

# Patient Experience

and patient/public involvement in health and care services

Winter 2023-24

**Patient  
Experience  
Library**

## **INSIDE**

**Safe Spaces for  
Patient Speakers**

**Covid Voices**

**Jungles, deserts  
and a mountain**

## Editorial



“Storytelling” is often seen as an important way to communicate patient experience, and rightly so. But how can storytelling be done well?

In this edition of our quarterly magazine, Sue Robins makes the case for safe spaces for patient storytellers (page 3). In her own experience as a speaker, she has encountered tokenism, a lack of care and sometimes, a lack of common courtesy. At other times, she has found practical

and emotional support, and a genuine recognition that her “stories” are something more than mere edutainment.

Lynn Laidlaw on page 4 recounts the experience of being part of a research team seeking the stories of people who are clinically vulnerable to Covid. As a clinically vulnerable person herself, this opened up questions of identity and competence. Could she objectively analyse stories that reflected – or diverged from – her own experiences? And how could she occupy the role of “expert by experience” and “researcher” simultaneously? Questions like these are vital to good quality coproduction in research.

Finally, our special feature on our evidence mapping work (pages 5 and 6) reveals the patchy way in which people’s healthcare stories are brought into the patient experience evidence base. While medical research has clear prioritisation processes, evidence-gathering on patient experience is, essentially, a free-for-all. We show how inequalities in health are linked to inequalities in research, and suggest some solutions.

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.

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**OF EVERYTHING WE DO**  
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**Patients**  
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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)

# Safe Spaces for Patient Speakers

Sue Robins



Health care organizations committed to learning from the patient experience often bring in patient speakers to share their health care stories. While this is well intentioned, harm can occur if patients are not supported before, during and after their speaking engagements.

I've been presenting at health care events and conferences for 20 years. I first shared my perspective as the mom of a son with a disability and more recently as a breast cancer patient. I've had a myriad of experiences as a speaker - all the way from being treated respectfully to being heckled on-stage.

If you are an organizer, please honour the patient story by honouring the speaker. If you are a patient speaker, be picky about who gets to hear your story. It is your right to ask for accommodations so you can feel safe sharing your story.

Here are a few examples of speaker support gone sideways.

I have been brought into a boardroom setting, told to tell my story and then asked to leave. (Clearly the patient story was just used as 'inspiration or as a 'sob story' to tick off a 'we included the patient voice' box.) I left feeling used.

I've sat on panels at health conferences with clinicians and been the only person not being paid. (Patient compensation is important. Plus, being the single patient speaker in a sea of professionals is a heavy burden to bear. Best to have two diverse patient speakers to carry the weight.)

Virtual events are wonderful for accessibility, but nothing feels worse than telling a personal story, the meeting ends, and you sit there alone in front of your screen, wondering how your story landed. (Stay online for a debrief with the speaker, listen to how the experience was for them, and importantly, learn from their feedback).

I recently was on a video panel speaking about the importance of language in health care. I shared a story about how medical professionals ask why I didn't get prenatal testing with my son, who has Down syndrome.

I told this story to illustrate how painful and unnecessary this question is. Instead of checking in with me to see how I was doing, I was curtly told that my answer was too long. While I appreciate direction, the lack of recognition about me speaking about a painful topic was insensitive. While all the other speakers spoke from their work roles, I spoke from my heart. I had made myself vulnerable, and again felt discarded afterwards.

It is important for organizers to think about why they are asking a patient to share their stories. Are they using patients for their stories? Is engaging patient speakers merely a tokenistic activity?

My best support has been from organizers who ask me what I need to be comfortable. The best first step is to have empathy for patient speakers and how they are often sharing difficult moments from their lives.

Recently, I gave a virtual talk about patient experience for an in-person hospital retreat. I had a prep meeting with the organizer and her team so I could gather more information about the audience, what they wanted for key messages and take-aways. It is crucial to give patient speakers the chance to collect this information so they can tailor their talk. There's nothing worse than being told to, 'just show up and tell your story.' This lack of direction does not help patient speakers be successful.

The organizer sent me details about logistics, and even emailed me photographs of the room so I would be prepared for what I would be seeing on camera. Importantly, she texted me afterwards to check on me and to share initial feedback so I knew how my talk was received.

It is important to provide emotional support and honour that patient speakers are often re-living the worst moments of their lives. Patients, be selective about who gets to hear your story. Organizers, treat your speakers well.

# COVID Voices

*Lynn Laidlaw*



As the UK Covid Inquiry rolls on, the focus seems to be upon politicians and high-level decision makers. But there is a great deal more learning that we need to do, and much of it comes not from the most powerful in society, but from the most vulnerable.

I was one of those people who ended up having to “shield” myself through the worst periods of the pandemic, so I was pleased to be able to help research the experiences of others who had to shield because of auto-immune conditions.

Our study, [COVID Shielding Voices](#), was co-produced by a core team (myself, Dr Charlotte Sharp, an Academic Rheumatologist and Joyce Fox, a public contributor) with a 4 person Patient Advisory Board and support from the Centre of Epidemiology at the University of Manchester, particularly from Prof Will Dixon and Prof Caroline Sanders. We were funded by Versus Arthritis.

We wanted to understand the experiences of people with auto immune conditions who shielded during the coronavirus pandemic. We were keen to explore the impact of shielding upon people’s lives, and to hear about the process for communicating to people that they were clinically extremely vulnerable.

We ran interviews and focus groups but also invited people to submit creative writing, photos and artwork. The wonderful range of responses and materials can be viewed [here](#).

The impact that shielding had on people and their families was profound. Participants in our study reported increased work in managing their conditions and accessing healthcare. There were practical implications for people’s lives including accessing basic food supplies. Managing their employment and home situations also became harder, including their children’s school attendance.

The declaration of the so-called [freedom day](#) in July 2021 increased biographical work as people went from feeling protected to “thrown to the wolves”. This increased the emotional work for clinically vulnerable people as they navigated these situations.

As someone who had to shield myself, I felt my own emotional impact to researching a topic I had lived experience of. I worried, for example, that I would only identify themes that resonated with me personally – introducing bias to my analysis.

As I have no formal research training, I also wrestled with imposter syndrome. Who was I to think I had the skills to do this research?

Co-producing our research prompted me to have an identity crisis. Was I a patient or researcher? Could I be both in a research culture that arguably defines people by their lived or learned experience?

The support of Charlotte, who led the project and mentored me, was crucial to helping me resolve these kinds of questions, and to our success as a team.

Working as a researcher and having responsibility for the conduct of the project was eye opening. I realised the amount of work and effort involved in setting up research and how this can impact on plans to involve people. Time and resources are always an issue. I felt I needed to be pragmatic in ways that felt uncomfortable at times.

The COVID Voices study (which has been submitted as evidence to the Covid inquiry) was one of the best, and most challenging things I have ever done. I am so proud of what we have achieved. One of the participants commented our research “was academically rigorous but full of emotions and care “. Some would argue that emotions have no place in research but, for me, it is my emotions that drive me to be involved and led to us co-producing COVID Voices.



# Jungles, deserts and a mountain

*Miles Sibley, Patient Experience Library*

An NHS aiming to be both patient-centred and evidence-based needs a coherent evidence base for patient experience.

Medical research databases are in daily use across the NHS. But historically there has been no equivalent for patient experience evidence. So we built the Patient Experience Library to plug that gap.

We have spent the last few years cataloguing tens of thousands of documents on patient experience and engagement. In doing so, we have noticed a lot of duplication. There are, for example, hundreds of reports on people's experiences of trying to get a GP appointment. And they all say much the same thing.

We also noticed gaps in the evidence base. It is hard to find studies on topics such as people's understanding of advance care planning, or experiences of pelvic mesh, or the intersection between religious faith and experiences in healthcare.

Why, we wondered, does the evidence on patient experience seem so patchy? How, exactly, does the variability manifest itself? And (in an NHS

that says it wants to tackle health inequalities) who gets heard, and who doesn't?

At the start of 2023, we decided to go looking for answers.

## A voyage of exploration

We sampled five different parts of the patient experience evidence base:

- Patient experience in digital healthcare
- People's experiences of the Covid pandemic
- Experiences in urgent and emergency care
- The healthcare experiences of homeless people
- Experiences of people with rare disease

We headed out into each of these areas to see what we could see. Using a variety of search terms, we collected hundreds of reports on each topic, and then applied thematic analysis to help us make sense of the overall shape of each part of the evidence base.

What we found confirmed our worst fears.

## Jungles

With every single sample of the evidence base, we found areas that were densely packed with repeat studies. This was not so much duplication, as saturation.

"Access to services" in particular is a topic that seems to get investigated over and over again, year after year. Funders are spending money, researchers are spending time and patients are expending goodwill for no good reason that we could see. Their efforts are simply adding to the pile of reports rather than to the sum of knowledge.

## Deserts

Other parts of the evidence base were, to say the least, sparse.

In digital healthcare, we found very little on people's experiences of the NHS app, or experiences with electronic health records, or attitudes to artificial intelligence in healthcare.

In the literature on Covid, just 6% of the reports we found had a specific focus on health inequalities - when we know that the poorest communities were hit hardest by the pandemic.



A mere 2% were primarily about the pandemic experiences of people who are clinically vulnerable.

On the healthcare experiences of people who are homeless, we found just two reports on experience of food insecurity, and one on experience of hygiene poverty. And yet these are fundamental determinants of health in the homeless population.

## Toolkit Mountain

As a bonus extra we took a sixth sample of the evidence base, looking at guidance notes, frameworks and toolkits for patient and public involvement. The quantity of published work is staggering: we found 536 PPI toolkits.

The problem is not with the quality: most of the guidance is well-written. But there is a mountainous quantity of it, and a great deal of it is both generic and repetitive. Guidance on engagement with “hard to reach” communities is largely noticeable by its absence.

## Why this matters

There is a lot of talk in healthcare about health inequalities.

If we want to understand health inequalities, we have to hear from the people who experience them. But our evidence mapping indicates that health inequalities are perpetuated – at least in part – because those same inequalities are built into the way that patient experience evidence gathering is being done.

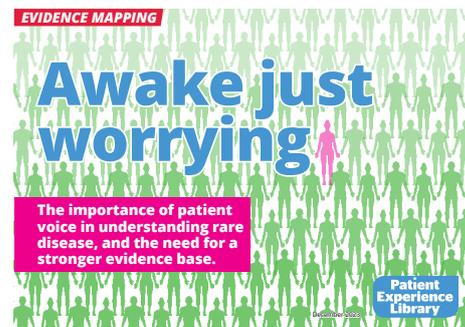


This is not a criticism of researchers. It is common to the point of cliché to hear that underserved communities are not actually hard to reach – it’s just that researchers aren’t trying hard enough. But that ignores the context in which researchers operate.

In medical research, there are clear prioritisation processes. Research funders, broadly speaking, know what they know, and they steer researchers away from duplication and waste. They also know what they don’t know – so they can point researchers towards filling the gaps.

Patient experience work is different because no-one – until now – has mapped the evidence base to find out what we know and what we don’t know.

So even when researchers are willing to make the effort to get to so-called “hard to reach” communities, they have trouble seeing who has already been spoken to and who hasn’t. They might struggle to see what topics have already been covered, and where the gaps are. And unlike medical researchers, they don’t get a steer on where to go next.



## What now?

Our evidence mapping can put an end to what is, essentially, a free-for-all in patient experience research.

We have created a foundation for prioritisation processes of the kind that are routinely used in medical research and we have laid the basis for tackling inequalities in health by tackling inequalities in evidence-gathering.

So we are now looking for partners and collaborators to help take this work to the next level. To a point where researchers can stop wasting time. Where research funders can stop wasting money. And where the so-called “seldom heard” can come out of the shadows, and their presence or absence in the patient experience evidence base can become fully visible.

Do you want to partner with us? Please get in touch: [info@patientlibrary.net](mailto:info@patientlibrary.net)

This project was funded by the Health Foundation’s Q Community. For reports and interactive data visualisations, visit <https://www.patientlibrary.net/evidencemaps>



## 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)



# Child protection

This report shows that child and adolescent health is not, for the most part, a matter for hospitals. Their wellbeing relates much more closely to “the environment and social circumstances in which children grow up”.

The facts are stark:

- Obesity affects 23% of Year 6 children in 2021/22 in England. 80% of obese young people remain obese as adults.
- In 2022, 29% of five year olds in England had tooth decay.
- Vaccination coverage has decreased in 13 out of 14 of the routine childhood vaccination programmes. The UK lost its WHO measles free status in 2018.
- 86% of UK cities exceed recommended limits for airborne particulate matter. The effects of air pollution have a greater impact on children and young people.
- Rates of poor mental health for children and young people are rising. Suicide is the leading cause of death in children and young people.

It can be hard for children to make their voices heard: conventional NHS mechanisms such as Friends and Family Test or national surveys tend to be hospital-based and can often be unavailable to, or inappropriate for, under 18s. Reports like this are therefore important in their advocacy for this very large and very vulnerable proportion of the population.

The report makes a series of recommendations - on food regulation, dentistry, vaccinations, air quality and more. And it makes the point that “prevention is better than cure, but we must also recognise that prevention in childhood is better than prevention in adulthood”.



# Storytelling as the foundation of learning

“As with most education, storytelling is often the foundation of learning”, says Naomi Shiner, the author of this paper.

Shiner’s story is that of a parent navigating the NHS with a child with Down Syndrome. Her educational goal is to “enlighten healthcare professionals about life with Down syndrome”.

Her first experience was the 18-week routine scan, at which the very much non-routine appearance of a second sonographer signalled a concern. Shiner quickly found herself ushered to “a beige, empty room, with nothing to do but wait for people to arrive and receive more information”.

The next step was an MRI scan of the baby’s head, which revealed a shortened corpus callosum. What, wondered the parents, might that mean for her future? There seemed to be no clear answers. If no-one could answer my questions, wonders Shiner, why had they bothered with the MRI?

A rollercoaster of mixed experiences followed. After the birth, one staff member loudly announced that baby Nina might have Down Syndrome. “The sudden silence that fell across the ward”, says Shiner, “was deafening”.

After a check for possible heart defects, “a neonatal consultant entered our side room holding rolled up leaflets in his left hand. With no words spoken, at that point I already knew we had an issue”.

Throughout her early motherhood experience (which included at one point, being suspected of harming her baby) Shiner detected “a noticeable difference in terms of compassion, information giving, time at appointments for discussion and importantly the opportunity to be involved in decision making”.

One staff member, the dietitian, “provided the gold standard experience, even being there during emergency admissions and communicating our needs across hospital trusts”.

Shiner concludes that “For Nina and I, there is no one solitary experience, each appointment and interaction whether positive or negative bleeds into the next. These engagements at times, can be emotionally and cognitively exhausting for us both”.

She asks healthcare professionals to learn more about the modern lives of individuals with Down syndrome, and reminds them that parents have “the determination to fight for our children...please do not make us”.



# Slaying dragons

Patient safety seems to be a permanent feature of news headlines these days.

Large scale harm in maternity services has been revealed at Shrewsbury and Telford, and at East Kent. There is an ongoing investigation at Nottingham. There have been deaths of babies at the hands of Lucy Letby. And then there are individual examples, such as the avoidable death from sepsis of Martha Mills.

So what is going wrong with patient safety? How can there be so many calamitous outcomes across so many services and locations?

This commentary from America offers food for thought.

The author argues that in patient safety work, the emphasis should be on “slaying dragons” – eliminating or at least mitigating risks to patients. Instead, he says, “current practice focuses almost exclusively on investigating dragons – tracking reports on the number and type of dragons that appear, how many villagers they eat and where, whether they live in caves or forests, and so on”.

Healthcare workers, he says, “invest untold time and effort in incident reporting, incident investigation (eg root cause analysis and its various subcomponents), and the occasional prospective risk assessment”. But “We cannot investigate a dragon to death. No more can we risk assess our way to safer care”.

He is equally critical of “the ritualistic invocation of plan-do-study-act (PDSA) cycles” on the basis that “the successful use of PDSA in healthcare is vanishingly rare”.

Three remedies are offered. The first is structured risk control tools, specifically designed for patient safety improvement.

Secondly, “we need to expand the ranks of dragon slayers. Clinicians cannot go it alone – and should not have to”.

Thirdly, the task of slaying dragons means “moving beyond analysis and grappling with the messy work of systems change”.

“The patient safety movement”, says the author, is “settled into the comfort of an obsolete standard of practice”. There is a complacency in which “ongoing patient harm has been treated as ‘inevitable’ and ‘the cost of doing business’ despite studies showing that it is possible to do better”.

# Journaling experience



In patient experience work, it is common to hear talk of people who are “hard to reach”.

Sometimes the phrase is seen as a convenient excuse for not trying hard enough. But some people really are hard to reach because of severe illness, or mental incapacity.

In this article, David (an intensive care patient), tells how the practice of diary-keeping enabled family members and staff to understand what he was experiencing as he emerged from six weeks of coma, ventilation and proximity to death.

As he recovered, David found himself disorientated and prone to vivid nightmares and hallucinations. At times he was overwhelmed by anxiety and paranoia. Through all of this, his partner Rose’s diary, along with his own scrawled questions and notes, helped them both to make sense of their fear and bewilderment.

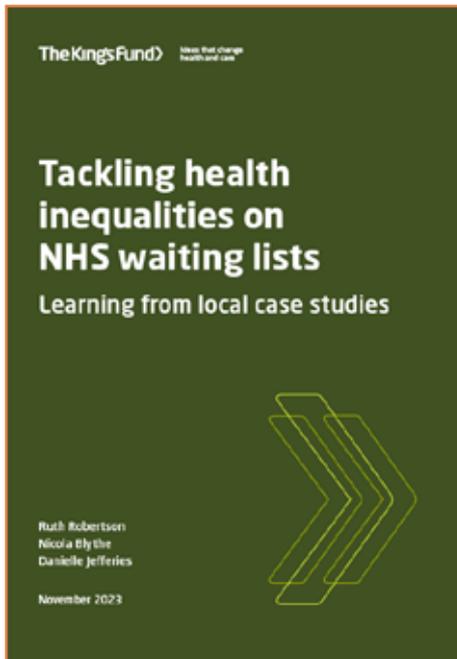
Rose also documented clinical updates, making her own record of procedures, treatments and clinical signs, along with notes on David’s reactions and progress.

The resulting booklet, says David, “helped me to appreciate the outstanding care both I and my family had received in those weeks”. It also enabled him to “create some sort of timeline and extract the true memories from my fragmented and delusional recall”.

Since leaving hospital, the diary remains a valuable resource, helping David to live with the continuing consequences of his illness. “The power in these entries lies in their ability to help me understand how dire my prognosis was. When I get frustrated with my life situation and residual health issues, finding myself struggling to move forward, I can look back to these early days and see how far I have travelled in my recovery journey.”

David comments that “Reading and reflecting on my diary has often grounded me, helped ease my anxiety and prevented me from slipping further into the grip of depression, proving in my case, the ongoing mental health benefits of the diary”.

David finishes with a request for health professionals: “In a world where intensive care is provided at huge expense, an ‘ICU diary’ costs a small amount of time, the price of paper and a pen and a moderate amount of teamwork. I hope I have demonstrated that the cost to benefit ratio for your patient is undoubtedly in its favour”.



## Unequal waiting

After the first wave of the Covid-19 pandemic, NHS England asked integrated care boards (ICBs) and NHS trusts to address health inequalities as part of tackling growing waiting lists for elective care. This report looks at three Trusts and ICBs to see what progress has been made.

A fundamental first step was for providers to disaggregate their waiting list data, to identify patients by ethnicity and deprivation. Two years on from NHS England's ask, only one of the three Trusts had achieved this. None of the ICBs were reporting disaggregated waiting times data to their board.

There were also barriers to the idea of a new approach. In one Trust, "work to reprioritise waiting lists had stalled because of resistance from clinicians". In the other two, "leaders were concerned about how clinicians would react to the work".

Data issues were another problem. These included poor quality ethnicity coding, and limited analytical capability.

Surprisingly, there appear to be no formal performance management or accountability structures for inclusive recovery within NHS Trusts or at ICB level: "health inequalities were not part of accountability conversations with NHS England". Moreover, "Interviewees were uncertain about what a meaningful measure of success would be, and noted that the policy on taking an inclusive approach to reducing the backlog did not set out a clear vision for this".

In spite of all this, there were some pockets of success. But these were more in terms of simple improvement projects than systemic change. And they were led not so much by executive teams as by individuals with a passion for addressing inequalities. The report makes the point that "the NHS needs to harness that enthusiasm and give these leaders the tools and ideas needed to make change in their clinical areas".

The authors conclude that "Waiting lists are one place where the causes, experiences and consequences of health inequalities coalesce. If the NHS is serious about addressing health inequalities, it needs to address inequalities on waiting lists for elective care as part of that".



## 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!



**Complaints Resolution & Mediation**  
Applying mediation techniques to support local resolution

Tuesday 13th February 2024 Virtual Masterclass

10% discount  
15% discount



Facilitated by:  
Richard Edwards Consultant Nockolds Resolution  
Jennie Jones Head of Complaint Resolution Services Nockolds Resolution

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## Complaints Resolution & Mediation

**Tue, 13 Feb 2024**  
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This course is suitable for anybody who deals with complaints as part of their job role, or anybody who may have to handle a complaint. This includes dedicated complaints teams & customer support teams and managers.

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**Further information and booking**



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Strategies and tools to help you deal with difficult conversations

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### Further information and booking

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

Thursday 22nd February 2024 Virtual Masterclass

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

**Thu, 22 Feb 2024**  
**Virtual, Online**

This one-day masterclass will look at the new PSIRF and the Complaints Standards Framework and through real life content, bringing the human focus for the patients, loved ones, and indeed staff to the forefront. It will support staff to explore what compassionate engagement looks like, feels like, and how to communicate it authentically and meaningfully.

In a supportive and relaxed environment, delegates will have the opportunity to gain in depth knowledge of the emotional component, relate to, analyse and realise the significance of and believe in their own abilities in creating practices that not only support the PSIRF but go beyond compliance to be working in a way that supports gaining an optimum outcome for patients, families and staff, in often a less than optimum situation.

**Further information and booking**

# 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](#).

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# 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)

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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.

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**Patient  
Experience  
Library**

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