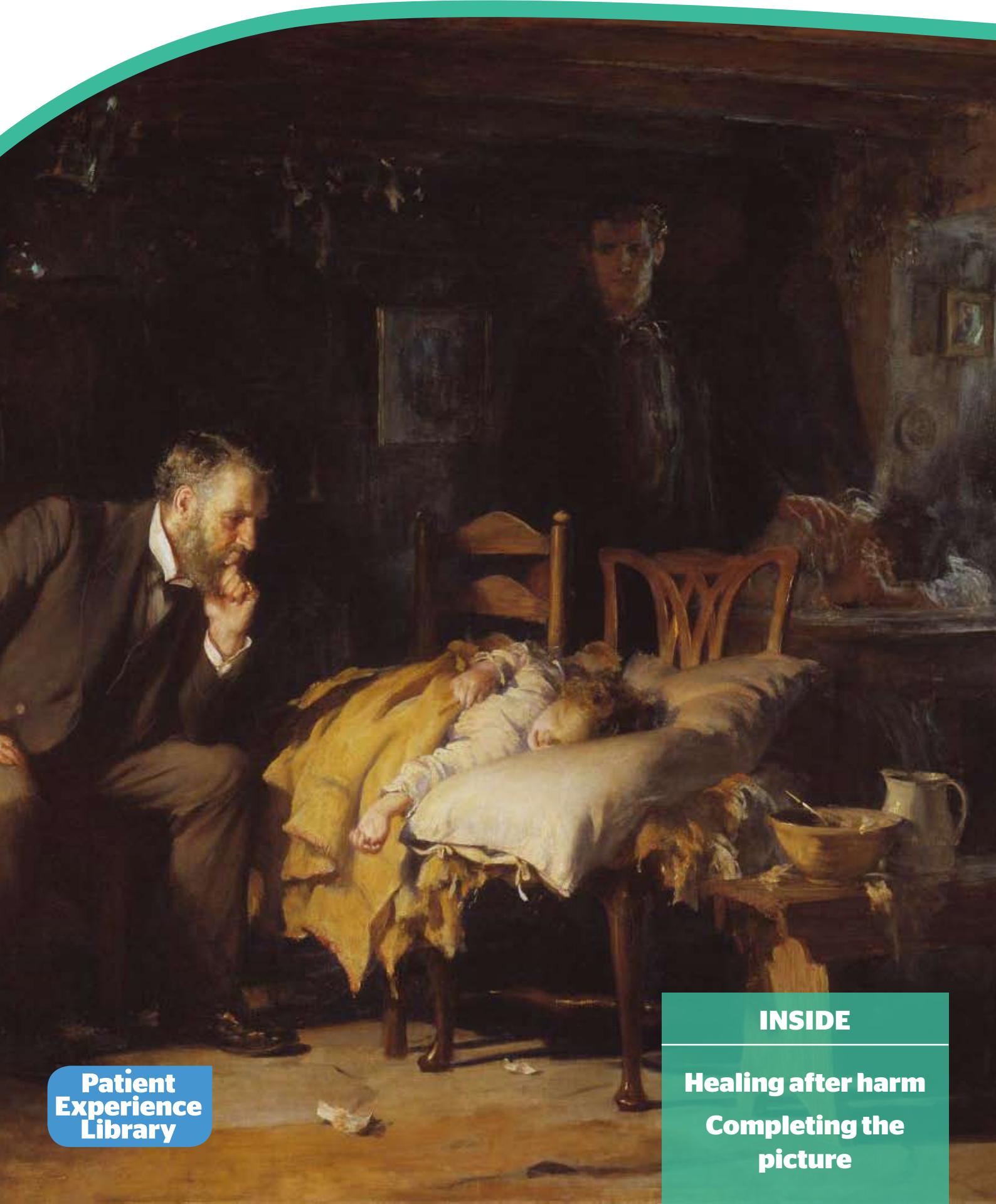


Patient Experience

and patient/public involvement in health and care services

Winter 2021



**Patient
Experience
Library**

INSIDE

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2020 might seem like a year we would all rather forget. But for our small team at the Patient Experience Library, it was a good year, with signs of a real shift in how patient experience is perceived.

Quote of the year was from Baroness Julia Cumberlege, in her [First Do No Harm](#) report. She said that patient experience “must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine”.

It is a powerful statement, from a highly respected advocate for patients.

We are determined to push patient experience up the evidence hierarchy, and with the help of some equally determined people over the last year, we have made great strides.

We joined forces with [Care Opinion](#) to offer seamless search across both our platforms. By doing so, we have created the UK’s biggest public evidence base on patient experience, giving access to over 60,000 documents and 400,000 direct comments simultaneously.

We gave every Trust in England one-click access to their key patient experience datasets. Our [surveys and feedback tool](#) combines multiple datasets, helping professionals and patients to cut through the measurement maze.

With [National Voices](#), we ran a series of evidence searches that formed the basis for their [Patient. Noun. Adjective.](#) report. Behind the headlines on waiting time targets, we found people experiencing delays before the clock officially starts; stop-starts along the way; cancellations; and changing goal posts.

With Groundswell and the [#HealthNow partnership](#), we carried out a literature review on people’s experiences of healthcare while homeless. [The report](#) will provide the foundation for an ambitious four year programme towards a more inclusive health system.

Our [Inadmissible Evidence](#) report had a huge impact, with over 4,000 downloads to date. It was picked up by authoritative sources including the [BMJ](#) and the [Matters of Engagement](#) podcast. And it was a big moment for us to have [Shaun Lintern](#) – an extremely effective health journalist and campaigner – writing the foreword to our annual [Patient Experience in England](#) report.

This is fantastic progress – but it is not enough.

Patient experience will never take its rightful place in the evidence hierarchy until NHS leaders start taking it more seriously. So we hope that in 2021:

- NICE – the National Institute for Health and Care Excellence – will make patient experience evidence part of its National Core Content.
- NIHR – the National Institute for Health Research – will help us to make a proper assessment of strengths and weaknesses in the patient experience evidence base.
- Health Education England will support our efforts to develop high quality accredited training for patient experience staff.
- NHS England will work with us on analytical tools that can cut through the morass of patient experience data.

We get no funding for our work, but we are motivated by knowing that you, our readers, are on this journey with us. We look forward to bringing you more news during 2021, and we hope you’ll stay in touch!



Miles Sibley, Editor info@patientlibrary.net

Healing after Harm

Joanne Hughes, *Harmed Patients Alliance*



In 2011 my world was turned inside out and upside down. My only child, Jasmine, passed away aged only 20 months old.

She had been a happy healthy child, who, following a nasty cold developed a post viral encephalitis. This was a condition that most children survive, using steroids to dampen down the immune system.

Jasmine was considered quite 'mild'. She was at home the day her diagnosis was made and the plan to give steroids set in motion. But overnight, she became distressed, developed a facial palsy and seizures. She was paralysed, anaesthetised, ventilated and transferred to intensive care. She never regained consciousness and life support was withdrawn 10 days later.

Another bereaved mother, Leilani Schweitzer, said this about losing her son to medical error:

"After he died, the little plastic ID band that was around his tiny wrist should have been slipped onto mine. There

*was nothing more that could have been done for him, but there was **plenty that needed to be done for me**. I needed an infusion of **truth and compassion**. And the nurses and doctors who took care of him, they needed it too. **We all should have been given ID bands and become patients that day**. Death is a full stop for the patient in the hospital bed, but it is only just a very **terrible beginning** for the survivors left in the room. Hospitals should **extend their care to these people** because the impact of these kind of experiences is slow, painful and toxic."*

When Jasmine died there was so much that needed to be done for me, and my husband Jeff. We had so many questions. We knew something had gone very wrong and were certain there had been errors in her care. We didn't believe Jasmine's death had been unavoidable. We expected the trusts and staff involved to be feeling the same way.

We also expected the staff and the hospitals involved to 'wrap around us', to care for us. Instead we experienced abandonment. No amount of friend/family support was beneficial until we could understand why this had happened. But no-one would give us honest answers to our straightforward questions.

Almost 10 years after Jasmine's death, we have still not had meaningful evidence-based explanations of what happened and why from the trusts involved. We still haven't got on to grief.

Recently I wrote about [Reframing Duty of Candour in our hearts and minds](#), looking at how Healthcare Harm comes with emotional and psychological injuries on top of the more obvious physical harm or bereavement.

Number one on the care list for me is full disclosure of what happened. Other care and support will be likely futile until the harmed patient or family have their questions answered and a truthful evidence-based explanation of events.

The Duty of Candour as set out by the Care Quality Commission falls short in failing to highlight that 'full disclosure is essential for healing'. Rather than being separate from support, full disclosure is the most important support element that harmed patients and families need to enable them to begin to heal.

In November, along with fellow bereaved parent James Titcombe, I launched [Harmed Patients Alliance](#). Our mission is to 'work collaboratively towards a future where harmed patients and families are respected and cared for, their needs are understood and met, their suffering is minimised and their recovery is enabled, where preventable second harm is eliminated'.

I hope for the sake of future families who may tragically lose someone they love due to Healthcare Harm, there comes a day where we can say mission accomplished. We welcome anyone who wants to see and contribute to this to sign up as members on our website homepage.

Completing the picture

Laila Hallam, Health Consumer Advisor, Honorary Affiliate The University of Sydney



You may have seen the painting shown here, and on the cover, before. It's a powerful image by Sir Luke Fildes. The child and doctor at the centre, in the glow of the lamp. The child ill and exhausted. The doctor earnestly observing. Watching. Sitting. Waiting. Thinking. I saw this painting as a statement on the medical profession. A reminder of the solemnity of their work. The gravity of life and death. The role of the family in the background, secondary and in the dark.

But then I was challenged to really look at the image. The Dad wasn't simply in the background, he was standing in the shadows, he was stoic, he was purposefully and intently studying the doctor for signals. Only then did I notice Dad's hand comforting his distraught wife. The Mum collapsed in prayer, or

distress, or both. Dad's hand gently on her shoulder, reassuring her, or maybe channelling his energy into her prayer. Her faith. Their hope.

I then read that Sir Henry Tate had commissioned Fildes to paint a subject of his own choosing. Fildes had earlier lost his own one-year-old child, Philip.

Was the painting drawn from the *family perspective* of an ill child? The family placing the child and the doctor into the centre of their story? The connection between doctor, patient and family? Of knowing how to work together, and each knowing when to step back?

Only then did I see how differently we can perceive the same image.

Perspective in medicine and health care is an interesting thing.

Clinical perspectives and patient perspectives are two sides of the same coin. Each real. Each valid. Yet only one is recognised as truth. Only one contributes to 'evidence'.

Clinicians are recognised for their expertise in disease and treatment. In contrast, patients and families are rarely acknowledged for their expertise in managing and living with illness.

This has led to an over-estimation of our doctors, and an under-estimation of patients.

As I've travelled through our health system as an involved family member, I have seen beautiful, gentle and attentive care. I have also seen lapses. Lapses so

obvious to our family, yet invisible to the system providing care. Some of which led to unnecessary and avoidable pain and suffering and wasted resources.

And all in the course of my father's illness. My observations. My experiences. Indelibly etched. Never asked for. Never collected. Absent in the established evidence.

I am not alone. There are many, many anecdotes whispered between patients in the community, that are not captured in the evidence. These are not simply stories. They are grounded in one's view of reality. That they are from only one perspective does not make them less true. That patients and families may be unwilling to share them with their providers does not make them less true. That they are not actively prioritised, collected and reported does not make them less true.

Rather, the failing is that unlike clinical perspectives, they are not systematically contributing to the body of evidence to be tested against. Instead, they remain stories, anecdotes, whispers in the winds, but mostly they stay silently in the shadows.

The evidence is incomplete.

COVID has challenged health systems to step-change. Vaccines, developed at ground-breaking speeds; telehealth, implemented in weeks after decades of ambivalent hesitancy. Here too, we must step-change. Reset system prejudices and bias by embracing patient expertise into our health evidence base for the benefit of better health care for all.

RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. Some are newly published - others are featured because they shed useful light on recent issues and developments. For full attributions, and copies of the original documents, click on the report pictures. Do you know of a stand-out report that we should be featuring? Contact us! info@patientlibrary.net



Gratitude in healthcare

There is a connection between staff experience in healthcare, and patient experience. The greater the wellbeing of staff, the more likely it is that patients will receive good care. Patient feedback can have an effect on that, as expressions of thanks from grateful patients can help to boost staff morale.

This study explores gratitude in healthcare and finds that the expressions and the effects of gratitude are more complex than they might at first appear.

One example is gift-giving. This can become problematic when a gift is given in anticipation of privileged treatment, so there is a need for “special caution for gifts that arise ‘out of the blue’ before the doctor has done anything to ‘deserve’ them”. The authors note that “Hospitals often channel donations from grateful patients and their families into philanthropic programs that seem, at first, to circumvent the compromising effects of individuals accepting gifts”. However, “these initiatives (sometimes called “grateful patient programs” in the United States) are not immune to exploitative tactics that can compromise trust in the doctor-patient relationship”.

The paper also warns of “the problematic nature of gratitude when it exacerbates a lack of autonomy”. For example, “For those who are able-bodied, gratitude may well comprise a comfortable and unproblematic response to kindness, but for disabled people it can signify an unbearable state of perpetual obligation”. Interestingly, “people who had access to paid personal assistance tended to feel a greater sense of control, comfort, and autonomy than those constrained by feelings of shame and frustration when having to be persistently grateful for the goodwill of others”.

The paper concludes by stating that “gratitude should be recognized as integral to the social relations that significantly influence what people think, feel, say, and do in relation to health care”.

Covid-19 experience: rapid review

Prepared for: Experience of Restart group (via National Voices)
October 2020

1. Background

This report has been prepared on the basis of discussion (hosted by National Voices) about patients/service users' experience of "restart" of health and care services, following the coronavirus crisis and lockdown.

The Patient Experience Library observed a rapid increase in reports of patient experience in relation to Covid-19 during this time. Much of the literature looks at people's experiences of being suddenly unable to access services in normal ways. Some is negative, but there are positive reports too - for example, an easier online access for those who are comfortable with IT and with remote consultations.

The literature as a whole will certainly hold clues as to what people want and need from restart. This rapid review offers an overview of the scale and nature of the literature, as a starting point for possible further research.

2. Method

This overview is based on a search of the [Patient Experience Library](#), which contains over 60,000 publications on patient experience and involvement. These include surveys, studies and policy documents from sources including government bodies, patient voice organisations, health charities and academic institutions. The library covers both formal literature and "grey literature", defined as publications that are ephemeral, poorly catalogued and hard to find.

Search terms used for this report were "covid", "coronavirus" and "lockdown". Relevance filters were applied to ensure that search results contained reports that were of high relevance to the search terms. Reports that made only passing mention of covid, coronavirus or lockdown were excluded from the final count.

3. Findings

3.1 Total reports
After relevance filtering, we were left with 322 reports on people's experiences of covid, coronavirus and lockdown.

Missing a trick on Covid?

There are many ways to understand the effects of Covid-19 on people's health and wellbeing. We can look at infection rates, and mortality data. We can study outcomes from treatments, and conduct clinical trials for possible vaccines. We can be "led by the science".

All of this matters - but another way to understand how Covid affects people is to ask them. Talking to people can help us to understand how variables such as age, ethnicity and pre-existing health conditions determine people's responses to the virus. It can also help us to understand the social and economic consequences of lockdown: loneliness, domestic violence and more.

There is an extensive body of evidence on all of this, and by early October the Patient Experience Library had amassed over 500 reports on people's experiences of the pandemic. By far the biggest contributor was the Healthwatch network, which has done sterling work under very difficult circumstances to gather wide-ranging evidence at the local level. Their reports shed light on the fine grain of local and even individual experiences, which tables of "science-led" statistics can never reveal.

Other reports come from health charities, polling organisations, think tanks and campaign groups. The work is of good quality and comes from credible sources. Taken together, it offers a body of evidence that could be an invaluable guide to policy and practice.

There is a problem however: a great deal of the literature is invisible to bodies such as the Department of Health and Social Care, and NHS England/Improvement. That is because it emanates from small organisations with small budgets and limited reach. It is published across hundreds of websites. It is what academics call "grey literature" - ephemeral, poorly catalogued and hard to find.

Our rapid review summarises the scale and nature of the evidence. It offers examples of reports that show how health inequalities are exacerbated by lockdown restrictions and reduced access to services. And it shows where the evidence base is strong, and where there are gaps that need to be filled.

Covid responses that are led by the science are, of course, necessary. But responses that put the human experience alongside the science are likely to be better informed and more effective. Our review offers a starting point for a fully rounded, evidence-based response.



Insights from compliments

This paper makes the valuable point that while there are standardised procedures for handling and reporting complaints, and standardised approaches to survey work, there appear to be no common methods for receiving and analysing compliment letters. This, say the authors, is “symptomatic of a tendency in healthcare... to focus on what goes wrong rather than what goes right”.

The exclusively positive nature of compliment letters is not their only unique feature. The paper makes the point that “patient and public involvement in healthcare is generally service initiated”. Formal feedback channels (eg patient surveys) are based on clear organisational rationales, with written aims and objectives. Compliment letters, on the other hand, are patient initiated. They are written informally and spontaneously by people who have no stated aims and objectives. So what are the writers of these letters trying to achieve?

Firstly, compliment letters could be contributing to safe practice. Traditional “health and safety” follows a “Safety I” model, focused on breaches of procedure, and learning from mistakes. But “Safety II” sees safe practice as something that emerges from organisational cultures, teamworking and personal relationships. These day-to-day working practices can be overlooked by staff, but patients who recognise and offer feedback on excellence can help “further the goal of understanding high-quality and resilient healthcare”.

Secondly, compliment letters can offer insights into patients’ own priorities for high-quality healthcare. In effect, patients are encouraging and supporting the healthcare practices they themselves most value.

The authors tested these ideas by analysing compliment letters, looking for instances where patients went beyond simply “acknowledging” excellent care, to “rewarding” or “promoting” examples of excellence. This would indicate compliments whose purpose was not simply gratitude, but an attempt to help improve services.

Part of the method was to identify the person(s) to whom the letters were addressed. Patients wanting to merely “acknowledge” behaviour might write directly to the staff concerned. But patients wanting to “promote” the behaviour might write to managers and chief executives. This could provide evidence that the written compliments were targeted at different audiences to achieve different effects. The study found that there were indeed differences along these lines.

The authors state that “Patient feedback data, despite vast amounts of data collection, have arguably had little impact on improving services”. But, they say, “Compliments are credible, specific and narrative, and positive, which might make them a relatively effective route to improve quality”.



Patients in waiting

Last March, just as the national lockdown was starting, NHS England asked providers to postpone all routine surgery for at least three months. The decision made sense in a crisis situation, when hospitals were filling up with Covid patients, and the Nightingales were on standby. But what did the decision mean for the huge numbers of people who were waiting for care?

To find out, we carried out a literature search, drawing out hundreds of recent reports on people's experiences of being on hospital waiting lists. At the same time, Care Opinion trawled through posts to their website, looking for individual accounts of waiting for care. National Voices then added a third strand - based on deeper conversations with "patients-in-waiting" via a carefully designed listening exercise.

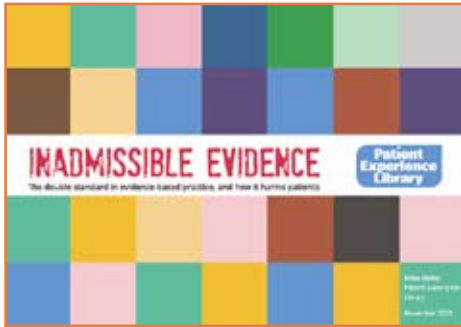
The research shows that patients' journeys through the system are characterised by waiting/delays before the clock officially starts; stop-starts along the way; cancellations; changing goal posts and reversals, which patients simply did not understand.

For some, this led to speculation about "tactical management" of waiting list targets at the expense of patient care. For others, a lack of control arising from fear of further deterioration or loss of income/employment severely curtailed their ability to "get on with one's life". Waiting affected family, work, and social lives.

The report points to opportunities to improve the experience of waiting. These can include pain relief and psychological support to deal with pain, as well as access to mental health support. Physiotherapy was suggested by some, while others asked for clear pathways to specialist advice if symptoms escalated. Clear communication between primary and secondary care was important, as patients often speak to their GP for support when waiting for specialist care. Alongside all of this was a need for information about employment and benefits.

These forms of support do not necessarily have to come from the NHS. A recurring theme was the importance of the voluntary and community sector, with support including helplines, information, peer mentoring, groups and policy information. People were often keen to get involved in charity work by volunteering and this also helped them to deal with their situation.

This is a comprehensive report, revealing the human experiences behind government statistics on waiting times and targets. But it is also a model for how to gain deep insight into patient experience by drawing on wide-ranging evidence from the literature, from online feedback and from face to face interviews.



Inadmissible Evidence

2020 is seen as the year of coronavirus. But it has also been a year of large scale avoidable harm in healthcare.

The report on rogue breast surgeon Ian Paterson was released at the start of the year, followed by the Cumberlege review of harms arising from pelvic mesh, sodium valproate and Primodos. We finished the year with the Ockenden report on Shrewsbury and Telford. A common factor throughout was a failure to take patient feedback seriously.

Against this background, our Inadmissible Evidence report asks why healthcare seems unable to accept patient feedback as a valid form of evidence.

The report points to a double standard which respects medical research while dismissing the experiences of patients as “anecdotal”. We recognise that at a one-to-one level with patients, staff offer deeply personal and compassionate care. But our healthcare system - at the highest levels - sends repeated signals that patient experience evidence is of less interest than medical evidence.

There has been a huge response to the report, with over 4,000 copies downloaded to date. Key themes were picked up by the [BMJ](#), and by the [Matters of Engagement](#) podcast, which dug into the question of how patient experience could be taken more seriously.

Our answers, set out in the report, include better research prioritisation, improved analytical tools and a professional learning infrastructure for patient experience work.

We continue to do all that we can to help put patient experience work on the same kind of evidence-based footing as clinical work. As we do, we are inspired by these words, from the [Cumberlege review](#):

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



More than bums on seats

“Public involvement is typically presented as being unquestionably a good thing in relation to healthcare” say the authors of this paper. But why do we want public involvement? What does it actually achieve?

The paper looks at how the “impact” of involvement is measured - particularly in health research. It finds plenty of confusion.

First there is the question of what is being counted. The authors say that measures which are easy to count, such as numbers of people involved, tend to be favoured. However, questions of how “involvement activities change power relations and empower the public, are largely not being captured”.

Some of the confusion over how to measure impact might come from the fact that “at least 65 frameworks have been developed for assessing the nature and impact of public involvement in health research”. And uncertainty over the value of impact measurement might arise from the fact that sometimes, the main purpose is to satisfy funders. This can mean that impacts “get overblown in an attempt to secure further funding -- a phenomenon referred to as ‘impact sensationalism’”.

Underlying all of this are differences of opinion about what involvement is for. Some see it as “a means to the end of achieving better research”. But “An alternative ‘democratic’ or ‘rights-based’ framing of public involvement... sees public involvement not so much as a means to an end (better research) but as an end in itself”. As one commentator put it, “Service users have not fought for a voice at the table merely to help improve the research process, but because they have a right to be there”.

The authors carried out a historical analysis of National Institute for Health Research (NIHR) policy. This suggested that policy had moved from being rights-based (‘nothing about us without us’), to “empowering” patients and public to “inform research” in ways that are more amenable to measurement. As a consequence, they say, “questions about how public involvement might enable the sharing of power, who power is being shared with, and in what ways, are easily side-stepped”.

The paper concludes that “We still know very little about whether and how public involvement changes power relations between researchers and the public, because this is rarely the focus of impact research”. It calls for “public involvement as a social practice of dialogue and learning between researchers and the public: an end in itself, not merely a means to an end (at worst, measured superficially as ‘bums on seats’)”.

Strengthening patient experience evidence

“Patient experience must no longer be weighted least in the hierarchy of evidence-based medicine”. So said Baroness Cumberlege in [First Do No Harm](#) - the recent review of large scale avoidable harm in healthcare.

It is an important and powerful statement - but how do we push patient experience up the evidence hierarchy? Unfortunately, there seems little urgency in government, whose response has been [described by Cumberlege as woeful](#).

Rather than wait for an official response, Care Opinion and the Patient Experience Library decided to act on their own initiative, and act quickly. We have joined forces to integrate search functionality across both platforms - linking over 60,000 written reports on patient experience with more than 400,000 direct comments from patients.

The rationale is simple: if we want patient experience evidence to be better used, the first thing we have to do is make it easier to find.

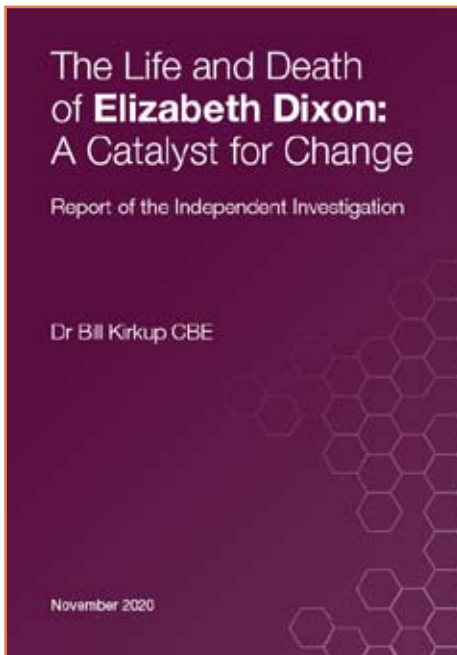
There are longstanding barriers to getting access to patient experience evidence. These have been documented in our recent [Inadmissible Evidence](#) report. Breaking through those barriers has been a key part of the mission of both Care Opinion and the Patient Experience Library. Both teams have spent years building better, faster and more transparent ways to hear from patients. But until now, both have worked separately.

The join-up, like the rationale, is simple. Enter a search term (eg “XYZ Trust”) into Care Opinion and exactly the same term will be automatically entered into the Patient Experience Library. Users can switch between direct comments from patients, and structured reports and surveys relevant to their search term.

It works in reverse as well: a search in the Patient Experience Library brings results from both the literature and from patient comments on Care Opinion. Users can search by provider, by health condition or by service (eg maternity). Both platforms respond simultaneously to whatever search term has been entered, giving a two-way join up of direct comments and written reports.

The initiative brings together two tried and tested systems to create the UK’s biggest public evidence base on patient experience.

Baroness Cumberlege has challenged healthcare to take patient experience evidence more seriously. Government seems to be taking its time to respond. But in the meantime, Care Opinion and the Patient Experience Library are providing the basis for a joined up response right across the NHS.



The Life and Death of Elizabeth Dixon

Bill Kirkup's report on the Life and Death of Elizabeth Dixon is by turns harrowing, desperately sad, and depressingly familiar.

The story, once again, is of a patient (this time, a baby) who died, and of bereaved relatives who had to spend years (this time, twenty years) fighting for the truth about what happened.

The report describes "failures of care by every organisation that looked after her, none of which was admitted at the time, nor properly investigated". That statement has echoes of the Morecambe Bay report, which found "a series of missed opportunities to intervene that involved almost every level of the NHS".

The report reveals "a cover up... propped up by denial and deception, which has proved extremely hard to dislodge over the years". That sounds like Gosport, where "Over the many years during which the families have sought answers to their legitimate questions and concerns, they have been repeatedly frustrated by senior figures".

The report says that "The fabrication became so embedded that it has taken a sustained effort... to demolish it". That mirrors the Northern Ireland Hyponatraemia inquiry, where investigators noted "how difficult it was to persuade some witnesses to be open and frank... concessions and admissions were extracted only with disproportionate time and effort".

There is a culture in healthcare that has to change - and it is not about individual staff, or individual organisations. It goes to the top.

It is about system leaders like NICE and Health Education England, whose National Core Content of evidence contains no dedicated component for patient experience.

It is about the Department of Health which, down the years, has failed to preserve organisational memory via an archive of patient experience evidence.

It is about NHS England, which knows that NHS staff struggle to make sense of patient experience data, but has not developed good analytical tools.

Kirkup's report says "It is vital that what happened acts as a catalyst for the significant changes that are necessary to ensure that this does not happen again".

Those "significant changes" should not be focussed solely on clinicians, with the usual litany of updating practice protocols and refreshing training. There also needs to be a focus on system leaders - NHS England, NICE, and Health Education England. They set the tone, they set the culture, and they need to set a lead in giving patient experience its rightful place in the evidence hierarchy.



Food is medicine

“Food is a form of medicine” says the foreword to this report. It is also an important part of patient experience - as shown by the inclusion of questions about food in various national patient surveys, and in the checklists for PLACE visits (Patient-led assessments of the care environment).

Unfortunately, “There is a poor public perception of hospital food; and frequent critical press coverage”. The report states that “There is clearly scope for improvement”.

The good news is that there are models of excellence: “hospitals of every type serving fantastic food, and without busting the budget”. So how are they doing it? The report points to four things that successful hospitals have in common:

1. They adopt a ‘whole-hospital approach’. This means integrating food into the life of the hospital -- treating the restaurant -- treating the restaurant as the hub of the hospital, where staff and visitors eat together; the chef and catering team are as important as other staff members; and food is considered as part of a patient’s care and treatment.
2. They have a chief executive who leads the change and understands the value of food and nutrition.
3. They concentrate on the things patients and staff care about; good food, attractive environment, and a belief that the hospital they are in serves nutritious food at the best available quality.
4. They have integrated multi-disciplinary working; bringing together catering, dietetics and nursing to help improve nutritional outcomes for patients, and to ensure that staff well-being is prioritised with nutritious food and drink available on-site at all times.

The report is mostly about patient experience of hospital food. But it makes two interesting comments about staff - one observation and one recommendation.

The observation is that “Staff on night shift are perhaps the most ill-served of all the groups we looked at, often eating from vending machines offering nothing healthy and nothing hot”.

The recommendation is that “To ensure quality is driven from the top, it is important that boards and chief executives are regularly eating the same meal as patients. This could include serving patient meals at board meetings. Even better, boards should make unannounced visits to the wards and eat with the patients. This would help the decision-makers better understand the issues faced at ward level”.



Ockenden's silver lining

The Ockenden report on maternity services at Shrewsbury and Telford could be seen as par for the course in a year that has been full of bad news. The pain of the families can barely be imagined, and we can only hope that there is some relief for them in knowing that the truth is finally starting to come out.

But is there any good news from the Ockenden review? Our answer is a clear “yes”.

The review gives us cause for hope because it nails the myth that in our evidence-based healthcare system, only some types of evidence are worth having.

NICE - the National Institute for Healthcare Excellence - offers clinical guidance, drawing on “the highest quality and best available evidence”. But none of that was able to prevent a potential 1,862 cases of harm stretching over a period of years.

The Care Quality Commission regulates healthcare providers, based on rigorous, evidence-driven inspection processes. But none of that was able to detect the scale or severity of harm occurring at the Trust.

It was families - with no formal methodology, no analytical rigour, and no peer review - who were able to reveal the truth about the failures in maternity care. In the end, patient feedback - so-called “anecdotal evidence” - proved more reliable than any other form of evidence.

This is the third time during 2020 that patients have shown that their evidence is vital. First it was [Paterson](#). Then it was [Cumberlege](#). And now it is Shrewsbury and Telford. In every single case, it was patient testimony, more than any other source of evidence, which revealed the shortcomings in care.

So we are hopeful that the tide is turning, and that the medical establishment must now start to take note of Baroness Cumberlege's demand that patient experience “must no longer be weighted least in the hierarchy of evidence-based medicine”.

We hope that in 2021:

- NICE will make patient experience evidence part of its National Core Content.
- NIHR - the National Institute for Health Research - will help us to make a proper assessment of strengths and weaknesses in the patient experience evidence base.
- Health Education England will support our efforts to develop high quality accredited training for patient experience staff.
- NHS England will work with us on analytical tools that can cut through the morass of patient experience data.

All of this would indicate that NHS leaders were starting to take patient experience seriously - accepting it as a valid form of evidence, and moving it up the evidence hierarchy.

The Ockenden report reveals some terrible truths - but we don't have to despair. If we can use it to get patient experience seen differently, we can ensure that some good comes from the pain.

EVENTS

Readers of this magazine can get a 10% discount on all the following with code **HCUK10pel**

Implementing the Duty of Candour with Empathy

Monday 25th January 2021 Virtual Masterclass

Key Learning Objectives:

- Why the duty of candour is so important for patients, staff and organisations
- What is needed to comply with the duty of candour
- Clarifying 'grey areas' and common difficulties
- Implications for safety and competency investigations
- What constitutes a meaningful apology
- An understanding of empathy, its importance and application in delivering the duty of candour
- How to be sure you are doing it 'right' and seeking evidence to demonstrate you are
- Explore the absence and presence of empathy in a real life context
- Examine different perspectives and what is going on in the 'World of Life'
- The emotional experience surrounding the duty of candour
- Recognise the different barriers impacting empathy and equity and strengthening an empathic response
- Link the human side of the duty of candour to the compliance and the importance of communicating with warmth, honesty and openness

Facilitated by:
Peter Walsh, Chief Executive Action against Medical Accidents
Ceryn Cleveland, Founder and Owner C & C Empathy Training

30% of the profits from this event goes to the patient safety charity Action against Medical Accidents (AAMA)

10% discount with code HCUK10pel
15% discount with code HCUK15pel

HEALTHCARE CONFERENCES UK, CPD, Patient Experience Library, 2020

Implementing the Duty of Candour with Empathy

MONDAY 25 JAN 2021
VIRTUAL, Online

This masterclass will provide participants with an in-depth knowledge of what needs to be done to comply with the duty of candour; clarify 'grey areas' and provide guidance on dealing with difficult situations which may arise. It will provide participants with an understanding of good practice in implementing the duty and, in particular doing so in a meaningful way with empathy, to not only comply, but to work with patients and loved ones in a way that puts the emotional experience at the heart of communication.

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[Find out more](#)

NHS Complaints Summit 2021

Delivering a person-centred approach to the handling, investigation, resolution and learning from Complaints in the NHS

Thursday 28th January 2021 Virtual Conference

Chair and Speakers include:

- Larry Wilson, Chair, The Patients Association
- Al Power, LibDem MP, Parliamentary and Health Service Ombudsman
- Professor Helen Young, Executive Director of Patient Care and Services, South Central Ambulance NHS Foundation Trust

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HEALTHCARE CONFERENCES UK, CPD, Patient Experience Library, 2020

NHS Complaints Summit 2021

THURSDAY 28 JAN 2021
VIRTUAL, Online

Delivering a person-centred approach to the handling, investigation, resolution and learning from Complaints in the NHS.

This National Virtual Summit focuses on delivering a person-centred approach to complaints handling, investigation, resolution and learning. Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints lead to change and improvements in patient care. The conference will reflect on the challenges and complaints that have resulted from the Covid-19 pandemic.

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[Find out more](#)

Investigation & Learning from Deaths in NHS Trusts

Monitoring & Improving Hospital Mortality During Covid-19

Wednesday 24th February 2021 Virtual Conference

Chair & Speakers include:

- Dr Martin Farrier, Clinical Director for Quality, Walsingham Wigan and Leigh H&S Foundation Trust
- Dr Zoe Brumwell, Anaesthetic and Intensive Care Trainee, University College London NHS Foundation Trust
- John Taylor, Assistant Coroner, North London

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HEALTHCARE CONFERENCES UK, CPD, Patient Experience Library, 2020

Investigation and Learning from Deaths in NHS Trusts

Wednesday 24 FEB 2021
VIRTUAL, Online

The NHS is the world's first health organisation to publish data on avoidable deaths. The National Guidance on Learning from Deaths has driven a strengthening of systems of mortality case review with emphasis on learning. By collecting the data and taking action in response to failings in care, trusts will be able to give an open and honest account of the circumstances leading to a death.

This National Conference focuses on improving the investigation and learning from deaths in NHS Trusts following the National CQC and NQB guidance, and Department of Health reporting requirements. The conference will also discuss the role of Medical Examiners providing a national system of medical examiners will be introduced to provide much-needed support for bereaved families and patient safety.

10% Discount with code **HCUK10pel**

[Find out more](#)

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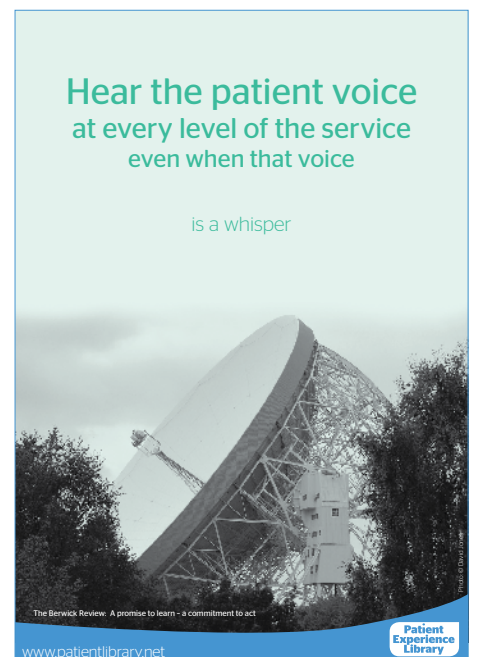
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Hear the patient voice at every level of the service even when that voice

is a whisper



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We are the national evidence base for patient experience and patient/public involvement. We have collated and catalogued over 60,000 reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

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You can see more about who we are and what we do [here](#).

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