

# Patient Experience

and patient/public involvement in health and care services

Summer 2021



**Patient  
Experience  
Library**

## **INSIDE**

**Each Baby Counts**

**Making stories  
meaningful**

## Editorial



After a year of lockdown, and with the Covid vaccination programme continuing apace, people are understandably desperate to get back to normal. For the NHS, however, getting back to normal might still be some way off.

There is now a huge backlog in elective care, with waiting lists topping the five million mark. Half of the general public, [according to Ipsos Mori](#), see “improving waiting times for routine operations” as the top priority in healthcare. So we need a mature dialogue between the NHS and the general public on waiting times.

Against this background, and with backing from the [Joseph Rowntree Reform Trust](#), we have created a [waiting lists tracker](#) that gives wide open access to data on waiting times for treatments at Trusts across England. The tool was [featured in the Independent](#), provoking a surge of visits to our website.

Transparency of data is essential in a publicly-owned NHS. And the question of transparency is also tackled by our contributors to this edition.

On [page 3](#), Nicky Lyon and Michelle Hemmington describe the Each Baby Counts initiative which, among other things, broke new ground by publishing data on the number of babies affected by potential brain injury or death in term labour. The data-driven approach has resulted in a significant reduction in overall stillbirth and neonatal death rates.

But data alone is not enough. On [page 4](#), Eleanor Stanley writes about the importance of personal stories that can “paint pictures that stick in the mind”. This is vital to patient and public engagement because today’s sophisticated audiences are no longer touched by polished organisational messages. They want information that is authentic and meaningful.

As always, we have been picking through some of the latest and best patient experience research, and summarising it through the rest of this magazine. And we’re always keen to hear from our readers, so if you know of a standout report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

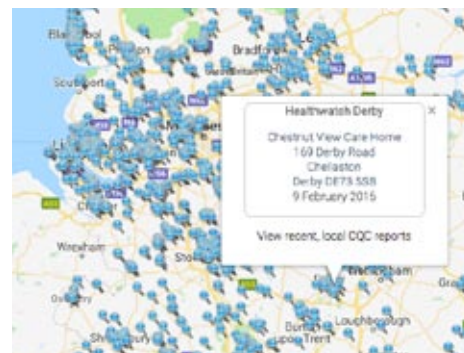
Miles Sibley, Editor [info@patientlibrary.net](mailto:info@patientlibrary.net)

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## Free resources

Our one-click [surveys and feedback tool](#) gives every NHS Trust in England instant access to all its patient experience data, all on one page. A cross-referencing function gives a quick and easy overview of common themes emerging from different datasets.

Browse the map, select your Trust, then click and collect!



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)

# Each Baby Counts

*Nicky Lyon and Michelle Hemmington*  
Co-founders, Campaign for Safer Births




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We urge that adequate resource and funding is given to ensure that all recommendations are implemented and sustained.

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Back in 2013, the two of us were bereaved mothers not only trying to understand why our sons had died but also trying to investigate how many other babies across the country were injured or dying following term labour. No one could tell us and there was little focus or recognition of potentially avoidable harm.

This led to us starting our Campaign for Safer Births, with the main aims being to highlight the issue and campaign for improvements.

In April 2014, we read an article in The Guardian that quoted David Richmond, the then President of the RCOG. David was raising this issue of avoidable baby death and brain damage. We wrote to him immediately. He responded telling us the amazing news that the college had secured funding for a new project and he asked us to consider being involved as parent representatives.

It was soon named Each Baby Counts (EBC) and we attended the first Advisory Group meeting in late 2014. Each Baby Counts published its inaugural report in June 2017 and, for the first time, the number of babies affected by potential brain injury or

death in term labour was published. At last a voice was being given to these babies and families.

Many parents have been involved with the EBC project over the years. Some have bravely documented their story for the EBC website and newsletters, whilst others have spoken at the annual report launches. We, along with the RCOG, would like to thank all parents who have been involved in, followed and supported the project.

So many powerful stories were shared, like that of the Dalhaug family who tragically lost one of their twin sons:

“The loss of Thor has devastated our lives, and we count ourselves amongst the lucky ones as we still have Harrison – we live for him. Every day, every birthday, every Christmas, every first has been a great joy tainted by deep sadness. We will carry the scars of Thor’s loss and the circumstances of his death for the rest of our lives. Every mother, every father and every family who has to suffer, and live with the consequences of a preventable loss share one thing, a simple thing, a deep and powerful wish that things could have been different – through Each Baby Counts, you have the power to make things different!”

Much has been learnt in the years since

2014 and there is now, rightly, huge focus on maternity safety. It is fantastic that this focus and activity has resulted in a significant reduction in overall stillbirth and neonatal death rates.

Sadly, the EBC rates published for 2018 remain static. However, we feel the focus on these cases has definitely been of value. We now know many of the reasons for harm occurring and recommendations have been developed to overcome these; however, there are still many recommendations to be fully implemented by trusts and there are areas where national work and outputs are needed.

We urge that adequate resource and funding is given to ensure that all recommendations are implemented and sustained. An area of major concern for us is that, with the end of Each Baby Counts and uncertainty on the future of the HSIB maternity investigation programme, this group of baby deaths and injuries may become invisible again.

Parents deserve to know why their baby died through thorough independent investigations. The numbers of these cases must be published for public record. Learning must be turned into local and national action. These babies must not be forgotten again.



# Making stories meaningful

Eleanor Stanley



'Bed 15 wants some water.' The cup arrives and I watch my 80-year-old mother gratefully take a sip. I ask what is happening with her treatment and despite my efforts to include her in the conversation, the staff direct their responses to me.

Don't get me wrong: Mum isn't unhappy. She gladly accepts her role as a passive recipient of care. But as I mull over her experience, I wonder how often these staff talk with one another about the patient experience of care... Certainly, there are no 'Hello, my name is' badges in this ward.

## Gaining traction?

Yet isn't patient experience gaining traction? There are several frameworks out there, including a [NICE quality standard](#). It's even mentioned in the NHS Long Term Plan. And through my work gathering positive case studies, I've met inspirational people at all levels of healthcare who are dedicated to patient experience. But amid the daily grind, the business of saving lives

may sometimes trump experience of care.

It doesn't have to be 'either/or'. In their seminal systematic review, [Doyle et al](#) found that patient experience is positively associated with clinical effectiveness and patient safety. And we know that [staff and patient experience are closely interlinked](#), each feeding into the other.

After all, many improvements to patient experience are as simple as courtesy: being polite, showing an interest, applying some empathy. When we face burnout, these are often the first things to go.

## Making the case for change

Patient experience teams have a crucial role to play in making the case for change. And patient stories - alongside quantitative data - can help show how patient experience filters through every stage of the health journey. That, in turn, can inform communications and relationships - from the tone of voice in appointment letters to a discharge process that enables and empowers.

There are many ways to raise the profile of patient experience work. For one thing, it makes for rich stories that showcase improvements in a way that most people can relate to. When it comes to storytelling, healthcare incorporates themes of Shakespearean proportion: birth and death; fear and loss; love, compassion and valour. When people talk frankly about their experiences, the result is often moving and compelling.

Today's audiences are wise to polished organisational messages - and authentic voices provide a welcome counterbalance. Communications colleagues will gladly seize the opportunity to share patient experience content across channels aimed at staff, patients and the wider public.

## Transforming care

But stories are not only appealing: they can also be genuinely transformative - not least, because they paint pictures that stick in the mind (the image of a patient drinking from a flower vase in the Mid-Staffs report is hard to forget). Combining these stories (or qual data) with hard facts (or quant) engages hearts and minds, triggering 'Eureka!' moments in which healthcare staff suddenly realise what it's actually like to be a real person using their service.

Back to the present day, a week after her discharge, my mother sits at home. How long will she need to take her new medication, I ask. Does she need to start leaving the house to build her strength? 'I'm sure they'll contact me if I need to do anything,' she shrugs. I wonder whether, if she'd been better included in the conversation during her stay, she might be a little more engaged now she's back home.

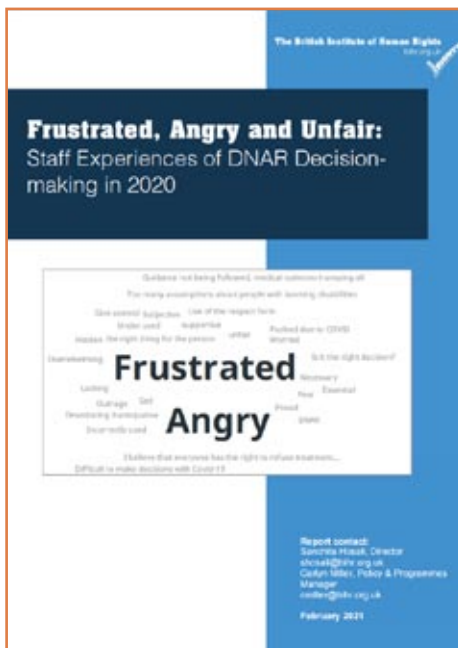
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## RECENT REPORTS

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)



# Human rights under Covid

There are many ways to look at patient experience.

We can take a consumerist view – thinking about patients as users of services, and asking for satisfaction ratings. We can take a person-centred view – thinking about the personal experiences and needs of people living with illness. This report takes a rights-based approach – thinking about the patient as a citizen with fundamental rights that are protected in law.

The focus is Do Not Attempt Resuscitation (DNAR) decisions, and the context is Covid-19. The starting point is a concern about the numbers of people accessing health, care and support services during 2020 who had experienced a DNAR order being placed on their file without consultation, or while feeling pressured to agree.

The report makes the point that DNAR decisions are not solely a medical matter. All medical decisions within the NHS are subject to the Human Rights Act – and since DNAR decisions are about people's legally protected human rights, all staff have legal duties to uphold those rights in decision-making.

Importantly, human rights do not extend only to the patient. The Act also protects family life, so consultation with family members can also be an important part of the decision-making process.

Within all of this is the point that human rights should not be restricted in a way that is discriminatory. But the report finds worrying evidence of discrimination – for example, blanket DNARs applied to people with learning disabilities, and frailty scales being used to justify DNAR decisions for people with learning disabilities, but no underlying health issues. It also raises a concern about “assumptions related to capacity”, and that people have not been involved in decisions about DNARs because they are assumed (but not necessarily known) to lack mental capacity.

Concerns about DNAR decision-making are not new. The report says that whilst Covid-19 has shone a brighter spotlight on these issues, they are part of a wider pattern of the discrimination experienced by disabled and older people within health and care. It finishes with a series of recommendations focussed on integrating human rights across decision making, policies and processes in healthcare.



## Doing nothing

“Rehabilitation research has long recognised the importance of sustained activity, including physical mobility, social interaction and cognitive stimulation” says this report. Environments that offer opportunities for activity are therefore considered ideal – however, “The lack of meaningful activity in hospital is recognised as a problem”.

The paper concentrates on stroke survivors, and says that studies consistently show that “patients in acute stroke units spend most of their time inactive and alone”. But it also says that inactivity is “an experience shared across patients suffering from diverse conditions, from psychiatric disorders, to cancer, brain injuries [and] end of life conditions”.

Planned activities, including mealtimes, medical visits and nursing care, were important stimulants, as were visits from family and friends. At weekends, however, there was “a significant downturn in terms of variety and frequency of these planned activities”. Patients “often stressed the fact that during weekends ‘nothing happened’”. Interestingly, “nursing staff also shared this view”. A healthcare assistant is quoted as saying “They get their care, obviously, but that’s it. It’s like – what happens now?”

Left to their own devices, patients struggled to find meaningful activities: “... while socialising was regarded as both enjoyable and helpful, patients in four-bedded bays could often be observed staring at the wall while being silent in the presence of each other. Similarly, while patients reportedly appreciated therapists’ encouragement to exercise on their own, it was rare to see them doing so”.

Some of this was due to the physical environment. The gym, for example, “remained closed when therapists were not on shifts”. The corridor was “cluttered with chairs, desks, trolleys, filing cabinets and various pieces of equipment, which made it prohibitively narrow for patients”.

De-personalisation was another influence. The bed areas were “typically rather bare”, with little in the way of personal belongings or pictures that might have stimulated activity and interaction between patients. The “loss of personal identity... both contributed and reflected the lack of... familiar occupations”.

All of this, say the authors, helps to explain “the lack of focus which characterised the time outside of planned routines, when meaningful activity unravelled into ‘doing nothing’ and even patients who appeared fully alert only a few moments earlier could be seen dozing off in their beds”.



## Learning from loss

The 2021 progress report from the Each Baby Counts programme will be its last. Set up in 2014, it aimed to reduce stillbirths, neonatal deaths and brain injuries incurred during labour. From now on, the work of investigation and reporting will be the responsibility of the Healthcare Safety Investigation Branch in England. Parental involvement has been central to the ethos of Each Baby Counts. Nicky Lyon and Michelle Hemmington, founders of the Campaign for Safer Births, and bereaved parents themselves, have been involved from the start. Many others have participated over the years.

The good news is that there has been a significant reduction in overall stillbirth and neonatal death rates over the life of the programme. Another important outcome has been the number of parents invited to contribute to local reviews of injury or death.

Baseline data, published in 2017, showed that parents were invited to be involved in only 34% of reviews. The data in this year's report shows that 70% were invited to contribute. Alongside the declining death rate, this is a huge step forward.

Is there more to be done? Of course there is. Edward Morris, President of the Royal College of Obstetricians and Gynaecologists says that while the programme has opened a discussion on a difficult issue, "it is now imperative that the health system shifts its focus from counting to acting".

The publication of the Ockenden report on Shrewsbury and Telford must, he says, "be a watershed moment for maternity services. The entire health system must recommit itself to challenging safety issues head on".

For their part, Nicky Lyon and Michelle Hemmington commend the programme for giving voice to harmed families. But, they say, "An area of major concern for us is that, with the end of Each Baby Counts and uncertainty on the future of the HSIB maternity investigation programme, this group of baby deaths and injuries may become invisible again".

Their final words, in this final report, are that "Learning must be turned into local and national action. These babies must not be forgotten again".



**Protect, respect, connect –  
decisions about living and dying  
well during COVID-19**

CQC's review of 'do not attempt  
cardiopulmonary resuscitation' decisions  
during the COVID-19 pandemic

Final report

# Living and dying well during COVID-19

This Care Quality Commission report, like “Frustrated, Angry and Unfair” ([see page 5](#)) looks at the practice of ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions during Covid-19.

It starts with the observation that “From the beginning of the COVID-19 pandemic, there were concerns that... DNACPR decisions were being made without involving people”. And its position on this is clear: “such actions were unacceptable”.

The review (set up at the request of the Secretary of State) heard about the experiences of over 750 people, with findings that give cause for concern. In the foreword, the Chief Inspector says this:

“What we have found through our review is a worrying picture of poor involvement, poor record keeping, and a lack of oversight and scrutiny of the decisions being made. Without these, we cannot be assured that decisions were, and are, being made on an individual basis, and in line with the person’s wishes and human rights.”

On the plus side, the report does not simply take a big stick to providers. It offers a series of practical recommendations, taking in information and training; consistent approaches to advance care planning; and improved oversight.

“Patient voice” is central: “providers must ensure that people and/or their representatives are included in compassionate, caring conversations about DNACPR decisions”. But staff voice is important too: “providers must ensure that all workers understand how to speak up, feel confident to speak up and are supported and listened to when they speak up”.

Last but not least, the CQC is willing to take its own share of responsibility. The final recommendation is that “CQC must continue to seek assurance that people are at the centre of personalised, high-quality and safe experiences of DNACPR decisions, in a way that protects their human rights”.



## A limpet on a ship



Patient and public involvement (PPI) is now commonplace in research – indeed many research bodies make it a condition of funding. But according to this paper, “little explicit attention has been paid to how the choreography and performance of collaborative research affects how PPI is imagined and practised”.

The words “choreography” and “performance” are important. The paper sees the steering committee or advisory group as arguably the most common place for PPI to happen. But formal meetings are not simply places where business is conducted on neutral terms. They can also be “powerful ritual structures” where “tacit rules constrain... what is on/off topic, who speaks and how, what actions should result from the meeting”.

The paper’s focus is “spatio-temporal dynamics” – in other words where and when PPI happens. It finds that hard to pin down.

In one meeting, a patient representative questioned the value of a prompt sheet for carers. “The chair listened attentively and suggested this might make for an interesting qualitative project – and then moved on to the next agenda item”. In another meeting, various challenges from a patient rep were not minuted. At other times, discussion of PPI was met with assertions that it had already taken place, or was planned for a later stage.

The impression, say the authors, was that PPI was “simultaneously everywhere and nowhere”.

The authors describe how frequently the metaphor of the jigsaw puzzle is used. Here, people with lived experience comprise the “missing piece”, which promises access to the “whole picture”. Health research “is presented as a collaborative practice in which all kinds of expertise smoothly join together: knowledge from ‘lived experience’ sits snugly alongside statistical reasoning and clinical trial bureaucracy”.

The jigsaw metaphor “conjures a harmonious choreography – one where all actors have a part and move forward together”. But the reality may be that PPI – and patient representatives – are more like a limpet on a ship. As one patient rep said, “you are just stuck on the side of something and people are very polite and they ask your opinion but basically they are doing what they want”.

# Person-centred dementia care

“Person-centred care” is a key goal for all NHS services – but it is sometimes easier said than done.

This study looks at the care of people with dementia in acute settings. It says that while many hospitals have committed to the Dementia Friendly Hospital Charter, “the context of acute care still challenges the ability to routinely deliver person-centred care”.

Examples of this context include:

- Standardised approaches such as time-based targets or routinised task care, which can disadvantage patients with needs that do not fit the prescribed approach.
- Organisational preoccupations with risk aversion, which can restrict patient choice and person-centredness.
- The tension between the drive to limit the time spent in a hospital against spending time to understand the patient and fitting in around their needs.

The answer, say the authors, is to rethink organisational and ward cultures. Their first point is that there is no ‘one size fits all’ model of person-centred care. Indeed, “A generic or formulaic approach to person-centred care might even make matters worse”.

Secondly, awareness and skills training for staff is not enough on its own. Crucially, “training of staff had to be combined with a recognition and valuing of the staff role itself”. In particular, “Endorsement from senior clinical leaders and management was needed in order that staff felt confident that they had the authority to adapt working practices to meet emerging needs”.

A third consideration is a dementia friendly environment on the ward – and within the hospital.

Approaches like these can come together within dementia specialist units. The paper acknowledges that these might not necessarily improve an individual's health status nor reduce hospital resource use. However, “patient experience and family carer satisfaction can be improved, which for many approaching the end of their lives, might be considered significant outcomes”.

The paper finishes with a set of pointers for improving institutional and environmental practices for patients, carers and staff.





## Women's voices at the centre

It has been good to see the government's [call for evidence](#) to help develop a women's health strategy. Anyone who doubts the need for this just has to look back over 2020: a year that saw a succession of large scale avoidable harm scandals, all affecting women.

In February 2020, the [Paterson Inquiry](#) reported on the criminal activities of Ian Paterson, who performed unnecessary breast surgery on thousands of women. The same month saw the launch of an [independent review](#) into avoidable harm in East Kent Hospitals' maternity services.

In July 2020, the [Cumberlege review](#) of medicines and medical devices described the "anguish, suffering and ruined lives" of thousands of women affected by treatments including pelvic mesh. And in December 2020, Donna Ockenden's [Emerging Findings](#) report referred to 1,862 contacts from people who believe that they may have suffered avoidable harm in maternity services at Shrewsbury and Telford.

These harms were avoidable because the providers knew about them. Patients and bereaved relatives had been speaking up – sometimes for years. But no one had wanted to hear them.

The call for evidence talks about "Placing women's voices at the centre of their health and care". But evidence shows that women are, by and large, perfectly capable of expressing their needs and concerns. Baroness Cumberlege described the women who contributed to her First Do No Harm report as "outstanding communicators and expert in the subject matter."

The problem is not with women's ability to speak. It is with the healthcare system's ability to hear.

Cumberlege went on to consider the tendency of medical professions to dismiss patient feedback as "anecdotal evidence". She said that patient experience "must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine".

We agree, and are working to address fundamental system weaknesses outlined in our [Inadmissible Evidence](#) report.

We call on NICE, Health Education England, the National Institute for Health Research and NHS England to join us. They set the tone, they set the culture, and they need to set a lead in placing women's voices at the centre of their health and care.

A full version of this article is available via [BMJ Opinion](#).



## Learning from women's experience

While the government promotes its [call for evidence](#) for its proposed women's health strategy, another instance of abusive medical practice against women has [come back into the headlines](#) - this time involving the use of harmful breast implants.

The pattern is the same as always: women, in good faith, consented to treatment and then suffered harm. They spoke up, and found their concerns dismissed or denied. After an investigation, the truth started to come out.

In this case, the French manufacturer of the implants went into liquidation, and the founder of the company was jailed. But that was not the end of the story for the women affected.

Many were left with chronic pain, and continuing anxiety about possible long-term effects on their health. They wanted financial compensation, and they wanted the German TUV Rheinland company, which issued safety certificates for the implants, to accept its own share of responsibility.

Now, after a nearly ten year legal battle, justice is being served. A French appeal court has upheld the women's compensation claims, and has also upheld a previous finding of negligence against TUV Rheinland.

[The BBC has said](#) that the ruling could help up to 20,000 other women, half of whom are British, who are taking similar legal action in France.

As long ago as 2012, the UK government [issued a report](#) on the scandal. It said that "We owe it to the thousands of affected women to learn any lessons".

But one lesson is not being learnt. Paterson, East Kent, Cumberlege and Shrewsbury & Telford all show that our healthcare system still has not learned how to take patient experience evidence seriously.

NICE still does not have patient experience evidence as a dedicated part of the National Core Content. Health Education England still sees no need for patient experience staff to have a professional qualification. The National Institute for Health Research still has no strategic overview of the patient experience evidence base. NHS England still offers little in the way of analytical tools to help people make sense of patient experience data.

Baroness Cumberlege has said that patient experience "must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine". That is the lesson that national NHS bodies still need to learn.





# Voice in the informal organisation

This paper considers the importance of employee voice, which, it says, “is widely recognised as fundamental to patient safety and quality of care”. The authors look at how both the “formal organisation” and the “informal organisation” can help or hinder employee voice.

In the formal organisation, voice is encouraged via values statements, policy commitments to candour, reporting systems, and formal roles such as Freedom to Speak Up Guardians. But these do not always work.

A notable finding of investigations into healthcare failures, according to this study, is a gap between “formally espoused values of openness and listening, and the realities of raising concerns as they are experienced by those at the sharp end”. Those realities are often governed by the informal organisation – the unwritten rules that manifest themselves through behavioural norms, social networks, power and politics.

Much in the informal organisation is good. Personal relationships and team spirit can supplement official rules (going the extra mile) and can also compensate for deficiencies, (areas where official rules and systems cannot cover all eventualities). However, the informal organisation can also have what the authors describe as a “dark side”. This can include “malign behaviours”, “subgroups and cliques” and “advantage and privilege”.

A key finding is that formal rules governing voice were not always well designed, complied with, or consistently interpreted. One example was ambiguity about what counted as a reportable concern requiring an organisational response. Participants reported that using the formally prescribed mechanisms for some types of concern was unlikely to result in action, or sometimes even acknowledgement.

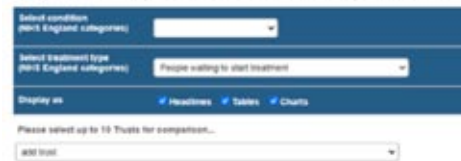
“Etiquette” was another issue. Employees with concerns had to “form a sense of how likely or unlikely the formal organisation was to take them seriously, and to gauge the potential personal risks that might arise from a decision to speak up”. Here, the informal organisation “provided clues and cues about what mattered, and the ‘etiquette’ (as opposed to procedures) governing the raising of concerns”.

The authors say that their findings have implications for efforts to improve voice in healthcare organisations. They point to the need to address deficits in the formal organisation, and to the potential of building on strengths in the informal organisation that are crucial in supporting voice.

### Waiting Lists

Get information on waiting times for treatment at NHS Trusts in England.

This data is sourced from [NHS England](#), and is published two months in arrears. The most recent available data is Please note that some data may not be available, either because the Trust does not provide treatment for the select



# Bringing waiting list data into the light

One of the biggest challenges facing the NHS after the Covid crisis is waiting lists. Half of the general public, [according to Ipsos Mori](#), see “improving waiting times for routine operations” as the top priority in healthcare.

So why is waiting list data so hard to find, and to make sense of?

The data is, of course, published, on the [nhs.uk](#) website. But it is buried in vast Excel files, with impenetrable layouts and incomprehensible abbreviations. As so often with NHS reporting, the data itself is good but the presentation leaves considerable room for improvement.

Tired of the monthly struggle to work out what on earth was going on with waiting lists, we decided to do something about it.

Our waiting list tracker takes waiting times for treatments in NHS Trusts in England and puts it all in one place. It is a huge breakthrough – bringing the data into the light and enabling anyone, at any time, to see how any part of the NHS is performing.

This matters because the experience of being on a waiting list is fundamental to people’s perceptions of the quality of care. Last year, we worked with National Voices and Care Opinion on a [report](#) that looked into this. People talked about “fighting the system”, and being in “an information vacuum”.

The tracker should also be useful to GPs – particularly at the point of referral, when patients are understandably keen to get some idea of how long they might have to wait for treatment. GPs can now see the latest figures for waiting times for any treatment at the click of a mouse. They can easily compare waits at different local Trusts. And one more mouse click prints off a simple “headlines” summary that they can give to patients as a handy aide-memoire.

Waiting list data has not been hidden for all these years for any good practical reason. Our waiting list tracker shows that it is entirely feasible to present the data in ways that anyone can understand.

Tools like these can be built quickly and affordably. They should be a fundamental part of a person-centred NHS.

You can use the waiting lists tracker [here](#).



## One size doesn't fit all

“We need to pay attention to how gender is made in the digital transformation of community care”, says this Swedish study.

The phrase “how gender is made” is central. The paper looks at artificial intelligence (AI) systems in community care. For example, an AI-based system that detects the fastest driving routes between care recipients or the likelihood of falls.

Advocates of AI in community care suggest that it can predict and prevent health deterioration, personalise care and increase patient participation. Opponents, however, claim that AI will depersonalise care, as the algorithms regard population averages and not the individual. As such, service users could become objectified through the lens of majority groups and universalism.

This matters, according to the author, because “Community care is not characterised by equality: most care personnel and older care recipients are women”. Care work is low-paid and has low status, whereas digital entrepreneurship is associated with masculine values. These power relations “are rarely acknowledged or recognised”.

Against this background, care providers “procure digital technologies and platforms in bulk...using the one-size-fits-all approach instead of working with care recipients and care personnel to co-create, design and deploy digital technologies and platforms”. From a feminist perspective, the one-size-fits-all model fails to consider the importance of context, pluralism and diversity.

AI-based systems work from huge amounts of data, so the quality of the datasets is crucial. Biased datasets, built from unrepresentative samples, or based on stereotypes and social constructs, can amplify inequalities and perpetuate discrimination. Hence the concern with “how gender is made”.

Using feminism as a framework for understanding the digital transformation of community care can, says the paper, help us move away from a one size fits all approach. Gender-transformative change does not happen automatically because gender expectations and power structures are reproduced and maintained if they are not recognised, acknowledged and questioned.

This requires “iterative work, in which assumptions and gender expectations are exposed and the design, implementation and use of technologies in community care are scrutinised, tested, evaluated, revised and tested again”.

**H HEALTHCARE**  
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## NHS Complaints Summit: Implementing the 2021 NHS Complaint Standards

WEDNESDAY 18 AUG 2021

VIRTUAL: Online



This National Virtual Summit focuses on implementing the New National NHS Complaint Standards that were published in March 2021 . Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints are welcomed and lead to change and improvements in patient care.

The conference will also reflect on managing complaints regarding Covid-19 - understanding the standards of care by which the NHS should be judged in a pandemic and in particular responding to complaints regarding nosocomial transmission of Covid-19 and delayed treatment due to the pandemic.

**Further information here**

Follow on Twitter [@HCUK\\_Clare](#)

Email [kate@hc-uk.org.uk](mailto:kate@hc-uk.org.uk)

[#NHSComplaints](#)



# Confused?



We are clearing a path through the patient experience measurement maze.

Let us help you with...

- **Surveys and Feedback tool.** One-click access to key patient experience datasets for your Trust, with cross-referencing to aid analysis.
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Hear the patient voice  
at every level of the service  
even when that voice

is a whisper



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