Literature Review:

Parental and family engagement in perinatal and neonatal incident reviews

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Contents

Abbreviations

ACOG	The American College of Obstetricians and Gynecologists
CCG	Clinical Commissioning Groups
EBC	Each Baby Counts
HCP	Healthcare professional
HHC	Harvard Hospital Consensus
LBGTQ	Lesbian, bisexual, gay, transgender and questioning
MBRRACE	Mother and Babies: Reducing Risk through Audits and Confidential Enquiries
PNMR	Perinatal Mortality Review
PMRT	Perinatal Mortality Review Tool
RCOG	Royal College of Obstetricians and Gynaecologists
SP	Standardised Patient

1. Introduction

Each year across the UK there are approximately 4500 perinatal deaths.[1] The loss of a baby has a devastating impact on the parents, the wider family and healthcare professionals (HCP). Often parents have many questions about the events surrounding the death of their child. The hospital organises a perinatal mortality review (PNMR) to systematically review the events surrounding the death. This is a vital process for both the family and the HCP but can additionally provide important information on how to improve the care for future pregnant women and their babies.

Parental engagement is viewed as a key element of this process. Evidence suggests that many parents are unaware of these reviews. For example, The Royal College of Obstetricians and Gynaecologists (RCOG) (2015) report *Each Baby Counts* (EBC) highlighted that families were only included in 34% of PNMRs.[2] The Mother and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE-UK) found that the process may be even less inclusive: the MBRRACE-UK *Perinatal Confidential Enquiry* (2015) found that parental views were sought in only 1 in 20 incident reviews.[3,4] Thus, the opportunity for parents to be involved and give their perspective is being lost.

An international body of literature demonstrates the lack of parental engagement in the PNMR process is not specific to the UK. It is a global problem. [5-13]

2. Aim and Objectives

The overall aim of this literature review is to critically evaluate two key bodies of literature:

1) Research and guidance focusing on *models* of incident review in perinatal deaths (and beyond) that involve parents/patient/family

2) Research and guidance focusing on *communication* in incident reviews, including healthcare professionals (HCPs) and the patient/family

Communication was separated into a stand alone topic for 2 reasons. Firstly, to ensure the wider interaction between HCPs and patient/family was covered. Secondly, communication was often not the main focus of the literature addressing models of incident review. Thus, in order to fully address this important aspect of parental engagement it was separated out.

In order to meet the aims; the following objectives were defined:

- Critically appraise models of incident reviews in perinatal/ neonatal care and the extent of parental/family engagement

- Widen the scope of the review beyond perinatal care to other healthcare settings where incident reviews/investigations involve patients with the aim of identifying elements that could be transferred to the perinatal setting

- Summarise the evidence base on what good communication with patients regarding incident reviews looks like, including when there has been an adverse event

- Identify potential support and training needs for staff who communicate with parents/patients regarding incidents/ adverse events

- Critically appraise research focusing on the economic evaluation of incident reviews

3. Search strategy

The first literature search was focused on models of incident reviews that incorporated parental or patient engagement. The articles were identified through searches on Embase, Medline, Cinahl, HMIC and PsychInfo. 44 articles and conference abstracts were retrieved. 23 were reviewed and rejected as they had no reference to parental involvement. The remaining 12 referred to parental engagement in some form.

A grey literature search was additionally performed in order to capture any other relevant guidance or reports. This search included: OpenGrey; OpenDoor; Google Scholar; OAIster database; and NICE. It yielded only 7 documents, of which 5 had no relevance.

The second literature search focused on communication. The articles were found through searches on the same databases. This search yielded 69 articles and conference abstracts. 28 articles were excluded after reading the abstract as they were outside the scope of the review. 4 could not be located. In addition, the references of all key papers were searched systematically to identify any other relevant articles which may not have been found through the original search criteria.

When determining if an article was relevant to the review, scenarios where "something has gone wrong" were included in addition to incident reviews (e.g. adverse events, patient safety review or medical errors). The purpose of this was to ensure that all lessons potentially relevant to perinatal incident reviews were consolidated from the literature. For the same reason, neither review was limited to neonatal or obstetric medicine. As the body of literature identified was relatively small, this ensured all learning identified in the wider health system potentially transferable to obstetrics was included.

The inclusion and exclusion criteria for the searches are summarised below.

Table 1: Inclusion and exclusion criteria for academic, international literature related to the area of research

Inclusion Criteria	Exclusion Criteria
English language	Non-English language
No time limit	Non-healthcare setting
International papers	
Communication of medical errors/disclosure/patient safety/incident review/neonatal death	

To ensure all articles were appraised systematically, a spreadsheet was developed that identified the key themes from each paper and their strengths and limitations. These data were used to collate common themes in the literature and to identify possible gaps in research.

4. Models of incident review in perinatal/neonatal care with parental engagement

4.1 Exploration of incident review with parental engagement

A Cochrane review identified a lack of randomised controlled trial (RCT) evidence on this topic.[14] It is unsurprising, however, that interventional studies have not been conducted to identify the best approach to parental engagement in incident reviews. Ethical constraints would likely make a robust RCT impossible. Even if this were not the case, exploring parental engagement is likely to be addressed more appropriately by qualitative research methods than interventional or observational studies. This is because researchers are able to explore the experience of patients and their families.

In the UK, research on this topic is based almost wholly on the PARENTS qualitative studies: PARENTS;[3] the PARENTS 2 study[15] and the PARENTS 2 consensus paper.[16]

In the PARENTS 1 study Bakthbakhi *et al* referred to the fact they believed they were the first research group to address this topic.[3]

The PARENTS study was specifically set up to investigate bereaved parents' views on involvement in the perinatal mortality review process. A semi structured focus group of 11 bereaved parents from South West England were interviewed 6 months after the death of their child.

Four key elements were elucidated: [3]

Transparency: Parents expressed a preference to be clearly informed of the review process, how to take part and to be kept updated. Parents also wanted to be reassured that if a review identified a preventable cause of death, they would be informed of any changes made as a result.

Flexibility and specificity: The PARENTS study reported mixed responses from participants about the most appropriate timeframe for an incident review. Some parents were concerned about whether they would have been able "to handle" involvement so soon after the death.[3] Other parents felt it was important to carry out the review when it was "fresh" in the mind of HCPs.[2] Parents felt their emotions had changed over the 6 months since the death of their baby and the decision to be involved in an incident review may also change. Therefore, flexibility was thought to be a key characteristic of the review design.

Parents also felt that "specificity" was an important element. Participants wanted a brief but *individualised* information letter about the incident review specific to the circumstances of their loss (e.g. stillbirth v neonatal death).

Inclusivity: Parents favoured a whole team approach, including the obstetric and neonatal teams, pathologists and the community-based teams. Parents also felt that the whole care pathway should be reviewed including the antenatal care.

Positivity: Parents wanted the good aspects of care to be highlighted within the review as well as the areas that could be improved upon.

The concern felt by some parents in the PARENTS study were also echoed in Garstang *et al's* systematic review of bereaved parents' preferences after a sudden death.[17] They noted there is potential for incident reviews to become a more "intrusive" process for parents. Whilst they may receive more information surrounding the cause of death, the process of the enquiry may increase their distress.[17] Again, emphasising the need for a flexible and individualised approach to parental engagement.

One of the strengths of the PARENTS study is that bereaved parents were involved throughout the process – from initial concept to publication. Conversely, this study was performed in South West England with 11 bereaved parents. This is a relatively small sample size, especially as the conclusions of the study may be given more weight as a result of the limited research available. As the study was based on a single focus group in one area, it is also not possible to tell how far these findings can be extrapolated to other geographical regions. Also, while the researchers used purposive sampling to increase the diversity of the focus group, the group chosen could have been more inclusive. For example, whilst the researchers included participants of different ages, there were no teenage parents in this study, again identifying a group that may have differing needs. There was also no mention of participants from the LBGTQ community or different ethnic groups or religions. Future research might be necessary to explore additional issues which may be specific to these groups.

The researchers in the PARENTS study could have considered conducting semi-structured interviews, either in addition to or in replacement of a focus group. Some participants may have felt empowered by sharing their views with those with similar experiences in a focus group. However, others may have felt inhibited about sharing a very personal experience in a large group setting. Some women may also have preferred to speak only with other women. Whilst the researchers comment on research assistants keeping observational notes, they comment relatively little on the interactions of the group; this arguably overlooks one of the key strengths of using a focus group as a data collection tool. Semi structured interviews may have offered the chance to explore the personal experience of participants and to gain further insight into differences in individual views.

The PARENTS consensus paper (2018) was produced following the publication of the original PARENTS study.[16] It involved 25 varied stakeholders attending: parents; obstetricians; midwives; and the researchers themselves.[16] The paper outlined 12 fundamental principles of parental engagement in incident reviews. These were grouped into 3 key areas:[16]

a) There should be a focus on individualised patient centred care and parents should be offered an advocate

b) The process of the perinatal mortality review should initially be explained face to face

c) Lessons learnt should be translated into action plans and the changes made should be monitored.

The *Yorkshire and the Humber Strategic Clinical Networks: recommendation for the improvement of stillbirth and bereavement care in Yorkshire and the Humber* (2015*) also supports the use of a patient advocate.[18] The Yorkshire and the Humber Maternity Clinical Expert Group report reviewed shared practice from across the Yorkshire and Humber region. One of the key recommendations is for the appointment of a bereavement midwife. It was felt that a dedicated midwife could provide vital expertise and support to families. A written summary for all women explaining forthcoming investigations and follow up consultations was also recommended.

The PARENTS consensus paper recommendations were also echoed by *The National Quality Board Learning from Deaths (LFD): guidance for NHS trusts* (2018).[19] This report was written in consultation with a large number of stakeholders. It specifically addressed family involvement in the review of deaths. Many of its key recommendations are broadly similar to those outlined in the PARENTS Study, including the need to maintain a transparent and flexible approach.

The LFD guidance recommends that the Trust should fully involve families (if that is their wish) and give them access to independent advocacy services. They should ask about any comments or concerns the family may have at the start of the process. [19] Families should be given clear written information about: timescales; investigators; framework of investigations; and how the family want to be involved. There should also be an offer to provide copies of any reports.[19] A single point of contact should be given to the family at the outset.

The PARENTS study was followed up by the PARENTS II study, which addressed the HCP perception of parental involvement.[14] HCPs strongly advocated engaging bereaved parents in the perinatal mortality review.

Many papers refer to the importance of parental involvement with the review process but do not delve any further. Although policy guidance now states parental engagement should

be sought, the literature has shown that there is relatively little information available on the methodology or system that should be used to incorporate it. Furthermore, there is little evaluation of different methodologies to indicate the best method of involving parents.

4.2 Existing models for perinatal mortality review

Perinatal mortality review with parental involvement has not been standardised across the UK or abroad. There is little evidence regarding current models for mortality reviews within perinatal medicine. However, over the last 2 years this has started to change, with the development of Healthcare Safety Investigation Branch (HSIB) protocols, Learning from Deaths research and the Perinatal Mortality Review Tool (PMRT). The gap in the literature, noted by studies including PARENTS and the importance of further developing perinatal incident reviews in papers such as Each Baby Counts (EBC), has started to be addressed.

A Perinatal Mortality Review Tool (PMRT) was launched for use throughout the UK in 2018. The tool was based on the work of the SANDS Perinatal Mortality Review and the Department of Health. A collaboration led by MBRRACE-UK were appointed to develop a standardised perinatal mortality review tool.[20] The collaboration included the PARENTS 1 and 2 study team and Bristol University. A key element of the PMRT programme is parental engagement. This project is still active so no formal evaluation of this work has been published yet.

In 2010, a population-based cohort study in the Netherlands followed the implementation of a national perinatal internal audit.[21] All 90 hospitals in The Netherlands took part, resulting in a review of 943 deaths between 2010-2012. The standardised perinatal audit included identification of substandard factors in care and recommendations for quality improvement.[21] The analysis showed term perinatal mortality decreased from 2.3 to 2.0 per 1000 births ($p<0.00001$) (a statistically significant reduction).[21] There was no parental engagement in this process. However, it does serve to demonstrate the impact standardised review of perinatal deaths can potentially contribute to obstetric outcomes. It may offer a template that parental engagement could be added onto.

4.3 Models for mortality review outside of perinatal medicine

The *Learning from Deaths* case studies[25] and the Royal College of Physicians[26] use the Structured Judgement Review (SJR) methodology which has been used and validated in adult medicine. Trained HCPs use "explicit statements to comment on quality of healthcare," allowing for reproducible judgements.[25,26] However, this does not incorporate patient involvement, which has been identified as key to perinatal mortality reviews.[26]

4.4 Economic Evaluation of Perinatal Mortality Reviews

Due to the minimal evidence focused on mortality reviews which include parental engagement, there is limited research focused on their economic evaluation. The University of Bristol Policy (in conjunction with the PARENTS study and PMRT) have predicted that hospitals (with a birth rate of 6,000 per annum) would need to fund the following[1]:

1) A dedicated perinatal mortality lead (1-2 sessions per week)
2) A dedicated perinatal loss clinic for follow up
3) Management in subsequent pregnancies (1 clinic per month)
4) Initial and ongoing staff training

However, there are no reliable estimates for how much a comprehensive service would be likely to cost. In the absence of a recommended model which has undergone rigorous evaluation, CCGs are likely to face significant challenges in planning the commissioning of these services and aligning care pathways with a rigorous evidence base. This literature review has identified a need for a comprehensive economic evaluation focused on the whole care pathway, from antenatal care to support following a death and in any future pregnancies.

5. Communication with parents during incident reviews

Communication skills in relation to medical errors and patient safety has been a point of interest for a number of years. Indeed, within obstetrics there has been engagement in assessing how best to communicate with bereaved patients in a more general way (rather than in the context of a formal incident review). These data, however, may be able to inform how best to incorporate patient engagement.

The discussion of communication with patients has been divided into 2: patient and healthcare professional (HCP). Although, undoubtedly deeply intertwined they are addressed separately in order to acknowledge the differing perspectives and needs.

5.1 The patient/family perspective

A systematic review by Garstang *et al.* addressed what bereaved parents want from professionals after the sudden death of their child.[17] 52 articles from Western Europe, Australia and North America were collated and appraised. The review found that parents raised the same key considerations as those outlined in the PARENTS study: transparency; full disclosure; timing; and prevention.[8, 17, 28-34]

Transparency [17, 19]: This term is used in a variety of papers with no singular definition. It recognises the fact that families need to be told clearly what is going to happen and how. They want to be treated as equal partners in the process. Clear written information should be given to the family with information regarding the process including the investigators and timescale.

Full disclosure[17,28-34]: Evidence shows that parents want full details about the death of their child. Indeed, it has been reported that when this information is not given, they can feel there is deliberate evasion which impacts on the patient-HCP relationship.[17] With full disclosure it must be remembered that the use of language must be understandable. Parents can struggle understanding post mortem results.[17]

The extent for full disclosure extended even to minor errors. Overall, the desire for explanation and an apology is frequently highlighted. Lastly, parents felt that full disclosure includes an explanation of how this will be prevented from occurring again in the future.[28]

Timing: Studies of child death have consistently found that the parents can be too distressed to understand the detail explained to them at the time of death or at follow up appointments.[17] Other literature confirms this, stating that parents appreciate follow up appointments after a death to enable them to find out further information that they previously were unable to take in.[28]

Prevention[17,28-34]: A preoccupation of parents is the importance of changes being made to ensure lessons are learnt and no other family goes through what they have.

Other topics covered by this body of literature on communication regarding patient safety included the following:

Location: Garstang et al. noted that the location of follow up communication is of importance. Some parents reported that returning to the hospital is traumatic.[17]

Antenatal: Carranza et al. noted that within obstetrics communications *prior* to delivery may be of importance. Expectant parents often anticipate birth will unfold according to plan. So far there is little known data assessing how much, if any, expectant parents want to know about risks of pregnancy and therefore any value in communicating potential complications surrounding birth. However, the authors highlighted this gap in knowledge: how do HCPs establish realistic expectations without increasing unnecessary anxiety?[4] If this balance is found successfully, it is hoped that if an incident did subsequently occur, communication would be easier for both the parents and practitioner.

Who: Parents have been found to value the support provided by continuity of HCPs. Parents have shown a preference for their own multi-disciplinary team (MDT) or bereavement midwife to take this role. Carranza et al recommended the concept of the "trained navigator" who could facilitate communications between the hospital and the family after an adverse perinatal outcome. Alternatively, McDonald et al suggest a "Patient Communication Consult Service (PCCS)" .[35] The descriptive study is based on the University of Illinois Medical Centre (UIMCC) which is a 450-bed tertiary centre. In 2004 the researchers piloted a comprehensive process for responding to patient safety incidents which led to the PCCS service. This is a service comprised of volunteers from healthcare providers from each department that were trained in "complex communications." When a team needs to disclose medical errors or cases with patients, the PCCS are available to be present.[35] The costs of this are not defined and it represents only one hospital's approach.

5.1.2 Communication with parents/family after adverse errors outside perinatal medicine

There are 2 key papers produced that address communication with the patient/ family following adverse errors: firstly, Massachusetts Coalition for the Prevention of Medical Errors produced the Harvard Hospital Consensus (HHC)[8] – *When Things Go Wrong* (2006) and the NHS *Learning from Deaths* (LFD) (2018) guidance and case studies.[19]

The HHC (2006) is a statement from 16 supporting hospitals on responding to adverse events, including both Women's and Children's hospitals. Open and honest communication is seen as essential to maintain and restore trust.[8] The authors outline 4 steps for *full* disclosure[8]:

1. Tell the patient/family what happened – this should be done by a "trusted" caregiver in a quiet area for communication
2. Take responsibility
3. Apologise
4. Explain what will be done to prevent future events.

More recently in the UK the National Quality Board produced *Learning from deaths: guidance for NHS Trusts on working with bereaved families and carers* (2018) .[19] The report produced a set of guiding principles Trusts should use when interacting with bereaved families, very similar to those of the HCC 2006. A key recommendation was to give clear, honest, compassionate and sensitive responses.[19] Contact and support should be via a single point of contact/liaision.[19]

5.1.3 Overview

Although there is a consensus in the literature that there is a need for empathic and open communication with parents, there is virtually no information on the practicalities or a framework for implementation. The HCC and LFD guidance have both started to fill this gap. However, further research is needed to assess the implementation of these methods and how families perceive them.

5.2. Healthcare Professional (HCP) perspective

In recent years there has been a growing body of evidence that "full disclosure" of adverse events is the best approach for *both* patient and HCP in perinatal medicine and beyond. The (ACOG), as early as 2009, affirmed its belief that a clinician should be open and transparent with parents. A joint statement by the American Academy of Pediatrics, American College of Nurse/Midwives and the American College of Obstetricians and Gynecologists (ACOG) noted their agreement that HCPs should have a shared commitment to "transparency".[28] Within obstetrics, Carensa *et al's Delivering the Truth: challenges and opportunities for error disclosure in obstetrics* (2014)" report highlighted that "transparency is critical to advancing healthcare quality".[28]

Despite this apparent consensus, some clinicians still questioned if full disclosure was in the best interests of the patient.[37] They also raised concerns about the process of disclosure and how to do it. In their prospective cohort study, Crimmins *et al.* found that 42% of the clinicians surveyed did not believe in full disclosure; 56% felt partial disclosure was needed[38] and 3% of physicians chose no disclosure.[38] However, this study was based in Emergency Medicine with only 48 participants including physicians and medical students which may limit its applicability to obstetric care.

5.3 Support for HCPs

In order for effective communication to be achieved, it is essential that HCPs are supported. Full disclosure is recurrently referred to as the basis of good communication. There is a growing discussion on how to enable this process and to identify the barriers that prevent it from occurring.

Three key barriers:

1) Fear of litigation and legal implications
2) Culture
3) Training needs

Fear of litigation: [28,30,31] Articles highlight fear of litigation as a principle concern preventing full disclosure and may be seen as a "prominent foil to the aspiration of openness" .[28] Fear of litigation appears to be a barrier to transparent communication after obstetric medical errors, according to Carranza et al.[28] The committee of medical liability and risk management have suggested that parents/ caregivers are less likely to pursue litigation against a HCP when there is full disclosure.[30]

However, some researchers have noted a theoretical risk that increased disclosure may increase the total number of families wanting to pursue lawsuits.[30] In the U.S., it has been suggested that state legislators and government should develop "apology laws" to help reduce liability risks associated with disclosure.[30]

Legal: Several organisations in the U.S. have reported successful disclosure programmes. The Veterans Affairs Medical Centre in Kentucky implemented a disclosure programme in 1999. Within 10 years, they noted that the median liability payments were one fifth of that paid by the private sector.[31] In addition, the University of Michigan Health System found a 50% reduction in legal fees after implementing their full disclosure policy in 2001. This result was matched by the Illinois Medical Centre in Chicago.[31]

Culture: The importance of an open, non-blaming culture was emphasised by all authors. However, the way in which this can be achieved was not expounded upon. The link between a non-punitive culture and a safer patient environment was frequently made. This "just" culture was seen as key to full disclosure. Although the ACOG were clear that removing blame did not eliminate individual responsibility. Instead, it recognised that competent individuals make mistakes.[31]

The healthcare culture surrounding incident reviews and errors is often described within the literature. Although the language used varies by author and publication, the essence of what they describe is, nevertheless, the same: a "just", "transparent" and "blame free" culture.[9,14,15]

5.4: The Second Victim

In the last ten years a new consideration within the incident review process has been identified. The concept of the "second victim" is gaining increasing recognition. *Scott et al.* describe the "second victim" as a HCP that is involved in an unanticipated adverse patient incident and is subsequently traumatised by the event. [36,39] In short, this concept recognises the potential for emotional distress to professionals, regardless of the preventability of the incident or even presence of medical error.[40]

The potential ramifications of this can be far reaching and may include feelings of isolation, guilt, and self-doubt. There may also be longer term results such as depression, post-traumatic stress disorder, reduced clinical performance and even suicide. [36] Therefore, a coordinated response to identify and help HCP staff that could become "second victims" should be in place too.[36] The best method of doing this is not clearly defined in the literature. Many agree that a "blame free culture" alongside compassion from team members and counselling after the event would be a good starting point.[36,41] These would enable affected HCPs to recover.[36]

5.5 Training for Healthcare Professionals

Ellis *et al* undertook a systematic review of parents' and healthcare professionals' experiences of stillbirth.[42] 52 suitable papers were used in the analysis. It concluded that parents and staff identified the need for improved training.[42]

The 5 key training methods were identified in the literature:

1. Standardised Patient (SP) [43-47]
2. Role Play[44]
3. Disclosure coaches[48]
4. Video recording
5. Education Programme

SP, where trained actors are used in roleplay, has been shown to be effective at improving "resident" doctor knowledge and preparedness in error disclosure in emergency medicine and others.[43]

Kim *et al* have additionally researched SP training with 79 medical students and 6 resident doctors.[45] It found that by the end of the programme they were more confident. The use of SP as a training method was also assessed by Sur et al in the paediatric ICU setting.[47]

Roleplay (without SP) has 3 main advantages over alternative methods: 1) it is cheaper than SP 2) it allows trainees to experience both the healthcare and patient perspective 3) it is easily set up.[43]

White *et al*[48] discuss the option of in-house training to create multi-disciplinary disclosure coaches. However, although the training was highly rated the candidates did not all emerge confident after the coaching.

Brown *et al*.[49] assessed communication training in radiology trainees. 109 trainees from 16 U.S. programs attended a full communication workshop. The comparison of the pre- and post-course questionnaire showed increased confidence in communicating adverse results[47]. However, the specific contents of the course are not alluded to.

As part of the "Seven Pillars" approach to patient safety McDonald *et al*. focused on education and training of their staff.[35] This led to the development of a formal training programme for both initial and continued training of clinical, support and administrative staff. A variety of methods were used: unit specific patient safety programmes; grand rounds; unit specific safety training; SP; role play disclosure training; and training the trainer programmes. Competencies needed to be maintained annually.

Overall, it appears the trainees appreciate practical sessions to practise these communication skills. Standardised patient and role play seem to be superior to lectures However, it has been noted that these are skills that will require on-going updates. The best way to do this was not identified within the literature.

Although this evidence is from outside of the perinatal setting – such as ITU, radiology, Accident and Emergency, the skills appear to be transferable.

A debate existed as to the best time to initiate the training for HCPs. In the American settings, "residents" were identified as an area where the need was greatest. [8,28,33] With seniority came improved skills in disclosure. However, medical school was also identified as a time when training would be useful.

6. Conclusion

There is very little data within the perinatal literature focused on models of parental engagement. Extending this search to outside the UK and to other areas of medicine did not notably increase the information available. This gap in research has already been identified by researchers such as those developing the PARENTS, PARENTS 2 and the roll out of the perinatal mortality review tool. These projects are developing our understanding of how parents want to be involved and the steps needed to allow this to happen.

The natural follow on from this would be to evaluate an implemented tool of parental engagement to assess how well that is working. With the implementation of the Perinatal Mortality Review Tool (PMRT), this may be possible.

The broader literature search on patient safety, adverse events and communication yielded a much higher amount of research. The broad themes identified in the patient safety mirrored the little evidence we do have regarding parental engagement wishes after bereavement: flexibility, transparency, inclusivity and a desire to prevent adverse errors reoccurring.

A key aspect of the discussion around support for staff has illuminated the "second victim" – the healthcare professional. This illustrates the need for perinatal mortality models to focus on the welfare of the staff as well as the parents/ family.

Development of parental engagement is an essential part of the challenge to improve perinatal mortality. In order to meet the ambitious objective to reduce incidence of neonatal death and stillbirth in the UK, more research, development and validation of perinatal incident models is needed.

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