

# Patient Experience

and patient/public involvement in health and care services

Summer 2023

# Partnership



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## INSIDE

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## Editorial



The idea of patients as “partners in care” has been gaining ground for a while. With a growth in long term conditions, and with more and more people “self-managing” their health and wellbeing, it makes sense for clinicians and patients to work closely together.

So when it comes to patient experience work, should we think of patients and service users as “partners in learning”?

On page 3, Maddie describes the experience of being disbelieved when she tried to share her own knowledge of her own condition. She calls for “trustful conversations” through co-production, where power dynamics between professionals and patients are actively examined, and people work together as one team, with everyone’s knowledge valuable and valued.

Karl Roberts on page 4 picks up the theme of learning with patients. He describes an approach developed by the NHS Leadership Academy’s Patient Faculty, in which patient partners and staff “plan together, train together and work together”. As the Leadership Academy merges with NHS England, Karl makes the case for the Patient Faculty’s legacy to be remembered and built on, and for the NHS to learn “with” patients, as much as “from” them.

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)

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The poster features a yellow background with a blue border. At the top, the word "Quality" is written in a large, blue, cursive font, with a small red heart icon containing a white 'I' above the letter 'y'. Below this, the words "IS TO BE AT THE" are written in white, uppercase letters on a red rectangular background. Underneath, the word "HEART" is written in large, bold, orange, uppercase letters. Below "HEART", the words "OF EVERYTHING WE DO" are written in blue, uppercase letters. A green rectangular box with white text contains the phrase "it must be understood from the perspective of". Below this box, the word "Patients" is written in large, bold, orange, uppercase letters. At the bottom left, the text "The Darzi Review: High Quality Care for All" is written in small, black, uppercase letters. At the bottom right, the text "www.patientlibrary.net" is written in small, black, lowercase letters. In the bottom right corner, there is a small blue logo for "Patient Experience Library".

## 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)

# Trustful conversations

**Maddie**



We hear a lot in healthcare about the importance of “patient voice” - often from providers, who want feedback on the quality of their services. Patients, however, might have very different reasons for wanting to talk about their experiences.

I started thinking about this a couple of years ago, when I was trying to make sense of my experiences of harm within psychotherapy and mental health services. I realised I had been taught to dismiss my own knowledge, and this had deeply affected my trust in myself and my confidence in what I know.

My accounts of my experiences were disbelieved. I was told I should ignore what my body and mind were telling me. I was told that things that had happened hadn't really happened. Plus, being diagnosed with “personality disorder” (a diagnosis widely considered to be flawed) meant I quickly got used to mistreatment and having my experiences dismissed.

This is what academics describe as “epistemic injustice”. It is what happens

when your knowledge is dismissed and denied by others, be that of your own body, illness, or experience.

I have lost count of how many times I have told someone something about my mental health, only for them to turn to the “experts” to confirm what I have said, as if I am an unreliable narrator of my own mind. What often happens is that service-user knowledge is only trusted if it is backed up by a researcher or professional. Service users' knowledge is not viewed as equal, it does not hold the same weight.

People with a diagnosis of “personality disorder” are often seen as manipulative and attention seeking, and this can cause their knowledge to be dismissed. For example, they might be disbelieved about their suicidality. Being described as “threatening” suicide or making “suicidal gestures” can lead to them being prosecuted (for example, being charged with wasting police time or obstructing a highway). The idea they are malingering when they attend A&E or primary care services means that patients often miss out on the healthcare they need.

In this way, epistemic injustice can lead to other kinds of injustice, for example health inequalities and legal injustices/misadministrations of justice. Epistemic injustice influences whose knowledge, ideas and contributions become public and whose don't, leading to large gaps in our understanding of certain experiences.

In order to avoid epistemic injustice we actively need to work toward epistemic

justice, and this requires questioning long held beliefs and correcting for prejudices we may have internalised. We can create an inclusive micro-climate through co-production - thinking about power dynamics, privilege and creating reflective spaces in which to consider the challenges of co-production.

Co-producing with the Co-Production Collective and other groups has provided me with a trustful atmosphere in which to learn how to trust my own knowledge and experiences again. Trustful conversation and inclusion of many different kinds of knowledge, my own experiential knowledge included, has supported me in recovering from the epistemic injustices I encountered within services.

One of the co-production experiences that sticks out is co-producing a response to a debate in an academic journal with other survivors, professionals and researchers, which felt contained and safe despite the difficult subject matter and having a big personal stake in the debate.

I believe co-production is a vital tool in our fight against epistemic injustice within health and social care services. Co-production tells us we are not just objects to be passively studied, we are all working together as one team, with everyone's knowledge valuable and valued.

This article has been adapted from a blog originally published on the [Co-Production Collective website](#).

# Learning with patients

**Karl Roberts**

**Head of Patient Faculty, NHS Leadership Academy**



The NHS talks a lot about learning from patient experience. Through surveys, focus groups and the Friends and Family Test, providers and commissioners try to gather and analyse feedback. Sometimes patients are told what has been done with their feedback, and sometimes they aren't.

As the Head of the Patient Faculty at the NHS Leadership Academy, I have always been interested in learning from patients. But even more important is to learn *with* patients. Clinicians talk about patients being “partners in care” – and those of us doing patient engagement work should perhaps think about patients as “partners in learning”.

So what does partnership in learning look like in practice? Here are a few illustrations from our Patient Faculty.

First of all, the job of the Patient Faculty is not to tell patients what to do. Our staff and our patient partners are

one team. We plan together, we train together and we work together.

Conventional “engagement committees” often have a predetermined organisational agenda, which patients are invited to join in with. Our model, however, is an Assurance Group chaired by a patient partner. The Group co-creates our work programme and we all – staff and patient partners – hold one another to account for delivering the programme on time and to the right levels of quality.

Healthcare organisations often have policies on patient and public involvement – a set of “rules for engagement”, which patients are expected to sign up to. We have gone a step further, with an Involvement Charter, which sets out two-way expectations for both patients and staff. Alongside this, a set of role descriptions helps people to understand how and where they can play their part in the team and how, together, we can achieve our wider mission.

Many of our patient partners contribute to leadership training at the highest level. But we know that it can be daunting for patients to work alongside NHS leaders, so we ensure that they are properly trained for the roles they undertake. Our Interviewing Principles and Practice course helps patient partners to feel confident in stepping up to the task of joining interview panels for senior positions. And our Storytelling training helps people to work out how best to get

their message across. The course shows patients how to introduce themselves to an audience, build rapport, and feel confident in “speaking truth to power”.

Sometimes in this kind of work, there can be a temptation to think that involving people with lived experience automatically ticks the inclusion box. We do not see it that way. Everybody carries their own personal attitudes and opinions, and people's accounts of lived experience are not helpful if they also contain prejudice and bias. So we offer training to help patient partners reflect on their own outlook and values before they go to work with people who are learning to be NHS leaders.

At the time of writing, the NHS Leadership Academy is being reorganised as part of the merger of NHS England and Health Education England. Many of our staff and patient partners in the Patient Faculty will be moving on to other things. We hope that NHS England will look after and build on our legacy.

As the Head of the Faculty, my parting words would be “don't just learn from patients – learn with them”. We have a tried and tested model for doing that, and we are happy to share our experience.

## 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](mailto:info@patientlibrary.net)



# Safe relationships, safe care

Patient safety has been identified as a key pillar of high quality healthcare, alongside patient experience and clinical effectiveness. According to this study, patients can play an active role - not least as “vigilant monitors”: asking questions, raising concerns and double-checking things like medication timings and doses.

There is a problem, however: patients can be reluctant to raise safety concerns if it means challenging staff - over infection risks from poor handwashing, for example. Key to this is vulnerability: patients are dependent on, and place their trust in, healthcare staff. Fear of damaging their relationship with staff has been identified as a significant barrier to patients' involvement.

When patients are admitted urgently to hospital, vulnerability is increased. There is a loss of integrity and dignity, and, at worst, a profound fear of the unknown, or of dying. In these situations, patients seek reassurance that the hospital is a place of safety, and that they can entrust themselves to the care of the staff. Signs of safety are both contextual (impressions of order, cleanliness and sufficient staffing) and relational (the perceived competence and responsiveness of staff).

One implication, say the authors, is the importance of relational work for patients as a way of keeping themselves safe. To demonstrate that they are ‘good patients’, they avoid being too demanding, comply with instructions, and display gratitude to staff for the care that they receive.

For patients, then, safety is about vulnerability to harm from both their health status, and from their dependence on the healthcare organisation and the professionals within it. They conduct risk work by seeking reassurance and undertaking relational work - but this can conflict with their additional need for vigilance, and double-checking aspects of their care.

“The difficulty for patients”, says the paper, “is that both options may increase their vulnerability, one from harm if trust is misplaced and another from potential damage to relationships from challenging healthcare professional expertise”.

The authors suggest that we need to rethink the idea of the ‘good patient’ - recognising and valuing vigilance alongside compliance. “Both patients and healthcare professionals”, they say, “need to recognise how their interactions co-produce safety at the point of care. Seeing safety as co-produced by patients and professionals... might allow risk work to take place without disrupting relationships”.

# Openness in healthcare



“Openness, transparency and candour are recognised as ethical responsibilities of health care organisations”, says this paper, and yet “delivering on these commitments in health care systems has often proved challenging”.

The authors point to Mid-Staffordshire as a prompt for extensive policy interventions to promote openness. But they go on to say that subsequent scandals “have continued to identify pathological organisational behaviours and norms, including marked deficits in openness”.

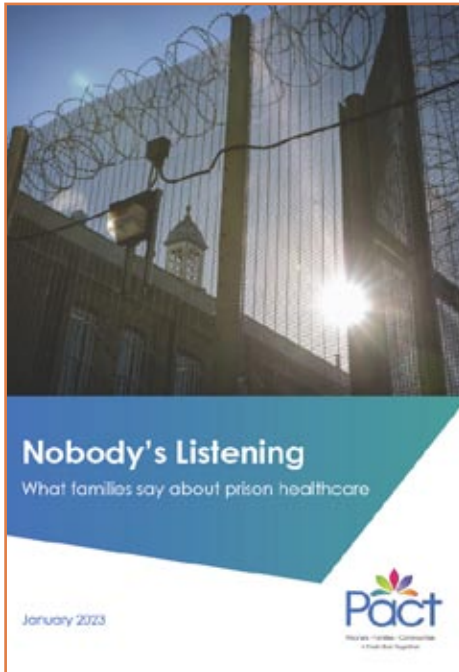
The paper identifies four necessary conditions for change:

- Authentic integration into organisational mission. Organisations that had made greater progress framed openness as part of mainstream business, not an optional bolt-on. Freedom to Speak Up Guardians were given significant investment to ensure that they had sufficient time to deliver the role.
- Functional and effective administrative systems. These included tight oversight of disclosure and investigation processes, rapid dissemination of learning and implementation of recommendations, and integration of different sources of organisational intelligence about concerns and risks.
- Flexibility and sensitivity in implementation. “Coldly efficient systems” for investigating concerns could be seen by staff, patients and families as unhelpful and even upsetting. There is a need to “soften systems by giving them a human touch”.
- Continuous inquiry, learning and improvement. This involved “protracted and dogged efforts to improve, sometimes using formal improvement approaches, sometimes more ad hoc”. The approach was open-ended and extended beyond discrete, time-limited improvement projects.

Against these, the paper lists four persistent challenges, including:

- Reliance on goodwill, for example from underfunded Freedom to Speak Up Guardians.
- A lack of care for staff, patients and families - for example, if they sense that raising concerns could be risky.
- Reliance on values, which can be ineffective against staff who remain resistant to greater openness.
- Marginality of patients and families. Here, the paper makes the point that “patients and families were mainly bit-part players in enacting the policies”.

This last point is important. The authors comment that “Disappointing, and perhaps surprising given their prominence in unearthing problems at Stafford Hospital and elsewhere... the principal mechanisms through which patients and family members can raise concerns about quality and safety remain largely the same as they were in the 2000s”.



## Prison healthcare and families

“Individuals in our criminal justice system represent some of the most vulnerable people in our communities”, says this report. It adds that “contrary to prison providing an opportunity to address health inequalities, evidence suggests that it often has a significant detrimental impact on health and wellbeing”.

Families can help - not just through supportive relationships but also by alerting prison officers to matters such as “mental health, drug use (prescription and illicit), propensity to violence and risk to self”. Indeed, NHS England states that “families are important to recovery and carers often hold information that allows services to work more effectively”.

This study, based on interviews with families supporting patients in custody, offers useful insight, starting with the fact that most had witnessed “a significant decline in their loved ones’ mental and physical health during their custodial sentence”. However, their ability to intervene was hampered by a lack of recognition for their role as carers, advocates, sources of information and vital support.

The report suggests a need to engage families at all stages in the criminal justice system, including arrest and police custody, during the judicial process, at reception into prison and during prison transfer, and at the point of release and during resettlement.

Through all of this, families themselves need to remain resilient. This can be hard when they “face the dual impact of losing a loved one to imprisonment as well as the anxiety associated with a loved one’s poor health”. Their needs include provision of accurate information about prison life and how to support a loved one in custody; information and guidance about how to support their loved ones’ health and wellbeing needs; and family-friendly, non-judgemental support.



## Strong support for the NHS

This report from the Health Foundation starts with the observation that “The NHS is under extreme strain and debate about the future of the health system is growing louder”. Within that debate, what do patients and public think?

The study finds, unsurprisingly, that “people are deeply concerned about the state of the NHS”. Only a third think the NHS is providing a good service nationally, down from previous polling in 2022 and 2021.

63% think the general standard of care has deteriorated in the last 12 months, and only 9% expect standards to improve.

Across the nations of the UK, just 10% think their own national government has the right policies for the NHS.

In spite of all this, public support for the founding principles of the NHS remains, according to the Health Foundation, “rock solid”. 90% want access free at the point of delivery, 89% want a comprehensive service and 84% want the NHS funded through taxation. “Each of these principles”, says the report, “commands majority support right across the party-political spectrum”.

Asked about priorities, 39% wanted to see more staff in the NHS, 35% wanted shorter waiting times for routine tests and operations, and 31% wanted shorter waits in A&E.

The authors state that “While both main parties have so far preferred to talk about reforming the health service rather than tax rises or spending increases, 82% of the public think the NHS needs an increase in funding, including 63% of Conservative voters”. They warn that “With just 8% of people in England convinced the UK government has the right approach to the NHS, our latest survey should ring alarm bells for the Sunak government”.





# Listening. Learning. Leading.

Ten years have now passed since the publication of the Francis Inquiry’s findings on avoidable harm at the Mid Staffordshire NHS Foundation Trust.

The government’s response, says this paper, “promised wide ranging interventions and legal and regulatory reforms”. The question posed by the authors is “What is the legacy for the safety of patients in England?”

There has undoubtedly been action. The duty of candour has been introduced, along with Freedom to Speak Up Guardians. There have been changes to Care Quality Commission inspections, and the Healthcare Safety Investigation Branch has been set up.

In spite of all this, “Recurrent organisational catastrophes remain a disheartening reality”. Oddly, the paper does not name any. But the roll call includes maternity services at Morecambe Bay, Shrewsbury & Telford and East Kent. The authors might also be thinking of medicines and medical devices - notably Primodos, Sodium Valproate and pelvic mesh. Perhaps they are also considering individual actors such as breast surgeon Ian Paterson, whose criminal activities went largely unchallenged by his employers.

The authors point to a common thread: “Failure to listen to the voices of patients and carers is a recurrent theme... and one that the system seems incapable of heeding”.

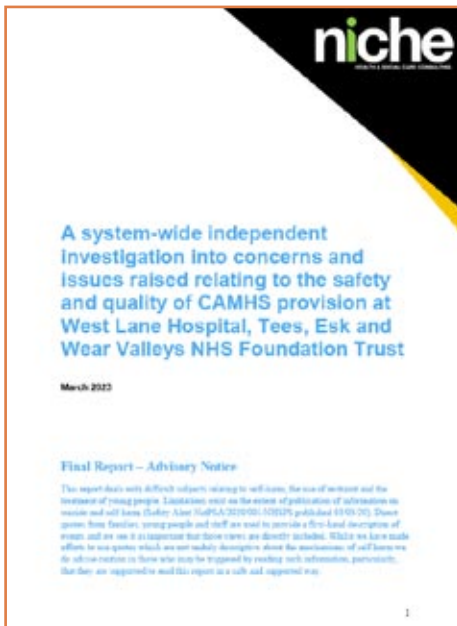
There are three simple recommendations:

Listening. “Psychological safety - a sense among staff and patients that it is safe to speak up without fear of retaliation or being undermined - is critical.”

Learning. “Collating, and acting on intelligence, quantitative and qualitative.”

Leadership. “Making patients ‘the first and foremost consideration’ [with] an uncompromising focus on addressing cultural and behavioural problems.”

With the ink still fresh on the East Kent report, and as we brace ourselves for the Ockenden report on Nottingham, these points need to be taken seriously.



## A familiar pattern

This report sets out the findings of an investigation into safety and quality issues in Child and Adolescent Mental Health Services (CAMHS) at the Tees, Esk and Wear Valleys NHS Foundation Trust. Issues included multiple instances of inappropriate restraint and, worst of all, the deaths of three young women.

The events occurred in a care environment in which there was “insufficient attention and importance being applied to risk”. Family members and carers said they “could not safely raise concerns”, and “felt actively judged and undermined by staff”. There was “a fundamental and consistent failure to inform parents about incidents involving their children under Duty of Candour”.

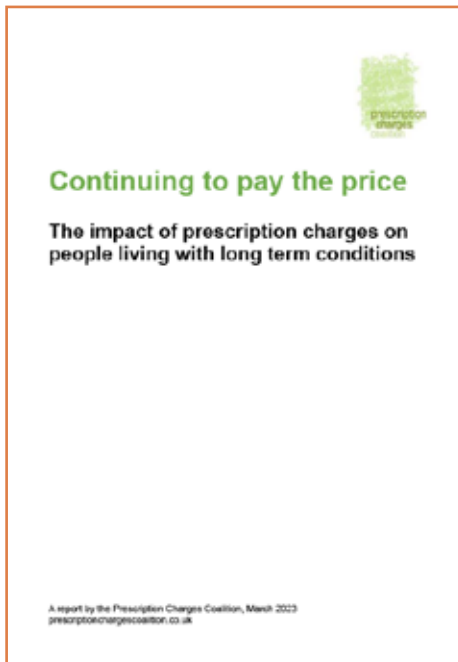
There is a great deal more in this report, and it all fits with a pattern that, after Mid Staffs, Morecambe Bay, Gosport, East Kent and others, has become all too familiar.

Elements of the pattern include the fact that the key unit - West Lane Hospital - was geographically isolated, and a closed culture developed. There was a constant turnover of staff, and tension between different staff teams. Risk registers were poorly maintained. Actions, when required, lacked urgency. Staff training was inadequate. Local observation rules were applied, inconsistent with established Trust-wide policy.

Over and above all of this was a complacent governance. The Board was “overly accepting of verbal reassurance in relation to quality and safety” and displayed “insufficient curiosity”. Reporting was “disjointed” and the Board Assurance Framework was “detached from the reality of the organisation”.

The investigators state that “It is clear from our research that patients and their families (and some staff) were ignored and that their concerns and complaints are now found to be, on the whole, justified”. This, too, is the kind of statement that we have seen too many times before.

The message for Boards and senior NHS managers is clear: dismissive attitudes towards patient experience lie at the heart of harm. Two years ago, our [Inadmissible Evidence](#) report called for an end to this double standard in evidence-based practice. Sadly, there is still no end in sight.



# Self-rationing healthcare

To understand patient experience, we sometimes have to go beyond the basic “how was it for you?” approach of things like the Friends and Family Test.

Long term conditions are a case in point. NHS strategies from the Long Term plan downwards say that with a growth in long term conditions, we need to encourage “self-management”, with people looking after themselves in their own homes and communities. But how well do we understand people’s experiences of self-management?

This report looks at one important aspect: prescription charges. It starts with some useful facts:

England is the only UK country where prescription charges still exist, having been abolished in Wales, Northern Ireland and Scotland.

Charges have risen almost every year since 1979.

Most of the income to the NHS from prescription charges comes from working-age people with long term conditions.

Aside from the addition of cancer in 2009, the list of exempt conditions has not changed since 1968, even though there are new conditions like HIV, and some, like cystic fibrosis, which people can now live with for much longer.

Some people can get help with the costs - but only if they know help is available. In this survey, 83% of respondents had not heard of the NHS Low Income Scheme, and 38% only found out about the Prescription Prepayment Certificate more than a year after their diagnosis with a long term condition.

30% of respondents reported missing, or taking a lower dose of their medication, and 64% said they would be more likely to take medicine as prescribed if prescriptions were free.

The authors conclude that “charging working-age people with long term conditions for prescriptions is leading to self-rationing of medications”. And they say that “This, in turn, is leading to increased pressure on the NHS and poorer health outcomes”.

Access to medication is a vital part of self-management, and self-management is a key thrust of NHS strategies. So it is hard to argue with the report’s finding that “the prescription charge exemption system needs urgent reform”.



## Technology-enabled lives

“Technology is central to our everyday lives” says this challenge paper from the TEC Action Alliance. But “all too often we separate it out for special treatment when it comes to supporting our care or health needs, as opposed to viewing it as a core tool which can help us live the lives we want to lead”.

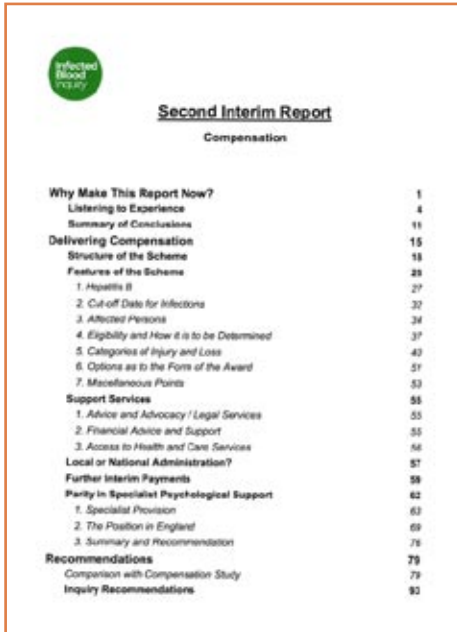
The focus of the report is technology-enabled care, or TEC for short. There are various examples of how it works in practice, including the case of “George” (a fictional persona) who has cancer. TEC can help George with pre-admissions screening, virtual appointments and remote monitoring. It can help him to manage multiple medications, and to manage his direct payments. Importantly for person-centred and holistic care, it can also help him to stay connected with family and friends who are central to his wellbeing and recovery.

The report also offers real-life case studies, as well as survey findings on public attitudes to TEC. But it notes that debates on digital healthcare are often about “digitising social care, health and housing: re-engineering systems and processes”.

We don’t hear so much about “technology-enabled lives, where the ambitions and aspirations of the individual come first, made possible by digital”. The debate is “over-focused on the needs of the NHS”, with less attention paid to the benefits to social care systems and even less on the benefits to people and their communities.

“To change this mindset”, say the authors, “we must amplify the voice of people with lived experience so that we deploy technology to support what they want rather than what suits the system”.

Their conclusion is that “It should go without saying that a better understanding of the needs and aspirations of people means that products and services can be developed that are more successful in meeting their needs”.



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## An unusual step

Sir Brian Langstaff, Chair of the Infected Blood Inquiry, describes this interim report as “an unusual step”.

It is unusual because even before the Inquiry has completed its work and presented its findings, it is recommending a compensation scheme for people harmed by infected blood.

The scandal has been described as “the worst treatment disaster in the history of the NHS”. People with haemophilia were particularly affected but so were many others, given transfusions for a range of conditions and circumstances.

One woman was infected in utero with HIV after her mother had a transfusion. Her sisters died, aged five and three, then her father, then her mother.

Around 380 children with bleeding disorders were infected with HIV and more than half have now died.

Other people were infected with Hepatitis C or Hepatitis B. The latter aggravates both Hep C and HIV, making the effects of those diseases worse. As well as losing their health, many lost their jobs. Family members have turned into carers.

Successive Secretaries of State – Andy Burnham, Jeremy Hunt, Matt Hancock – acknowledge the harm caused not just by the treatment, but by a persistent failure of response at the government level, which has compounded the harm.

Sir Brian has this to say: “People infected and affected have over decades sought recognition that wrongs had been done to them, and had been rejected”. He goes on, “Once it is accepted, as it has been, that compensation should be paid, then it should plainly be paid as soon as possible. Many who should benefit from compensation are now on borrowed time. They know too many who have already died”.

“I cannot in conscience”, he says, “contribute to that further harm...This is why I am taking the unusual step of issuing one set of recommendations in advance of all others”.

His recommendation? “It is time to put this right... a compensation scheme should be set up now and it should begin work this year”.



# How restrictive practices affect women

The Mental Health Act allows a person to be detained in hospital in order to protect their safety or the safety of others. Alongside this are restrictive practices, ranging from restraint, seclusion and rapid tranquilisation to more subtle practices such as locked doors or restricted mobile phone access.

There is a difficult balance: restrictive practices are in place to promote safety but they can also limit a person's freedom, rights and daily activities.

The starting point for this study was that although the potentially damaging effect of restrictive practices is likely to be experienced by both men and women, it is possible that restrictive practices are harder for women. That is because restrictions in inpatient settings could mirror the lack of power and control that women hold in society as well as abusive life experiences they might have experienced. Further, women accessing mental health services are more likely than men to have suffered abuse both in childhood and as adults, and female inpatients are significantly more likely to have a history of sexual abuse than male inpatients.

From semi-structured interviews, an overarching theme of powerlessness emerged. Within that were four sub-themes:

**Restrictions perceived as punitive.** Women felt that threats of restrictive practices were used to ensure they followed the rules. Loss of privileges were seen as ways for staff to keep control.

**Not being heard.** One example was ward rounds where women felt unable to contribute to decisions that were made about restrictions. Some women described having to speak aggressively, or protest in an attempt to be heard.

**Impact of restrictions on relationships.** Restrictions on visitors or mobile phone access affected the ability to form and maintain relationships. Some women felt 'awkward and ashamed' in front of their friends and families because of the restrictions placed upon them.

**Safety and support.** Women felt that some rules needed to be in place to keep the ward calm and settled. Rules providing structure and routine were seen as good for patients' mental health. However, as their mental health improved, they perceived restrictions as more punitive.

The authors emphasise the importance of reflecting on how gender might influence treatment; of being aware of women's different experiences of trauma; and of wider social and political issues resulting in the oppression of women.



# Who's excluded?

Discussions about digital healthcare tend to focus on the technology: the platforms through which patients can book appointments, the apps that help them with physical and emotional wellbeing, or the increasing role of AI in helping clinicians to make sense of big data.

But digital healthcare is not just about fancy tech and clever software. It's also about how patients organise and mobilise online. This article, by BMJ editor and cancer patient Tessa Richards, is a case in point.

It describes a webinar flagged by Richards' cancer Facebook group. She admits approaching it with a degree of cynicism, anticipating an "experts talk at patients" experience. Instead, she found a conference organised and moderated by patients, where the debate was assertive, informed and supportive.

In a reversal of the standard "patients included" approach to big healthcare jamborees, this conference featured professionals who were included not by right, but because they had been hand picked and invited by the patients.

This is part of a growing trend. Patients these days are not waiting to be invited to engage. They are doing things for themselves, in online communities. Other examples are the Melanoma Patient Network of Europe, featured in [this edition](#) of our quarterly magazine (page 4), and the [Light Collective](#), shown here (page 4).

There is a lot of talk in digital healthcare about digital exclusion. Usually the assumption is that the people at risk of exclusion are the patients. Rarely, if ever, do health professionals consider their own risk of exclusion from online debates and initiatives being run by patients.

When patients organise online, they can travel light and move fast, in ways that large healthcare institutions can't. Health professionals need to keep up - or risk being left out.



## Hearing from bereaved families

In 2021, the Justice Select Committee called for major reform of the inquest system, and stated that much more needs to be done to put bereaved families at the heart of the process.

This report from a Family Consultation Day shows why. It looks at the experiences of people whose relatives died under the care of mental health services. It says that “Too many families told us they felt marginalised from before their loved one died, right up until the inquest hearing and after”.

Key findings from the Family Consultation Day included:

**Inadequate communication.** One example was that after a death, care providers were already looking to protect their own reputations and positions. This was described as lacking respect for those that had died and for grieving families.

**Poor information and support.** There was a lack of advice on bereavement support, what to expect of investigations and inquests, and the coroner’s role. Some did not know they could request a post-mortem.

**Opaque investigations.** Families described flaws in the independence, impartiality and quality of investigations. Many families remain angry, suspicious and distressed at the ways care providers conducted investigations.

Once inquests got underway, families felt “utterly unprepared for what was to come”. The onus fell on them to work out their rights to legal representation, and to find the money to pay for it. Some found inquests taking place in venues that were hard to travel to. Some found the process itself unnecessarily adversarial. Some found themselves having to deal with the press and media.

When asked what needs to change, the families’ comments echoed those of so many others who have experienced harm in healthcare: “If one thing united the group it was the desire to ensure others were not placed in the same position as them in the years to come”.

There are many recommendations in the report, all coming from the families who took part in the Consultation Day. And all stem from the sense that “Ultimately, families are faced with a completely alien system that has inconsistent levels of information, empathy, openness and sensitivity”





## Open access training for patient experience

Evidence on people's experience of care comes from many different sources: patient surveys, local Healthwatch reports, academic research, online feedback and more. This open access course helps you to understand how to keep track of it all - and to start making sense of it.

Designed by the Patient Experience library for the NHS Leadership Academy, the course covers:

- Who does what in patient experience evidence gathering.
- Key concepts in patient experience work.
- Why patient experience matters.
- Challenges of hearing from patients.
- How to find different types of patient experience evidence.
- How to start making sense of patient experience evidence.

The course is free, and learners can log in at times that suit them, with the ability to pause part way and carry on at another time if they want.

It is designed to be helpful for people

who are new to patient experience work, as well as for people who are familiar with the basics but need to consolidate their knowledge.

As well as people in PALS teams, complaints, local Healthwatch etc, the course could be helpful for patient reps on engagement committees - and for any nursing directorate staff or Trust Board members who need a good grounding in patient experience work.

To find the course, simply go to <https://leadershipnhs.uk/>, select your region and create an account (free), or log in if you are already a user of the Leadership Academy website.

After that, look for "Patient Experience" in "Leadership Modules" and get started!

# HEALTHCARE CONFERENCES UK

**Patient Involvement & Partnership for Patient Safety**

10% discount for members  
15% discount for students

Wednesday 24th May 2023 Virtual Conference



Chair & Speakers Include:

Ruth Evans Managing Director Patient Experience Network	Anastasia Lungu-Mulenga Head of Community Engagement and Patient Experience Solent NHS Trust	Professor Helen Young Executive Director of Patient Care & Service Transformation South Central Ambulance NHS Foundation Trust
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HEALTHCARE CONFERENCES UK



## Patient Involvement & Partnership for Patient Safety FRIDAY 6th OCTOBER 2023 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 developing the role of the Patient Safety Partner (PSP) in your organisation or service. The conference will also cover engagement of patients and families in serious incidents, and patient involvement under the Patient Safety Incident Response Framework published in August 2022.

**Further information and booking**  
or email [kate@hc-uk.org.uk](mailto:kate@hc-uk.org.uk)

Measuring, Understanding and Acting on  
**Patient Experience Insight From Insight to Improvement**

10% discount for members  
15% discount for students


Thursday 12th October 2023 Virtual Conference



Chair and Speakers Include:

Chris Graham Chief Executive The Picker Institute	Ruth Evans MBE Managing Director Patient Experience Network	Josie Broad Senior Manager NHS England
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HEALTHCARE CONFERENCES UK



## Measuring, Understanding and Acting on Patient Experience Insight From Insight to Improvement THURSDAY 12th OCTOBER 2023 VIRTUAL, Online

This conference will focus on measuring, understanding and acting on patient experience insight, and demonstrating responsiveness to that insight to ensure Patient Feedback is translated into quality improvement and assurance.

Sessions will include learning from patients, measuring patient experience, using the NHS Improvement National Patient Experience Improvement Framework, demonstrating insight and responsiveness in real time, monitoring and improving staff experience, and the role of human factors in improving quality.


**Further information and booking**  
or email [aman@hc-uk.org.uk](mailto:aman@hc-uk.org.uk)

Virtual Masterclass

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


10% discount for members  
15% discount for students

Tuesday 27th June 2023 Virtual Masterclass  
Thursday 9th November 2023 Virtual Masterclass



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

HEALTHCARE CONFERENCES UK



## Engaging Patients & Families in Complaints under Patient Safety Incident Response Framework (PSIRF) and the Complaints Standards Framework THURSDAY 9th NOVEMBER 2023 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.

New frameworks such as PSIRF are now in place, but how do we not only comply with these, but go beyond compliance to have real authentic compassionate engagement and involvement with patients, families and indeed staff to make a real positive difference?

Connecting new knowledge with emotions can really support long term learning, which is an important part of this masterclass.

**Further information and booking**  
or email [kate@hc-uk.org.uk](mailto:kate@hc-uk.org.uk)

# 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](#) and [Waiting Lists Tracker](#). 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 over 70,000 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.

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

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**Patient  
Experience  
Library**

