



# PARENTS 2 study: consensus report for parental engagement in the perinatal mortality review process

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## ABSTRACT

**Objective** The PARENTS 1 study (Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death) found that parents would endorse the opportunity to give feedback into the perinatal mortality review (PNMR) process. In subsequent focus groups, healthcare professionals were positive about parental engagement, although they considered that there may be significant challenges. The objective of this study was to develop core principles and recommendations for parental engagement in PNMR in the UK.

**Methods** A two-round Delphi technique was followed to reach consensus on core principles for parental engagement in the PNMR process; Round 1 included a national consensus workshop and Round 2 an online questionnaire. The consensus meeting was attended by a national panel of stakeholders (clinical and academic experts, parent advocates, managers and commissioners) in stillbirth and neonatal and bereavement care. To develop recommendations for parental engagement, participants discussed four key areas comprising: communication with parents, including receiving feedback; the format of the PNMR meeting; the parental engagement pathway; and challenging aspects of engaging with parents in reviews. Content analysis was conducted to generate recommendations from the meeting for a subsequent anonymous web-based survey. Attendees of the consensus workshop and members of the PARENTS 2 Project Advisory Board were asked to rank recommendations using a 9-point Likert scale from 1 (not important) to 9 (critically important). It had been agreed a

priori, in compliance with established Grading of Recommendations, Assessment, Development and Evaluation (GRADE) criteria, that 'consensus' would be achieved if over 70% of participants scored the principle as 'critical' (score of 7–9) and fewer than 15% scored the principle as 'not important' (score of 1–3). Principles for which consensus was achieved were included in the core recommendations.

**Results** Of the 29 invited stakeholders, 22 participated in the consensus meeting and 25 (86% response rate) in the subsequent online questionnaire in June 2017. Consensus was agreed on 12 core principles. Of the 25 participants, 96% agreed that a face-to-face explanation of the PNMR process was of critical importance, 72% considered that parents should be offered the opportunity to nominate a suitable advocate, 92% believed that responses to parents' comments should be formally documented, 96% indicated that it was vital for action plans to be translated into lessons learnt and that this process should be monitored, and 100% of stakeholders voted that a plain-English summary should be produced for the parents following the meeting. There was good agreement on a further seven principles.

**Conclusions** Key national stakeholders were unanimously supportive of parental engagement in the PNMR process and agreed on core principles to make this process feasible, meaningful and robust. A 6-month pilot of parental engagement in the PNMR process (PARENTS 2 study) in two UK units took place after the consensus on core principles. In collaboration with the National Perinatal Epidemiology Unit, the

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## INTRODUCTION

Following a stillbirth or neonatal death, a systematic, multidisciplinary review of the circumstances and care leading up to and surrounding that death should take place within the hospital<sup>1</sup>. Learning from these deaths during the perinatal mortality review (PNMR) process and ensuring better information for, and better communication with, parents could help improve transparency and the quality of care provided to bereaved parents and their families. Importantly, learning from previous deaths would help identify areas in which more could be done to improve patient safety in the future<sup>2</sup>. Improving lessons learnt from PNMRs and the quality of such reviews aligns with national and international targets to reduce the number of stillbirths by 50% by 2020<sup>3</sup>.

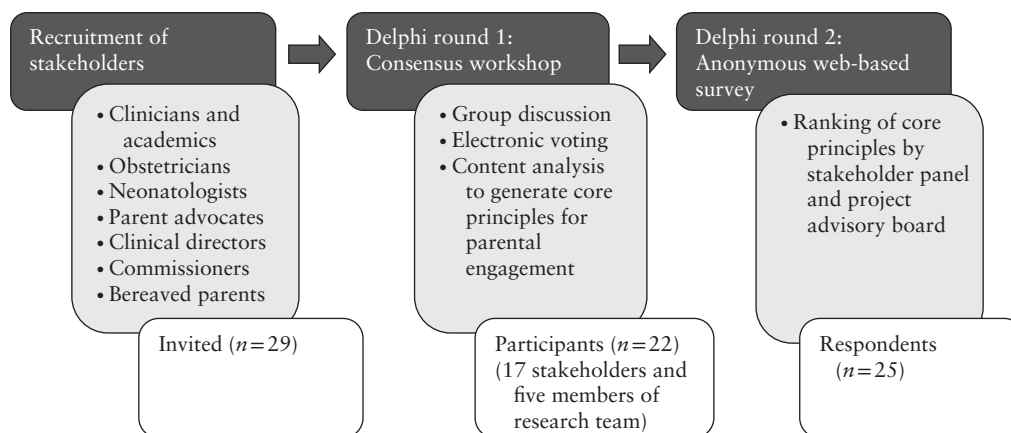
The 'Each Baby Counts' report of the Royal College of Obstetricians and Gynaecologists<sup>4</sup> and the MBRRACE-UK perinatal confidential enquiry<sup>5</sup> showed, in 2015, that the quality of the PNMR process was inconsistent across the UK and rarely included any formal input from bereaved parents into the review. Similar to the Kirkup report<sup>1</sup>, MBRRACE-UK and Each Baby Counts both recommended that all trusts and health boards should inform parents of any local review taking place, offering them the opportunity to engage in the process and to receive feedback from the review<sup>4</sup>. However, there was a lack of evidence on how to engage parents meaningfully in the PNMR process. This was addressed previously by the PARENTS (Parents' Active Role and ENGagement in The review of their Stillbirth/perinatal death) portfolio of studies<sup>6,7</sup>, which investigated the best way to enable parental engagement in the PNMR process. In the PARENTS 1 study, 11 bereaved parents who experienced the death of a baby at various gestational ages were

interviewed, and the majority were in favor of an opportunity to contribute to PNMRs<sup>6</sup>. Subsequently, focus-group meetings took place involving a range of maternity healthcare professionals<sup>8</sup>. The participants agreed that parental engagement in PNMRs would be beneficial and could improve the quality of the review<sup>8</sup>. Despite having reservations about the financial and emotional support that might be required to enable such a process<sup>8</sup>, healthcare professionals perceived that involving parents could help families in the future, improve patient safety and help to prevent future perinatal deaths<sup>7</sup>.

Before piloting parental engagement in PNMRs, we sought to reach expert consensus on how best to engage parents. Here, we report the findings of the PARENTS 2 consensus study, which generated recommendations on parental engagement.

## METHODS

This study received ethical approval from the UK Health Research Authority (Integrated Research Application System (IRAS) 216 018 (date of IRAS approval: 03/05/2017); Research Ethics Committee reference: 17/WM/0123). The study methods for this consensus have been published in detail in the full PARENTS 2 study protocol<sup>7</sup>. We followed a modified Delphi method to achieve consensus on recommendations on parental engagement in PNMRs<sup>9</sup>. The Delphi method is an iterative process that uses systematic repeated rounds of anonymous voting to achieve expert group consensus in areas in which there is little or no definitive evidence<sup>9,10</sup>. We used a modified Delphi method to allow expert members of the panel to discuss the principles for parental engagement in a group meeting prior to anonymized voting. This modified method has been perceived as being more cooperative and effective in other research studies<sup>11,12</sup>. We conducted two sequential Delphi rounds, including a national stakeholder consensus workshop and an anonymous web-based survey. Figure 1 illustrates the process followed to reach consensus on core principles for parental engagement in the PNMR process.



**Figure 1** Consensus process followed to generate core principles for parental engagement in perinatal mortality review process.

## Recruitment of stakeholders

A national stakeholder panel of clinical and academic experts in perinatal loss and neonatal and bereavement care were sampled purposively from key informants through the International Stillbirth Alliance, stillbirth and neonatal death charity (Sands), Child Bereavement Care UK and Bliss UK charity groups. Parent advocates and bereaved parents were also invited to attend. Twenty-nine stakeholders were identified.

## Delphi round 1: consensus workshop

A 5-h consensus workshop took place in June 2017, to which the 29 experts and stakeholders were invited. The consensus-meeting program was e-mailed to the participants in advance. Results and themes from the qualitative analysis of the focus-group interviews of parents and healthcare professionals were presented to the panel alongside current evidence in this area of practice.

The workshop focused on four key areas including: the format of the PNMR meeting, the parental engagement pathway, challenging aspects of involving parents in the reviews and communication with parents, including receiving feedback. The expert panel was divided into four breakout cohorts containing four or five members each, with a balanced mix of stakeholders in each group. All groups discussed all four areas. The participants were then asked to generate ideas for solutions to any problems identified, addressing specifically the four key areas, with the overall aim of creating a set of core principles on how to implement a PNMR process with parental engagement. A facilitator and transcriber who was also a member of the research team (D.B., C.B., D.S., C.S. and M.L.) was assigned to each group to facilitate discussion and transcribe by paraphrasing.

Each participant was asked to submit their solutions to the facilitator, who collated information to inform the initial draft of overarching core principles for parental engagement. Following discussion of each workshop key area, the groups reconvened, and the facilitator presented a synopsis of the main points made by participants to the wider panel. In addition, after each workshop, anonymized voting took place. Participants and the project research team were asked to vote using electronic keypads on specific questions that had emerged previously from the focus groups with parents and healthcare professionals<sup>6,8</sup>. Immediate results for each question were presented to the participants and were followed by additional discussion of residual issues. Content analysis was conducted by the research team on the data collected from these discussions to generate an updated list of principles for engaging parents in the PNMR process. Content analysis is a systematic way of determining inferences or categories within data<sup>13</sup>. Two members of the team read the transcriptions and field notes, independently coded the data and subsequently developed themes to produce the consensus recommendations. The final list of principles was used in the web-based survey in Round 2 of the Delphi procedure.

## Delphi round 2: web-based survey

The national stakeholder panel from the consensus meeting was invited via a personalized e-mail from the research team to complete an anonymous web-based survey (smart survey). The independent members of the project advisory board (PAB) and research team were also invited to complete the survey. The PAB were purposively sampled to include academic and clinical experts in perinatal death and bereavement care. Twenty-nine participants were invited to complete the web-based survey. The principles of the Delphi consensus process and the survey had been piloted first by the PAB to ensure face validity (readability and ease of completion). Participants were asked to rank the principles generated from Round 1 of the Delphi survey on a 9-point Likert scale ranging from 1 (not important) to 9 (critically important). This scale was created by the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) working group, and has been widely used in other consensus research studies including core outcome set development studies<sup>14</sup>. To minimize bias, it was agreed *a priori* that consensus would be achieved if over 70% of participants scored the principle as 'critical' (score of 7–9) and fewer than 15% of participants scored the principle as 'not important' (score of 1–3). Principles would be excluded if 70% of participants scored the principle as 'not important' and fewer than 15% of participants scored it as 'critical'. These criteria have been used successfully in other consensus studies<sup>15</sup>. Principles outside the range of these predefined criteria were deemed 'borderline'<sup>15</sup>. Responses to each round were analyzed using descriptive statistics and histograms.

## RESULTS

### Delphi round 1: consensus workshop

The national stakeholder consensus meeting was attended by 17 participants in addition to five members of the research team. The distribution of participants according to each stakeholder group for each round of the consensus process is shown in Table 1.

**Table 1** Distribution of participants, according to stakeholder group, of first and second rounds of Delphi survey aimed at developing core principles for parental engagement in perinatal mortality review process

| Stakeholder            | Number of participants |         |
|------------------------|------------------------|---------|
|                        | Round 1                | Round 2 |
| Neonatologist          | 1                      | 1       |
| Charity representative | 2                      | 2       |
| Clinical commissioner  | 1                      | 1       |
| Clinical psychologist  | 1                      | 1       |
| Bereavement midwife    | 3                      | 2       |
| Parent representative  | 3                      | 3       |
| Clinical academic      | 4                      | 4       |
| Child-death reviewer   | 1                      | 1       |
| Ultrasonographer       | 1                      | 1       |
| Research team          | 5                      | 6       |
| Project advisory board | 0                      | 3       |
| Total                  | 22                     | 25      |

In-meeting electronic voting took place during the four workshops. Participants and research-team members ( $n = 22$ ) were asked their opinion on seven questions relating to parental engagement in the PNMR process. All questions and responses are illustrated in Figure 2.

#### Workshop 1: communication with parents

**Providing information about engagement sensitively.** Stakeholders thought that it is crucial that parents are informed about the review process and are offered the opportunity to share their perspectives of care as part of the PNMR, before they leave the hospital. This should be supported by giving parents an information leaflet describing the review process prior to discharge. It was suggested that parents be advised that they would be sent a follow-up letter in the post with the timeline, the estimated date of the review meeting, information about the PNMR and the offer to be included in the process. In addition, there was discussion around the feasibility of an earlier interim debriefing appointment with parents within 1 or 2 weeks following discharge in order to obtain feedback from them about any aspect of their care. This would mitigate the wait for the consultant postnatal

appointment, which could take place up to 12 weeks after discharge. A bereavement care midwife or nurse was suggested as a potential healthcare professional who would be able to coordinate this appointment and provide a continued point of contact.

**Obtaining feedback.** Stakeholders were asked their opinions on parental engagement and receiving feedback to input into the PNMR. Parental engagement may include parents being asked for feedback about their care (including praise or criticism), the ability to put questions to the PNMR panel about the circumstances around the death of their baby and the sharing of knowledge obtained from parents that cannot be obtained by a review of the medical notes. Participants were asked to discuss a sample parental letter and feedback form that was developed as a draft by the Sands/Department of Health PNMR Task and Finish group (2012–2015), which was set up to establish what information would be required for hospital reviews. The parental letter and feedback form were subsequently revised in light of the findings of the PARENTS 1 study<sup>6</sup> (Appendix S1). Thirteen (59%) of the stakeholders agreed that the language of the new form needed revision to improve its clarity. Participants felt it was important

| Question 1  |              |              |              |                  |                   |                     |             |
|---|--------------|--------------|--------------|------------------|-------------------|---------------------|-------------|
| Should we have a free-text box included in the parental feedback form?  | Yes          |              | No           |                  | Unsure            |                     |             |
|   | 17 (77)      |              | 2 (9)        |                  | 3 (14)            |                     |             |
| Question 2  |              |              |              |                  |                   |                     |             |
| Should we have the option of positive feedback in the parental feedback form?                                     | Yes          |              | No           |                  | Unsure            |                     |             |
|   | 18 (82)      |              | 0 (0)        |                  | 4 (18)            |                     |             |
| Question 3  |              |              |              |                  |                   |                     |             |
| Should we differentiate between clinical and non-clinical care within the parental feedback form?                 | Yes          |              | No           |                  | Unsure            |                     |             |
|   | 8 (36)       |              | 10 (45)      |                  | 4 (18)            |                     |             |
| Question 4  |              |              |              |                  |                   |                     |             |
| Should we use the draft parental feedback form developed by the Department of Health and Sands task group?        | Yes          |              | No           |                  | Unsure            |                     |             |
|   | 9 (41)       |              | 0 (0)        |                  | 13 (59)           |                     |             |
| Question 5  |              |              |              |                  |                   |                     |             |
| What do you think is a proportionate amount of time to spend on parental feedback?                                | Up to 5 min  | Up to 10 min | Up to 20 min | Up to 30 min     | More than 30 min  | As long as it takes | No response |
|   | 2 (9)        | 2 (9)        | 4 (18)       | 1 (5)            | 0 (0)             | 11 (50)             | 2 (9)       |
| Question 6  |              |              |              |                  |                   |                     |             |
| How should we offer feedback lessons from the perinatal mortality review meeting to parents?                      | Face-to-face | Written      | E-mail       | All of the above | None of the above | Parental choice     |             |
|   | 0 (0)        | 0 (0)        | 0 (0)        | 1 (5)            | 0 (0)             | 21 (95)             |             |
| Question 7  |              |              |              |                  |                   |                     |             |
| Do you think a formal report should be produced for the parents following the perinatal mortality review meeting? | Yes          |              | No           |                  | Unsure            |                     |             |
|   | 19 (86)      |              | 0 (0)        |                  | 3 (14)            |                     |             |

Data are presented as  $n$  (%). Sands, stillbirth and neonatal death charity.

**Figure 2** In-meeting electronic voting responses of 22 participants of consensus workshop related to parental engagement in perinatal mortality review process.

that it was made clear in the information letter given to parents that 'being involved in the review process' did not mean having to attend the meeting itself, and a parent representative could be present instead.

*Individualized parent-centered approach.* An individualized approach was favored by the participants, starting from the type of perinatal death that had occurred (for example, stillbirth or neonatal death). It was thought that, fundamentally, most parents would ask some similar questions, such as 'Why did my baby die?' and 'Was there something that I did to contribute to my baby dying?'. However, additional questions and comments from parents were likely to differ from case to case.

Stakeholders considered the implications of having free-text boxes, as opposed to set feedback questions, in the parental feedback form, such as the risk of this approach leading to too many questions or questions that the PNMR would not be able to answer. Anonymized voting during the consensus meeting showed that 77% (17/22) of the attendees felt that free-text boxes should be included in the parental feedback form. Stakeholders preferred more inclusive, neutral terminology for the free-text questions, such as 'How did you feel you were looked after?'. It was thought that there should be a responsibility to try and answer all questions that parents submitted and to ensure that there is a robust system in place to address their questions, in line with current risk-management procedures. However, parental expectations should also be managed, and parents should be advised that it may not be feasible during the PNMR meeting to provide a response to all submitted questions.

Workshop participants discussed the challenges of obtaining feedback and questions about their care from families with whom it may be more difficult to engage, such as non-English speaking parents, those in complex social situations or young people who prefer using technology to communicate. Offering parents the option to submit feedback and questions via different formats, such as e-mail, smartphones and audio recordings, was suggested as a solution to facilitate their input. It was recommended that an advocate or parent representative should be appointed as a person who could potentially support all parents through the process, answer any queries with regard to the feedback form and represent them, their views and questions at the PNMR meeting at which their baby's death would be discussed. In one group, it was considered essential that the parent advocate should not 'wear two hats', and should be fully independent of the healthcare professionals involved in the clinical management of the mother and baby. However, some participants thought that this might not be practical within the clinical setting. It was therefore agreed that a parent advocate should attend the meeting with the sole purpose of representing the parents; however, it was acknowledged that this may not be feasible in some hospital units owing to lack of resources.

Finally, additional points related to parents' feedback were discussed. On voting, most participants ( $n = 18$

(82%)) agreed that the parents should have the opportunity to give positive feedback and to comment on individuals and/or systems related to their case. The stakeholders were asked if the feedback should explicitly differentiate between clinical and non-clinical care, for example, by including separate questions and text boxes for each of these two aspects of care; the majority (64%) of them disagreed or were unsure.

#### *Workshop 2: format of perinatal mortality review meeting*

*Attendance.* The stakeholders agreed that all healthcare professionals who were involved in the care of the parents should attend the PNMR meeting. This should include, as a minimum, the lead consultant obstetrician and neonatologist, midwives, nurses, a pathologist and an advocate representing the parents. Some participants felt that parents should be asked which healthcare professionals they wished to attend this meeting. It was felt that involvement should be mandatory for members of staff who were involved in the case, and that, if they were unable to attend, they should submit a formal report to be read at the meeting or attempt to join by conference call.

*Terms of reference.* It was agreed that the purpose of the PNMR meeting should be stated clearly at the start of the meeting in the 'terms of reference'. Furthermore, the length of discussions related to parental questions and feedback should be flexible; 50% of attendees voted that it should take 'as long as it takes' to fully address parental questions and feedback in the meeting. Participants discussed who should chair the PNMR meeting and whether the chair should be internal, external or independent of the hospital trust or health board. They agreed that, regardless of who the chair was, it was vital that they had experience and specific training for this role and that there should be external representation at the meeting as per Perinatal Mortality Review Tool guidance<sup>16</sup>.

#### *Workshop 3: parental engagement pathway*

*Adaptive structure.* The stakeholders argued that the PNMR process should be adaptable to the individual needs of the parents, enabling them to engage and contribute if and as much as they wished. The stakeholders voted unanimously that parents should be offered feedback on the summary findings from the PNMR meeting. Parents should be given the choice of how to receive that feedback, i.e. face-to-face, written or by e-mail. Eighty-six percent of attendees agreed that a formal report of the meeting should be produced for the parents in plain English. The participants considered that parents should be offered a follow-up meeting or appointment with their lead consultant or bereavement midwife or nurse. Follow-up should continue for as long as required by the parents, extending, if necessary, into subsequent pregnancies.

*Dedicated resources.* The participants contemplated the additional financial resources required to support parents through the PNMR process and whether funding to support parental engagement could be commissioned at every hospital. Additional resources would include a dedicated bereavement midwife or nurse to provide a continual point of contact for bereaved families, active participation in their care, bereavement support and personalized continuity of care, so that parents ‘do not have to repeat their story lots of times to health professionals’. In addition, it was suggested that the involvement of a senior administrator to ensure that formal reports and investigations are available for the PNMR meeting would create a high-quality process that would be more robust and meaningful to parents. One stakeholder

recommended that a health-economic assessment may be necessary to facilitate the commissioning of such a service.

Following the conclusion of the Delphi process, a flowchart was developed by the research team, depicting a pathway for a pilot of parental engagement in the PNMR process. The draft pathway, approved by two UK health trusts (Bristol and Manchester) for local pilot implementation, is depicted in Figure 3.

#### Workshop 4: challenges

Stakeholders discussed challenging aspects of parental engagement in the PNMR process, including the financial implications, medicolegal issues, dealing with complaints, managing long complex questions and supporting parents

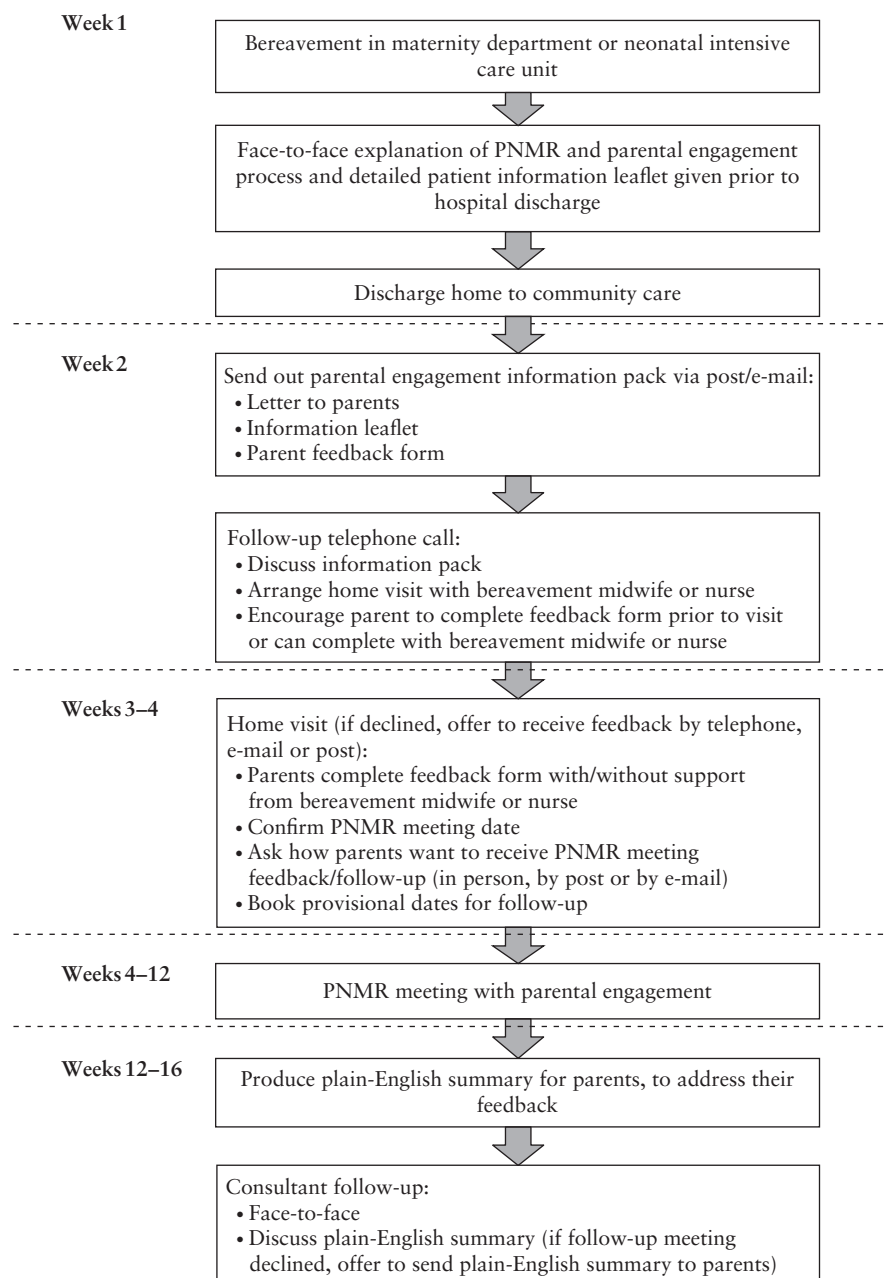


Figure 3 Draft pathway for parental engagement in perinatal mortality review (PNMR) process.

as well as staff during the process. When considering the medicolegal aspects, stakeholders thought that establishing an open and transparent culture could prove helpful to parents and potentially reduce the number of complaints and amount of litigation in the future. It was agreed that, when dealing with complaints, the pre-existing separate formal procedure will still be followed to ensure that parents' concerns are addressed and not missed. The link person or bereavement-care midwife or nurse could provide ongoing communication with parents and facilitate both the review and the complaints processes. The participants discussed the idea that staff could be supported by receiving specific bereavement-care training and by having protected time to attend the PNMR meeting and to address any feedback received on their behavior and care. Furthermore, the need for emotional support for staff was discussed in detail by stakeholders.

### Delphi round 2: web-based survey

Twenty-nine stakeholders, including the attendees of the consensus meeting, invitees who did not attend the meeting, the PAB and the research team, were invited to rank 14 recommendations generated from the content analysis of the consensus workshops. Of these, 25 stakeholders completed the web-based questionnaire (response rate, 86%). Respondents included patient and charity representatives, clinicians, commissioners and researchers (Table 1). Results from the web-based survey are displayed in Table 2.

### Recommendations

Twelve of the 14 recommendations were scored as 'critical', receiving a Likert score of between 7 and 9, by more than 70% of the participants and were scored as 'not important' (Likert score of 1–3) by fewer than 15%. These, therefore, reached consensus and comprised the 12 core principles for parental engagement in the PNMR process (Table 2). There were two 'borderline' consensus principles: 'there should be four different feedback forms (for stillbirth, neonatal death, coroner's case and termination for fetal abnormality)' and 'the meeting should take place within approximately 12 weeks from the baby's death'.

## DISCUSSION

### Main findings

Using a modified Delphi method, 25 key stakeholders reached consensus on 12 fundamental principles of parental engagement in the PNMR process; this is the first consensus process to date on this topic. The recommendations give specific guidance on how best to involve parents in the review of their baby's stillbirth or neonatal death in the UK. Recommendations focus on: when to provide information to parents about the PNMR process; how to obtain feedback and support parents; who

should represent the parents at the PNMR meeting; the outputs of the meeting (including action plans for lessons learnt and a plain-English summary); and how to follow up with parents. As a next step, these recommendations should be piloted and evaluated.

### Strengths and limitations

This is the first study in which recommendations for parental engagement in the PNMR process have been developed using consensus techniques. In fact, to our knowledge, this is also the first study of patient involvement in learning from deaths across disciplines. The involvement of multiple stakeholders, including bereaved parents and their representatives, improves the reproducibility and generalizability of the developed recommendations in the UK. Furthermore, a range of methods including evidence from parents and healthcare professional focus-group interviews and the stakeholder consensus meeting were used to develop the recommendations in the web-based prioritization survey<sup>6,8</sup>. Interestingly, content analysis of the stakeholder consensus meeting workshops revealed broadly similar findings to those of the parent and healthcare professionals focus-group interviews we had previously carried out<sup>6,7</sup>. Parallel themes included: provision for an individualized flexible approach for receiving feedback from parents; the necessity for feedback to be inclusive; the opportunity for parents to give positive feedback; the importance of communicating to parents the lessons learnt from their engagement; and the need for a parental advocate. The consensus workshops provided an opportunity to explore these themes in more detail, for example, to consider who could or could not take on the role of the parent advocate. In keeping with our findings, the UK National Child Death Review guidance published in October 2017 recommends a 'key worker' or advocate to represent the 'voice' of the parents at professional meetings, to ensure that their questions are effectively addressed and to provide feedback to the family afterwards<sup>17</sup>. Our consensus studies have provided details to help to put this recommendation into effect.

A limitation of this consensus study is that the stakeholders were chosen deliberately and included members of the research team, introducing the possibility of selection bias; however, a balanced range of different stakeholders participated. To mitigate bias, the research team took part in the workshops as facilitators or transcribers rather than as participants. Although the number of participants in the web-based survey was relatively small, it was similar to that in previous Delphi technique studies<sup>15</sup>. There is no standard method for the calculation of the most appropriate sample size in Delphi studies<sup>10</sup>. Moreover, we had a very good response rate from a diverse range of stakeholders, including parent representatives. Another potential limitation was that we used a modified Delphi method, opting for an open in-person discussion meeting instead of anonymous voting in Round 1. Anonymity in the Delphi process can counterbalance the influence of experts or more influential personalities; we attempted to

**Table 2** Core and borderline principles for parental engagement in perinatal mortality review process, as voted by 25 participants of second round of Delphi survey

| <i>Principle</i>  | <i>Score 1–3<br/>(not important)</i> | <i>Score 4–6<br/>(important but<br/>not critical)</i> | <i>Score 7–9<br/>(critical)</i> | <i>Consensus<br/>reached</i> |
|---|--------------------------------------|---|---------------------------------|------------------------------|
| <b>Core</b>   |                                      |   |                                 |                              |
| 1. There should be a face-to-face explanation of the perinatal mortality review process, supported by a written information leaflet, prior to hospital discharge.   | 0 (0)                                | 1 (4)   | 24 (96)                         | Yes                          |
| 2. The form to obtain parental feedback should be completed in a face-to-face consultation at a private location of the parents' choice (if declined, option to receive feedback by telephone, e-mail or post should be offered). | 3 (12)                               | 4 (16)  | 18 (72)                         | Yes                          |
| 3. The parents should be offered the opportunity to nominate a suitable advocate or bereavement-care midwife or nurse, who will complete the feedback form with the parents and attend the perinatal mortality review meeting.    | 3 (12)                               | 4 (16)  | 18 (72)                         | Yes                          |
| 4. All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible.   | 1 (4)                                | 0 (0)   | 24 (96)                         | Yes                          |
| 5. Staff involved in the case who cannot attend the perinatal mortality review meeting should, at the very least, submit their comments.  | 1 (4)                                | 1 (4)   | 23 (92)                         | Yes                          |
| 6. Responses to the parental feedback should be formally documented in the perinatal mortality review meeting.  | 1 (4)                                | 1 (4)   | 23 (92)                         | Yes                          |
| 7. If necessary, action plans should be made from the parental responses and monitored.   | 1 (4)                                | 0 (0)   | 24 (96)                         | Yes                          |
| 8. A plain-English summary should be produced for the parents following the perinatal mortality review meeting.   | 2 (8)                                | 1 (4)   | 22 (88)                         | Yes                          |
| 9. The feedback from the perinatal mortality review meeting should be discussed at the consultant follow-up meeting, supported by the plain-English summary.  | 0 (0)                                | 0 (0)   | 25 (100)                        | Yes                          |
| 10. The consultant follow-up meeting should take place as soon as possible after the perinatal mortality review meeting (approximately 2–4 weeks).  | 0 (0)                                | 4 (16)  | 21 (84)                         | Yes                          |
| 11. Parents should have the option to nominate a second member of staff (who could be the designated parents' advocate) to attend the follow-up meeting with the consultant.  | 2 (8)                                | 5 (20)  | 18 (72)                         | Yes                          |
| 12. If the parents decline to attend the consultant follow-up meeting, then the written plain-English summary should be offered to be sent to the parents instead.  | 2 (8)                                | 0 (0)   | 23 (92)                         | Yes                          |
| <b>Borderline</b>   |                                      |   |                                 |                              |
| 1. There should be four different parental feedback forms (for stillbirth, neonatal death, coroner's case and termination for fetal abnormality).   | 6 (24)                               | 3 (12)  | 16 (64)                         | No                           |
| 2. The meeting should take place within approximately 12 weeks from the baby's death.   | 2 (8)                                | 6 (24)  | 17 (68)                         | No                           |

Data are presented as *n* (%) of respondents who scored principle from 1–9 on Likert scale.

achieve this by using anonymized voting in the workshops and anonymous voting in Round 2. Even though the participants were practicing across all different regions of the UK, the principles generated may not be applicable to other countries or lower- and middle-income settings,

compromising the external validity of this consensus. Future research should include other settings and involve an even broader range of stakeholders, including perinatal pathologists, representatives from the coronial system and medicolegal experts.

## Interpretation

The recommendations developed as part of this consensus study show a possible way for engaging parents in the review of their baby's perinatal death. The general principles could also be applied to learning from deaths in other medical specialities and other serious-incident reviews. Public enquiries in the UK have revealed that, in many hospitals, learning from patient deaths was not taking place and opportunities to improve care were being missed<sup>2,18,19</sup>. The National Quality Board in the UK published its 'Learning from Deaths' guidance in 2017, which proposed that learning from deaths should be critical to clinical governance, and that parental/patient engagement should be integral to such a process<sup>2</sup>. What has not been previously shown is how parental/patient engagement should be implemented. The PARENTS 2 consensus study has provided preliminary evidence on how parental engagement could be implemented following a perinatal death.

Two principles were deemed 'borderline': the need for four different feedback forms (one each for stillbirth, neonatal death, coroner's case and termination for fetal abnormality) and that the meeting should take place within approximately 12 weeks from the baby's death. Although these recommendations emerged as being important from the previous parent and healthcare professional focus groups<sup>6</sup>, and most consensus-survey participants classified these recommendations as 'critical', they did not reach the *a-priori* consensus threshold necessary for inclusion in the final set of principles. The reasons behind this could have been that stakeholders thought that having four feedback forms would be too complex or, conversely, not specific enough. Also, having a PNMR meeting within 12 weeks after the perinatal death might not be feasible in all hospital units in the UK, as this may not allow for completion of the postmortem examination and multidisciplinary case discussion.

The stakeholders discussed challenging aspects of parental engagement in the PNMR process including the prospect of litigation. There is good evidence to suggest that there is an association between poor communication and complaints or litigation<sup>20–22</sup>. Data on written complaints in the National Health Service in the UK (2016–2017) showed that the largest proportion of complaints was attributed to communication issues<sup>23</sup>. The communication-and-resolutions program in the USA aims to promptly offer financial and non-financial resolution when adverse events are caused by substandard care<sup>24</sup>. Patient and family involvement is extensive and integral to this program. A study by the University of Illinois found that by encouraging transparency and taking a proactive approach with patient engagement, the communication-and-resolutions program may help to resolve malpractice disputes faster and at a lower cost<sup>24</sup>. By enhancing the quality of communication with parents through engaging them in the process of the review, there is potential to reduce the number of complaints or amount of litigation.

A 6-month pilot of parental engagement in the PNMR at two geographically distinct hospital trusts in the UK is currently underway and has had over a 75% recruitment rate so far<sup>7</sup>. The findings of this pilot will directly inform the UK national standardized PNMR tool and national bereavement care pathway<sup>16,25</sup>. Future studies will be able to explore the impact of widespread implementation of the tool and parental engagement in the PNMR process on complaints and litigation related to perinatal death.

## Conclusions

The stakeholders involved in this consensus project were very supportive of parental engagement in the PNMR process and recommended ways to make it both feasible and meaningful to parents, staff and patient safety. What is now needed is a comprehensive assessment of the effectiveness and cost-effectiveness of parental engagement in PNMR, before widescale national, or even global, implementation is considered.

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## SUPPORTING INFORMATION ON THE INTERNET

The following supporting information may be found in the online version of this article:



**Appendix S1** Preliminary parent feedback form developed by Sands and the Department of Health