary and Health Service Ombudsman contributed a report that highlighted complaints arising from serious failings in NHS mental health services. It found that *“workforce challenges”* were a contributory factor.

*“The complaints... demonstrate how patient care and safety is jeopardised by these 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”*.

### 3.4 Learning from deaths

Towards the end of 2017, NHS England hosted two “Learning from Deaths” events – one for bereaved families and one for health professionals.

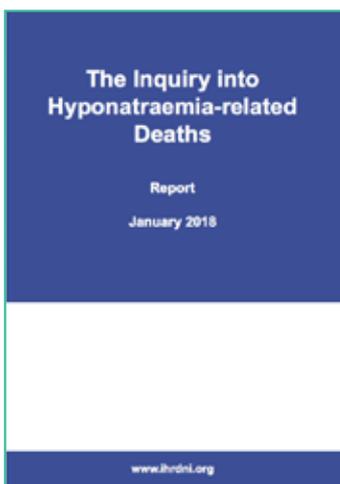


The events coincided with the publication of a report by Bishop James Jones, into the experiences of the Hillsborough families. It reveals striking parallels with the experiences of people who have sought justice following avoidable deaths within health and care services.

The Bishop remarked that *“The [Hillsborough] families know that there are others who have found that when in all innocence and with a good conscience they have asked questions of those in authority on behalf of those they love the institution has closed ranks, refused to disclose information, used public money to defend its interests and acted in a way that was both intimidating and oppressive”*.

He observed that a lack of honesty does not come from individuals – it is institutionally embedded. It is *“a cultural condition... an instinctive prioritisation of the reputation of an organisation over the citizen’s right to expect people to be held to account”*.

The report urged the Prime Minister and Home Secretary to *“ensure that those responsible for our national institutions listen to what the experiences of the Hillsborough families say about how they should conduct themselves when faced by families bereaved by public tragedy”*.



The Bishop’s remarks could easily apply to the findings of the Hyponatraemia inquiry into the deaths of five children in the care of health services in Northern Ireland. The children died in the late 1990’s and early 2000’s, but bereaved families had to wait until January 2018 for a full and final account of what happened.

The report describes *“an underlying institutionalised reluctance to admit major shortcomings”* and *“no acknowledgement of any of the very many failings in care”*. There was *“defensiveness, deceit and a strong inclination... to close ranks”*. Furthermore, *“clinicians did not admit to error for the obvious reasons of self-protection... this defensiveness amounted to concealment and deceit”*.



The Parliamentary and Health Service Ombudsman (PHSO) reported on the case of Averil Hart, who died of anorexia nervosa, aged 19. Her death resulted from *“multiple serious departures from the standards of care expected”*, and *“a long series of missed opportunities to recognise her deteriorating condition”*.

The PHSO examined the experience of Mr. Hart (Averil’s father) and found that *“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”*.

Responses to requests for information *“were delayed and appeared evasive, and information he requested was often not provided”*. Responses to complaints *“were equally unsatisfactory, and often appeared defensive or protective of the organisation concerned”*. There was *“a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection”*.

The report finishes by saying that *“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”*.



In June 2018, Bishop James Jones was back, with a report into more than 450 deaths at the Gosport War Memorial Hospital.

The foreword to the report said that *“what has to be recognised by those who head up our public institutions is how difficult it is for ordinary people to challenge the closing of ranks of those who hold power... 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’”*.

It went on to say that *“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. 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”*.

### 3.5 The robots are coming



“Wisdom of patients” describes a project carried out by specialists in risk analysis and behavioural science. They took large volumes of patient feedback on Trusts and hospitals, from sources including Twitter, Facebook and Care Opinion. They then applied a “collective judgement score”, and compared it with CQC inspection ratings for the services in question.

They found that on average, the better the patient feedback prior to a CQC inspection, the greater the likelihood of a more positive CQC rating. There is, overall, *“a positive association between the collective judgement score and subsequent inspection outcomes”*.

The paper concludes that *“The near real-time, automated collection and aggregation of multiple sources of patient feedback should be used to help prioritise inspections”*.

Another study looked at the increasing tendency among patients to bypass formal feedback mechanisms and air their views via Twitter, Facebook and other social media. It considered



the role of machine learning in helping providers to track large volumes of patient comments on social media and to *“automate the laborious process of analysing the unstructured text”*.

The authors noted that *“The performance of machine learning algorithms is attractive”*. One system in particular could predict NHS Choices star ratings *“with an admirable 97% accuracy”*. However, *“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”*.

In other words, computational systems can excel at some tasks, and improve efficiency in some of the more laborious aspects of data handling. But the job of *“distilling ‘messy’ patient data into clear and actionable insight”* is – for the time being, at least – best left to humans.



*“We live in a digital age”* says this report. It looks at ways to strengthen the voice of the citizen and patient within the NHS digital agenda - not least because *“the systems and processes that lead to the adoption of technology tend to marginalise the voice of most patients and the public”*.

This may be because *“projects are nervous about involving the public, and are worried about adverse publicity, particularly in the wake of the Care.data scandal”*. But the report counters any such perceptions with real-life examples of successful approaches to involving patients and public in digital healthcare initiatives.

It finishes with a summary of key points of good practice, followed by suggested ways to strengthen patient/public involvement in the development of a digital NHS.



This report looks at artificial intelligence (AI) in healthcare which, say the authors, could put patients more in control. But they also observe *“a risk that the public could experience it more as a barrier than an open door, blocking access to care, offering opaque advice and dehumanising healthcare in every sense”*.

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

The report calls for a *“people powered”* AI for healthcare, based on principles of control, simplicity, dialogue, equity and accountability. These, it says, are *“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”*.

## 4. About the Patient Experience Library

The Patient Experience Library is the UK evidence base on patient experience and patient/public involvement, with over 50,000 studies and reports from government bodies, Healthwatch, academic institutions, think tanks and health charities.

Visit [our website](#) to get free access to our [weekly newsletter](#), [Knowledge Maps](#) and other resources.

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The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN

# Appendix

## A.1 Sources of evidence

There are multiple mechanisms for patient feedback and multiple sources of patient experience evidence. Making sense of them all can be difficult. Here, we offer a basic analysis.

**Table 1**

Type	Description	Sources
1. Surveys	<p>Mainly numerical data, often presented in spreadsheet format, and capable of statistical analysis.</p> <p>Large sample sizes, with national overviews, broken down to local detail.</p>	<p>Care Quality Commission patient surveys for:</p> <ul style="list-style-type: none"> <li>• Accident and emergency</li> <li>• Adult inpatients</li> <li>• Children and young people - inpatient and day case</li> <li>• Community mental health services</li> <li>• Maternity services</li> </ul> <p>NHS England surveys for:</p> <ul style="list-style-type: none"> <li>• GP practices</li> <li>• Cancer services</li> </ul> <p>The NHS Friends and Family Test</p>
2. Studies	<p>Written reports, often with qualitative evidence based on patient stories and observations.</p> <p>Tend to feature small sample sizes, with a focus on specific named services and/or health conditions. Often with recommendations for improvements to policy and practice.</p>	<p>“Patient voice” bodies including Healthwatch, National Voices, Patients’ Association, health charities and think tanks.</p> <p>Care Quality Commission inspection reports - especially the “Caring” domain.</p>
3. Research	<p>Academic papers, usually featuring rigorous methodology, theoretical frameworks and peer review.</p>	<p>Health research bodies including NIHR, NICE, Academic Health Science Networks, Collaborations for Leadership in Applied Health Research and Care.</p> <p>Universities</p>
4. Online feedback	<p>Direct comments from service users, sometimes backed up with analytics including sentiment analysis.</p>	<p>Care Opinion</p> <p>Hootvox</p> <p>LHM rate and review (used mainly by local Healthwatch)</p> <p>NHS Choices star ratings</p> <p>Twitter</p>
5. Other (local)	<p>Feedback gathered via complaints and compliments, Patient Participation Groups, patient engagement committees and forums etc.</p>	<p>NHS Trusts, Clinical Commissioning Groups, GP practices etc.</p>

Note: Patient experience/patient engagement leads may also be looking at data from sources such as Patient Reported Outcome Measures (PROMs) and Patient-led Assessments of the Care Environment (PLACE). We have not included these because, while being patient-led, they focus on clinical outcomes (PROMs) and physical environments (PLACE) as opposed to being specifically about patient experience.

## A.2 Quantity of evidence

We are not aware of any way in which the scale of patient experience work is added up across the NHS to give a total sum of activities and participants. However, it is possible to get an indication of the scale of patient experience work in two ways: by looking at the number of people contributing to national surveys, and by looking at the number of published reports on patient experience.

### A.2.1 The number of people contributing to national surveys

**Table 2**

Survey	No. of respondents
GP Patient Survey 2018	758,165
Adult Inpatient Survey 2017	72,778
National Cancer Patient Experience 2017	69,072
Emergency Department Survey 2016	44,500
Children and young people 2016	34,708
Maternity Services Survey 2017	18,426
Community Mental Health Survey 2017	12,139

In addition:

- Healthwatch England's [2016/17 annual report](#) states that the Healthwatch network heard from 341,000 people about what they think of health and social care services.
- The NHS England Friends and Family Test hears from very large numbers of people every month. In May 2018, there were 1,289,716 responses to the [Friends and Family Test](#).

### A2.2 The number of published reports on patient experience

Again, we are not aware of any way in which this is added up nationally. However, a useful guide is the number of reports that have been added to the Patient Experience Library over the last year. The library is the most comprehensive national database of patient experience reports, so the figures below are a good indication of the scale of reporting.

Between July 2017 and June 2018, we uploaded 6,803 reports to the Patient Experience Library.

We include CQC inspection reports because the “Caring” domain can give insights into patient experience. However, these reports represent the assessments of inspection teams so are not, strictly speaking, patient experience reports. If we discount CQC inspection reports, we are left with 2,789 reports on patient experience and patient/public involvement published between July 2017 and June 2018.