## DEMOS

# A NEW POLICY TO AMPLIFY PATIENT VOICE AND IMPROVE SAFETY IN HOSPITALS

POLLY CURTIS CLAUDIA WOOD

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### **FOREWORD** BY MEROPE MILLS

Martha Mills died aged 13 in the summer of 2021 after sustaining a pancreatic injury from an everyday bike accident while on holiday with her family. The inquest into her death heard that she would likely have survived the sepsis that killed her had consultants made a decision to move her to intensive care sooner. Her mother, Merope, later wrote in the Guardian<sup>1</sup> about the failures in Martha's care urging other parents to follow their instincts when their children are ill. She trusted the clinicians against her own instincts - they didn't listen to her concerns and instead "managed" her. "We had such trust; we feel such fools," she wrote. The piece prompted a huge reaction across the NHS and beyond. Many hospital trusts wrote to Martha's parents, asking them to come and speak to their leadership teams about their experience, in order to help them improve patient safety in their hospitals.

Here, Merope writes about the messages she would like to send to those who work in the NHS.

The first thing to say is that I am not an expert on health or hospitals, and I can talk only about my own experience, on one ward in one hospital. Having said that, in the 18 months since Martha died, I have learnt a lot about what went so catastrophically wrong with her care. My eyes have in many ways been opened. And I feel emboldened by the fact that many medics who responded to my Guardian article said they recognise the problems and patterns of behaviour I identified.

I'm a fierce supporter of the founding principle of the NHS, but Martha's death has altered how I

think about practices and behaviour in hospitals. It's worth underlining that Martha was on a well-funded ward, the doctors were not over-stretched and ICU had a bed available for her. Funding clearly needs to be at the centre of almost all discussions about the crisis-ridden NHS, but ours is not a tale of cuts or insufficient resources. People within the health service care desperately about funding, of course, but they are also more familiar than the general public with the NHS's deep-seated problems and how things go wrong in hospitals. I want to tell Martha's story, to identify some of these problems and to make some suggestions – in the spirit of boosting and improving our invaluable health system.

My ultimate aim is for what happened to Martha – a healthy 13-year-old who loved life and had vast promise – never to happen again. An uncountable number of NHS mission statements involve a pledge to put patients at the centre of practice: I'd like to see a particular change that would make this aspiration more of a reality every day on hospital wards.

Hospital doctors do an indispensable job, and in a crisis we depend on them utterly (their veneration within our culture is in part a reflection of this dependency): we put ourselves in their skilled hands. But clinicians themselves are the first to say that errors happen in medicine, that doctors are only human. They even admit that, for understandable and unsurprising reasons, hospital mistakes have often been covered up. Martha's death wasn't caused by fatigue or pressure, but I recognise that many doctors face these challenges every day. I'd argue that effective measures to give patients more power would ultimately make doctors' lives easier not harder, by encouraging a more open and non-hierarchical – a safer – medical culture.

When we arrived at King's College Hospital in London, I was so relieved that Martha would be

<sup>1</sup> Mills M, "We had such trust, we feel such fools': how shocking hospital mistakes led to our daughter's death', The Guardian, 3 September 2022,

getting the best possible care: it was one of the few centres in the country for the specialist treatment of her bike injury. And I felt so lucky that she ended up on Rays of Sunshine ward, where she would be treated by the 'liver team', which King's calls 'worldclass', and has a very high status within the Trust. Along with my husband Paul, I put Martha in the hands of these experienced consultants, many of whom are also professors, and the junior doctors they worked with. It was a relief; it felt right. I began planning for Martha's 14th birthday, and the consultants said she'd be back at school before too long.

I understood at the time that senior doctors are often in a rush, and have many patients to see. Partly because I knew this, I was so grateful to the consultants when they explained her treatment to me, and I absorbed the idea of their status and importance. Even when things started to go wrong, I didn't understand that the liver team doctors might not be doing all they could. I was, most of the time, a more-or-less passive recipient of their expertise and reassurance.

No one now disputes that when Martha developed a fever that never abated, when she started to bleed from her tubes in a way the doctors had never seen with her injury, and especially when she developed extremely low blood pressure and a rash (among many other symptoms), she should have been moved from Rays of Sunshine to paediatric intensive care. I've been told that had she been moved there, special steps would have been taken to control the infection – that her treatment and observation would have been completely different. But this didn't happen, a failure that investigators into Martha's death have called 'indefensible'. I want to do what I can to protect others from this fate.

As Martha deteriorated, as different consultants came and went, and as the bank holiday weekend arrived, I began to express my anxiety but was told that 'infections come and go' and that 'she'll turn a corner soon'. I became increasingly worried and began to seek outlets to communicate that things weren't right. But no sense of emergency or gravity was communicated to me by the liver team ... right up to the point when Martha had a seizure and was finally admitted to intensive care, very soon after which I was told that she was 'at high risk of death'.

A national authority on sepsis worked just down the corridor at King's but the consultants, though they knew Martha had severe sepsis and were perplexed by her condition, didn't ask for his help. It's been explained to us that the liver team is 'very hierarchical'. (Nurses identified Martha as 'at risk' seven days before she died, but their opinions weren't absorbed.) We found out later that a crucial reason why the consultants didn't consider referring my daughter is that for years they had been dismissive of their junior colleagues in paediatric intensive care. There was no formal 'outreach' between the two departments.

Sometimes such problems develop within even the best hospitals – silo thinking, poor interdepartmental relations, a team with a particular reputation. Given that, it must make sense to introduce patient-centred measures that might lessen their negative effect.

By Martha's bedside, I was told not to look up her symptoms on the internet, to leave everything in the doctors' hands. Now, to a degree that I can never fully express, I wish I'd done more, challenged the doctors, asked for a second opinion from outside the ward. For the future, I'd like to make such action easier for other patients and their carers – to make such challenges a little more acceptable and run-ofthe-mill.

The airline pilot and impressive campaigner for patient safety, Martin Bromiley, often points out that once they get to a certain level, many doctors are subject to remarkably little oversight. Given that context, it seems to me irrefutable that patients would benefit from a little more power. Patient safety experts throughout the world say that listening to patients and their caregivers is an essential aspect of care. In some ways – not in others – Paul and I knew more about Martha's deterioration than the doctors did. After all, we hadn't left her bedside. Allowing patients and caregivers more agency makes hospital wards safer.

We should all be clear that challenging doctors is hard. The atmosphere on a hospital ward doesn't encourage it. Some medics are wonderfully open and unassuming, but perhaps the majority of consultants - often due to time-pressure or their sway over junior doctors – find themselves conducting their ward rounds with briskness or swagger. (As Martin Bromiley says, doctors are often people who have never failed at anything in their lives.) What I was encouraged to see on these visits was confident decision-making in action, an individual display of expertise. I was talked to, rather than listened to. (Martha was too: though she was a calm, 'easy' patient, and though a fast heartbeat is a symptom of sepsis, the doctors on at least one occasion attributed her tachycardia to 'anxiety'.)This is never a good situation, but when it contributes to the unnecessary death of a child, something needs to be done.

After I wrote my article in the Guardian, one surgeon wrote to me to say: 'After decades in the NHS I have observed that teaching hospitals in general, and tertiary referral units in particular, often attract "high fliers" for whom career progression may appear more important than team working and basic medical care ... In some units consultants are still gods and it is dangerous when there is a culture that junior doctors and nurses (let alone patients and families) feel unable to challenge their decisions.'

After Martha's death, I learned about the canteen in (at least) one hospital where special areas are reserved for consultants, almost like an Oxbridge 'high table'. The medical world is wearily familiar with such cultural issues – hierarchy, failures in communication – as it is with the weekend 'skill dip', with consultants absent on Saturdays and Sundays and wards seeming like the Mary Celeste. But there is a shortage of doctors and privileges are hard to erode.

On the day my article came out, a medic was brave enough to comment on Twitter: 'I am convinced that telling new medical students that they are the "top 0.1%" is a big contributing factor to the sense of entitlement that oozes from our profession'. As if to justify that tweet, another medic posted on Reddit, as part of a thread of doctors talking among themselves about Martha's case: 'The patients' degree of entitlement, and inability to accept mistakes, is just simply unsustainable, wholly incorrect and an enormous burden.'

The posts on that thread made palpable the 'us' and 'them' assumptions of many medics, the view that laypeople are hopelessly uninformed and need to be 'managed'. Many of the doctors posting chose to ignore the likelihood that I had talked to King's, been involved in investigations and participated in the inquest: they simply assumed that my article was emotional and sensationalist, and couldn't represent what really happened.

I desperately wish that I'd felt able, with no fear of being the target of ill-temper or condescension, to ask for a second opinion from outside the liver team when I became concerned about Martha's deterioration. I did question the registrar's diagnosis of her rash – and explicitly raised the possibility that it was a sepsis rash – but was dismissed and regarded as overly anxious. Parental anxiety was, against the hospital protocol, used as a reason why a second opinion wasn't obtained. I wasn't listened to, and that made the ward less safe. My challenge wasn't welcomed, and I was ignored; it turned out, tragically for Martha, that I was correct.

Such questioning – and listening – should be codified, allowed, seen as usual. Investigators have concluded that a kind of 'blindness' was evident in the liver team on Rays of Sunshine ward – a second opinion or review could have introduced some light. It might even have led to the involvement of the national expert on sepsis down the corridor. It's almost certain that Martha would then (as investigators told us) have been admitted immediately to intensive care.

There are two other problems I'd like to highlight here, one specifically to do with communication, and the other to do with how Martha was passed from consultant to consultant. Again, my aim is to encourage changes that mean patients and their families become just a little more empowered.

Something I think about every day is that the doctors looking after Martha knew she had sepsis (severe sepsis in fact) seven days before she died, but not once used that word when talking to Paul or me. Everything was done to play-down our anxiety; we were indeed 'managed' and condescended to; euphemisms were employed. We were told that her bleeding was a 'normal side effect of infection', which was dangerously misleading. Because I wasn't dealt with honestly, I failed to sound alarms and to protect my child. I'll never forgive myself.

I had no choice but to accept what I was told; I had no access to any notes about Martha's care (it turned out that the consultants, with one exception, didn't actually contribute to the patient record about her). We weren't told about a build-up of fluid around Martha's heart, which was another sign of sepsis (perhaps because it was decided to delay the relevant scan until after the bank holiday). This was another expression of 'us' and 'them' or 'not in front of the children'.

If I'd had more information about Martha's deterioration, I would have spent every single waking minute trying to educate myself about sepsis and septic shock. Is it too cynical to suggest that this is exactly what the doctors didn't want – an over-involved, Googling mother who might make an almighty fuss on the ward, disturbing everybody and challenging their control? I can only conclude that the power balance needs to be shifted, even slightly – no fuss would be needed if an alternative means was available.

As doctors should be encouraged to ask for help or advice from colleagues, so open, honest, 'us' and 'us' discussions need to take place involving doctors, nurses and patients and their families and carers. Discussions which involve the truth, even if the truth involves 'scary' medical terms. Patients and their carers can take it: they'd much rather things were done that way. As much as possible should be done to break down the assumption that laypeople 'just don't understand'. Allowing patients and families more agency would contribute to this.

On paper, Martha was allocated a named consultant at King's, but in practice this meant nothing. There was no name by her bedside, and a different consultant every day took up the reins of her care, starting from scratch, relying on incomplete notes written by junior doctors on the patient record. Only a named consultant that existed in reality, and was kept informed and felt responsible, would have been fully alert to the trends and abnormalities that characterised Martha's deterioration.

What's more, it turns out that there was actually a disagreement between the medical consultants and surgeons on the ward as to who was responsible for Martha's care (and the type of injury she had). If she had been allocated a proper named consultant, I would have, without doubt, contacted them when my doubts grew more serious about the decisions being made on the ward. I would have contacted them about her rash, when that day's duty consultant remained at home, on call. Again, I can see why a named consultant might not want to be badgered by an 'over-anxious' mother about a patient they are not seeing at that moment. But given what happened to Martha, I'd argue that, in this area too, patient power needs to be increased.

There are policies I've heard about since Martha died – explored by Demos in this paper – that I'd urge the NHS to consider: in particular, I'd like to explore a 'patient and family activated escalation system', like Call 4 Concern which exists in some trusts, or a version of Ryan's Rule, which was introduced in Queensland, Australia in 2013 and has proved popular with the public. This rule would allow patients, parents or caregivers to request an immediate review if the patient's health condition was getting worse or not improving as well as expected. Such a review would be carried out by a senior clinician not directly involved in the patient's care, almost certainly from ICU. Doctors might not immediately welcome such a codified challenge to their authority on the ward, but 'Martha's Rule' would, I believe, save lives.

If nothing else, I believe Martha's Rule would be valuable simply by introducing patients and their carers to the idea, the language, of a 'review'. The NHS ultimately belongs to them, and they should be allowed a second opinion, with no stigma attached, if things are looking bleak. In a situation where patients often feel powerless, it is a measure of patient-power. It would give patients and families an obvious route to travel if they were scared and unconvinced. If I had seen a poster on the ward outlining Martha's Rule – and I did look at all the posters – I'm sure I would have acted on it. And my wonderful daughter might have survived.

## INTRODUCTION

This report is a response to that call from Martha Mills's parents to rebalance the power between patients and medics with one purpose only: to improve patient safety.

Significant evidence shows that failing to properly listen to patients and their families contributes to safety problems in the NHS. Twenty years ago, the Royal College of Surgeons of England declared: "Communication is the area of greatest compromise in the practices of most surgeons in the NHS and the source of most complaints".<sup>2</sup>

A 2019 study of patients who had experienced a "safety incident" while in hospital found that 22% of patients identified poor communication between staff and patients as the main cause of the problem – the most frequently occurring category.<sup>3</sup> Successive independent inquiries, most recently looking at maternity services, have also highlighted the problem. The review into East Kent's maternity services opened with a quote from William Osler, known as the father of modern medicine after he set up John Hopkins Hospital, Baltimore, at the end of the 19th century: "Listen to the patient, [they are] telling you the diagnosis".<sup>4</sup>

There is also public awareness among citizens that the NHS can feel unresponsive at times. A recent survey and national conversation with the public held by Engage Britain found that 27% of those surveyed reported feeling dismissed, patronised or "told off" when seeking help and 39% said they had had to "fight" to get the healthcare they needed for themselves or their relatives in the past.<sup>5,6</sup> communications between medics, patients and their families in order to improve safety. Its 2019 Patient Safety Strategy, entitled "Safer culture, safer systems, safer patients",<sup>7</sup> included a framework to involve patients in patient safety including by "encouraging patients to ask questions".

The Patient Safety Strategy is an ambitious attempt to improve outcomes for patients, including by tackling the cultural problems we highlight here. The NHS has also attempted a "Just Culture", introduced a "Duty of Candour" and experimented with "Shared Decision Making". However, successive attempts to address these issues and change the culture in the NHS are proving painfully slow.

Fundamentally, this is about culture change and improving the relationship between medics and patients. Culture is hard to pin down, unwieldy to change and stubborn to fix. Ask anyone working in any hospital and they will tell you the ward or team that is a cultural outlier. This is not revelatory. Patients know it, medics know it, the whole system has tried to fix it, but the problems persist.

In the rest of this paper, we focus on one specific policy change designed to redress the balance of power and nudge the culture change that is required: **Martha's Rule.** 

The NHS itself understands that it needs to improve

<sup>2</sup> Teasdale G M and Council of the Society of British Neurological Surgeons, The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995, June 2002, http://www.bristol-inquiry.org.uk/final\_report/the\_report.pdf

<sup>3</sup> National Institute for Health and Care Research, '*Communication problems are top of patients' concerns about hospital care'*, 9 April 2019, https://evidence.nihr.ac.uk/alert/communication-problems-are-top-of-patients-concerns-about-hospital-care/

<sup>4</sup> Ibid.

<sup>5</sup> Engage Britain, *Health and care: Policies for the people, shaped by the people,* no date, https://engagebritain.org/policy-ideas-health-and-care-shaped-by-the-people/

<sup>6</sup> Engage Britain, Is the NHS and social care working for everyone?, no date, https://engagebritain.org/is-the-nhs-and-social-care-working-foreveryone/

<sup>7</sup> NHS Improvement and NHS England, *The NHS Patient Safety Strategy Safer culture, safer systems, safer Patients,* 2 July 2019, https://www.england.nhs.uk/wp-content/uploads/2020/08/190708\_Patient\_Safety\_Strategy\_for\_website\_v4.pdf

### THE RIGHT TO A REVIEW

The central insight from Martha's parents' experience, born out through the wider evidence, is that there is a delicate and difficult dynamic between patients (and their families) and medics in high stakes scenarios.

The balance of power can mean that people don't express concerns that could prove invaluable. The opposite is also true: patients can challenge in ways that disrupt and prevent urgent treatment. The wider evidence shows that this is having an impact on patient safety and, in the worst cases, costing lives.

Around the world hospitals have introduced schemes that give patients or their loved ones a right to request a review from a separate team of clinicians if they feel they are not being heard or responded to. Martha's Rule would be based on these systems and the evidence that they contribute to improved outcomes for patients.

#### **CONDITION H(ELP)**

Condition H(elp) is a system devised by the University of Pittsburgh's Medical Centre. It was launched as a result of the case of Josie King, who died in 2001 due to hospital errors and poor communication. The H(elp) system allows patients and their relatives to directly summon the Rapid Response Team (RRT), using an in-hospital 911 call. The project was launched in September 2005 and in a review in August 2007, the Children's Hospital of Pittsburgh found it had responded to 42 calls from patients and parents. Analysis found that every one stemmed from a communication breakdown between a patient or parent and the caregiver (physician or nurse) involved.<sup>8</sup>

Condition H(elp) and a variety of similar family activated RRT systems systems have been introduced across the US in the last two decades.<sup>9</sup> Evaluations of these systems have been positive showing no overuse or abuse of the system by patients and no significant increase in workload. Crucially, they have consistently led to better clinical outcomes.

An evaluation of 193 RRT calls a month over three months at a Medical Center in Jacksonville found an unequivocally positive impact on outcomes: they saw a significant decrease in cardiac arrests from 25.2 per month to 17.4 following the introduction of the family activation system. Deaths resulting from these cardiac arrests also fell, from 12.3 per month to 5.9, then to 3.1. Interestingly, overall mortality rates in the centre did not drop significantly upon introduction of RRT for use by clinical staff (32.5 deaths per 1000 admissions to 31.0 per 1000 admissions), but when family and patient RRT activation was introduced, the mortality rate fell to 22.9 deaths per 1000 admissions. After an RRT call, transfer to a higher level of care (e.g. ICU) increased from 12.8 per month to 45.4 per month.<sup>10</sup>

The Jacksonville system has been welcomed by patients and families who have used it, but there have also been wider benefits – it led to proactive ward rounds and critical care outreach efforts, as the team found there were trends in the type of patients that they were being called about. They learnt from the patients and their families' insights.

<sup>8</sup> Dean B S, Decker M J, Hupp D, Urbach A H, Lewis E, Benes-Stickle J, Condition HELP: A Pediatric Rapid Response Team Triggered by Patients and Parents, Journal For Healthcare Quality, Volume 30, May 2008, https://journals.lww.com/jhqonline/Abstract/2008/05000/Condition\_ HELP\_\_A\_Pediatric\_Rapid\_Response\_Team.5.aspx

<sup>9</sup> Landro L, 'Patients Get Power of Fast Response', The Wall Street Journal, 1 September 2009, https://www.wsj.com/articles/SB10001424052 970204047504574384591232799668

<sup>10</sup> Gerdik C, Vallish R, Miles K, Godwin S, Wludyka P, Panni M, *Successful implementation of a family and patient activated rapid response team in an adult level 1 trauma center*, Resuscitation, Volume 81, October 2010, https://www.researchgate.net/publication/45286582\_ Successful\_implementation\_of\_a\_family\_and\_patient\_activated\_rapid\_response\_team\_in\_an\_adult\_level\_1\_trauma\_center

#### **RYAN'S RULE**

In Australia, Queensland Health developed what became known as 'Ryan's Rule' after the death of Ryan Saunders in 2007 from an undiagnosed streptococcal infection, which led to toxic shock syndrome. Ryan's parents worried he was getting worse and didn't feel their concerns were acted on in time.

Ryan's Rule is an escalation process to help minimise a similar event happening. Families call a dedicated phone number (13 HEALTH) and ask for a 'Ryan's Rule Review', and a Ryan's Rule nurse then visits and assists.<sup>11</sup> There is a similar system called REACH in New South Wales, Call for Help (C4H) in Western Australia and HearMe in Victoria.<sup>12</sup>

#### CALL 4 CONCERN

In the UK, a similar scheme called Call 4 Concern has been adopted by some hospitals. It is another patient escalation system, whereby patients and relatives can call or bleep a hospital's in-house Critical Care Outreach Team any time of the day if they are concerned about a change in condition which they feel their care team is not recognising. It was pioneered by the Royal Berkshire NHS Trust, launched with a pilot in 2009/2010. Posters and leaflets are around the hospital, including on every bedside locker.

In the first year of trial (1st September 2009 to 23rd September 2010), the CCO team received 37 C4C referrals representing 0.5% of total CCO activity. A review was taken in the first six months, when there had been 12 C4C calls, 11 from relatives. They were broken down as follows:

- Two calls required critical intervention/readmission to ICU
- Two required clinical intervention
- Three required ordering further testing
- Three required clinicians to clarify things with the patient and family and improve communication
- Two involved reassuring the patient/family.<sup>13</sup>

The two calls that led to critical intervention are powerful in showing how such a simple alert system can save lives. In the first case, the patient was becoming increasingly unwell and his son felt his concerns were not acknowledged by the ward nursing staff. The subsequent CCO assessment found that the patient required aggressive fluid resuscitation due to large gastric losses, and was developing a chest infection. After a surgical and medical review the patient was readmitted to the ICU.

In the second case, a C4C referral was made when the patient's wife raised concerns about his restlessness and abnormal breathing. The patient's wife said that the nurses on the ward were not concerned about the patient's condition, and she felt that they were too busy. The CCO assessment found that the early warning score was inaccurately underscored, and the patient was septic. Tracheostomy care was given, investigations were ordered and antibiotics commenced after consultation with the patient's medical team.

In 2019, a further evaluation of C4C referrals in Royal Berkshire was carried out. Over a seven year period, 534 calls to C4C were made. The study found the service was being appropriately activated, with only 5% of referrals deemed not to be a C4C. In a fifth of cases (114 patients) significant interventions were required, such as further specialist review and admission to higher levels of care. The remaining referrals related to significant concerns for patients and their families, with the researchers concluding these were important for the "promotion of improvement in safety culture through patient and family empowerment".

They also found 11 calls were actually made by staff on behalf of a relative, demonstrating how C4C had become an established service, accepted by clinical staff.

C4C's positive impact on patient outcomes, satisfaction, and minimal impact on CCO workload has meant C4C has been adopted in several other hospital trusts: Dorset Trust, East Sussex and North Essex NHS Trusts, County Durham and Darlington Trust, and Brighton and Sussex University Hospital Trust.

On the basis of this evidence, we believe that there is a case for more hospitals to introduce the scheme, a 'Martha's Rule', and for NHS England to encourage this to happen. A standardised, system-wide, family or staff activated RRT should be introduced across the NHS in order to empower patients to voice their concerns and nudge clinicians to listen to them more.

<sup>11</sup> Clinical Excellence Queensland, '*Ryan's Rule'*, 13 September 2022, https://clinicalexcellence.qld.gov.au/priority-areas/safety-and-quality/ ryans-rule

<sup>&</sup>lt;sup>1</sup>2 Bucknall T, Quinney R, Booth L, McKinney A, Subbe CP and Odell M, When patients (and families) raise the alarm: Patient and family activated rapid response as a safety strategy for hospitals. Future Healthcare, Volume 8, November 2021, https://pubmed.ncbi.nlm.nih. gov/34888450/

Odell M, Gerber K and Gager M, Call 4 Concern: Patient and Relative Initiated Critical Care Outreach, Royal Berkshire NHS Foundation Trust, October 2010, https://www.fons.org/Resources/Documents/Project%20Reports/PFC4CFinalOct2010.pdf

### RECOMMENDATION MARTHA'S RULE

At the heart of every interaction in a hospital is not a prescription, or an act of surgery or a diagnosis. It is a relationship between a medic and a patient, and sometimes their family or carer. The evidence is clear: poor communications in hospitals - between medics and patients and their families - is a factor in too many avoidable deaths. We undervalue communications and non-technical skills in practice and in training. But sometimes the problem is so big and sprawling, and yet so embedded and ingrained, that it feels almost impossible to tackle. A story like Martha's should force focus on this area. This paper is designed to do that. We evaluate the scale of the problem and the work going on, and then offer one practical step that could be taken now, in hospitals up and down the country, to make immediate progress: Martha's Rule.

#### MARTHA'S RULE

#### THE RIGHT TO REQUEST A CLINICAL REVIEW

This is modelled on the Call 4 Concern system that has been adopted in a number of hospitals in the UK and to a certain extent "Ryan's Rule" in Australia. These schemes give patients a direct line to ask a separate clinical team to request a review, or a second opinion. Research in hospitals that have adopted it have found that it improves treatment in lifesaving ways and is rarely abused. It requires thoughtful implementation but has proved manageable and effective.

Martha's Rule would mean that in the event of a suspected deterioration or serious concern on the part of a patient on a hospital ward, or their family or carer, they would have the right easily to call for a rapid review or second opinion from an ICU/HDU doctor within the same hospital.

In the models we have evaluated we have identified clear elements that improve effectiveness:

- The referral point must be independent of the treating team
- The referral point must be reliable
- The system must be communicated effectively, for example via posters in high traffic areas
- In best practice more junior staff members are also encouraged to use it along with patients and their families

#### **Recommendation 1**

NHS England should develop best practice guidance to allow hospitals to adopt this system as soon as possible.

#### **Recommendation 2**

Hospitals should adopt Martha's Rule as a matter of urgency and communicate it clearly to patients.

#### Recommendation 3

The Care Quality Commission, that inspects hospitals, should consider Martha's Rule standard practice in inspections and include their implementation in inspections.

#### FURTHER RECOMMENDATIONS

We considered three further recommendations, but have chosen to focus on Martha's Rule as potentially the most immediately effective:

- The right to access patient notes. This could shift the power dynamic between patients and doctors, and put the onus on the doctors to communicate in an inclusive and more relational way with patients. To implement real time open notes in acute settings it would take testing, and training, to make it achievable in practice.
- The right to a named consultant. This was already recommended by the Francis review but hospitals have not consistently adopted it. The government should now review the extent of the implementation in order to understand the barriers, and work with the CQC to consider its implementation in its inspections. It should be considered best practice.
- A review of medical training to improve nontechnical skills. Non-technical skills in medical training are undervalued and inconsistently delivered. Training is largely on the job, delivered by people already steeped in the NHS culture that is, rather than the culture it aspires to have. In light of the safety consequences identified here, this should be reviewed.

## CONCLUSION

This paper doesn't reveal anything patients, medics and NHS leaders don't already know. Sometimes communications problems between patients (and their families) and clinicians can lead to deadly mistakes. This is linked to stubborn pockets of poor culture within hospitals and teams across the system.

It's also not a problem that's isolated to the NHS it's seen in all healthcare systems around the world. A study in January this year found that one in four people treated in a US hospital experiences some form of avoidable harm.

The NHS has made huge efforts to address culture problems that lie underneath some of these issues - but successive reviews have been slow to have an impact.

Our recommendations are designed to be actionable and to focus on preventing avoidable deaths now. The evidence suggests that 'Martha's Rule' could help do this. We hope that hospital leaders across the country will see the potential too and that NHS England will support them to implement it.

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#### **ABOUT THIS WORK**

This work is part of Demos's work on Relational Public Services, looking at how public services could be reformed according to a more relational, rather than transactional model that has been encouraged by recent successive waves of public service reform across the state.

Polly Curtis Claudia Wood

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15 WHITEHALL, LONDON, SW1A 2DD
T: 020 3878 3955
HELLO@DEMOS.CO.UK
WWW.DEMOS.CO.UK