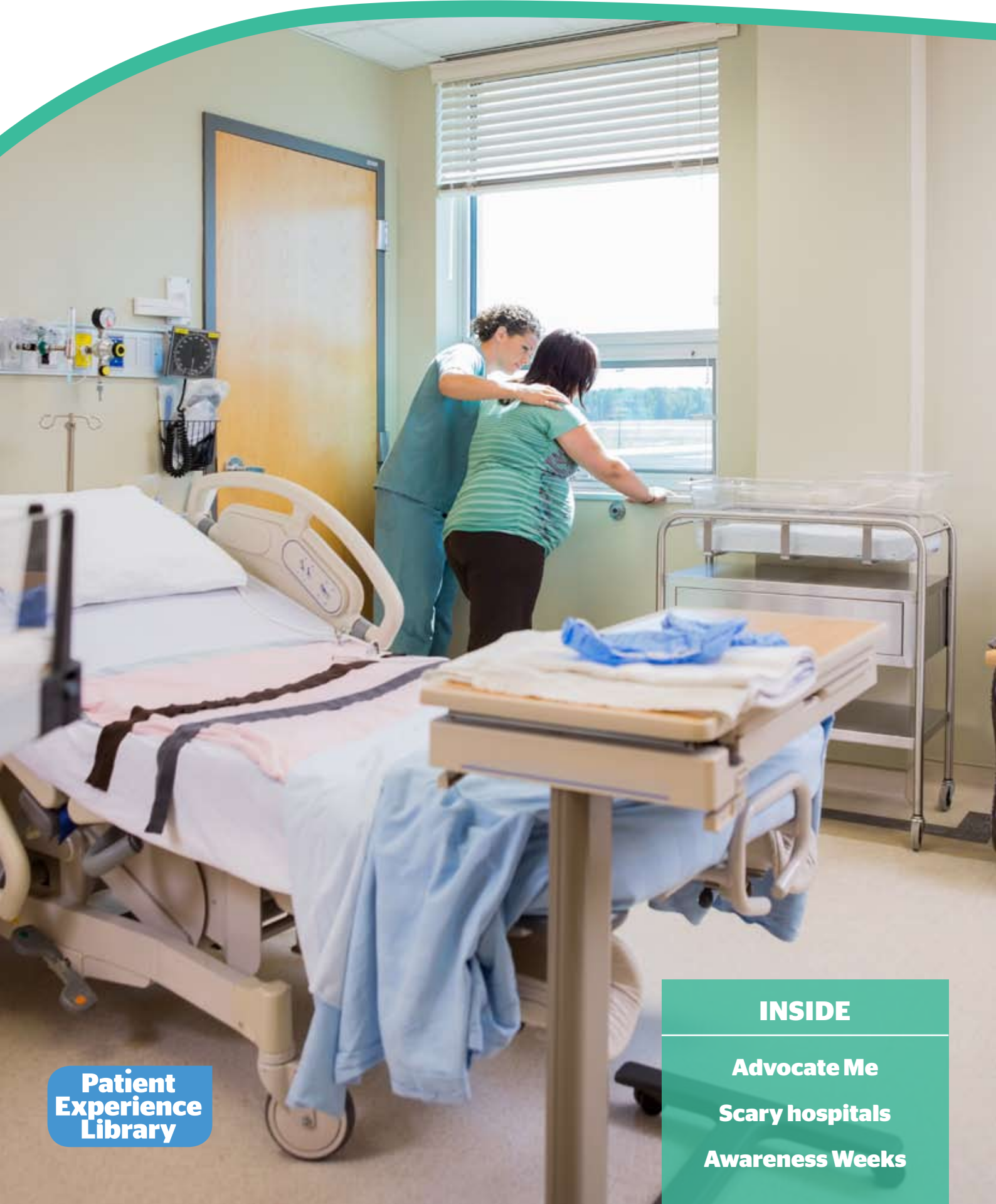


Patient Experience

and patient/public involvement in health and care services

Summer 2018



**Patient
Experience
Library**

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You probably know a powerful patient advocate. The sort of person who seems to have boundless energy, expert knowledge, and an ability to tell it like it is. But what happens when experts by experience have their own moments of vulnerability?

In this edition, Sue Robins talks of her experience of moving from patient advocate to cancer patient. Her account is a powerful illustration of how independence and assertiveness can dry up in the face of illness. Patricia Cantley tackles similar themes. Her parents had to summon up their courage to ask questions about their son's care - fearing, among other things, that any complaint might affect their daughter's prospects as a medical student.

We have to remember how hard it can be for patients and relatives to say what matters to them. The people who are actually voicing concerns may just be the tip of the iceberg.

Talking of which, there are more and more people living with long term health conditions. It is important that their experiences are understood, which is why many charities and patients' groups run awareness raising campaigns. But do such campaigns work? On page 5 Martin Taylor questions their effectiveness, and suggests a different approach.

This edition carries our usual top picks from the evidence base on patient experience and patient/public involvement - you can browse through these on pages 6 to 14

Last but not least, we'll be joining the celebrations for the 70th anniversary of the NHS. As you might expect, we're looking at it from the point of view of patients, and those unsung heroes of the NHS workforce, the patient experience staff. Our poster series on page 15 is free to download, and we hope you'll have fun deciding where to stick them!

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

Miles

Miles Sibley, Editor

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During April - June 2018, we added 2,090 documents to the Patient Experience Library.

Most of these were CQC inspection reports. We collect these because the "Caring" domain in particular can shed light on patient experience.

Around 1,530 came from health charities, think tanks and other government bodies, with around 560 coming from the local Healthwatch network.

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

Advocate me

Sue Robins is a New York Times published writer, health conference speaker and mother of three



I never wanted to be an advocate. When my youngest son was born with Down syndrome, the title of Advocate was foisted upon me. I was also suddenly a Special Needs Mom.

Thrown neck-deep into the health system, I quickly learned to speak up. I figured out that most advocacy work is relationship-based. I got to know my son's clinicians and recognized the value of chitchat, being nice, giving thank you cards and remembering people's birthdays.

I've been to protests and marches for fair funding for people with disabilities. I've spoken to the media about policies that segregate my kid. I lobbied for a medical Down syndrome clinic and then fought hard when an administrator tried to shut it down a few years later. I have a fierce reputation as a strong advocate.

Last year my advocacy efforts came to a screeching halt when I was diagnosed

with breast cancer. Many people said watch out cancer world, strong advocate Sue Robins is here - but I've often failed miserably at advocating for myself as a cancer patient. Newly diagnosed, I was meek, prickly and vulnerable. Intellectually, I knew how to speak up for myself, but emotionally I sat as still as a little mouse, hunched over, compliant and broken.

My son was one step removed from me, and I could hide behind my role of the strong Mama Bear. Cancer is exceedingly personal and breast cancer is an especially intimate sort of cancer - my breast tumour was an affront to my feminine body.

Sitting in exam rooms in thin gowns, exposing my breasts to strange hands and painful machines, I couldn't figure out a way to salvage my dignity, never mind advocate for myself. Be brave and strong, they said. I was scared and weak instead.

People told me to buck up, to advocate for myself as I had for my son. This only served to pile guilt at my own helplessness on top of me. I craved compassion instead.

I turned to writing to process my cancer patient experiences using both a personal journal and my blog. On my blog, this caused me some trouble.

Cancer hospitals don't like accounts of experiences, even anonymous ones, unless they are positive. I asked the patient engagement person if there was a way to share photos I had taken during radiation and she told me they don't 'privilege' one patient's story over another. Then she added that

the writing on my blog was raw. More injured, I left the public eye and turned inward.

A poetry workshop was freeing - I could fictionalize my cancer experiences in poetry and not worry about being factual. A friend showed me how to make a collage from my radiation photos that the cancer hospital wasn't interested in. Art was a different way to speak up for myself. I was advocating, but coming at it sideways.

I poked my head back into published writing. I co-authored a journal article about my experience having radiation. I wrote a guest editorial for a journal about suffering. I am hopeful my story gives clinicians pause to consider how patients feel when they are in their care. It may help others behind me in the cancer world. Making meaning from my experience helps me heal too.

There are many ways to speak up for ourselves. Some people fundraise, lobby governments, give direct feedback to clinicians, and bring along support people to appointments. Other folks just hang in there, endure and try to forget about the whole damn thing. That's okay too.

Just as there's not one right way to do cancer, there's not one right way to advocate. The most important thing is to be kind and forgiving of yourself as you find your own way.

This essay was edited for our magazine from an original version which appeared in the [Cancer Knowledge Network's blog](#)

Scary hospitals

Patricia Cantley, Consultant Physician, Midlothian Hospital at Home Team, Edinburgh Royal Infirmary and Midlothian Community Hospital



My Mum always told me to be wary of doctors, a statement she had good cause to make in light of some of the care my disabled brother received.

Recently, I've remembered a time my brother was admitted to hospital. That experience shaped how I viewed hospitals and continues to influence me as a doctor today. I think it's worth us all remembering how strange and scary hospitals are for those who have a disabled child.

Iain had Duchenne muscular dystrophy. In the genetic lottery, it's a pretty ghastly set of cards to draw. A normal start in childhood is followed by slow wasting over several years until people cannot manage even the simplest of daily tasks.

When he was in his mid teens and I was a medical student, Iain ended up in hospital. There could not have been a more unsuitable environment for a disabled teenage boy.

When you are living with a disability, you develop your own routine.

Hospitals also work to a routine, and it's unlikely that yours and theirs is going to match. Iain needed to be turned every hour overnight. At home he would call out, and one of my parents would shuffle through and adjust his position.

In hospital, however, patients were turned according to when the charts said they should be. Each time Iain dropped off to sleep he was woken for a routine "turn", then lay awake at other times begging for a shift in position only to be told it wasn't the time yet. He hated it.

The power imbalance in hospitals can be very scary. It can be hard to ask what is happening, or get information. We were concerned to find the ward house officer returning repeatedly for blood samples, without any explanation. This was a traumatic experience, with Iain's limbs being contracted and misshapen. Venepuncture was challenging, and on the last occasion was undertaken by the appropriately named "femoral stab".

Finally, my mother plucked up the courage to ask why Iain needed so many samples. It was hard to know how to react when we were told that the problem lay with a faulty laboratory analyser.

Quite quickly my parents asked that Iain be discharged home. They were terrified that this would tarnish my prospects as a medical student, but felt they had to act.

The story has a happy ending, in the sense that Iain did get home. It took him a while to recover but he did over time. He later died in his sleep at the age of

21, part way through an Open University science degree. He had several more fulfilling years and he certainly got something out of seeing me qualify as a doctor. He had a clear view that he would never be admitted to hospital again.

I sometimes wonder how the story would play out today - there is much talk of being "patient centred", so perhaps the difficulties of the 1980's would not be a problem now. Although when I've spoken with friends who are disabled, it seems that the mismatch between patients' and healthcare professionals' routines in hospital can still be a problem.

In my medical career, I see myself as a translator. Whether it's for patients or their families, I have tried to interpret for them the mysteries of their illnesses and the treatments we offer. It's hard to take in new information when you are scared and vulnerable. So I scribble notes for people and draw them pictures.

We need to do everything we can to redress the imbalance, not only in power and knowledge, but also in our respective states of mind. Many of our patients may be feeling scared or even frightened witless when, for us, it's just another day at work.

My Mum is less wary of doctors than she used to be. But I carry her words with me to this day.

This article is adapted from a longer commentary that appeared originally in [BMJ Opinion](#).

Awareness Weeks – Why?

Martin Taylor, Volunteer Research Blogger at Parkinson's UK



So I've reached the 4th Parkinson's Awareness Week since the fickle finger of fate bestowed an elderly person's disease upon me aged just 32.

Other famous part IV's include Rocky IV, where Rocky travelled to the Soviet Union to defeat both Ivan Drago and communism in the boxing ring. Hearts on fire, strong desire...

So I've decided to aim a left hook at the concept of Awareness itself. Woah! You can't do that! I hear you exclaim. Well I'm about to, maybe not punch the concept, but certainly examine the purpose and usefulness of it.

You see a lot of what passes for awareness seems to be people with the condition sharing how it's well... a bit awful, especially when you've been with it for a while. Parkinson's UK for example, shared a video of a chap who now has to wear rubber pants because of urinary incontinence. The whole concept of the #uniteforparkinsons campaign is to share what your illness looks like. It may be cathartic for those doing so, and for that alone it's probably worthwhile, but if the idea is to spread awareness to those who

don't have a connection to the illness, I'm not sure that this will either be achieved or have any particular impact.

I question the impact for two reasons. Firstly, who can tell me the date of another disease awareness day/week/month? You probably can if you have a direct connection but otherwise you probably don't care. That doesn't make you a bad person it makes you a human being, which is the second reason - human nature.

Until I got Parkinson's Disease (PD) I had no interest or knowledge of the condition. My reaction to any awareness campaign for an illness probably amounted to... "Oh that's a shame, glad I don't have that"... back to playing/reading/watching whatever I was doing previously. If I was feeling generous, I may have donated a cheeky fiver... which is another driver for Awareness - fundraising for charities... a cash grab if you will.

Again nothing wrong with that. Charities need donations and in the PD world, charities do a lot of good things which I've seen first hand. However, I would imagine most of the Awareness only reaches those impacted by PD in some way already, so the bulk of donations will also come from this source.

This is a fundamental problem with Awareness. Ultimately it's inwards facing - those receiving the awareness are already impacted by the condition in some way.

A common theme from PD awareness is that of the bus driver who mistakes someone with PD for being drunk and throws them off the bus. This is taken

as evidence by awareness raisers that there is still work to do etc...

The problem is that because Awareness is primarily inwards facing, the poor bus driver was probably totally unaware. Put bluntly, whilst sad, it's ultimately not their fault. I know from driving each day to work, that people slow down to stare at car crashes. People can be cruel, so just as someone with alopecia might get treated ignorantly and be called Kojak, someone with PD might get treated ignorantly because they look drunk. No amount of awareness raising will stop that because penetration beyond the community itself is minimal.

So how about a change in focus and a re-brand to...

PD EMPOWERMENT WEEK

Sharing knowledge and information that is useful to the community. Like...

- Exercise and how it can slow disease progression
- Diet and how it can potentially contribute to wellbeing
- Progress in Research, and how to participate in and influence the research agenda
- How best to optimise medication and self care in general

Let's change the whole concept of awareness so it is driven by the community for the community rather than highlighting how awful our lives are and can or might be.



Staffing and patient experience - more evidence

We hope that the new NHS Workforce Strategy will acknowledge the connections between staff experience and patient experience. We were flagging up the links throughout the consultation period, and since then, yet another report (this time from the Parliamentary and Health Service Ombudsman) reinforces the point.

The PHSO's job is to pick up complaints that have not been resolved by the NHS. This report highlights a series of such complaints, arising from serious failings in NHS mental health services. But it also considers how and why mistakes might be made in the care of people with mental illness.

A frank assessment of "The state of mental health provision in the 21st century" pulls no punches. It refers to recent CQC findings of:

- unsafe staffing levels
- staff on acute wards lacking the skills to anticipate and de-escalate violent situations
- information about risk not being available to all staff involved in a patient's care

It goes on to mention a King's Fund report which revealed "a 13% reduction in mental health nurses between 2009 and 2017, with inpatient care losing nearly 25%. Almost 10% of all posts in specialist mental health services in England are vacant".

The effect on patient experience can be seen in the complaints case studies that form the main part of the report. But the PHSO is in no doubt that "workforce challenges" are at the heart of the problem.

"The complaints we have included in this report demonstrate how patient care and safety is jeopardised by these workforce challenges. They show clinical staff ill-equipped with the skills to manage potentially violent situations, being expected to work double shifts leading to exhaustion, and clinicians having to treat conditions they have no experience of. Unless these workforce challenges are addressed it is difficult to see how the transformation of mental health care, envisioned in the Five Year Forward View for Mental Health, can be realised."

This is the fourth consecutive report to make the links between staff experience and patient experience very clear indeed. We will be reading the new workforce strategy with interest, to see if lessons are being learned.



PALS vs robots

Nesta's recent report, *Confronting Dr Robot* adds to the debate about ways in which artificial intelligence (AI) and machine learning might affect healthcare.

According to the authors, AI could put patients more in control. But, they say, *“there’s a risk that the public could experience it more as a barrier than an open door, blocking access to care, offering opaque advice and dehumanising healthcare in every sense”*.

They say that *“today’s AI is narrow and not capable of the holistic thinking and complex judgement required for many clinical tasks”*. For them, *“the path towards AI replacing humans is not solely determined by technical capability. Technology implementation will need to address trust, accountability and similar factors”*.

These thoughts are echoed in *Lending a hand*, which looks more specifically at the role of machine learning in helping providers to track large volumes of patient comments on social media and to *“automate the laborious process of analysing the unstructured text”*.



The paper makes the point that *“enthusiasm for collecting patient experience data does not guarantee that these data will be used to monitor improvements and assure the quality of care”*. It goes on to say that *“the eagerness for collecting [data] dissipates into confusion as busy staff struggle to transform reams of patient comments into useful information. The inevitable result is that, despite the best efforts of staff, information which patients share in good faith is wasted”*.

Machine learning could provide a solution: *“The performance of machine learning algorithms is attractive. One system in particular can predict NHS Choices star ratings with an admirable 97% accuracy”*. However, there is a need for caution in considering how to apply AI within patient experience work. *“Previous research has highlighted the disconnect between the collection of patient feedback, a relatively straightforward endeavour and its subsequent use to drive improvement activity, a far more elusive task”*.

In other words, computers can collate and sift data, but it takes skilled and experienced staff to work out what really matters, and to spot where the opportunities for service improvement lie.

As the authors themselves acknowledge, computational systems are good - they can excel at some tasks, and improve efficiency in some of the more laborious aspects of data handling. But it may be that the job of *“distilling ‘messy’ patient data into clear and actionable insight”* is - for the time being, at least - best left to humans.



A better deal for patient experience staff

On page 6 of this edition of Patient Experience Quarterly, you can read about the links between staff experience and patient experience. Usually, the case is made with reference to clinical staff, but we have always argued that providing professional care and support to patient experience staff is equally important.

In a blog piece for BMJ Opinion, we made the point that PALS teams and others are swamped by patient feedback from multiple sources, presented in a bewildering variety of formats, and published across far too many different websites. We outlined the kind of professional recognition and support that clinicians take for granted, and argued that patient experience staff deserve similar - especially in an NHS that says that “experience of care” matters.

By happy coincidence, our commentary coincided with a paper from a team of academics who had been looking at the “usefulness and use” of patient surveys.

They said: *“The value of data for organizational quality improvement is not commensurate to the volume of data the system supplies. This misalignment is... in many ways, the consequence of national survey programs being set up to satisfy a national agenda rather than being designed with respect to local circumstances.”*

“... gleaning information from experience data requires the same analytical capability as interpreting clinical data; however, that capability is often unavailable. Staff across health systems consider patient feedback to be valuable but have neither the time nor the expertise to use it...”

“The paradigm regarding patient experience feedback is heavily rooted in large national initiatives... which are accompanied by a sluggish bureaucracy and political concerns. It is likely that these initiatives are neither capturing, nor producing, what is most useful to the organizations trying to use patient feedback to improve care”.

“In order for patient-reported feedback to be an effective improvement tool, and avoid the ethical grey zone around soliciting patient input and not acting on it, feedback programs need to make efforts to facilitate data comprehension and use.”

It's not that the national surveys are no good. In fact, they are packed with potentially useful data. Developing that potential, however, means helping patient experience staff with analytical tools, and an all-round improvement in the training and continuing professional development that is available to them. The pay-off could be staff who feel better supported - and patients whose experiences are better understood.





Hospital visiting Canadian style

It has been heartening to see calls for *an overhaul of hospital visiting rules* from Jane Cummings, Chief Nursing Officer for England. On the 70th anniversary of the NHS, she thought it might be a good time for hospitals to sign up to John's Campaign (for the right of people with dementia to be supported by their family carers) and pledge their welcome to carers.

According to Cummings, *"A flexible approach to embracing the presence of carers has led to improving the overall experience of care, changing the atmosphere in wards and services, and helping to make best use of current resources. It has also led to better communication, fewer complaints, reduction in falls, violence, delirium, length of stay, improvement in hydration and nutrition, acceptance of therapy and medication, generally improved well-being and maintenance of function, complementing the work of the #endpjsparalysis and the last 1000 days programme"*.

Over in Canada, the debate about hospital visiting has been going on for a while. So we thought it would be worth revisiting the deliberations of a Better Together Policy Roundtable on the topic of "family presence".

The family presence approach aims to change the concept of families as "visitors" to families as partners in care in hospitals. It enables patients to designate a family member or loved one who can remain with them 24/7 and be a part of their care team. Families can be present during many aspects of the healthcare experience, including rounds, procedures and transitions.

The roundtable looked at the evidence supporting family presence, considered the current state of family presence in Canada, set about dismantling the myths and challenges of family presence, and looked at case studies of family presence policies. It then moved on to equipping participants with knowledge about how to implement family presence policies across their organisation or jurisdiction.

We welcome Jane Cummings' call for a review of hospital visiting restrictions, and her clear support for the John's Campaign principles and pledge. We hope that this is just a first step towards the kinds of family presence approaches that the Canadians are championing.



I could not survive another day

NHS England has *recently announced* new funding for community perinatal mental health services. These will allow pregnant women and new mothers with mental health difficulties to access specialist services in every part of the country by April 2019.

We hope that the new services will be evidence-based - not just in terms of clinical need and treatments, but also in terms of understanding women's experiences through pregnancy and beyond.

A good example is Hyperemesis Gravidarum (HG) - a severe complication of pregnancy associated with extreme nausea and vomiting. Other symptoms include headaches, heightened and warped sense of smell and extreme fatigue.

Alongside the physical complications, HG can lead to depression, social isolation, financial and relationship problems, and even to Post Traumatic Stress Disorder.

This report describes the experiences of women who had ended pregnancies while suffering HG. 95% described their symptoms as "intolerable", and 84% said they would have wanted to continue with the pregnancy if they had not been suffering HG.

Shockingly, the researchers found that 47% of women did not receive treatment for HG. Of these, 40% requested treatment but were denied it, and the others did not ask for treatment and were not offered any. A quarter of women who were not prescribed medication reported that it was because their doctor said it would harm the foetus or there were no medications suitable for pregnancy.

The authors conclude that women are terminating wanted pregnancies because they are being denied antiemetic treatment. They state that women who have terminated due to HG carry a significant burden of guilt, remorse and often anger upon finding out subsequently that treatments are, in fact, available.

Hyperemesis Gravidarum is a physical health condition. But it is one which can have profound consequences for women's mental wellbeing - especially if the symptoms and medications are poorly understood by professionals.

As new community perinatal mental health services are rolled out across England, it is vital that they help to improve understanding of HG. That means listening to women's experiences, and recognising that better physical and mental health for HG sufferers may depend, as much as anything, on better professional responses.



PPI in a digital age

“We live in a digital age” says the opening statement to this report. And the NHS is working hard to develop things like electronic patient records and telehealth, propelled by reviews including *Wachter* and *Topol*.

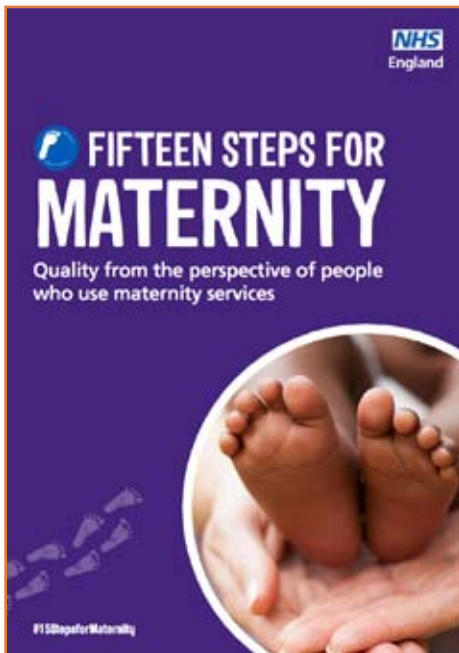
This report looks at ways to strengthen the voice of the citizen and patient within the process - not least because “*the systems and processes that lead to the adoption of technology tend to marginalise the voice of most patients and the public*”.

This may be because “*projects are nervous about involving the public, and are worried about adverse publicity, particularly in the wake of the Care.data scandal*”. But the report counters any such perceptions with real-life examples of successful approaches to involving patients and public in digital healthcare initiatives. These include:

- Technology for bringing together patient data - including patient data sharing.
- Technology for connecting directly with patients - including tools for self diagnosis and self management.
- Technology for communicating and engaging with citizens. This includes crowdsourcing techniques and other forms of citizen science.

A series of case studies illustrate how these principles are being applied across the country, and the report is rounded off with a summary of key points of good practice, followed by suggested ways to strengthen patient/public involvement in the development of a digital NHS.

This is a good report that raises some important issues. And, following her own good practice recommendations, the author finishes with a call for interested readers to get in touch, to share ideas and continue the discussion.



15 steps for maternity

The Nursing and Midwifery Council has recently been *consulting on its “fitness to practise”* role – its work in regulating the safety and professionalism of registered nurses and midwives.

The *consultation document* states that “*The context in which patient safety incidents occur is extremely important*”. It says that “*By considering the context we are asking what caused an incident, rather than who is to blame*”.

This is vitally important, given the learning from major failures at Trusts including Mid Staffordshire, Morecambe Bay, and Southern Health. In every case, part of the context for avoidable harm and death was an organisational culture that devalued patient experience and dismissed the concerns of patients and relatives.

So the publication of NHS England’s “15 Steps for Maternity” is timely, and welcome. The subtitle, “Quality from the perspective of people who use maternity services” points to its value in enabling the patient voice to be heard alongside regulators and inspectors.

The authors are keen to point out that the 15 Step Challenge is not a performance management tool or an audit. Instead, it aims to build an understanding of how people feel about the care provided, how confidence can be built by positive first impressions, and what might be done to increase levels of confidence as part of continuous improvement.

The challenge is based on a quote from the mother of a child needing frequent hospital admission. Her observation was that, “*I can tell what kind of care my daughter is going to get within 15 steps of walking on to the ward*”. And sure enough, a series of practical guides prompt people taking the challenge to record immediate impressions of a healthcare service – taking in features such as “welcoming”, “safe”, “clean” and “calm”.

Anyone who has read the report of the Francis Inquiry will know that these are powerful pointers towards the underlying wellbeing of staff, systems, and, ultimately, patients.

The 15 Steps Challenge has value in its own right as a means of getting service users’ feedback. But it can also offer important clues to that vital question of “context” that underpins health professionals’ ability to do their jobs safely and well.

**NHS operational productivity:
unwarranted variations
Mental health services and community health services
Summary document**

Foreword by Lord Carter of Colest

Like all parts of the NHS, mental health and community services face a number of challenges that can be partly addressed through operational and structural improvements. NHS mental health and community health services account for about £17 billion of NHS expenditure in England, comprising the £20 billion spent on acute services, and providing critical support for over 2 million patients every day.

The role and importance of mental health services are clear, but that of community health services, with a wide range of local specialisations and provisions, is not. If the aspirations expressed in the Five Year Forward View are to be met, we will need to shorten the average length of stay in England acute hospitals from its current 7 days to something approaching Denmark at 5.5 days or the United States at 5.1 days¹, although some estimates put these even lower. To achieve this, the provision and efficiency of community health services will have to be significantly strengthened. The key challenge for mental health services, by contrast, is in meeting the significant levels of unmet demand. Even taking into account the significant expansion in children's mental health services, worldwide consensus means that by 2020/21 we only plan on meeting the needs of a third of children with diagnosable mental health conditions. Improving the productivity of services is an important part of the answer to how we go further in such sectors.

Operational improvement – £1 billion savings opportunity to support patients

Since January 2017 we have engaged with many mental health trusts and providers of community services, and talked to the healthcare teams and patients who use their services. As a result of that engagement, this review has identified critical and unwarranted variations in all key resource areas. It is clear from the performance of some providers that parts of the sectors know what to do well – the challenge we face is how we raise the average standard of performance closer to the level of the best. Our work has identified four important areas where operational improvement must be made:

1. Staff: we spend £10.4 billion per year on staff, giving detailed attention to how they use their time, particularly at the moment of critical labour shortages in all grades, is of the utmost importance. Effective rosters, job planning, managing sickness absence, maximising the critical role of community staff, appropriate skills mixes, and effective training all lend themselves to detailed management attention. This is, however:

¹ NHS, *Health in a Minute 2017*. <https://www.nhs.uk/health-in-a-minute/health-in-a-minute-2017-health-in-a-minute/>

A raw deal for children

“Even taking into account the significant expansion in children’s mental health services, workforce constraints mean that by 2020/21 we only plan on meeting the needs of a third of children with diagnosable mental health conditions”.

This statement comes from the foreword to Lord Carter’s review of unwarranted variations in mental health services and community health services.

The review considers a range of productivity and efficiency issues across various mental health and community health services. But let’s stay with those children with diagnosable mental health conditions.

Back in 2016, the *Five Year Forward View for Mental Health* said that “too many people have received no help at all, leading to hundreds of thousands of lives put on hold or ruined, and thousands of tragic and unnecessary deaths”. It spoke of “a real desire to shift towards prevention”. But that desire sounds hollow in the light of Carter’s revelation that two years from now, two thirds of children who may need treatment will have to go without.

Children who do get treatment for mental illness might be considered lucky – except for the fact that their experience, as patients, is consistently poor.

The Care Quality Commission’s most recent *Children and Young People’s Survey* found that patients with a mental health condition, and their parents and carers, reported significantly worse experience for matters including information and communication, transition and continuity, respect for patient-centred values, involvement of family and friends, and awareness of medical history.

At the start of 2017, Prime Minister Theresa May described mental illness as a *hidden injustice*. We have said before that the injustices are not hidden – they are in plain sight.

Lord Carter’s review outlines ways in which productivity and efficiency improvements across mental health and community health services could save the NHS nearly £1 billion by 2020/21. Putting that saving towards better preventative work in children’s mental health might be a good way to start addressing the injustices that the Prime Minister is so concerned about.



Adult inpatients: Problems persist

The latest CQC national patient survey is a useful addition to the evidence on adult inpatient experience.

We now have a nearly ten-year cycle of these surveys, enabling us to start getting a clear picture of patient experience trends over time. Encouragingly, there have been consistent improvements for how well doctors and nurses care for patients. 78% of patients said they “always” had confidence in nurses this year, compared with 72% in 2009. And fewer patients now say that doctors had spoken in front of them “as if they weren’t there” (23% compared with 29% in 2009).

Hospital discharge, however, remains one of the weakest areas of patient experience for adult inpatients. 19% of respondents thought hospital staff did not take their family or home situation into account when planning their discharge, while a quarter (25%) of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital. Less than two-thirds of patients (62%) left hospital with written information telling them how to look after themselves post discharge, a figure which has deteriorated since 2013 (67%).

The problem is not just with hospital staff. 17% of survey respondents said they left hospital not knowing what would happen “next” with their care, and 22% said they did not receive enough help from health or social care professionals to help recovery or to manage their conditions.

These kinds of issues have been repeatedly highlighted in local Healthwatch reports, going as far back as 2013. If patient experience of hospital discharge remains poor, it is not for want of evidence.

Another persistent feature of the CQC patient surveys is that inpatients with a pre-existing mental health condition report a poorer experience of care across most areas of the NHS patient experience framework: information sharing, respect and dignity, coordination of care, confidence and trust, respect for patient centred needs and values, and perceptions of overall experience of care. This too, appears to be a persistent issue, and again, it is troubling to see the evidence mounting up but the problems remaining unresolved.

NHS @ 70 – Power to the Patients

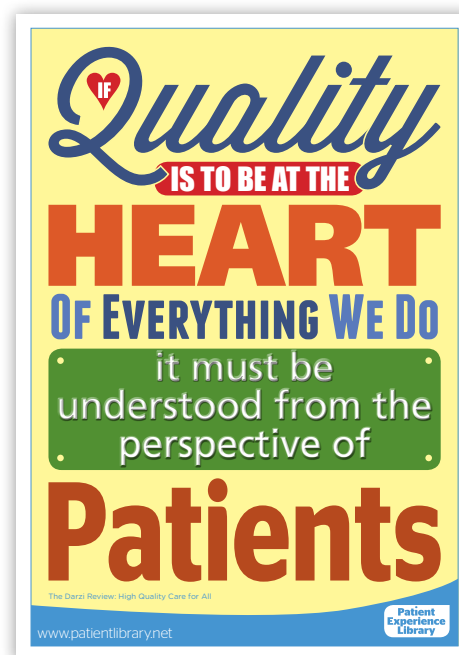
70
YEARS
OF THE NHS
1948 - 2018

It's the 70th birthday of the NHS, and we'll be celebrating by curling up with a nice big pile of patient experience evidence reports. We may even indulge ourselves with a bit of extra cataloguing!

Our present to our readers is this wonderful poster set, created for us by *Rob Bowker Graphic Design*. The posters combine striking designs with inspirational quotes taken from the Darzi Review, the Berwick Review, and the report of the Francis Inquiry.

[Download the whole set for free from our website.](#)

We already have ours up around our office, and very splendid they look too! Where will you stick yours?



The Patient Experience Library

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