Strengthening open disclosure in maternity services in the English NHS: the DISCERN realist evaluation study

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Disclaimer: This report contains transcripts of interviews conducted during research that contain language that some readers may find offensive and contains descriptions of events that some readers may find distressing.

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Scientific summary

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Scientific summary

Background

A range of interventions have been introduced in the UK NHS to improve post-incident communication and support of injured families. However, there is limited evidence on the progress of this work and how improvements in open disclosure (OD) are to be embedded.

Study aims and objectives

The aim was to identify the critical, underlying factors for improving the incidence and quality of post-incident communication with families in NHS maternity services. This required examination of what is necessary and required in different contexts for OD processes and practices to be strengthened for families, doctors and midwives (henceforth clinicians) and service managers. Following a realist evaluation approach, the study objectives were to:

1. establish initial hypotheses to focus investigation of OD improvements in NHS maternity services in England
2. examine the scope of OD in NHS maternity services from the perspectives of regional and national stakeholders
3. refine our initial hypotheses in relation to the analysis of regional and national stakeholder perspectives
4. conduct an in-depth study of OD improvement within services
5. verify data interpretation and study output development with different stakeholders (families, clinicians, service managers and national policy-makers).

Overview of methods

A qualitative study using realist evaluation methodology to evaluate the progress of OD in English NHS maternity services was conducted (May 2019–March 2022) in three sequential study phases (SPs).

Realist approaches are theory-driven and designed for investigation of complex social interventions. They consider if and how an intervention works in different circumstances from the perspectives of different people. Initial hypotheses, developed from the use of a realist evaluation conceptual tool [context–mechanism–outcome (C–M–O) configurations], are developed from literature synthesis and 'tested' by primary research to identify potential causal relationships that explain how an intervention works.

A Project Advisory Group (PAG), including families, participated in study decisions, from initial theory development, case-study sampling, data collection and interpretation of study findings against a background of rapid policy change. Primary data collection was from November 2019 to January 2022.

A patient involvement and public engagement strategy sought to maximise family involvement in all stages of the study cycle.

Study phase1a: literature review

A scoping review examined recent (2014–22) policy recommendations for family engagement improvements in NHS maternity services. Documents were identified through database searching and

included if they were related to safety, incidents, harm, reviews and investigations in maternity care. Academic papers; essays; conference abstractions, papers and presentations; and research studies were excluded.

The realist synthesis of primary evidence of the progress of interventions for strengthening OD in international maternity settings included 38 documents appraised for relevance and rigour. Documents were from key database searches, included all English language sources (post 2000), without predetermined exclusion criteria for research methods. Only primary research evidence or evidence synthesis was included. Programme theories were developed with our PAG for testing during later SPs.

Study phase 1b: national and regional stakeholder interview study

National and regional stakeholders (*n* = 44), and families (*n* = 23), were interviewed following a topic guide developed from our literature synthesis. Families included in the study have histories of significant injury, including the stillbirth, death or serious injury of their baby and/or themselves (dating from 2007 to 2021).

Study phase 2: ethnographic case studies

Three maternity services in two Trusts were identified for in-depth ethnographic research by purposive sampling, based on their capacity to accommodate research immediately following the coronavirus disease 2019 (COVID-19) pandemic, and evidence of their positive deviance in improvement work on openness identified from public data sets.

Across these services, we conducted: staff interviews (*n* = 75) and three return staff interviews, family interviews (*n* = 4), observations of staff and family meetings (*n* = 52) and observations of informal unit and office activities (all observations totalled 93 hours, with 30 hours of in-person observations). Families recruited from the case-study services had histories of significant injury dating from 2018 to 2020. We also collected and analysed locally available documentation relating to candour and being open.

Study phase 3: interpretation:

We conducted five interpretive forums to inform the interpretation of findings. These were a forum with project advisors (*n* = 14), including families (*n* = 6), a family forum with several SP1b study participants (*n* = 5) and three service case-study forums, comprised of clinical and service managers and clinicians. Total forum participation was approximately *n* = 65.

All data were managed using NVivo 20 (QSR International, Warrington, UK) and analysed concurrently by two researchers using a retroductive approach. This technique involved the ongoing examination and theorisation of findings to identify causal explanations for how, for whom, and in what ways OD might be improved. We used the five programme theories identified from the realist review to organise the analysis and reporting of our stakeholder interview and ethnographic case-study findings. Findings from our forums are included in the synthesis and discussion of findings.

Results

Literature reviews

Our scoping review of policy documents (*n* = 39) identified a shift from a paternalistic view of injured families as passive recipients of care to active contributors in reviews, investigations, learning and quality improvement. Two overlapping policy trajectories were identified: one related to the Duty of Candour (DoC) and one related to maternity safety more widely. Seven themes were identified: building trust in organisations; improving systems of care and ensuring accountability; improving the safety of maternity care and saying sorry; shifting to individualised, relational care; enhancing communication; conceptualising families as active partners rather than passive recipients; and enabling families to guide

the process. Although the progression of how family involvement is discussed and considered in policy is moving in a positive direction, we note the opportunity for future, specific, actionable recommendations to ensure these ideals translate into practice.

In the realist synthesis, documents (*n* = 39) were appraised for 'fitness-for-purpose', that together documented primary evidence of 21 OD improvement interventions from which we identified 5 initial programme theories. Interventions documented were predominantly from USA, Australasia, and, more recently, UK sources. We identified limited evidence of the effectiveness of interventions documented. We found a difference between interventions that were adjuncts to more general safety improvement projects, and organisation-wide interventions focused on post-incident communication and care of injured families.

Identified programme theories were: receiving a meaningful acknowledgement of the harm that has happened, being involved during the review/investigation process, making sense of what happened, receiving care from clinicians who are skilled and feel psychologically safe during post-incident communication and knowing that things have changed because of what has happened.

Findings by programme theory

Receiving a meaningful acknowledgement of the harm that has happened

National stakeholders described factors that prevented or slowed improvements in initial post-incident communication and ongoing care of injured families. These were: the risks of litigation and reputational damage which may be associated with an apology and the obligation to be candid. This was particularly challenging when the extent or circumstances of injury were uncertain. Variation in the confidence and willingness of clinicians to undertake initial and ongoing disclosure with families was noted across the case studies. Alongside general medicolegal and ethical challenges to disclosure improvements, wider erosion of compassionate disclosure with families in relation to the escalation of organisational compliance in maternity safety initiatives was noted by stakeholders. Interviews with families on their post-incident experiences (2007–11) highlighted an ongoing lack of compassionate care and of prompt disclosure in many services. Many families distrusted post-incident communication, suspecting that information was being withheld. In the case-study services, the main concern for OD leads was the recovery of family trust in the service. Here, the tension between disclosure as a mandated directive and as ongoing communication was notable, with lack of investment and organisational support for the latter. A significant context of OD work was the churn of work schedules and the speed of family transfers. This complicated efforts to develop consistency of communication and care across initial, mandated and ongoing post-incident meetings, particularly where the uniqueness and flux in the needs of harmed families were paramount and families were already distrustful. These conditions led to a situation where OD was sustained as an individual and selective initiative conducted by some clinicians with some families.

Being involved during the review/investigation process

We examined experiences of the implementation of family engagement through the Perinatal Mortality Review Tool (PMRT) and independent Health Safety Investigation Branch (HSIB) reviews/investigations from national, in-depth, case-study perspectives. We found PMRT implementation sometimes lacked relational care for families. Additionally, families were sometimes suspicious of the independence of external incident reviews. The case-study services reported inadequacies in family inclusion, with limited proactive approaches to family involvement. A range of family involvement approaches and rationales for involvement were found across and within the case-study services, with an emphasis on families as contributing value to organisational learning for safety improvement. The tension felt by clinicians between sharing uncertain knowledge of an incident with a family and sustaining OD is identified, as is the tension between the different goals of families and services, with the former desiring answers about their case and the latter seeking system-based learning for ongoing safety improvement.

Making sense of what happened

We explore the practices of knowledge construction in incidents and the management of this knowledge from the perspectives of national stakeholders, staff and families. The impact of widespread organisational defensiveness over documentation sent to families, along with confusion over the purpose of reports, generated distrust. Nationally, the poor quality or inaccuracies in clinical records exacerbated differences between service and family perspectives. In the crafting of reports, during ongoing family debriefings on report findings and through informal avenues and networks, the support for families to make sense of what happened could sometimes be recovered. However, we identify the privilege and capacity required for families to gather information and garner personal networks and expertise independently of services for this to take place.

Receiving care from clinicians who are skilled and feel psychologically safe during post-incident communication

We identified a national underinvestment in the training of clinicians in the care of injured families and in specialist OD skills. Interviews with junior clinicians, including Band 5/6 midwives; obstetric trainees and clinical fellows, highlighted the importance of early, non-judgemental, post-incident support for junior staff. The ongoing impact of avoidable harm on clinicians is examined, along with the impact of the limited involvement of staff in Trust-level investigation and review processes. We mapped the organisation and reported use of post-incident staff support for the three case-study services and found that debriefs, organised within a few weeks of the incident, and opportunities for meeting with families were most valued by staff. Services designed or commissioned by organisations without consultation with front-line staff themselves were underused and there was also a tendency for expert clinicians to see OD work as a personal rather than a professional or service imperative.

Knowing that things have changed because of what has happened

The importance for injured families and staff involved in an incident to see learning and service change following an incident was clear in national and case-study findings. Demonstrating that changes were in progress was key to a service demonstrating trustworthiness to the injured family. Some injured families felt a personal responsibility to ensure that change was secured. However, in most cases, services did not maintain contact with families after their review or investigation debriefs. For some clinical leads, there was a tension between 'quick wins' and protracted, significant, service investment. For wider staff groups, there was a lack of effective service-level communication strategies for updating on learning and change from incidents. Embedded, ongoing multidisciplinary team meetings, where non-judgemental discussion of incidents and their effects could take place, were identified as important for establishing a wider culture of openness. The extent and tone of clinical governance (CG) outreach to front-line staff were also significant in shaping staff attitudes and behaviours towards incidents and harmed families.

Discussion

Realist analysis identified the significant factors and contexts that impacted efforts to strengthen OD in maternity care. We explored several layers of context influencing the progress of this work. Nationally, we identified an ongoing tension between policy prompting OD and a medicolegal context where this openness continued to place clinicians and services at reputational or legal risk. Trust-level clinical leadership and the maturation of related service approaches (notably, family and patient involvement expertise and access to post-pregnancy support pathways) played a significant role in supporting OD. For families, variations in post-incident communication and care depended on two main factors: first, the assignment of an incident to one or more national maternity safety improvement programmes that entailed particular expectations of, and processes for, family involvement, and second, the capacity of a family to proactively seek out explanations and to foster relationships for personalised support from some clinicians. In the case-study services, where some harmed families were proactive in demanding a hearing and ongoing care, and where individual clinicians reached personal judgements on a family's entitlement to this, examples of improved OD were observed. Overall, variations in post-incident

communication and support for families were explained by a lack of service investment and by individual differences in attitudes to risk and family entitlement from clinicians.

Conclusions

This study is the first to establish a national overview and in-depth analysis of the progress of interventions intended to support OD with families. It provides an evidence base of experiences of harmed families (incidents ranging from 2007 to 2021) and of clinicians and managers working in this field (2020–1). There are growing calls for service-level improvements in responsiveness to the experiences and needs of families post incident as well as to their calls for greater openness. However, we find that without dedicated investment in and focus on the post-incident care of families and the emotional and organisational demands of this work on clinicians; without an understanding of these needs by external agencies incentivising improvement; and without national revision in the medicolegal landscape where this work happens, candour about harm in health care will continue to divide the interests of families, staff and services.

Research gaps and recommendations

Research was conducted immediately after the COVID-19 pandemic, with services under considerable strain. Three high-performing services were recruited for the observational research; therefore, generalisation from findings is limited. Access to observe external (HSIB) investigations was not possible. Despite ongoing revisions to the patient and public involvement (PPI) strategy, families often marginalised by maternity services remain under-represented in this study. A multi-methods study across English maternity services to establish the validity of findings and family recruitment strategies ensuring diversity are recommended for the future.

Study registration

This study is registered as PROSPERO CRD42020164061. The study has been assessed following RAMESES realist guidelines.

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