

PARENTS

Parents' active role and engagement
in their stillbirth & neonatal death review



The PARENTS Study

- Why engage parents in the perinatal review process?
 - Potentially help parents deal with their grief more effectively
 - Drive improvements in patient care and safety
- What were the aims of the PARENTS Study
 - Develop, implement and evaluate parental engagement in the Perinatal Mortality Review (PNMR) process using input from an National Consensus meeting

Recommendations for parental engagement in the PNMR

- There should be a face-to-face explanation of the perinatal mortality review process, supported by a written information leaflet, prior to hospital discharge.
- The form to obtain parental feedback should be completed in a face-to-face consultation at a private location of the parents' choice (if the parent declines offer by telephone, email, or post).

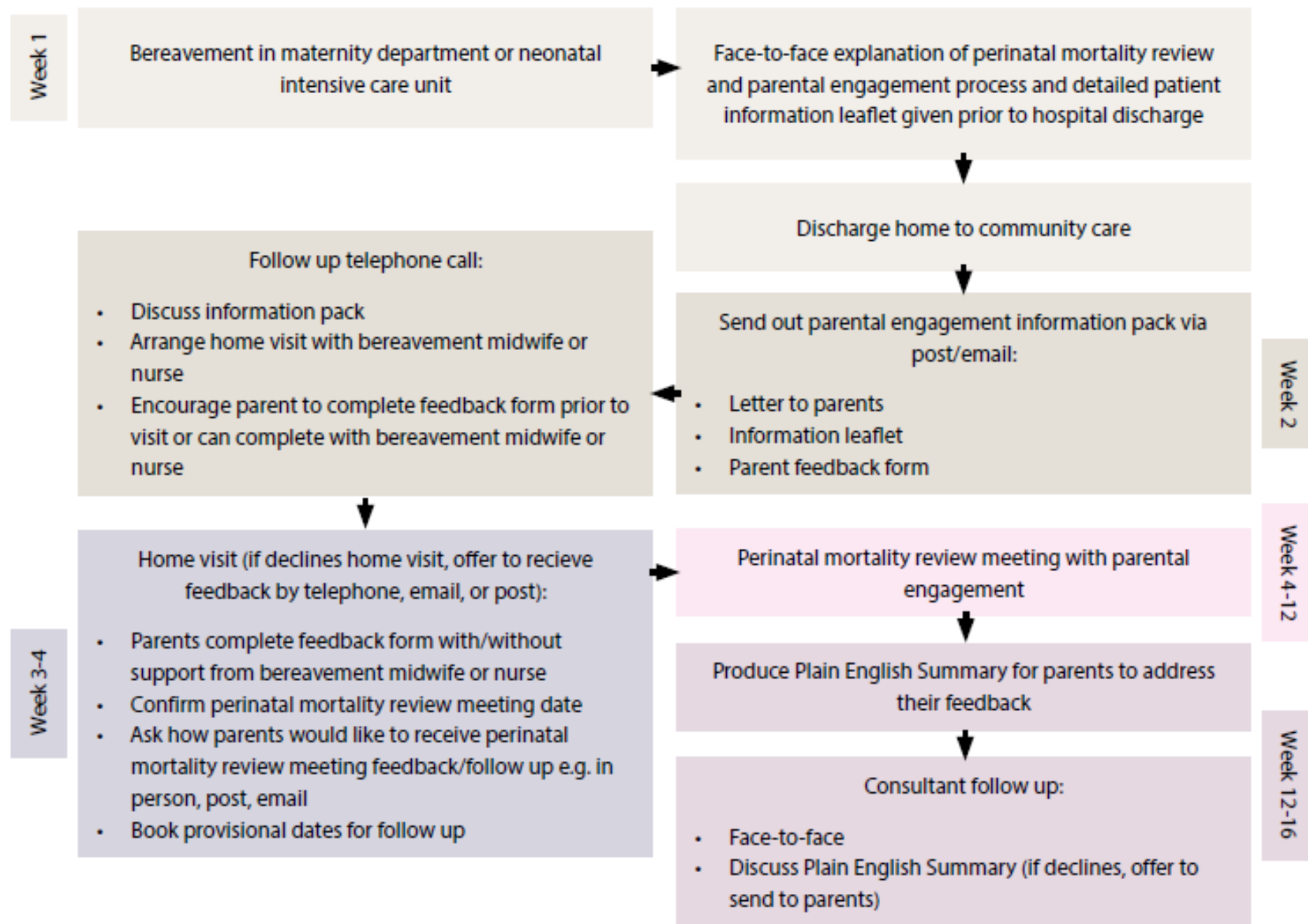
Link to forms. <https://www.nbt.nhs.uk/www.nbt.nhs.uk/WCHResearchPARENTS>

- The parents should be offered the opportunity to nominate a suitable advocate or bereavement care midwife or nurse; a person who completes the feedback form with the parents and attends the perinatal mortality review meeting to provide their feedback in the review process (parents not to attend in person).
- All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible.
- Staff involved in the case should attend the perinatal mortality review meeting where possible (if unable to attend they should submit their any comments to the chair prior to the meeting).
- Responses to the parental feedback should be formally documented to inform the perinatal mortality review tool.

Recommendations for parental engagement

- Action plans should be made from the parental responses if necessary and included in the perinatal mortality review tool.
- A plain English summary should be produced following the perinatal mortality review meeting via the perinatal mortality review tool which includes responses to parental feedback.
- The responses to parental feedback should be discussed at the consultant follow up consultation, supported by the plain English summary.
- The consultant follow up meeting should take place as soon as possible after the perinatal mortality review meeting (approximately 2-4 weeks).
- Parents should have the option to nominate a member of staff (which could be the designated parents' advocate or bereavement care midwife or nurse or a second person) to attend the follow-up meeting with the consultant.
- If the parents decline attending a consultant follow up meeting, then the written plain English summary should be offered to be sent to the parents instead (via post or email).

Parental engagement in perinatal mortality review flow chart



Resources

The expected minimum requirement, per hospital, to enable parental engagement (approximately 6,000 births per year) :

- A dedicated perinatal mortality lead (1-2 sessions per week)
- Bereavement midwife or nurse (full time equivalent)
- Part-time administrator (1 day per week)
- A dedicated perinatal loss clinic for follow up and management in subsequent pregnancy (1 clinic per month)

Lessons from the PARENTS Study

- Approach and timing of parental engagement described in flow chart were appropriate for parents.
- Point of contact and ongoing support was essential (through their bereavement midwife or nurse).
- Parents prefer to talk through their experience with midwife first rather than complete the feedback form alone.
- The feedback form was useful to facilitate their engagement.
- Individualised Plain English Summary required for parents.

Lessons from the PARENTS Study

- Parental engagement helps to focus the perinatal mortality review meeting.
- Feedback from parents on care often positive and all aspects of care commented upon.
- Discussion in the perinatal mortality review meeting including parental feedback takes 20-40 minutes per parent (set).
- Complaints and litigation should continue to be actioned according to individual Trust policy.
- Trusts should consider the additional impact parental feedback could have on staff and support should be considered.

Relevant Publications

- Bakhbakhi D, Siassakos D, Storey C, et al. PARENTS 2 Study: United Kingdom consensus report for parental engagement in the perinatal mortality review process. Ultrasound Obstet Gynecol 2018 doi.org/10.1002/uog.20139
- Bakhbakhi D, Siassakos D, Storey C, et al. PARENTS 2 study protocol: pilot of Parents' Active Role and ENGagement in the review of Their Stillbirth/perinatal death. BMJ Open 2018;8:e020164. <http://dx.doi.org/10.1136/bmjopen-2017-020164>
- Bakhbakhi D, Siassakos D, Burden C, et al. Learning from deaths: parents' active role and engagement in the review of their stillbirth/perinatal death (the PARENTS 1 study). BMC Pregnancy Childbirth 2017;17:333. <http://dx.doi.org/10.1186/s12884-017-1509-z>
- University of Bristol policy Brief: <http://www.bris.ac.uk/policybristol/policy-briefings/engaging-parents-baby-loss/>

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