

Patient Experience in England



Foreword



How often have you read that patients are at the heart of everything the NHS does? Maybe you have even written something similar yourself. It's such an easy phrase that you can find it littered through countless official reports and mission statements.

Of course no one would disagree with the aspiration, but evidence suggests we still have a long way to go.

This year the NHS has been rocked by the impact of coronavirus. Years of effort to reduce long waiting times have been wiped away in a matter of months, with more than 50,000 people now thought to be waiting more than a year for treatment. As the NHS looks to recovery it will have to work even harder to involve patients, not just in decisions about their care but also supporting those who will have to endure longer waits.

Listening to patients should not be seen as a chore, or a tick box. Patients have the lived experience that doctors, nurses, managers and politicians need to hear. Their concerns need to be acted on.

The last 12 months have provided sobering reminders of why dismissing patient concerns can be the first step in a chain that allows poor care to go unchecked.

In November 2019 the full scale of poor care in the maternity department at Shrewsbury and Telford Hospital Trust emerged, with a leaked report suggesting the failure stretched back 40 years. There are now 1,900 cases being investigated by an independent inquiry - many of the families were dismissed when they first complained.

In February 2020 the independent inquiry into rogue breast surgeon Ian Paterson found he was able to harm hundreds of women over many years in part due to the failures to act on obvious warning signs.

In July, Baroness Julia Cumberlege revealed the findings of her review into the use of pelvic mesh, epilepsy drug sodium valproate and hormone pregnancy test Primodos. She found thousands of women and their babies had been harmed because of the refusal to listen, and the defensive and unresponsive nature of the wider healthcare system.

These are perhaps extreme ends of the spectrum of what happens when we stop listening to patients. They remind us why the insights provided in this year's Patient Experience Library annual report are so important.

Shaun Lintern
Health Correspondent, The Independent

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

Cover image: Southampton General Hospital /©Banksy

1. Introduction



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

First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020. Page 10

This quote, from the recently published Cumberlege review, says it all. Or maybe not quite all. Because patients also know when things have gone well with their care and treatment. So whether we are looking for the good or the bad in healthcare, patients are a vital source of evidence.

The Patient Experience Library is founded on the principle that “If you can’t find the evidence, you can’t use it”. We set up the library because we thought that a healthcare system which was aiming for person-centred care might need a comprehensive evidence base to help it understand patient experience.

With 70,000 visits to our website last year and 100,000 document downloads, it seems that plenty of other people think the same.

We want to see patient experience work put on the same evidence-based footing as clinical work. To help make that happen, we are:

- Improving access and transparency. The library holds over 60,000 documents on patient experience and involvement. There is free search for any that are less than three years old, and free use of our [surveys and feedback analytical tool](#).
- Improving understanding. Our weekly and quarterly [publications](#) offer handy summaries to help healthcare staff and patient activists to keep abreast of the latest and best in patient experience research.
- Preserving the evidence. Our extensive archive offers a rich seam of learning over years and decades - including, for example, over 11,000 reports from the [Healthwatch network](#).

We are doing all of this with zero funding, so any offers of help would be much appreciated! In the meantime, we are sustained by the enormous goodwill of our many friends and supporters whose advice, encouragement and moral support give us the stamina to keep going.

Miles

Miles Sibley, Editor info@patientlibrary.net

2. What we learned in the last year: Surveys

This year's crop of surveys is mostly based on work that was carried out pre-Covid. It is strange to revisit reports which contain no mention of an escalation of critical care, disruption to hospital visiting, delays in routine care and so on.

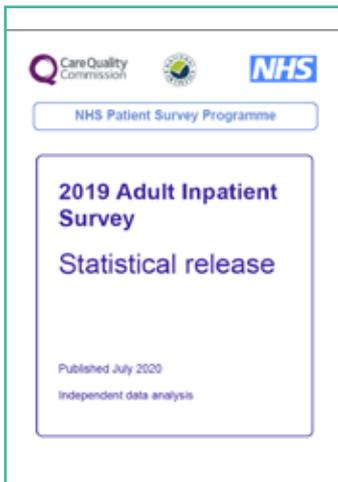
The surveys are, nevertheless, relevant. They paint a picture of how hundreds of thousands of people have experienced different aspects of care. And as the NHS works through the Covid crisis, the surveys might help us to spot differences in patient experience across the pre- and post-Covid threshold.

Most surveys are carried out annually, but some are conducted less often. Surveys that appeared in our [2019 Patient Experience in England](#) report, but do not feature in this one are as follows:

- Personal Social Services Survey of Adult Carers in England.
- National Neurology Patient Experience Survey.

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

2.1 Adult inpatients



“Generally”, says this report, “people’s experiences of inpatient care are good, and show signs of improvement or sustained good performance across many themes”. It is encouraging to see that fundamental needs such as cleanliness and hydration, and respect and dignity are among the positive experiences reported.

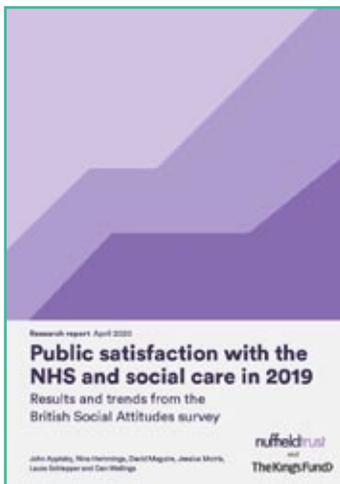
Improvements over previous years’ results were seen in a number of areas: more people said that doctors did not talk in front of them as if they were not there, more said that staff answered their questions in a way they could understand, and more people said they “always” trusted doctors and nurses.

Less encouraging is that yet again, hospital discharge emerges as an area where people’s experiences have not been so good. This is not just about the practicalities of getting back home. An associated problem is communication about medications, with many people not being given clear information, or being told what side effects to look out for after leaving hospital.

Hospital admission is also problematic: all three questions in this theme have shown a decline and are below expected limits of variation.

The report notes the fact that financial pressures, staff shortages and issues with the provision of social care have put strain on NHS adult inpatient services. It says that the government has introduced policy changes, guidance and new initiatives to address these pressures, especially those brought about by an increasingly ageing population. And this year for the first time, the survey undertook additional analysis to better understand the experiences of patients who self-reported as being frail, with regard to ensuring they are supported after leaving hospital. Frail respondents, however, reported worse experiences for all four questions analysed.

2.2 British Social Attitudes



The opener to this report says that after falling for the last two years, public satisfaction with the NHS overall rose significantly in 2019.

Overall satisfaction was 60% – a 7 percentage point increase from the previous year. Public dissatisfaction with the NHS was 25%, down from 30% in 2018. And although 42% thought that the general standard of care provided by the NHS would get worse over the next five years, that was actually an improvement on the 2018 survey, where 51% expected care to get worse.

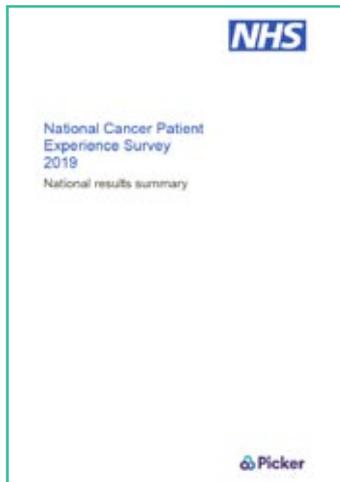
The reports notes that the top reasons for public satisfaction have not changed over the last five years of the survey. These include the quality of care, and the fact that the NHS is free at the point of use.

Similarly, the top reasons for dissatisfaction have remained unchanged over the last three years. However, staff shortages have overtaken waiting times as the main reason for dissatisfaction.

Satisfaction with social care remains “stubbornly low” at 29% – some way below any of the NHS services. Moreover, users of social care were more dissatisfied than users of any other service, with almost half (47%) saying they were dissatisfied.

The authors conclude that “Given the well-publicised and continued failings of the NHS to meet headline targets such as waiting times for elective, emergency and cancer treatments... it may seem paradoxical that the latest results for overall satisfaction with the NHS show a significant rise”. But, they say, “How the British public responds reflects a more complicated set of factors – some based on personal experience, some on politics and others subject to beliefs about the nature of the NHS as an institution”.

2.3 Cancer patient experience



Results from the 2019 survey remain broadly consistent with those from previous years, with most patients reporting positive experiences in most aspects of their cancer care.

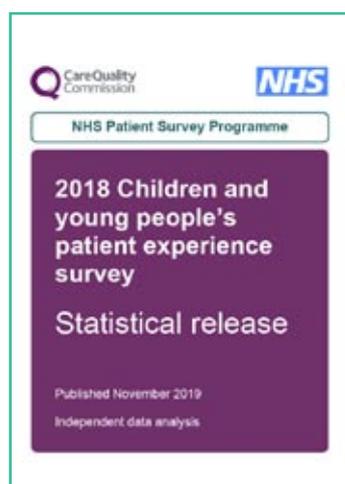
There was an increase in the number of people who had been given the name of a Clinical Nurse Specialist, and 85% had found it easy to contact the CNS. Additionally, 94% of respondents said that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.

Views about general practice were less positive – only 58% of respondents thought the general practice staff had definitely done everything they could to support them during treatment.

There was an improvement in the number of people receiving a care plan, albeit from a rather low base (35% in 2018, up to 38% in 2019).

There were some declines in experience of care, mostly of just one percentage point. The report states that “Whilst these differences appear small, most of these questions were around communication with hospital staff which is key for ensuring patients are informed and involved at every step of their cancer care pathway”.

2.4 Children and Young People



For the first time, this survey was able to consider changes over time, comparing latest results with the 2016 results for most questions. Mostly, the experiences of children, young people and their parents and carers saw little change.

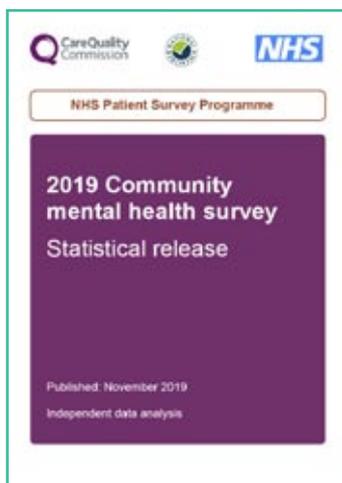
For children and young people, overall experience was positive: 91% felt looked after “very well” or “quite well”. 95% felt that they were able to ask questions, and 90% were able to talk to a doctor or nurse without their parent or carer being there if they wanted to. On the downside, only 71% ‘always’ understood what staff said, and fewer than half (46%) thought they had been involved ‘a lot’ in decisions about their care and treatment.

Parents and carers also gave plenty of positive feedback. 91% said that staff had agreed a plan for their child’s care with them, and just 2% said that they were not able to ask staff questions about their child’s care. 90% said that staff “completely” explained operations and procedures, and 90% said that staff had answered their questions in a way they could understand.

Digging down from the headlines, some disparities in experience emerged from subgroup analysis. In particular:

- Parents and carers of children with mental health conditions reported significantly poorer experiences. (This echoes the results of similar analyses of other NHS patient surveys, such as the 2018 Adult inpatient survey and the 2018 Urgent and emergency care survey.
- Parents and carers who reported that their child has a developmental disability, a neurological condition, or ‘another long-term condition’, reported more negative experiences.
- Parents and carers of Asian children reported significantly poorer experiences around feeling able to raise concerns. Parents and carers of Black children also reported significantly poorer experiences on feeling that they, as a parent, had been well looked after.
- Notably more positive experiences of care emerged for only one group of patients and in one area: parents of children who had cancer in the last five years reported more positive experiences of staff being aware of their child’s medical history.

2.5 Community mental health services



The results from this survey make for troubling reading. It states the following:

“This report shows that people’s experiences of mental health remain poor across most areas. Many of those areas, such as accessing and planning care, identified as in need of improvement in 2018 have declined further in 2019, continuing the negative trend of results consistently declining over the 2014 to 2019 period. Fifty per cent of questions with comparable data available for this time period fall below the expected limits of variation for a second consecutive year.”

The “key areas for improvement” listed by the report are extensive, covering support and wellbeing; crisis care; accessing care; staff; planning care; reviewing care; and giving feedback.

Some of the statistics are grim: Almost a quarter of people (23%) were not involved in agreeing their care with NHS mental health services. Almost a third of people (29%) have not had a formal meeting with anyone from NHS mental health services to discuss how their care is working in the last year. Nearly a third (31%) of all respondents did not know who to contact out of office hours within the NHS if they had a crisis.

The report states that “Mental health care has been high on the national agenda for a number of years”. But it is hard to see, from the survey’s findings, how good intentions at the national level are following through into patient experience at the community level.

2.6 GP patient survey

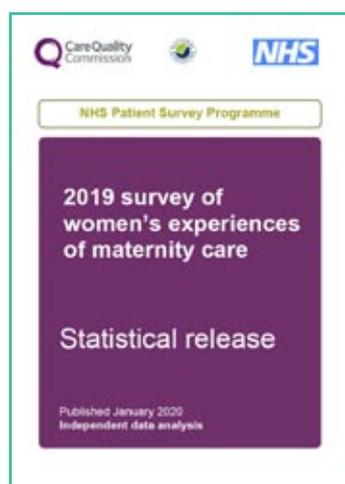


The headline findings from the latest survey show some slight declines since 2018, but are nevertheless generally good. 95% of respondents had confidence and trust in the last healthcare professional they saw, and 89% found the receptionists at their practice helpful. 67.4% said that their overall experience of making an appointment was good (down from 68.6% in 2018).

The vast majority of patients still book appointments by phone (77.8%) as against online (11.6%). This is in spite of the fact that people find it progressively harder to get through to the GP practice by phone. In 2012, 80.8% said that it was easy to get through - in the 2019 survey, that figure was down to 68.3%.

Awareness of online services has increased in all areas covered by the survey: booking appointments, ordering repeat prescriptions and accessing medical records. Actual use of those services has also gone up. Less than one tenth (7.4%) now report having no awareness of online services.

2.7 Maternity care



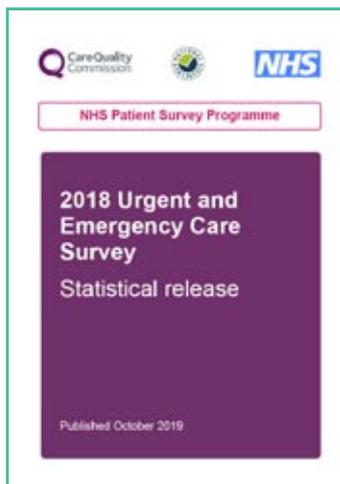
Women's experiences of maternity services showed improvements before, during and after birth in the areas of involvement, interaction with staff and feeding choices.

One encouraging trend is the proportion of women who were “always” treated with kindness and understanding, up from 65% in 2013 to 76% in 2019. Those saying that they “definitely” had confidence and trust in the staff caring for them during their labour and birth increased from 78% in 2013 to 84% in 2019. And in terms of year on year increase, 84% said their concerns were taken seriously when raised during labour and birth, against 82% in 2018.

Areas for improvement start with continuity of carer. The [2018-19 NHS Planning Guidance](#) aimed to increase the number of women receiving continuity of carer to 20% by March 2019. But the survey results show that in 2019 only 9% of women had the same midwife during their maternity journey. This might be mitigated somewhat by the finding that 52% said their team of midwives were always aware of their medical history at antenatal appointments, rising to 77% postnatally.

With respect to perinatal mental health, the survey asked if women had been given information about any changes they might experience to their mental health after having their baby. One out of four (25%) said that they only received this information ‘to some extent’ and about one out of eight (12%) said they did not receive this information. In addition, 20% of women said they were not told who they could contact if they needed advice.

2.8 Urgent and emergency care



This biennial survey covers people’s experiences of using Type 1 services (major A&E) and Type 3 services (urgent care centres, minor injury units, urgent treatment centres).

The report states that “Despite widely recognised pressures and challenges on these services, most results have not significantly changed between 2016 and 2018. Areas where results were less positive point to pressures on staff time or flag persistent issues with leaving hospital or the urgent care centre”.

Some of the most positive feedback is about interaction with staff, covering confidence and trust, perceptions of being listened to, and experiences of being treated with dignity and respect.

One area for improvement has to do with waiting times, particularly in Type 1 services. Here, the operational standard is that 95% of people should experience waits of four hours or less. However, 41% of Type 1 respondents said that overall, their visit to A&E lasted for more than four hours. Those who waited longer than four hours had a worse than average experience for all patient experience themes covered by the survey.

3. What we learned in the last year: Research

Every year, thousands of reports on patient experience and involvement are published - by government bodies, health charities, patient voice organisations and academic institutions. This overview outlines a few of the key themes that have emerged over the last twelve months.

If you are looking for more regular summaries of the literature as it gets published, please sign up for our [free weekly newsletter](#). Or you can search the full Patient Experience Library [here](#). For full attributions, and copies of the documents mentioned on the following pages, click on the report pictures.

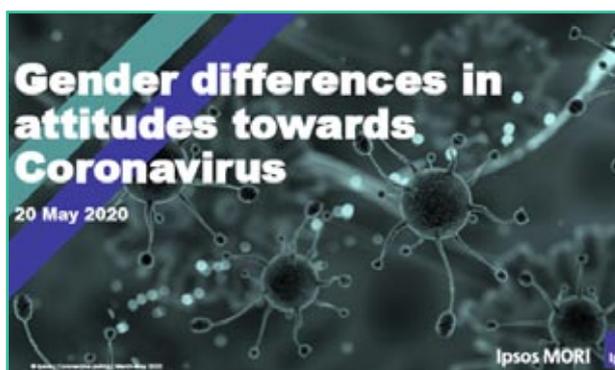
3.1 Living with the pandemic

A notable feature of the Covid-19 crisis has been the release of [questionable statistics](#) on matters such as the quantities of personal protective equipment distributed, the scale and effectiveness of “test and trace”, and infection and death rates.

One way to both check the validity of the numbers, and to dig deeper for greater insight, is to gather qualitative evidence, alongside the numerical data. That means talking with patients, carers and the wider public about their personal experiences of the pandemic.

So it was surprising to see a rapid abandonment of patient experience evidence gathering as the lockdown began. According to [this article in the BMJ](#), “This included stopping all work with patient participation groups (PPGs); stopping the collection and reporting of patient experience data; delaying responses to complaints; and stopping any local gatherings of patient groups”. The author goes on to make the point that “How quickly and easily this work was stopped raises questions about how it is really valued”.

Happily, many organisations picked up the slack – some useful examples are as follows:



This study explored how the public experience of coronavirus varies between men and women. Interestingly, it found that although men are more likely to contract Covid-19, they are less concerned about the disease as a whole than women.

Women are more likely to think the effects of the virus will be greater across various areas including the economy, public services and our system of government. This could be because in some very direct ways, women are more seriously affected than men. For example, one third of women responding to the survey said that their workplace had closed, against one quarter of men. And respondents in general thought that working from home would be more likely to damage a woman’s career than a man’s.

When it comes to mental health, women are finding it harder than men to stay positive – both on a day-to-day basis, and when thinking about the future. They may be less trusting of the government’s handling of the crisis, and more likely to be anxious and sleeping less well.

The authors are careful not to speculate on the possible implications of all this, stating that “What this means for the future is uncertain”. But they do note that nearly seven in ten women think the government acted too late, and that women are more uncomfortable about some aspects of returning to normal.



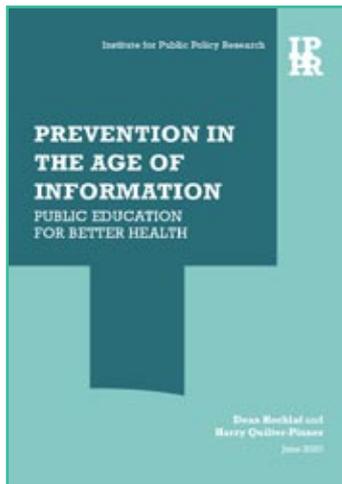
This report looked at the knock-on effects of coronavirus for people whose care has been disrupted. It is based on interviews with 12 people in the week beginning 20th April, while the national lockdown was in full force.

It seems that some people are nervous about accessing healthcare settings where the risk of infection with coronavirus is higher. Others feel that their problems are not important enough to merit treatment when there are other, more urgent, priorities for the NHS.

In choosing not to seek care, responsibility often trumps fear: “... the primary reason for delaying care was to avoid adding to the burden on the NHS”. But the sense of responsibility was accompanied by anxiety. “Some participants were afraid that by following guidance to self-isolate and avoid risk, they would be discharged from services, or ‘sent to the back of the queue’.”

People whose care was cancelled or postponed could be left feeling in limbo: “the feeling of having built up to a potential resolution and having it snatched away was a source of disappointment, and where no timetable was available for it to be rescheduled, hopelessness”.

An important learning point for health professionals is that in helping people deal with uncertainty, clear personal communication is crucial. “People appreciated being informed at each step of the process, having the time to ask questions and where staff acknowledged the unique situation we are all in.”



This report states that the Covid-19 crisis shows how rapidly disinformation spreads.

A poll revealed that nearly half (48%) of all British people had either seen or been sent “fake news” about Covid-19 online since the outbreak began. In addition, almost two in five (17%) said they did not know whether they had come across fake news, suggesting that the ability to identify and report the spread of misinformation is less than perfect.

In this context, health education, on its own, is insufficient. We need to build health literacy (people’s ability to understand health information), and work towards the goal of patient activation (enabling people to exert control over the determinants of health).

The report makes a series of recommendations, including the introduction of a permanent “disinformation unit” to correct false information and help shape public health narratives.

The authors conclude that “New technologies have created opportunities to reach wider audiences, but ... It is also clear that the NHS and health sector more broadly need to take a more proactive approach. As an extremely trusted source of health information, it is imperative the NHS stays ahead of the curve”.

3.2 Online engagement

Covid-19 has precipitated rapid moves to online engagement with patients and public. Telehealth, debated for years, became a common feature of healthcare almost overnight. Online test and trace was kick started (not altogether successfully to begin with). And alongside all of this, healthcare policymakers, providers and researchers had to find new ways to engage with their public audiences and stakeholders.



In May 2020, the launch of the [coronavirus contact tracing app](#) on the Isle of Wight ignited debate over the pro's and cons of sharing personal health data. While advocates of test and trace said that digital solutions were essential, privacy and human rights advocates were not so sure.

Against this background, a briefing paper from the House of Commons Library makes for useful reading. It offers a comprehensive but concise summary of all the main points of the data-sharing debate, including legalities, practicalities and ethics.

It includes some lessons from (recent) history – not all of which inspire confidence in the state's ability to safeguard personal health data. These include the following:

- The abandonment of the national Care.data programme, linked to concerns over the opt-out system in place and over patient confidentiality.
- A finding by the Information Commissioner that the Royal Free Trust failed to comply with the Data Protection Act when it provided patient data to Google DeepMind.
- An NHS investigation which found that none of the 80 NHS Trusts affected by the 2017 WannaCry ransomware attack had applied an advised Microsoft patch update.

The report looks forward as well as back – examining cross-border data sharing after Brexit. We learn that in any US-UK trade talks, one negotiating objective of the United States would be to “Establish state-of-the-art rules to ensure that the UK does not impose measures that restrict cross-border data flows”.

In response, the UK Minister for Trade has said that “We would seek to review any rules in place to safeguard data... and ensure that they are not overly protectionist. We set up the pipework, but whether or not the taps are turned on is a matter for the regulators”. Patients may or may not be reassured by this.



Of course, trust is a two-way street. This study of online feedback describes it as “an equalising mechanism, enabling people to give feedback at a time of their own choosing, in their own words, often unmoderated and often anonymous”.

But is anonymous feedback a good thing? Patients may want it because they “fear that being identifiable may compromise the care they receive if they make critical remarks”. Healthcare professionals, on the other hand can “see patient anonymity as... a risk to the reputation of individual practitioners or organisations, given that anyone can say anything, no matter how unfair or damaging”.

This, say the authors, “constitutes an ‘anonymity paradox’, whereby patients see anonymity as a prerequisite but professionals see it as a barrier”.

This study explored anonymous online feedback via the **Care Opinion** platform. It found that in general, staff understood why anonymity might be important for patients. At the same time, “anonymous feedback creates an unfamiliar and uncomfortable situation. [Staff] are encouraged to name themselves and engage in tailored, personalised conversation, but with a faceless, nameless other”. It found that “In spite of themselves, [staff] may try to work out who someone is”.

The paper concludes that the ‘anonymity paradox’ “is at its heart a question of unequal power, risk and vulnerability” It suggests that “Staff used to engaging directly with patients and families... need support in dealing with anonymous feedback, and the uncomfortable situation of unequal power it may create”.



Online feedback platforms such as Care Opinion take their responsibilities seriously – for example by moderating comments to safeguard confidentiality, and removing offensive comments. By contrast, patient engagement via social media can be a bit of a “wild west”.

This paper looks at the use of social media by groups seeking to promote an anti-vaccination message. Their tactics, according to the authors, include misinformation and anti-science sentiment. And these can be hard to counter because vaccination narratives can be complex, and the science may not be 100% clear cut.

Tips for managing this kind of engagement include the following:

- Facts matter - but complex evidence needs to be explained in straightforward language.
- Emotions matter too - so facts need to be humanised with stories about the actual effects of preventable disease on real people.
- It is important to create safe online spaces for information and debate - for example by quickly removing aggressive comments, and reporting offensive posts.
- Responses must be concise and respectful - and selective too, to avoid amplifying misinformation, or giving false legitimacy to some anti-vaccine views.

The paper looks specifically at the anti-vaccine issue, but could also be useful to guide online responses to other contested areas in healthcare.



Building dialogue and trust means, for the foreseeable future, moving engagement online. This report makes the important point that hosting a meeting online is somewhat different from chatting with friends or family.

A key difference lies in making use of the wide range of features that videoconference platforms offer. “Don’t assume that online meetings are the ‘poor relation’ of face-to-face meetings” says the guidance. “Online platforms allow for lots of different kinds of interaction, including the chance to use break out rooms, run polls, allow people to share their screens with each other, and to use ‘chat’ to comment and share responses.” Hosts who

are familiar with these tools have a much better chance of offering enjoyable and effective online engagement.

If you want to share your screen, show powerpoint slides, move people to break out rooms, etc, it might be worth having someone to help. “Trying to facilitate, present and manage the technicalities is really hard - so splitting the roles, with a ‘presenter/facilitator’ and ‘technical support/producer’ working hand in hand really helps.”

The guide offers further tips - for example playing music as people wait for the meeting to get underway, not stressing too much about bad hair days, and having a back-up plan for that crucial moment when the screen freezes or the video clip fails to load.

3.3 Patient safety

Four years ago, when we published the first Patient Experience in England report, we featured [Learning, Candour and Accountability](#), the Care Quality Commission’s call for openness and learning in healthcare. The CQC said “We owe it to [bereaved families] to stop talking about learning lessons, to move beyond writing action plans, and to actually make change happen”.

Every year since then, we have had to include inquiry reports on avoidable harm and death. All of them have told of concerns raised by patients and relatives being dismissed and denied.

Last year, for “Patient Experience in England 2019”, we expected to be commenting on the investigation into avoidable harm in maternity services at the [Shrewsbury and Telford Hospital NHS Trust](#). Announced by the Secretary of State in April 2017, we thought the task would be complete by our publication deadline of September 2019. Instead, all we could say was that “the Shrewsbury and Telford investigation rolls on”. And now, in 2020, all we can say is that the scale of the investigation has grown to unimaginable proportions, and the report is still awaited.

In the meantime, two further reports, from the Paterson Inquiry, and the Cumberlege review, detail extensive harm, and extensive dismissal of patient concerns.



This report is not simply a story about a rogue surgeon. It would be tragic enough if that was the case, given the thousands of people whom Ian Paterson treated. But it is far worse. It 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.

These are not our words. They form the opening paragraph to this report, in a foreword by the inquiry Chair, Bishop Graham James.

He goes on to describe a “capacity for wilful blindness” and says that the report is “primarily about poor behaviour and a culture of avoidance and denial”.

The experience of patients, he says, “led many of them to consider the Heart of England NHS Foundation Trust and Spire were primarily concerned for their own reputation”. When they complained to regulators, they “believed themselves frequently treated with disdain”. Only by taking their cases to sympathetic lawyers did some patients find themselves heard – but

“By that stage many others found their exhaustion was too great and their sense of rejection so complete that they scarcely had the emotional or physical strength to fight any further”.

The Bishop warns that “It is wishful thinking that this could not happen again”.



The report of the Independent Medicines and Medical Devices Safety Review (otherwise known as the Cumberlege Review) describes “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’être. It has failed to listen to their concerns... and

has too often moved glacially”.

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

This is not mere politeness. Cumberlege is experienced and forthright, and she means what she says. She also means it when she says this: “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”.

3.4 The evidence-practice gap

Plenty of evidence on patient experience is published via studies and surveys. Much of it is very good, but it is not necessarily put to good use. Here are the latest pointers to the evidence-practice gap in patient experience.

This study aimed to develop categories that could help clarify potential uses for different types of patient feedback. A scoping review returned no fewer than 37 feedback types. These were sorted into 12 characteristics and then into 4 categories, as follows:



- 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.

These categories might help us to make sense of the wide range of patient feedback types in use across the NHS. But do they help us to make sense of the feedback itself?

Unfortunately, the paper finds that few of the routinely collected feedback types elicit “ready-to-use” data. And where useable data is easy to extract, it is “most suitable for measuring accountability, not for informing ward-based improvement”.

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



This report looks at how patient feedback is gathered and used in NHS mental health services. It found that half of Trusts collecting patient experience data were not actually using it. A quarter of Trusts struggled to collect it at all, and only one quarter used patient feedback to support change.

There is of course an ethical dimension to this: why ask patients for feedback if it is not going to be used? But the study also raises questions of cost-effectiveness. The authors make the point that “For patient experience processes to be cost-effective for NHS providers, they need to find ways of collecting and analysing patient experience feedback and then using it to drive change”.

Increased patient experience activity in mental health services can, they say, lead to reduced rates of violent incidents, faster discharge and improved staff morale. All of these could be seen in terms of cost-effectiveness. But to achieve outcomes like these, “it is necessary to act on feedback in ways that facilitate meaningful change”.



“Despite the abundance of patient experience data in the NHS”, says this report, “there is limited understanding of how these data inform... the changes to services that are made as a result”.

The study looked at how patient experience data is collected, interpreted and - crucially - translated into quality improvements in acute NHS hospital trusts in England. A key finding was the “remarkable extent” to which patient experience work was organised differently across different Trusts.

There were various combinations of teams and remits, with two Trusts having no formally designated patient experience team at all. Quality Improvement teams were often quite removed from patient experience data work, with patient experience teams having limited contact with QI teams and vice-versa.

The report concludes that for patient experience data to lead to improvements in quality of care, it is not sufficient to focus solely on the data that NHS trusts collect. Equally important is what happens next - the study suggests that turning data into improvement depends on three key factors:

- **Autonomy:** The ability of staff to trigger action.
- **Authority:** To ensure that action is seen as legitimate.
- **Contextualisation:** To act meaningfully in a given situation.



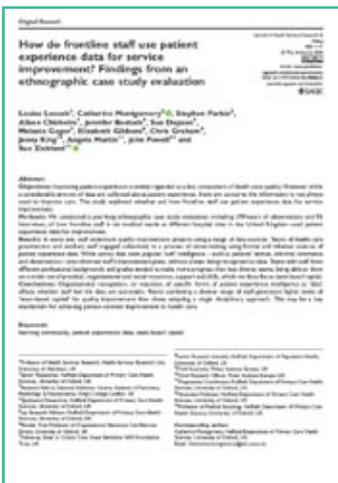
This report from the Health Foundation looks at quality measurement - including patient experience - across breast cancer care, children and young people’s mental health care and renal care.

A key question is what is being collected and why: “All the [data] we collect feels like a huge task and nothing happens to it... we’re told we have to collect it, but [we’re] not aware that it goes anywhere else.”

Getting the data back in useable form is also problematic. The authors observe that where interviewees had experience of data feedback, many felt it was not quick enough: “it is painfully slow, which makes it irrelevant”.

Even where the indicator data are released in a timely and comparable form, the interviews suggested that the potential usefulness for trusts, wards or teams was limited by the data being hard to locate online, with multiple spreadsheets to choose from and large Excel workbooks to download and navigate.

Encouragingly, interviewees across all five case study sites expressed a desire for more emphasis on, and greater measurement of, patients’ experience of health care services. For some, this would mean questioning whether what is measured also reflects what is important to patients.



When looking at how patient experience data is used for quality improvement, an important question is what actually counts as data. This study found that “it was not initially obvious to frontline staff what patient experience “data” were, where to locate them in the organization or how to use them”.

Even where some types of data (eg patient stories or free text comments) were recognised as valid, they “remained under-utilized due to lack of confidence in how they could be used”. Emotional responses also affected data use: “Negative feedback was reported to be useful, but in practice could be challenging or difficult to accept for staff and, depending on the form it took, inhibited efforts at improvement”.

The study acknowledges that sometimes the links between patient experience and quality improvement can be spotted by frontline staff having daily contact with patients. However, “Staff with the least power in the organization - unqualified nursing assistants, ward administrators, cleaners and porters - may be rich in this kind of tacit, embodied intelligence but are unlikely to be able to mobilize such knowledge for improvement without wider team capital behind them”.



This study focused exclusively on online patient feedback. Its premise was that while online customer feedback has become routine in many industries, it has yet to be harnessed for service improvement in health care.

It found that most online feedback is positive in its tone. Patients are keen to give praise, and they also want their feedback to elicit a response as part of a conversation. In spite of this, many professionals, especially doctors, are cautious about online feedback, believing it to be mainly critical and unrepresentative, and rarely encourage it.

Health organisations, for their part, are not fully prepared to use online feedback for service improvement. The study identified several disconnections between patient motivations and staff and organisational perspectives. These, say the authors “will need to be resolved if NHS services are to engage with this source of constructive criticism and commentary from patients”.

4. About the Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement, with over 60,000 studies and reports from government bodies, patient voice organisations, academic institutions, health charities and more.

Visit our website to get free access to our [publications](#), [Healthwatch maps](#), [surveys and feedback tool](#) and more.

Contact us (info@patientlibrary.net) to ask how we can help you manage your data on patient experience and involvement.

Follow us on Twitter: [@patientlibrary](#)

Funding declaration: In the light of concerns about [drug company funding](#) of some patient voice organisations, we declare that the Patient Experience Library receives no funding or help in kind from industries involved in drugs, treatments and medical devices.

www.patientlibrary.net

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Appendices

A.1 Sources of evidence

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

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

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

(By size of response.)

Survey	No. of respondents
GP Patient Survey 2018	770,512
Adult Inpatient Survey 2019	76,915
National Cancer Patient Experience 2019	67,858
Urgent and Emergency Care Survey 2018	Type 1: 42,707, Type 3: 7,419
Children and young people 2018	33,179
Maternity Services Survey 2019	17,151
Community Mental Health Survey 2019	12,551

In addition:

- Healthwatch England's [2018/19 annual report](#) states that the Healthwatch network enabled 336,000 people to share their story.
- The NHS England Friends and Family Test hears from very large numbers of people every month. In February 2020 there were [1,319,638 responses](#).

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 August 2019 and July 2020, we uploaded 9,986 reports to the Patient Experience Library. Some had been published in previous years - the total published between August 2019 and July 2020 was 4,744.

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 2,481 reports on patient experience and patient/public involvement published between August 2019 and July 2020.