

# Patient Experience

and patient/public involvement in health and care services

Autumn 2024



**Patient  
Experience  
Library**

**INSIDE**

**Change My Heart,  
Change My Mind**

**Dad's drugs**

## Editorial



Modern medicine is a powerful force for good. Vaccines, for example, have massively reduced diseases that used to be commonplace - including smallpox, polio, meningitis, measles and more. Other drug treatments bring relief for millions of people living with long term conditions.

But medicines are just one part of healthcare and healing. On page 3, Lisa Ridgway describes her path back from a deep depression to living life with purpose and fulfilment. The “leap of faith” that saved her was not medicinal - it was an insightful and caring intervention from a doctor who pointed her towards a role in research. The outcome for Lisa was healing for her heart as well as for her mind.

On page 4, our anonymous contributor I♥dad is looking after an elderly parent with heart disease. The father has numerous medications that he has to take on a daily basis. But these have unpronounceable names, and are boxed up in confusing packaging. People trying to self-manage long-term conditions need effective medicines - but they also need much better help to understand what the drugs are, and how to take them.

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*

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.

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## 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)

# Change my heart, change my mind

*Lisa Ridgway*



My brother, who lived in Australia, died in 2016 of blood cancer, 9 years after the diagnosis. I live on Vancouver Island in British Columbia. I was his bone marrow match and donor and flew twice to Australia for two transplants over 4 years. Each trip required work-up, infinite tests, coordination and collaboration across two countries.

Miraculously the process worked out. Sadly, however, the outcome did not. I was plunged into a dark hole, with treatment resistant depression, when my brother died.

What happened next defies belief. I became a patient of one of Canada's top psychiatrists, Dr. Wei-Yi Song. Under his watch and over 7 years I had many therapeutic interventions.

I did rTMS (repetitive transcranial magnetic stimulation) for 40 days in

a row. I tried many anti-depressants, with no success. At one point, taking five pills a day, I screamed with my mouth shut. I did a full ketamine therapy, a few years later, as patient "zero" on Vancouver Island. I spent 10 good months in a mental wellness program. But despite Dr. Song's best work, nothing really rescued me. I paid for and had a pharmacogenomic test in 2017, to try and identify the best medication. The report from the US company was gibberish. To his credit, Dr. Song kept trying. He just would not give up and this perseverance saved my life.

In a gigantic leap of faith, he gave my name to a world recognized neuroscientist at my local university. And something clicked when I met Dr. Hector Caruncho. Working with him and his students I found purpose.

Over a few years I became his patient partner and a Researcher in the Department of Psychiatry. Then a professor from the University of British Columbia called me. I became Dr. Fidel Vila-Rodriguez's patient partner too and a Researcher at the Centre for Brain Health at UBC. I work on research teams and in these laboratories, drafting funding applications, drafting publications, working my heart out and helping my mind in the process.

I now study pharmacogenomics, biomarkers, and rTMS, all as they relate to the best outcomes for treatment resistant depression. I strategize with my health authority

and with BC on research policy priorities. I liaise with government authorities at all levels on how to include patient partners in health research.

Thanks to this work I no longer have treatment resistant depression. I stopped taking anti-depressants. Now I use my brain and work with others who have bigger brains. We are changing access to treatment for depression across BC. And in the process I thumb my nose at the stigma of mental illness.

Becoming a patient partner supported by the Strategy for Patient-Oriented Research in Canada made me well. I now celebrate my power and my ability as a patient partner. To patient partners and people with lived experience, on clinical and medical research teams, never doubt your ability to change health care. Believe in yourself. You are a rock star. You give research teams something they can't measure. You give what happened to you when you took the drugs, when you fought with your demons, when you and some others almost gave up.

You can change health research and health care. It will take time. You will only do it with others by your side. And you will change peoples' hearts and minds, including your own.

# Dad's drugs

*I♥dad* (The author of this article uses the name "I♥dad" to protect his father's identity.)

My Dad is in his 90's and has a weak heart. Like so many older people, he spends most of his time self-managing his health condition, out of sight and out of mind of NHS services. But occasionally things go wrong, and I am starting to get used to the sudden call to say that he has been taken into hospital because of bad chest pains or severe breathlessness, or a troubling degree of anaemia.

After the latest emergency admission and life-saving intervention (thank you NHS), Dad was discharged with a fresh list of medications. Back at home, he and I sat down to try to make sense of it.

We were faced with an alphabet spaghetti of drug names: bisoprolol, clopidogrel, edoxoban, furosemide, glyceryl trinitrate, lansoprazole, sodium valproate. These names are hard to read, hard to pronounce, and hard to remember. But remember them we must - because my father's life quite literally depends on it.

So why give patients lists of drugs that are so difficult to read?

I know that drug companies would say "it's because there are naming conventions that we have to follow". And perhaps health professionals would say that those conventions help to ensure clarity in what is being prescribed, and that that is important for patient safety. But for patients, unpronounceable names make it hard to get clarity. So they risk making mistakes and undermining their own safety.

There are other confusions too.



▲ Here is the sodium valproate that Dad has been given. One box says "Epilim". The other says "Dyzantil". This box does also say "sodium valproate" but only as a sub-heading.



▲ And here's the bisoprolol. Each box says "Bisoprolol" but they don't look the same.



▲ Here's the lansoprazole. Dad's discharge sheet says he must take one tablet per day. Reading more closely, it says "one 30mg tablet per day". But the box he has been given contains 15mg tablets. So he actually has to take two per day.

It's all very confusing.

Dad and I have both had a good education. If we're struggling, what must it be like for people who have lower levels of literacy, or are trying to figure this stuff out on their own?

Self-management as a strategy makes sense: the hospitals are clogged and they don't want yet more people turning up there. It makes sense to patients as well - no-one wants to be in hospital if they can avoid it. So patients and families want to be "partners in care". But we need help.

Is it too much to hope that drugs could be more simply, or at least more consistently, named? That box colours and designs could also be consistent? That if dosage advice says "one 30mg tablet", we could get a box containing 30mg tablets?

I have left Dad with his medications and next time I visit, I'll go through them again with him, to check that he is on top of his doses and timings. In the meantime, I cross my fingers and hope not to get another emergency call...

## 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)



# Choice of place of birth

“Choice has been a key aspect of maternity care policy in England since 1993” says this paper. But, it says, “a gap remains between the birthplaces women want and where they actually give birth”.

Choice of place of birth matters, say the authors, because “where a woman gives birth will likely affect how she gives birth” - taking in both personal preferences and medical needs. They also note that “research has shown that unfulfilled birth preferences can lead to lower maternal satisfaction and even trauma”.

The choices available to women include the hospital labour ward, alongside maternity unit, freestanding midwifery unit and home birth. These birthplaces “sit along a spectrum of medicalisation with different interventions and options available in each setting. The labour ward sits at the medicalised end and home birth at the demedicalised end”.

Preferences for any of these locations can be shaped by “social, cultural, historical and medical discourses which are disseminated through friends, family, antenatal classes and the media”.

The researchers found that the majority of study participants preferred to give birth in an alongside maternity unit (AMU) - a midwife-led unit attached to a hospital. This was because of its ability to offer women a compromise between low-intervention care and close proximity to specialist care if needed.

Preferences ahead of labour and birth are, however, different from actual decisions when the time comes. The paper states that “Despite the growing popularity of the AMU as a birthplace preference, the data showed that the majority of women decided to give birth in the labour ward”. This, it says “was in line with a wider pattern of medicalisation in the data as women progressed from birthplace preferences to decisions”.

The authors conclude that “This lack of congruence could have implications for women’s childbirth satisfaction and as such it is important that maternity care professionals understand women’s birthplace preferences and the reasons behind them”. This, they say, “might include if or how elements of the AMU could be incorporated into women’s labour ward births in order to personalise care and facilitate the kind of birth experience they had hoped for”.



# Culture at the heart of harm

This report was published on the 20th May 2024. For a day and a half, it made the headlines. And then the Prime Minister called the general election, and the news cycle moved on.

The findings of the Infected Blood Inquiry run to seven volumes. There is a huge amount of detail. But anyone interested in patient experience need only glance at the first few pages of this volume to see a recognisable pattern. The report refers to:

- Repeated and ongoing failures to acknowledge that people should not have been infected.
- The absence of any meaningful apology and redress.
- Repeated use of inaccurate, misleading and defensive lines to take which cruelly told people that they had received the best treatment available.
- A lack of openness, transparency and candour, shown by the NHS and government, such that the truth has been hidden for decades.
- Deliberate destruction of some documents and the loss of others.
- Refusal to provide compensation (on the ground there had been no fault).

These are direct quotes from the report.

In an otherwise excellent account, there is one mis-step, where the commentary states that “It will be astonishing to anyone who reads this Report that these events could have happened in the UK”.

On this point, the authors are wrong - because these events are not astonishing. They are par for the course.

We know this because we have seen it all before - in inquiry reports from Mid Staffordshire, Morecambe Bay, Southern Health, Gosport, Cwm Taf, Shrewsbury & Telford, East Kent. And in the case of injuries from Sodium Valproate, Primodos and pelvic mesh. And in residential care at places like Winterbourne View and Whorlton Hall.

The lesson that we keep failing to learn is that patient safety is not simply a matter of better training, better guidelines, and better regulation. At some point, the NHS has to get serious about understanding and tackling harmful cultures in healthcare. Those cultures are at the heart of the kinds of avoidance, denial and cover-up referred to in this latest inquiry report. They are harmful to staff as well as to patients. And they need to end.



# How experience shapes experience

Patient experience is not a “one size fits all”. People’s expectations for their health, and for the health services they use, are shaped as much by social and cultural factors as by their medical histories and conditions.

This study looks at adverse childhood experiences (ACEs) and asks how those might affect health, wellbeing and behaviour in later life.

The report gives examples of ACEs such as child maltreatment or growing up in a household with substance misuse. These are associated with increased risks for health-harming behaviours (eg smoking) and negative physical and mental health outcomes. They also correlate with increased use of health services.

A questionnaire survey of over 1,600 people confirmed previous research findings – for example linking high ACE exposure with greater medication use. Alongside this, the study team found a relationship between ACEs and medication adherence, with individuals with two or more ACEs being more likely to report poor medication adherence.

Another relationship was between ACEs and vaccinations. ACE exposure was linked to having not received all routine childhood vaccinations. This could have implications for vaccine uptake or hesitancy in adulthood.

A further consideration was how comfortable people with adverse childhood experiences feel in medical and healthcare settings. The study found that individuals with multiple ACEs were substantially more likely to perceive that professionals do not care about their health or understand their problems.

Additionally, individuals with four or more ACEs were more than twice as likely to report low comfort in using hospitals, GP and dental surgeries and almost three times more likely to have low comfort in using A&Es compared to individuals with no ACEs.

The report concludes that early life experiences influence individuals’ relationships with health services as adults. Despite increased use of medication, individuals with multiple ACEs may be less likely to take medication as directed, or to use preventative healthcare. They may also experience greater discomfort in using healthcare environments compared to those with no ACEs. These findings, say the authors, are of use in the development of trauma-informed responses to ensure individuals who have experienced childhood adversity are effectively supported to live healthy lives.

# Mesh conflicts of interest



“When medical research and vested interest collide, objectivity, research integrity, and best clinical practices are sometimes the victims.”

This opening sentence sets the scene for a paper on industry funding for pelvic mesh research. Specifically, it examines conflict of interest (COI) reporting by US physicians studying mesh safety and effectiveness.

The researchers retrieved 56 papers on mesh from the PubMed database and cross checked the authors with the United States Centers for Medicare & Medicaid Services Open Payments database. They found that 53 out of the 56 papers (95%) had at least one American physician author in receipt of industry funding. The majority of this funding (47 out of 53 articles) was undeclared.

Reviewing the amounts of funding received, the researchers found that “Of 247 physician authors, 60% received > \$100 while 13% received \$100,000-\$1,000,000 of which approximately 60% was undeclared”.

They also found that “The majority of publications explicitly stated that mesh was safe and beneficial (57%, n = 32) although only 10 of those 32 substantiated this with evidence”.

The paper considers possible reasons for non-disclosure. These, it speculates, could include “journal laxity, researchers’ sense of impunity, conviction that they are not swayed by industry largess, or convincing themselves that funding received was not related to the reported research”.

Whatever the reasons, the researchers conclude that “Self-reporting of financial COI by researchers appears to be unreliable and often contravenes requirements agreed upon by international medical journal editors”.

They go on to state that “Industry funding both declared and, to a greater extent, undeclared, permeates almost all research on pelvic mesh and almost certainly shapes the quality of and conclusions drawn from those studies. This biased evidence in turn skews the risk benefit picture and potentially drives overuse of pelvic mesh in clinical practice”.





# What patients know

Healthcare nowadays repeatedly emphasises the importance of using patients’ lived experience to inform policy and practice.

In spite of that, says this paper, “The biomedical establishment is known to give a deflated level of credibility to a patient’s narratives”. Moreover, it “lacks the necessary interpretive resources to make sense of a patient’s experience of illness and healthcare”.

Part of the problem, say the authors, is that “what we call experiential knowledge is not explicit”. Indeed, “patients themselves are not always aware of the variety of knowledge they have acquired and the value it can have in building more equitable care relationships”.

The paper suggests that rather than talking in vague and generalised ways about patient experience, we need to give a more pragmatic meaning to the idea of experiential knowledge.

The starting point is to understand patients’ three main sources of learning: self, system and community.

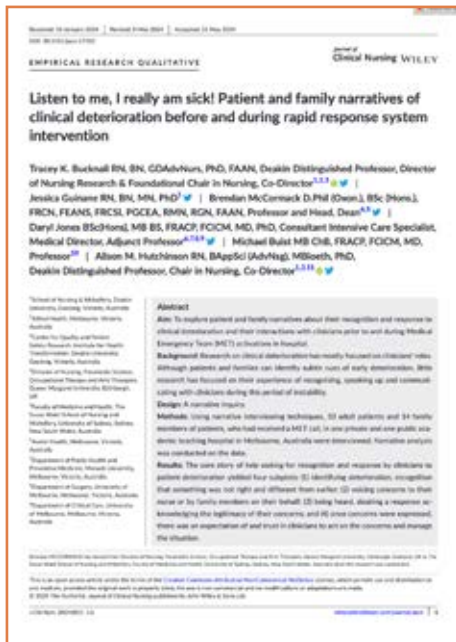
- Learning from self means being attentive to one’s own body and mind through phases of wellbeing and illness.
- Learning from the system means developing an understanding of the “rules of the game” of healthcare - for example, how to navigate services, or how to talk to health professionals.
- Learning from community means drawing on peer support and getting insight from other people’s knowledge and experiences.

The paper goes on to describe how patients can use these learning sources to build six types of knowledge: embodied, monitoring, navigation, medical, relational, and cultural knowledge.

This more pragmatic definition can, say the authors, help to highlight the variety and specificity of patient knowledge. It need no longer have a vague meaning in contrast to professionals’ skills and knowledge formalised by academic training.

That, in turn, can help to give patient knowledge “its rightful place at the heart of care relationships”.

# Listen up



This Australian study starts by noting that “Unexpected deaths in hospitals have often been preceded by periods of clinical instability that have been missed, misinterpreted, or mismanaged by ward staff”.

To mitigate the risks, providers have put in place rapid response systems which activate Medical Emergency Teams. However, “the delay or failure by clinicians to initiate a MET call remains a serious concern”.

Patients and their families also have a role - not least because they “are often aware of the changes in the patient’s condition and therefore, are well placed to advocate for them”. But “Despite reporting concerns to clinical staff, some patients and families find their concerns are not acted upon”.

Against this background, the study explored patient and family narratives about their recognition and response to clinical deterioration, and their interactions with clinicians prior to and during Medical Emergency Team activations.

The core story told by patients and families was one of “help seeking” in response to a perception of the patient becoming “intensely unwell”. There were four common stages:

- Identifying deterioration. This involved a recognition that “something was not right” and that the patient’s condition had become different from earlier.
- Voicing concerns. This is the point at which worries about the deterioration are conveyed directly to clinical staff.
- Being heard. Having spoken up, patients and families want a demonstrative response that acknowledges the legitimacy of their concerns.
- Expectation and trust. People want to see clinicians acting on their concerns and managing the situation.

Each stage has its own challenges. Identifying deterioration can be difficult if the patient has communication limitations or physical and cognitive impairments. Voicing concerns can be hard if people are not sure when and who to report them to. Health status, health literacy and language barriers can also affect people’s ability to engage.

The study highlights “the importance of the relationship between patients and nurses and critically the communication within that relationship”. Psychological safety is important, and hesitancy to report concerns can arise “because of the staff attitudes, busyness and poor responsiveness by clinicians”.

The authors state that “Treating patients and families as knowledgeable allies and partners in care builds trust and promotes continuity of care”. They say that “Improving communication between patients, families and health care professionals is the first line of defence for the patient safety”. And, they say, “implementing ‘speaking up’ strategies by patients and families also requires clinicians to ‘listen up’.

# A good death?



This paper starts with the statement that “The demands and costs of health care resulting from increasingly ageing populations have become a major public health issue”.

However, it says, “concern with cost containment in the delivery of care has sidelined recognition of the... pain and suffering which can be involved in the experience of death and dying”.

The authors are particularly concerned with the idea that end-of-life care is “framed within the discourse of the ‘good death’, promising comfort, control, and personal choice as an outcome of pre-emptive discussion and advance care planning”. To test this, they explored patient, family, and public perspectives of death and dying, and how these correspond to policy and professional stereotypes about ‘the good death’.

The study was based on participants’ accounts of different experiences of death and dying as well as observations regarding ‘types’ of death and imagining their own. While some deaths were described as peaceful and comfortable, other participants referred to the unpleasantness of dying and of being a witness to suffering.

The authors report “Graphic accounts of the prolonged and miserable experience of death and dying, for both patients and the family members who were charged with providing care”. These, they say, highlight “the limitations of palliative and end-of-life care in relation to enablement of ‘the good death’”.

The paper states that “In the real world, family members confront not only the burden of care but also the bureaucracy resulting from the provision of care within a complex but poorly resourced and uncoordinated system of health and social care services”. And, it says, “drastic differences in the experience of dying result from the perpetuation of deeply entrenched inequality and differences in social, material, and economic resources available to patients and families”.

In conclusion, the paper states that “The study findings highlight the tremendous challenges faced by families caring for dying patients at home”. It says that the findings “raise questions about the feasibility - and desirability - of continuing current policy to promote home as the default place of death and what it is reasonable to ask family members to do in providing increasingly demanding care”.



## People not structures

“Putting people’s needs at the heart of services should be central” says this report. It goes on to say that “While health and social care services work together to deliver excellent care in many places, our joint investigations show that there are significant areas for improvement”.

The report presents a series of case studies, based on formal Ombudsman complaints.

One is about Oliver – a young man with complex medical and care needs. After the family moved to a new area, it took the council three years to review Oliver’s Education, Health and Care plan, five years to agree that he needed to be educated at home, and six years to accept that Oliver’s parents were entitled to a carers’ assessment.

Pearl’s dementia meant that her behaviour became increasingly challenging with outbursts of aggression. She entered respite care but the family brought her home because they were concerned about the quality of care. The NHS Trust did not provide adequate advice to the family regarding medical care and did not recognise the extent of Pearl’s deterioration, leaving them to cope without adequate arrangements in place.

Arthur is a young child needing 24 hour medical and care support. He had a ‘Child in Need’ plan in place, created by the council and the NHS but the arrangement was not reviewed for several years. The council and the Clinical Commissioning Group/Integrated Care Board disagreed on what support was required and who should pay for it, with the pressure and uncertainty causing significant stress for Arthur’s family.

The Ombudsmen say that “The evidence of our casework shows that a lack of communication between health and social care services is an issue that lies at the heart of many system failures”. They say that “In some cases that lack of communication is life limiting: years of education lost that cannot be recovered, inadequate care in the last days of life and families left in uncertainty at the start of young lives”.

An important conclusion is that “simple actions to communicate effectively on the frontline can prevent people experiencing poor care”. And a key recommendation is that Integrated Care Partnerships, Integrated Care Boards, Directors of Adult Social Care and NHS Trusts “must focus on the experience of people using services and prioritise joined up communication and activity that puts those people first, every day”.



# Planning for failure

This opinion piece offers a reflection on learning from the UK Covid-19 Inquiry. Its starting point is the oft-repeated observation that Covid took the UK government by surprise because it had been “planning for the wrong pandemic”. But, says Professor Cristina Pagel, “the core problem is that there was never a plan to prevent or control a pandemic at all - of any disease type”.

She cites the Inquiry’s view that “Planning was focused on dealing with the impact of the disease (in this case, influenza) rather than preventing its spread. As a consequence, the levels of illness and fatalities of a pandemic were assumed to be inevitable and there was no consideration of the potential mitigation and suppression of the disease”.

Pagel’s own opinion is that “The plan, based on coping with pandemic deaths rather than reducing them, crumbled quickly in 2020”. This, she says, “meant that a huge amount of crucial policy was made on the hoof” with the result that “some of the most vulnerable people were left exposed: care home residents; care home workers who struggled to isolate with no sick pay; key workers who could not stay home and had no access to personal protective equipment...”.

For Pagel, this raises a question about the values that informed pandemic strategy. Whose values were they, she asks - the government, the health secretary, parliament, the public?

A key learning point is that for future emergency planning, “Public deliberation is needed in advance - before the emergency”.

Emergency planning always involves complex policy options - but, says Pagel, “The population needs to buy into these policies - for legitimacy and successful implementation”. She calls for “plans to elicit, codify, and communicate our nation’s values and priorities in future emergencies”. These would then “underpin a more transparent and effective process for preventing, mitigating, and dealing with future emergencies”.



## Listening to the silence

There are well-known links between staff experience and patient experience. Basically, if staff feel well looked after, patients, too, are more likely to feel well cared for.

Feeling well looked after includes feeling free to speak up about concerns. Which is why the National Guardian's latest report on Freedom to Speak Up is worth a read.

There are, she says, "pockets of excellent practice", with some organisations showing improved staff survey results, not just for the speaking up questions, but also for NHS People Promise themes like "We are a team".

In spite of that, the latest NHS staff survey shows that the number of respondents feeling confident to speak up about unsafe clinical practice is at a five-year low.

One possible reason is a say/do gap, where organisations are saying one thing, but workers are experiencing another. The National Guardian notes that 86% of survey respondents felt that their organisation encouraged reporting of errors and near misses, but at the same time, 50,000 felt that workers involved in these types of incidents were not treated fairly.

Another learning point is the importance of belonging. There is a strong correlation between results for the question about inclusion: "I think that my organisation respects individual differences (e.g. cultures, working styles, backgrounds, ideas, etc)" and a question about confidence: "If I spoke up about something that concerned me I am confident my organisation would address my concern". The implication is that those organisations which people feel are more inclusive, are also those where people feel more confident their concerns will be addressed.

The National Guardian says that "When I visit organisations, I ask senior leaders to look at these results, but also to listen to the silence. Who are you not hearing from? Why are you not hearing from them? Are they fearful, disenfranchised, disillusioned? What more can you be doing?"

And, she says, "The NHS may be broken, but by listening to our people, we can begin to fix it".

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

Thursday 12th September 2024  
Monday 2nd December 2024

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

NHS Framework Approved Training

H HEALTHCARE CONFERENCES UK

## Engaging Patients & Families in Complaints

**MONDAY 2 DECEMBER 2024**  
**VIRTUAL, Online**

### *NHS Framework Approved Training*

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

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**

**Virtual Masterclass**  
**Engaging People and Communities in Health**

Tuesday 10th December 2024

Facilitated by:  
Rebekka Francis

H HEALTHCARE CONFERENCES UK

## Engaging People and Communities in Health

**TUESDAY 10 DECEMBER 2024**  
**VIRTUAL, Online**

Join us to transform your approach to public engagement in health and make a meaningful impact on your community.

Unlock the power of public engagement in health with our comprehensive workshop. Whether you're new to this field or seeking to deepen your expertise, this session is designed to elevate your skills and understanding.

**Further information and booking**

**NHS Complaints Summit**  
Implementing NHS Complaint Standards

Thursday 12th December 2024

Chair and Speakers Include:

<b>Ben Wesson</b> Head of Customer Enquiries and Complaints, People and Organisational Effectiveness, IMAC & Member/PSO working group	<b>Al Power</b> Lakson Officer and Steve Haseley Engagement Manager Parliamentary and Health Service Ombudsman	<b>Paula Brennan</b> Patient Safety Manager Gosport Durness & Darlington Acute Hospitals NHS Trust
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H HEALTHCARE CONFERENCES UK

## NHS Complaints Summit

**THURSDAY 12th DECEMBER 2024**  
**VIRTUAL, Online**

This National Virtual Summit focuses on the New PHSO National NHS Complaint Standards which are now being used and embedded into the NHS. Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints are welcomed and lead to change and improvements in patient care. The conference will also reflect how involving people and their families in complaints and integrating the process with the new Patient Safety Incident Response Framework (PSIRF) to ensure patient safety actions and learning.

**Further information and booking**

# Want more training?

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

# Confused?



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

## We can help you with...

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

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

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

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

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

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



# The Patient Experience Library

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.

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