Patient Experience Library

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Ockenden report: the refusal of our healthcare service to take patient experience seriously

Miles Sibley *director*

In March 2015, Bill Kirkup published his report on avoidable harm in maternity services at the Morecambe Bay NHS Trust. His introduction carried a warning: "It is vital that the lessons, now plain to see, are learnt... by other Trusts, which must not believe that 'it could not happen here.'"[1]

With the publication this week of the Ockenden report, we now know that one of those other Trusts was the Shrewsbury and Telford NHS Hospital Trust.

Donna Ockenden's newly published report must, we hope, offer some consolation to the hundreds of families who have suffered such grievous harm. "For more than two decades," she says, "they have tried to raise concerns but were brushed aside, ignored and not listened to."[2] Ockenden clearly feels a deep sympathy for their pain and she commends their courage.

But why should patients and families have had to show that kind of courage in the first place?

Why did the families at Morecambe Bay have to fight against "a series of missed opportunities to intervene that involved almost every level of the NHS"?[1]

Why did women harmed by another recent maternity disaster, at Cwm Taf, in Wales, find that "they were ignored or patronised, and no action was taken, with tragic outcomes including stillbirth and neonatal death of their babies?"[3]

These failings are not only to do with the specifics of maternity care—staffing levels, fetal monitoring, caesarean rates, and all the rest. Those may have been the primary causes of avoidable harm. But they are compounded by a much bigger problem: the refusal of our healthcare system to take patient experience seriously.

Feedback—opportunity or threat?

Instead of seeing patient feedback as a foundation stone of high quality, evidence based care, healthcare providers too often see it as a threat. This is what James Jones observed when he described the interests of patients and relatives caught up in the Gosport scandal as being "subordinated to the reputation of the hospital and the professions involved."[4]

It is what Julia Cumberlege meant when, in reporting on the thousands of women and babies injured by Primodos, Sodium Valproate, and pelvic mesh, she described "a culture of dismissive and arrogant attitudes that only serve to intimidate and confuse."[5]

It is what Robert Francis exposed when, in the Mid Staffordshire inquiry report, he said that "for all the fine words printed and spoken about candour, and willingness to remedy wrongs, there lurks within the system an institutional instinct which, under pressure, will prefer concealment, formulaic responses, and avoidance of public criticism."[6]

Time and again—and independently of one another—these reports come to the same conclusion: that an NHS which is meant to be both person centred and evidence based will not, when the chips are down, treat patient feedback as evidence.

So here we are again. Another large scale failure. Another "watershed" moment. Another series of apologies and promises to "learn from mistakes."

From mistake to disaster

Healthcare is a high risk business. In any service or specialty, there is always a chance that mistakes will be made. But within every major scandal in recent years, there has been an element, not of error, but of intent.

At Shrewsbury and Telford, the Ockenden report finds that, "the maternity governance team inappropriately downgraded serious incidents to a local investigation methodology in order to avoid external scrutiny."[2] That was not a mistake. Somebody thought that through.

At Gosport, "The obfuscation by those in authority... made the relatives of those who died angry and disillusioned."[4] Obfuscation is not a mistake. It is a deliberate attempt to deceive.

Another recent inquiry—into the deaths of children in Northern Ireland—found "defensiveness, deceit and a strong inclination... to close ranks."[7] That cannot be attributed to unintended error.

So mistakes in healthcare might be inevitable—but disasters are not. And learning from them is not just about "learning from mistakes." It also means looking for uncomfortable truths about the ways in which we—with full intent—treat patient experience and feedback.

The culture of patient experience

None of these providers—at Mid Staffordshire, Morecambe Bay, Gosport, Cwm Taf, Northern Ireland, Shrewsbury and Telford—are "bad apples." They all take their cue from an overarching culture which sees patient experience work as having little value. Evidence for this is plentiful:

- The National Core Content, for example, is the series of research databases that are made available to all NHS staff because they are deemed essential for underpinning evidence-based practice. Patient experience is noticeable by its absence

- In a healthcare system fixated on both professionalism and status, patient experience staff—almost uniquely in the NHS workforce—have no systematic training or qualifications.
- Healthwatch, set up in the wake of the Mid Staffordshire inquiry as a supposedly strengthened patient voice network across England, has seen its funding cut by 50% since its inception.[8]

These are not mistakes either—they are decisions. They send the clearest possible signals that the work of patient experience staff is not all that important. And yet these are the staff to whom harmed families turn first, and from whom they need expert and influential support at times of huge vulnerability and crisis.

Redressing the balance

We can do better—indeed, we must. Julia Cumberlege has said that patient experience "must no longer be considered anecdotal and weighted least in the hierarchy of evidence based medicine."[5]

We should certainly learn from mistakes at Shrewsbury and Telford and elsewhere. And we can hope that Ockenden's "immediate and essential actions"—workforce planning, ring-fenced money for training, better investigations, and so on—might help to reduce mistakes in future.

But we also need to ask some searching questions about intent—specifically how we mean to build an NHS that is person-centred and evidence-based.

That must surely involve an intention to take patient experience more seriously—to build a proactive learning infrastructure with an evidence base accessible to all. To develop a patient experience workforce with professional qualifications and status. To provide patient voice organisations with adequate funding for this most crucial of roles. To do otherwise would, truly, be a bad mistake.

Competing interests: MS is a Director of the Patient Experience Library. The library receives no core funding and accepts no advertising.

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3 Broderick, C. 2019. Listening to women and families about Maternity Care in Cwm Taf.
4 Gosport War Memorial Hospital. The Report of the Gosport Independent Panel. June 2018.
5 Cumberlege J. First Do No Harm. The report of the Independent Medicines and Medical Devices Safety Review. July 2020.
6 Francis R. The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 1: Analysis of evidence and lessons learned (part 1).
7 The Inquiry into Hyponatraemia-related Deaths, 2018.
8 Letter from Healthwatch England Chair to Secretary of State for Health and Social Care, 23rd February 2022.