

Patient Experience

and patient/public involvement in health and care services

Winter 2019



**Patient
Experience
Library**

INSIDE

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Editorial



We're delighted to kick off our first edition in 2019 with a refreshing blast from the Mighty Casey Quinlan. Tired of hearing empty promises about better record-sharing with patients, Casey devised her own version of an electronic health record via a QR code tattooed to her chest.

We're not recommending that other readers take such radical action! But we see Casey's assertive stance as similar to the [#wearenotwaiting](#) movement, whereby patients stop waiting to be "empowered" and simply take matters into their own hands.

Our other contributors - Jen Gilroy-Cheetham and Leigh Kendall - take their own stances on the need for health professionals to understand what matters to patients.

Jennifer makes the point that "The day to day activities and rituals that are familiar to staff, aren't for the patient". Her request is that staff take the time to make sure patients understand - really understand - what is happening. For Leigh, "Great communication isn't automatic, it's something you fight like hell to achieve". One example is that with death being a taboo topic, staff may prefer to avoid talking about it. But assumptions about patient sensitivities can be disempowering and - ironically - insensitive.

We have some excellent studies and surveys that have been published over the last few months. At the risk of blowing our own trumpet, we have included a couple of our own pieces that were picked up by the Journal of Clinical Nursing and the Canadian think tank, Policy Options. These make the case for an evidence-based approach to patient experience, and suggest ways in which the evidence could be better organised, and therefore better used.

We're always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!

Miles

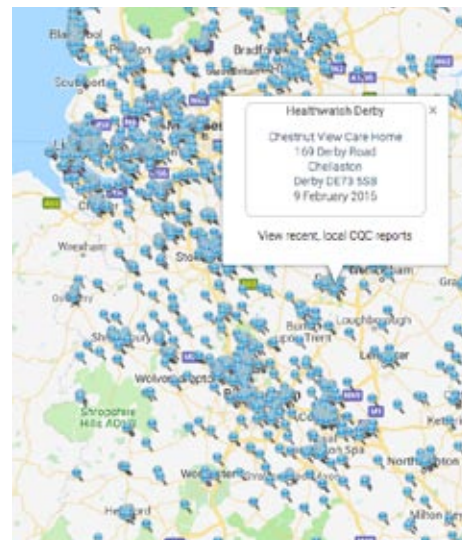
Miles Sibley, Editor

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Free resources

Our [Knowledge Maps](#) offer a quick and easy view of what patients are saying about healthcare services across England. Feel free to click and browse at will!



Spread the word about patient-centred care with our [posters](#) for offices, wards, meeting rooms and waiting areas. The quotes are from sources such as the Berwick Review and the Francis Inquiry - so as well as being visually striking they're also on solid policy ground!



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

Tattoo You

Casey Quinlan – known as [Mighty Casey](#) online – calls herself the comedy health analyst, on the theory that you should stop screaming, laughing hurts less.



I used to say that I'd happily get a barcode tattooed on my neck if it meant I'd never have to fill out another ****ing health history form in a doctor's office.

Paper records are so ... 19th century. 21st century health care certainly must involve a lot of easily-shared data, with health history and diagnostic information travelling literally at light speed between doctor's offices, hospitals, and clinics. Not only does it speed care, it can ensure safety: the right record, with the right patient, makes the right care clear.

A while ago, I had a V-8 forehead slap moment, realizing that a QR code would be a great way to accomplish my objective. QR code reader smartphone apps are in relatively common use, and I also figured that a tattoo would be a conversation starter in the rooms where I work to shift the medical-industrial complex's thinking on patient engagement and participatory medicine.

Even though it took me over six months to find a tattoo artist willing to do this – and then another couple of months to gather the shekels to pay for it, I finally presented myself at Graffiti's Ink Gallery for my inkapalooza.

This was not my first tattoo rodeo. I had done what I thought was required due-diligence in researching the size and pixel resolution on the QR code itself, and had had a couple of meetings with the artist to make sure we were on the same ink dot. I created a page on my website, password-protected it, created a QR code that linked to that page, and we were good to go.

On the web page, after you plug in the password that's inked at the bottom of the tattoo, you see my Microsoft Healthvault record, including my full health history, medication record, allergies, emergency contact, primary care info and insurance info. You can also get my living will.

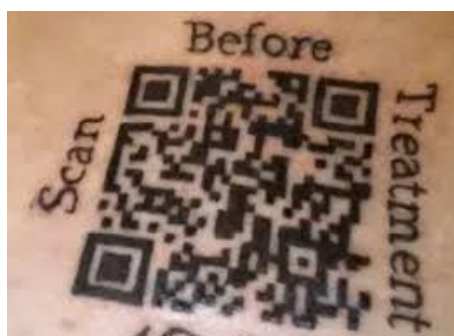
I think I scared the artist-kid during the actual tattooing process, by the way. For the uninitiated, getting a tattoo on a bony part of your body – in my case, the sternum – can hurt like a mother. I knew going in that this would be

ouch-y, but at [redacted] years of age, after navigating cancer treatment and other slings and arrows of outrageous medical fortune, tattoo ouch-ies ain't a thing in my world.

The artist had, I discovered later, booked out 3 hours, figuring that I'd be asking for frequent breaks due to the pain. I didn't stop him once, and he finished up in just over an hour. He looked at me like he was waiting for me to eat some broken glass, or a couple of razor blades. Again, given my time on the planet and my life experience, 60+ minutes of having my sternum hammered by a tattoo needle wasn't a big deal.

Why did I do this? Because I've been waiting for the medical-industrial complex to deliver on their promise of health information exchange, the promise that they've been making for years, but have yet to fork over. I can securely move money around the globe at the click of a mouse. But my healthcare record – which is MINE, as much as it is the property of the medical providers who gave the care it describes – is in fractured bits and pieces all over ever'where.

So I rolled my own, and nailed it to my sternum. Any questions?



Stuck in a room

Jennifer Gilroy-Cheetham

Jen works for the [Innovation Agency](#) and blogs her personal patient story [here](#).

Twitter: [@gilroy19](#)



It's easy to forget how significant time is when you're not in a hospital bed. For a patient, time is everything. The time you wake, the time you have your breakfast, the time you're due to have your scans or others tests - and of course visiting time.

When I became a patient I realised I had forgotten how we focus on time. It's hard to understand this until you become that patient in a room, waiting and watching the clock.

Hospitals are not the most interesting of places and rightly so, their main purpose is to help, heal and cure. But as a patient, waiting and wondering, a conversation with the domestic or the nurse who is generally offloading her frustrations is a distraction which helps time to go quicker.

Obviously there are times when you don't feel up to conversation but when you are, knowing there is a team ready for you makes you feel supported, and feeling supported helps you feel safe.

...when you're the patient, especially when you're not familiar with the ward environment, what goes on around you can be daunting and very scary

In the NHS we talk about safety culture but seldom do we ask patients about what makes them feel safe, what makes them feel that the wards, clinics and services they attend are supporting them and putting their safety first.

For me it's about the skills and actions demonstrated so well by the staff on the ward where I've spent a total of six weeks in the last year. A startling contrast to a ward where I spent a horrendous bank holiday weekend.

That weekend, what made the difference may just have been my own perceptions, but when you're the patient, especially when you're not familiar with the ward environment, what goes on around you can be daunting and very scary. For example:

- The day to day activities and rituals that are familiar to staff, aren't for the patient.
- It's easy for staff to vent their frustrations (for example with IT) and not necessarily understand how this externalisation of emotions can affect a patient.

- As a staff member I'm sure that jargon is important, but as a patient when I hear it, I may not know what you're talking about.

My plea to NHS staff is that they take time to make sure the patients feel safe. That means making sure we understand - I mean really understand - what is happening. I might nod my head when you tell me things but I may not want to admit I've no idea what you've just said or what is going on.

People don't plan to get sick, most would rather be at home. If there are ways in which you can make their experience more positive by having a conversation, introducing yourself, showing a smile or by using less jargon, please do.

In the NHS we talk about safety culture but seldom do we ask patients about what makes them feel safe

Great communication isn't automatic

Leigh Kendall, writer and patient leader, *Headspace Perspective*



I recently had the privilege of speaking at a prestigious national conference about the campaigning I have been leading about improving communication in health services.

For the past four years in my son Hugo's memory, I have been striving to raise awareness of the importance of effective communication between patients and staff. My aim is to improve safety and experience, and to get better provision of services to support bereaved parents.

I spoke about how dedicated staff saved my life from a rare, life-threatening pregnancy complication, and gave Hugo the best chance of life. But I also explained how poor communication on many occasions made difficult situations much worse.

One example was the dismissive response to my complaint about staff in adult intensive care who refused to make arrangements for me to see my dangerously-ill son in neonatal intensive care (NICU).

I asked for a face-to-face meeting with senior staff on the ward and explained the impact of their actions. In essence, the intensive care staff did not understand the needs of a new mother: it transpired that while other women had experienced similar difficulties, no one had given them feedback about it before. As a result of the conversation, there is now better awareness of the needs of other new mothers, and better communication between that ward and NICU.

During my presentation, I shared other examples of fighting to get my voice heard: with death being a taboo topic, many prefer to avoid the topic for fear of causing offence, or saying the 'wrong thing'.

A particular example is the exclusion of bereaved parents from the neonatal and maternity CQC surveys because it has been on the "too difficult" pile. This is unacceptable because of the loss of valuable intelligence about how to improve services, and save lives. I presented a paper about this to the All Party Parliamentary Group for Baby Loss at the House of Commons last year.

Thankfully, attitudes are now changing: the CQC is looking at ways to seek the views of bereaved parents, and the [National Bereavement Care Pathway](#) is doing a fantastic job helping health professionals support families after the loss of a baby.

My background has helped: I have worked as an NHS Communications professional for a number of years. As

such, I understand how 'the system' works, and I speak fluent NHS. In addition, I am white, middle-class and articulate. Even so, I have had to fight to get my voice heard. We need to ensure the voices of those in seldom-heard groups are heard, too. Seldom-heard means those less able to advocate for themselves, for whatever reason.

We need to remember that without clear, open, honest, inclusive communication greatness doesn't happen.

In the panel discussion after the session presentations, I was asked what advice I would give to hospitals to involve families in investigations where things had gone wrong in maternity care.

My advice was to proactively engage with families. There is no "one size fits all" answer, but by showing patience, kindness, and compassion; through being honest and open families and health professionals can work together.

Health professionals need to involve families in a way that is relevant to them - to ask what matters to them, truly listen to the answers, and act accordingly. This is the way all voices can be heard, and patient safety and experience improved.

Great communication isn't automatic, it's something you fight like hell to achieve.

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



Speaking up in the ICU

Intensive care units (ICUs) are places where “*stakes are high and time is compressed*” according to this study from America. So the ability of patients and families to voice concerns may be of more pressing importance than in other care settings.

The paper opens by rehearsing some familiar arguments about why people need to feel comfortable in asking questions or raising concerns. These include understanding the risks and benefits of care, and consenting to treatment on the basis of informed choice. Safety is a factor, as “*families – vigilant stakeholders – may be the first to detect a change in a patient’s clinical status*”. And families can help to ensure continuity of care as medical team members come and go.

All of this “*may be particularly important in the intensive care unit , which provides high-intensity, high-acuity, error-prone and preference-sensitive care*”. But, say the authors, “*voicing concerns in the ICU can be problematic for patients and families: the physical environment may be perceived as strange or dangerous, patients are at high risk of death, power asymmetries are extreme, multiple clinicians and teams are involved, and the complexity of care may be overwhelming*”.

The study appears to be the first to address family comfort with speaking up in the ICU. And worryingly, it found that 50%-70% of patients and families “*expressed hesitancy to voice concerns in real time about some common care situations with safety implications, including a possible mistake or mismatched goals related to aggressiveness of care*”.

The authors sort patient-perceived barriers to speaking up into three types: mechanistic (how to do it), contextual (team is too busy) and cultural (fear of being a troublemaker).

Their conclusion is that “*Educational strategies should include both encouraging and supporting patients and families to voice concerns with clear steps and a genuine invitation, and preparing clinicians to respond meaningfully when patients speak up*”.



Autism: Families speak out

Despite growing awareness of autism, parents of children with the condition have not always been well-served. MPs have described waiting times for treatment as “*scandalous*” and the *Southern Health debacle* has been a low point in the clinical treatment of vulnerable patients and the moral treatment of bereaved relatives.

So this report from Healthwatch Norfolk is a timely contribution to the debate, and a reminder of why – from the point of view of families – there is a need for change.

The study found that some families felt that once they were “in the system”, the service they received was good. But “*many described the continuous fight they had to undertake to get the right support for their child*”.

The challenges they faced included the following:

- There is frustration amongst parents about the long waits they experienced to access health and social care services including an Autistic Spectrum Disorder (ASD) diagnosis.
- Families felt that professionals did not understand what it was like to live with ASD – physically getting to an appointment could prove a challenge.
- Parents stated the need for reasonable adjustments to be made in health and social care services, with particular regard to waiting rooms in clinical settings.
- A lack of communication led to parents often feeling forgotten due to the considerably long waiting times they experienced and not knowing where they were in the process.

Some parents also saw a need for more support to wrap around the wider family unit, including the autistic child’s siblings.

The report’s focus is the experience of families in Norfolk, but its findings will echo with similar families right across England. Equally, the recommendations are aimed at health services in Norfolk, but should be read by commissioners and providers elsewhere – and, indeed, by NHS England.



Just one thing after another

It is well known that one of the big challenges to our healthcare system is the increasing number of people living with long term health conditions. This is one of the key factors propelling health and social care towards greater integration of services, and towards initiatives designed to help people “self-manage” their own health in their own homes and communities.

The drive towards self-management is not without risk, and some commentators consider that it could *place additional burdens on patients*, rather than empowering them.

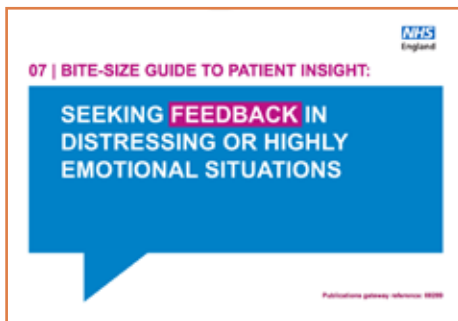
This report from the Taskforce on Multiple Conditions is a welcome addition to the literature – not least because it takes an ethnographic approach, as opposed to exploring clinical perspectives and interventions.

The report’s key question: *“What is it really like to live with several long-term conditions that can be managed but not cured?”* is explored through ten in-depth interviews. The interviewees represent a range of demographics and locations across England.

The authors make the point that *“many people... seeking support with one condition are also living with other conditions and too often experience siloed, condition-based, care and support”*. It also notes that *“The point at which each person goes from one to many health conditions... seems to track issues of deprivation, culture, lifestyle and place”*.

The report concludes that three basic principles – mobility, active involvement in care planning, and regular goal-setting – are fundamental to helping people with multiple long-term conditions to achieve a good quality of life.

“Patient experience” work often concerns itself with people’s access to, and satisfaction with, services. This report, by contrast, starts with the person rather than the service(s) they use. The result is a person-centred view of patient experience – and a useful set of insights.



Emotional feedback

The last edition of our [Patient Experience magazine](#) opened with the observation that one of the biggest make-or-break factors for quality of patient experience is “communication”.

With impressive timing, NHS England promptly released a new guide on how to seek feedback in distressing or highly emotional situations. It recognises that talking with people in these circumstances is not easy. *“People who experience distress may become quiet and reserved, or on the other hand might become angry and confrontational, and these scenarios can make communication a challenge”.*

The guide considers the ethics of asking people for feedback when they are very upset – for example after a bereavement. Might questioning them at such a time be intrusive, or make them feel worse? Conversely, it considers the ethics of not helping people to talk about their experiences – of effectively excluding them from a process that should be open to all.

They may be no simple answers to these questions. But the guide considers matters such as timing, methods, and people’s capacity to discuss their experiences – especially if they are both unwell and distressed.

As always, it is crucial not to treat feedback as a tick-box exercise. The guide makes the important point that feedback *“is a way of creating a humanising atmosphere and improving relationships between everyone involved”.*

Conversations with people who are angry or upset may not be comfortable. But we are reminded that people *“feel that sharing their experience can help improve the experience for others”.* And in some situations, *“the opportunity to provide feedback can be a way of intervening before frustrations boil over, or can form part of the healing process”.*

The document adds to the [Bite-Size Guides](#) series, some of which we have featured previously, and all of which provide useful summaries for busy practitioners.



Health care can't be patient centred without evidence

Regular readers will know that the Patient Experience Library is committed to evidence-based practice in patient experience work. We were pleased to see our message being picked up recently by an influential Canadian think tank and by the Journal of Clinical Nursing (JCN).

Our starting point is that if the NHS wants to be patient-centred, it has to understand patient experience. And that means it has to work from the evidence.

That may sound obvious - but it is easier said than done. Patient experience evidence is published across hundreds of different organisational websites, all of which are designed and structured differently, and some of which are not well maintained.

Even dedicated patient experience teams can find it hard to keep up - and the problem is that if you can't find the evidence, you can't act on it.

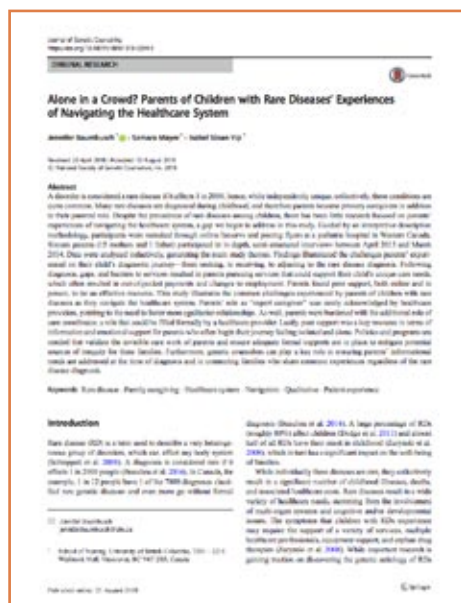
We built the Patient Experience Library to tackle that problem, reckoning that if clinical research databases are feasible, why not a patient experience research database?

Our JCN article, written with colleagues from the universities of Exeter and Brighton, develops the theme further. It describes how we tracked some of the policy drivers for patient experience work, and looked at how healthcare organisations have tried to turn policies into practice.

It is clear that serious efforts are being made to hear the patient voice. But in seeking to meet the call that 'something must be done', the system has created an avalanche of patient feedback. Again, a comparison with clinical work is instructive. Clinicians, too, have to deal with huge quantities of information. But they have management information systems that help them make sense of complex data. They have clinical databases that make research accessible and searchable, and they can look up clinical guidelines that help them remember key practice points.

We argue that a rethink is needed on how we tap into patient experience. A rethink that takes account of these challenges and acknowledges the possibility of unpalatable answers which may disturb, or at least question, the current balance of power between organisations, professionals and patients.

Alone in a crowd



Rare diseases affect fewer than 1 in 2,000 people. But while individual diseases might be rare, there are considerable numbers of people within the population as a whole who are living with a rare disease.

Around 80% of rare diseases affect children, and almost half have their onset in childhood – so this Canadian study turns its attention to the experiences of parents whose child has a rare disease.

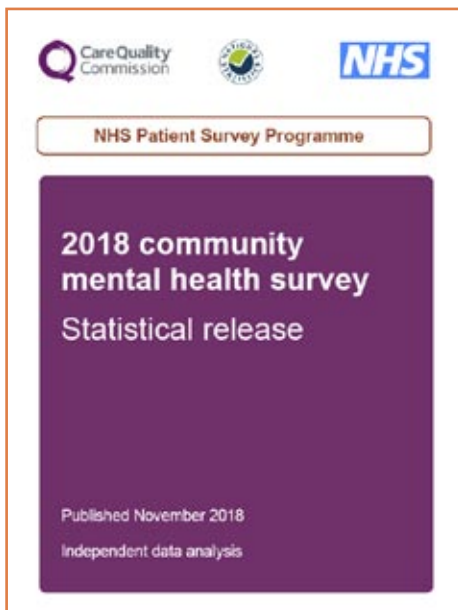
The study found that parents shared common experiences of navigating the healthcare system – despite the uniqueness of their children's diagnoses. Main themes were “the diagnostic journey”, “seeking and accessing services”, and “peer support”.

For diagnosis, parents described a complicated experience, with numerous doctors' appointments and persistence in their pursuit of a definitive diagnosis for their child. But receiving a label or diagnosis was not the same as receiving help. Many parents felt that they were left with the responsibility of figuring out their next steps, and adopting the role of care coordinator. Given the complex health needs of their children, most families had interactions with many specialists and health services. A common experience was the lack of formal care coordination and communication between healthcare providers.

Parents also spoke about the barriers they faced in accessing services. Sometimes the processes they had to follow were challenging to understand and could create contentious relationships with healthcare providers. Accessing services also led to employment changes for some parents. One reported missing months of work and leaving the workforce due to her child's hospitalisations.

Peer support from other parents of children with rare diseases emerged as a key resource. Even though most children had unique diagnoses, parents found that their experiences of navigation and coordination of healthcare services were similar. Social media was considered a good way to connect because their children's intense care needs often meant parents were not able to attend groups in person.

The paper concludes that “the broader research mandate about rare diseases must move beyond diagnostics and treatment to address the very real and pressing issues that arise from the patient – and by extension family – experience in navigating healthcare systems”.



Parity of esteem – not yet

At the start of 2017, Prime Minister Theresa May announced that *it would take years to improve mental health services*. What she didn't say was that services would get worse before they got better.

Evidence of worsening quality comes from the Care Quality Commission's national patient survey for community mental health services, which shows that patient experience has deteriorated across several areas.

In some areas, this represents a continued negative trend, with a consistent decline in results since 2014. In other areas, the results declined significantly this year, having remained relatively stable between 2014 and 2017.

The news is not all bad. There has been a steady improvement in people's awareness of who to contact out of office hours when having a crisis. And better than average experiences were identified for people diagnosed with a psychotic disorder. Against this, though:

- Only 43% of respondents had 'definitely' seen NHS mental health services enough for their needs in the previous 12 months.
- The percentage of respondents who "definitely" felt that staff understood how their mental health affects other areas of their life had decreased.
- People's experiences of how services plan their care are at their lowest point since 2014.

As far as overall experience is concerned, 71% of respondents felt they were "always" treated with respect and dignity by NHS mental health services. This compares with 82% of adult inpatients in acute hospitals (physical health), who felt they were "always" treated with respect and dignity. It seems that "parity of esteem" is still some way off.

To see the survey results for your local area, visit our [Patient Experience in Trusts](#) map



The overwhelming nature of patient feedback

“All feedback collected ideally needs to have the ability to be meaningfully used by those providing frontline care. Otherwise, it becomes unethical to ask patients to provide feedback which will never be taken into account.”

So say the authors of this paper, which visited three hospital sites to ask “*what is impeding the use of patient experience feedback?*”

It might come as no surprise to hear that “*the most striking element is the overwhelming nature of the industry of patient experience feedback. Ward staff... reported feeling overwhelmed and fatigued by the volume and variety of data that the Trust collected*”.

Difficulty in managing the sheer volume of feedback was compounded by other factors including:

- layers of hierarchies and bureaucratic processes surrounding data collection which were said to be to be confusing to staff and patients alike.
- not enough staff or appropriate expertise... to be able to work effectively to produce meaningful conclusions from the data they received.
- fractured and disparate teams [who] struggled to make sense of the data or to be able to assist ward staff to do so.

Furthermore, “*timeliness was seen as one of the main concerns with it being difficult to engage ward staff with data that are not real time. A specific example of this is the NHS Inpatient Survey where patient feedback is viewed months after it has been collected*”.

These practical barriers to making use of patient experience feedback sit alongside a cultural barrier within the hospitals that were studied. “*Patient experience was sometimes said to be the poor relation of patient safety and finance with a lesser emphasis and priority placed on it.*”

According to the paper’s authors, “*The participants interviewed for this study nearly all saw an immense value in patient experience feedback, and most believed it should receive a high priority at a strategic and Trust board level*”.

However, they “*largely seemed powerless to prevent the tsunami of ongoing data collection*”. They know that “*staff find interpretation of data sets difficult or impossible... but there was no strategy in place or forthcoming at any of the three organizations we studied to address this issue*”.



Hot spots and blind spots

This paper tackles similar issues to the one shown above (page 13), but with a specific focus on complaints data.

It makes the point that complainants are often motivated by the desire to “*correct an ongoing problem or prevent recurrence*”. Importantly, they can have “*valid information that the institution does not know or has failed to take sufficiently seriously*”. However, “*The use of health care complaints to improve quality and safety has been limited by a lack of reliable analysis tools and uncertainty about the insights that can be obtained*”.

The solution, according to the authors, is to develop data-driven approaches to understanding and learning from complaints. The method involves focusing on three key areas: harm hot spots, near-miss hot spots, and institutional blind spots.

Hot spots of serious harm were safety problems during examination, quality problems on the ward, and institutional problems during admission and discharge. Near misses occurred at all stages of care – and the authors found that patients and family members were often involved in error detection and recovery.

One type of “blind spot” is hospital discharge, where transfer of care, sometimes involving multiple services, can lead to errors which may go unnoticed by providers while being obvious to patients. Crucially, “*the more stages and staff groups a patient trajectory entails, the more likely that the patient is the only person who was present for each encounter. Accordingly, health care complaints are particularly suited to providing insight into continuity of care issues*”.

Unusually, the research did not confine itself to simply exploring the issues. In this case, the researchers went further – developing an analytical tool and testing it in the course of the study. Healthcare providers wanting to get a better understanding of complaints would do well to take a look at it.

The authors conclude that “*health care complaints provide added value because they are patient-centred, focus on problematic care episodes, and provide an end-to-end account of care that includes concrete details not captured in incident reports or case reviews*”.

NHS England is promoting a series of courses for patients, public and professionals on topics relating to patient experience and patient public involvement.

Examples include:

- Empowering citizens and patients to participate
- NHS England Patient and Public Voice (PPV) Partners' Induction Webinars
- Developing patient and public participation skills and understanding
- Understanding the value of engagement
- Measuring the impact of engagement
- Planning your engagement activities

[Further details can be found here](#)

A Problem Shared: Patient Experience Network with MES

30 January 2019

This event will be free to attend and will focus on two of the challenges we often hear our members face:

1. 'Keeping the energy of Patient Experience going' - avoiding burnout, being resilient, being valued; together with how to avoid going into 'auto-pilot' and how to avoid becoming part of 'the industry'
2. How to get Patient Experience into the Board Room and on a par with finance and quality, moving from being merely an agenda item to driving real interest and passion at the board level and an ambition to improve

The day will include a mix of presentations, round table discussion and thought leadership on these key topics with the intention of giving participants food for thought and new ideas to take back to the office.

Places are available on a first come first served basis and can be [booked here](#).

If you have any questions please get in touch - we can be reached on 07811 386632 or e-mail us on info@patientexperiencenetwork.org

Foundations in Patient Experience

Following the success of our Foundations in Patient Experience course, we will be running a new course in April 2019.

The course supports the following learning objectives:

1. Help people working in patient experience and engagement fully understand their responsibilities and work strategically as leaders in their field.
2. Strengthen knowledge of research evidence, its relevance to patient experience, to other patient and organisational outcomes.
3. Understand the historical and policy context for patient experience and efforts to improve it in the UK and internationally.
4. Strengthen the personal impact and effectiveness of students, confidence in role, skills in sense-making, influencing and collaborative working.
5. Increase confidence in understanding, analysis and use of different types of data on patient experience.

The course is structured into four modules. Total fees for the course, including learning materials and the residential, are £1400. The course is CPD-accredited with each module the equivalent of 8 hours of learning. Students may obtain The Point of Care Patient Experience certificate by submitting a piece of written work.

We welcome applications from people working in patient experience within the NHS, Patient Advice and Liaison Service or third sector organisations concerned with patient experience.

If you are interested in taking part, [please see details here](#).

The Patient Experience Library

We are the national evidence base for patient experience and patient / public involvement. We have collated and catalogued over 50,000 reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

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