

Patient Experience

and patient/public involvement in health and care services

Spring 2019



**Patient
Experience
Library**

INSIDE

**Two Truths
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What happens when two or more versions of truth, otherwise in conflict, come together to create a new version of the truth?

That is the question posed by Jessie Cunnett, the first of our contributors to this edition of Patient Experience Quarterly. She makes the point that when it comes to issues of patient safety or fitness to practise, different stakeholders have different

ways of understanding what matters. Clinicians start from a medical perspective. Lawyers want to determine right and wrong. Patients and their relatives work from subjective experience.

As Cunnett sees it, professional regulation in its current legalistic form is not keen on subjective accounts. It wants to identify statements of fact so that all doubt is removed. But for her, the facts must be judged in context. And the patient experience is an essential part of understanding evidence roundly and in a meaningful way.

Our other contributors pick up the idea of differing – sometimes conflicting – truths. Mark Hudson nearly died – and that changed his life for the better. He has dyslexia – and gets his ideas across through his writing. His dream of being a doctor was shattered – but he is able to help people recovering from the experience of intensive care. Liza Morton nearly died as a baby, and then became, in her own words, a “medical curiosity”. She owes her life to science, but wonders whether there is more room for recognising the emotional toll of treatment – for both patients and clinicians. Mark’s and Liza’s stories show that in healthcare, objective science and subjective experience are closely intertwined.

There are yet more truths to be found in our round-up of the latest studies and surveys on patient experience. Our mission (in a “post-truth” world) is to put patient experience work on the same evidence-based footing as clinical work. So it is heartening to see excellent evidence being produced by academics, charities and government bodies. We continue to collate, catalogue and preserve as much of it as we can.

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

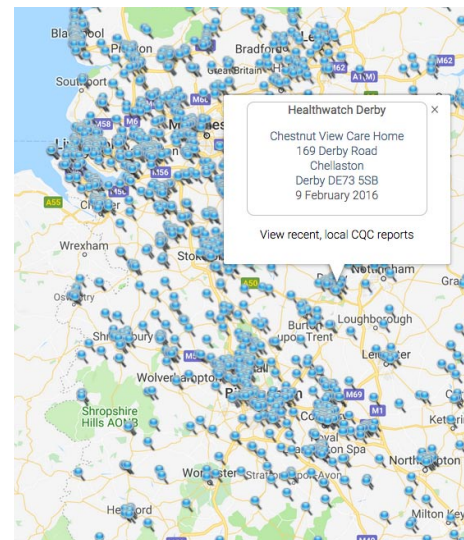
Miles Sibley, Editor

info@patientlibrary.net

www.patientlibrary.net

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!



The Power of Two Truths

Jessie Cunnett



What happens when two or more versions of truth, otherwise in conflict, come together to create a new version of the truth?

Health care provides a complex landscape on which to consider concepts of truth and fact. Medicine seeks the scientific and rational application of objective evidence and yet the human experience of healthcare is subjective, emotional and multi-layered.

A recent article about absolutism struck a chord on this matter. [Oliver Burkeman](#) says we all engage in absolutist thinking, because it's easier clinging to simple rules to navigate what would otherwise be an overwhelmingly complex planet.

Does this mean that in our attempts to make sense of events we aim to remove all variables? Seeing anything that can't be proved as evidential fact as irrelevant.

Professional health regulation provides an opportunity to explore this tension. After a complaint about a health professional, it is right to investigate the facts to see whether the individual was at fault. A huge amount rests

on a fitness to practise decision: the safety of patients, the livelihoods of the professionals concerned and confidence in the health professions as a whole.

Health care regulation has been in the spotlight lately with the painful impact on patients and families set out following the tragic failings at Furness General Hospital. The challenging circumstances of the recent [Bawa-Garba case](#) provide another view of the complexities.

The legal profession aims to see such situations in absolutist terms as it tries to determine the facts. But the relationship between care giver and care receiver is built on much more than binary rules. The pure facts of a situation are entwined with expectation, hope and emotion. Can it ever be possible to judge through an absolutist lens where the stakes are so high for everyone involved? Lives and livelihoods, professionalism and values, acceptance and loss, grief and anger.

The patient and family truth tends to hold less value in individual regulatory investigations, from Mid Staffordshire, to Morecambe Bay and on to Gosport. At the centre of all of these are families searching for truth and for reassurance that the lives of loved ones haven't been lost in vain. Why, despite long and hard campaigns, is patient and family experience not seen as being as valuable as other sources of evidence?

Perhaps because the experience of the patient and family is complex, with information presented in narrative form as the situation unfolds. An experience that doesn't differentiate between organisational or professional

boundaries. The patient and family view is subjective, with those personally impacted at the centre, re-telling the experience as it happened to them, with all the emotion in full view. Professional regulation in its current legalistic form is not keen on narrative, emotion or subjective accounts. It wants to identify statements of fact so that all doubt is removed.

If the goal is to protect the public by being assured that registered professionals are fit to practise we must move to a position where we can judge this in context. To consider circumstances from a rounded knowledge base in which the narrative of patients and families plays an essential role in understanding what happened and what being safe and fit to practise looks like. To do this, we need to place the patient at the centre of the hypothesis. In a complicated system of multi-disciplinary professionals we need to locate the consistent factors and not be so precious about professional boundaries.

By placing the patient experience at the centre of the argument we can broaden our knowledge and interrogate the evidence roundly and in a meaningful way. We can then seek to understand a world in which the power of two truths can be seen as the best way to understand what happened and to guide us towards ensuring patients are safe from harm.

Jessie Cunnett is Head of Public Support at the Nursing and Midwifery Council

Prior to working with the NMC Jessie led a number of pioneering projects as Director of Patient and Public Involvement Solutions [@ppisolutions](#)

Nearly dying made my life better

Mark Hudson



I am an Intensive Care Unit survivor, a sepsis survivor, a stomite, living with load of autoimmune issues and battling mental health issues. But less about my hang-ups.

“How can nearly dying be a good thing?” I hear you say. It’s simple – from a young age I wanted to be a doctor because there is nothing more important than helping sick people get better.

However my dyslexia made it difficult for me to get into a medical degree and my autoimmune hepatitis and ulcerative colitis made it a steep uphill slope. So I pivoted to chemistry because I loved it and I thought working in the pharmaceutical industry could be my way of helping people.

Before my final year my colon gave out leaving me bleeding and pleading to die. I had my colectomy and completed my degree but it took its toll on me. I had two good years with a large pharmaceutical company before I started having twists and peristomal hernia repairs. This led to my ICU

I have a motto for my medical life: survive, adapt and thrive. You can’t change what happened to you but you can make the most of it and be the best you can be.

admission, with an induced coma for 2 and a half weeks and a stay of 17 weeks in hospital. I suffered from delirium, depression, anxiety, ptsd, muscle weakness, fatigue and cognitive and memory issues. My family were told multiple times that I was not going to survive (spoiler: I didn’t die in case you were wondering).

I won the fight but I can hear you thinking, ‘Mark I don’t see how this made your life better’. Ok, ok I am getting to the point but the prelude was needed to explain why the next bit is so important.

Being an ICU survivor has opened opportunities that were not even possible to think about before. I became a peer volunteer for InS:PIRE, a post ICU rehabilitation clinic/service, and got to help people by sharing my story. I’ll say that again – I got to help people and not in a small or casual way. My input was welcomed by the clinic staff and helped patients to realise that what they are going through is normal. This role is the single most fulfilling job I’ve ever done. No feeling can match an ICU survivor coming up to you and shaking your hand and thanking you.

As an advocate for improving ICU and post ICU care on Twitter I have had world leading experts in ICU care thank me for sharing my experiences or

giving my insights. It is amazing – me, who is just a guy in Scotland with no special medical training or education is being treated as an equal by Drs, Nurses, Occupational Therapists, Physiotherapists (our affectionate term for Physiotherapists, since they terrorise patients to get up on day one after surgery) etc from all over the world.

A stoma care nurse explained to me that I speak about my experiences in an eloquent way. I thought well I am glad I fooled someone because I got a C in higher English and get anxiety about talking in public. I have improved greatly since then, but I don’t think I am a great public speaker, passionate but not great.

This brings me on to my poetry. Poems help me to convey serious issues in bite size chunks for busy people like Drs and nurses. I spoke at an event with other survivors, who said they were moved by my poems which was a great feeling. I have been asked about potentially working as a ‘patient expert’ in research and I have volunteered to be a patient reviewer for the BMJ.

None of these wonderful life changing experiences would have been open to me if I had not nearly died in ICU. The person I am today makes a difference, maybe not how my six year old self expected to but it doesn’t lessen it. I get to help people, and there is no greater thing in life than to help your fellow humans.

I have a motto for my medical life: survive, adapt and thrive. You can’t change what happened to you but you can make the most of it and be the best you can be.

The heart of medicine

Liza Morton



At a few days old, I was transferred to hospital, where, already in congestive heart failure, I was attached to an external cardiac pacemaker. When this restored life – in a world first for an 11 day old baby – I was diagnosed as having complete heart block and fitted with an implantable pacemaker.

Now an adult and mother of one, I am tremendously grateful to the NHS, advances in medicine, and those pioneers for my life. Yet, growing up with a heart condition has not been easy. Early pacemakers were unreliable and often needed reprogramming. I remember lying still, surrounded by men in white coats armed with a magnet, leads, cold gel, stethoscopes, and electrodes. They would make my heart beat faster, then slower, as they interrogated the pacemaker.

I was a medical curiosity.

I was also a little girl who just wanted to do things that other little girls took for granted. But those early pacemakers propelled my heart to beat at a fixed rate whatever I did, limiting me physically. I turned blue when cold, vomited on overexertion, and often felt

dizzy. I wasn't allowed to attend dance or horse riding lessons, jump on a trampoline, take part in gym lessons, or join in with skipping games.

Sometimes, I felt that these limitations were dismissed perhaps because nothing could be done about them. Yet, instead of being told I should be able to lead a normal life, it would have helped me to have these obstacles validated so I was better supported to find my own way.

By the age of 7, I had been fitted with five pacemakers. I was a quiet child and was often told how brave I was. However, I was never sure if this was an observation, expectation, or demand. Often I didn't feel very brave. I just developed a fine ability to keep very still and quiet. If you wriggle when having a catheter inserted or an injection it hurts more and takes longer.

Being a "good patient" was rewarded with a smiley sticker. Although it helped to have treats to look forward to during difficult experiences, it is important that they are not used as a "reward" for suppressing emotion. Looking back, it would have helped if I had been told it was okay to cry, scream, or feel angry, even if after the event, because these are normal responses to pain or threat.

I was fortunate that my care throughout my childhood was delivered by the same team, enabling me to build a close bond with them. However, this has not been the case since reaching adulthood. My experiences have led me to trust medical professionals who listen to me and acknowledge my lifelong

Looking back, it would have helped if I had been told it was okay to cry, scream, or feel angry

experience of living with this condition and those who involve me in my care, are honest about the limitations of their knowledge, seek guidance, and remember I am not just a medical condition.

The misguided care I have experienced (difficulties in the emergency department, accessing specialist care, and during pregnancy) has occurred when this has not been the case.

When I have been cared for by a nurturing, mutually supportive team it is apparent in the sense of camaraderie, warmth, and compassion. By contrast, my experience of stressed out staff has been that of being snapped at, forgotten, and consequently feeling unsafe.

I often wonder if medical professionals would be better able to accommodate the emotional needs of their patients if they had space to explore their own feelings about the difficult work they are required to do.

Dr Liza Morton is a Chartered Counselling Psychologist:
www.drlizamorton.com

[@drlizamorton](https://twitter.com/drlizamorton)

This piece originally appeared as a longer article in the *BMJ*.

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

Wicki BMC Medicine (2018) 16:217
<https://doi.org/10.1186/s13059-018-1216-2>

BMC Medicine

EDITORIAL

Open Access

Patient, study thyself

Paul Wicki

Abstract

The past 15 years have seen the emergence of a new paradigm in medical research, namely of people living with medical conditions (whether patients, parents, or caregivers) using digital tools to conduct N-of-1 trials and scientifically grounded research on themselves, whilst using the Internet to form communities of like-minded individuals willing to self-experiment. Prominent examples can be found in amyotrophic lateral sclerosis/motor neurone disease (the 10thm study on [FriedrichsMed](#)), Parkinson's disease ('digital patient' Sara Ruggani), and diabetes (the 'open artificial pancreas' of the [iN1AveHortWaring](#) movement). Through transparency, data sharing, open source code, and publication in the peer-reviewed scientific literature, such activities conform to expected scientific conventions. However, other conventions, such as ethical oversight, regulation, professionalisation, and the ability to translate this new form of relatively biased data into generalizable decisions, remain challenged. While critics worry such participant-led research merely muddies the waters of high-quality medical research and exposes patients to new harms, the potential is there to enroll millions of active minds in unravelling the wicked problems of complex medical disorders that degrade the human health span.

Keywords: Patient engagement, Medical informatics, Patient-reported outcomes, Smartphones, Machine learning

Background

At the time of BMC Medicine's launch 15 years ago, I was conducting what I thought was fairly 'high-tech' neuropsychology research for my PhD. Each week, I would drive out to the homes of people living with amyotrophic lateral sclerosis (ALS) to administer computerized psychological tests and invite them to our neuroimaging unit to have MRI and PET brain scans [1]. Since then, the most visible changes to medical research have been technological: for example, the heavy 486 laptops and the stack of inch-thick paper test batteries that I wheeled around in a 22 kg suitcase would now work more reliably as software apps on a 0.5 kg iPad [2]. However, I do not believe that the consumer electronics revolution of smartphones, tablets, and social media is the most profound change to have taken place during that time.

Patients are doing it for themselves

Instead, I think the largest shift in the past 15 years has been social, wherein patients, caregivers, parents, and family members have realized that 'research' is not just something that professionals do to them

when they venture forth from their ivory towers, but that science and research are a set of tools and thinking methods that can be applied by anyone. My own wakeup call arrived in 2003, when I volunteered to take over as webmaster for an online community of people with ALS in the UK, called BUILD-UK [3]. As I was studying the supposedly rare issue of dementia in ALS, I was relentlessly grilled by patients rightfully asking why I was studying a potentially rare consequence of the disease that would take years to reap insights when patients were dying right now. Could the money not be better deployed towards clinical trials? I was surprised and impressed at the way they dissected clinical trial protocols, posed many of the same research questions I wondered about at conferences, and actually generated solutions that could immediately help other patients like them, rather than waiting for a peer-reviewed article to appear in print several years later. Most research professionals I spoke to seemed to merely tolerate 'lay people' having these discussions. However, not until one patient requested knowledge of their trial group allocation and actually had their study medication sent to a lab for testing, were they taken seriously [4].

**BMC**

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Patient, study thyself

Patient and public involvement (PPI) is a topic frequently discussed by health professionals and researchers. Good practice and ethics are important considerations – so the debate is often about how to “empower” patients, rather than simply exploit their experience and goodwill.

But what happens if patients stop waiting to be empowered, and simply start conducting research on themselves, and on their own terms?

The idea may sound bizarre – dangerous even. But modern medicine is built, at least in part, on knowledge gained by pioneering doctors who have [experimented on themselves](#). So if it's ok for doctors, why not for patients?

This paper outlines examples of patients with complex medical conditions who – singly or in groups – have tested drug treatments, monitored disease progression, and developed home-made technological devices. They have published their results – not through academic journals, but through online forums which also offer shared knowledge and peer support.

Through transparency, data sharing, open source code, and publication in the peer-reviewed scientific literature, these activities conform to expected scientific conventions. However, other conventions, such as ethical oversight, regulation, and professionalisation may be adhered to poorly or not at all. While critics worry such participant-led research merely muddies the waters of high-quality medical research and exposes patients to new harms, the potential – according to this paper – is to enrol millions of active minds in tackling the problems of complex medical disorders.

We have previously discussed the way in which health professionals debate different types of patient/public involvement, without necessarily realising that [their own roles can chop and change](#) in the process. Is it time for professionals to stop talking about how they “involve” and “empower” patients, and start talking instead about how they partner with, and learn with patients?

Let's be clear: we do not advocate patients experimenting on themselves. But as this paper shows, some patient groups are heading in that direction. Health professionals – and their debates – may need to find ways to keep up.

Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience.

Jane K O'Hara,^{1,2} Karina Aase,³ Justin Waring⁴

¹Lancs Institute of Medical Education, University of Lancs, Lancs, UK
²Healthcare Quality and Safety Research Group, Bradford Institute of Health Research, Bradford Teaching Hospitals NHS Trust, Bradford, UK
³Faculty of Health Sciences, Centre for Healthcare Innovation, University of Birmingham, Birmingham, UK
⁴Centre for Health Innovation, Learning and Learning, University of Birmingham, Birmingham, UK

Correspondence to:
Dr Jane K O'Hara, Lancs Institute of Medical Education, University of Lancs, Lancs LS2 9JT, UK.
jane.o'hara@lancs.ac.uk
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Redley and colleagues' study¹ suggests that involving patients in their care can be challenging, even when patients express a preference for involvement. Their paper examines a key opportunity for patient engagement—the ward round—and investigates the links between patients' expressed preference to be involved and their observed level of involvement during subsequent ward rounds. The authors report little relationship between the two, concluding that involvement is affected by a range of contextual factors.

This finding, while disappointing, comes as little surprise to those who have spent any time in the ever-changing clinical environment of an acute hospital ward. What patients want in terms of active involvement, and what they can and do receive, varies in all kinds of ways. The reality of involving patients and families is that both preferences and opportunities for involvement are situated within a complex, dynamic healthcare system. Furthermore, it could be argued that by focusing only on a single opportunity for involvement—in this case shared decision-making within the ward round—we fail to recognise the role of patients and families as active partners across their care experience and the actions and adjustments they routinely make to support the quality and safety of their care. Put simply, these adjustments represent a source of resilience in our healthcare systems. In this editorial, we explore how facilitating these adjustments across the range of care experiences might create better quality and safer care.

WHAT IS SYSTEM RESILIENCE, AND WHY SHOULD WE SEEK TO ENHANCE IT?

Healthcare is increasingly recognised as a 'complex adaptive system',^{2,3} within which resilience is seen as:

... the intrinsic ability of a system to adjust its functioning prior to, during or following changes/disruptions in order to sustain required operations under expected or unexpected conditions.⁴

Thus, resilience is an attribute of a system that allows it to flex and adapt to unpredictable circumstances. Traditionally, such flexing has been seen in negative terms, described variously as 'violations' or 'work-arounds'.⁵ However, this flexibility may be what is needed to allow care delivery to meet the needs of varying conditions, to produce positive outcomes, and importantly, to support more patient-centred care.⁶

It has been suggested that the main solution for supporting resilience is to manage, or 'dampen' performance variability, particularly where variability may have a disproportionate impact on desired outcomes.⁷ We believe that patients, their families and carers, due to their unique positioning outside, inside and across healthcare system boundaries, are well-placed to provide this dampening function, and in doing so, may help to create better quality, safer care, more of the time.

HOW MIGHT PATIENTS AND THEIR FAMILIES BE A SOURCE OF HEALTHCARE RESILIENCE?

Consider for a moment the experiences when you, your family or friends, have sought care from health services. It is conceivable that you have had to undertake unexpected activity to achieve your goals. Examples might include chasing appointment times, or correcting the information on which clinical decisions are made. This type of activity may be understood as 'reaching in' to services and compensating for system complexity, and it is often necessary to achieve more

Patient powered resilience

We all know that our healthcare system struggles at times. Newsfeeds routinely contain stories of workforce pressures, finance pressures, winter pressures and more.

The answer, according to some, is to develop “resilience” within healthcare services and systems. But what does that actually mean?

For the authors of this paper, resilience *“is an attribute of a system that allows it to flex and adapt to unpredictable circumstances”*. They explain that *“flexibility may be what is needed to allow care delivery to meet the needs of varying conditions, to produce positive outcomes, and importantly, to support more patient-centred care”*.

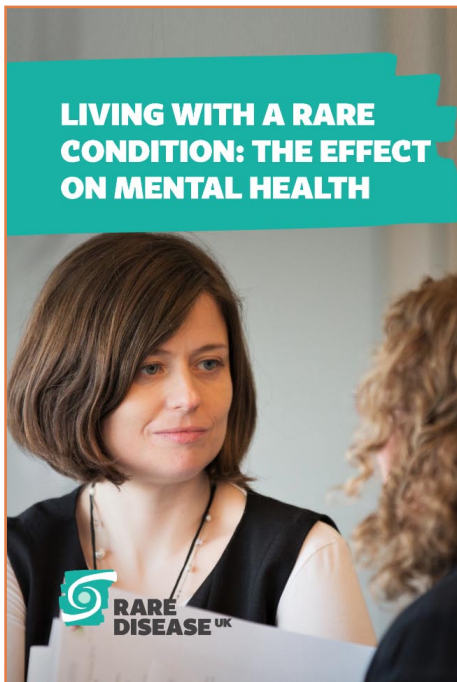
That might sound like a cue for hollow laughter from staff trapped in highly inflexible IT systems, reporting requirements, management procedures and so on. But help might be available from an unexpected direction – the patients.

The paper observes that patients, families and carers sit within *and* outside *and* across organisational boundaries. *“Their movement across... boundaries means that they are uniquely positioned to understand how different system components work, often in ways that elude the understanding of professionals”*.

From this perspective, they may be able to act as knowledge brokers, filling structural holes and helping to *“manage the inconsistencies and unwanted variability in the care system”*.

Examples include *“undertaking their own reconciliation of their medications following discharge from hospital, or proactively contacting their GP or community pharmacy where medications have been changed”*.

Patient and public involvement is often thought of in terms of how to “reach out” to service users, and encourage them to contribute to professional agendas for service delivery. But this paper argues that *“What is needed is to provide everyday opportunities for [patients] ‘reaching in’ to healthcare systems”*, bringing with them *“a unique source of insight and resilience”*.



Rare disease and mental health

We have previously touched on the experiences of parents who have children with rare diseases. We featured a [Canadian study](#) which described a complicated experience, with numerous doctors' appointments, and the need for persistence in pursuit of a definitive diagnosis. It found contentious relationships with healthcare providers, and a lack of formal care co-ordination and communication between services.

This UK study touches on similar issues, and explores the effect on the mental health of adult patients living with rare disease, and their carers. It notes that living with a chronic or progressive condition can adversely affect mental health, and that for some conditions, mental health problems are directly associated with the underlying diagnosis.

The report is based on a survey which found over 90% of respondents feeling low, stressed or worried about their condition. 88% have felt emotionally exhausted, and 70% have felt at breaking point. Poor care co-ordination can also have a negative impact. And parents and carers have the additional burden of worry about their child's wellbeing: more than 95% felt that worrying about their child affected their own mental health.

Over 80% of respondents put feelings of this kind down to health professionals having a poor awareness of their condition, along with a sense of not being believed. Mislabelling and misdiagnosis can delay the start of appropriate management and treatment, and can also prevent people from seeking help.

In spite of this, around half of patients and carers affected by rare disease are never asked about their mental health.

Healthcare professionals might be tempted to think that rare disease is a niche topic. And it is true that a single rare disease may affect a relatively small number of people. But there are over 6,000 known rare diseases, so a much larger number are affected overall.

The report is clear that awareness among healthcare professionals needs to improve. Understanding the patient and carer experience might be a good place to start.

The Patient Experience Library
All the insight you need



Developing a patient safety strategy for the NHS

Proposals for consultation December 2018
Response from the Patient Experience Library, January 2019

Introduction

NHS Improvement has invited comments on proposals for a patient safety strategy. The aim is to “make sure people receive the safest care possible”.

We are pleased to see reference to Gosport, Mid Staffordshire and Morecambe Bay at the very start of the consultation document. The fundamental learning point from those incidents is that when the patient voice goes unheard, people die.

Patients can sometimes spot risks and errors that have been missed by busy health professionals. And they can give voice to concerns that dysfunctional organisational cultures would prefer not to hear.

Sir Robert Francis said that a healthcare system that listens to patients “will be more likely to detect the early warning signs that something requires correction, to address such issues and to protect others from harmful treatment”. Our response, set out below, will focus on the need to put patient experience, and patient voice, at the centre of a patient safety strategy.

Our comments come from our unique experience in maintaining the UK’s national evidence base on patient experience. That evidence base should itself be embedded within a systematic approach to patient safety across the NHS.

We are grateful for the opportunity to comment on the consultation proposals, and we offer the following response in a spirit of partnership.

The language and culture of complaints

During January and February, NHS Improvement was inviting comments on [proposals for a patient safety strategy](#). Importantly, the proposals made repeated reference to a “just safety culture”. This matters, because a key learning point from Mid Staffs, Morecambe Bay, Gosport and elsewhere is that regulation and procedure alone cannot protect patients from unsafe cultures.

So where do unsafe cultures come from? Sometimes they can arise from the visible effects of poor leadership, bullying of staff, or workforce pressures. But some influences on culture are less visible. When culture is just “the way we do things around here”, staff can become oblivious to the ways in which their behaviour and attitudes can affect patient safety.

One example is the language that is commonly used to describe patient feedback. We can start with the language of “complaints”.

When a health professional flags up something that has gone wrong, it is called an incident report. But when a patient does the same, it is called a complaint. The word “complaint” is synonymous with words like “objection”, “grievance” and “criticism”. Culturally, it creates a tone of negativity.

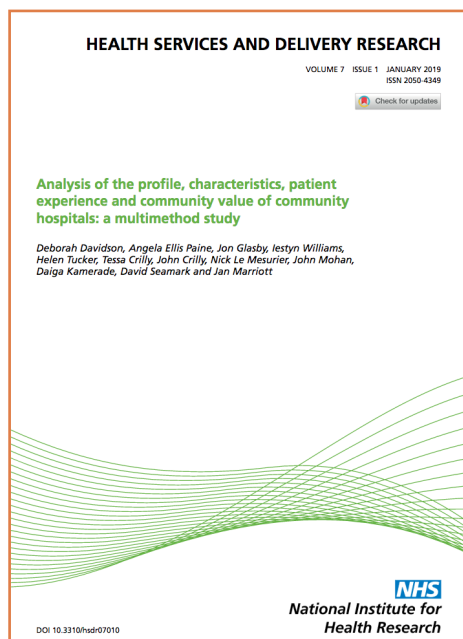
So it is perhaps unsurprising – [as we have already reported](#) – that some health professionals see complaints as “a breach in fundamental relationships involving patients’ trust or patients’ recognition of their work efforts”. Within a culture like this, it can be “rare for [professionals] to describe complaints raised by patients as grounds for improving the quality of care”.

A similar language problem affects wider patient feedback (patient surveys, focus groups, social media posts) – frequently described as “anecdotal evidence”. The term indicates a cultural tendency to see patient feedback as subjective, irrational, and potentially unreliable.

A “just safety culture”, as called for in the draft patient safety strategy, would make it clear to patients that their feedback was valued and would be acted on. It would treat patient stories as valid evidence, having equal weight with clinicians’ stories, set down in their written notes.

Healthcare providers could start down this path by changing their language. They could start describing patient complaints as a form of incident reporting, complementary to that practised by staff. And they could recognise that reference to patient feedback as “anecdotal evidence” is indicative of a dismissive and disrespectful safety culture, and should not be tolerated.

You can read our BMJ opinion piece on this topic [here](#).



The community value of community hospitals

In some parts of England, Sustainability and Transformation Plans have led to battles over the future of community hospitals. To health service managers, the institutions can sometimes appear outdated, poorly located and possibly no longer fit for purpose. To local communities, they can represent cherished assets, where generations have been cared for, and for which Leagues of Friends have tirelessly fundraised and volunteered.

For this study, the starting point was that there is no agreed definition of what a community hospital is. Furthermore, little is known about patients' experiences of them or how they are supported and valued by local people.

The study found that patients and carers experience community hospitals as qualitatively different from other settings. Key to patients' and carers' experiences of community hospitals was their closeness to "home" through their physical location, environment and atmosphere. Relationships also counted - particularly community hospitals' provision of personalised, holistic care; and their role in supporting patients through difficult psychological transitions.

A further finding was that community hospitals are highly valued by their local communities. People support their hospitals through giving time, raising money, providing services and giving voice. This can contribute to hospital utilisation and sustainability, patient experience, staff morale and volunteer well-being.

The study concludes that community hospitals enable the provision of local intermediate care services, delivered through an embedded, relational model of care, and generating deep feelings of reassurance. However, it says that current developments (including the withdrawal of GPs, shifts towards step-down care for non-local patients and changing configurations of services, providers and ownership) have the potential to undermine these positive experiences and values.

BRIEF REPORT

Effectiveness of SIESTA on Objective and Subjective Metrics of Nighttime Hospital Sleep Disruptors

Vincent M. Arosa, MD, MAPP¹; Nolan Machado, BA¹; Samantha L. Anderson, BA¹; Nimmi Desai, MD¹; William Matsack, MSN¹; Stephanie Blassore, MSN¹; Anibalais Toulou, RN¹; Jacqueline Ramon, RN¹; Mary Ann Francisco, MSN¹; Cynthia L. Ford, PhD, RN, CCRN¹; Edward K. Leung, PhD¹; Andrea Valencio, BA¹; Shannon K. Martin, MD, MS¹; David O. Meltzer, MD, PhD¹; Jeanne M. Farmer, MD, MPE¹; Jay Balachandran, MD¹; Koon L. Knutson, PhD¹; Sabak Mahdavi, MD, MS²

¹University of Chicago Medicine, Chicago, Illinois; ²Prider School of Medicine, Chicago, Illinois; ³Children's Hospital Los Angeles, Los Angeles, California; ⁴Stanford University, Stanford, California; ⁵Northwestern University, Chicago, Illinois

Study Design: We created Sleep for Inpatients: Empowering Staff to Act (SIESTA), which combines electronic “nudges” to forgo nocturnal vital signs and medications with interprofessional education on improving patient sleep. In one “SIESTA-enhanced unit,” nurses received coaching and integrated SIESTA into daily huddles; a standard unit did not. Six months pre- and post-SIESTA, sleep-friendly orders rose in both units (flashing vital signs: SIESTA unit, 4% to 34%, standard, 3% to 22%, $P < .001$ both; sleep-promoting VTE prophylaxis: SIESTA, 15% to 42%, standard, 12% to 28%, $P < .001$ both). In the SIESTA-

enhanced unit, nighttime room entries dropped by 44% (-8.3 disruptions/room, $P < .001$), and patients were more likely to report no disruptions for nighttime vital signs (70% vs 41%, $P = .05$) or medications (84% vs 57%, $P = .031$) than those in the standard unit. The standard unit was not changed. Although sleep-friendly orders were adopted in both units, a unit-based nursing empowerment approach was associated with fewer nighttime room entries and improved patient experience. *Journal of Hospital Medicine* 2019;14:38-41. © 2019 Society of Hospital Medicine

Although sleep is critical to patient recovery in the hospital, hospitalization is not restful,^{1,2} and inpatient sleep deprivation has been linked to poor health outcomes.^{3,4} The American Academy of Nursing's Choosing Wisely⁵ campaign recommends nurses reduce unnecessary nocturnal care.⁶ However, interventions to improve inpatient sleep are not widely implemented.⁷ Targeting routine disruptions, such as overnight vital signs, by changing default settings in the electronic health record (EHR) with “nudges” could be a cost-effective strategy to improve inpatient sleep.⁸

We created Sleep for Inpatients: Empowering Staff to Act (SIESTA), which pairs nudges in the EHR with interprofessional education and empowerment,⁹ and tested its effectiveness on objectively and subjectively measured nocturnal sleep disruptors.

METHODS

Study Design: Two 18-room University of Chicago Medicine general medicine units were used in this prospective study. The SIESTA-enhanced

unit underwent the full sleep intervention: nursing education and empowerment, physician education, and EHR changes. The standard unit did not receive nursing interventions but received all other forms of intervention. Because physicians simultaneously cared for patients on both units, all internal medicine residents and hospitalists received the same education. The study population included physicians, nurses, and awake English-speaking patients who were cognitively intact and admitted to these two units. The University of Chicago Institutional Review Board approved this study (12-1766, 166858).

Development of SIESTA

To develop SIESTA, patients were surveyed, and focus groups of staff were conducted. Overnight vital signs, medications, and phlebotomy were identified as major barriers to patient sleep.¹⁰ We found that physicians did not know how to change the default vital signs order “every 4 hours” or how to batch-order morning phlebotomy at a time other than 4:00 am. Nurses reported having to wake patients up at 1:00 am for q8h subcutaneous heparin.

Behavioral Nudges

The SIESTA team worked with clinical informaticists to change the default orders in Epic[®] (Epic Systems Corporation, 2017, Verona, Wisconsin) in September 2015 so that physicians would be asked, “Continue vital signs throughout the night?” Presumably, this question was marked “Yes” by default and hidden. While the default protocol for heparin q8h was maintained, heparin q12h (9:00 am and 9:00 pm) was introduced as an ap-

¹Corresponding Author: Vincent M. Arosa, MD, MAPP. Email: vma@uchicago.edu. Telephone: 773.702.8150. Twitter: @VincentArosa. Additional Supporting Information may be found in the online version of this article. Received: March 1, 2018; Revised: August 14, 2018; Accepted: August 29, 2018. © 2019 Society of Hospital Medicine DOI: 10.12788/jhm.2019

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Sweet dreams are made of this

“Disruption to sleep is known to interrupt recovery and increase the chances of poor health and wellbeing.” So says the Care Quality Commission in its most recent *Adult Inpatient Survey*. In spite of this, the survey findings show that 1 in 5 patients were bothered by noise at night from hospital staff.

This American study starts from a similar premise: “Although sleep is critical to patient recovery in the hospital, hospitalization is not restful, and inpatient sleep deprivation has been linked to poor health outcomes”.

The study tested the effectiveness of the SIESTA intervention - based on patient and staff feedback, from which “overnight vitals, medications, and phlebotomy were identified as major barriers to patient sleep”.

One important finding was that some sleep disruption was due to basic system errors as opposed to uncaring staff. For example, the electronic health record contained various default settings, but physicians did not know how to change the default vital signs order ‘every 4 hours’. They were also unaware of how to batch-order morning phlebotomy at a time other than 4:00 am.

The SIESTA system was introduced to two general medicine units, but in one it was enhanced with nursing education and empowerment. This included giving nurses pocket cards describing the mnemonic SIESTA (Screen patients for sleep disorders, Instruct patients on sleep hygiene, Eliminate disruptions, Shut doors, Treat pain, and Alarm and noise control). Nurses were also coached to collaborate with physicians to implement sleep-friendly orders.

In both units, the intervention was associated with a significant reduction in orders for overnight vital signs and medication administration. However, addition of nursing education and empowerment in the SIESTA-enhanced unit was associated with fewer nocturnal room entries and improvements in patient-reported outcomes compared with those in the standard unit.

The authors conclude that “even when sleep-friendly orders are present, creating a sleep-friendly environment likely depends on the unit-based nurses championing the cause”.

Research Article

**Social Factors and Patient Perceptions
Associated With Preventable
Hospital Readmissions**Jocelyn Carter, MD^{1,2}, Charlotte Ward, PhD^{3,4},
Anne Thorndike, MD, MPH^{1,2}, Karen Donelan, ScD, EdM^{1,5},
and Deborah J. Wexler, MD^{2,4}**Abstract**

Background: Preventable hospital readmissions are costly and erode the quality of care delivery. Few efforts to incorporate the patient perspectives and social factors associated with readmission preventability exist. **Objective:** To identify patient perspectives and social barriers to care related to readmission. **Methods:** Prospective cohort study of 252 respondents readmitted within 30 days of hospital discharge from 2 inpatient adult medicine units at Massachusetts General Hospital, Boston, Massachusetts between January 2012 and January 2014. **Results:** Few participants indicated that their readmission was due to unsustainable health care after discharge. Almost half indicated that they needed more general assistance to stay well outside the hospital. Those reporting a barrier related to at least 2 measures of social determinants of health were more likely to have preventable readmissions (44% vs 20%, $P = .004$). Participants with a history of homelessness or substance use disorder were more likely to have preventable readmissions (44% vs 20%, $P = .04$ and 32% vs 18%, $P = .03$, respectively). **Conclusion:** Strengthening nonmedical support systems and general social policy may be required to reduce preventable readmissions.

Keywords

patient perspectives, readmissions, hospital medicine, social determinants of health, readmission preventability

Introduction

The rising cost of hospital readmissions has garnered increasing attention from clinical, health policy, and process experts alike. Despite ongoing efforts, hospital readmissions continue to be associated with a significant proportion of health-care costs. In 2014, 18% of US hospital admissions covered by Medicare resulted in a 30-day readmission (2). This was associated with over US \$15 billion in health-care costs (2). Up to 27% of those readmissions are classified as preventable. As the Centers for Medicare and Medicaid services defined quality indicator, health systems are accountable for rates of 30-day readmission as well as the financial penalties incurred for elevated rates of readmissions (3). Health-care systems have made significant investments in programming and services such as case management and home nursing to prevent readmission.

Ongoing efforts to understand key drivers of readmission, readmission preventability, and effective readmission reduction strategies continue (4–7), yet underlying reasons for persistent elevation in 30-day readmission remain elusive.

Relatively few studies have incorporated the patient perspective by asking patients to identify reasons for their own readmissions (8–11) or examined patient perspectives on reasons for readmission within the context of clinical, demographic, and social characteristics (1,12,13).

To better understand patient perceptions of reasons for hospital readmission, we interviewed general medical patients readmitted within 30 days of discharge over a

¹ Division of General Internal Medicine, Massachusetts General Hospital, Boston, MA, USA

² Harvard Medical School, Boston, MA, USA

³ Center for Healthcare Studies, Northwestern University, Chicago, IL, USA

⁴ Center for Health Statistics, University of Chicago, Chicago, IL, USA

⁵ Program Institute for Health Policy Center, Massachusetts General Hospital, Boston, MA, USA

⁶ MGH Diabetes Center, Boston, MA, USA

⁷ General Hospital, 30 Fruit Street, Box 15, Boston, MA 02114, USA.

Email: jcarte@partners.org

Corresponding Author: Jocelyn Carter, Division of General Internal Medicine, Massachusetts General Hospital, 30 Fruit Street, Box 15, Boston, MA 02114, USA.

Email: jcarte@partners.org

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Reducing readmissions

Towards the end of 2017, Healthwatch England [published a briefing](#) on emergency readmissions to hospital. It noted that numbers had been rising for some years, and said that in 2016/17, over half a million emergency readmissions had been reported across 84 hospital Trusts.

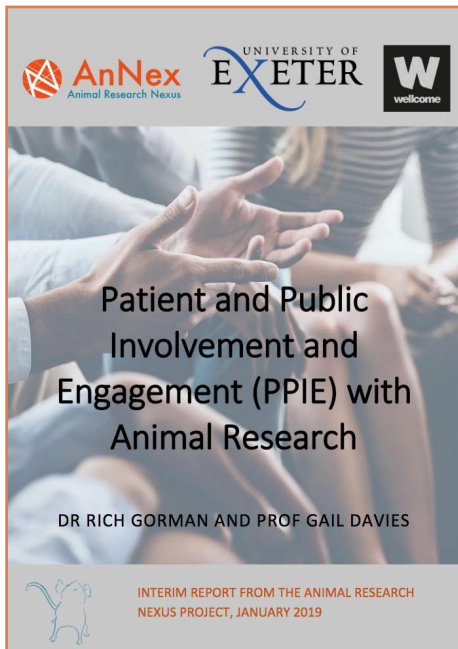
Worryingly, only four of the 125 Trusts contacted were able to provide information outlining the reasons for emergency readmission. Many Trusts explained that the information was not kept electronically, or was stored on paper records, making it too difficult to analyse.

Our featured report this week sheds some light on the matter - and interestingly, its starting point is not medical records kept by healthcare providers, but the perceptions of patients who have experienced hospital readmission. Furthermore, it did not concern itself with in-hospital discharge procedures, but looked instead at the challenges patients face after leaving hospital, including social determinants of health (SDoH) such as safe housing, food access and economic stability.

The study found that high proportions of patients cited non-medical factors as reasons for readmission. There was an increased risk of preventable readmissions associated with a history of homelessness, substance use disorder, or at least two unmet SDoH health related needs. Indeed, patients with at least two unmet SDoH needs were almost three times more likely to have a preventable readmission rather than a non-preventable readmission.

The authors state that their data underline important vulnerabilities and reflect the growing complexity and evolving scope of current medical practice.

The study was conducted in America so may not, on the face of it, be directly applicable to the UK. However, the NHS Long Term Plan sets a clear steer towards personalised care and integrated services. That means understanding people's personal circumstances, and co-ordinating a range of services around the individual. In this context, closer joint working between health services, social services and voluntary organisations could be a way to ensure successful hospital discharge and fewer readmissions.



Patient involvement in animal research

This report opens by stating that “*Patient and Public Involvement and Engagement (PPIE) is increasingly embedded within healthcare research*”. It notes that “lay people” can become involved at various points within research processes. And increasing openness within the research community means that patient and public involvement is ever more extensive. So perhaps we need to start raising questions about PPIE and animal research.

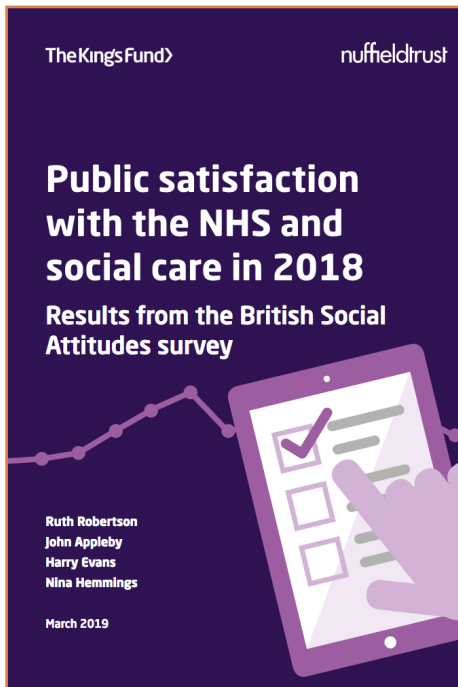
The study found that patients and public can see value in opening up conversations about animal research. It can help to alleviate anxieties by providing opportunities to learn more about how animals are used. But for some people, being involved in research that uses animals is an ethical and emotional challenge.

Funders often believe patients and public should be involved with all types of research, including animal research. However, there is also apprehension about how to organise PPIE around animal research, how to manage potential concerns, and whether it can make a meaningful difference to research.

For researchers using animals, PPIE can be an opportunity to engage people’s lived experience and help ensure research will be meaningful and beneficial. However, these conversations can be uncomfortable and there are challenges around how best to communicate and listen.

The authors see public involvement with animal research as an emerging area, informed by changing research cultures of communication and openness. And as PPIE practices are increasingly embedded in research funding and strategy, public involvement with animal research is likely to become more common.

This may not be easy - many people could find it challenging having conversations about animal research. But, say the authors, there are also potential problems from not having these conversations for research transparency, authentic engagement, and research translation.



Public satisfaction on the slide

"In 2018, the outpouring of affection that accompanied the NHS's 70th birthday did not stem falling levels of public satisfaction with the service." So say the King's Fund and Nuffield Trust in their annual overview of public satisfaction with the NHS and social care.

The report highlights various points of detail - for example that older people were more satisfied than younger people, and that supporters of the Conservative party were more satisfied than supporters of the Labour party. And within the overall picture, there is good news - for example, that satisfaction with inpatient services is at its highest level since 1993, and satisfaction with outpatient services is at its highest level since the survey began.

One striking detail is the huge gap between the best rated service (outpatients, at 70% satisfaction) and social care services, with a satisfaction rating of just 26%. With an NHS Long Term Plan that calls for the integration of health and care services, this must be a cause for concern.

The yearly detail, however, may be less important than the longer term trends: the authors point out that the data gives its richest insights when viewed over decades rather than years. So the 2000s were characterised by increasing satisfaction, while the 2010s are characterised by decreasing satisfaction. And although levels have fluctuated, the broad trend shows a falling level of satisfaction, which in 2018 was 16 percentage points lower than in 2010.

The four main reasons for satisfaction were the quality of care; treatment free at the point of use; the range of services available; and the attitudes and behaviour of NHS staff. Conversely, dissatisfaction arose from long waiting times; staff shortages; a lack of funding; and money being wasted.

The report concludes that with less firm commitments to reducing waiting times than in the past, and the government's strategy for dealing with critical workforce issues still outstanding, we must wait to see when the decade-long slide in public satisfaction with the NHS will come to an end.



Patient-driven data

“Without good data it is difficult to know whether services and treatments are leading to improved outcomes.”

This is the opening statement from “Neuro Numbers”, the latest report from the Neurological Alliance. The paper makes the point that 1 in 6 people have a neurological condition – including autism, cerebral palsy, dementia, multiple sclerosis, parkinson’s disease and many more. In spite of this, “neurology is barely mentioned in the NHS performance architecture”.

The report states that *“During the development of the NHS Long Term Plan there was a very clear message from NHS England that if the benefits of a proposal could not be evidenced, it would not be included”*. But where does this leave people with neurological conditions, for which *“there are so few national datasets”*?

The authors go on to say that *“For many of the rarer neurological conditions – which we estimate represent over 150,000 neurological cases – there is little or no data collected at all, meaning this group of patients is virtually invisible to the health system”*. As they see it, *“it is time neurology was prioritised for improvement in terms of data collection, so the system can make evidence based decisions about care”*.

As with some other patients’ groups, the members of the Neurological Alliance are not waiting. They have taken the initiative in developing their own datasets, such as the neurology patient experience survey – and this report outlines a series of facts and figures underscoring their assessment of the state of care for neurology patients.

The Neurological Alliance state that they intend to *“address some of the shortcomings in the current data and to develop new data sources”*. This is an impressive ambition, and one to keep an eye on.

The National Institute for Health Research is looking for members of the public for:

- The Invention for Innovation programme
- The Research for Patient Benefit programme
- The Health Services and Delivery Research programme

Please visit the [NIHR website](#) for an Information Pack with more details about the work and how to apply.

The deadline for applications is 1pm on Friday 26 April 2019. Shortlisted candidates will be invited to attend an interview. Please check the Information Pack and Application Form for full details, including interview dates and locations.

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](#)

Thinking big about online feedback in health and care services

Wednesday 1 May 2019, 1 pm - 4:30 pm, City Hall, Bristol

Are you intrigued by the possibilities of public online feedback in health and care services? Would you like to understand how online feedback can help improve care, build trust and boost morale?

This is your opportunity to hear from people working with online feedback in practice.

Come and learn from their experience! Speakers include:

- **Hayley Hughes**, Associate Director of Patient Centred Care, Taunton and Somerset NHS Foundation Trust and Somerset Partnership NHS Foundation Trust

- **Alex Ward-Booth**, Head of Insights and Public Engagement, Bristol, North Somerset & South Gloucestershire CCG
- **Caroline Millar**, Lay Board Member, City and Hackney GP Confederation

WHO SHOULD ATTEND?

- Service managers and lead clinicians
- Quality improvement leads
- User involvement teams
- Patient experience teams

Meet the Care Opinion team, and hear from staff in services where online feedback has become a key part of quality improvement, staff learning, culture change and organisational transparency.

Attendance is free, but advance registration is essential as we have limited capacity.

To find out more, or reserve your place, please email sarah.ashurst@careopinion.org.uk

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