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Cite this as: *BMJ* 2024;386:q1301<http://dx.doi.org/10.1136/bmj.q1301>

PATIENT SAFETY

Patient safety commissioner: “The NHS’s relentless focus on finance and productivity is failing patient safety”

Patients’ concerns about substandard care are the “canary in the coal mine,” says Henrietta Hughes—but they too often go ignored, she tells **Erin Dean**

Erin Dean *freelance health journalist*

When thinking about the difference patients can make in improving care, Henrietta Hughes recalls a recent visit to a stroke unit.

“One of the patients said, ‘In the toilets, it would be much better if you had toilet paper on both sides of the cubicle, because if you’ve had a stroke you’ve only got a 50% chance of being able to reach it,’” she says. “Now, the power of that story is that you can have a unit full of experts—clinical nurse specialists, professors, people with PhDs—and they know everything about stroke, but they’ve never been in a cubicle with a patient who’s had a stroke when they’re on the toilet.”

For Hughes, that one moment crystallises the kind of insight that only a patient can bring. However, evidence that NHS patients often aren’t listened to keeps on coming.

Hughes spoke to *The BMJ* in the same week that the public inquiry into the use of infected blood, which claimed more than 3000 lives, was published.¹ This is one of a number of issues where patient led campaigns have demonstrated the devastating human cost of failures in patient safety.

“The patient’s anecdote is the canary in the coal mine,” says Hughes, who also works as a GP locum in London every week. “It’s the thing that tells us there’s something going wrong. But too often we hear about patients who have raised concerns being gaslighted, dismissed, and fobbed off.”

Listening to patients

In September 2022 Hughes became England’s first patient safety commissioner, an independent role funded by the Department of Health and Social Care. The job was created after a recommendation in the 2020 *First Do No Harm* review,² which looked into three devastating medical scandals: hormone pregnancy tests that are thought to be associated with birth defects and miscarriages; sodium valproate, an antiepileptic drug that can cause birth defects when taken by pregnant women; and pelvic mesh implants, which have been linked to crippling complications.

This review, which focused on three failures of care that affected women and other people who menstruate, highlighted the need to better protect and listen to patients. Julia Cumberlege, who produced the *First Do No Harm* report, recommended that an independent patient safety commissioner be

appointed as “the golden thread, tying the disjointed system together.”

Too often, patients raising concerns were passed off as “difficult women,” says Hughes. “It shows a very dismissive and very old fashioned, patronising attitude to patients who have identified problems and need to have their voices heard.”

The three strands of work that Hughes is currently focusing on are: developing a safety management system, including an overhaul of the complaints process and clinical negligence; embedding patient safety and the patient voice throughout the healthcare system; and ensuring that patients’ voices are heard in their own healthcare.

Martha’s rule

As part of that latter strand Hughes leads the oversight group for “Martha’s rule,” named after 13 year old Martha Mills, who died from sepsis after her parents’ concerns about her deterioration in a London hospital were not acted on.^{3 4}

Martha’s rule is one of the areas where Hughes believe that she and her team have really made a difference. “I’ve never seen something happen at that scale and speed before, particularly in such a collaborative way,” she says. But she does add that some organisations may have to implement the rule slightly differently, as they don’t have access to critical care outreach teams around the clock. These teams, often staffed by senior nurses, are the responders when a family triggers a clinical review.

“We need to take the local context into account,” says Hughes—“and take an approach that’s very respectful to patients and families but also to the staff who work in a wide range of settings.”

Valproate and mesh

While Martha’s rule is leading directly to change, other victims of patient harm are still waiting for justice.

In February Hughes published a government commissioned report looking into what kind of reparation should be offered to the people harmed by sodium valproate and mesh surgery.⁵ Three months later she received a letter from the then health minister Maria Caulfield, which didn’t commit to the recommendations and said that legislation would be needed for the recommended financial compensation.⁶ In her letter Caulfield said that the

government was “exploring a host of non-financial redress options” and that she was “keen to do what I can regarding the availability of information available to patients, as well as any improvements in access to the support patients are entitled to.”

Hughes seems frustrated with this response. “The time for redress is now for those patients who were harmed by valproate and mesh,” she says. “I recognise that it’s complex, but those patients have been campaigning for decades to get recognition, to get the financial and non-financial aspects of redress that would make a huge difference to their and their children’s lives.”

Through her work as a GP, Hughes realised that the way in which sodium valproate was prescribed meant that pharmacists often had to split packs and issue tablets in plain white boxes without warnings about the effects they could have on unborn children. After she raised the issue the law was changed last year so that safety warnings would be provided with every pack and the tablets would be issued in their original packaging.⁷

But three children a month are still born to mothers who are taking sodium valproate, despite the longstanding knowledge about the harm it can cause, says Hughes. She blames this on the “disjointed nature of primary and secondary care, community care systems not talking to each other, and patients falling between the cracks.”

Cultural change

Hughes, a former medical director at NHS England and national guardian for the NHS, doesn’t look into individual cases. But she does believe that knowing where to seek support can be tricky for patients and families in a disjointed system.

“There’s over 100 patient safety organisations, and one of the things that we’ll be working on this year is doing the *Patient Safety Atlas of Powers*, an easy-to-read guide of the arm’s length bodies and regulators and what their roles and remits are,” she says. “Because as far as I’m concerned, they don’t join up. They don’t reference the next step in the chain.”

NHS trusts that actively listen to patients are more likely to get it right when it comes to supporting their staff too, says Hughes, and she’s keen to bring some of the learning from her national guardian role into creating better routes for patients to be heard.

Organisations that work alongside providers, such as commissioners and regulators, also have a critical role to play in improving culture, she says. Focusing too much on finance at a provider level means that “the culture becomes toxic, and we’re just on the road back to the Mid Staffs scandal.”⁸

When considering the challenges of her role, Hughes reflects that she’s “swimming against the tide” when it comes to making a lasting cultural change. “People are quite comfortable with the way they do things already,” she says.

Last year she pointed out in a report that neither the Department of Health and Social Care nor NHS England had patient representatives on their boards, nor did they regularly hear a patient story at board meetings. She still believes this to be the case.⁹

“I’ve been continuously raising this concern that I have, that safety is seen as some kind of sideshow rather than as central and paramount,” she concludes. “The relentless focus on productivity, finance, and performance is really missing a huge opportunity to start with patients and start with safety.”

How patients were involved in the creation of this article

Members of *The BMJ*’s international patient and public advisory panel collaborated with us on this interview by suggesting the questions to be posed to Henrietta Hughes. They also shared topics of interest to them, which helped inform the interview question selection.

Competing interests: I have read and understood the BMJ Group policy on declaration of interests and have no relevant interests to declare.

Provenance and peer review: Commissioned; not externally peer reviewed.

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