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| **ISA ISPID  Abstract Submission  Nº: 265**   |  | | --- | | Topics: **Implementing best practices** | | Type: **Oral** | | **Parents' Active Role & ENgagement in Their Stillbirth/Perinatal death review (PARENTS study)** | | **Bakhbakhi, Danya** 1; **Storey, Claire**2; **Burden, Christy** 3; **Jones, Ffion** 3; **Yoward, Freya** 3; **Siassakos, Dimitrios**3 *1 - North Bristol NHS Trust & University of Bristol. 2 - International Stillbirth Alliance. 3 - University of Bristol.* | | **Introduction** A task group commissioned by the Department of Health (DH), and more recently the 2015 MBRRACE-UK Confidential Enquiry into stillbirth, both recommended that parents’ perspectives of their care should be sought and included in the standardised multidisciplinary review of their stillbirth or neonatal death, and the outcome of the review should be shared with the parents.  However, the perinatal mortality review process has been inconsistent in the UK, with little or no input from bereaved parents.  We aimed to identify what type of involvement in the review process parents consider appropriate and useful.  **Material and Methods** Fifteen participants in the South-West, with diverse personal experience of a stillbirth or neonatal death at least six months prior to the study, participated in a focus group, as part of a pilot study recommended by the DH task group.  Thematic analysis was used to summarise their views about parental involvement in the mortality review process.  **Results** *Transparent* - The majority of participants were unaware that a formal review process takes place after the death of a baby. *Flexible yet Specific* - The participants expressed the view that parental input to the review process should be optional and flexible; some parents did not wish to be involved initially but to have the option to contribute to the review or learn about its conclusions later. Brief circumstance-specific information about the review should be included in discharge packs and discussions. Parents believed that some direction as to how to contribute to the process (e.g. example questions, framework with subsections) would be useful, alongside an opportunity for free text input. *Inclusive -* Participants believed the review should be transparent, should capture both medical and emotional aspects of each case, and should produce lessons to be learned for not just obstetric and/or neonatal but also community care. *Positive -* Finally, participants commented that the review should include any positive feedback for individual or team excellence.  **Conclusions** This study with a diverse sample found that bereaved parents were unanimously in favour of being given the opportunity to exchange information with mortality review panels. Parents would welcome a system that was flexible and responsive to their individual circumstances and wishes; an ‘open door policy’ within pragmatic limits. | |  |  |  |  | | --- | --- | | **CONTACT** | | | Name: | **Danya** | | Lastname: | **Bakhbakhi** | | E-mail: | **danyabakhbakhi@yahoo.co.uk** | | Country: | **UK - United Kingdom** | | Institution | **North Bristol NHS Trust & University of Bristol** | | Cellphone: | **+447709549773** | | City: | **Bristol** | |