Patient and family empowerment in patient safety in the UK; is this the start of a golden age or another false dawn?

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Introduction

The last two or three years have seen an unprecedented number of developments in the UK (England in particular) which can be loosely described as being advances or planned advances in patient and family empowerment (or "engagement" in patient safety). This editorial the potential and challenges for each of these developments, which include:

- "Martha's Rule": an English version of "Ryan's Law" in Australia, or "Patient Activated Rapid Response" as it is known elsewhere. This will enable patients or families to raise concerns about patient's treatment or deterioration to generate an urgent re-assessment and/or intervention
- "Hillsborough Law": the creation of a legal offence where an individual in public position oversees a cover-up or deception. This will fill a gap in the existing statutory Duty of Candour, which may itself be updated following other inquiries and reviews which are due to report in 2025
- "Patient Safety Partners": a scheme in England which recruits and supports patients / members of the public to work with NHS staff on patient safety related committees or projects
- The "Harmed Patient Pathway": an initiative which aims to "change the paradigm" of how healthcare organisations think about and respond to patients/families who have suffered harm under their care, and set out clear commitments and practical actions needed to be taken to respond in a just and restorative way
- "Independent Advice and Advocacy": attempts to address a gap in availability of these services for harmed patients and their families and raise awareness of their importance

"Martha's rule"

Martha's rule is a patient safety initiative which is being rolled out in the NHS in England, which enables patients or their families to prompt an urgent review of their treatment if they believe that their condition is deteriorating or not being adequately addressed. At the moment this applies to critical care in hospitals but, as is discussed below, there are arguments that a similar approach could be applied elsewhere. There had been similar approaches elsewhere in the world, notably in Australia where "Ryan's rule" has been introduced[i]. In England a number of hospitals had already been piloting a version of it called "Call for Concern". These approaches, sometimes described as Patient Activated Rapid Response (PARR), were discussed in this journal in 2023[ii] . However, the story of Martha's rule becoming a reality in England was sadly, but not for the first time when it comes to patient safety improvements, as a result of a tragic and avoidable loss of life and remarkably successful campaigning by grieving parents.

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. Just three years later, Martha's parents saw Martha's Rule, which they had campaigned for, being piloted in 143 hospitals in England. By December 2024 NHS England were confident enough to declare that early data indicated that Martha's Rule was "already saving lives in NHS hospitals." [iii]

Martha's Rule is made up of 3 components to ensure concerns about deterioration can be swiftly responded to:

1. An escalation process will be available 24/7 at all the 143 sites, advertised throughout the hospitals on posters and leaflets, enabling patients and families to contact a critical care outreach team that can swiftly assess a case and escalate care if necessary.
2. NHS staff will also have access to this same process if they have concerns about a patient's condition.
3. Clinicians at participating hospitals will formally record daily insights and information about a patient's health directly from their families, ensuring any concerning changes in behaviour or condition noticed by the people who know the patient best are considered by staff.

NHS England reported that:

- 573 calls made to escalate concerns about a patient's condition deteriorating in September and October, including from patients, their family, carers and NHS staff.
- (286/573) of these calls required a clinical review for acute deterioration
- around 1 in 5 (57/286) of the reviews lead to a change in the patient's care – such as receiving potentially life-saving antibiotics, oxygen or other treatment – while remaining on their current wards

Of course, there are a number of other measures that health services have introduced to identify deteriorating patients and intervene as appropriate, not least in England the National Early Warning Scores system "NEWS" [iv]. However, what makes Martha's Rule (and its international cousins) is that it is primarily designed to empower patients and families to intervene and escalate.

The question that comes to mind however is why a similar approach is not being adopted in healthcare. One obvious candidate, particularly in England where there has been a virtual torrent of maternity service scandals – many of them identified with failure of staff to listen and act on concerns expressed by mothers or family members – is maternity care. The inquiry into failings at Shrewsbury and Telford NHS Trust's maternity service was led by Donna Ockenden and this finding was at the centre of her report. [v]

One of Ockenden's recommendations was for "Independent Senior Advocates" in maternity services to support women and family who have concerns or suffer adverse outcomes. NHS England decided to interpret the word "independent" in a rather unique and as it turned out highly controversial way. Initially it proposed that all of the advocates would be NHS staff based in the NHS trusts who run the maternity services. However, after concerns raised by the charity Action against Medical Accidents (AvMA) and various patients and maternity organisations there was a concession to have at least a small number of the advocates employed independently from the NHS. Pilots of this approach are currently taking place called Maternity and Neonatal Senior Advocates. The results will be interesting to see, particularly whether genuine independence delivers different results. At the very least, the initiative is at least another positive example of efforts being made to empower patients and families in one part of the NHS. An alternative model might have been for a maternity version of Martha's Rule in place as an early intervention/prevention measure, and genuinely independent advocated being made available for those women/families who do have adverse outcomes.

The Duty of Candour and 'Hillsborough Law'

November 2024 saw the tenth anniversary of the introduction of the statutory duty of candour in England. Scotland and Wales have adopted similar regulations, and Northern Ireland plans to follow suit. I think it is fair to say that very few would want to go back to the days when cover ups were frowned upon, but it was tacitly accepted that they would continue not to be outlawed. Its implementation and regulation have been far from perfect. Not surprising perhaps, given that it was rushed in by a very reluctant government due to the pressure of the Mid Staffordshire public inquiry findings and a longstanding campaign, and little or no time or money was provided for the NHS to

prepare or train its staff properly. The Department of Health and Social Care published the results of a call for evidence about the duty of candour in November 2024.[vi] Unsurprisingly the results were somewhat disappointing and three amin themes emerged:

- culture (of the health and care system)
- inconsistency (in understanding and applying the duty)
- training (the lack of it, the need for further training)

A final report on the wider review of the duty of candour will not be published before the final report on the Infected Blood scandal and the "Hillsborough Law" planned legislation. Collectively the recommendations from these may lead to strengthening and improving the existing duty. An article in this journal *Will the new 'Hillsborough Law fill the gaps in the existing Duty of Candour in healthcare'*[vii] explains the significance of the planned legislation which pertains to all public bodies but would address the current lack of a criminal offence for individuals overseeing deliberate breaches of the duty of candour.

"Patient Safety Partners"

The new role of Patient Safety Partner was introduced in 2022 by NHS England as part of its Framework for Involving Patients in Patient Safety[viii]. This set out the ambition for safety-related clinical governance committees (or equivalents) in NHS organisations to include two Patient Safety Partners (PSPs). PSPs can be patients, carers or members of the public who want to support and contribute to an organisation's governance and management processes for patient safety. To date there has been no evaluation of the Patient Safety Partner programme, but it has been criticised for not drawing on earlier work to pilot a structured approach to involving patient safety work carried out by the (now defunct) National Patient Safety Agency and the charity Action against Medical Accidents, which recruited trained and supported "patients for patient safety champions" to work with regional NHS teams on patient safety. The evaluation of the project[ix] found that key elements for the success of such a scheme were:

- training both for the 'champions' and staff who need to work with them
- involving 'champions' with lived experience of healthcare harm
- central, local and regional mutual support networks for 'champions' and staff to support them – ideally from an independent body

Not surprisingly, a small-scale survey of PSPs[x] came up with very similar themes about what PSPs lacked to be more effective, and great inconsistency in the way the programme was being rolled out. Nonetheless, this is a very welcome attempt at embedding patients in patient safety work locally. With more resources and a more co-ordinated approach drawing on past experience it could become a big success.

The "Harmed Patient Pathway"

The Harmed Patient Pathway is the joint concept of the Harmed Patients Alliance (HPA) and the charity Action against Medical Accidents (AvMA). It aims to set out the needs of harmed patients and their families when harm has been suffered in healthcare and provide guidance on how these can be met as effectively as possible by a positive and caring approach by healthcare organisations. It is an attempt at creating a paradigm shift by identifying harmed patients and their families as a specific group with specific needs to whom the healthcare organisation has a moral duty of care (not just people to be sympathetic to, or consider allowing to be involved in the organisation's investigations). It borrows the terminology of a 'pathway' as used by the NHS in the UK to describe clinical pathways of treatment for patients with particular conditions to emphasise that point. The Harmed Patient Pathway is also based on a "just and restorative" approach which is increasingly being advocated in patient safety.

AvMA and HPA have worked with NHS organisations and their own networks to arrive at a draft set of six core commitments, which health providers would be expected to sign up to, backed up with a set of essential elements for meeting each commitment.[xi] These were consulted widely upon between October and December 2024 and may change slightly based on feedback received but at the consultation stake the six core commitments were:

1. We ensure compassionate and honest communication with harmed patients and their families that supports dignity, trust and just relations.
2. We do our best to ensure that harmed patients/families get the support they need, including access to specialist independent advice and support.
3. We support meaningful involvement of harmed patients/families in investigations or other review processes related to their treatment.
4. We provide harmed patients/families with opportunities to contribute to patient-safety and patient-experience improvements in a meaningful way.
5. We respect that harmed patients/families may choose to use external or parallel processes to seek answers and accountability as well as to improve safety for others. We will not allow this to change or needlessly delay our engagement with them.
6. We promote a just and restorative culture in our organisation that is fair to harmed patients/families and to staff, and we have policies, systems and support for staff to enable this.

The feedback received from the consultation is still being analysed but in spite of the commitments and essential elements being challenging, particularly in an over-stretched and under funded healthcare system like the NHS, the feedback has been overwhelmingly positive. It is hoped that official bodies such as NHS England may themselves formally approve and promote the Harmed Patient Pathway. The 'pathway' has already influenced and complements the recent guidance published by NHS England on "Engaging and involving patients, families and staff following a patient safety incident". [xii] However, it goes much further, is not primarily focused on 'learning' as an outcome, but with that being just one part of a just and restorative approach that helps avoid 'second' or 'compounded harm' a supports the recovery of the patient/family members. The final version of the Harmed Patient Pathway will include further guidance to support organisations in understanding and meeting their commitments.

Independent advice and support

Fulfilling some (but not all) of the commitments in the harmed Patient Pathway described above is made particularly challenging because of a widespread shortage of resources. It is likely that is especially believed to be the case with regard to commitment 2: *We do our best to ensure that harmed patients/families get the support they need, including access to specialist independent advice and support.* Unsurprisingly, some health providers who are struggling to provide essential health services may see this as desirable but a luxury they cannot afford at the moment. Some of them make the point that in a national service like the NHS, that access to such specialist services would most appropriately be funded centrally. At the end of 2022 the Harmed Patient Alliance published a paper *"Signpost to nowhere".* [xiii] I am happy to declare that I was the chief researcher and author of the paper. The paper made the case for a centrally funded independent advice and advocacy service for people affected by avoidable harm in healthcare. It pointed out the irony that independent advice for people making complaints about the NHS is funded (quite rightly), whilst people who the NHS has harmed do not have access to a specialist service to support them, unless they are lucky enough to access support from a charity like Action against Medical Accidents, which is funded solely from its own fundraising. The paper even suggests ways that such a service could be funded in as economic a way as possible by spreading the cost across different parts of healthcare and regulation and pooling resources. It received widespread support including from key stakeholders in the NHS itself and regulators. However, nothing has happened since - apart from the pilot of Maternity and Neonatal Senior Independent Advocates, which was already planned when this paper was published. That

project itself, whilst on the one hand being a laudable attempt to empower women and families in maternity care, shows a surprising lack of understanding of the meaning of 'independence' and its importance when it comes to providing advice and advocacy.

There continues to be fear of independence more generally when it comes to supporting patients and families who have suffered harm and certainly a resistance to providing funding to address the unmet need. This is a good example of where the paradigm shift demanded by the Harmed Patient Pathway could move things forward. If it is accepted that providing access to (genuinely independent and specialist) advice and advocacy is part of organisations' duty of care to its patients and families who have suffered harm, it makes the case even stronger.

Conclusion

There is much to be pleased about with regard to the attention that patient and family empowerment is now getting as borne out by the initiatives described above. As to whether we are entering a golden age or are likely to look back on this as another false dawn, much will depend on whether the Harmed Patient Pathway is embraced and promoted and achieves the paradigm shift that it aspires to. Each of the initiatives has potential (some of which can already be seen to have begun being realised) either in terms empowering patients/families to play an active role in protecting their own safety and directly averting avoidable harm e.g Martha's Rule; or more generally supporting patient safety work and initiatives e.g.; Patient Safety Partners; or by ensuring better openness and transparency which supports learning for patient safety when harm has occurred and protects patients/families from second or compounded harm e.g. Duty of Candour, Hillsborough Law and Independent Advice and Advocacy. Individual initiatives on their own are less likely to be effective unless there is that paradigm shift overall of accepting a moral duty of care to harmed patients/families; understanding their needs and how to respond to them in a just and restorative way. It is possible that if the Harmed Patient Pathway really gains traction it can help bring about that paradigm shift, which can only make healthcare safer and fairer for all of us.

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[ii] Ngoya Ntumba M, Edwards E, Haegdorens F, Walsh P, Subbe CP. Patient activated rapid response – the '999' for patients admitted to hospital. Journal of Patient Safety and Risk Management. 2023;28(4):156-162. doi:10.1177/25160435231199338

[iii] NHS England: https://www.england.nhs.uk/2024/12/marthas-rule-already-saving-lives-in-nhs-hospitals/#:~:text=%E2%80%9CWith%201%20in%205%20clinical,best%20are%20considered%20by%20staff.

[iv] NHS England: https://www.england.nhs.uk/ourwork/clinical-policy/sepsis/nationalearlywarningscore/

[v] Dept of Health & Social Care, England: https://www.gov.uk/government/publications/final-report-of-the-ockenden-review

[vi] https://www.gov.uk/government/publications/findings-of-the-call-for-evidence-on-the-statutory-duty-of-candour/findings-of-the-call-for-evidence-on-the-statutory-duty-of-candour#results

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[viii] https://www.england.nhs.uk/publication/framework-for-involving-patients-in-patient-safety/

[ix] https://www.avma.org.uk/wp-content/uploads/2016/02/Evaluation_Report_final.pdf

[x] https://www.pslhub.org/learn/patient-engagement/patient-safety-partners/how-do-patient-safety-partners-feel-about-their-role-analysis-of-online-survey-results-r10938/

[xi] https://harmedpatientpathway.my.canva.site/

[xii] NHS England: https://www.england.nhs.uk/wp-content/uploads/2022/08/B1465-2.-Engaging-and-involving...-v1-FINAL.pdf
[xiii] https://www.avma.org.uk/wp-content/uploads/Signpost-to-Nowhere.pdf