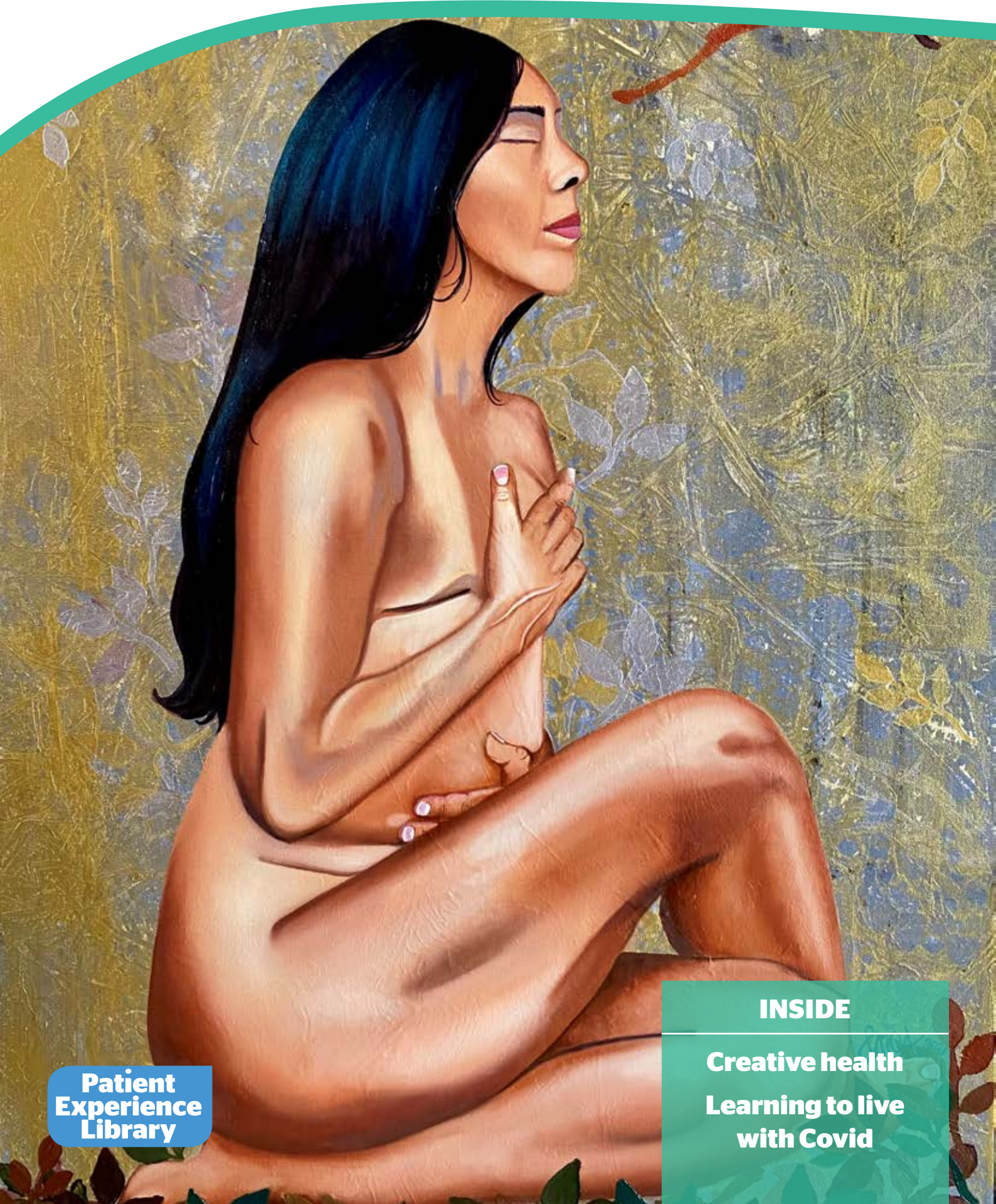


Patient Experience

and patient/public involvement in health and care services

Spring 2025



**Patient
Experience
Library**

INSIDE

**Creative health
Learning to live
with Covid**

Editorial



“Patient experience” is sometimes thought of as a kind of customer satisfaction exercise. NHS England, for example, describes the [Friends and Family Test](#) as a means to help service providers “understand whether patients are happy with the service provided”.

But NHS strategists have known for many years that a major challenge is the growth in long-term health conditions. So for many people, “patient experience” means learning to live with illness and vulnerability.

On page 3, Adriana Ford explains how an art project helped her to express her experience of cancer. It sparked her interest in the connection between art and health, and led her to set up the Breast Cancer Art Project which helps many others to share their stories through art and to navigate their cancer diagnosis.

Lara Wong on page 5 examines the UK government’s “learning to live with Covid” rhetoric. She sees that as a euphemism for abandoning any real learning at all - with serious consequences for clinically vulnerable people. For Lara, this is not just a health issue but a matter of equality and rights. We all benefit from better quality air - and we all suffer when we normalise sickness.

Along with these comment pieces, we 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

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Services

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Comment

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Creative health

Adriana Ford, Founder, Breast Cancer Art Project

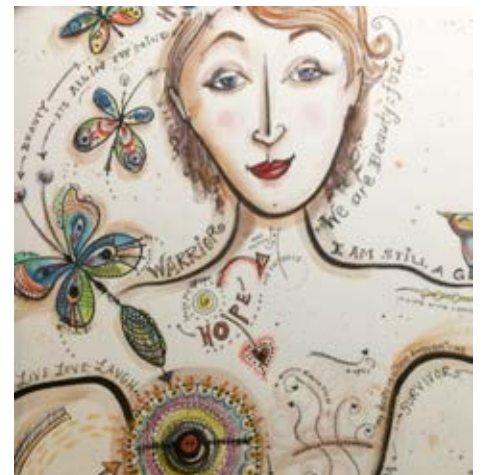


The psychological impact of a life-threatening health diagnosis is often devastating. Life suddenly becomes uncertain, mortality becomes real, and the ripple effect quickly works its way through to family and friends, work, education and all things that are held dear and woven into one's life.

At this point there is some comfort to surrendering your health to medical experts, knowing that their job is to take care of your body and keep you alive. However, tackling the psychological impact of a diagnosis is very different. It's essentially a 'you job' - activated the moment you receive the news, but it is the part of the process that you receive little to no help with.

Interactions with less empathetic medical professionals can worsen the psychological burden of a diagnosis, but the opposite can also be true. I have experienced both.

When I was diagnosed with stage 3 breast cancer in 2016, it was difficult to process what was happening and what the future, if it were to exist, might hold. Almost immediately I went into survival mode, navigating my way through a labyrinth of appointments and treatments, while trying to maintain a form of normality. Yet, emotionally, I was suffering. "I've seen people like you



Creative health



before” a nurse said, “be careful, it will hit you at the end”. She was right, it did hit me, but her message wasn’t helpful to someone, who thought that their life had been irrevocably changed.

After the chemotherapy, surgeries and radiotherapy, when ‘normality’ was meant to resume, I was left feeling lost and emotionally battered. I needed an outlet, something restorative to help me make sense of what I’d been through. It was around then that I discovered creative health.

Through a project led by Cardiff University, I was supported, along with other patients, to express my experience of cancer through art. With guidance of a mentor, I created a painting through which I expressed more of my feelings about my cancer diagnosis than I had through all the preceding months. It was cathartic, and sparked my interest in the connection between art and health.

My experience gave me the gumption to set up the Breast Cancer Art Project,

‘BCAP’. I wanted to create a space for others to share their stories through art and creativity, to engage with the art of others, and to help navigate their breast cancer diagnosis.

Inclusivity is at the heart of BCAP. It is open to all, from anywhere in the world. It is free, and any media is welcome. We have had paintings, drawings, poems, journals, crafts, music and sculptures all submitted in digital form - the options are endless. Artworks come from complete beginners (just like me) through to professional artists, and they all sit side by side. There isn’t a hierarchy or judgement about what should or should not be included.

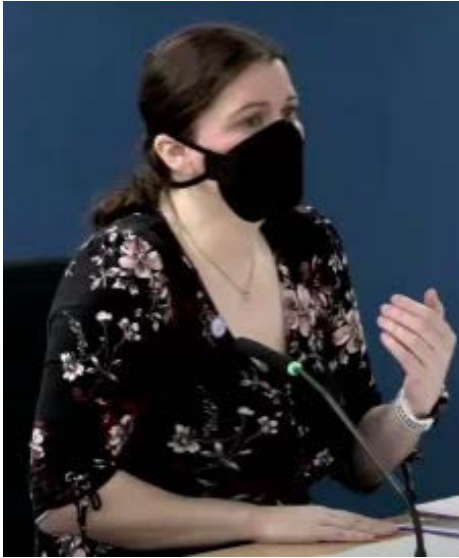
BCAP is primarily an online platform, but we have collaborated on exhibitions and have received hundreds of original artwork contributions from around the globe - mostly from those with breast cancer, but also from family and friends who are indirectly affected. It is a gallery of experiences - the good, the bad, and the ugly.

While they might be looked upon as ‘alternative’ in the medical world, I truly believe there is a need for spaces and services like the Breast Cancer Art Project. There is growing evidence of the benefits and potential of creative health - for example through a World Health Organisation report: [What is the evidence on the role of the arts in improving health and well-being?](#) Another report, the [Creative Health Review](#), shows how policy can embrace creative health. One particularly useful resource is the [Creativity, Health and Wellbeing Alliance](#), which provides support and networking.

It is my hope that we will see more advocacy, awareness, opportunities and support for creative health projects. I also hope that our medical teams can point patients in this direction and appreciate the emotional impact and vulnerability of a life-threatening illness, and that more patients can find some emotional healing through art.

Covid, Learning, and Rights

Lara Wong, Founder: [Clinically Vulnerable Families](#)



Three years ago, the UK entered what was supposed to be a new era – one where we had learned from the pandemic, adapted, and built a future where health and safety coexisted with normal life.

Instead, 'Learning to Live with Covid' became a euphemism for abandoning any real learning at all.

And for those who were (and remain) Clinically Vulnerable, this failure to 'learn' has developed into a glaring equality issue, creating systemic disadvantages in work, education, healthcare, and often basic participation in society.

From the beginning, we knew that having 'underlying conditions' (clinical vulnerability) meant a higher risk of severe illness and death from Covid. But this recognition never led to protections.

Instead, as the world moved on, Clinically Vulnerable (CV) people were left behind – stripped of recognition, access to accommodations, and more broadly the right to participate in society safely.

This is an equality issue, yet it has been treated as an afterthought. The consequences can be stark:

- **Employment discrimination:** Without legal protections, CV people have been forced out of jobs or denied 'reasonable adjustments' to work remotely or with personal safety.
- **Unequal access to education:** By not addressing ventilation or supporting individual masking those who are most at risk have found themselves excluded from schools and universities without ventilation improvements or remote alternatives.
- **Mask discrimination and abuse:** Those who continue to wear masks face harassment and exclusion.
- **Unequal access to justice:** For no clear reason, courts require people to unmask, forcing CV people to choose between their safety and their right to participate or advocate in legal proceedings.
- **Barriers to healthcare:** Masking has been dropped in hospitals and GP practices, making medical settings less safe for those at high risk. Many CV people are now challenged by healthcare professionals if they choose to protect themselves.
- **Mental health and social exclusion:** Some CV people remain isolated, unable to safely attend events, use public transport, or engage in social life because the world has decided their safety is no longer a priority.

This is systemic discrimination. Covid is now a persistent presence, and yet, instead of designing systems that protect those most at risk, we have chosen to erase their needs entirely.

This isn't just about Clinically Vulnerable people, although they are the most affected. The truth is, we all benefit from better quality air. We all suffer when we normalise sickness and presenteeism because viral infections can cause long-term damage and unnecessary loss of life.

Managing risks should never have been presented as 'personal responsibility'. Instead, government should be setting clean air and ventilation standards, and enforcing them through simple tools like CO₂ monitors – especially in high-risk settings like hospitals, schools, and offices. The gold standard would be keeping CO₂ levels below 800ppm, ensuring fresher air and reducing the risk of airborne infection. Instead, people are still forced to breathe stale air in crowded rooms.

We don't have to accept sickness as inevitable. And we certainly don't have to abandon those who need protection the most.

The pandemic exposed deep inequalities – now we have a choice. We can continue to ignore them, leaving the most vulnerable to fend for themselves, or we can finally learn.

Learn that airborne transmission matters. Learn that basic protections such as ventilation and masking should be a right, not a privilege. Learn that an inclusive society means ensuring everyone has the ability to participate safely.

This is about equality. This is about human rights. And this is about making sure Learning to Live with Covid finally means just that.

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



Same journey, different experience

This paper starts with the observation that weight loss is the primary driver of remission from type 2 diabetes for people also living with overweight and obesity.

Success or failure in journey in weight loss is often judged in terms of a patient's adherence to treatment. But there are other influences on weight management over time, including biological factors, family and social culture, and the availability and accessibility of food options. So success or failure in adherence to treatment may not be simply a matter of the patient's own actions.

Taking this as its starting point, the study found four key points in the journey towards weight loss and diabetes remission where people's perceptions of success and failure became relevant. Those were:

- Coming to terms with diagnosis. This could include having to deal with a sense of shame and self-blame, and also with a sense of surprise that they were the type of person who would develop diabetes.
- Lightbulb moments. These were the moments at which people came to terms with what living with diabetes meant to them. Sometimes these were linked to disruptive events that led to a sudden realisation of a need for change - for example, relationship breakdowns or a career change.
- Sustaining change. Patients lamented the limitations imposed by diabetes on their everyday lives. But embracing the change as a "new normal" was linked to continued success in managing diabetes, whereas a desired return to a "pre-diagnosis normal" was associated with regaining weight.
- Becoming expert/building confidence. Many people had to work to become confident in adapting to diabetes. But successful adaptation was connected with personal pride, and some patients had begun to support others' adaptation as well.

Across the study's diverse patient-participants, these key moments were broadly consistent. But it was how these were managed that varied, with the time taken to reach each moment, and the order of moments, influenced by the different participants' circumstances.

The authors point to evidence that diabetes remission services have sub-optimal uptake and adherence, and they suggest that this could occur because linear support models are misaligned with people's experience and expectations. They conclude that "adapting to accommodate the different perspectives of people with type 2 diabetes may increase uptake and adherence to remission programmes".



Seen and heard

Urgent and emergency care is never far from the headlines, as can be seen from [this BBC news page](#). Stories from all over the country tell of ambulance queues, long waits in A&E and patients being treated in corridors.

In this context, a report from the British Red Cross shines a spotlight on a key driver of demand: frequent attenders at A&E.

Focussing on patients and services in Dorset, its opening finding is that frequent A&E attenders “constitute a small and vulnerable minority... whose needs are consistently not being met”. This small minority has a disproportionate impact on urgent care: “1.7 per cent of Dorset’s population account for 13.8 per cent of the county’s A&E attendances”. They are also more likely to arrive by emergency ambulance than non-frequently attending people.

So are frequent attenders simply attention-seekers? Apparently not: their visits “are more likely to be classed as ‘high acuity’ (urgent) by clinicians”.

The study identifies two cohorts. One is aged 70+ and 98.2 per cent have two or more long-term conditions. The other is younger but has a significant link with deprivation. Depression, seizure, self-injury and substance misuse are particularly prevalent presentation reasons, and they are more than twice as likely as the study’s control group to have two or more long-term conditions.

The authors state that “Focusing on these root causes will not only alleviate pressure on urgent and emergency care, but will also advance the broader objectives of reducing health and healthcare inequalities”. The report sets out recommendations which, it says, can form an approach that “prevents people from getting to crisis point in the first place by tackling the underlying systemic causes”.



Better support for dementia

This report starts by forecasting a large increase in the number of people living with dementia in the coming decades. It estimates up to 1.7 million people in England by 2040, against 900,000 across the UK at present.

It notes the focus on the search for a cure but says that too little attention has been paid to how people with dementia, and their unpaid carers, should be supported to live well.

Progress is held back by, among other things, a lack of clear national standards for what 'good' dementia support looks like; a lack of resources and prioritisation for long-term strategic planning; and an absence of consistent training requirements for staff.

Added to this is a failure to reform the social care system and a challenging financial backdrop, both of which have limited investment in dementia-suitable care models. One consequence is that unpaid carers have increasingly been taking on more complex caring roles, yet have seen a contraction in the support available to them.

There are, however, actions that could be taken now.

Local authorities could use their commissioning powers to develop dementia-friendly support across a range of settings. They could also improve access to carers' assessments and ensure unpaid carers have access to high-quality information, training and guidance.

Integrated care systems could ensure better coordination across health and care services, and could develop systematic data collection to understand the patient journey across the whole health and social care system.

National bodies could take a more leading role in setting and signalling what principles underpin 'good' dementia care. They should equip the workforce to provide a high standard of care. And they should produce national guidance on data collection to improve understanding of the incidence of dementia, and the needs of people with dementia and their carers.

These seem like positive suggestions - but the authors point to "a worrying inertia among policy-makers and politicians, despite the inevitable rise in the number of people the system will need to support in future". And they say that in order to make progress, "Dementia needs to have a sufficiently high policy profile".



Surveillance in mental health care

“Inpatient mental health settings are challenging environments” says this paper, where “both patients and staff have reported feeling unsafe on wards”. Causes include abuse, coercion, aggression and violence – again, from both staff and patients.

In this context, some mental health service providers in the UK are increasing their use of surveillance-based technologies including closed circuit television, body-worn cameras and remote monitoring devices such as smart watches, GPS trackers and infrared cameras.

The paper states that use of these technologies is justified on the basis that they may be able to reduce aggression, violence, self-harm and suicide attempts. They may also help to reduce staffing costs. However, “the use of some of these technologies on inpatient wards is controversial”, with patient and service user groups expressing ethical concerns.

The authors say that “a comprehensive review of the evidence underpinning the use of surveillance technologies in inpatient settings has not yet been undertaken”. This systematic review is, they say, the first of its kind.

Key findings included the following:

- “The reviewed studies were generally of low methodological quality, lacked lived experience involvement, and a considerable proportion disclosed conflicts of interest”.
- There is “a particular lack of research on certain types of surveillance technologies, such wearable sensors and GPS electronic monitoring, reflecting the novelty of these technologies in inpatient settings”.
- Only two studies specified that they included wards with patients under the age of 18, meaning that “the literature fails to account for the unique ethical considerations” of surveillance of children and young people.
- There was also “some quantitative evidence indicating that a substantial proportion of patients did not consent to the use of VBPM [Vision-based patient monitoring and management] or understand the reasons for being monitored via video”.

The authors state that their findings “highlight the danger of surveillance technology use infringing upon patients’ human rights, choice and autonomy”. Overall, however, they come to a view that “The findings of this review suggest that the current evidence base does not support the use of surveillance technologies as a means of improving safety, care quality or reducing costs in inpatient mental health settings”.



Commercial influences on involvement

“Patient and public involvement is increasingly advocated in health policy, research, and practice” says this paper. As part of the trend, “Pharmaceutical companies are increasingly interacting with, and investing in, patients through, for example, training and networking opportunities and/or funding of patient organizations”.

The funding can be extensive: “in 2022, the International Alliance of Patients’ Organizations... was almost entirely industry-funded (98%)”. In the same year, “two-thirds of the European Patients Forum’s funding came from industry”.

The funding is not necessarily altruistic however. “Patient organizations are also powerful actors in policy, research and practice...they ‘have assets that the industry covets’, including the trust of patients and support of broader public”.

This can create potential conflicts of interest. The authors ask “if the industry is funding patient organizations, then it calls into question: whose voice is being amplified?”. As an example, they state that “industry-supported patient organizations... can provide pharmaceutical companies with an alternative way of ‘informing’ patients about their products as they are unable to market/advertise prescription drugs directly to patients”.

Another example is industry co-funding of patient organizations and/or patient and public involvement initiatives that set research agendas. The paper notes that “the Irish Platform for Patients Organisations, Science & Industry (IPPOSI), a leading actor in patient and public involvement activities... receives two-thirds of its funding from industry”.

Potential conflicts are not always obvious: “Studies have found relatively high levels of non-disclosure of industry funding by patient organizations. For example, an Australian study found that 48% of a random sample of pharmaceutical industry-funded groups did not disclose their industry funding”.

The paper suggests practical steps to address commercial influences on patient and public involvement. One is evidence-based training for patients and patient groups around interactions with industry, and on governance matters relating to management of conflicts of interest. Another is mandatory disclosure of industry funding of patient groups, ideally within one open access repository. A third is that governmental and independent research funders should make reimbursement of patient and public involvement a requirement, thus limiting the need for industry interactions.

The paper concludes that “It is imperative that we have structures, processes and supports in place which are fit for purpose to ensure that patient and public involvement contributors have their voices heard, and ultimately acted upon”.



Women's reproductive health conditions

“It has been more than two years since the publication of the Women's Health Strategy for England and although there are patches of progress, it has been too slow and the strategy lacks an implementation plan.”

So says the House of Commons Women and Equalities Committee in this report on women's reproductive health conditions. Dame Lesley Regan, Women's Health Ambassador for England, adds that “the onus should not fall on women and girls to advocate for their own health needs”.

The Committee notes that conditions such as endometriosis, adenomyosis and heavy menstrual bleeding are highly prevalent. And yet “many who experience them find their symptoms dismissed and normalised by those they turn to for help”. For some conditions, access to diagnosis and treatment can take years, leaving women to “endure pain that interferes with every aspect of their daily lives”.

The problems are ascribed to a ‘medical misogyny’ which has contributed to poor awareness of these conditions. This is “mirrored in a lack of medical research, treatment options, specialists, and the de-prioritisation of gynaecological care as evident by waiting lists, which have grown faster than any other specialty in recent years”.

The report covers various issues, including:

- Education and awareness. For example, girls leaving school not knowing what constitutes a ‘normal’ period and unequipped to spot the symptoms of reproductive health conditions.
- Diagnosis, treatment and support. Women being told symptoms such as heavy, painful bleeding and incontinence are ‘normal’, that they are either too young to have a condition, or too old to expect treatment.
- Painful investigations. Harrowing experiences of painful procedures such as hysteroscopy and having a contraceptive coil fitted.
- Medical research. Research into women's reproductive health conditions inadequately prioritised by funders and not incentivised enough in clinical academia.

The Committee makes wide ranging recommendations on these and other matters. And, it says, “The Government should publish an implementation plan for the Women's Health Strategy for England detailing timelines, costs and resource”.



Unknowns of drug company payments

This paper opens with a call for new government legislation to ensure full transparency of industry payments in the UK’s healthcare.

It cites the 2020 Independent Medicines and Medical Devices Safety Review, which investigated harms to thousands of women and families from Primodos, Sodium Valproate and pelvic mesh. The review noted that payments to clinicians from drug or medical device manufacturers often lack transparency and “may influence their practice, and the course of action they recommend to patients, such as preferentially using particular procedures or drugs”.

One outcome of the review was a 2023 government consultation which included a proposal for the “expansion” of Disclosure UK, described in this paper as “the payment database managed by the Association of the British Pharmaceutical Industry (ABPI), and the central pillar of the UK’s disclosure system for drug companies”.

The paper’s assessment of this proposal is blunt: expanding Disclosure UK “will not ensure transparency”. Reasons for this include the following:

- Unclear naming rules. There are no unique recipient identifiers, so companies can use multiple names and abbreviations.
- Entries for NHS Trusts receiving payments may be made in the name of their constituent hospitals, departments or clinics.
- Some payments may be misattributed, which becomes evident through cross-referencing Disclosure UK entries with the trust’s official address information.

According to the paper, “These challenges in accurately identifying payment recipients pervade the entire database”. Consequently, potential conflicts of interest can be detected only by those “well-versed in the intricacies of Disclosure UK and capable of undertaking forensic research”.

The proposal to expand Disclosure UK comes, say the authors, from a government that accepts an “industry-driven discourse” – one that “conceals the divergence of interests between the industry and the public”. They recommend a legislative solution: either a bespoke Sunshine Act or extension of the transparency provisions in the Health and Care Act 2022.

Irrespective of the chosen approach, says the paper, it should be combined with standardising company disclosure practices, and heavy fines to deter substandard reporting.

Unnecessary litigation



There are an estimated 11,000 reported incidents causing severe harm or death in the UK annually, according to this study. One outcome is an estimated £1.7 billion worth of clinical negligence claims, with a further £1.8 billion to administer and settle claims, and long-term liabilities amounting to £65 billion.

In this context, the study explored the experiences of patients, families and staff involved in incident investigations and asked what might influence patient or family decisions to litigate.

The research came up with five key themes:

- Cautious hope colliding with fear. Families were “overwhelmed by opaque and unfathomable processes” but in spite of this, proceeded with “cautious hope”. Over time however, a sense of injustice was fostered by systems “driven by fear of legal repercussion”.
- On the side lines of organisational agendas. Patients and families experienced widening power gaps, leaving them disillusioned by a lack of compassion, acknowledgement and accountability. Staff experienced a “parallel isolation”, sometimes separated from the patient and family they cared for and feeling “guilt and apprehensions of unknown outcomes”.
- Awaited, yet unwelcome report. Patients and families waited in anticipation of investigation reports, but then found them to be “disheartening, disrespectful, dishonest”.
- Left with an incomplete narrative. People reflected on being drip-fed information. For some, life became an all-consuming effort to get answers to their questions and help to prevent the same thing happening to others.
- Litigation as a last resort. Litigation was often not financially motivated, but was an avenue people were forced down in the hope of being finally heard and getting answers to their questions.

The paper makes five recommendations, the first of which is that “Investigatory processes should be relational, centering the needs (including emotional) of patients, relatives and staff affected by safety incidents to avoid compounding harm”. Other recommendations cover improved information for families, action to counter social inequities, and action to address system level fear of litigation.

The paper concludes that “Current investigation processes fail to acknowledge and address the emotional harms that are experienced by those affected. As a result, patients and families are experiencing compounded harm and pursuing unnecessary litigation, staff are fearful, investigators are shouldering unmanageable responsibility, and the healthcare organization not visibly learning or improving”.

Antivaccine activism



Last February, a six year old child in Texas died of measles - the first US death from the measles in nearly a decade. The child was not vaccinated.

By the end of March, the Texas Department of State Health Services was reporting over 300 cases of measles across the state.

Against this background, this opinion piece - published at the start of January 2025 - seems prescient.

The author notes how the antivaccine movement gained momentum in the early 2000's, around false claims that vaccines cause autism. The arrival of COVID-19 also saw the arrival of "health freedom" protests, which "became a signature feature of political activism on the far-right".

Now, says the author, "As COVID-19 begins to dissipate and new hospitalizations decline, antivaccine activism has pivoted to childhood immunizations". This, he says, "could portend the beginning of regular breakthrough childhood infections due to low immunization coverage".

There are two key implications for health policymakers:

- First, they need to identify areas of the country at greatest risk for breakthrough childhood infections, while also guiding local or state vaccine advocacy initiatives.
- Second, they need to get much better at addressing parental concerns about immunisation. In particular, this means explaining the risks of severe childhood illnesses (which for measles includes hospitalisation, hearing loss, pneumonia and death) against the vastly lower chance of any side effects from vaccines.

There is a further question, involving political will. The author notes fears that "in states where partisan leanings are strong... there will be continued declines in childhood immunizations". These could be accompanied by the introduction of "onerous legislation" that could "ban pediatric COVID-19 immunizations... stop disease data collection, halt school vaccine mandates, or encourage alternative or unproven immunization schedules".

The paper concludes that "Urgent action is needed to forestall the return of diseases once believed to be consigned to history".



Caring while complaining

This paper starts with the observation that “recent large-scale surveys in the UK have found an apparently paradoxical relationship; that reported commitment to the NHS as a system has remained stubbornly high even as reported satisfaction with healthcare received has plummeted”.

To explore this paradox, the study team looked at online feedback given via the Care Opinion platform, focussing particularly on experiences in emergency care.

The feedback described numerous accounts of poor care, many related to non-medical aspects of healthcare such as long waiting times, lack of access to food, water and sanitary care, poor communication, inadequate pain management, and lack of empathy.

But despite these highly critical accounts, many patients stated that they were not ‘complaining’ about the NHS. Alongside expressions of discontent, story-authors “explicitly recognise the extreme pressures the NHS is facing, articulate support for staff and recognise good care”.

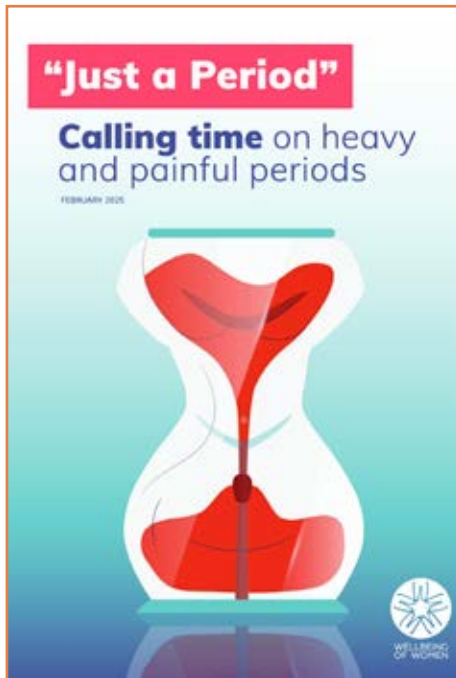
The researchers noted three distinctive but interrelated features:

- First, there was a widespread recognition of the pressures the NHS, and emergency care in particular, faced. This shifted the responsibility (and blame) for unacceptable care away from ‘the NHS’ as a valued social good, to systemic problems with how it was funded and managed.
- Second, the critical accounts contained empathy, gratitude, praise, and support for NHS staff. Through highlighting good experiences alongside bad, stories that were primarily negative could still articulate support for health-care services and staff.
- Third, the stories emphasised explanations for why the author or their family member had ended up using emergency services. This could be seen as a way in which some patients differentiate themselves from other, less legitimate, users of emergency services.

Taken together, these features resulted in a ‘yes, but’ structure that allowed authors to vigorously critique the care received whilst simultaneously expressing commitment to the NHS as a whole.

The paper states that “these narrative features show that the apparent paradox of ongoing loyalty to ‘the NHS’ alongside dissatisfaction with actual care experiences may not, in fact, be a paradox at all”. Instead, it says, “dissatisfaction with and normative support for national healthcare services are often entangled, rather than opposed”.

The paper concludes that awareness of this entanglement “allows us to understand how people continue to express loyalty and support for an institution (the NHS) while describing harrowing and sometimes dangerous experiences of care”.



Just a period

“During the last few years, we have seen a definitive shift towards conversations around the menopause becoming more routine and informative” says this report. Prior to this, it says, discussions about the menopause were “conducted under the radar or secretly because of the embarrassment and stigma associated with this predictable life event”.

The report’s goal is that within the next few years we will be able to say the same about menstrual health. The authors state that “It is unacceptable that women are suffering severe period pain and heavy bleeding in silence, or that their symptoms are dismissed”. This, they say, “often means that girls and women fail to receive appropriate care for easily treatable conditions”.

A key finding is that for women affected by heavy and painful periods, it takes an average of 22 months from symptoms starting to seeking help. They then have to “jump another hurdle of ensuring their symptoms are taken seriously”.

Across three surveys of more than 7,500 women, 50% had felt dismissed by healthcare professionals, who didn’t take their symptoms seriously.

Respondents also described a lack of empathy shown by healthcare professionals when carrying out extremely personal and ‘invasive’ investigations.

And of the 69% of women with period symptoms who had sought help from a healthcare professional, the majority weren’t given treatment (58%), diagnosis (84%), or a follow up referral (81%).

The report makes a series of recommendations, including:

- Better menstrual health education in schools.
- Workplaces to adopt women’s health policies which support menstrual health.
- A public health campaign on menstrual health and period problems for teens and young women.
- More funding for menstrual health research.

The report concludes that “We need to start taking menstrual health seriously”. Millions of women, it says, have benefitted from breaking the silence on the menopause. And it finishes by saying that “We must now also call time on heavy, painful periods and ensure no one is told their symptoms are ‘just a period’”.



Systems Approach to Learning: Patient and Staff Involvement in Learning from Patient Safety Incidents

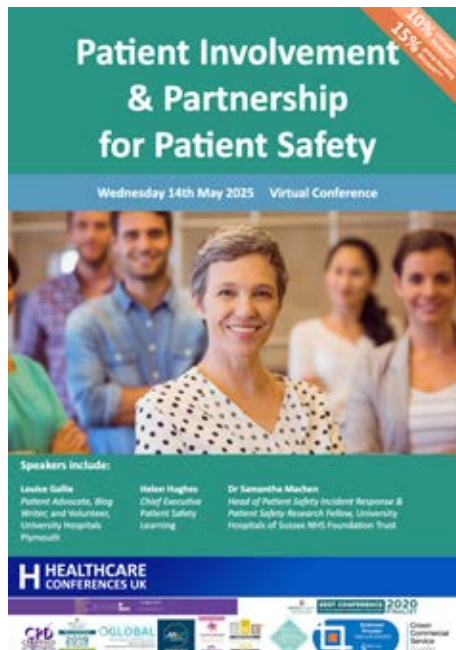
Tue 29 Apr 2025
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Training to support the development of expertise involving patients, families, carers and staff when things go wrong, in line with NHS guidance, based upon national and internationally recognised good practice. To include the duty of candour and 'being open' principles.

This course covers the end-to-end systems-based patient safety incident response based upon the new NHS PSIRF and includes:

- Duty of candour regulations
- Being open and apologising when things go wrong
- Challenges/complexities associated with cases where there is more than one investigation
- Effective communication, including dealing with conflict and difficult conversations
- Effective involvement of those affected by a patient safety incident throughout the incident response process to ensure a thorough and richer investigation
- Sharing findings
- Signposting and support: including loss, trauma and stress

Further information and booking



Patient Involvement & Partnership for Patient Safety

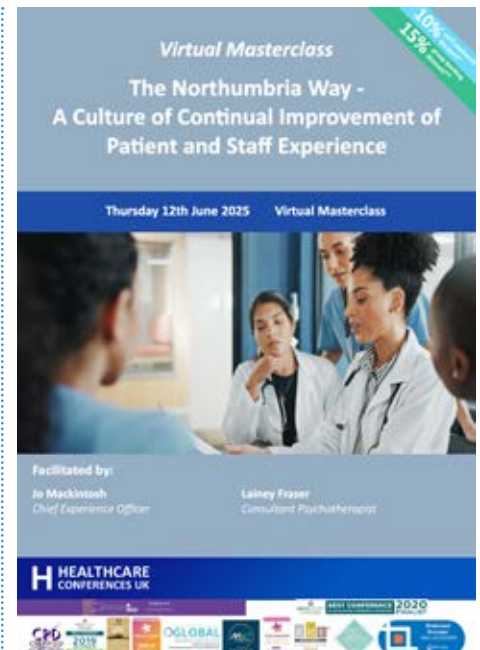
Weds 14 May 2025
Virtual, Online

This conference focuses on patient involvement and partnership for patient safety including implementing the New National Framework for involving patients in patient safety, and the role of the Patient Safety Partner (PSP) in your organisation or service. The conference will also cover engagement of patients and families in their own safety, and patient involvement under the Patient Safety Incident Response Framework:

Further information and booking

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](#).



The Northumbria Way - A Culture of Continual Improvement of Patient and Staff Experience

Thu 12 June 2025
Virtual, Online

Northumbria Healthcare NHS Foundation Trust has developed a well-recognised and award winning patient experience improvement programme that spans more than a decade. In 2018, the organisation took steps to invest in the health and wellbeing of its staff, by developing a similar, integrated staff experience programme.

This session will provide attendees with the opportunity to understand the 3 key elements of the Northumbria programmes; measurement and reporting; improvement approaches; and collaborative working practices.

Attendees will consider how to enable an organisational culture that reinforces the interconnectedness of staff experience and patient experience and reflect on the principles of collaboration and engagement methodologies to drive improved experience and better care outcome for people and communities.

Further information and booking

The Patient Experience Library

The Patient Experience Library acts as the national evidence base for patient experience and engagement in healthcare. Our mission is to:

Democratise the knowledge

Evidence on patient experience comes from patients. It is unethical for researchers to extract knowledge from patients and then publish findings via inaccessible professional research databases.

So our [open access repository](#) puts the knowledge back into the hands of patients.

Professionalise the practice

The patient experience workforce includes PALS teams, complaints handlers, patient engagement teams and people in the 150 local Healthwatch across England. They are almost unique among healthcare staff in having no formal qualifications and no systematic support for professional development.

So we are building a learning infrastructure for patient experience work, including [analytics](#) and [publications](#).

Change the culture

There is a tendency within healthcare to dismiss patient feedback as “anecdotal evidence” and to persistently exclude some communities and voices.

So we are helping people to spot the signs of [harmful](#) and [exclusive](#) cultures.

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](#)

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www.patientlibrary.net

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