

# Patient Experience

and patient/public involvement in health and care services

Autumn 2022



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**Patient  
Experience  
Library**

## Editorial



Patient experience is all about how people feel treated. Not just in terms of their medical treatment and clinical outcomes, but in how they feel treated as human beings. That is why NHS strategies repeatedly talk about “respect and dignity” and why patient experience surveys also ask about those two important aspects of care.

On page 3, Mark Gamsu looks at the South Yorkshire Integrated Care Board’s “Start with people” strategy. It features a prominent photo of Mark’s local butcher who, it turns out, was completely unaware that his image was being used to promote good practice in involvement. Mark wonders whether the picture (along with others in the document) was used to provide “local colour” rather than as a way of respecting the views of the people of South Yorkshire.

On pages 4 and 5, Bettina Ryll argues for a more respectful way of communicating with people about their illnesses. Medical language is complicated, and there can be a temptation to simplify. But perhaps we should treat patients as adults, with a desire and capacity to learn. Feeding them baby language can create confusion and anxiety and is, perhaps, disrespectful.

We - the Patient Experience Library - continue to do what we can to help people make sense of the complicated world of patient experience and engagement. 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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# A Barnsley Chop

**Professor Mark Gamsu, Leeds Beckett University**

Personal Blog



As a resident of Sheffield I was keen to have a look at the newly launched “[Start With People](#)” strategy, from the South Yorkshire Integrated Care Board (ICB). It sets out how the ICB will work with people and communities .

The strategy is strong on principles – particularly with regard to the aspirations that the ICB has with regard to developing strong and trusted relationships with the public in South Yorkshire.

I was surprised but pleased to see a photograph of Dean in the strategy. Dean is the butcher I go to every Saturday down at the Moor Market. So when I popped down for some home cured bacon (which I strongly recommend) and a couple of Barnsley Chops I showed Dean his photograph.

Both Dean and his wife were surprised to see him in the strategy – they knew

nothing about it and had not been approached for their permission. To be honest, I was surprised too – I know that he has an excellent reputation for a finely cut piece of sirloin, but I was not aware that he had strong views on collaboration and co-design in the NHS.

There is a serious point here – if you say that your NHS strategy puts the relationship with the public at the heart of your work then you need to live by that. The photographs in this strategy are of real South Yorkshire people – yet it feels as though they have been used as stock images to bring a bit of local colour to give the report authenticity. That is not right.

Moving on... to inequalities. The strategy identifies issues that the ICB will be focussing on and references the [NHSE Core20PLUS5](#) framework. However, the connections between them are not clear. It is also hard to understand the ambition with regard to scale and impact. These feel like a disparate collection of projects that have been hoovered up into this space.

What is lacking is an analysis that tells us what the problem is, its scale and the actions that the NHS will be taking to address it.

I think part of the reason for this deficit lies in the very simplistic ‘Theory of Change’ that the ICB is using. Most theories of change start by analysing the problem that needs solving – and then considering what the goal should be with regard to addressing this problem. Many also recognise that a

key early step is to consider who needs to be involved, influenced or engaged in order to take effective action.

The theory of change in this strategy does none of these things. Sadly, I do think the NHS has history here – tending to default to project delivery planning tools when trying to achieve system change.

Finally... a real problem. For me the most important paragraph in the whole document is tucked away at the end of the section on the Voluntary and Community Sector, which states:

*“We know that working with VCSE partners is crucial due to the distrust many communities have in NHS organisations, because of a range of factors”.*

I wonder if this is really the case. If so, which communities distrust the NHS, and why? What might this mean for the health of populations, and for the way that NHS services are provided? What actions need to be taken to change this perception? And most importantly has the lack of trust maybe got something to do with inequalities?

So, coming full circle – yes, it is really important to be upfront about principles. But communities will not trust us if they feel that we are just paying lip service to how we represent and involve them, or if we present unconvincing strategies to address the real problems they and the health system face.

# No more baby talk

**Bettina Ryll**

Founder, [MPNE](#) - the Melanoma Patient Network Europe



When it comes to fake news in cancer, some people will call for a single source of expert-approved, quality-controlled, patient-appropriate information. Or recommend that 'patients should not google but just trust their doctor'. The latter is anachronistic in times where we use search engines for everything, and blind trust in authorities has been replaced by transparency and co-determination.

The former reveals a lack of understanding of digitally enabled social communities; the nature of scientific and medical information and the characteristics of connected patient groups.

A cancer diagnosis is often isolating, so patients seek out others in the same situation. They might join various communities - groups for information, groups for emotional support, groups dedicated to substages of their disease. Formats vary from highly structured forums with strict rules to informal discussion groups and from public twitter exchanges to private conversations.

Communication channels themselves constantly evolve, based on factors like ease of use, confidentiality and cost. So digitally enabled communities are best understood as a constantly evolving ecosystem, underpinned by personal trust and mutual understanding.

Communicating scientific and medical information into this environment is surprisingly complex, and it is difficult to simply separate information into 'correct' and 'false'. Partly because of the inherent relativity of scientific information due to experimental or methodological constraints. And partly because our understanding is always time-bound and continuously evolving - with new evidence, concepts need to be adjusted and corrected, something that can be perceived as lack of expertise by a lay audience.

Unlike simple information such as 'the Queen has died', complex information has to travel with additional meta-level information such as its trustworthiness, its relevance to the audience, its limitations and further implications. In MPNE, we have coded some of these factors under the [V2A2, a tool for effective patient information](#) (V2 stands for validity and verifiability). Interestingly, many patient communities already have an established credibility, legitimacy and emotional connection due to the shared experience of a challenge like cancer.

In light of the above it must become clear that a single source of expert-approved, quality-controlled, patient-appropriate information cannot be the solution to fake medical news, as

networks are distributed and flexible, medical and scientific information is complex, and patients are a diverse and constantly changing group.

The challenge might appear daunting. But shifting the focus from the information unit (one piece of fake news) to the pattern of its distribution offers a surprisingly simple insight: distributed problems require distributed solutions. So the way to protect patients from falling prey to fake news is to locate the level of control at the level of the single patient.

And the most effective first step? Stop the baby talk with patients. Use correct medical terminology - and put it in writing.

Medical information is new and complex for most people. Clinicians and other health care professionals, understandably, are tempted to simplify. There is also research on how much cancer patients actually retain after a visit to their oncologist. The short of it: not much.

But just thinking about it - did any of us learn those French verbs by being told them in a short stint once? Even without being told just beforehand that cancer was going to kill us or the person we love? With the best of intent, none of us is likely to pick up and retain complex information in a situation of shock, especially when time is short. So the only thing we can do is to make sure that patients - once they regain some composure and benefiting from their unique abilities as adult learners - are able to start learning effectively by themselves as rapidly as possible.

## No more baby talk

Being aware of the correct medical terminology offers a huge advantage. It is often given a bad reputation: it's too complicated, it's not accessible, it's Latin-based, or Greek. Ancient Greek. But this tends to miss its advantages. A deliberate feature is the uniqueness of terms: one term means one item and one item alone. That's how physicians can understand diagnoses even without speaking each other's languages.

What happens now when well-meaning people try to make 'complicated' medical information accessible to lay patients? They translate it into common language. The thing about common language? It's not standardised, terms are not unique and that makes it vague at best. And what happens next? Patients enter it into google....

There are actually two issues with this: Firstly, vague search terms lead to the return of contradictory and misleading information. Secondly, and for that very reason, no trustworthy source will rely on common language.

The example I tend to use is from my own field of work, Melanoma - often referred to as 'skin cancer'. But 'skin cancer' is a group of different cancers - basaloma, squamous cell carcinoma and melanoma, that all come with very different disease characteristics, outcomes and treatment options. Add the stark differences between

*Term of the day*

# arthralgia

**Arthralgia** is greek and is the medical term for joint pain.

In Melanoma, **arthralgia** is a typical side effect of both **targeted therapy** and **immune therapies**.

Find out more about side effects on the [VigilAccess webpage](#).

MPNE

8 Sep, 10:15 AM 27th Nov 2018

early and late stage Melanoma to the mix - and it is hardly surprising that a search for 'skin cancer' returns nothing but inconsistent and highly alarming results. So rather than helping, well-intended over-simplifying 'baby language' rather contributes to anxiety and misconceptions.

This is not an appeal to forgo accessible language whenever possible. A lot of medical jargon can be replaced, albeit with some effort (try to explain something like 'mitigated' in as few words as possible). It is however an appeal to provide patients with the correct medical terms for their condition, their stage of disease and their treatments (or anything else you suspect they might google), ideally with an accessible explanation - and that in writing.

In MPNE, we have started using 'term

of the day' cards, not unlike those vocabulary learning cards that many of us will have used when learning those French or Latin or German verbs back at school...

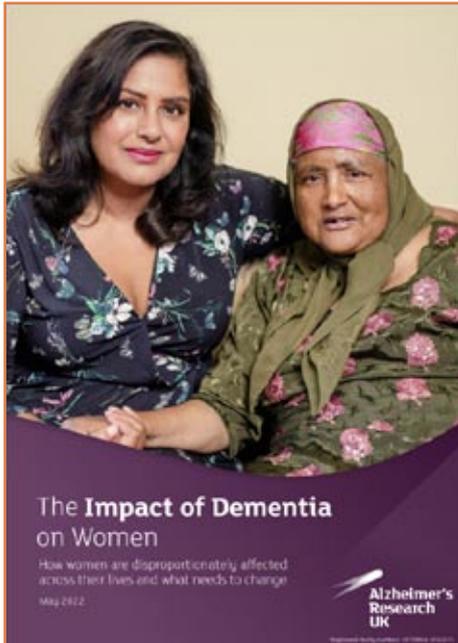
It never fails to surprise me how the understanding of a few basic concepts makes the difference between patients who are able to accurately inform themselves about their disease and those who are not. Self-motivated, knowledgeable adult learners in connected patient communities do not only keep themselves safe - they are also teaching and protecting those around them.

In times of increasingly restrained healthcare resources, patients will have to play a more proactive part in their own care. Enabling them to do so should therefore be in all our interest.

So - no more baby talk.

## 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)



# Dementia disproportionate for women

Dementia has been the leading cause of death for women in the UK for over a decade. Nearly two thirds of the UK citizens living with dementia are women. And the lifetime risk of developing dementia is one in five for women, against one in ten for men.

Even so, says this report, 'it is still not fully understood why dementia is more prevalent in women'.

One possible reason is that low levels of physical activity can be a contributory factor, and women in the UK have one of the lowest physical activity rates in the world. Another risk factor is loneliness, and almost double the number of women over 70 live alone compared to men.

Alongside individual lifestyle issues are more systemic problems.

One example is that the UK has the largest difference in male and female healthcare experiences in the G20 countries, with women receiving worse healthcare than men. To compound the problem, women with dementia receive less health monitoring and fewer GP visits than men.

Another is that women experience drug effects differently from men, with higher risks of negative side effects. But 72% of randomised controlled trials do not report sex-specific outcomes. Moreover, female volunteers for dementia research studies are likely to be excluded because of old age and multiple health conditions.

The disproportionate effect of dementia on women extends to the fact that around two thirds of unpaid carers of people with dementia are women. More than one million unpaid carers live in poverty in the UK, and 81% experience isolation, depression and anxiety. These are all contributory factors for cognitive decline.

The report makes three recommendations:

- The UK government's Dementia and Women's Health strategies should recognise the disproportionate effect of dementia on women.
- Regulators and funders should set out expectations for reducing the gender gap in clinical trials.
- Research organisations should have plans to 'break the bias' and demonstrate that female researchers can participate on an equal basis with male researchers.



# Do complaints improve quality?

‘Most patients and families submit complaints to prevent harm from occurring to others’ says this paper. And from the provider perspective, complaints ‘are increasingly recognised as a critical source of insight for quality improvement’.

But does complaints handling actually lead to improvement? This study considered how national policies shaped practice in one English Trust, and looked for any discrepancies between policies-as-intended and their reality in local practice.

It found four areas where ‘the design of national rules and policies functioned to undermine a patient-centric and improvement-focused approach to complaints’. These were as follows:

- **Muddled routes.** The paper cites a ‘confusing landscape of routes for raising concerns’ and confusion over the role of PALS (Patient Advice and Liaison Service) as against the complaints team.
- **Asymmetry.** Investigative procedures at the Trust were ‘predominantly structured to judge the ‘well-foundedness’ of complaints’. Internal evidence was regarded as superior, reflecting ‘a persistent belief that complaints are subjective and subordinate to clinical perspectives and hospital data’.
- **False information.** Complaints administrators considered the KO41a official complaints data collection system to be inappropriate, with one describing it as supplying ‘false information’.
- **Adverse incentives.** Performance targets for complaint handling led to pressure not to exceed response timelines set out by national policy. This could create adverse incentives such as a focus on reducing complaints volumes.

The authors emphasise that procedural problems like these are not necessarily ‘a consequence of sinister or malign organisational actors seeking to impose silence’. Instead, they can be seen as case of ‘well-intentioned staff confined by an overly formalised and bureaucratic system’.

The paper finishes with recommendations for change, including patient involvement in complaints investigations, the establishment of independent investigation bodies, and more meaningful data analysis.



# Eliminating out of area placements

‘The lack of capacity within the mental health system is well established’, says this report from the Royal College of Psychiatrists (RCP). It adds that ‘services all over the country are struggling to meet demand’.

One consequence is inappropriate out of area placements, where a patient is admitted to an inpatient unit far from home because no appropriate bed is available locally.

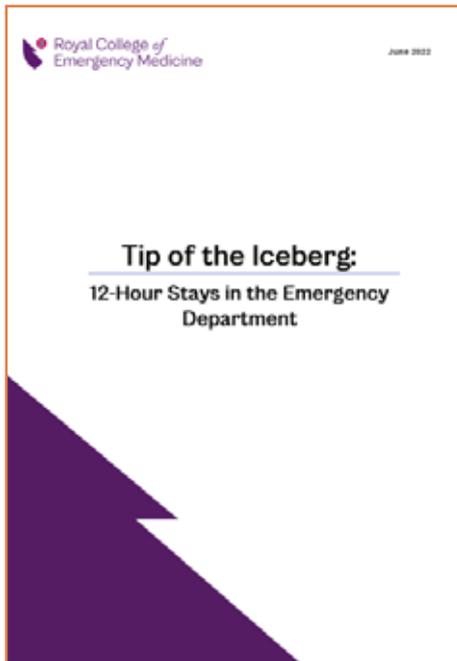
Inappropriate out of area placements ‘were always intended to be the absolute last resort’. However, ‘NHS data shows that inappropriate out of area placements are still heavily relied on to manage pressure on the system’.

The report says that ‘Patients... have been left paying the price. Sometimes hundreds of miles away from home, they are unable to access their usual support networks while at their most vulnerable, often finding their care seriously disrupted with long term implications for their recovery.’

The RCP recognises NHS Long Term Plan commitments to tackle the problem. But, it says, ‘The government’s deadline to eliminate inappropriate out of area placements... by the end of March 2021 has now been missed by a full year’. And in March 2022, ‘over half of all inappropriate out of area placements saw patients travel more than 100km from home because a local bed was unavailable for the eighth month running’.

The report makes a series of recommendations, taking in staffing, improved therapies and the condition of the mental health estate. But with increased demand on mental health services as a result of the pandemic, there is a sense of urgency. ‘Systems must be put in place that bridge the gap between the current status quo and the full delivery of the Long Term Plan, to ensure that all patients requiring intense treatment and support receive the best possible standard of care’.

Ultimately, the RCP’s position is clear: ‘This situation is unacceptable, and patients experiencing an acute mental health crisis can’t afford to wait any longer’.



## Emergency waits: transparency please

‘Emergency Department [ED] crowding is one of the most serious policy challenges facing the NHS’ says this report from the Royal College of Emergency Medicine (RCEM).

It goes on to say that ‘crowding is not only dangerous, but also inhumane and undignified for patients who have no option but to stay for treatment in precarious conditions’.

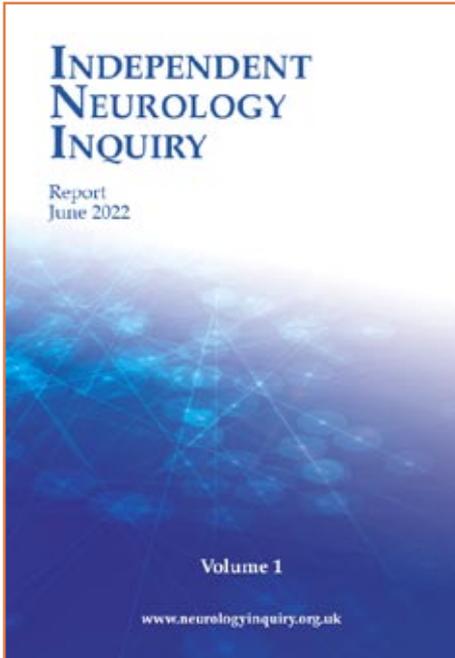
The report concentrates on a key measure: the numbers of patients waiting 12 hours or more beyond a decision to admit (DTA). It describes the numbers as ‘staggering’ and says that in the first four months of 2022 alone there were more than 79,000 12-hour DTA waits; nearly as many as the cumulative total of the 11 years since data collection began (83,000 12-hour DTA waits from August 2010 to December 2021).

In any case, says the RCEM, the 12 hour DTA measure ‘does not capture the true extent of the delays experienced by the patient’. A better measure, they say, would be 12 hours from time of arrival (TOA). This tracks performance ‘from the moment the patient steps foot into the ED’ and would be ‘a clear, patient centred measure, which brings performance measurement in England in line with the rest of the devolved nations’.

The report makes the point that ‘While hospitals currently have access to their own performance data, the Government and NHS England have still not indicated when the data on 12 hours TOA will be publicly available’.

Publishing these figures matters because ‘Behind every single metric is a patient and the NHS is failing its commitment to provide care to the public without any unnecessary delay; a key pledge outlined in the NHS Constitution’.

‘This data’, says the RCEM, ‘must be published immediately’.



## Learn from this

This report covers the events which led to the largest ever recall of patients within Northern Ireland's healthcare system. Over 5,000 people were subject to potential misdiagnosis, mistreatment and avoidable harm at the hands of neurologist Dr. Michael Watt.

Failures outlined by the inquiry report include:

- Definitive diagnoses being given in the absence of objective imaging.
- Using treatment procedures in a manner which was outside the guidelines
- The prescription of treatment in grey area cases to the point where, for many years, Dr Watt was an obvious outlier.
- A willingness to circumvent established procedures for transfer between the independent sector and the NHS.

The report makes the point that 'The failure to learn from complaints was one of the more disturbing aspects of the investigation conducted by this Inquiry. Time after time, information was raised in a patient complaint, which needed to be independently investigated. Consistently the answer given to the complainant was obtuse and unhelpful'.

A further, depressingly familiar observation is that 'there was no consistent method of dealing with clinical complaints and the emphasis remains on timely resolution... the approach was focused on responding within stipulated time periods and 'resolving' complaints'. The result was that 'the opportunity for learning from complaints often seems to have been missed'.

The Inquiry Panel says that it was 'struck by the determination of the patients of Dr Watt to ensure that issues were properly investigated and that lessons will be learned from this Inquiry'.

It says that 'when patients describe issues that may reflect a lack of safety, they must be heard, and appropriate action initiated'. But it also states that 'Patients are not, and cannot be, responsible for the safety of the health system. That sits with those responsible for governing the system'.



# Encouraging openness

‘Openness, transparency and candour are recognised as ethical responsibilities of health care organisations’, says this paper. But, it says, ‘delivering on these commitments in health care systems has often proved challenging’.

To find out why, the authors looked at organisational responses to national policies on openness. Their findings highlight four necessary conditions for change:

**Authentic integration into organisational mission.** Organisations that had made greater progress towards openness treated it as part of mainstream business, not an optional bolt-on.

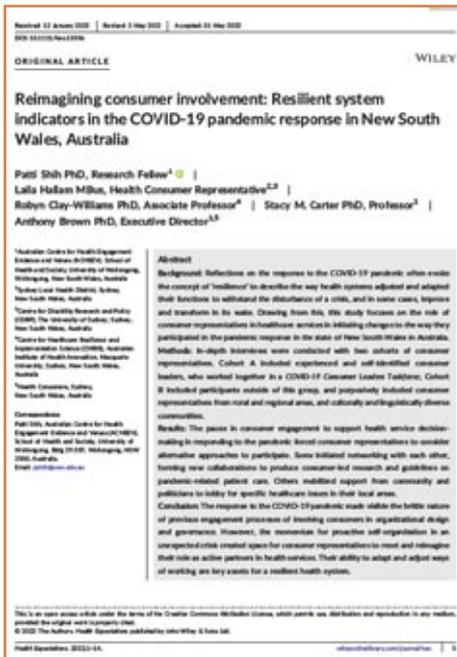
**Functional and effective administrative systems.** Organisations where openness was most advanced had good systems for oversight of disclosure and investigation processes, rapid dissemination of learning, and integration of organisational intelligence about concerns and risks.

**Flexibility and sensitivity in implementation.** Both staff and patients were unhappy with ‘coldly efficient systems’ that appeared to serve the system rather than helping those who had been harmed. Doing openness well required judgement, flexibility, and the occasional workaround - and permission from management to work this way.

**Continuous inquiry, learning and improvement.** Improved openness was the result of an organisational ethic of reflection, learning and improvement, with sometimes ‘protracted and dogged efforts’ to do better.

The paper also notes four persistent challenges that hamper progress towards openness: reliance on staff goodwill to take on extra tasks; lack of care for staff and patients who have the courage to speak up; too much reliance on ‘values-driven’ approaches, and a reluctance to tackle recalcitrant staff; and a tendency to see patients and families as bit-part players, rather than as having a crucial role.

This last is picked up in the ‘discussion’ part of the paper, which comments that ‘the principal mechanisms through which patients and family members can raise concerns about quality and safety remain largely the same as they were in the 2000s’. Their ‘continued marginality’ is, it says, ‘Disappointing, and perhaps surprising given their prominence in unearthing problems at Stafford Hospital and elsewhere’.



# Creative Engagement

This paper states that ‘Consumers are a crucial source of healthcare knowledge and solutions’, and their participation in decision-making contributes to the ‘political legitimacy’ of healthcare systems. In spite of this, ‘the international literature suggests that the participation of consumers and the broader community in COVID-19 responses was very limited. In the urgent rush to respond to outbreaks, healthcare services tended to rely on biomedical and bureaucrat-controlled approaches with limited community involvement’.

Consumers commonly saw the health service response to Covid-19 as ‘command and control’, with most services halting their consumer engagement activities, and introducing significant policy and service design decisions without consumer representatives. One example was the management of family visits in healthcare facilities, with visitors seen as an infection risk, leading to blanket bans on nonpatients entering facilities.

This ‘resulted in poorer patient experiences’, according to the authors. ‘Without family visitors, backgrounding patient information... was less comprehensive; discharge home was less informed and co-ordinated; and patients suffered poorer mental and emotional health.’

As some consumer representatives ‘lamented the almost overnight reversal of decades of improvement of consumer participation’, others started to rethink their role and purpose. One group set up an online forum, organised workshop sessions, and collected feedback and experiences via Care Opinion. Others developed community-led initiatives to support socially isolated older people, campaigned to include birth partners for labouring women, and got a Covid testing site moved to a location that was safer for people and traffic.

The collaborative approach required consumer representatives to adapt to working with each other. Until then, most were unknown to each other, having predominantly attended meetings with health services alone and disconnected from one another. The pandemic was seen as a ‘circuit breaker’ that ‘forced them to be creative in rethinking and resetting their ways of operating’.

The authors conclude that ‘The response to the COVID-19 pandemic made visible the brittle nature of previous engagement processes’. However, they say, ‘the momentum for proactive self-organization in an unexpected crisis created space for consumer representatives to reset and reimagine their role as active partners in health services’.

This matters, they say, because consumers’ ‘ability to adapt and adjust ways of working are key assets for a resilient health system’.



# Compassionate communication

NHS waiting lists are growing across the board, with longstanding problems exacerbated by the Covid pandemic. This paper describes how one hospital Trust reduced the waiting list of a paediatric service from 1109 to 212. Waiting times were reduced from a maximum of 36 months to a 70-day average.

The first part of the improvement process tackled administrative inefficiencies. Workplace observation found that clinicians lacked time to verify and cleanse waiting list data, so the primary target list of patients was not up to date and it was hard to know who was waiting for an appointment and who had been discharged.

Another problem was the need to gather various reports - school reports, speech and language therapy (SaLT) reports and opt-in/consent forms. Bottlenecks were arising because 'Too many people were involved in chasing too many reports and too much valuable clinician time was being used on clerical tasks'.

Cleansing the data, improving ways to verify reports, and confirming discharge status resulted in a reduction of the primary target list from 1109 to 556 children.

Alongside administrative improvements, the team took a 'compassionate communication' approach to dealing with patients.

The existing system had failed to do this for patients. As one staff member said, 'A lot of people just don't want to do the data cleansing - a lot of these children then don't get diagnosed and they get forgotten about in the system... What if that was my child?'

There was a similar problem with SaLT reports, which could only be actioned once patients or carers had submitted a formal opt-in. Many had been unaware of this, so the compassionate communication approach introduced follow-up calls to check that people wanted to opt in. Improved flow got the waiting list down to 212, with average waiting times reduced from 421 days to 70.

The approach acknowledged the situation of 'children and their parents stuck in a system of disconnected processes'. Importantly, it also acknowledged 'burden and stress on both administrative and clinical staff'.

The authors state that 'Compassionate interactions between staff and patients are necessary to operate responsive, inclusive processes'. Their view is that 'If compassionate leaders can reframe [quality improvement] from 'eliminating waste' and 'increasing productivity' to 'unburdening staff to deliver high quality care', perhaps this potential can be realised more broadly across the NHS'.

# Getting it wrong?



'Randomised trials are conducted to provide evidence to support better and more informed decisions about medicine' says this paper.

Generally, around 70% of trial data relates to outcomes. However, say the authors, 'Not all outcomes are created equal'. Trial teams (researchers), patients and healthcare professionals can all have different ideas about what matters most. But it tends to be trial teams who decide what is to be designated as the 'primary' outcome.

This designation matters because the primary outcome generally drives the size of the trial, and judgements as to whether the trial intervention is effective. Other outcomes are, by definition, less important.

The study showed a series of published trials relating to breast cancer and kidney disease to patients with lived experience of those conditions, and to healthcare professionals with relevant expertise. The question was whether their view of what was most important in each trial matched the trial teams' own choice of primary outcome.

The answer was that in just 28% of cases, patients and healthcare professionals agreed with trial teams. 'Given that so much hinges on the primary outcome', says the paper, 'even our small study should give some pause'. It goes on to say that in the collective view of patients and professionals, 'trial teams got the choice of primary outcome wrong more often than they got it right'.

The authors state that 'The kindest thing that can be said about this is that it represents research waste. Less kindly, it means patients and healthcare staff have spent their time, energy, goodwill and perhaps hope on a trial that has failed to provide the key information that people like them need in order to make better treatment decisions'.

'The solution', they conclude, 'is not difficult: ask people with lived experience of an illness or condition, and their healthcare professionals, what they want to know most'.

Their prescription is not limited to trial teams: 'Funders, ethics committees and others involved in study approval have a role to play too. All should be asking to see researchers' rationale for the choice of primary and other outcomes to ensure that the choices made are the right ones'.



# What actually is person-centred care?

‘A great deal of ink has been spilt over person-centred care’, says this paper – ‘a bewildering array of definitions, interpretations, and operationalised accounts exist’. The authors add that ‘it is no small irony that many researchers lamenting the absence of a clear definition themselves offer new models and definitions... thus adding to the already crowded conceptual space’.

The problem perhaps starts with terminology. The paper notes that the term ‘person-centred’ is not definitive – it ‘sits alongside and overlaps with other terms, including ‘patient-centred,’ ‘people-centred,’ and ‘personalised’.

There have been many attempts to define person-centredness. The authors point to a series of studies, among which are definitions of the ‘Seven dimensions of person-centred care’, the ‘Four Interactive Components of the Patient-Centred Clinical Method’, the ‘Five person-centred processes’ and the ‘Four principles of person-centred care’.

In spite of all this, the authors do not dismiss the idea of trying to define person-centred care. ‘There are’, they say, ‘good reasons to give the idea of person-centredness some definite shape and to indicate and illustrate what it means in certain contexts’.

At the same time, they welcome vagueness and variability. ‘Central to person-centred care is a critical, questioning, reflective attitude... Maintaining both vagueness and variety in person-centred care is an essential part of... this reflective attitude, because it enables and upholds its responsiveness to particular people and circumstances’.

‘Vagueness’ and ‘responsiveness’ go hand in hand, because ‘To adopt a fixed definition is to pre-judge in some sense what is required by particular patients and healthcare contexts, which is liable to impede the enactment and achievement of person-centred care’.

The paper recognises that ‘vagueness and variety’ might not sit well with the biomedical model of healthcare, on which, for example, clinical guidelines are based. It states that the pursuit of person-centred care might involve ‘uncomfortable and costly compromises’ even if ‘this is not often recognised in the policy documents which largely commend person-centred care as an unqualified good’.

The authors conclude that ‘Person-centred care challenges us to think again about what medicine is for and, on more radical interpretations, can recentre and destabilise established medical practices and frameworks’.



# Patient Experience in England

It is now six years since we began producing our annual overview of patient experience evidence, and we never cease to be impressed by the quality and quantity of published research.

The national patient surveys are produced with a commendable rigour in both the evidence gathering and the analysis. Their findings are always illuminating, and as the years pass, the trends and patterns in patient experience become clearer.

The research studies, by patient voice organisations, health charities, academic institutions and policy think tanks, show a variety of approaches. Formal research is grounded in theory, and quality assured through clarity of method and peer review. Other evidence gathering is less formal, but is based on long-term relationship building in local communities, leading to trusted dialogue and deep insight.

Put together, all of these sources and methods create a rich source of knowledge for an NHS that wants to be both person-centred and evidence based.

But challenges remain.

The last year has seen publication of avoidable harm investigations from the Ockenden review and, in Northern Ireland, the Independent Neurology Inquiry. Both, yet again, reveal a reluctance to take patient feedback seriously, with terrible consequences.

We can tackle this - indeed many people already are, as evidenced by the wealth of ingenuity and effort that has gone into the work featured in this report. The part the Patient Experience Library plays is to help people find their way through the mountain of feedback. Here, once again, we present our top picks from the last twelve months of evidence gathering, with summaries of the key points to help you make sense of it and, we hope, to encourage you to dig deeper.

As always, we are driven by Baroness Cumberlege's demand that patient experience must 'no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine'



# The feedback safety valve

This paper looks at the potential for patient feedback to be a proactive force for good. The authors propose online patient feedback as a kind of safety valve – ‘especially valuable for monitoring unnoticed and unresolved safety incidents’.

But why would safety incidents go unnoticed and unresolved? The paper suggests three reasons:

- Healthcare staff have difficult-to-monitor ‘blindspots’ such as problems in patients accessing care, errors in clinical notes, errors in post-care planning, and miscommunication issues.
- Organisational culture can allow defensiveness, low safety standards, and concealing errors due to fear of consequences.
- Where healthcare staff do not believe safety reporting systems are effective, prioritised, or drivers of change, they are less likely to use them.

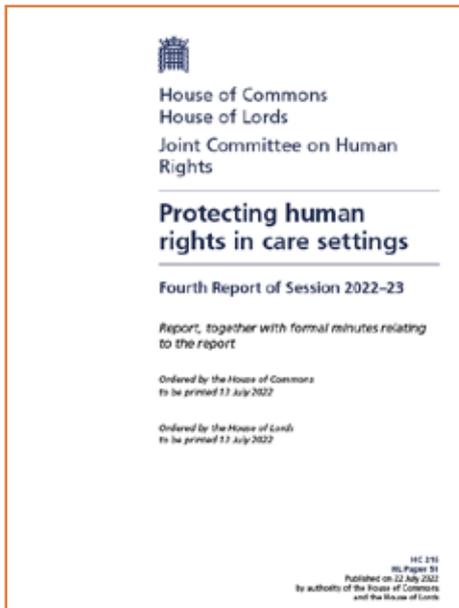
Patients, on the other hand, can more easily see the blindspots because they are directly affected by them – they have a greater ‘proximity to error’. They are also independent of organisational culture, so ‘may report on incidents that staff overlook or are reluctant to report’. Finally, if mainstream reporting systems (eg formal complaints) seem ineffective, online platforms can ‘provide patients and families with a forum to make public incidents they believe have been dismissed or otherwise ‘unresolved’ within hospitals’.

The study analysed online patient feedback for all acute NHS Trusts in England for the years 2013-2019. This amounted to 146,685 individual items of feedback pertaining to 134 acute English NHS Trusts over 7 years.

The key findings were:

- Online patient feedback can provide information on unnoticed and unresolved safety incidents within hospitals, with these data being independent of staff-reported incidents and predictive of patient safety outcomes.
- Over a quarter of high-scoring feedback was related to patients and families reporting safety concerns that, from their perspective, had been dismissed, or asking safety questions that should have been addressed by hospital staff.
- The automated measure of patient-reported safety incidents was associated with hospital mortality, whereas staff-reported incidents were not.

The combined result could be that online patient feedback can function as a safety valve, revealing hospitals that are poor at detecting and responding to safety incidents. The authors make the point that ‘neither staff nor patients have complete information, each group has unique insights and blindspots, and thus combining their perspectives is beneficial’.



## Rights in care

‘Patient experience’ is not simply a matter of ‘satisfaction with services’. Sometimes it is a matter of human rights.

This report from the House of Commons and House of Lords Joint Committee on Human Rights makes the point with some force.

It starts by noting that the UK government is bound by domestic and international obligations to ensure that people in care settings have access to the highest attainable standard of health, and protection against inhuman or degrading treatment. However, it says that ‘too often these standards are not met, and individuals suffer’.

One example is ‘Do Not Attempt Cardio-Pulmonary Resuscitation’ notices (DNACPR). The committee states that ‘During the pandemic we were hugely concerned to hear that these were being applied to care users without their knowledge, in a blanket fashion, contrary to the right to life’.

The report highlights ‘ongoing issues’ with Deprivation of Liberty Safeguards (DoLS). It says that ‘There are often unacceptable delays in authorisation of DoLS and there is often no access to legal aid if care users wish to challenge their deprivation of liberty’. And although the DoLS system is meant to be replaced by a new Liberty Protection Safeguards System, there is no timetable for this to be rolled out.

A further concern is visiting arrangements for those in care settings during the pandemic, and ‘the harm caused by blanket bans on visiting’.

The report makes various recommendations, including that:

- Training on human rights must be given by all registered providers to their staff.
- Government should work with stakeholders to raise awareness about the appropriate use of DNACPR notices.
- Government should set a timetable for rollout of the Liberty Protection Safeguards System.
- Government should introduce legislation to give care users the right to nominate one or more individuals to visit and to provide support or care.

Beyond this, the committee calls for privately funded care users to have the same legally enforceable rights as publicly funded users, and for the complaints system to be simplified.

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*Virtual Masterclass*  
**Outstanding Staff Engagement to improve Patient Experience**  
Monday 24th October 2022 Virtual Masterclass

Facilitated by:  
Mr Perkinster Grewal  
General & Muscular Surgeon, Muscular Factory & Patient Safety Trainer, and  
Executive Intelligence Practitioner

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Implementing NHS Complaint Standards  
Thursday 3rd November 2022 Virtual Conference

Chair and Speakers include:

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- Dr Peter Latham, Chief Parliamentary and Health Service Ombudsman
- Ki Moran-Jones, Head of Clinical Complaints and Patient Safety Investigations, and Lead for Safety of Care, Gloucestershire Hospitals NHS Foundation Trust

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**Measuring, Understanding and Acting on Patient Experience Insight**  
From Insight to Improvement  
Friday 2nd December 2022 Virtual Conference

Chair and Speakers include:

- Lois Galle, Patient Advocate, King's College London, Vice-Chair, University Hospitals Plymouth
- Clive Graham, Chief Executive, The Prince of Wales
- Mr Perkinster Grewal, General & Muscular Surgeon, GMS Human Factors Trainer

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Supporting Organisations: OGLOBAL, etc.

## Measuring, Understanding and Acting on Patient Experience Insight From Insight to Improvement

**FRIDAY 2 DECEMBER 2022**  
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# The Patient Experience Library

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