

# Patient Experience

and patient/public involvement in health and care services

Autumn 2020



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**INSIDE**

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I once sat in a meeting at which NHS staff were discussing the possible closure of a community hospital. They knew the proposal would be controversial, and that the planned public meetings would be fully attended. The advice from the communications lead was “Make sure you stick to the facts. Take the emotion out of it”.

I was troubled by that. Healthcare, after all, is emotional. The people attending those public meetings were likely to be older people in need of nearby care. The hospital was a much loved local institution for which many of them would have fundraised, where many would have been looked after, and where some would have worked.

Their loyalty to the hospital came, for this postwar generation, from a deep understanding of the importance of high quality healthcare for all. Of course they were emotional.

In this edition, our contributors speak from personal experience, and do not shy away from the emotional aspects of healthcare. Lynn Laidlaw (page 3) outlines her journey from illness to eventual diagnosis and on into medical research. It is, she says, “the emotions that stand out”. She wants to think about how we translate both positive and negative emotional experiences into learning to improve all co-production and involvement.

Francine Buchanan (page 4) describes “the overwhelming sense of lack of control or dread that I feel when walking into an emergency room”. Part of her response is to take detailed documentation which, she hopes, will give her some credibility when talking with clinicians. She recognises a power imbalance in the professional-patient relationship and suggests that power cannot be afforded to patients until their expertise, born of personal experience, is recognised and understood.

Lesley Goodburn on page 5 talks about the shock of her husband’s sudden death from pancreatic cancer. The staff she encountered did not seem to see the vulnerable, frightened couple before them and so were unable to relieve their emotional and psychological suffering. So Seth’s legacy uses drama to help health professionals gain insights that they might not pick up from less “emotional” forms of communication.

As always, we also bring you our top picks of the latest and best in patient experience research, with handy summaries of the key points. 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

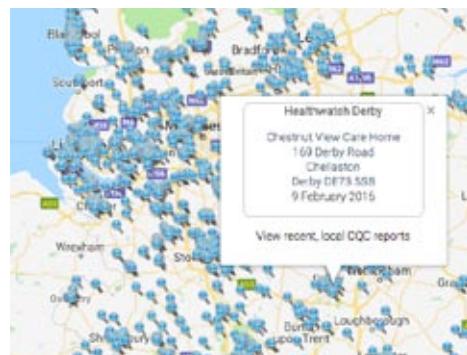
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[www.patientlibrary.net](http://www.patientlibrary.net)

## Free resources

Our one-click [surveys and feedback tool](#) gives every NHS Trust in England instant access to all its patient experience data, all on one page. A cross-referencing function gives a quick and easy overview of common themes emerging from different datasets.

Browse the map, select your Trust, then click and collect!



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](mailto:info@patientlibrary.net)

# Diagnosis to involvement: an emotional journey

Lynn Laidlaw, Patient Partner



My life changed just over seven years ago when I became unwell and started a four year diagnostic odyssey, eventually being diagnosed with a rare, auto-immune, rheumatic disease.

I emailed doctors and researchers, travelled around the UK, pushed for answers and refused to give up. My odyssey was emotion filled, from anger and despair, to hope, and gratitude to my family for being on the journey with me. Eventually I managed to get a diagnosis and effective treatment and I came to terms with my experience.

It prompted my interest in medical research and involvement. I used all the research I could access, but much of it was behind paywalls or written in technical medical language. When I thought about what was important to me, I saw that often research didn't reflect these priorities. No-one wants research to succeed more than people living with medical conditions - surely involving people and their unique insight could help?

So began my second odyssey, into involvement and co-production. It has proved strikingly similar in terms of travelling, emailing, advocating for involvement and refusing to give up. It took much hard work and effort, emotional and practical, to become involved to the extent that I am now with many different projects and learning more about co-production.

Reflecting on my odysseys, it's the emotions that stand out: the high of being involved in a research grant application, the joy of a consultation with a healthcare professional who understood, the feeling of self-worth that I can contribute. It's fantastic when everything comes together, and people collaborate to ensure research meets everyone's needs.

I have reflected that involvement and co-production mirrors published research, in that we mainly hear about the positive outcomes. Much research is never reported yet can we not learn from things that haven't gone so well? Is the system reluctant to acknowledge the learning potential from failures? All forms of involvement can have both positive and negative impacts on those involved, but issues of unequal power and agency that lie at the heart of medical research often go unchallenged. We need to acknowledge potential emotional harm.

Increasingly I am questioning whether my involvement efforts are worth it, whether the many emotional highs compensate for the crushing lows. I can't get involved until someone

chooses to involve me, I don't always have control over the terms of my involvement and often the time and effort I invest is barely acknowledged. It's an ongoing, internal debate but involvement MATTERS so much it's difficult to walk away.

I have been having this debate with different people on platforms such as Twitter. It can be wonderful to see my experiences reflected by others, but the downsides include the limited ability to express complexity and nuance. Questions and frustrations at systemic issues can be read by people in different ways, leading to emotional harm. We are involved because of our lived experience, and the nature of that, including the emotional labour, means the process of involvement is underpinned by passion and emotion. Does this cause unintentional clashes, even amongst those who are working towards the same goal?

How can we translate both positive and negative emotional experiences into learning to improve all co-production and involvement? It's challenging to remain unemotional and so completely balanced when this is fundamentally about personal emotions. I want to try and kick start conversation and debate, concentrating on critiquing and fixing the system. I hope that others would like to join me.

This is an edited version of an original blog by Lynn Laidlaw, published by the UCL Centre for Co-production in Health Research

# Expertise: What is it? Who decides?

*Francine Buchanan*



Our health care system is filled with experts in surgery, pharmacy, community care and social work, but it lacks anyone focused on the dark corners where all these areas intersect. It is in these dark corners that I find myself hanging out, and where I have to find the solutions that no one else seems willing to.

I am a caregiver to a son with complex medical needs. Our family has learned how to navigate life in these dark corners, outside the hospital where we use machines you find only in an intensive care unit: a ventilator, pulse oximeter, a feeding pump and oxygen tanks. Whereas medical experts know how these machines sustain your life physically, many lack the experience of troubleshooting a ventilator malfunction while on public transport.

This is a form of mastery gained exclusively from hands-on experience – an experience few health care

professionals have had. As a caregiver to a son with complex medical needs, I possess a level of knowledge few people do.

Does the knowledge I have gained fulfilling my role in these intersections endow me with expertise? If not, why do I feel the need to be considered an expert? I own a vehicle, but don't feel the need to become a mechanic. However, when it comes to health care, patients and caregivers everywhere are pushing for expert status. What is the driver?

One reason may be the sense of powerlessness that comes with interacting with the health care system, the overwhelming sense of lack of control or dread that I feel when walking into an emergency room.

What has made those ER interactions more bearable is the paperwork I bring with me documenting past interactions with medications, complications we have experienced, and notes from prior doctors on my son's treatment plans. That paperwork is my backup, my evidence, my knowledge for all to see. I hope that it shows others that I have some credibility, so that when discussing my son's condition with the experts they listen to me. I think it is this credibility, power, and voice that patients and caregivers crave when we look to be seen as "experts."

Within children's hospitals, there are disease specialists, technicians trained on specific diagnostic tools, child life experts, nurses and administrators. Each is considered an expert in their job and not seen as a "non-expert" by anyone.

Maybe it is the system that surrounds them – bosses evaluating them, metrics and surveys measuring how good a job they are doing. Maybe that is what is missing from the patient world – we just don't have anyone giving us grades, or giving us letters after our name. There isn't a system in place to assess the knowledge patients and caregivers attain from their lived experience, or to support us in developing our expertise.

By arguing the question of whether patients and caregivers are expert or not, are we missing the point that the idea of expertise is just a substitute for having power, credibility and a voice at the table? I am not sure power can be afforded to us until the value of our area of expertise – the patient experience – is truly recognized and understood.

There are many barriers to patients and caregivers gaining expertise. Being told we are not capable of achieving it because of who we are and our circumstances should not be one of them.

Francine Buchanan is a mom and primary caregiver to an amazing little boy who is thriving with complex medical needs. When she isn't watching or playing baseball with her family, she is a PhD student at the University of Toronto studying physician/patient communication. This article is an excerpt from a [longer article published in Healthy Debate](#).

# Seth's legacy

*Lesley Goodburn, Patient Advocate*



Experience of care is shared every day, in a myriad of ways. The common thread is usually that people have something to compare their experience against. Something that is familiar, that provides an internal measure for their perception.

There is one exception to that premise and that is palliative and end of life care.

For the person who is dying this experience only happens once: at a most vulnerable time, so it's important to support the person and their family to define what is important to them, to really listen, understand and then take action. To be compassionate.

In 2014 my life was good. I was married to Seth and we had everything to look forward to. We were celebrating our 10th wedding anniversary and we booked the trip of a lifetime to China. For a couple of weeks Seth seemed lethargic, to and fro to the GP; he was eventually referred to A&E. The next day he was told he had late stage pancreatic cancer and he died 33 short and heart-breaking days later.

Our experience of the care we received was varied and although in some respects we got the best possible medical care our pastoral, psychological and spiritual care was patchy. Why? Because no-one was asking the important questions, then really listening, and responding to them. As a result, Seth died in an acute hospital when he wanted to be at home.

Six months after Seth died, I began to write about what happened on each of the 33 days and also found myself writing letters to healthcare professionals explaining what it felt like on some of those days. But 8 months after sharing, no-one came back to me and nothing changed.

Sharing our experience did not prompt action.

Undeterred, 2 years after Seth died, we launched [Seth's Story - Homeward Bound](#) a play, a film and educational resource for use by health and care professionals to reflect on their compassionate practice. Using drama to tell our story had a profound effect: prompting reflection on practice and real changes to person and family centred care.

To understand and act on experiences of care at the end of someone's life you have to have important and courageous conversations about the disease and what's happening, what's important to the person and their loved ones, what they are afraid of and what they might trade to achieve their goals.

Sadly, Seth and I were not supported to have these conversations. Instead

we were surrounded by people who wanted to intervene, who wanted to try and stave off death for as long as possible. People who did not see the vulnerable, frightened couple before them and who did not hear their voices, who did not act with compassion to relieve our emotional and psychological suffering in the same way as they relieved the physical pain.

When Seth was diagnosed, he asked me to share our story to raise awareness of the signs and symptoms of pancreatic cancer. I added 2 other aims: to raise awareness of the need for psychological support for people affected by a late diagnosis with a short prognosis and to improve end of life care.

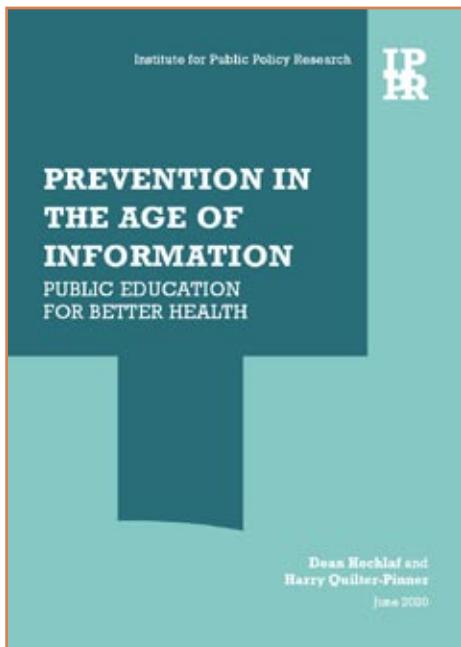
For the last six years that work has been undertaken under the banner of [#SethsLegacy](#). Working to ensure that the voice of people shapes the way in which we understand the experiences of those with pancreatic cancer, those who face the end of their lives, and the loved ones who support them.

That work is Seth's Legacy.

## Pancreatic cancer: Facts

For every 10 people diagnosed with pancreatic cancer 1 gets life saving surgery, 2 get chemotherapy and 7 get NO treatment whatsoever. 1 in 4 people die within a month of diagnosis and 50% of all people diagnosed die within 3 months. Source : [Pancreatic Cancer UK](#)

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)



# Tackling health misinformation

"Over half of the disease burden in England is deemed preventable", says this report, "with one in five deaths attributed to causes that could have been avoided". It notes however, that progress has stalled on reducing the number of people with preventable illness, and that compared to other high-income countries, we are underperforming.

The authors call for a paradigm shift in prevention policy – from interventions that "blame and punish" to those that "empathise and assist". Regressive taxes and bans have not, they say, delivered the transformation required.

Key to any new prevention strategy is the online information environment. Over 60% of British adults use the internet to check symptoms or self-diagnose, with the NHS website considered to be the most trustworthy. There is also, however, a "pernicious prevalence of false information". Polling shows that less than half of the population believe obesity is linked to cancer (misinformation), while over a third either agree that vaccinations can cause autism, or say they don't know (disinformation).

The report states that the Covid-19 crisis shows how rapidly disinformation spreads. A poll revealed that nearly half (48%) of all British people had either seen or been sent "fake news" about Covid-19, online since the outbreak began. In addition, almost two in five (17%) said they did not know whether they had come across fake news, suggesting that the ability to identify and report the spread of misinformation is less than perfect.

In this context, health education, on its own, is insufficient. We need to build health literacy (people's ability to understand health information), and work towards the goal of patient activation (enabling people to exert control over the determinants of health).

The report makes a series of recommendations, including the introduction of a permanent "disinformation unit" to correct false information and help shape public health narratives.

The authors conclude that "New technologies have created opportunities to reach wider audiences, but ... It is also clear that the NHS and health sector more broadly need to take a more proactive approach. As an extremely trusted source of health information, it is imperative the NHS stays ahead of the curve".

## **First Do No Harm**

## The report of the Independent Medicines and Medical Devices Safety Review



# Do no harm

Two years ago, the report of the Gosport inquiry was published. We posted it on our website as a [Featured Report](#), with the headline, “An end to anecdote”. We felt that it was time to move on from a longstanding culture of dismissing patient feedback as “anecdotal evidence”.

We have continued to argue the case via the BMJ, pointing to the [use of language](#), to a [double standard in evidence-based practice](#), and to [issues with organisational culture](#).

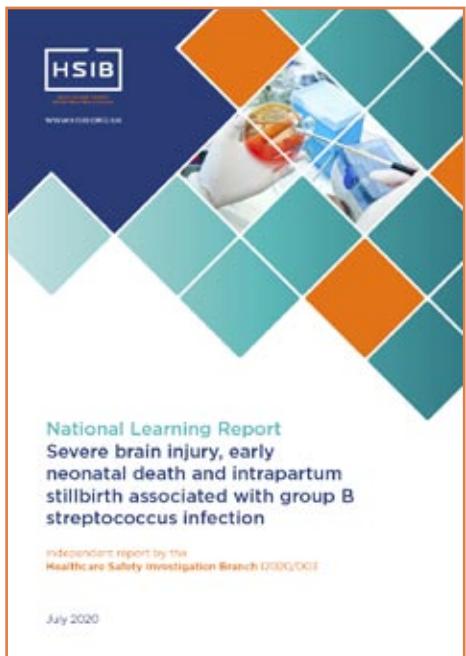
Yet more evidence of the need for change has now emerged via the Cumberlege Review. Here is what Baroness Cumberlege has to say about “patient stories”:

“The patient groups, some of whom have campaigned for decades, have been invaluable to us; well informed, knowledgeable, and research based. They never failed to ensure we learnt from them and were up to date with emerging developments. They are outstanding communicators and expert in the subject matter.”

This is not mere politeness. Cumberlege is experienced and forthright, and she means what she says. And she also means it when she goes on to say that “The healthcare system... does not adequately recognise that patients are its raison d’être. It has failed to listen to their concerns... and has too often moved glacially”.

The words “healthcare system” are important. The NHS is full of dedicated staff who, at a one-to-one level with patients, offer deeply personal and compassionate care. But too often the system as a whole seems institutionally deaf to the patient voice. Evidence of this has been plentiful in recent years, in inquiry reports from Mid Staffs, Morecambe Bay, Southern Health, Gosport, the Hyponatraemia inquiry, and Cwm Taf. Shrewsbury and Telford will be next.

We will continue to argue the case for taking patient feedback seriously, and putting patient experience work on the same evidence-based footing as clinical work. As Cumberlege says, "Patients often know when something has gone wrong with their treatment. All too often they are the first to know. Their experience must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine".



## Work as experienced

This report sheds useful light on one aspect of safety in maternity care – namely, harms associated with group B streptococcus (GBS) infection. GBS is the most common cause of severe infection in babies within the first week of life, with a further 40% of GBS infections developing in babies aged 7 to 90 days.

The report examines the difference between “work as imagined” (how people think care and treatment is carried out), “work as prescribed”, (how guidelines set expectations for care) and “work as done” (how patients are actually treated).

There were various reasons for differences. Sometimes, local practice was not in line with national guidance. Sometimes, “lack of staff availability” meant that antibiotic prophylaxis (critical for the baby’s safety) was delayed or “missing”. Sometimes “workload within the maternity unit” influenced decision making.

These are important factors – but the report appears to miss a further area that is vital for safety in maternity care.

Beyond “work as imagined, work as prescribed and work as done” is “work as experienced”. Here and there through the report, it is possible to pick out references to patient experience. For example:

“...mothers are not always provided with all the information recommended by the RCOG in relation to GBS... in some cases this limited their ability to make decisions”

“The mother and father... felt that their concerns about getting into hospital in time were not heard.”

“When mothers make more than one telephone call for advice, they may not speak to the same clinician each time”

Joining up comments like these, we can see that the “work as experienced” by mothers might include inadequate information, a sense that anxieties are not being addressed, and difficulty communicating with clinicians at crucial moments.

But why do we have to do this joining-up ourselves? Why would a national learning report not be more explicit about the need to consider – and learn from – “work as experienced”?

We know from Morecambe Bay, Cwm Taf and Shrewsbury and Telford that “patient voice” is critical to safety in maternity care. So we must hope that future HSIB reports recognise that “work as done” is not where healthcare stops. “Work as experienced” is the ultimate end, and needs to feature much more prominently in safety culture.

# Engagement under the radar

Original Manuscript

Journal of Health Communication  
Volume 24 Number 1-2  
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Article reuse guidelines:  
sagepub.com/journals/terms-and-conditions  
DOI: 10.1177/1081882618780262  
jhc.sagepub.com

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**Abstract**  
Storytelling has long been used as a theoretical framework for understanding how we share information and learn about health – and illness – online. But is it all about storytelling on social media platforms? To explore this and to what extent personal stories shape health communication in these places, this article looks closely at a Twitter thread concerning the BRCA gene mutation – a hereditary cancer condition. Theoretically, the study advances a new conceptual framework to explore social media practices within issue-based and long-lived social media threads. Methodologically, it develops a platform-oriented discourse analysis approach. Findings show that non-narrative content is actually more common than storytelling in Twitter conversations about BRCA, with a number of patient advocates acting as gatekeepers of scientific information. Most BRCA storytelling is mediated and shared in third person, with those at the heart of these stories becoming exemplars within the BRCA ‘subculture’.

**Keywords**  
Community of practice, epistemic community, experiential knowledge, hereditary cancer, interactivity, issue public, lay expertise, patient advocacy, storytelling, Twitter

**Introduction**  
Social media platforms thrive on multiplying ways for people to connect via seeking, producing and sharing content. Health is a sector, among others, subject to “platformisation” (Holloway, 2015), namely to the norms and values embedded in platforms’ design to enhance connectivity. While acquiring value for both platforms and – public and private

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A great deal of work goes into the process of patient and public involvement in healthcare. Search the [Patient Experience Library](#) for terms like “involvement”, “participation” or “co-production” and you will find a plethora of principles, toolkits and evaluations.

But while health professionals wrestle with the challenges of public engagement, some members of the public are getting on with it in their own groups and on their own terms.

Many online peer support groups communicate via platforms such as Facebook and Twitter – and because their engagement is informal, loosely structured, and (sometimes) private it can be hard for outsiders to tap into the knowledge that these groups co-create. They operate, in effect, under the healthcare system’s radar.

This study looked at one such group, to see how participants interacted. BRCA is a gene mutation that increases the risk of developing breast, ovarian and other cancers. A BRCA Twitter thread has been running since before 2013, and is seen by the paper’s author as a “resilient public” – able to sustain dialogue and mutual support over many years.

A key finding was that the Twitter thread was not simply an outlet for “patient stories”. Information sharing was as important as storytelling, drawing from non-profit organisations and generalist news media, as well as traditional scientific sources.

Contributors to the thread adapted their communication styles to the inbuilt features of the platform: emojis allowed a wide range of expression, hashtags were used to enhance outreach, and when referencing sources, URLs replaced formal citations.

The more influential participants did not behave like social media “microcelebrities”, reliant on relatable personas. Instead, they built influence by acting as gatekeepers of scientific information – regularly offering selected sources for others to find and read.

The study concludes that within the BRCA Twitter public, the “experiential” and the “expert” intersect. And it finishes with a question: how might professionals see social media as “a potential means to collaborate in both the integration of lay and scientific expertise, and the gatekeeping of quality information”.

People's Perspective: Preparing  
for a challenging winter 2020/21

***Nothing about us, without us.***

July 2020



## Involve us now

As we head into the autumn, it is worth considering this report from the Academy of Medical Sciences. Its sits alongside a [scoping document](#) which explores the implications of a possible Covid resurgence combined with the existing backlog of care and the added risk of a flu epidemic.

As might be expected from a medical sciences body, the scoping document is loaded with graphs and tables, and packed with discussion of percentages and ratios. But the very first paragraph says this, “Mitigation strategies should not pose further disadvantage to the most vulnerable in society or the highest risk patients or communities. To maximise their effectiveness (and to ensure they do not exacerbate inequalities), preparations for winter must be informed by engagement with patients, carers, public and healthcare professionals... and, whenever possible, be developed through co-production.”

The Academy’s deliberations have been informed by a Patient and Carer Reference Group, which provided guidance on priorities and concerns for winter 2020/21. A series of public discussion workshops were also undertaken, and these led to publication of this companion report, giving the “People’s Perspective”. The report’s opening paragraph states “We have rarely experienced more meaningful and genuine involvement than we have with this project”.

At just three pages, the People’s Perspective is concise and punchy, and very much worth a read. Its key message is “involve us now”, and it calls on government to lead by example.

The Academy of Medical Science’s report is described as a “rapid review”. It is all the more to its credit that it did not exclude public involvement on the grounds that the processes are too slow.

The Academy has shown a government that aims to “follow the science” how an even better approach is to combine the science with knowledge gained from patient and public experience. Following both, together, will always give a better chance of deeper insight.

Original Scholarship

What Words Convey: The Potential for Patient Narratives to Inform Quality Improvement

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Policy Points

- Narratives about patients' experiences with care often contain meaningful information about quality improvement because they convey simple actionable information that healthcare providers can use to improve patient experience surveys and describe multiple additional domains that are important to patients.
- The content of narrative feedback from patients can potentially be translated to improved quality: multiple ways clinicians can learn from their own patients, groups of clinicians can learn from the experience of their peers' patients, and health system administrators can identify and respond to patterns in patients' accounts that reflect systemic challenges in quality.
- Care must be exercised by patients and providers to ensure that patient narratives are rigorously collected, analyzed fully, and effectively used for quality improvement.

The Milbank Quarterly, Vol. 97, No. 1, 2019 (pp. 176–227).  
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# Stories vs surveys

How are we meant to make sense of patient feedback? There is so much of it, from so many sources, that the task of extracting meaning can feel overwhelming.

This American study explores the problem, noting the additional difficulty that free text comments from patients might be “garbled, fragmented, or laden with multiple plausible inferences”. Perhaps because of this, some clinicians “remain skeptical about the accuracy of patients’ comments... and are uncertain about the actionability of this feedback for improving quality of care”.

The temptation is to respond by channelling patient feedback into formal surveys, where questions are predetermined, and designed to generate quantifiable results. But, say the authors, patients’ own stories convey what matters most to them. So “their focus often extends beyond the domains of experience assessed by conventional closed-ended survey questions”. How, they ask, can patients’ stories “enhance improvement processes above and beyond what is possible using standardized survey metrics alone?”

The answer is that providers need to “invest in interpretive analysis in order to help clinicians understand, respond appropriately, and ensure maximum benefit”.

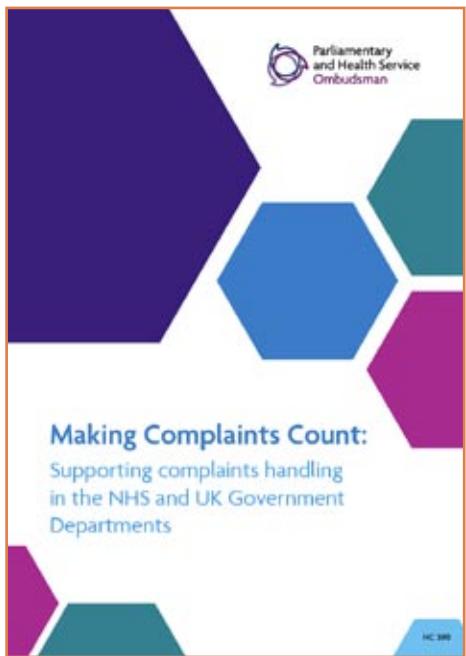
In particular, they need to focus on the “actionable content” within patient stories – looking for “the who, what, when, and where of the event, as well as how the experience felt to the patient”. This is more prevalent than might be imagined: “Overall, 80% of narratives contained actionable content. Fifty-six percent had multiple actionable events, and 17% contained four or more distinct actionable elements”.

The study recognises that “coding and labeling of narrative content is labor-intensive if done by human coders”. It notes the number of companies competing to sell machine reading and natural language processing programmes to healthcare providers. But it warns that “we know of no analyses... comparing the efficacy of human and machine coding, let alone the capacity of NLP to capture the nuances of actionability introduced in this paper”.

There is still a need for “the skill and subtlety people... bring to the task – for example, the capacity to identify emerging patterns, cross-cutting connections, and nuances of language”.

The paper concludes that “Patient experience surveys paved the way for patients’ experiences to be routinely measured”. However, patients’ stories “convey far more nuance, detail, and emotional content than do their survey scores. As a result, their collective narratives may fuel quality innovations that are far more patient-centered than those that rely on quantitative measures alone”.

# Making complaints count



"The current complaints system is not meeting the needs of the public." This stark assessment from the Parliamentary and Health Service Ombudsman sets the tone for a report which is unflinching in its critique of how NHS organisations handle concerns raised by patients.

Importantly, the report avoids dumping blame on complaints managers. It recognises that "Some receive commendable help from their organisations to do their job, but many others... receive limited access to training and are asked to address serious and complex issues with little assistance".

The PHSO points to three core system weaknesses:

- There is no single vision for how staff are expected to handle and resolve complaints. Too many organisations provide their own view on 'good practice' and staff are left confused as to which one to follow.
- Staff do not get consistent access to complaints handling training to support them in what is a complex role. When staff do get training, the quality and consistency of what is covered is variable.
- Public bodies too often see complaints negatively, not as a learning tool that can be used to improve their service. This often leaves complaints staff feeling that they are not valued or supported by senior leaders in their organisation and lacking the resources to carry out their role effectively.

The report sets out proposals for a more consistent and responsive complaints handling process that works for everyone. However, it warns that "change will not happen unless there is effective and inclusive leadership... to make the cultural transformation needed to recognise complaints as a valuable source of learning".

The King's Fund Ideas that change health and care

## Technology and innovation for long-term health conditions



Author  
Ben Collins

August 2020

# Tech for health

## What do we think of IT in healthcare?

The topic has been debated endlessly over the years, with arguments over matters such as digital inclusion versus exclusion, and the extent of public trust in NHS data security. On top of that are the frustrations of staff faced with clunky software and out of date hardware.

This report from the King's Fund revisits the issues in the light of Covid-19, which has prompted healthcare organisations to move services online “at a dramatic pace”.

It is optimistic about the potential of digital technology to support ambitious transformation of care - for example by delivering more responsive care for people with unpredictable, cyclical conditions, or calibrating treatment more precisely for diseases that affect individuals in different ways. Another benefit is “the power of technology to stitch together different health and care services, allowing staff... to deliver joined-up care”.

It is important, however, not to get too carried away with grand visions. The report makes the important point that “the success of digital innovation often depends on what might appear to be small details”. Examples are the length of time it takes to log on to a system, how hard it is to rectify a small inputting error, or how long it takes to get through to the call centre if you forget your password.

Making digital innovation work means engaging in “iterative cycles of improvement to gain feedback from service users and test improvements”. Early collaboration is vital, to enable creative thinking before solutions are pinned down. And when it comes to trust, “the solution lies, in part, in placing patients firmly in control of their own data and how it is used, with simple arrangements for opting in and out of data sharing”.

“One overriding message”, say the authors, “is that harnessing technology to deliver transformative change in health care is harder than it might initially appear”. Their conclusion is that “The types of innovations most likely to spread are often those that fit within existing structures, making small improvements to existing ways of doing things rather than delivering transformative change”.

# Do pain scales work?

"Managing pain can be extremely challenging" says this paper, because "it is a private sensory experience". While things like blood pressure and pulse can be objectively measured, assessments of pain usually depend on self-reporting by patients.

Healthcare providers try to understand pain levels by asking patients to use tools such as numerical scales or face scales. Use of these is written into clinical guidelines, implying a belief that they can "provide a meaningful measure to inform clinical responses".

However, the study points out that laboratory-based efforts to demonstrate the reliability of pain scales "neglect social and contextual influences outside the study environments". For patients, these can include the effects of distress, confusion and anxiety. For health professionals, they can include scepticism, or habituation to seeing people in pain.

The study took the experiences of patients with Sickle Cell Disorder (SCD) as a way of exploring the usefulness of pain scales. SCD is characterised by chronic and acute pain, but patients do not always have visible signs of pain. Their need for opioid-based analgesics can lead to them being seen as "drug-seekers". And the fact that SCD is a "racialised condition" can create problems with understanding and trust.

Patients' coping strategies can also conflict with observers' expectations of how people "should" behave when they are in pain. For people with SCD, coping strategies can include socialising, watching television or listening to music. These patients, say the authors, "do not adopt a visible sick role".

One interviewee explained that he had been having painful episodes since he was very young, and so had become good at coping with it. For this reason, he did not "look as sick as other people" when he was in pain, which translated into being discharged too early or not being admitted to hospital at all.

The study concludes that "While very commonly used, pain scales have numerous drawbacks and are prone to profound social and communicative influences that may not be adequately taken into account". There is, it says, "considerable uncertainty inherent in scale use, and considerable scope for future work to explore this uncertainty and improve pain communication".

Acknowledgements

Communicating and understanding pain limitations of pain scales for patients with sickle cell disorder and other painful conditions

**JHP**  
Journal of Health Psychology  
in the Academy 2018  
Volume 23 Number 10  
Article first published online: 03 Oct 2018  
DOI: 10.1177/0177960018770966  
<http://journals.sagepub.com>

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**Abstract**  
Pain communication in healthcare is challenging. We explore use of pain scales to communicate pain severity via a case study of people with sickle cell disorder (SCD). We show how pain communication and complex social interactions between patients, healthcare professionals and visitors in acute settings can affect pain management. Future research is needed to develop pain management for any patient. For SCD, medical context shapes pain communication, further complicating clinical assessments. However, SCD pain is particularly severe, making range band or intensity compared with ratings from non-SCD patients, potentially encouraging problems in managing pain-related.

**Keywords**  
patients; pain communication; pain management; pain scales; qualitative methods; sickle cell disease; sickle cell disorder; social interactions; trust

Managing pain can be extremely challenging for individuals and healthcare providers (Hadjistavropoulos et al., 2011). Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP, 2017 Paragraph 1) – in particular, the emotional component of pain is often sensory experience and/or must be inferred from observation or communication. One form of communication – self-report – has become a "gold standard" (Schlaepfer and Craig, 2005), tested with pain scales (Schlaepfer and Craig, 2005), tests described as reliable and valid (Finsen et al., 2004; Clark et al., 2003; Finsen-Valemo et al., 2011).

While pain has been treated as a fifth vital sign (American Pain Society, 2009), an important consideration of how well the body is coping is functioning – it is subject to various social and contextual influences (Hadjistavropoulos et al., 2011), including, crucially, trust between healthcare provider and patient (Schlaepfer and Craig, 2005).

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# Is everybody appy?

“The past decade has witnessed an explosion of mental health (MH) smartphone applications (apps)”, according to this study from the United States. It states that “More than 10,000 MH apps are available for download, offering features such as symptom and behavior tracking, diagnostic screening, psychoeducation, and relaxation and mindfulness exercises”.

However, analysis of depression app trials has reported a dropout rate of almost 50%, and a median daily engagement rate of 4%. These findings, say the authors, “highlight a striking mismatch between the degree of enthusiasm, effort, and capital being dedicated to MH app development as compared to the extent of our knowledge regarding apps’ effectiveness and their potential for sustained use”.

The study looked at factors that could affect take-up and use of apps. These included the following:

- Relative advantage: Do MH apps demonstrate an advantage over pre-existing modes of care? This matters because “If patients, providers, or healthcare systems do not see the added value of an app, they will not use it”.
  - Useability: Here, simplicity is key. In fact, say the authors, “the first question to ask is whether the complexity of an app is needed at all... many app functions can be achieved through simple text messaging”.
  - Recipients: The paper states that “recipients of an innovation are central in determining successful implementation”. This depends partly on values and beliefs: recipients “may think that apps are impersonal, contain unreliable information, or do not have proper privacy regulations”. But it is also about skills, knowledge and resources: “MH apps serve no purpose if users do not own a smartphone or do not know how to download or use an app”.
  - Context: This is also critical. User ratings influence the order in which apps are presented in online app stores. But “72% of the 29 most popular depression apps contained no information regarding suicide prevention, and some of these apps contained potentially harmful negative content”.

The paper concludes that “the evidence base is still uncertain regarding the effectiveness and usability of MH apps”. It goes on to say that “As the initial hype surrounding MH apps settles, there is an urgent need for reflection and humility regarding the current state of the field in order to develop strategies that are realistic, grounded in evidence, cognizant of context, and more likely to result in successful implementation outcomes”.



# Patient Experience in England

“Listening to patients should not be seen as a chore, or a tick box” says Shaun Lintern in the foreword to this year’s Patient Experience in England report.

Lintern has considerable form as a leading reporter for the Health Service Journal and the Independent, and as a persistent advocate for patient safety. So he knows what he is talking about.

His comments come in a year when health news has been dominated by Covid. But as he points out, this has also been a year which saw publication of the report on rogue breast surgeon Ian Paterson, and of the Cumberlege review of harms arising from pelvic mesh, sodium valproate and Primodos. In both cases, women’s voices were ignored and suppressed over years, even decades.

Happily, there is also plenty of good news on patient experience coming out of this year’s crop of surveys and studies. Patient Experience in England rounds up twelve months of reporting, and summarises key findings. As well as a blow by blow review of the national patient surveys, our thematic overview of recent research draws out cross-cutting learning on matters such as online engagement, patient safety and the evidence-practice gap in patient experience.

The Patient Experience Library is not part of the NHS, and we get no funding for our work. But we are sustained by the enormous goodwill of our many friends and supporters, whose advice, encouragement and moral support give us the stamina to keep going. One of those is Shaun Lintern, to whom we’ll give the last word:

“Patients have the lived experience that doctors, nurses, managers and politicians need to hear. Their concerns need to be acted on.”

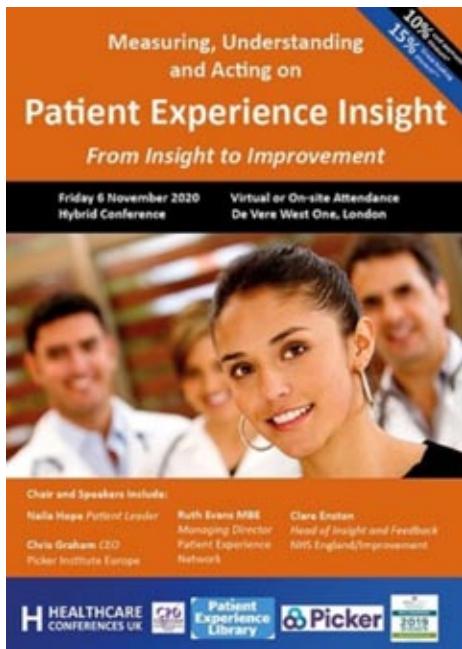


# Virtual Conference

## Measuring, Understanding and Acting on Patient Experience Insight:

From Insight to Improvement

**Friday 6 November 2020**



Chaired by Chris Graham Chief Executive Officer Picker Institute Europe, and with an extended session from Ruth Evans MBE Chief Executive Patient Experience Network, this CPD conference will focus on measuring, understanding and acting on patient experience insight, and demonstrating responsiveness to that insight to ensure Patient Feedback is translated into quality improvement and assurance.

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- Learn how to use the National Patient Experience Improvement Framework in practice
- Understand the national context for patient experience
- Reflect on CQC key lines of enquiry for patient experience
- Understand how to work with staff to act on patient experience feedback in real time

- Use a Human Factors approach to deliver change and improvement based on patient experience insight
- Identify key strategies for developing a patient experience culture
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