

# Patient Experience

and patient/public involvement in health and care services

Winter 2022



**Patient  
Experience  
Library**

**INSIDE**

**Know I'm here  
Unlocking records**

## Editorial



In June last year, just two days after being appointed Secretary of State for Health and Social Care, Sajid Javid was telling the House of Commons that we must [learn to live with Covid](#).

Six months later, the arrival of the Omicron variant has been a sharp reminder that the Covid pandemic is far from over.

As various levels of Covid restrictions come and go, we need to remember that for some people, those restrictions are more or less permanent. As a heart transplant recipient, Tania Daniels is one of them. On page 3, she offers a glimpse of the “financial, physical, and psychosocial toll of this ongoing quarantine for the immunocompromised”.

People who continue to self isolate need more than “pat advice about masks and staying 6 feet part”. They have lives to lead, bills to pay, family obligations to meet, and health needs to attend to. Tania’s message is simple: “Know we’re here – still waiting to connect fully back into life”.

Cancer Mum (page 4) has the task of “managing the health of a family member with serious health problems”. For her, part of the solution is ready access to health records – and part of the challenge is persistent barriers to access.

This is partly a matter of our rights, as citizens, to our own healthcare data. But for patients with multiple complex conditions, it can also be a matter of life and death. Technical issues can be solved, says Cancer Mum, but “Until the NHS... accepts the patient has a moral and legal right to access their health information there will be limited progress”.

As always, we have been picking through some of the latest and best patient experience research, and summarising it through the rest of this magazine. And we’re always keen to hear from our readers, so if you know of a standout report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

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# Know I'm here

*Tania Daniels*



By now, many of you might have heard about the millions of immunocompromised people, worldwide, who have varying degrees of response, if any, to the Covid-19 vaccines.

We are patients who have weakened immune systems, whether due to a vast array of underlying health conditions, immunosuppressive medications, or both.

My intent here isn't to rehash the eloquent reporting by many excellent science journalists, or to replace the research studies, interviews, and social media posts by the numerous physicians and scientists trying to solve these issues. In short, the current status for us is "get vaccinated, but act like you're not," meaning mask up, social distancing, avoid people whose vaccination status you don't know, and avoid large crowds.

That's a hard thing to accomplish in reality when the rest of the world isn't necessarily following the guidelines.

What I do want to discuss here is the financial, physical, and psychosocial toll of this ongoing quarantine for the

immunocompromised. Many newspapers and media outlets have included interviews with real-life patients that help put faces to an abstract concept, but the consequences are often glossed over.

Financially, many of us still have to support ourselves and our families. Some of us are being told to return to the office, with no options for remote work, if we even had those options to begin with. Paid leaves and some government programs are expiring. Some are dipping into savings and retirement to stay afloat, and many are scared about what this means long-term.

Physically, we all (and by all, I mean the entire world) experienced the toll of staying cooped up for a year, unable to sustain our normal exercise or therapy routines. For the immunocompromised, being physically active, at whatever level is individually possible, is critical for us to stay healthy. Prolonged loss of access to these services can exacerbate our health situations, and loss of access to therapists can create a looping cycle of declining health.

All of this leads to an array of psychosocial issues. The world was reminded in 2020 that we are social creatures, and friends, family, colleagues, and being part of a community is critical to good mental - and physical - health. Although many immunocompromised groups have connected on social media platforms this past year, it can't replace the joy of being in the presence of people we care about, or even general community interactions.

Look, I get it. The first thing we need is for the researchers to figure out how to get us as protected as possible, which so

many are valiantly working on. Pulling apart the complex web of underlying conditions that get someone labelled as "immunocompromised", in addition to the vastly different medication regimens we are on, is a huge task. This is going to take time, perhaps a lot longer than we'd like - especially now that we've seen the speed with which new variants continue to develop.

In the meantime, we need more than pat advice about masks and staying 6 feet apart. We are people, not just protocols. We need to be seen for the whole individuals that we are, with lives of our own, with real bills coming due, family obligations to meet, attending to our own physical and mental health needs. We need an open dialogue with our medical practitioners about this, individualised to our unique needs, and not just an approved statement from a government agency or some healthcare system's legal team.

So my message to policymakers, healthcare providers, employers and anyone else who cares to listen is simple: Know I'm Here.

Know I'm here and know *we're* here. The millions of immunocompromised community members. Hopeful, but waiting to connect fully back into life.

Tania is a grateful heart transplant recipient who runs [9 Lives Health Advocacy](#) on the belief that every patient deserves compassion, empathy, and respect as they manage their unique health challenges.

# Unlocking records

*Cancer Mum: Carer, Writer, Accessible Medical Records Advocate.*  
*I use the @CancerMum Twitter handle to protect my son's identity.*  
[My blog is here](#)

The last few weeks have been a thought provoking time for those of us with a keen interest in accessing our personal health information.

NHS England's report: [Putting data, digital and tech at the heart of transforming the NHS](#) envisages health services accessible on our phones, live booking and scheduling of appointments, and "access to your complete healthcare records".

The Nuffield Trust's [Fit for the Future report](#) describes citizen access to health records across Europe, with cross border systems ensuring seamless mobility. One project allows patients in Estonia to access prescriptions in Finland and vice versa.

Webinars run by the British Medical Journal have provided a global overview of record access, including American laws giving citizens a right of access to their personal health information and making the blocking of access to personal health information an offence.

By contrast, the UK has failed to provide both equitable national access to health records and to address the moral and legal right of access. Despite the General Medical Services Contract requiring all General Practitioners to grant patients prospective access to their digital record from April 2020 many patients are still being refused mandated access. The NHS Digital intention to switch on automatic access for prospective records on the 1st December 2021 has been delayed due to opposition from General Practice.

In secondary care, many medical records remain locked in organisational silos. The introduction of Local Health and Care Records and commercial solutions has introduced an inequity of access across the NHS, with local politics and funding influencing both provision and priority of citizen access.

This matters to our family for two reasons. We want to read the information written about us and correct any errors and omissions. It is our right and we should not need to fight for access. Secondly, managing the health of a family member with serious health problems is difficult when multiple hospital records are not joined up. We need to share information between different hospitals to ensure the right care is given, particularly in an emergency. It could save his life.

But the reality for our family is that we do not have complete medical records. Our digital primary care records failed to transfer repeatedly via the GP2GP transfer system and each family member has less than five years digital health records. Historical paper records are warehoused and not routinely scanned into the digital system.

In addition to these technical disparities, we have frequently encountered cultural opposition to sharing our own health data with us. Our primary care practice refused to grant access to our health records for three years until it was mandated in the terms of the GP contract. We had to quote the terms of the contract to staff before our request was granted.

Accessing secondary care information is equally difficult. Every year a family member has to submit a Subject Access Request to a London teaching hospital. The clinical nurse specialist, the only point of contact, refuses to give copies of new radiology reports and multidisciplinary team (MDT) management plans. The attitude is "it's all fine, you don't need to know anymore".

This year the records team did not recognise the terminology used in the MDT title so the request failed. The request for the information to be returned by secure email was ignored and a parcel containing a file of two years records (not requested) and CD containing multiple radiology scans (not requested) was delivered and left outside our house visible to passers-by. This scenario breaches several of the General Data Protection Regulations (GDPR).

GDPR regulations are routinely flouted by healthcare staff. We have no reporting system to challenge these barriers and information blocking continues. Technical issues can be solved with vision and learning from other countries, but changing organisational and professional culture is more complex.

Until the NHS adopts individual patient-centred care and accepts the patient has a moral and legal right to access their health information there will be limited progress. There is much to do.

## 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)



# A hidden web of influence

This paper looks at how the pharmaceutical industry - and the organisations it funds - interact with Parliament to form part of a multi-layered web of influence. It concentrates on All Party Parliamentary Groups (APPGs), stating that “These informal cross-party groups revolve around a particular topic and... facilitate engagement between parliamentarians and external organisations”.

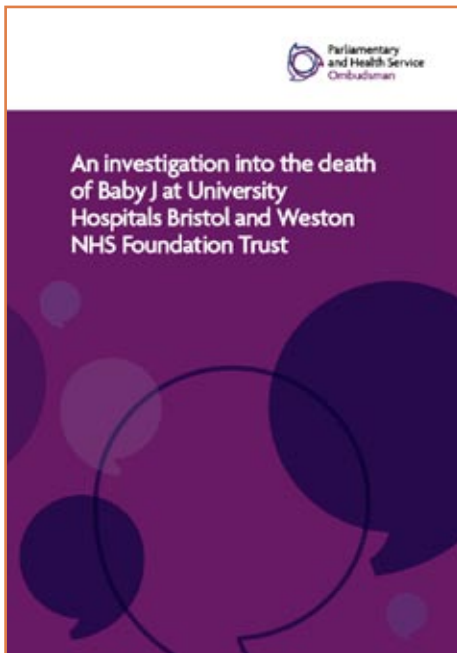
According to the authors, “APPGs do not receive any funding from Parliament, but they can choose to accept payments to cover costs of events, secretariats, travel, reports, and other activities”. Consequently, “concerns have been raised that some corporate interests exploit the unique opportunities for access offered by APPGs, turning them into a backchannel for lobbying”.

The study looked at financial reports between 2012-2018 from 146 health-related APPGs, finding that payments from external donors totalled £7.3 million. Of this, it says, the pharmaceutical industry and industry-funded patient organisations provided a total of £2.2 million. The authors state that their study “shows pharmaceutical industry funding at the upstream stages of the policy process”.

To help manage any conflicts of interest, “transparency must be improved at the level of donors (pharmaceutical industry) and recipients (APPGs)”. The paper points out that “Troublingly, pharmaceutical companies are not required to disclose these payments at all and are therefore missing from Disclosure UK, a transparency initiative”.

In addition, “the payments from patient organisations with conflicts of interest identified in our research suggests that industry might deploy a multi-layered “web of influence” strategy through partnerships with patient organisations”. However, “Regulating these indirect types of conflicts is more complicated than direct conflicts of interest as they are inherently hidden as they do not need to be explicitly reported”.

The authors conclude that APPGs “must go further in ensuring that the public to which they are accountable are fully aware of who funds them, why, and the impact”. Furthermore, “Making this information easily accessible in one place is crucial given the frequent role of industry funded patient organisations in APPG activities, evidenced by their numerous in-kind payments, and the risk that the patient voice might speak with a ‘pharma accent’ when involved in policy discussions”.



## Another bad apple?

Six years ago a baby (called Baby J in this report) died in the care of the NHS in Bristol.

Instead of comforting the parents and explaining what went wrong, staff at the hospital made things worse. Here is what the Parliamentary and Health Service Ombudsman has to say:

- “Doctors should have considered a hospital post-mortem, but they did not do this and did not talk to Mr and Mrs N about a post-mortem.”
- “The Trust’s staff were not open and honest with Mr and Mrs N about the events surrounding J’s death as they should have been.”
- “Immediately after J’s death doctors failed to give Mr and Mrs N important information they needed.”
- “Doctors [said] they had done tests which were negative, when those tests had not been done.”
- “Staff talked about deleting a recording made during one meeting while Mr and Mrs N were out of the room, because it might get the Trust into difficulty.”

The Ombudsman finds that “Mr N and his wife suffered serious injustice in... the way the Trust responded to their questions after J died and in its handling of their complaints.”

These are damning statements. At the same time, we must be aware that the Trust is not a lone “bad apple”. Its behaviour is part of a pattern.

This latest report echoes findings from previous PHSO reports such as *Missed Opportunities*, *Ignoring the Alarms*, and *The Life and Death of Elizabeth Dixon*.

The story mirrors the treatment of patients and bereaved relatives at Mid Staffordshire, Morecambe Bay, Southern Health, Gosport, Cwm Taf, Northern Ireland (Hyponatraemia), Shrewsbury & Telford and East Kent.

Avoidance and denial were also featured in the healthcare system’s responses to the criminal activities of breast surgeon Ian Paterson, and the harms to thousands of women from devices including pelvic mesh.

Our [Inadmissible evidence](#) report looks at the system level weaknesses which are at the heart of these multiple failures of candour and care. Trusts must not escape accountability for fatal errors. But nor must the national bodies which could be offering better support to providers.

# Online feedback - Caring for care



This study opens with the statement that “the number of people who go online to... provide feedback about their healthcare experiences has been slowly and steadily growing”.

The trend is not always welcome: “A key concern expressed by healthcare professionals, especially doctors, is that online feedback is produced by an unrepresentative minority expressing extreme views”.

The authors, however, wanted to know what patients themselves thought. So their study looks at how people who posted online feedback across different platforms in the UK understood the relationship between online feedback and care improvement.

They found that a major motivation for providing feedback was to improve care for other patients and their families. People hoped that their comments would inform healthcare services and result in tangible changes. Feedback of this kind was a form of advice, suggestion or recommendation directed at the service provider.

Alongside this - and regardless of any actual changes made to services - providing online feedback was seen as participation in care itself -- for example, by helping other patients and their families prepare, or by making healthcare practitioners feel appreciated.

People’s feedback practices were shaped by both their own experiences of care and by a strong moral commitment and sense of responsibility towards other patients and service users, as well as healthcare professionals and the NHS itself.

The authors describe this as “caring for care”. The phrase “invokes an understanding of care that is characterised as much by frustration, concern and vulnerability as by love, affection and nurture”.

They say that “People providing online feedback in the context of public healthcare services do so both as patients... and as public healthcare citizens”. Furthermore, “the amount of practical and emotional labour that goes into people’s online feedback practices... contrasts with an understanding of feedback as done quickly or even flippantly”.



# A make or break for digital health?

The announcement of [extra government funding to digitise the NHS](#) must, surely, be welcome. As always, however, it makes sense to dig beneath the headlines.

For patients, adoption of digital healthcare is not just about cash and affordability. All kinds of public attitudes and experiences are in the mix.

This paper sheds light on one in particular: the willingness or otherwise of older people using health-related apps to share their self-collected data.

The first research question addressed the use of mobile devices that enable older adults to track and share their health-related data. It found increasing use of smartphones and tablets by over 65's - showing that many older adults have the tools to use health-related apps. However, use was lower among the over 80's - the age group that would potentially benefit the most from mobile health interventions

The second research question considered levels of interest in health-related apps. This matters because both age and interest in technology are factors in take-up of digital health opportunities. The study found, however, that levels of interest are lower among older people.

A final research question addressed the willingness of older adults to share self-collected health-related data. It found that a considerable number of older adults were willing to share data - but more so with doctors or hospitals than research institutions or health insurance companies.

People who already used health-related apps were more open to sharing their data, as were people with a higher interest in technology, a higher income, and a higher education.

The authors suggest that given the potential for health apps to improve health and behavioural outcomes, there should be efforts to increase health app use among older adults. However, they warn that discussions need to be held around the practicalities of data sharing, as well as around legal, ethical, social, and technical matters. These discussions should include issues such as informed consent, data privacy, data security, and data ownership.

The study finishes by pointing to a need for new models of participant involvement, with the goal of creating a trusted relationship between data providers and institutions working with data.





## Better care for patients and planet

In an NHS struggling with elective care backlogs, staff shortages and winter pressures, health professionals could be forgiven for thinking that the CoP 26 climate conference in Glasgow was not particularly relevant. That, however, would be a mistake.

Previous editions of this magazine have featured reports that have shown how the climate crisis damages population health - with the poorest and most vulnerable, as always, being the worst affected.

In September, for example, 200 health journals worldwide [published the same editorial](#) on health and the climate crisis. It called on health professionals to “join in the work to achieve environmentally sustainable health systems”, and made the point that “Better air quality alone would realise health benefits that easily offset the global costs of emissions reductions”.

The World Health Organisation’s CoP 26 Special Report reinforces the message. It says that health and social justice need to be placed at the centre of climate negotiations, and that the global health community needs to “act with urgency”.

To hard-pressed NHS staff, this might seem like just another burden. But some NHS Trusts are already showing that change is both feasible and beneficial.

Have a look at the great video on [this page](#), where a healthcare worker describes her Mary Poppins electric bike that speeds her along on her daily rounds.

[This video](#) shows how reduction in single use plastics (disposable gloves) became a big selling point underpinning a hand hygiene campaign. It also saved the Trust a lot of money.

[Here](#) we see climate awareness being built into professional training and practice, with benefits for staff, patients and the planet.

The WHO report covers worldwide issues. But it is dedicated to the memory of [a little girl from London](#). Ella Kissi-Debrah died at the age of nine after a series of hospitalisations for severe asthma attacks. The coroner’s ruling recorded air pollution as an official cause of death for the first time.

We can do better. And the Trusts featured in the videos above are showing how.

# Rationality vs complaints



“Mechanisms for raising complaints and concerns often disappoint those who use them, or fail to produce a resolution that meets their expectations”.

So say the authors of this report, who immediately point to one cause of difficulty: the fact that complaints come from highly personalised experiences and motivations, but are met by complaints procedures “oriented towards organisational objectives”. Another way to describe this is as a difference between “communicative rationality” and “functional rationality”.

Communicative rationality is what happens when people engage in deliberation, constructive disagreement, and negotiated consensus. Functional rationality, however, “belongs in the domain of the System”. It enables people to work towards organisational objectives that have already been established, and are not up for negotiation.

In healthcare complaints, functional rationality can lead to a “tangled web of pathways for speaking up, reporting issues, raising grievances, commenting on care and complaining”. Each pathway can have “its own procedures, policies and personnel, as well as timelines and terms of reference, all oriented towards its own, functionally rational objective”.

Straightforward concerns about uncontroversial matters can be well served by such pathways. But for both patients and staff, many concerns are more complex – and when complex concerns are channelled into predetermined pathways, they can become “stripped of meaning”. The overriding goal is “packaging them in a form that could be processed”. Ultimately, “the collection of patient experience data... can become estranged from understanding patient experience itself, preoccupied instead with processing data for its own sake”.

The authors ask what a better way of responding to complaints and concerns might look like. Importantly they do not suggest that existing functionally rational processes should be jettisoned. But they do suggest a greater role for communicative rationality, via processes (independently facilitated if need be) that can allow for a more sense-making response. This, they say, could “ensure that wider considerations were deliberated, rather than being discarded by functionally rational processes that had no means of addressing them”.



# The impact of memory making

Children’s palliative care deals with life limiting conditions in childhood, defined as “A disease or illness for which there is no reasonable hope of a cure and from which the child will die before the age of eighteen”.

This paper states that “The diagnosis of a life limiting or life-threatening condition has a profound and lasting effect on families and poses a huge challenge to lead a normal family life”. Importantly, “The loss of the child encompasses an entire journey into a new life, rather than being a single event”.

Memory making can help families through this journey by continuing, in a meaningful and comforting way, the bond with the child who has died. The process is described as “the creation of individual pieces of art with families [including] Fingerprint pendant projects, memory boxes or the retention of a lock of hair”.

The study asked bereaved parents about their experiences of memory making. Three main themes emerged:

The process of **making the memories** enabled parents to “make the most of precious time”. Some who had not previously considered the concept of memory making “expressed gratitude that the subject was broached, and the opportunity afforded them to create memories and tangible pieces of art”.

The **impact of memory making** was described as “overwhelming” but was also expressed in terms of joy and comfort. One mother described how tangible memories communicate “an invitation to mention her baby son, appreciating that though it is difficult for people it is welcomed”.

Memory making also helped with the **end of life care journey**. It helped parents to deal with “anticipatory grief” and, in the words of one mother, to realise that “her baby’s time was drawing close”.

The findings, say the authors, “demonstrate the importance and the willingness of parents to have the opportunity to create special and precious mementos with their child when time is short”. They recommend these as worthy issues to consider when planning the care of families facing the loss of their child, in order to guide, support and navigate their journey with them.



# Maternity Voices

This report from the Care Quality Commission looks at the crisis in maternity services.

The report is frank. It states that “Issues such as the quality of staff training; poor working relationships between obstetric and midwifery teams, and hospital and community-based midwifery teams; a lack of robust risk assessment; and a failure to engage with, learn from and listen to the needs of local women all continue to affect the safety of some hospital maternity services”.

The latter point about listening to the needs of women is vital. Avoidable harm inquiries into maternity services at Morecambe Bay, Cwm Taf, Shrewsbury & Telford and East Kent have all pointed to a failure to take patient experience seriously.

The report looks at Maternity Voices Partnerships – a key link between maternity services and patients. It finds that working relationships between MVPs and maternity services vary – some are good, others less so.

Where relationships are good, MVPs can help with information materials and public outreach, as well as internal provider matters such as safety reviews. Importantly, they have “direct channels of contact” with the Head of Midwifery, and “felt confident that they would be able to raise safety concerns”.

On the downside, some MVPs felt that their role was not well understood by providers. This includes “the MVP not being involved early enough in the process to give meaningful feedback and the trust being defensive to suggestions from the MVP”.

There are disparities in funding for MVPs, and some MVP Chairs are expected to go above and beyond their paid role. This is seen as “a barrier to women from some communities or groups getting involved, perpetuating issues with a lack of diversity”.

The report calls for “true engagement” with Maternity Voices Partnerships, and says that “local maternity systems need to improve how they engage with, learn from and listen to the needs of women, particularly women from Black and minority ethnic groups”. Crucially, “They also need to make sure that targeted engagement work is appropriately resourced”.



# Lines in the sand

Page 5 of this magazine issue features a paper discussing the hidden web of influence exerted through the funding of All Party Parliamentary Groups by pharmaceutical companies.

This Australian paper picks up similar themes, looking at the extent to which pharmaceutical industry money might compromise the independence of patient groups.

It references a Finnish study showing that 71% of 55 surveyed groups received pharmaceutical company money and a study of US patient groups showing that 83% received funding from drug, device and biotechnology companies.

The consequences can be troubling – for example, “patient groups in the USA that advocated to maintain ready public access to opioids were more likely to be funded by opioid manufacturers than groups that advocated for restricted access”.

Against this background the authors considered the risk of harm to patient groups’ independence and asked what practices and policies are currently in use by patient groups to mitigate such risks.

Study participants described “pressure from pharmaceutical company funders to act in ways that prioritise company interests over their group’s interests”. This raised concerns over independence – however, “there was little consensus around what constituted an acceptable behaviour limit or ‘line in the sand””.

Transparency was another risk area, but “Ways of declaring industry funding were variable, sometimes inadequate. In particular, there was an over-reliance on industry declarations, which may be hard to find, lacking detail or absent altogether”.

Further risks – and mitigations – included “sponsor exclusivity, brand marketing, agenda setting, advocacy partnerships and content of patient group communications and events”. On these, the authors “identified variation between patient groups in where they drew the line between acceptable and unacceptable practices”.

All of this, say the authors, “is part of the increasingly recognised link between industry sponsorship of healthcare stakeholders and outcomes that favour the sponsor’s interests”. This, they say, is “a pattern that is being repeated across clinical practice, medical education, guideline development and medical research”. There is “urgency about identifying and managing financial conflicts of interests in the health sector in order to protect the public’s interests, including their health”.



# Trust and data sharing

“In most health systems at present, the point of care is also a point at which health data are generated.” So say the authors of this paper, who also note that “In some cases, healthcare practitioners are being asked to act as points of contact for the consent or opt out process for data-sharing”.

There is, however, growing evidence of “data-related harms, such that certain groups (e.g. people living in poverty, trans people, and ethnic minorities) face particular threats from...datasharing within administrative, health, welfare, and/or social care systems, including, but not limited to, intensification of discrimination”.

Concerns were most acute for asylum seekers, those experiencing domestic violence, transgender people, offenders, and ex-offenders. The authors remark that “those who are vulnerable to the greatest potential harms and discrimination from data-sharing are already those in society who are most marginalized and disadvantaged”.

The authors are careful to balance their assessment: “This is not to say that people with vulnerabilities do not see the potential benefits to be had in terms of improved direct care”. But the question of control remains: “...even those who have the most positive views of data-sharing do not want others to have unfettered access to data in their NHS records”.

There is criticism of data sharing engagement approaches which propose “hypothetically based trade-off scenarios where risks (privacy violation) must be considered alongside benefits (new drugs being developed)”. This, say the authors, “does not allow a flexible engagement of the participants with the premises on which the trade-off is based”.

The paper suggests that “public engagement work should not be so focused on majoritarian perspectives that it ignores the concerns about potential harms for vulnerable groups. Public engagement can be enriched by careful consideration of the wider context that surrounds the topic of interest and the wider lives of those with whom we seek to engage”.



## Sleep and noise in hospitals

There is nothing new about the issue of noise and sleep in hospital. As long ago as 1859, Florence Nightingale remarked that “Unnecessary noise is the cruellest absence of care”.

Hospitals continue to look for ways to reduce noise at night - recognising that disrupted sleep not only affects patients’ experience, but also their ability to recover well from illness and surgery. Our recently completed literature review for the Royal Cornwall Hospitals Trust sheds light on some of the issues.

At heart is the simple fact that hospitals are noisy places. Sounds come from “conversations between and among patients, staff, and visitors, as well as the sounds of slammed doors, carts that are in need of repair, phones, beepers, buzzers, and paging”. Beepers and buzzers can be unrelenting, with one study detecting 350 alarms per patient per day.

There are practical measures that can be taken: slow door closures can be fitted, foam pads can be added to bin lids, call bell volumes can be reduced.

However, noise is not just a matter of decibels. Those beepers and buzzers might not actually be very loud - but “Electronic sounds were consistently more arousing than other sounds at the same noise dose”. Additionally, “perceptions and tolerance of noise can be very personal”. One person’s background chatter can be another person’s sleep destroying irritant.

Key to noise control is a recognition that “noise does not happen by accident”. One paper notes that disruptive noise “exists only because there are underlying cultural norms that permit and tolerate the disturbance”.

Staff participation is therefore crucial to successful noise control. It should not, for example, be assumed that staff know how to control call bell and alarm volumes. And one study that compared noise control measures with and without staff involvement found that “addition of nursing education and empowerment... was associated with fewer nocturnal room entries and improvements in patient-reported outcomes”.

Ultimately, noise is cultural as well as practical - and “Unless...the accountability for the auditory environment is with the staff, the noise issue will belong to no one”.

## EVENTS

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**H HEALTHCARE**  
CONFERENCES UK

# Patient Involvement & Partnership for Patient Safety

THURSDAY 24 FEBRUARY 2022 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.

This conference will enable you

to:

- Network with colleagues who are working to involve patients in improving patient safety
- Reflect on patient perspective
- Understand how to implement the June 2021 National Framework for Involving Patients in Patient Safety
- Improve the way you recruit, work with and support Patient Safety Partners

- Develop your skills in embedding compassion and empathy into patient partnership
- Understand how you can improve patient partnership and involvement after serious incidents
- Identify key strategies for support patients, their families and carers to be directly involved in their own or their loved one's safety
- Learn from case studies demonstrating patient partnership for patients safety in action
- Examine methods of involving patients to improve patient safety in high risk areas
- Self assess and reflect on your own practice
- Gain CPR accreditation points contributing to professional development and revalidation evidence

### Information and booking

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## Free Zoom event

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# Patient experience and engagement symposium

Wednesday 2 March 2022 9.30am - 1.00 pm

What can we do to strengthen patient experience and engagement in the NHS and the wider health and care system? Who are the key players in the NHS and what do we need to do to empower them to be more effective?

This half day event will discuss the opportunities and challenges, with input from:

- Olivia Butterworth, Head of Public Participation and Improvement, NHS England
- Rachel Matthews, Head of Experience, National Voices
- Keymn Whervin, Associate, Patient Engagement, National Voices
- Laura Sheard, Associate Professor, York Trials Unit

- Meerat Kaur, Senior Public Involvement Manager, NIHR Centre for Engagement and Dissemination
- Hannah Davies, Chief Executive, Healthwatch Leeds
- Helen Mulholland, Engagement Manager, Sheffield Clinical Commissioning Group

Discussion groups will give participants the opportunity to feed in their own ideas and experience. Learning points will be written up to form the basis for further exploration of the opportunities for accredited learning for people involved in patient experience and engagement work.

Information and booking:

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



# 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)

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Experience  
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