Patient Experience

and patient/public involvement in health and care services

Winter 2020

Patient Experience Library

Editorial

Patient stories are in big demand these days. Board meetings of healthcare organisations often feature a patient – filmed, or in real life – recounting their experience of care. Annual reports carry mini case studies from (mostly grateful) patients. Proposals for service change are illuminated by testimony from patients who look forward to forthcoming improvements.

Of course, negative stories are also heard. They are channelled into complaints procedures or, better still, dealt with swiftly and compassionately by staff who know that a quick response is better for both patient and provider.

But what happens to the stories that don't fit the neat binary of satisfaction/complaint? How do we talk about the messy realities of living through illness, or travelling across "care pathways", or entering the strange world of "patient engagement"?

In this edition, we hear three such stories. Sue Robins wanted to write her way through her experience of cancer. But she discovered that her account did not fit the healthcare system's preferred narrative of illness, cure, and gratitude to the healers. For her, uncomfortable stories need to be heard – without interruption, correction, or looking on the bright side. Hearing is the start of healing.

Tony Roberts looks at the story of "DNAs" – the shorthand for patients who "did not attend" their appointments. Healthcare professionals can see a DNA as a failure of motivation on the part of the patient. It can be frustrating and dispiriting. Patients, on the other hand, can see DNAs as a failure of motivation on the part of healthcare providers – to schedule appointments more sensitively, to consider transport needs, to understand the struggle to adhere to institutional routines. They too experience frustration and disappointment.

Finally, Douglas Findlay tells his story of patient leadership. His experience has been interesting, stimulating and challenging. But he wonders whether it really counts as leadership. He sets out some thoughts on how healthcare organisations could rethink their approach.

More patient stories run through our round-up of the latest research on patient experience and involvement. And as always, we're 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!
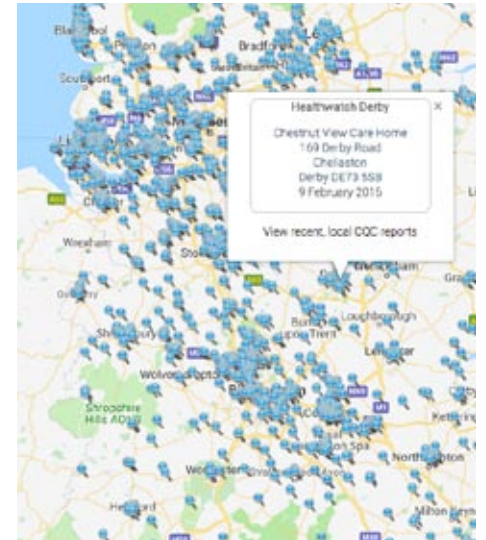
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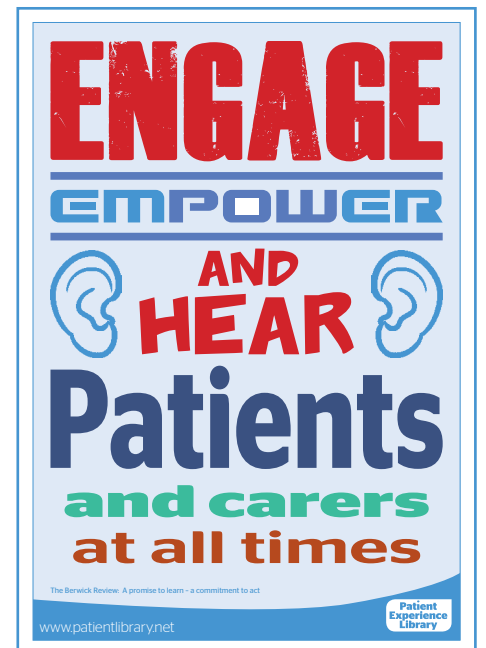
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Free resources

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!

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The Berwick Review. A promise to learn - a commitment to act

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Comment

Do you have opinions, insights or good practice examples that you'd like to share with our readers? Drop us an e-mail to receive our guide for contributors: *info@patientlibrary.net*

The Patient Storyteller

Sue Robins www.suerobins.com

Sue is the mother of Aaron, who has Down's syndrome, as well as being a breast cancer patient, health care activist and New York Times published writer. She believes the revolution in health care will happen when patients rise up and tell their own stories. This is an edited excerpt from Sue's recently published book – Bird's Eye View: Stories of a life lived in health care.

My writing in the early days after my cancer diagnosis was a hot mess, reflective of the chaos I was experiencing. My journal entries two weeks after my partial mastectomy surgery are particularly painful.

March 3, 2017

I'm circling the drain here.

Have a terrible awful huge swollen spot under my incision. A seroma? A hematoma? Not sure. Went to family doctor today and am grateful to be on antibiotics and more pain killers. Terrified it is going to burst or get infected and I'm going to end up in emergency. Or with sepsis. I think this is awfully big. Have to wait to see surgeon. I see how this health stuff is all consuming....

Earlier in the day, Aaron said, "Mom, stop being like an animal." "An animal?" I say, confused. "Yes, a monkey" – and then he jumped around like a monkey. I can see why he thinks I'm like a monkey with my endless tidying up and puttering. You should be more like a human being, he decided. I agree.

I tried all sorts of storytelling to write my way through my cancer. I wrote in my journal, and in the variety of little notebooks that I carried around with me. I typed out thoughts on my phone. I texted myself. I crafted stories to make sense of things and posted on my blog. I signed up for a poetry class, where all I wrote about was cancer and memories of my beloved grandmother.

Writing made me feel a wee bit better. A family member told me, "Your blog is too difficult for me to read." I smiled and nodded. Was I to write things to make her feel better?

"Well then don't read it then," I thought, hurt by her criticism. I know now that I was trying to sort out my own chaos through my writing. This was a good thing, not a bad thing. Life's chaotic interruptions are what shape us. Loss, loss and more loss are the hallmarks of life.

Nobody is guaranteed a pain-free life. It is a sad day indeed when we cannot express our own sorrow in whatever way makes the most sense for us.

What stories can do is neutralize our chaos, but we need time and space to tell them. Health care is reluctant to entertain true patient stories. They interfere with the system's preferred narrative, which is what Arthur Frank (*The Wounded Storyteller*) terms as restitution.

A restitution story sounds like "I was sick, the hospital cured me and now life is better than ever!" Tacked onto this is that clinicians are trained as heroes who always save the day. If our days are not saved, then they are no longer heroes. People don't want to hear the failed hero story. The only failed hero of this story of restitution is me, the patient.

Hospitals expect sick people to get well and to never talk about the actual visceral, traumatic experience of being ill. This is medicine's obsession with their own curative model. This happens a lot in the cancer world, where a chase for the cure is especially strong. In reality, there is no cure for cancer.

The way out of the chaotic storm of illness is to tell stories. The best sorts of people create space for stories. They can sit with an uncomfortable story without minimizing it, interrupting, looking for the bright side, correcting the storyteller or running away. Encouraging patients to tell their own stories in their own way paves the road towards healing.

DNA By Design

Tony Roberts, Director, Fostering Change

> "If they were motivated to change, they would attend their appointments".

For many years in mental health care, I've heard phrases like this from health professionals blaming patients for failure to attend appointments.

The logic goes something like:

- Billy has been referred to me as an expert in his problem
- Billy needs to be motivated to change
- A sign of Billy's motivation is that he attends his appointments
- Billy doesn't attend his appointments, therefore he isn't motivated to change
- And I can't help Billy if he is not motivated
- So I will discharge him

Logic like this fails to account for any barriers that stand between patients and their desired state – many of which are erected by the very service that is supposed to be helping. Here are some of them:

TRANSPORT: Many mental health services are clinic based, and aren't always in accessible locations. So the responsibility to get to the appointment falls on the party with the fewest available resources. Staff get paid to attend appointments, patients don't. Staff get mileage allowances, patients don't. Staff often have their own cars – patients often rely on public transport. Staff often have access to parking. Many patients don't.

TIMING OF APPOINTMENTS:
Appointments are often only available in office hours. People with work or childcare arrangements may not have time to race across town for an appointment. People with depression have their lowest mood earlier in the day. So why are they offered early appointments, when they are more likely to be feeling awful?

CONFIDENCE IN PROFESSIONALS:
Being professional involves reflection and introspection. Blaming patients for not attending is the antithesis of reflective practice. It moves professionals towards institutional arrogance. I can't be wrong. I'm too much of an expert to be wrong.

CONFIDENCE IN THE "THERAPY":
Mental health care should have the broadest range of available therapies. But we have CBT and we have Things That Aren't Called CBT But Realistically They Are Just CBT By Another Name. Diversity of service provision is key to finding an approach that is compelling to the person experiencing it. If it is compelling, they are more likely to want to get there.

The point about all of this is that systems are perfectly designed to achieve the results they get. If a service gets poor results, this is because it is perfectly designed to get poor results.

In a study with mental health patients, I explored the value of simply narrating your story and having an artist reflect it in a work of art. The feedback was astonishing, with one participant stating "I've been in mental health services for 18 years and this is the first time I've ever told my story".

Over 100 participants attended more than 600 sessions with a DNA rate of 0%. That is because we designed the study in partnership with the very people who would be joining. We explored ways to overcome their barriers to access. We worked around people's lives instead of expecting them to work their lives around us. We paid particular attention to what would make it compelling.

In short, we asked: how do people want to experience this? And how can our design guarantee that experience?"

I get that professionals feel frustrated when people don't attend appointments. But we shouldn't allow our frustration to become blame. Because in that direction, we only widen the gap between us and the people we exist to serve.

We need to understand that DNAs are designed into a service by prioritising the needs of the service above the needs of the people using it. With that insight, we can move beyond blame and start finding solutions.

Patients who lead

Douglas Findlay

...for Patient Leadership to be successful, it needs to become part of the organisational culture

Like much in the NHS, Patient Leadership is a bit of a curate's egg and whilst I don't like the title, Patient Leader does describe what the role is supposed to be about: patients who lead.

I've been a patient leader for 5 years and I can now see why the recruitment process was so rigorous and the initial training so detailed.

For me, the role has included being a contributor to research, a participant on senior clinician recruitment interview panels, helping with staff awards, being a committee member for both a medical school bid and for a possible facility closure. In recent months, I have been a steering group member for an Emergency Department re-design project and a representative on an Integrated Care Partnership clinical pathway redesign group.

The work has been interesting, stimulating and challenging. However, little of it has been what I would consider to be leadership. This brings me to the conclusion that either I am not leadership material, or that there has been little opportunity to lead within the involvement being offered to me.

Reflecting on this, I realise that in order for Patient Leadership to be successful, it needs to become part of the organisational culture, and for this to happen it should be a thread that runs throughout the places that Patient Leaders operate.

I am often faced with the conundrum that patient involvement looks and feels like tokenism. But it would be unkind to characterise it as such because the underlying desire of the individuals with whom I work, is mostly to make patient involvement a reality.

So, how could we do better?

Firstly, the culture of NHS organisations is often driven by results. Staff and services are commonly so stressed that the introduction of a potentially innovative or disruptive (voluntary)

role in a well-trodden path of top-down organisation, is asking too much for staff to understand or work with.

Secondly, patient leaders tend to be drawn from a typically self-selecting demographic. The stereotypical white middle-class retired volunteer is thankfully not too entrenched in my local experience, but nevertheless, people from seldom heard groups are not well represented.

Meetings are often scheduled during a typical 9-5 working day (despite the fact that many NHS organisations operate 24/7). Does this demonstrate a lack of imagination or an unwillingness to try harder? Not yet retired, I have occasionally volunteered at night and I'm not alone amongst my Patient Leadership colleagues in wanting greater flexibility.

Finally, we need to consider co-production. Where co-production is done well, patients and carers are brought into any proposed change projects at the very start of the planning process. They are chosen for their appropriate skills and they are true partners in the sense that they have as much of a voice in decisions as anyone else.

A major theme running through current NHS policies is the drive to include patients in their own health, care and safety, and I see the Patient Leader model as one great way of achieving this aim.

Read more about Leadership Development as a Patient Leader here.

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*

From setbacks to success

For some time now, health and social care services have been looking for "New Care Models" – propelled by the Five Year Forward View, Long Term Plan, Sustainability and Transformation Partnerships and the rest.

Patient and public involvement has played a big part, with views being sought through the usual mechanisms of public engagement and formal consultation. Often the discussions focus on what works best for patients, and how services can be made better for more people.

This American study works from the other end. The authors realised that a focus on success can sometimes mean missing an important part of the story: what innovators learn when things don't work out as planned. As they see it, healthcare leaders need to understand that setbacks and failures are inherent to innovation. Rather than being feared by people designing new care models, they should be seen as an opportunity to learn.

Fundamental to understanding setbacks is understanding patient experience. As the paper puts it, "When refining a new care model, examine which patients don't benefit".

One example was a programme to reduce avoidable hospitalisations among older adults. This sent advanced practice nurses into hospitals and patients' homes during transitions – such as after a major illness or surgery – to help coordinate care and offer services. But the model only worked for some patients, not all.

Discussions with patients and families found that having the same nurse practitioner visit patients in the hospital and their homes was pivotal because it engendered trust and led to clearer communication about their goals. What had appeared to be a design flaw in the care model was actually an issue about personal relationships.

Learning from failure is not always easy. According to one contributor, "One of the challenges of deliberately looking for blind spots is that many health care organizations haven't developed the discipline for doing so". Crucially, "You need to have a culture where people aren't going to be slammed for failing". And judging what works is not just a matter for clinicians. "We also need to consider what's important to patients – how do they define success and failure?"

A climate for change

What is the biggest challenge facing UK health and social care? Ageing population? Funding? Workforce?

According to the Lancet there is a much bigger challenge: climate change.

It says that "The nature and scale of the response to climate change will be the determining factor in shaping the health of nations for centuries to come". However, "A lack of progress... threatens both human lives and the viability of the national health systems they depend on, with the potential to disrupt core public health infrastructure and overwhelm health services". It goes on to say that, "Ensuring a widespread understanding of climate change as a central public health issue will be crucial".

We took this as a cue to see what public engagement is going on around health services in respect of climate change. Here's what we found:

- The newly published Public Health England Strategy 2020-25 contains just one reference to climate change in its 39 pages.

- The PHE Infectious Diseases Strategy has four mentions of climate change, but they all say much the same thing, and there is no reference to public engagement.

- The HM Government green paper, Advancing our health: prevention in the 2020s, has nothing whatsoever to say about climate change.

- To find climate change in the NHS Long Term Plan, you have to go all the way through to page 120, where it finally gets one mention in the Appendix.

This is surprising, because we know that some providers are working hard on environmental responsibility. There is a good summary here on how hospitals can cut greenhouse gas emissions, and an argument here for how the NHS can behave as an environmental anchor.

Given that "the response to climate change will be the determining factor in shaping the health of nations for centuries to come", we hope to see NHS England and Public Health England encouraging much greater efforts to engage with patients and public on the climate emergency.

Burnout and bias

"Despite efforts on multiple fronts, substantial morbidity and mortality differences persist between white and black patients, regardless of their socioeconomic status and level of education."

The opener to this paper touches on the important topic of health inequality. The NHS Long Term Plan is peppered with references to health inequality, many of which focus on public health issues such as smoking, obesity and air pollution.

This American study, however, tackles a different aspect of health inequality, by looking at black patients' experience of racial bias in healthcare. Specifically, the paper asks whether resident physicians showing signs of burnout are more likely to display racial bias in their encounters with patients.

Burnout is described as "emotional exhaustion, depersonalization, and a decreased sense of efficacy". It is, according to the authors, common among resident physicians, and largely driven by work-related factors. These include work intensity, suboptimal supervisor behaviour, lack of flexibility and control, educational debt, and work-home conflict.

The study found that staff with symptoms of burnout did indeed display higher levels of racial bias towards patients. To understand the effect of this, it refers to previous studies, which have shown that "physicians with higher implicit bias toward black people demonstrate fewer patient-centered behaviors during clinical interactions with black patients; in turn, their black patients have greater distrust, have lower level of adherence to treatment recommendations, and are less likely to follow up".

In the NHS, it is well known that staff experience is closely linked with patient experience. So with an NHS workforce under pressure, the implications of this study are serious. Not just for the care and safety of individual patients, but also for more strategic efforts to reduce health inequalities.

As the report says, "given the high prevalence of burnout and the negative implications of bias for medical care, symptoms of burnout may be factors in racial disparities in health care".

Cost effective feedback

Why do healthcare providers collect feedback from patients?

At a time when budgets are tight, and the NHS workforce is stretched, it is worth asking why time and money are spent on patient surveys, Friends and Family Test and other engagement activities.
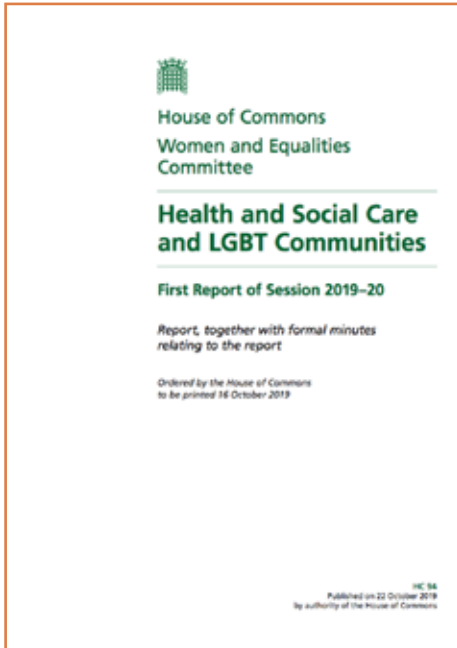
Some providers might cite quality improvement as a motive. Others might talk about person-centred care. Still others might refer to patient safety. All of these would be good reasons for trying to understand patient experience. Especially so in mental health services, since Care Quality Commission patient surveys repeatedly show that people with mental health conditions generally have poorer patient experience.

This paper looks at how patient feedback is gathered and used in NHS mental health services. Worryingly, in the context of pressures on finances and staffing, it found that half of Trusts collecting patient experience data were not actually using it. A quarter of Trusts struggled to collect it at all, and only one quarter used patient feedback to support change.

There is of course an ethical dimension to this: why ask patients for feedback if it is not going to be used? But the study also raises questions of cost-effectiveness. The authors make the point that "For patient experience processes to be cost-effective for NHS providers, they need to find ways of collecting and analysing patient experience feedback and then using it to drive change".

Increased patient experience activity in mental health services can, they say, lead to reduced rates of violent incidents, faster discharge and improved staff morale. All of these could be seen in terms of cost-effectiveness. But to achieve outcomes like these, "it is necessary to act on feedback in ways that facilitate meaningful change".

The authors of the study are now looking to work with NHS providers to implement recommendations from their report and evaluate the organisational and clinical cost-effectiveness of collecting, analysing and using patient experience feedback to improve service quality.

House of Commons
Women and Equalities
Committee

**Health and Social Care
and LGBT Communities**

First Report of Session 2019–20

*Report, together with formal minutes
relating to the report*

Ordered by the House of Commons
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HC 94
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Over the rainbow

Take up of the Rainbow Badge across the NHS demonstrates the scale of health service support for LGBT patients and staff.

An important principle underpinning the Rainbow Badge initiative is that wearing the badge is not, on its own, enough. Participating providers are expected to develop practical measures for a better and more inclusive experience for their LGBT employees and patients.

We recently pointed to evidence of the need for this, and now a House of Commons committee has weighed in with further evidence.

The report on Health and Social Care and LGBT Communities says that "Good quality medical care is the foundation of our health and social care service", and that "Treatment that is respectful and inclusive is a cornerstone of these services".

However, LGBT people are often less healthy than the wider population, and tend to receive lower levels of care than non-LGBT people. The committee found that "Too often medical professionals focus on sexual health rather than broader health needs and differences when supporting LGBT people".

The report states that "too few health and social care providers are actively thinking about LGBT people when they plan their services". Furthermore, "senior leaders are not doing enough to ensure that LGBT-inclusion is hardwired into commissioning strategies. This problem filters all the way down to training, where medics of the future are not taught how to provide LGBT-inclusive treatment".

The committee concludes that "training currently sends the message that sexual orientation and gender identity are not relevant to providing 'person-centred care'".

Encouragingly, the committee heard many examples of good practice – and while these are not as widespread as they should be, they are seen by the committee as "a clarion call to the health and social care sectors to take up the work that some very dedicated and inventive individuals have already begun".

RESEARCH ARTICLE   Open Access

How organisations promoting vaccination
respond to misinformation on social media:
a qualitative investigation

Maryke S. Steffens[1], Adam G. Dunn[1,2], Kerrie E. Wiley[1] and Julie Leask[1,3]

Abstract

Background: Vaccination misinformation is associated with serious public health consequences, such as a decrease in vaccination rates and a risk of disease outbreaks. Although social media offers organisations promoting vaccination unparalleled opportunities to promote evidence and counterbalance misinformation, we know relatively little about their internal workings. The aim of this paper is to explore the strategies, perspectives and experiences of communication working within such organisations as they promote vaccination and respond to misinformation on social media.

Methods: Using qualitative methods, we purposively sampled 21 participants responsible for routine social media activity and strategy from Australian organisations actively promoting vaccination on social media, including government health departments, local health services, advocacy groups, professional associations and technical scientific organisations. We conducted semi-structured, in-depth interviews to explore their perspectives and practices. Applying the Communication principles as a lens, we used framework Analysis to explore the data both inductively and deductively.

Results: Organisations promoting vaccination face multiple challenges on social media, including misinformation, anti-science sentiment, a complex vaccination narrative and anti-vaccine activists. They developed a range of sophisticated strategies in response, including communicating with openness in an evidence informed way, creating safe spaces to encourage audience dialogue, fostering community partnerships, and countering misinformation with care.

Conclusions: We recommend that communications consider directly countering misinformation because of the potential influence on their silent audience, i.e. those observing but not openly commenting, liking or sharing posts. Refutations should be straightforward, succinct and avoid emphasising misinformation. Communications should consider pairing scientific evidence with stories that speak to audience beliefs and values. Finally, organisations could enhance vaccine promotion and their own credibility on social media by forming strong links with organisations sharing similar values and goals.

Keywords: Misinformation, Immunisation, Vaccination, Anti-vaccination movement, Social media, Health communication, Health promotion, Public health, Qualitative methods

When PPI goes wrong

Patient and public involvement in healthcare is generally seen as A Good Thing. But what happens when PPI takes off in directions that neither health professionals nor some patient advocates might have expected?

This paper looks at the use of social media by groups seeking to promote an anti-vaccination message. Their tactics, according to the authors, include misinformation and anti-science sentiment. And these can be hard to counter because vaccination narratives can be complex, and the science may not be 100% clear cut.

Calm and rational dialogue is further compromised by notions of a "war" between people labelled on one hand as "anti-vaxxers" and on the other as uncaring professionals who are "in it for the money". Study participants described being "bombarded" on social media, and treading through a "minefield". They recounted crude language, vitriol and personal attacks.

So how do organisations promoting vaccine use deal with this particular type of patient and public involvement?

Using facts and evidence was important – even in the context of "anti-science sentiment". However, complex evidence needed to be explained in straightforward language.

Emotions matter too – so facts needed to be humanised with stories about the actual effects of preventable disease on real people.

It was important to create safe online spaces for information and debate – for example by quickly removing aggressive comments, and reporting offensive posts.

Responses had to be concise and respectful – and selective too, to avoid amplifying misinformation, or giving false legitimacy to some anti-vaccine views.

Alongside all of this, say the authors, is a need to publicly strengthen the pro-vaccination voice. Partnerships with other organisations played an important role in sharing and amplifying the collective voice. But the belief that vaccine-promoting organisations as a group were failing to adequately engage in the social media landscape was a source of frustration for some participants.

This is an insightful paper – focussed on the anti-vaccine issue, but potentially useful to guide online responses to other contested areas in healthcare.

How helpful are involvement strategies?

Why do organisations publish patient and public involvement (PPI) strategies?

Presumably it is to help readers understand how and why the organisation carries out its involvement work. But, say the authors of this paper, PPI strategies can also have symbolic importance.

For example, "The presence of a PPI strategic document on a website or the production of this evidence on request is interpreted as a signal that efforts are being made". On the other hand, "The absence of documentation can be negatively interpreted… as a lack of intent".

So are PPI strategies just for show, or do they have practical value?

The authors used the National Involvement Standards (4Pi) framework to assess the extent to which various PPI strategies demonstrated principles, purpose, presence, process and impact. They found that not one met the full range of standards.

Further findings were that:

- Readers were required to work hard to disentangle the 'why' (strategic aim) and 'how' (plan of action) of involvement. There were limited, absent, and confusing aims that were rarely, if ever, logically linked to the proposed process of involvement.

- Documents differed in accessibility of language and content. Some were closer to Plain English and clearly explained NHS or organisational structures, but managerial and technical language with jargon and acronyms dominated the sample.

- Very few documents stated any meaningful detail about who was to be involved, for example by offering data about the local community or demographic information about the patient population across services. This, according to the authors, is especially concerning when considering issues of inclusivity, equity and equality.

The paper aims to "open the debate about the limitations of PPI strategic documents". It suggests an alternative approach – based on continually testing and learning from practice. Through small tests of change or Plan-Do-Study-Act (PDSA) cycles, professionals, patients and public can learn together about what works, how and why. The authors state that this "has the potential to release practitioners from the tokenistic cycle of monitoring and reporting… replacing it with a richer understanding".

Briefing
November 2019

Briefing: The
measurement maze

A snapshot of national quality indicators across three
clinical areas, and their impact on clinical teams
Sally Al-Zaidy, Aoife Molloy, Catherine Turton and Ruth Thorlby

The Health Foundation

The measurement maze

Measuring patient experience is never easy. Perhaps that is why there are so many approaches – including the Friends and Family Test, CQC and NHS England patient surveys, complaints processes, local Healthwatch reports, and more. But does the plethora of measurement systems create more confusion than clarity?

This report from the Health Foundation looks at quality measurement – including patient experience – across various care services. Its findings will resonate strongly with anyone who has to deal with the morass of patient experience data.

Interestingly, its findings on the often contentious Friends and Family Test are broadly positive. "While many interviewees acknowledged that it is a fairly limited tool, it was still seen as a valuable resource, without which there would be a considerable gap in measuring patient experience."

Other comments, however, reflect concerns about the value of data collection and use. A key question is what is being collected and why: "All the [data] we collect feels like a huge task and nothing happens to it... we're told we have to collect it, but [we're] not aware that it goes anywhere else." Another is the timeliness of data feedback: "it is painfully slow, which makes it irrelevant".

Even where the indicator data are released in a timely and comparable form, the interviews suggested that the potential usefulness for trusts, wards or teams was limited by the data being hard to locate online, with multiple spreadsheets to choose from and large Excel workbooks to download and navigate.

So how can we find a clearer path through the measurement maze? One suggestion is about analytical tools. "Any approach to enabling greater use of data for local improvement will need to consider the lack of analytical capacity within NHS organisations." Another suggestion is more radical, involving a national overhaul of measurement systems. "There is a case for... streamlining and simplifying. It is currently not clear whether [anyone] maintains an overview of all the indicators in use across the system."

Encouragingly, interviewees across all five case study sites expressed a desire for more emphasis on patients' experience of health care services. For some, this would mean questioning whether what is measured also reflects what is important to patients.

Shrewsbury and Telford is not an outlier

In response to a leaked report on the deaths of mothers and babies at the Shrewsbury and Telford Hospital NHS Trust, the media have picked out revelations of a "toxic culture" that appears to have been at the heart of the disaster.

The culture included dismissive attitudes towards patients and bereaved relatives who raised concerns. There was, apparently, "A long-term lack of transparency, honesty and communication with families".

But denial and defensiveness in the face of patient concerns is not unique to Shrewsbury and Telford. It runs through other inquiry reports, including the Francis report on the Mid Staffordshire disaster, and avoidable deaths reports from Morecambe Bay, Southern Health, Gosport, and Cwm Taf. They crop up again in Ombudsman reports such as Learning from Mistakes and Ignoring the Alarms.

Evidence repeatedly shows that a poor culture of responsiveness to patients who have been harmed is not unique to one or two "bad apples". It is widespread.

We need to recognise that the culture of any one healthcare provider does not arise in isolation. It is part of, and to some extent derives from, an overarching NHS culture which also has a tendency to be dismissive of patient feedback. Evidence of this includes the following:

• We tolerate the use of dismissive language. Patient feedback is routinely referred to as "anecdotal evidence".

• We are comfortable with a double standard in use of evidence. Medical evidence is cherished, preserved and used. Patient experience evidence is treated as disposable.

• We are content to weaken the independent patient voice. Healthwatch, set up as a strengthened successor to the Local Involvement Networks, has seen its funding reduced by over a third.

We can tackle all of this. The term "anecdotal evidence" must be challenged wherever it is used. Directors of Nursing could lead on this. Patient experience evidence should be embedded in professional training, clinical guidelines and practice protocols – just as medical evidence is. NHS England has the Patient Experience Library at its disposal – it just needs to start using it. Healthwatch funding should be restored to its original 2013 level. That is a job for the Secretary of State.

None of this would be hard to do. But it all needs explicit commitment from people in leadership positions

What do patient surveys mean?

Shrewsbury and Telford, Morecambe Bay and Cwm Taf offer ample evidence of the need to pay attention to patient experience in maternity care. In every case, women and birth partners raised concerns, only to be met with institutional defensiveness and denial. The result was serious harm and avoidable death.

Efforts to understand experience of maternity care can help to underpin evidence-based practice. This can improve risk management and contribute to quality improvement. But what do we actually mean by "women's experiences of maternity care"? This paper says that the concept is ambiguous and ill-defined.

Many healthcare systems use large-scale surveys to explore patient experience – but there is no universally accepted definition of what is meant by "women's experiences of maternity care". So what is actually being explored via patient surveys?

Sometimes the basic concept is interpreted as meaning "women's satisfaction with their maternity care". But, say the authors, measurement of "satisfaction" has limited usefulness for understanding and improving the quality of care. That is because surveys tend to extract high reported levels of contentment. This may be in part because of an "acquiescence bias" that may mask critical issues.

As satisfaction with care has generally been reported as high (regardless of the actual quality of care that was being provided), focus has shifted from the measurement of "women's satisfaction with their maternity care" to "women's experiences of their maternity care". However, the study finds that clear conceptual boundaries between these concepts do not exist. Consequently, it concludes, the concept of "women's experiences of their maternity care" is philosophically immature.

The study raises important and intellectually challenging questions for patient experience staff. If we have no clear definition of "women's experiences of maternity care", what are patient surveys actually studying, and why? And once they are complete, what do the survey results actually tell us?
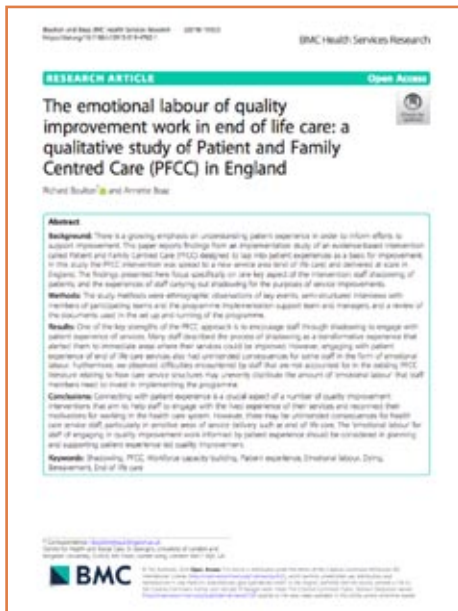
Emotional labour in patient experience

"Connecting with patient experience is a crucial aspect of... quality improvement interventions", according to this study. "However", it says, "there may be unintended consequences for health care service staff, particularly in sensitive areas of service delivery such as end of life care".

The study looked at the technique of "patient shadowing", intended to help practitioners see healthcare services from the perspective of patients and their families. The process enables them not only to see the problems with their service, but also to empathise from the perspective of the patient. Shadowing has been described as creating "a sense of empathy and urgency among caregivers by highlighting and clarifying the patient and family experience in a way that cannot be understood unless one 'walks in their footsteps'".

The researchers evaluated an improvement programme that included elements of patient shadowing and found that "the emotional power of shadowing was cited by staff... as initiating many transformative effects". However, they also found other consequences.

One of these was anxiety – particularly in respect of "putting colleagues under scrutiny". This was compounded if staff were being asked to do shadowing by more senior members of a team. Another was "resistance". For example, some staff expressed concern that patients may not feel comfortable with being observed, even though the assumption was largely unfounded.

The researchers observe that "Shadowing cannot be considered as a tool that is socially, politically or culturally neutral". Indeed, "Many varied social, cultural and political attitudes to shadowing were found among services: some staff felt surveyed or scrutinised by being shadowed by colleagues, whilst others reacted to shadowing as if it were thrust upon them".

The paper concludes that "Even though it is an intended consequence of shadowing to instil an emotional response... there was also potential for [shadowing] activities to intensify the strain upon staff, particularly those at lower levels of care service hierarchies". "This", say the authors, "emphasises the importance of organisational support for staff wellbeing when carrying out service improvements in this way".

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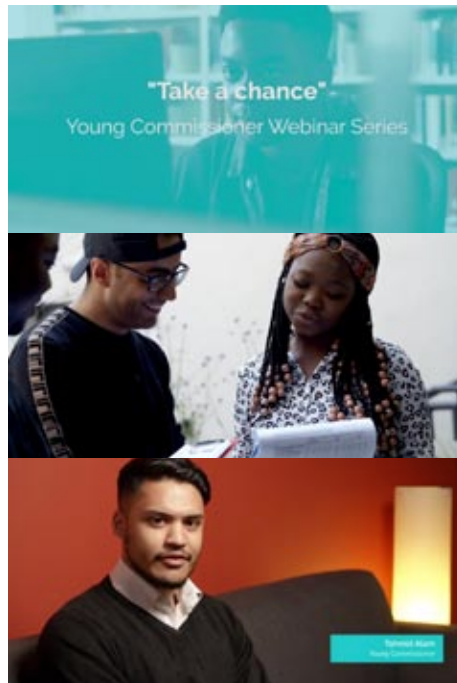
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- Webinar 2 Review & Analysis: This 30 minutes webinar series will help you to deliver and review the young commissioner model's impact on real world problems.

Further details from:
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Sue Robins (see The Patient Storyteller, page 3 in this magazine) is coming to the UK for a book tour, picking out themes of patient experience and humanity in health care from her new book, Bird's Eye View. Dates include London, Nottingham and Liverpool in mid-March. For details, or to see whether Sue could speak at your event,

Contact:
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