

Patient Experience

and patient/public involvement in health and care services

Winter 2018



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**Patient
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We kick off 2018 with another great batch of topics and insights from the world of patient experience and involvement.

Our comment pieces cover both angles. On “experience”, we have the story of the stolen biscuits. This is a useful reminder that sometimes it’s the small kindnesses that count, and that organisational attitudes are revealed not in the grand vision statements, but in day-to-day actions. On “involvement” we have a discussion of “virtue signalling”, whereby moral posturing may be seen as more important than effective engagement. An item on culturally sensitive approaches to antenatal classes covers both angles, showing how well handled involvement can lead directly to improved patient experience.

Our collection of reports and studies contains some gems. The Care Quality Commission published three national patient surveys during the autumn, on Emergency Departments, Community Mental Health Services and Children and Young People’s experiences. All provided useful insights in their respective areas. But putting all three together alongside the May 2017 Adult Inpatient survey revealed a stark fact - that people with mental health conditions have consistently poorer patient experience across the board. As the new [Mental Health Policy Research Unit](#) gets up and running, we hope that the CQC’s findings will be central to their agenda.

Our own innovation in the run-up to Christmas was the latest in our series of Knowledge Maps. The [Patient Experience in Trusts](#) map takes all the key patient experience data for every NHS Trust in England and puts it all together in one easy to use map. The map was developed with help from patient experience staff in Trusts and CCGs, and will undoubtedly make life easier for them. But it also makes the evidence more accessible to patients who are, after all, the actual source of all the data.

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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New
documents
Oct-Dec '17
2,025

During October - December 2017, we added 2025 documents to the Patient Experience Library.

Most of these were CQC inspection reports. We collect these because the “Caring” domain in particular can shed light on patient experience. Around 500 came from health charities, think tanks and other government bodies, with around 300 coming from the local Healthwatch network.

Subscribers to the Patient Experience Library can view all of these, and search through over 40,000 documents on patient experience and patient/public involvement by logging in from the [Welcome Page](#) of our website. For details of how to subscribe, [click here](#).

Patient engagement as virtue signalling

Jennifer Johannesen



My son Owen had multiple severe disabilities all his life, and passed away at the age of 12. In the 7 years since his death, I have been considering the

ways in which organizations shape or influence families' experience of their children's care. For example, I have long thought that 'patient-centred care' can be interpreted as a rather sophisticated way to manage patient behaviour and minimize conflict.

I have recently applied this critical perspective to 'patient engagement' initiatives where healthcare organizations enrol high-performing patients in advisory or leadership capacities, ostensibly for the purpose of giving their voices a platform, and improving care or service delivery.

While I'm supportive of patients and families contributing to public healthcare in ways they feel are personally meaningful, I think it's worth asking some difficult questions about the motivations of organizations who invite patients to advisory and decision-making tables.

Why are organizations so interested in 'patient engagement' when the term itself is poorly or inconsistently defined, and there is limited evidence of meaningful impact? Why is it required to the degree that it is, by regulators, accreditors and management teams? The reality is that outcomes and impact are simply not measured, and any successes attributed to patient engagement seem to centre around the nature of engagement itself (e.g.

number of times a group meets).

Certainly, good feelings are generated through patient engagement activities. I've heard patients, clinicians and administrators alike report that positive interpersonal relations and having common goals contribute to feelings of comradery and shared purpose. While it's nice to build bridges between patients and professionals, this doesn't strike me as enough justification to fuel the drive of patient engagement efforts we see in contemporary healthcare settings.

The demonstrable value of patient engagement for the organization seems to be what's known as 'virtue signalling', which is defined by Wikipedia as "the conspicuous expression of moral values to enhance standing within a social group."

Consider the following: patient engagement activities are communicated excitedly and extensively, regardless of whether the activities themselves are beneficial. For example, a patient information brochure might be stamped with a 'Patient Reviewed and Approved' label, to let everyone know that patients were involved in writing it. Does that mean the brochure is better? Not necessarily. The stamp doesn't assure quality - it signals virtue.

Patient engagement activities are displayed publicly so as to convey any number of moral values. For example, engagement can convey an organization's benevolence, open-mindedness, fairness, etc. - the details don't matter, and there is no need to substantiate how activities might

convert to outcomes. The moral value gained by the mere presence of patients is enough to bring high reputational dividends to the organization, thereby enhancing its standing among other institutions, funders, regulators, and even among patients.

That patient engagement activities are not measured or critically assessed is the most telling indication that the outcomes of those activities are not seen as truly important. This lack of measurement is especially notable given the degree to which healthcare organizations measure every other activity, from clinical outcomes, to patient safety, to expenditures.

Consequently, because there are no quality or performance measures in place, there is little impetus to invest time and money in creating a sustainable, productive, representative patient advisory that has meaningful impact. As organizations extract sufficient value out of simply assembling patients and publicly announcing their efforts, we can assume that any change will not likely come from them.

Patients ought to insist on accountability, compensation, outcome measures and other criteria that require healthcare organizations to take their contributions seriously. Otherwise, patient engagement efforts will continue to be a virtue-signalling exercise that undervalues patient input while simultaneously making organizations feel good about themselves.

Jennifer Johannesen is an author, lecturer and bioethicist, based in Toronto Canada.

Jeremy Hunt stole my biscuits

Ceinwen Giles



“It’s outrageous.” “Pretty soon there won’t be anything left to cut.” “What the actual....???”

These were the comments I recently heard from nurses and fellow patients at my immunology clinic. The source of their ire was not, as one might expect, the cutting of access to treatment or extended waiting times—it was biscuits.

I’ve been attending the clinic for five years, for treatment administered by IV every four weeks, so I’ve gotten to know many of the other patients fairly well. We have an odd sort of camaraderie, sitting together hooked up to bits of equipment and drugs for hours at a time. We chat about families, holidays, and current events, but few conversations have become as animated as what I now think of as “Biscuitgate.”

Biscuitgate started three months ago when we turned up to find that the clinic’s biscuit tin was empty - due not to oversight, but rather to financial cuts.

“It started years ago”, one fellow patient mused. “They cut the Branston pickle in the cheese sandwiches, and it’s been downhill from there.”

“That Jeremy Hunt stole my biscuits”, muttered another patient loudly.

Indeed, the last few years have seen cuts to sandwiches, orange juice, and yogurt. The biscuits and tea were all we had left.

Here’s the thing: I don’t even usually eat these biscuits. But having witnessed the uproar that the de-biscuitisation of the clinic caused, I decided to fight for the right of my fellow patients to have their infusions with a side of cookies whether I personally eat them or not.

Online research showed that a catering box of 100 biscuit packets costs approximately £18. The NHS Trust where I receive my treatment has an annual budget of more than £800 million.

I approached a non-executive director of the hospital and told her of our plight. During hours of a somewhat unpleasant treatment, the biscuits are a small kindness. When the treatment makes us tired and nauseous, the biscuits offer a small sugar boost and can help settle the stomach.

The director understood how much small things can matter, and the biscuits made a short-lived reappearance. But this month they were cut again. Word on the street (or hospital corridor) is that although the matron has approved the biscuits, an

operations manager has refused to sign off the request.

I wondered whether I was fighting an unimportant battle. The clinic does, after all, provide me with very expensive drugs for free. However, having debated this topic far and wide, my conclusion remains the same: the biscuits matter.

Good patient experience is fundamental to healthcare quality, not just a nice-to-have afterthought. Whoever is responsible for the raid on the biscuits has, as far as I can tell, made a unilateral decision without understanding their true value. I’d say that £18 spent on biscuits is probably more than returned in terms of an increase in trust and respect for the hospital and its staff, as well as improved adherence to treatment protocols.

I’ve raised another complaint, but have yet to hear if any change is in the offing. In the meantime, if you see a group of people outside a hospital with a sign saying “These cuts really take the biscuit”, you’ll know why.

Ceinwen Giles is a director at Shine Cancer Support and a trustee of the Point of Care Foundation. She also works as a consultant in patient involvement and experience and is an associate at [Swarm](#).

This article first appeared as a [BMJ Opinion blog](#)

Culturally sensitive approaches to antenatal classes

Duygu Bozkurt



“Informed choice” for pregnant women and their birth partners is a long-held principle in maternity services. It has been championed

over many years by organisations such as the National Childbirth Trust, and has found its way into the *NICE quality standard on patient experience*, which covers opportunities for patients to discuss preferences and to have the right to choose.

But informed choice is not simply about understanding factual matters such as what services are available and where. Choice is also shaped by cultural factors.

We spoke to Duygu Bozkurt, a researcher who led a study of culturally sensitive approaches to antenatal classes, as a basis for developing service provision targeted at a vulnerable community. Her work was based on discussions with Turkish-speaking women at the Minik Kardes project in Hackney – a community hub with a culturally sensitive approach to parenting and early years education.

“Turkish-speaking women are mainly from Turkish, Kurdish and Turkish Cypriot ethnic backgrounds”, says Duygu. “They can be vulnerable if they are newly arrived in the UK – especially if they do not speak English well. Apart from the language barrier, that can also mean that they are

unsupported and socially isolated. They have to contend with low income or unemployment and poor housing. Domestic violence is also an important issue, although disclosure rates are relatively low.”

All of this, according to Duygu, can mean that pregnant women – and particularly those about to be first-time mothers – can find it hard to access primary care and diagnostic facilities, imperative in ensuring antenatal well-being.

“At Minik Kardes Children’s Centre, we have been delivering targeted antenatal classes for Turkish speaking women. We cover antenatal and postnatal services, the roles of midwives and health visitors, and birth planning. And we talk about stress relief during labour, contraception after birth, and breastfeeding. In order to build resilience within the family, we also talk about changing roles from being a couple to being parents, and what this would mean to them, providing them with a future oriented perspective.”

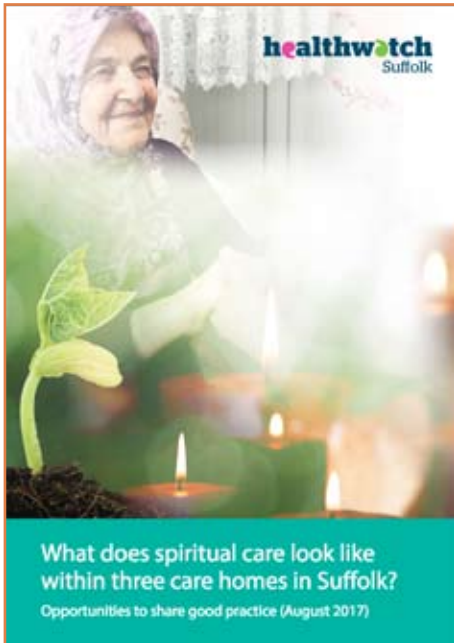
The project establishes a better link between the participants and the health professionals who attend antenatal sessions as guest speakers, and work at the hospital where participants are to give birth. It also highlights the areas for change needed in a patient-centred approach. As such, it contributed to the process of making informed choices by both patients and the professionals. For example, while doing an initial assessment, a professional can choose

“Antenatal sessions also helped me a lot about the after care. Although it was my first child, I knew how to breast feed. I did not give up breast feeding and I never started ready meals in a panic.”

to give information about support services for victims of domestic violence before asking questions about relationships, or after receiving their answer even if it was a ‘no’.

Duygu followed up by interviewing the women after they had given birth. “I wanted to see how they had been able to use their learning in the delivery suite, and at home with the new baby. Their comments indicated increased knowledge and confidence, which shows the value of specially tailored antenatal teaching. It’s not just about having leaflets available in languages other than English. It’s about taking antenatal education to places where women meet, and enabling culturally sensitive conversations in safe spaces.”

Bozkurt, D. (2015) Turkish Speaking Women’s Feedback on NHS Antenatal Services Minik Kardes Children’s Centre, London.



What Does Spiritual Care Look Like?

Case studies of good practice in care homes

“36% of British adults would not define themselves as ‘religious’. Yet research is unveiling that spiritual beliefs offer... health and psycho-social benefits [including] improved coping styles, social support, protection against mental illness, and physiologically, an improved immune system”.

So says this report from Healthwatch Suffolk, which looks at how spiritual needs are answered in care home settings.

The project was triggered - at least in part - by one of the Care Quality Commission’s five key inspection questions: ‘Are they (the service provider) responsive to people’s needs?’ The CQC recognises that, to be responsive, providers must give consideration to every individual’s religion and beliefs.

Through visits to care homes, and discussions with residents and staff, a multi-faith project team explored aspects of good spiritual care, which can encompass all beliefs, whether strictly religious or not. The report makes the point that spiritual care is not just about having dedicated times or special areas for prayer and contemplation - it can be built into everyday activities. For some people, it may mean respecting and accommodating dietary requirements related to religious observance. For others, it could mean including popular hymns in singing and music sessions. One of the study team explains her experience of finding a Jewish care home for her mother so that she could fully participate in the very social aspects of Judaism.

Care homes are where many people spend their final years, and the report notes that *“When having to face mortality questions can arise. This can happen to anyone having a big life change or illness, whether terminal or not. None of us are as prepared for that as we may think we are, we can all have an awakening of spirituality at that time”.*

Health and care services tend to have systems and procedures that aim, above all, to guide clinical practice. But any service that aims to be “person-centred” should consider people’s spiritual wellbeing alongside their physical and mental health. This - perhaps more than we realise - can be an essential part of the quality of patient experience.



CQC vs Twitter: which is better?

Patient feedback on social media shows positive association with CQC inspection ratings

The likelihood of patient feedback being dismissed as merely “anecdotal” is, thankfully, diminishing. Healthcare professionals know that patients can give them useful insights into quality and effectiveness – picking up issues that they themselves might miss.

Now a new study lends added weight to the idea that patient feedback is not just an optional extra, but a key part of performance and risk management within the NHS.

“Wisdom of patients” describes a project carried out by specialists in risk analysis and behavioural science. They took large volumes of patient feedback on Trusts and hospitals, from sources including Twitter, Facebook and Care Opinion. They then applied classifications and sentiment analysis to produce a “collective judgement score”, or CJS. Finally, they compared the CJS with CQC inspection ratings for the services in question.

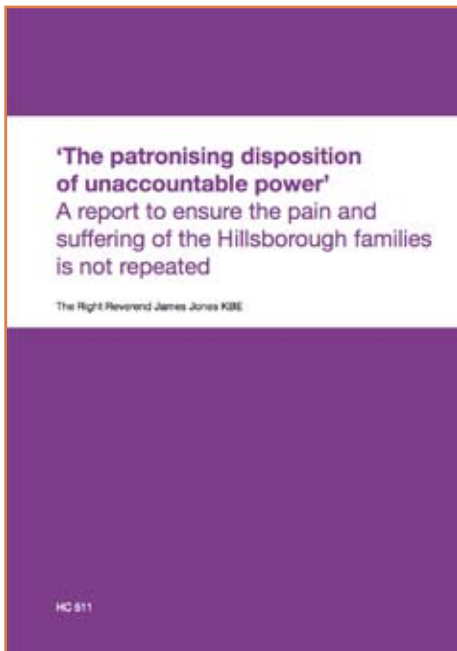
They found that on average, patient feedback ahead of a CQC inspection is better for hospitals that subsequently get a higher CQC rating. The better the patient feedback in the 90 days prior to a CQC inspection, the greater the likelihood of a more positive overall rating.

Interestingly, some ‘Inadequate’ hospitals scored a high collective judgement score (from the social media feedback), as did some ‘Requires Improvement’ hospitals. So it would appear that patients are better collective judges of organisations performing well than they are of organisations performing poorly.

In spite of this, the researchers state that “*while the collated patient feedback cannot perfectly identify poorly performing organisations, it can identify those organisations that are most likely to be performing poorly. Indeed, not a single organisation with a [low] CJS was rated ‘Good’ or ‘Outstanding’.*”

So is patient feedback via social media a better guide to service quality than a CQC inspection? Probably not – or at least, not yet. The authors of this paper are clear that “*there is still a lot to be learnt about the use of aggregated patient feedback. It is possible that the predictive power... could be improved.*” But the paper concludes that “*The near real-time, automated collection and aggregation of multiple sources of patient feedback should be used to help prioritise inspections.*”

Be warned – if you’re not a statistician, this paper may not be an easy read. But if you persevere, you may find yourself thinking twice about how you use your social media feedback.



The Patronising Disposition of Unaccountable Power

Important learning for NHS bodies from the Hillsborough disaster

It was good to see NHS England hosting two “Learning from Deaths” events during the autumn – one for bereaved families and one for health professionals. The events were part of efforts to ensure that the recommendations contained in the CQC’s *Learning, candour and accountability* report are implemented in a clear and structured way.

In the same week that the events took place, Bishop James Jones published this report, which aims to “ensure the pain and suffering of the Hillsborough families is not repeated”. The report reveals striking parallels between the experiences of the Hillsborough families and of people who have sought justice following avoidable deaths within health and care services.

The Bishop remarks that *“The [Hillsborough] families know that there are others who have found that when in all innocence and with a good conscience they have asked questions of those in authority on behalf of those they love the institution has closed ranks, refused to disclose information, used public money to defend its interests and acted in a way that was both intimidating and oppressive”*.

Institutional reactions of this kind have been documented in the Francis report on Mid Staffs, the Kirkup report on Morecambe Bay and the Mazars report on Southern Health.

NHS staff do excellent work under difficult conditions. Day after day, they care for people, cure sickness and save lives. On the rare occasions when things go wrong, a poorly handled institutional response can let down staff, as well as patients.

The Bishop observes that a lack of honesty does not come from individuals – it is institutionally embedded. It is *“a cultural condition... an instinctive prioritisation of the reputation of an organisation over the citizen’s right to expect people to be held to account”*.

The report urges the Prime Minister and Home Secretary to *“ensure that those responsible for our national institutions listen to what the experiences of the Hillsborough families say about how they should conduct themselves when faced by families bereaved by public tragedy”*.

Mid Staffs, Morecambe Bay and Southern Health are public tragedies where avoidable deaths were followed up by inadequate investigations and dismissive treatment of bereaved families. We hope that those responsible for the NHS Learning from Deaths programme will take careful note of the contents of this report.



New Knowledge Map shifts power balance

“Patient Experience in Trusts” map puts all key patient experience evidence in one place.

Huge numbers of patients give feedback on their experiences of health and care services. Over 45,000 responded to the national Emergency Department patient survey. 78,000 contributed to the Adult Inpatient survey. Many thousands more give time and goodwill to share their experiences through other surveys. And as taxpayers, they foot the bill for the significant cost of the work.

We think that patients and public should be entitled to see what happens to all their feedback. But survey findings are published across multiple websites - CQC, NHS England, NHS Choices and more. Within each website, survey results are shown separately across hundreds of different web pages. Health professionals can struggle to find what they need. Members of the public may not even know where to begin.

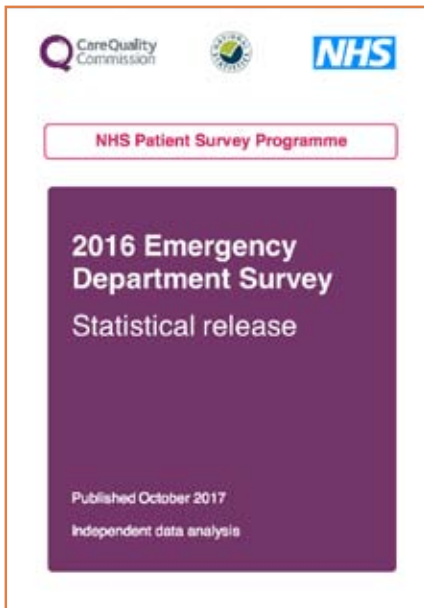
This is a real problem, because we know from research that patients can be reluctant to give feedback if they cannot easily see where their comments have gone and how they are being used. Building strong and trusted relationships between patients and professionals depends, at least in part, on a two-way dialogue based on a free flow of information.

In a major breakthrough for patient experience reporting, we have brought all the key Trust data together into one easy to use map. Users simply look for their local Trust, click on the map pin and get all the key patient experience data for that Trust all in one place.

This is a huge increase in the accessibility of patient experience data. It strengthens Trusts’ transparency and public accountability. And since knowledge is power, the map evens up the power balance by giving patients easy access to their own evidence.

The map also makes life easier for policymakers, commissioners and providers. And it helps the NHS on its journey towards providing information digitally and seamlessly.

The “Patient Experience in Trusts” map is part of our *Knowledge Maps series*, helping to make important sources of evidence more visible.



CQC national patient surveys

Injustice for mental health patients exposed

The Care Quality Commission has been busy over the last few months, with the national patient surveys for Emergency Departments, Community Mental Health Services and Children and Young People all published during the autumn.

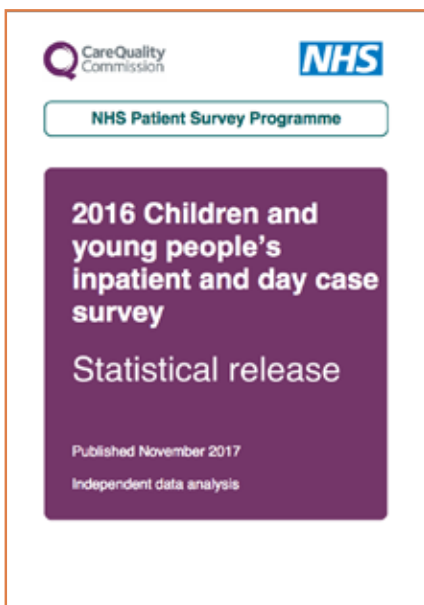
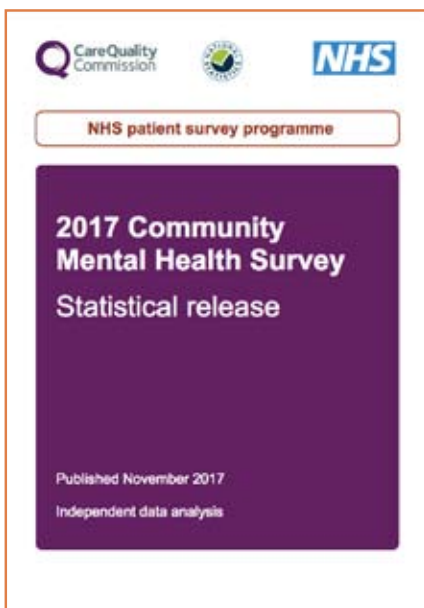
All contain the usual mix of good news and room for improvement. Confidence in clinicians, for example, tends to be high, while those old bugbears “information” and “communication” tend to show room for improvement.

The surveys will no doubt be picked over by Trusts looking for clues to service quality and risk management issues at the local level. At the national level, however, there is one particular cause for concern running through all the CQC survey findings. That is that patient experience is poorer across the board for people with a mental health condition.

We could start with the Community Mental Health Survey, which reported little sign of improvement for “*substantial concerns*” raised in the previous year’s patient survey, and stated that services “*have even declined slightly in key areas*”. The Emergency Dept Survey and Children and Young People’s Survey also revealed poorer experiences of care for people with mental illness. And earlier in 2017, the Adult Inpatient Survey produced further evidence along the same lines.

That’s four national patient surveys in a row showing that when it comes to patient experience, people with mental health conditions – children as well as adults – are worse off.

Right at the start of 2017, Prime Minister Theresa May described mental illness as a “*hidden injustice*”. But the injustices experienced by mentally ill people are not hidden at all. They are exposed in survey after survey produced by the Care Quality Commission. The evidence is plain to see. It is time that the government started to act on it.





Healthwatch England “State of Support” briefing

Healthwatch funding cut. Again.

In December, Healthwatch England took the step of publishing a letter to the Secretary of State for Health, along with a briefing about the state of funding for the local Healthwatch network.

The documents describe a 37% reduction in funding since the network’s first allocation in 2013/14. They say that this is “putting at risk the ability of the network to deliver on its statutory obligations”. By way of evidence, they state that:

- Local Healthwatch operate on very tight budgets and with very small staff teams (often only two people) covering very large geographical areas and populations.
- There are problems with one or two year contracts not providing sufficient stability to enable long term planning and retain staff.
- There are concerns around some councils’ confusion between commissioning statutory Healthwatch activity and funding wider voluntary and community sector projects.

Healthwatch was set up in the wake of what the Francis Inquiry described as “*appalling suffering*” and avoidable deaths at the Mid Staffordshire Trust. It was meant to be a stronger and more effective patient voice organisation than its predecessor, the Local Involvement Network. But it is hard to see how it can fulfil that expectation with the financial rug being pulled each and every year since its inception.

Last year, our report *What Price Patient Voice* described a widespread failure to understand the value for money offered by Healthwatch and other patient voice initiatives. There is no consensus on what value for money looks like, and no benchmarking of funding levels for patient voice work.

Without a clear value proposition, Healthwatch will struggle to develop a strong business case. That makes the network vulnerable to further funding cuts.

It also means that local authorities are free to do what they want with funding that is intended for the statutory functions of local Healthwatch. They can cut as deep as they like. They can do so arbitrarily. And they can get away with it.

Online feedback in Quality Improvement

*Tuesday 30 January, 10:30am - 3:30pm
Friends Meeting House, 6 Mount St,
Manchester M2 5NS*

There is a growing view that the experiences of patients and carers have much to contribute to quality improvement work in health and care services. At this free staff workshop we'll hear from speakers using Care Opinion in QI: they'll be ready to share their ups and downs, learning and reflections, and to discuss how near real-time feedback from people using services can make a difference to QI.

Speakers include:

- **Shaun Maher**, principal educator, Quality Improvement Team, NHS Education for Scotland
- **Samantha Whelan**, patient experience midwife, Royal Oldham Hospital
- **Adele Bryan**, interim general manager for Mental Health and National Learning Disability Directorate, Nottinghamshire Healthcare
- **Laura Sheard**, patient experience researcher, Bradford Institute for Health Research
- **James Munro**, chief executive, Care Opinion

This event is free but spaces are strictly limited and **advance registration is essential**. To register your interest, please contact: sarah.ashurst@careopinion.org.uk

Patient Experience Insight Summit

*Thursday 22 February 2018
The Studio Conference Centre,
Birmingham*

The National Patient Experience Insight Summit will focus on measuring, understanding and acting on patient experience insight, and demonstrating responsiveness to that insight to improve care. Through national updates and case study presentations the conference will support you to measure, monitor and improve patient experience in your service, and demonstrate responsiveness to the feedback you receive.

NHS Complaints Summit 2018

*Friday 9 March 2018
De Vere West One Conference Centre,
London*

This National Summit focuses on delivering a person-centred approach to complaints handling, investigation, resolution and learning. Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints lead to change and improvements in patient care.

Conference: making healthcare more human

*Wednesday 28 March 2018
The Wellcome Collection,
183 Euston Rd, London, NW1 2BE*

A CPD-accredited conference exploring how to make healthcare more human for patients and staff in the NHS.

Unlike other conferences, this will be a multi-professional event, focused on bottom-up change and the involvement of both staff and patients in the change process. It will be highly participative and interactive, stimulating ideas whilst also focusing on the practical ways to make a difference to both patients and staff. You will be encouraged to challenge traditional ideas about the role of staff and patients, seeing patients as partners in the design process, and staff as people to be cared for too.

Cost: £200 - discounts available for multiple delegates
Audience: HR directors; organisational development managers; finance directors; medical directors; improvement leaders; NHS quality leads.

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](#)

The Patient Experience Library

Our ground-breaking initiative has collated and catalogued the whole of the UK's collective intelligence on patient experience. We can offer access to over 40,000 documents on patient experience and patient/public involvement, from government bodies, Healthwatch, think tanks and health charities.

Visit our website to get free access to our weekly newsletter, *Knowledge Maps* and other good stuff.

Contact us (info@patientlibrary.net) to ask how we can help you with *Insight Reports* on service design, commissioning and policy matters.

Subscribe for access to the full Library content - 40,000 documents on patient experience and patient/public involvement, with fast, precision search.

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

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