

# Patient Experience

and patient/public involvement in health and care services

Spring 2024



**Patient  
Experience  
Library**

**INSIDE**

**My missing  
childhood  
Transparency  
now**

## Editorial



Numerous NHS strategies talk about the importance of being “patient-centred”. Healthcare staff are often brilliant at this, and platforms such as Care Opinion are full of appreciative feedback from patients who have felt listened to and cared for.

Why, then, do healthcare institutions so often get it wrong? What causes the shift from careful and attentive listening by individual staff to careless and dismissive responses at the organisational level?

Our contributors to this edition have both tried to raise serious concerns with NHS bodies and have both run into organisational brick walls.

In 1978, Liza Morton was the youngest baby in the world to be fitted with a cardiac pacemaker. She recently asked to see her paediatric medical records - partly to make sense of her childhood experiences, and partly because the records could hold important information for her ongoing cardiac care. But the records have been destroyed. No-one had thought to tell her, and no-one seems to want to take responsibility.

Kath Sansom has spent years campaigning for women harmed by pelvic mesh. She recently replied to a government consultation on industry payments to healthcare providers - an issue on which mesh campaigners have long been calling for greater transparency. The government has taken four months to respond and has failed to answer any of the points she raised.

We stand by Liza and Kath in their fight for information and for justice. And we condemn healthcare bodies whose reluctance to engage with patients is an affront not just to patients but also to the many, many healthcare staff who work day in and day out for a patient-centred NHS.

As always, we also bring you the latest and best patient experience research, packaged in handy summaries for busy people. And we're always keen to hear from our readers, so if you know of a standout report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

Miles Sibley, Editor [info@patientlibrary.net](mailto:info@patientlibrary.net)

[www.patientlibrary.net](http://www.patientlibrary.net)

## Services

Feel free to browse the [Patient Experience Library](#) - a wealth of reporting on all aspects of patient experience and engagement. We can build tailor-made local libraries for your Trust or Integrated Care Partnership - drop us a line to find out how.

Check out our [research-based publications](#), and sign up to our weekly newsletter for regular updates. We offer bespoke search and literature reviews like [this](#) and [this](#) - get in touch to find out more.

Our [Patient Surveys Tracker](#), [Waiting Lists Tracker](#) and [Evidence Maps](#) help you make sense of the things that matter to patients. Let us know if you want to talk about custom-made analytics, adapted to your specific requirements.

Contact: [info@patientlibrary.net](mailto:info@patientlibrary.net)



## Comment

Do you have opinions, insights or good practice examples that you'd like to share with our readers? Drop us an e-mail to receive our guide for contributors: [info@patientlibrary.net](mailto:info@patientlibrary.net)

# My missing childhood

*Dr Liza Morton, Counselling Psychologist, Glasgow Caledonian University*



Our medical records detail the most important events in life; birth, early development, illness, pregnancy—all the way to our final moments. So why is it still so challenging to access this vital information in a way that supports us as patients?

Recently, I've been reflecting on this regarding my experience as the youngest baby in the world to be fitted with a cardiac pacemaker in 1978 and my dependence on lifelong pioneering cardiac care. I spent a lot of my childhood in hospital where a world-leading cardiology team learned how to fit and maintain each new development in pacemaker technology. I am currently fitted with my 11th pacemaker and have experienced countless complications along the road.

Growing up, my paediatric medical notes were a source of mystery. At medical appointments, my consultant added scribbled observations to a file bursting at the seams with letters, results, and medical images, while my mum and I nervously waited. During frequent hospital stays this important

folder lay at the bottom of my bed. While tempted, I knew not to touch it. A prompt for discussion between doctors and nurses, to me it was forbidden.

More recently, medical information has become digitalized but during consultations the computer screen is angled so that I still can't see what is being written about me.

In the hope of filling the gaps about my medical experiences, I submitted a request to access my paediatric medical records. I was astounded to learn all of the cardiology medical records detailing the first eighteen years of my care had been destroyed.

When I tried to find out why, I was sent around the houses. I have spoken to the service that commissions congenital cardiac care in Scotland, to the health board responsible for the national service, to the Scottish Public Services Ombudsman, and to the Information Commissions Officer, the independent body set up to uphold information rights. None of them seem to want to take responsibility.

In Scotland, government guidance states that childhood medical records should be retained until the patient's 25th birthday unless the illness could have potential relevance to adult conditions, in which case, they should only be destroyed on the basis of specific clinical approval.

I have found no evidence that a clinician approved the destruction of my records. What I have found, however, is that the record was not labelled with a "do not destroy" sticker. And so an assumption was made that

they could be disposed of. Nobody thought to check with me.

My health board says that an adequate clinical summary of my childhood notes was provided when I moved to adult care and that this summary means I am not at clinical risk. But I have been unable to find the summary record that the health board is referring to.

From a medical perspective, as one of the longest-living survivors in the world completely dependent on a cardiac pacemaker, this has left me in a vulnerable position. My care was a first, and my healthcare needs are lifelong. It is impossible to know which parts of my medical history may become relevant.

On a personal level, I feel very sad that such a significant part of my childhood has been destroyed. I will never know how many cardiac procedures I have endured; how many hospital stays, the story behind some of my scars, or what happened to me. Like the child sitting in the hospital bed, my childhood medical notes and the opportunity to better understand my childhood experiences are now forever beyond my reach.

My childhood medical records have been wrongfully destroyed without my knowledge or consent, and in breach of the law, my data protection and patient rights. I have been completely silenced as a patient. This sets a precedent for children's health rights everywhere.

Liza Morton is co-author of [Healing Hearts and Minds: A Holistic Approach to Coping Well with Congenital Heart Disease](#).

# Transparency now

*Kath Sansom. Founder, Sling The Mesh  
@MeshCampaign*



Last September, when the government announced a consultation on the [disclosure of industry payments to the healthcare sector](#), I was happy.

Thousands of women have been harmed by pelvic mesh - not least because manufacturers of medical devices have been able to buy their way into positions of influence. Patients' voices and experiences, by contrast, have been diminished and dismissed.

In 2020, Baroness Cumberlege's [First Do No Harm](#) review recommended mandatory reporting for industry payments made to teaching hospitals, research institutions and clinicians. Whilst arguments may be made for the benefit of these collaborations, it is widely accepted that transparency round their existence is the first step in assessing their overall impact on healthcare.

So I was happy about the government's consultation - until I read the proposals in detail.

It turns out that much of the disclosure process is unworkable and will have little practical use. In brief:

- Industries will be allowed to disclose their payments to healthcare on their own websites. But how are patients and public supposed to keep track of fragmented declarations across hundreds of separate websites?
- Industries will have a further option to publish payments information via Disclosure UK. This innocently named portal is actually run by the Association of British Pharmaceutical Industries. And publication here as well as across industries' own websites creates still more fragmentation of data.
- Industries are offered a get-out: there is an option to exempt publication of "commercially sensitive information". This entirely misses the point of mandating disclosure.

I raised these points in a written submission that was jointly signed by some leading supporters of our Sling the Mesh campaign. I heard... nothing.

Then, at the end of February, four months after our submission, I had a response. A covering email explained that the delay in replying was down to an "administrative error". Once again, we see a lackadaisical attitude towards the concerns of mesh victims.

The reply is wholly inadequate, and fails to address any of our concerns. But an interesting glimmer of transparency came from another bit of slipshod practice on the part of the Department.

By accident, they sent us an email distribution list linked to the consultation. It suggests that the "stakeholders" with whom the government has been in touch are overwhelmingly trade bodies, regulators, or government representatives.

Clearly, the government consultation on transparency of payments was a joke. And it flies in the face of the First Do No Harm Review, a report that through its 277 pages, weaves a message of women not being listened to.

Industry needs to be mandated to log its payments to healthcare on one transparent and open database that is easily searchable. They do this in the USA, where the 2010 Sunshine Act requires manufacturers of drugs and medical devices to report all payments over \$10 to [the Centers for Medicare and Medicaid Services \(CMS\)](#), a branch of the US Department of Health. And they do it in France, where the 2014 Bertrand Law means that payments are recorded on a government register that is searchable by the public, the "[Transparence Santé](#)".

When government prioritises consultation with industry over listening to the concerns of patients, they effectively silence the voices of those they are meant to serve. But in this case, we - the victims of manufacturers of pelvic mesh - refuse to be silenced.



## An opportunity lost

The NHS has no shortage of strategies. Many of them - Transforming Community Services, the Five-Year Forward View, the Long-Term Plan - have made the point that the UK has an ageing population, and a growth in long-term conditions. The strategic response depends in large part on encouraging people to “self-manage” their conditions in their own homes and communities.

Central to self-management are homecare medicines services. These provide up to half a million people with the medicines they need, along with any necessary help to administer them.

This House of Lords report examined these services and found a great deal of room for improvement.

A key concern was safety. “No one”, says the report, “not the Government, not NHS England, not patient groups, not regulators - knows how often, nor how seriously patients suffer harm from service failures in homecare”.

Another was financial. “The Government does not know how much money is spent on homecare medicines services. It is therefore impossible to make any assessment on value for money. Given that the figure is most likely several billion pounds per year, this lack of awareness is shocking and entirely unacceptable”.

The report points to “serious problems with the way services are provided. Some patients are experiencing delays, receiving the wrong medicine, or not being taught how to administer their medicine”.

Homecare medicines services are mainly provided by private companies. So in some cases, the taxpayer is effectively paying for the service twice - once for the private provider to deliver it, and again for the NHS to pick up the pieces where private providers fail.

“Most concerningly”, say the peers, “we found a complete lack of ownership of these key services... no one person or organisation was willing to take responsibility for driving improvements or exploiting the full potential of homecare medicines services to bring care closer to home. Simply put, no one has a grip on this”.

The report makes recommendations on transparency, procurement, enforcement of standards and digital infrastructure. It concludes, with a masterpiece of understatement, by hoping that the analysis will “be of assistance” to NHS England and the Department of Health and Social Care.



## Detecting patterns of harm

David Fuller worked for the NHS for 31 years. “His employment”, says this inquiry report, “started only two years after he committed the brutal murders of two young women in Kent, whose deceased bodies he sexually assaulted”. He went on to commit 140 known offences against deceased women and girls in the mortuaries at Maidstone and Tunbridge Wells NHS Trust.

How can such appalling crimes have gone undetected for so long? The report offers a series of answers - and as with so many instances of large-scale avoidable harm, they fit a recognisable pattern.

The first is that “This is not solely the story of a rogue electrical maintenance supervisor. David Fuller’s victims and their relatives were repeatedly let down by those at all levels whose job it was to protect and care for them”.

The report also notes that “The culture... at Tunbridge Wells Hospital, as observed by the Inquiry, was not one of questioning and curiosity. There was a lack of curiosity about David Fuller’s work behaviour in relation to the mortuary”.

There was evidence of siloed working at Maidstone and Tunbridge: “mortuary staff felt ignored by senior managers and separated from the rest of the Trust... mortuary staff were ‘functionally isolated’.

Compliance, too, was an issue. At Maidstone and Tunbridge there was “a culture... in the mortuary where Standard Operating Procedures were routinely ignored and security breaches were not thoroughly investigated”.

We have all seen this before. The Cumberlege review of medicines and medical devices including pelvis mesh rejected the idea of “rogue” individuals. The inquiry into Ian Paterson, the jailed breast surgeon, noted a lack of professional curiosity about his practice. The East Kent investigation remarked on siloed working between Canterbury and the Margate and Ashford site. Problems with compliance were, once again, seen with Paterson.

We need to learn from these patterns. That means rejecting simplistic notions of “rogue operators” and instead taking on the harder work of tackling system-level weaknesses. It means understanding that lack of professional curiosity creates opportunities for wrongdoing. It means acknowledging that siloed practice is dangerous practice. It means knowing that when policies are ignored, harm ensues.

The patterns are clear, and every single inquiry report - Mid Staffs, Morecambe Bay, Shrewsbury and Telford, East Kent, Paterson, Letby, Fuller - makes them clearer. An NHS that keeps promising to learn the lessons needs to start learning what patterns of harm look like.



## Building trust

“The NHS is looking to advances in digital health technologies and data to help tackle current pressures and meet rising demand” says this report from the Health Foundation. “But”, it says, “ensuring new uses of technology and data have the backing of the public is critical if they are to become business as usual”. The authors surveyed 7,000 members of the public to test their views.

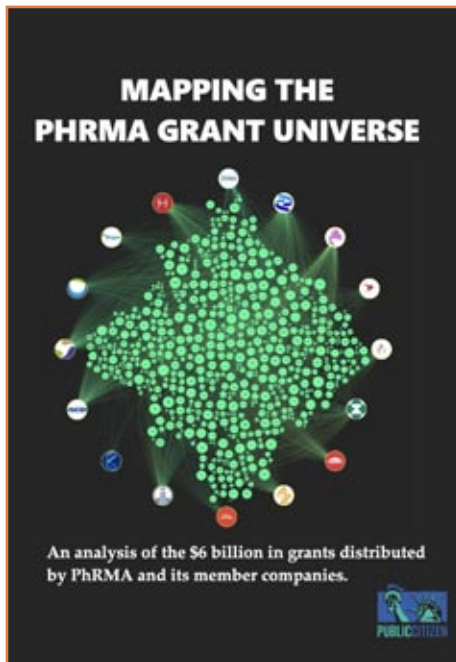
The good news is that people are generally supportive of technology in healthcare. Over half of those surveyed (51%) said that the NHS should make more use of self-monitoring devices, such as blood pressure or heart rate monitors. And nearly half (48%) said the NHS should be making more use of electronic health records.

There was less support, however, for the use of chatbots to check symptoms or get health advice and less support for video conferencing to speak to a health professional. The authors note the difference between technologies aimed at supporting the public, and those that might be perceived to come between the clinician and patient.

As far as healthcare data is concerned, the survey found that nearly two-thirds (61%) knew ‘very little’ or ‘nothing at all’ about how the NHS is using the health care data it collects.

In spite of this, two-thirds said they trust GP practices, local NHS hospitals and clinics and national NHS organisations with their health data ‘a lot’ or ‘moderately’. But national and local government organisations and health technology companies are less trusted. There is, says the report, a need to “grow trust in organisations with currently low trust levels”.

The authors conclude that “Over the coming years, policymakers and NHS leaders will need to prioritise meaningful public engagement on the future of technology in health care”. And they say that “it is important that this public engagement is inclusive, seeking out the voices of those who can often be excluded in public consultations”.



## Pharma's levers of power

“The pharmaceutical industry is one of the most powerful industries in the nation” says this US study. The industry has various levers of power, but this report looks at one in particular: “the billions in grants the industry has given out to the most powerful advocacy organizations in the country”.

The study analysed hundreds of publicly available documents and built a dataset of grants given out by the Pharmaceutical Research and Manufacturers of America (PhRMA) and its member companies.

It discovered \$6 billion in total grants dispersed by the PhRMA Network to more than 20,000 different recipients from 2010 through to 2022. 13 of the nation's largest and most powerful patient advocacy organisations received \$266 million between them. Among those were the following:

- The American Cancer Society received \$6 million from AstraZeneca, \$4.7 million from Merck, and \$3.4 million from Pfizer, all manufacturers of expensive cancer drugs.
- The American Diabetes Association received more than \$11 million in grants from Sanofi and more than \$7 million from Eli Lilly. Along with Novo Nordisk, the companies control 90% of the insulin market globally.
- One of the nation's most prominent spinal muscular atrophy organisations, Cure SMA, received more than \$5.8 million from Novartis, the manufacturer of the SMA gene therapy that costs \$2.25 million per dose.

Additionally, the study found many op-eds that were published by PhRMA Network grant recipients criticising US government efforts to rein in drug prices. In some cases, the author and grant recipient received a grant around the time of the op-ed's publication for “advocacy”.

Furthermore, 740 lobbyists were hired by both grant recipients and members of the PhRMA Network. These grant recipients received \$577 million from the PhRMA Network.

In conclusion, the authors state that “The PhRMA Network companies are not mission-driven charities. They are some of the largest and most profitable companies in the world, hyper-focused on returning value to shareholders. It's impossible to know how much the money affects the decision-making process of the grant recipients. But it is hard to believe \$6 billion had no effect”.





## Misinformed choice

“Informed choice” is a principle enshrined in the NHS Constitution – a document based on medical ethics and law. Informed choice means that patients should have sufficient information and understanding before making decisions about their medical care.

It is surprising, then, to see NHS England announcing a potentially misleading addition to the NHS App. Heralded as a “new feature to improve patient experience”, the app will now show mean (average) waiting times for treatments at English acute Trusts.

Official figures published via [the NHS England website](#), however, do not use averages. They use a “92nd percentile” figure. Why? Because under the NHS Constitution, 92% of people waiting are meant to be treated within 18 weeks. And the 92 percentile figure is always higher – much higher – than the average.

NHS England says that the average waiting times information will help “by better informing patients about their care”. But unsurprisingly, some disagree.

[Patient Safety Learning](#) cites “senior figures close to the project” as saying that “the NHS App will give patients ‘disingenuous’ and ‘misleading’ information about how long they can expect to wait for care”.

The President of the British Orthopaedic Association agrees. [He has said](#) that “as an example, the mean average waiting times for patients could be around 22 weeks whereas the 92nd percentile figure is 63 weeks, showing just how far apart these two metrics are”. He goes on to say that “It is unacceptable that patients may be given such false hope”.

So there seems to be a double standard at work. Official statistics – aimed at policymakers and practitioners, use the helpful and reliable 92nd percentile figure. But the NHS App, aimed at patients, offers averages that could be misleading.

By putting averages into the NHS App, NHS England risks undermining the NHS Constitution’s promise of informed choice. It also risks undermining public confidence and trust. And that is not something that a struggling NHS can afford to do.



## Groundhog Day strikes again

This review was commissioned in response to a BBC Panorama programme that showed “appalling levels of abuse, humiliation and bullying of patients at the Edenfield Centre in Prestwich”. The report says that “The horror of what was shown could not fail to touch anyone who watched the programme”.

By the same token, anyone who has read other reports of abusive cultures (Winterbourne View, Whorlton Hall, Muckamore Abbey) cannot fail to get a sense of history repeating itself. All the familiar patterns are there.

We hear that “Some patients and families described not being believed when they raised concerns or complained about the care received... Others shared how they did not always feel safe to disclose concerns, with many accounts of feeling intimidated, undermined, ignored, or fearful that ‘bad news’ was not welcomed”.

Another Groundhog Day moment describes “a Trust that was not sufficiently focused on understanding the experience of patients, families and carers... The lack of both curiosity and focus on improvement led to missed opportunities for organisational learning”.

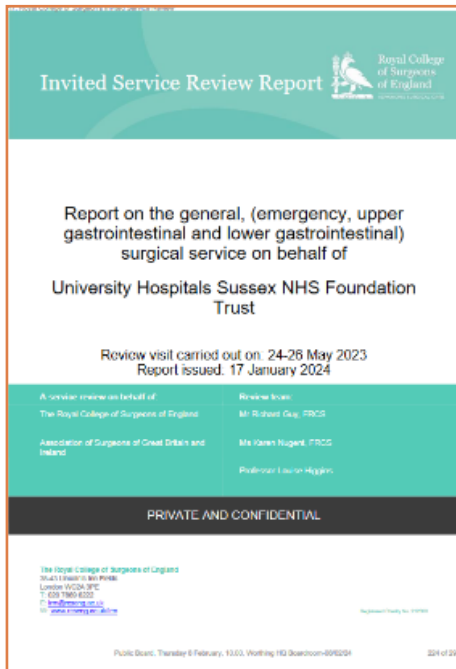
In common with health professionals elsewhere, staff at Edenfield talked of “feeling exasperated, tired of not being listened to and disconnected from the Trust leadership... staff have felt fearful to speak up for many years”.

Of course some patients and families tried to raise concerns. But “there was a lack of clarity and accountability throughout all the complaints process... making a complaint was discouraged”.

The new Chief Executive at the Trust has said ‘We cannot change the past, but we are committed to a much-improved future’.

It is true that we cannot change the past. But we can learn from the past. From Mid Staffordshire, Morecambe Bay, Gosport, Shrewsbury & Telford, and East Kent. From Cwm Taf in Wales and the hyponatraemia deaths in Northern Ireland. From the widespread harms caused by Primodos, Sodium Valproate and pelvic mesh. From Letby, Paterson and Fuller.

The literature on harm - and harmful cultures - is extensive. It contains all the lessons we need. Healthcare providers need to stop trotting out wearily familiar apologies, and start taking seriously the job of learning from patient experience.



## A turning point for transparency?

This report is marked “Private and Confidential”. It is not hard to see why. It sets out the findings of an independent review of services at the University Hospitals Sussex Trust, and includes patient safety issues as well as concerns about culture and behaviour.

In spite of that, the report has been [posted on the Trust’s website](#), as one of the papers to be discussed at a recent (8th February 2024) Board meeting in public.

That seems like a bold move. The report contains some very worrying findings, including the following:

- A high volume of complaints from patients, and delays in responding.
- Consultant surgeons being dismissive and disrespectful towards other members of staff and displaying hierarchical behaviours towards allied healthcare professionals, particularly junior members of staff.
- Reports of two trainees being physically assaulted by a consultant surgeon in theatre during surgery.
- A culture of fear amongst staff when it came to the executive leadership team, with instances of confrontational meetings where consultant surgeons were told to ‘sit down, shut up and listen’.

In the past, and in other Trusts, reviews of this kind have tended to be suppressed. For example, the 2015 Morecambe Bay investigation revealed “the reluctance of the Trust to share the report [of the 2009 Fielding review into the Trust’s maternity services] even when being pressed for it”.

It is all the more surprising, therefore, to see the UH Sussex Trust receiving the review team’s report in January 2024, then immediately putting it into public Board papers in the first week in February.

In a preamble to the report, the Trust’s Chief Executive says “There are some tough messages for staff and us as Trust leaders [but] Problems can’t be solved without first being openly acknowledged”.

Everybody knows that things go wrong in healthcare. Far too often, the response is avoidance and denial. This response seems different. Might it be a turning point for transparency? We must, surely, hope so.



# Constraining co-creation?

“The last decade has seen an explosion of interest in co-production and co-creation” says this paper. But, it says, “the extent to which these new forms have resulted in meaningful change...is not fully clear”.

To explore the issue further, the researchers looked at five local Healthwatch organisations in different parts of England. Local Healthwatch was established to “strengthen the collective voice of local people” and has been described as “a source of genuine co-production”.

“The institutional context for co-creation”, according to the authors, was “promising”. Healthwatch had support at the policy level, and “The ability of Healthwatch to bring the views of marginalized and ‘seldom-heard’ groups to the table formed an important part of their appeal”.

The result was that “stakeholders across the whole system had a shared interest in demonstrating that co-creation was happening in a visible, tangible way”. So far so good. But here the research team sounds a warning: “this performative need had a strong influence on the activities pursued by the five Healthwatch”.

The study found that Healthwatch “took care in how they positioned their organizations... conscious of the need to demonstrate activity and impact”. Crucially, “co-creation depended on trusting relationships... which in turn required that they be taken seriously as part of the system rather than be seen as outsiders”.

The authors state that “this disposition also meant that some activities were shunned”. And “Healthwatch maintained a cautious distance from other voices of the public that challenged system organization in a more fundamental way”.

Ultimately, “Healthwatch deliberately constrained the scope of their contributions according to their perceptions of acceptability. The full richness of insights, ideas and critique... that co-creation may offer was carefully filtered before it even reached discussion and decision-making forums: ‘feasible’ solutions took precedence over ‘innovative’ ones”.

The paper concludes that “Even though they were not explicitly ruled out-of-bounds, Healthwatch officers knew that to be considered legitimate and serious players in the governance of health and social care, they needed to be selective about which issues they brought to the table”. Consequently, “the forms taken by co-creation in practice were largely conservative and constrained”.



# Online records access here to stay

In 2021, NHS England announced plans that patients aged 16 and over would have prospective access to their primary care records online, by default. By November 2023, one in four general practice surgeries across England still did not offer online record access (ORA).

Why the delay? Part of the answer, according to this paper, is that “Although patients often welcome transparency, studies show many doctors... express scepticism about patient access”.

So this study set out to explore the experiences and opinions of English GPs about the potential impact of ORA on both patients and doctors.

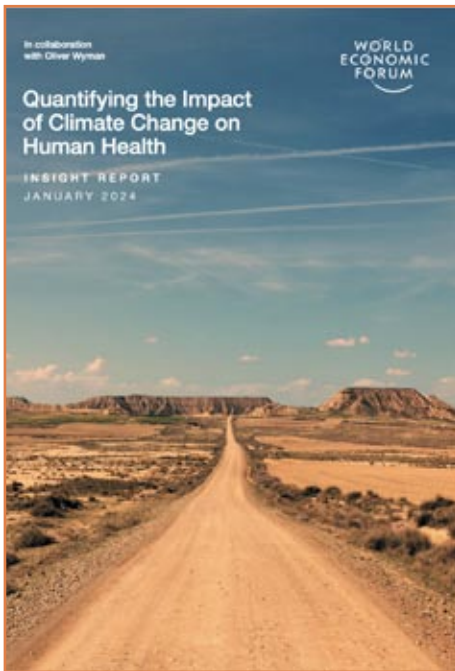
There were plenty of negatives. The vast majority (91%) of those surveyed “somewhat agreed” or “agreed” that after obtaining full online access, a majority of patients would “worry more”. 85% believed that most patients would “find their GP health records more confusing than helpful”. And 95% “somewhat agreed” or “agreed” that after full online access, a majority of patients would “contact me or my practice with questions about their health record”.

Against this were some positives. 70% “somewhat agreed” or “agreed” that a majority of patients would “better remember the plan for their care”, with 61% believing patients would “feel more in control of their healthcare”. Around half (52%) “somewhat agreed” or “agreed” that a majority of patients would “better understand their health and medical conditions” after accessing their online records or “be more likely to take their medications as prescribed” (50%).

Interestingly, 60% “somewhat agreed” or “agreed” that a majority of patients would “find significant errors in their GP record”.

The authors state that “we cannot help but observe a trend towards contrastive views between clinicians and patients”. And they say that their findings “suggest patients in England may be vulnerable to negative stereotyping with regard to their capacity to understand and emotionally cope with reading their own health information”.

A key implication is the importance of supporting GPs and their staff to become better prepared for talking about and writing documentation that patients will now read. The paper concludes that “in England, patients’ online access to their GPs’ records is here to stay. In the coming months, it will be crucial for GPs, primary care staff and patients to adapt to this radical change in practice”.



## The elephant in the room

Patient experience during the Covid crisis was bad. Thousands of people died in isolation from family and friends. Lockdown exacerbated loneliness, anxiety and mental ill-health. Even the arrival of vaccines was, for some people, a cause of fear rather than hope.

Patient experience through the climate crisis will be worse. But while the NHS can claim to have been taken by surprise by Covid, it cannot make the same claim for global heating.

This report from the World Economic Forum explains how scientists have spent at least the last twenty years warning of the impacts of climate change - including those on human health.

Some impacts are well-known - floods droughts, wildfires and rising sea levels. Others, such as the probable arrival in Europe of diseases like malaria, dengue and Zika may not yet have permeated the public consciousness.

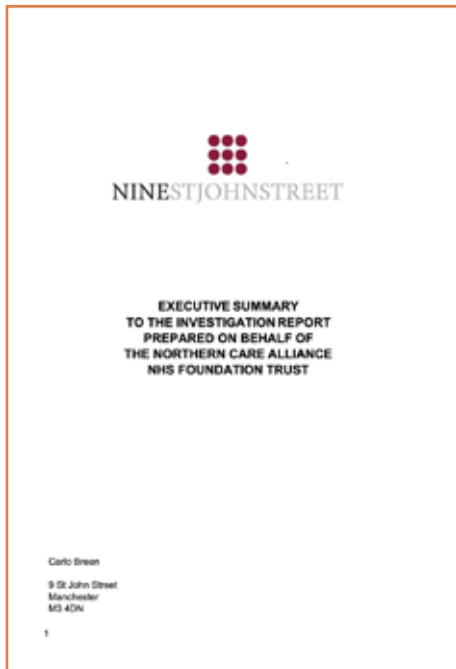
Equally, the uneven consequences across population groups may be poorly understood. The report makes the point that “climate change will exacerbate global health inequities. The most vulnerable populations, including women, youth, elderly, lower-income groups and hard-to-reach communities, will be the most affected”.

We have seen with Covid how a massive disruption to human health also causes huge disruption to healthcare systems. The report says that climate change will likewise create “a significant additional burden on already strained infrastructures”.

The report offers both scenarios and solutions, and issues a clear call to action. “Unlike the case with COVID-19, which took governments and the global healthcare industry by surprise, a unique window exists to adapt and prepare healthcare infrastructures, workforces and supply chains for the escalating impact of the climate crisis”.

Importantly, the task is not restricted to healthcare professionals and policymakers: “Collaborative efforts involving multiple stakeholders and industries are essential”.

In today’s NHS the talk is primarily about waiting lists, workforce and increasingly, productivity. Few, if any, are thinking seriously about the far bigger elephant in the room. But both patients and professionals need to ready themselves.



## The death of Patient A

In February 2007 a patient (Patient A) died in the operating theatre of the Salford Royal Hospital. This report states its purpose as “to examine what led to the death of Patient A, and what action the Trust took or did not take following their death”.

It reveals a litany of poor professional practice, combined with abuse of power, centred on a spinal consultant, Doctor F. Concerns around this doctor’s practice included:

- Negligent and fraudulent clinical practice, leading to serious life-threatening harm to patients.
- Poor clinical practice, including not treating patients in a dignified manner during physical examinations.
- Bullying, intimidation and harassment of colleagues, including unsolicited sexual contact with female staff.
- An extramarital affair between Doctor F and a senior divisional managing director of the Trust, which allowed poor clinical practices and behaviours to continue through undue protection of Doctor F.

The report details harms to other patients of Doctor F. These included a paused operation, with failure to proceed with the next phase for 90 minutes, and no communication with senior colleagues. There were poor preoperative documentation and consent processes. One spinal procedure involved multiple misplaced screws and a life-threatening haemorrhage due to direct vessel damage.

The report’s author says that the patients and/or their families should receive a full and transparent explanation and an apology for the level of care they received from Doctor F and the Trust. And, he says, “Lessons need to be learnt from these unfortunate events”.

These are depressingly weak recommendations. We know what the lessons are because arrogance, dysfunctional cultures and reluctance to concede error have already been detailed in multiple inquiry reports: Mid Staffs, Morecambe Bay, Gosport, Cwm Taf, Shrewsbury & Telford, East Kent and more.

The lessons are clear. It is time we started acting on them.



**NHS Complaints Summit**  
Implementing NHS Complaint Standards

Friday 19th April 2024 Virtual Conference  
Thursday 11th July 2024 Virtual Conference

10% group booking discount  
15% group booking discount

Chair and Speakers Include:

- Ben Wilson, Head of Customer Enquiries and Complaints, People and Organisational Effectiveness, MMC & Member PICO working group, Complaints Standards Framework
- Jo Power, Liaison Officer, Parliamentary & Health Service Ombudsman
- Justine Sharpe, Safety and Learning Lead, NHS Resolution

HEALTHCARE CONFERENCES UK | SOCIALCARE CONFERENCES UK

Supporting Organisations: NHS Elect, patient safety learning

## NHS Complaints Summit

**Fri, 19 Apr 2024**  
**Virtual, Online**

This National Virtual Summit focuses on the New PHSO National NHS Complaint Standards which are now being used and embedded into the NHS. 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 are welcomed and lead to change and improvements in patient care. The conference will also reflect how involving people and their families in complaints and integrating the process with the new Patient Safety Incident Response Framework (PSIRF) to ensure patient safety actions and learning.

### Further information and booking



Virtual Masterclass

**Engaging Patients & Families in Complaints**  
under Patient Safety Incident Response Framework (PSIRF) and the Complaints Standards Framework

Monday 13th May 2024 Virtual Masterclass  
Thursday 12th September 2024 Virtual Masterclass  
Monday 2nd December 2024 Virtual Masterclass

10% group booking discount  
15% group booking discount

Facilitated by:  
Carolyn Cleveland, Founder and Director, C&C Empathy Training Ltd.

HEALTHCARE CONFERENCES UK | EMPATHY TRAINING LTD

## Engaging Patients & Families in Complaints under Patient Safety Incident Response Framework (PSIRF) and the Complaints Standards Framework

**MONDAY 13th MAY 2024**  
**VIRTUAL, Online**

This virtual masterclass will build confidence in compassionately engaging and involving families and loved ones to work within the requirements of PSIRF and the Complaints Standards Framework. But more than this, the masterclass will support staff to go beyond compliance to understand the issues and emotional component on a deeper level; to have real authentic engagement and involvement with patients and families.

### Further information and booking

or email [kerry@hc-uk.org.uk](mailto:kerry@hc-uk.org.uk)



A Joint Healthcare Conferences UK and C&C Empathy Training E-Learning CPD Accredited Course

**Using Empathy to Compassionately Engage with Patients and Families within Complaints**  
Linking into PSIRF, Complaints Standards Framework and the Duty of Candour

10% group booking discount  
15% group booking discount

AVAILABLE NOW

NHS FRAMEWORK APPROVED TRAINING

CREATED FOR:

- Complaints Managers
- PALS Officers
- Family Liaison Officers
- PSIRF implementation Leads
- Learning Response Leads
- Front-line staff
- Management and Executive Teams
- Students

FACILITATED BY:  
Carolyn Cleveland, Founder of C&C Empathy Training

INCLUDES:

- Training videos
- Accompanying presentations
- Links to useful resources

12 MONTHS ACCESS | 4 CPD HRS | £225+VAT

[www.healthcareconferencesuk.co.uk/empathy-e-learning](http://www.healthcareconferencesuk.co.uk/empathy-e-learning)

## Using Empathy to Compassionately Engage with Patients and Families within Complaints

**ONGOING**

Linking to PSIRF, the Duty of Candour and Complaints Standards Framework, this course will develop skills and confidence in empathy, compassionate engagement, involvement and good complaint and patient safety incident handling. Examine through real-life content, a just, fair and learning culture to gain deeper understanding of the complexities of the emotional impact, to prevent second harm. Along with managing personal wellbeing.

This brand new course has been designed to give learners the live training experience, with interactive participation for learners to allow expression of their own. Throughout the journey, you will be accompanied by your own participation colleagues, who have been filmed during an actual session, to give honest, authentic and real time, thought provoking discussions and analysis.

### Further information and booking

or email [aman@hc-uk.org.uk](mailto:aman@hc-uk.org.uk)

## Want more training?

Our training tracker gives you access to a range of courses on patient experience and engagement - face-to-face, online and bespoke. To find the course you need, use our training tracker [here](#).



# Confused?



Patient experience evidence comes in different formats at different times from multiple sources. It is hard to make sense of it all.

## We can help you with...

**LIBRARY SERVICES:** Free access to the [Patient Experience Library](#), [Healthwatch maps](#) and [Quote Selector](#).

Struggling to keep track of local reports from public meetings, focus groups, surveys, Healthwatch, Maternity Voice Partnerships, Cancer Alliances etc? Ask us about tailor-made local libraries for your Trust or Integrated Care Partnership.

**EVIDENCE SERVICES:** Free access to [research-based publications](#).

Need to contextualise your own local evidence gathering? Ask us about bespoke search and literature reviews like [this](#) and [this](#).

**ANALYTICS:** Free access to our [Patient Surveys Tracker](#), [Waiting Lists Tracker](#) and [Evidence Maps](#). Looking for more like this? Ask us about customised analytical tools to support your insight and engagement work.

Get in touch! [info@patientlibrary.net](mailto:info@patientlibrary.net)

# The Patient Experience Library

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

[Visit our website](#) to get free access to evidence and analytical tools.

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

We welcome copy from contributors for the “Comment” section of this magazine, but cannot guarantee publication and we reserve the right to edit for reasons of space or style. Drop us an e-mail to receive our guide for contributors: [info@patientlibrary.net](mailto:info@patientlibrary.net)

Published items do not necessarily represent the views of the Patient Experience Library.

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.

Can't wait for your next edition of Patient Experience to appear?  
**[Sign up to our newsletter](#)** for weekly updates on what's new in patient experience and patient/public involvement!

**Can't wait a whole week?** Follow us: [@patientlibrary](#) 

---

[www.patientlibrary.net](http://www.patientlibrary.net)

The title and content of this publication © Glenstall IT, April 2024. The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN

**Patient  
Experience  
Library**

Cover: 'Transparency' icon from [thenounproject.com/WiStudio](http://thenounproject.com/WiStudio) CC

