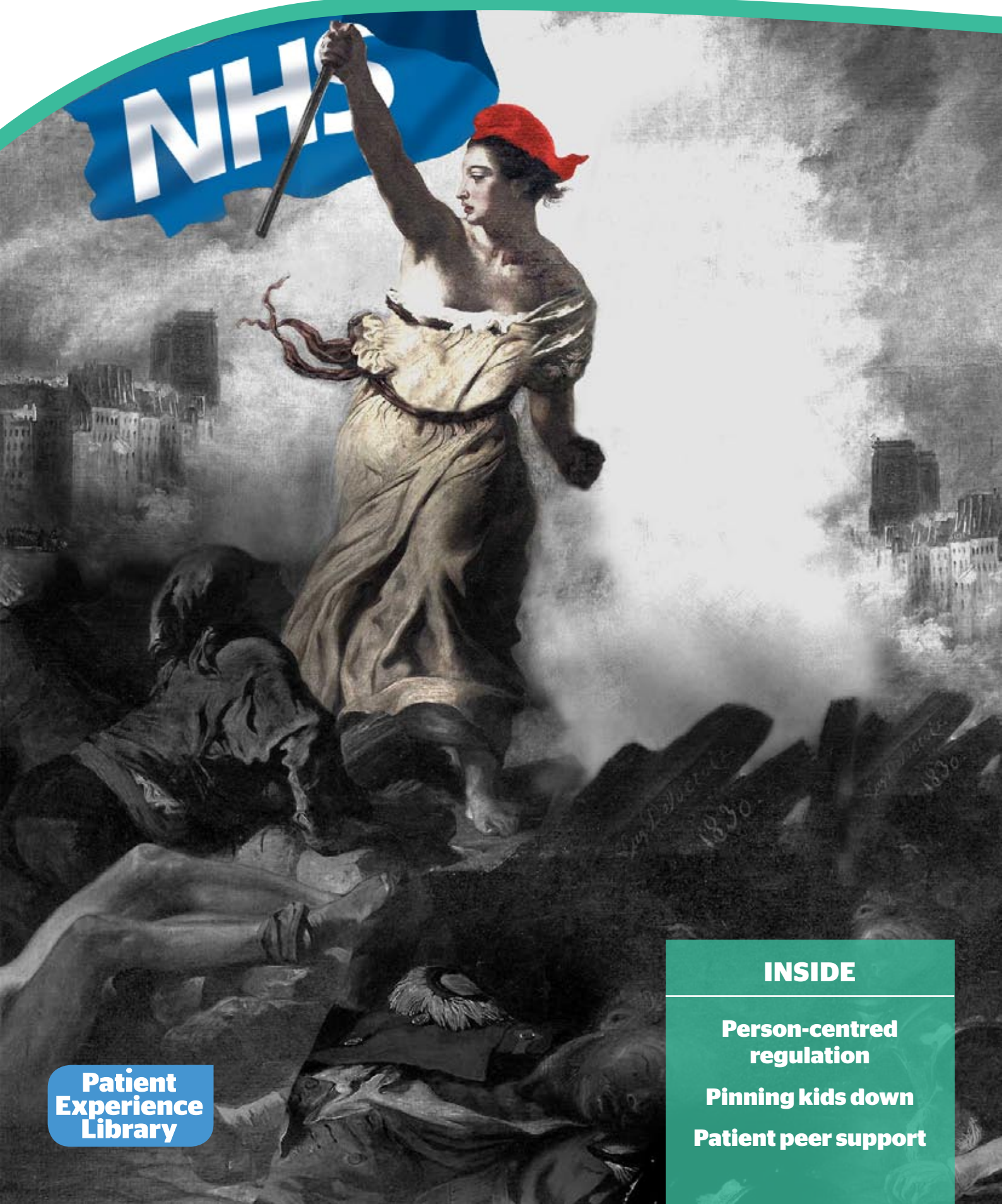


# Patient Experience

and patient/public involvement in health and care services

Spring 2020



**Patient  
Experience  
Library**

## INSIDE

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## Editorial



There is a lot of talk these days about person-centred care. The [Royal College of Nursing](#) says that “being person-centred is about focusing care on the needs of the person rather than the needs of the service”. And the [Health Foundation](#) says that person-centred care “ensures that people are always treated with dignity, compassion and respect”.

These are good definitions – not least because they do not assume that “care” only ever happens in clinical settings. On [page 3](#), Michelle Sokol looks at how regulators can also take a person-centred approach. “Fitness to practise” involves judgements about whether clinicians are meeting the required professional standards. But, says, Michelle, those judgements must take into account the views of patients, relatives and carers.

Brooke Batchelor ([page 4](#)) draws on her experience as a paediatric nurse to think about how we look after children. Sometimes clinicians and parents – with the best intentions – hurry or even force children through procedures that are distressing for them. Brooke suggests other, less traumatic ways to gain the child’s co-operation and stop them from spiralling into a fight or flight response.

On [page 5](#), Karl Roberts challenges another assumption – that “care” is a one-way process – provided by health services for patients. In his article, he looks at peer support, and how patients’ own knowledge and skills can be a source of all-round learning on how to develop person-centred care.

Regular readers will know that for us, the best learning comes from matching personal insight and experience with rigorous research. So this edition also includes our usual round-up of the latest research on patient experience and involvement.

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! [info@patientlibrary.net](mailto:info@patientlibrary.net)

*Miles*

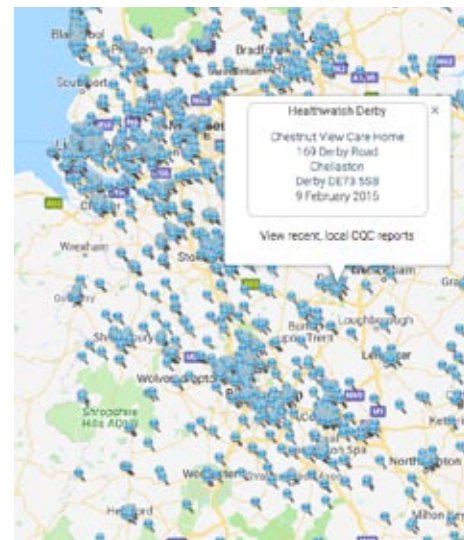
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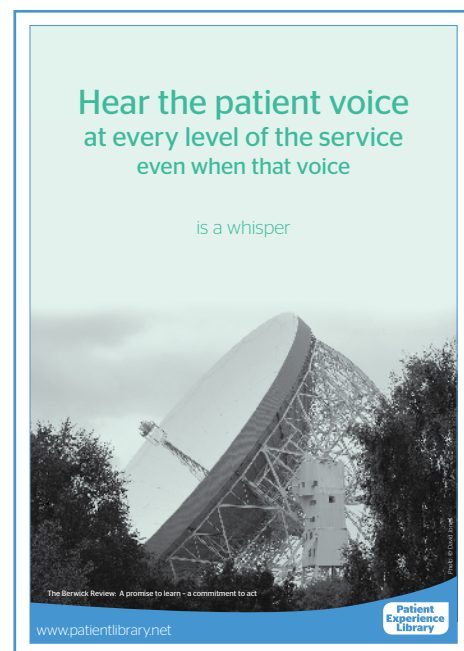
[www.patientlibrary.net](http://www.patientlibrary.net)

## 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!



## Comment

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



# Person-centred regulation

*Michelle Sokol*

*Research Officer, Nursing and Midwifery Council*



“If patients and families are not allowed to feed into the regulatory system then how can it serve the patients whom it’s been set up to protect?”

“If patients and families are not allowed to feed into the regulatory system then how can it serve the patients whom it’s been set up to protect?”

This important insight emerged from research into patient and family experience of the Nursing and Midwifery Council’s fitness to practise process.

The NMC sets out the professional standards that nurses, midwives and nursing associates must uphold. Failure to do so can result in people being ‘struck off’. But the standards and regulation must not ignore the fact that people are the reason for the existence of fitness to practise.

Patients, families and carers who raise concerns about nursing standards often do so because they want to prevent the same poor experience from happening again. While reasons for a complaint may be multifaceted—from the desire for accountability to searching for answers to questions surrounding care—the motivation of improving the quality of care remains.

So if benefits for the quality of healthcare are at the heart of public and patient complaints, we need to see public and patient voices as an extremely valuable source of intelligence. They let us know what people want and expect, and where care falls short.

This ties in with the move, across the NHS, towards person-centred care. Although person-centred care is not perfectly implemented, it is the standard required of health professionals.

In nursing, the NMC, as the regulator, sets this standard, and its new approach aims to ensure this standard is followed by listening to and acting on public referrals through its fitness to practise process. To take a person-centred approach, regulators must ask, “What is the responsibility of the regulator to the people we serve?”

Ultimately, the aim of regulation is “Better, safer care” but this raises questions about who defines “better, safer care” and how fitness to practise might support it.

The challenge is not to argue about patients versus practitioners, but to recognise our common ground: wanting the highest quality of care for ourselves, our families, friends and neighbours. In this context, a person-centred approach to regulation involves at least three core components:

1. Valuing patient and family experience.
2. Acting on patient and family intelligence.
3. Moving beyond commodification of patient experience.

Patients and families who bring concerns to the regulatory system are an asset. As one patient told me, “someone has to take the baton and stand up and say actually we’re going to do this and we’re going to do it properly... you can’t go round in circles forever, because all it’s taken is millions of post it notes, millions of white sheets of paper, white boards, cups of coffee, sympathetic nods, we understand and then nothing”.

To achieve person-centred regulation, regulators need to start seeing person-centred care as an ethical imperative.

When care falls below standard, we must support patients and families, value their experience and act on the knowledge that they bring.

# Pinning kids down

Brooke Batchelor  
Paediatric Nurse Educator



Larissa was an 8 year old I saw regularly in hospital. She had a chronic medical condition that will require regular medical attention for the rest of her life...

When I first met Larissa, I arrived at her bedside with the numbing gel in hand. Larissa took one look at it and ignored me. I attempted to explain that she was going to have a blood test when her Mum stepped in. "Brooke, she knows what that is for and she says it doesn't work. She knows what putting it on means. She won't let you or anyone else do it."

Very briefly I was thrown off-track. 'What happened to her?' I asked her mother. Her mother proceeded to tell me about her past experience when restraint was used.

"When she had her first IV, she was taken to a room, wrapped up and pinned down. It took 4 adults, including myself, to hold her down so that they could put the IV in. Now, she puts up a bigger fight and it is nearly impossible."

Larissa fights. There is no reasoning. So it is decided that treatment needs to be administered against her will...

Putting in an IV can be a quick, trauma free experience to us but to a child, it can have long lasting effects.

Larissa is a real person and she is suffering. In fact, every time she comes to hospital, she suffers more. The suffering gets worse as she not only has to deal with the fears associated with the present treatment, but during these times she also re-lives the fear and emotions of her previous hospitalisations. So now, her response is to avoid and fight.

Larissa fights. There is no reasoning. So it is decided that treatment needs to be administered against her will and we use restraint... again... and again.

She is immobilised by numerous adults at a time. This is where trauma occurs - when we are unable to successfully fight or flee threatening situations.

There are other, less traumatic ways, to gain the child's co-operation and stop them from spiralling into a fight or flight response, such as:

- adequate preparation for the procedure - this can start at home
- participate in some Medical Play with the child

- slowing ourselves and our approach - working on a time frame that considers the child
- honesty - if it will hurt, be honest about it
- giving the child choices to give them a sense of control
- let the child know you are a team and will get through this together
- embrace the tears - tell them that it is ok to cry or express emotion about the upcoming procedure. This stops tension from being stored and the tears will also release stress hormones helping them stay calm
- learn about therapeutic/comfort holding - the best way to hold your child during procedures that is not restraint

We may not realise the unseen psychological damage we can cause a child when we are caring for their physical health.

When we pin down a child and overpower them in order to perform a clinical task, it is really important to ask ourselves if the potential to cause trauma is worth it.

And remember that something that seems small to an adult, can be traumatic for a child.

Larissa's name and identifying factors of her story have been changed for privacy. A fuller version of this account can be seen here

# Patient peer support

*Karl Roberts*

*Head of Patient Faculty Codesign and Practice  
NHS National Leadership Academy*



You may have heard of learning events that are run on the basis of “patients included”. The idea is that healthcare organisations should consciously open up opportunities for patients to sit alongside health professionals on conference platforms, and in audiences.

The NHS Leadership Academy recently ran a learning event that went far beyond the traditional “patients included” formula.

Our Patient Leaders Symposium brought together people from all over the country for shared learning and peer support. But it was not “patients included” – it was fully patient-led. There was a co-designed agenda, and workshops run by patient leaders. And the event as a whole was chaired by one of our Experience of Care partners.

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Our Patient Leaders Symposium... was not “patients included” – it was fully patient-led.

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As a turnaround from the usual approach, this was a “professionals included” event. NHS staff were warmly welcomed and invited to share their expertise. We were pleased to hear a presentation on the NHS People Plan, and to have a workshop session on personalised care.

Other topics, covered by patient leaders, included “Patients as mentors” and “Using evidence to influence change”. The packed programme also featured case studies of how patient leaders had initiated and supported quality improvement projects.

One of these looked at improvements to an A&E waiting area, where relationships between patients and staff had got so bad that the reception desk had had security screens installed.

After discussion with patients, more comfortable seating was installed, and refreshment machines were kept in working order. Pain relief on triage was re-introduced. Pagers were introduced for people who were caused distress by waiting in crowded areas. Staff were encouraged to come out to the waiting area and explain and apologise for delays. The result was that the security screens could be taken down, and numbers of complaints dropped.

Sometimes, with training and workshop events, the lunch break is seen as “down-time”. But in another turnaround, the lunch break at our symposium was taken as an opportunity for “up-time”, with the formation of a patient partners choir.

Expert facilitation from [Rainbow Connection](#) took around forty participants (some of whom swore they couldn’t sing!) from zeroes to full-throated heroes in less than an hour, with a fantastic release of energy, solidarity and common purpose.



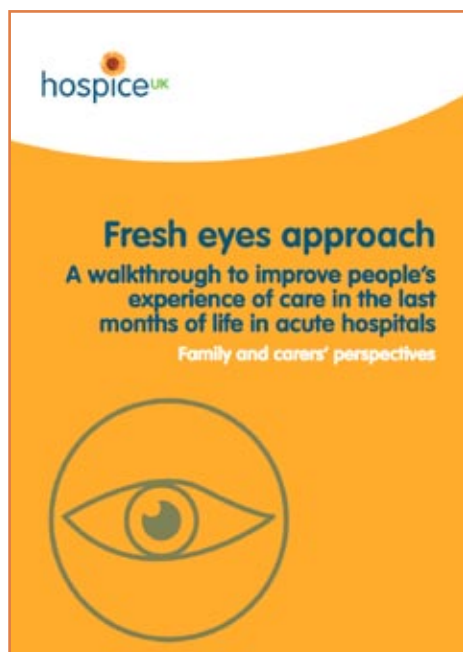
The NHS Leadership Academy runs events like these because peer support is a basic part of our approach. It is not for us to tell patient leaders what to do, any more than it is to tell senior NHS staff what to do. Instead our role is to facilitate. So we work with our Experience of Care partners to enable them to develop as leaders, share their learning and support one another.

If you’d like to join us, or if you know someone who might like to be part of our patient leadership programme, please get in touch.

[Karl.roberts@leadershipacademy.nhs.uk](mailto:Karl.roberts@leadershipacademy.nhs.uk)

## 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](mailto:info@patientlibrary.net)



# Fresh eyes on end of life care

“Caring for people who are dying is an everyday occurrence in acute hospitals” says this report from Hospice UK. “With around 46% of all deaths in England occurring in hospital, it is important that hospitals provide good quality, compassionate care.”

The report describes a way of exploring the patient, family and carers’ experiences by walking through a potential journey – from the hospital car park, through the Emergency Department, an acute assessment ward, a general ward, mortuary and bereavement services.

The Fresh Eyes team members consider their first impressions of the ward or service from the perspective of a service user, recording how it appears, looks, sounds and smells. They talk and listen to staff – trying to understand usual practice (for example how a deceased person travels from the ward to the mortuary). They also wander through public areas such as restaurant facilities, chapels, faith and spiritual spaces using available signage to self-navigate.

The method includes both objective and subjective perspectives, with feedback indicating where there were differences in views. Differences of opinion can be helpful in indicating areas which may need further attention.

Photographs are taken to help reveal unloved, often simple to fix areas -- for example, dirty windows, clutter, out of date/unconsidered notice boards and poor signage. Generally, staff knew the issues, and the visit helped to raise the profile for necessary change. Many hospital trusts said it was relatively easy to fund improvements to mortuary visiting areas and bereavement suites through charitable sources.

This is an excellent report – clearly written and with plentiful photos to illustrate the kinds of “unloved” areas that busy staff perhaps stop noticing, but which might add to the distress of people at a sensitive and vulnerable time. A concluding “key actions” section offers helpful tips for improvement.





## Credit where it's due

In the autumn 2019 edition of Patient Experience magazine, we featured a [report from the Lancet](#) which analysed the health impacts of climate change.

It said that “The nature and scale of the response to climate change will be the determining factor in shaping the health of nations for centuries to come”. However, “A lack of progress... threatens both human lives and the viability of the national health systems they depend on, with the potential to disrupt core public health infrastructure and overwhelm health services”.

The report went on to say that “Ensuring a widespread understanding of climate change as a central public health issue will be crucial”.

We took that as a cue to see what public engagement was going on around health services in respect of climate change. Our findings were disappointing: we [reviewed four major national strategies on healthcare](#) and found that none contained any serious reference to climate change, much less to engaging NHS staff, along with patients and public, in debate and action.

So it is now encouraging to see the launch of a [Greener NHS](#) campaign to tackle the climate ‘health emergency’. The campaign is calling on [individuals](#) and [organisations](#) to start work immediately on actions to cut carbon emissions and other environmental harms.

A [Healthy Returns infographic](#) offers handy ideas for where positive changes can be made. And a [Powerful Points library](#) is being set up to enable people to submit their own facts and figures about sustainable development in health and care.

There is recognition that this will require leadership from the top: a [linked website](#) says that “Engagement and sustainability both need to be owned by boards and staff. Engagement and sustainable development programmes must also draw in service users, communities and the wider public, local councils, third sector and Health and Wellbeing Boards”.

We will offer credit where it is due. Last October we were disappointed that health strategies appeared lacking on the crucial issues of climate, health, and public engagement. Now, we take fresh heart from what looks like a surge of energy from NHS England.



## Person centred care needs person centred feedback

One year ago, the [NHS Long Term Plan](#) was published. It says that one of the “five major, practical, changes to the NHS service model” is that “People will get more control over their own health, and more personalised care when they need it.”

That is a worthy ambition, but how will we know if personalised care actually works? The obvious answer is, “ask the patients.” – but this report hints at some challenges.

The first of these, ironically, is that conventional feedback mechanisms are not personalised. The report describes “procedure-driven, standardised approaches such as surveys and checklists [that] are too narrow”. In an echo of the Long Term Plan’s call for personalisation, it says that “patient experience feedback is about being heard as a unique individual and not just as part of a group. This requires their experience to be considered as a whole, rather than reduced to a series of categories”.

Underpinning personalisation is the concept of “choice.” But a second challenge is that patients cannot always choose how and when to offer feedback. “In general, only sanctioned channels get monitored and responded to with feedback from other channels ignored.”

Personalisation also depends on dialogue. So a third challenge is a failure to close feedback loops, which leaves some patients feeling treated impersonally: “The lack of organisational response to their survey feedback meant they perceived it as a ‘tick box exercise’ and they thought that their comments would not be used.”

Conventional surveys and “sanctioned channels” have their uses. But an NHS aiming for personalised care has to understand personal patient experience. And that might mean rethinking how it goes about getting feedback.



## Learning from NHS Inquiries: Comparing the Recommendations of the Ely, Bristol and Mid Staffordshire Inquiries

MARTIN POWELL

### Abstract

If one of the key reasons for an inquiry is to learn lessons and prevent similar events from reoccurring, recommendations must be implementable and implemented, but it is clear that lessons have not been learned and recommendations not implemented. This paper compares the 'implementability' of recommendations from the three inquiries of Ely, Bristol and Mid Staffordshire to stress the importance of learning lessons. It examines two broad issues of 'what' and 'whom'. First, some 80 per cent of the Ely recommendations were aimed at the institution, while 72 per cent of the Bristol and Mid Staffordshire recommendations were aimed at the system. Moreover, about 7 per cent of Ely's forty-four recommendations have a clearly identified agent, compared to 35 per cent at Bristol and 41 per cent at Mid Staffordshire. Second, the policy tool of 'sermons' accounts for some 89 per cent of Ely recommendations, compared to 66 per cent at Bristol and 43 per cent at Mid Staffordshire. However, the earlier sermons did not appear to prevent the events at Mid Staffordshire occurring. Pulling these issues together, it can be suggested that, given the large number of potentially responsible agencies, recommendations should be 'active' with a clearly identified agent and that a clear policy tool or mechanism should be identified rather than rely on a vague tendency to sermonise.

**Keywords:** NHS, inquiries, recommendations, learning

### Introduction

It has been noted that if one of the key reasons for an inquiry is to learn lessons and prevent similar events from reoccurring, recommendations must be implementable and implemented. However, it seems that in a version of *Grounding Day* it is stated that "lessons will be learned" but it is clear that this has not always been the case. A number of commentators point to some similarity of inquiry findings. For example, Shaddad stated that most of the hundred plus NHS inquiries that have been held since the Ely inquiry have highlighted common areas for concern: inadequate leadership systems and process failures, poor communication, disempowerment of staff and patients, 'incidents' and 'errors' stick up this point.<sup>1</sup> The sequence of the same themes despite repeated inquiries raised two possibilities either the NHS as an institution is unable or unwilling to

implement the changes embodied in the recommendations, or the recommendations themselves are incapable of being implemented because of the way in which they are produced or imposed.

This paper compares the 'implementability' of recommendations from the three inquiries of Ely, Bristol and Mid Staffordshire in order to stress the importance of learning lessons.<sup>2</sup> The Ely inquiry was set up in 1987 to look into allegations of various forms of misconduct on the part of members of the staff at the Ely Hospital, a psychiatric hospital in Cambridgeshire (see Hinton, in this issue). It was chaired by Geoffrey Hinton, the former Conservative Chancellor of the Exchequer in the Thatcher government, and reported in 1988. The Bristol inquiry was set up in 1996 to examine the 'sudden deaths' in paediatric cardiac surgery at the Bristol Royal Infirmary between 1984 and 1995, with Professor Sir Ian Kennedy as chair. It reported in 2001.

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# Carrots, sticks and sermons

There has been a sudden acceleration of avoidable harms inquiries, with [East Kent](#) and the [Paterson Inquiry](#) coming hard on the heels of reports from the ever-widening investigation at [Shrewsbury and Telford](#).

As always, there are calls for "lessons to be learned". Jeremy Hunt, as Chair of the Health Select Committee, has [called for an inquiry into the safety of maternity services](#), asking "Why do these mistakes appear to be repeating themselves?"

The answer to that question could come from the ways in which inquiries themselves frame their findings and recommendations.

This report looks at the 'implementability' of recommendations from the three inquiries of Ely, Bristol and Mid Staffordshire. Its premise is that "If one of the key reasons for an inquiry is to learn lessons and prevent similar events from reoccurring, recommendations must be implementable".

So every recommendation must comply with two basic requirements. First, it must be clear who the recommendations are aimed at, "for example 'the Care Quality Commission (CQC) should...' rather than... 'consideration should be given to...'".

Secondly, actions must relate to a clearly identified policy tool or operational mechanism. Typically, these would be "incentives, authority and persuasion; the economic, legal and communications families".

This may seem obvious. But analysis of inquiry reports shows that "The vaguest recommendations involve either a lack of clarity regarding who they are aimed at, or are seemingly aimed at everyone. One example, from the Francis Inquiry, is to "require every single person serving patients to contribute to a safer, committed and compassionate and caring service".

Recommendations such as these can be described as "sermons" – moral arguments that are not linked to "carrot and stick" policy tools and are not ascribed to anyone in particular. The analysis shows that "sermons are the main policy tool, accounting for some 89 per cent of Ely recommendations, compared to 66 per cent at Bristol and 63 per cent at Mid Staffordshire".

The paper concludes that "Given the large number of potentially responsible agencies, [inquiry] recommendations should be 'active' with a clearly identified agent and a clear policy tool or mechanism should be identified rather than a vague tendency to sermonise".



## Racism in Medicine

# Racism in medicine

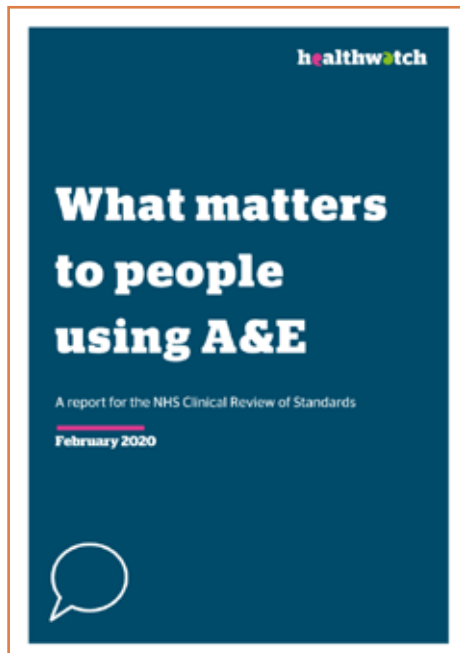
The BMJ's [Racism in Medicine](#) issue looks at the experiences of NHS staff, exploring inequalities in training and professional development, recruitment, and so on. But, commendably, the issue also covers aspects of patient experience and looks at how some health inequalities are embedded in institutional culture and practice.

[One article](#) discusses “Bibi-itis” – defined as “the belief that older Asian women express psychological distress through physical symptoms”. This, says the author, is a form of “casual clinical stereotyping that can cause unrecognised bias leading to missed diagnoses, delayed treatment, and preventable unwanted outcomes”.

[Another](#), on ethnic disparities in maternal care refers to research showing that between 2014 and 2016 the rate of maternal death in pregnancy was 8 in 100,000 white women, compared with 15 in 100,000 Asian women and 40 in 100,000 black women. It quotes Christine Ekechi, a consultant obstetrician and gynaecologist, who says “People think of racism in an overt, aggressive way. But that’s not always what it is. It’s about biased assumptions – and we doctors have the same biases as anyone else.”

[Neglect of older ethnic minority people](#) in UK research and policy is the subject of a third article. This explains how ethnic health inequalities are undermonitored and poorly understood because of a lack of data and research. It says that “Policy efforts to reduce inequalities, improve population health, and plan for the provision of health and social care are therefore not adequately informed by evidence”.

There are other articles, too, that are worth a read – and in an NHS whose Long Term Plan talks of wanting to “to develop and embed cultures of compassion”, they should be read. As Zosia Kmietowicz, the BMJ’s news editor puts it, “we can all play a part in reducing the disparities and inequalities faced by patients and doctors”.



## What matters in A&E

“Good patient experience is an essential indicator of high-quality health care and should be central to national performance measures.” So says Healthwatch England in its opener to this report on patient experience in A&E.

However, “while the current four-hour A&E target does help illustrate performance across the NHS... the lack of detail means it tells us far less about the quality of care people receive and their overall experiences”.

The report comes in the context of the [Clinical Review of Standards](#) (CRS) which is looking at updating and supplementing NHS performance targets. Part of the aim is to ensure that NHS standards “drive improvement in patient experience”.

But Healthwatch England makes the point that “time alone does not dictate how people feel about their experience of A&E”. Other factors that shape patient experience are:

- Quality of clinical care
- Quality and frequency of communication
- Staff attitude
- Whether the A&E is working well with others services such as NHS 111 and GPs
- The quality of the A&E facilities themselves

“This doesn’t mean that waiting times are unimportant”, says the report. It acknowledges that “national performance against the current target is a serious concern” that has “left the public lacking confidence in the NHS”.

However, the challenge is to “do things differently, not just count things differently”. And “if the CRS realigns targets around patient priorities [it] has a real opportunity to improve experiences for people in A&E”.





# Safety in mental health services

This study reports that “In the UK in 2017, the CQC considered over a third of mental health services deficient in terms of safety. Of particular concern were sexual safety and the use of restrictive practices such as restraint and seclusion”. In spite of this, “Service user and carer perceptions of the safety of mental health services have not been widely reported”.

Interviews with service users revealed physical safety issues, but also dealt with psychological safety, and experiences within services that had led to fear and distress.

One such example is physical restraint, which might prevent self-harm but can also cause further psychological harm. “The trauma of experiencing restrictive practices was graphically described by participants.”

In such circumstances, it can be hard for patients to raise concerns or complaints. One interviewee remarked that “If you are ill enough to be detained, you do not have the mental energy to start formulating complaints and pursuing a complaints procedure”.

Communications in general were problematic, with carers expressing “frustration at not being listened to, especially about potential early warning signs that were likely to be antecedents to incidents”.

Psychological harm can also come from a sense of being locked out of services. “Accessing help in a crisis had been universally inadequate, distressing and occasionally life-threatening for all participants.”

Inadequate access can relate to practical difficulties: “one example... is crisis services with limited opening hours”. But there may also be a kind of double standard operating: “Evidence suggests more assertive patients gain access to services in primary care, but in mental health services, assertiveness can hinder access to services with participants being seen as difficult”.

All of this has particular relevance for an NHS whose Long Term Plan is steering it in the direction of personalised care. Choice is fundamental to personalisation, and “In other care settings, patients have the right to choose between care providers and can avoid certain individuals or services. For mental health service users however, this autonomy often cannot be exercised due to lack of treatment providers and threat of compulsory treatment”. This, say the authors of this paper, makes it “even more important that if autonomy is overridden, safety should be assured”.

## Anonymity and power



This paper says that online feedback is “an equalising mechanism, enabling people to give feedback at a time of their own choosing, in their own words, often unmoderated and often anonymous”.

But is anonymous feedback a good thing? Patients may want it because they “fear that being identifiable may compromise the care they receive if they make critical remarks”. Healthcare professionals, on the other hand can “see patient anonymity as... a risk to the reputation of individual practitioners or organisations, given that anyone can say anything, no matter how unfair or damaging”.

This, say the authors, “constitutes an ‘anonymity paradox’, whereby patients see anonymity as a prerequisite but professionals see it as a barrier”.

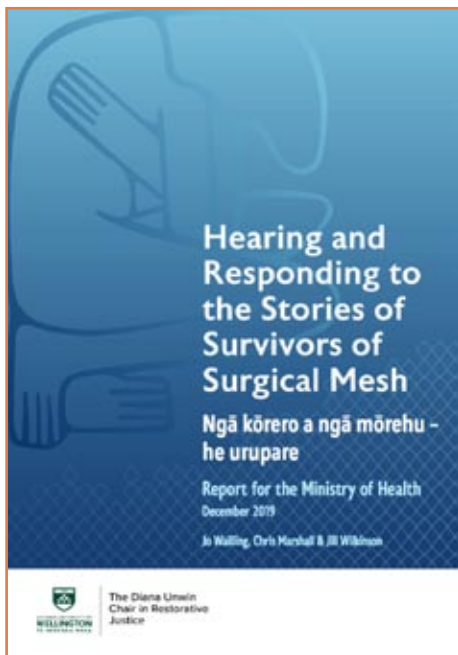
This study explored anonymous online feedback via a series of interviews with NHS staff registered as “responders” for comments received via the Care Opinion platform.

It found that in general, staff understood why anonymity might be important for patients. At the same time, “anonymous feedback creates an unfamiliar and uncomfortable situation. [Staff] are encouraged to name themselves and engage in tailored, personalised conversation, but with a faceless, nameless other”. It found that “In spite of themselves, [staff] may try to work out who someone is”.

Sometimes, “the perceived unequal relationship and feeling of vulnerability can spark more problematic responses and feelings”. The study reports that “Staff may...feel helpless, frustrated, unfairly attacked, and that their professionalism has been impugned with ‘no redress’”.

Importantly, “Feedback on Care Opinion needs to be seen within the wider landscape of staff response to feedback of any kind, whether anonymous or not”. The paper refers to other research showing that medical staff are “strongly supportive in principle of incorporating patient feedback into quality improvement work. Yet they also expressed a simultaneous view questioning the credibility of survey findings and patients’ motivations and competence in providing feedback”.

The paper concludes that the ‘anonymity paradox’ “is at its heart a question of unequal power, risk and vulnerability” It suggests that “Staff used to engaging directly with patients and families... need support in dealing with anonymous feedback, and the uncomfortable situation of unequal power it may create”.



## Hearing Survivors of Surgical Mesh

This report from New Zealand opens with the observation that “The use of surgical mesh, especially in urology, gynaecology and obstetrics surgical procedures has been a matter of local and international concern for some years”.

Much of the concern was raised by women who had suffered harm from mesh products. But they were up against a healthcare industry whose “[evidence was mired in a multimillion pound deal, industry funded research, and undisclosed conflicts of interest](#)”.

Part of the response in New Zealand was to establish a restorative justice approach to address the needs of those affected by mesh harm. The approach would enable storytelling, provide validation and help to rebuild trust.

Restorative justice is described as a process in which “those with a personal stake in a harmful episode come together... to speak truthfully about what happened and its impact on their lives... and to resolve together how best to promote repair and bring about positive changes for all involved”.

Patient stories were gathered via Listening Circles, individual meetings and an online story database. From this, says the report, “a complex and nuanced picture of the harms and needs created by surgical mesh has emerged”. Participants described life-changing physical and psychosocial harms, including:


- Loss of trust in healthcare providers
- Injuries and needs rarely being acknowledged or validated, leaving some feeling desperate or contemplating suicide
- Erosion of dignity and grief over losses to physical wellbeing, relationships, identity, employment and financial status.

Mesh injury has also “rippled out through the lives of... families and loved ones. It has deeply affected the emotional wellbeing of partners, children, relatives and communities”.

The report makes it clear that the listening process is not an end in itself. A section on “proposed actions” sets out a series of important next steps. Central to that is including “the mesh community and clinicians in transparent and inclusive dialogue in order to rebuild trust and secure lasting change”.

As UK health services [revisit their own approaches](#) to patient safety and “just culture” it may be worth reflecting on how safety investigations are conducted. For the survivors and bereaved relatives from Morecambe Bay, Gosport, Shrewsbury & Telford and elsewhere, there may be healing to be found in the kinds of restorative justice approaches described in this report.





Could you be a  
public contributor  
on national and  
regional NIHR  
committees?

**The Patient & Public Involvement team at the  
National Institute of Health Research (NIHR)...**

...are looking for patients, carers and members of the public to join one of our national and regional committees. The committees prioritise and recommend which health and social care research projects should be funded. Public members would be involved in the decision making and have an equal footing with the clinical and academic members. They have the key task of bringing a patient and public perspective to the discussions.

More information about the programme committees and how to apply can be found [here](#).

**Is your event  
listed here?**

Use this space to advertise  
future patient experience-  
focussed events.

Patient Experience  
Quarterly is published the  
first weeks of:

January

April

July

October

Get in touch:

*[info@patientlibrary.net](mailto:info@patientlibrary.net)*



Calling all  
young patients  
and carers  
aged 14 – 25

Would you be interested in sharing your experience of  
the NHS with healthcare staff participating in our current  
learning programmes?

As part of their learning, our participants are asked to listen to the voices of  
patients and carers and consider the impact of positive and negative experiences  
of the NHS.

We're currently recruiting young patients and carers aged 14 – 25 who are  
willing to share their story.

Register your interest:

[www.leadershipacademy.nhs.uk/eoc](http://www.leadershipacademy.nhs.uk/eoc)



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# The Patient Experience Library

We are the national evidence base for patient experience and patient / public involvement. We have collated and catalogued over 60,000 reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

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Cover image with apologies to Eugène Delacroix

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