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Dr Brummell is an Intensive Care and Perioperative Medicine Consultant at University College London Hospital. Her interests are in patient safety, healthcare policy, qualitative research, communication with families, end of life care, medical ethics and medical law. Dr Brummell undertook a PhD at University College London looking at learning and organisational learning as an outcome of healthcare policy, specifically evaluating the NHS Learning from Deaths programme. She is now undertaking an MA in Medical Ethics and Law at Keele University. In 2023 Dr Brummell was awarded a Churchill Fellowship to look at Improving family involvement and bereavement care in end of life care in adult Intensive Care. Dr Brummell is the Academic Career Development co-lead for the NIHR Central London Patient Safety Research Collaboration and a Medical Examiner at UCLH.



When “Learning from Deaths” doesn’t really learn: what families need the NHS to understand

Families affected by a loved one’s death due to problems in healthcare often want what happened to be understood, acknowledged and for real change to occur.

In 2017, the NHS in England introduced the Learning from Deaths programme. Its aim was simple: to ensure that when patients die, especially where problems in care may have contributed, organisations learn and improve. But nearly a decade on, an important question remains: Is the system truly learning and are families genuinely part of that process?

Drawing on my PhD research evaluating this national programme, this blog shares what we found and what it means for families.

Families made this programme happen, but were not always included

The Learning from Deaths programme did not emerge in isolation. It was driven by families many of whom had to campaign, often for years, to have their voices heard. This campaigning exposed deep failures: families not being listened to, deaths not properly investigated and opportunities to learn missed. Yet despite this, meaningful involvement of families in the programme's development was limited and concerns about engagement were raised from the outset. This unfortunately set the tone for what followed.

Family involvement: expected, but inconsistent in reality

The policy clearly states that families should be treated as equal partners, involved in investigations, supported with compassion and kept informed. But in practice, this didn't consistently happen.

Across the research:

- Family engagement was variable and often inconsistent
- Some families were meaningfully included, but many were not
- Involvement could depend on local culture, leadership, and resources (not on need)

For families, this creates a postcode lottery of experience at one of the most vulnerable times in their lives.

The emotional reality: involvement is not “simple”

One of the most important findings, often overlooked in policy, is that involvement itself carries emotional weight. Working with bereaved families:

- Can involve significant emotional labour and distress
- Requires careful, trauma-informed support
- Can sometimes unintentionally cause further harm if not handled sensitively

At the same time, families' contributions are invaluable. They bring:

- Insight into what really happened
- Awareness of communication failures and missed opportunities
- A perspective that professionals often cannot see

The challenge is not whether to involve families, but how to do it safely, respectfully, and meaningfully.

When stories become “policy language”

Another striking finding was how families' lived experiences can become diluted.

In meetings and reports:

- Raw, emotional accounts of injustice were often translated into bureaucratic or technical language
- This shift risks losing the meaning and urgency behind those experiences

For families, this can feel like:

- Not being heard

- Being reduced to data
- Or having their story reshaped into something unrecognisable

True learning requires holding onto the reality of those experiences, not smoothing them out.

The bigger problem: learning becomes a “tick-box exercise”

One of the clearest findings from the research is this: much of what is called “learning” is actually compliance.

Hospitals often:

- Produce reports
- List “lessons learned”
- Describe actions taken

But there is limited evidence of real change in systems or culture.

This matters deeply for families. Because without genuine learning:

- The same mistakes can happen again
- The purpose of investigations is undermined
- Trust in the system is eroded

What actually helps learning and what gets in the way

The research identified clear factors that shape whether meaningful learning happens.

What helps:

- Compassionate, honest engagement with families
- Strong leadership that prioritises learning
- Psychological safety for staff to speak openly
- Time and resources to do investigations properly

What gets in the way:

- Defensive organisational cultures
- Lack of resources and competing pressures
- Hierarchies that silence voices (including families’)
- Treating learning as a reporting requirement rather than a real process

So, what needs to change?

If we are serious about learning from deaths, we need to move beyond policies and paperwork. This research suggests three key shifts:

- 1. From involvement to partnership:** Families must not just be “included”, they must be respected as equal contributors, with support tailored to their needs.
- 2. From reporting to real learning:** Learning should be judged by what changes, not by what is written in reports.

3. **From process to humanity:** Grief, trauma, and lived experience must be recognised, not translated away.

A final thought

Families have already done the hardest work; speaking up, reliving trauma, pushing for change.

The responsibility now lies with the system.....

To listen.

To learn.

And to ensure that no family has to fight the same battle twice.

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