



In their own words

Parents' experiences of the
hospital review of their care,
Sands Survey 2021

The review made us feel people cared and it wasn't just one of those things.

Mother of a baby who was stillborn, England, 2019

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Some parents experience clear, sensitive and timely communications around hospital review into their care, after their baby has died, but not all parents are even aware a review will take place. Our survey illustrated a stark variation in parents' experiences and clear lessons about how to improve care for all parents.

Background

More than 4,500 babies die before, during or shortly after birth every year in the UK. When each tragedy occurs, a hospital review is undertaken to understand why the baby died and whether the care mother and baby received throughout pregnancy, labour, birth and after birth (if the baby lived for a period) was appropriate. A review aims to answer the question: could anything have been done differently to prevent the baby from dying? A proportion of deaths may be referred to a coroner or procurator fiscal (Scotland), or to an external investigation body, such as the Healthcare Safety Investigation Branch (HSIB) in England, but the vast majority of baby deaths will only be reviewed by the hospital itself.

When a hospital review is undertaken, it is parents who have the greatest stake in understanding why their baby died. Historically, though, the quality of hospital review after the death of a baby has been poor and the opportunities offered for them to be heard, as part of the review process, have been virtually non-existent¹²³⁴

Sands chaired a multi-disciplinary group in 2012 to improve the quality of review. The outcome was a collaboration which developed the Perinatal Mortality Review Tool (PMRT) - a tool to support robust, standardised review, which was rolled out across the UK in 2018.

Research shows that engaging parents in the review of their baby's death improves the focus and therefore quality of the review process⁵. The PMRT's Parent Engagement Pathway⁶ supports healthcare professionals in doing this well. Resources include a week-by-week flowchart for communicating with parents, template information and letters, and a guide to sensitive and plain English explanations for medical terminology

The Survey

Sands' role as a key member of the PMRT collaboration is to ensure meaningful parent engagement in review, based on what parents have told us, as well as evidence and best practice. We wanted to know what parents' experiences of the PMRT review process is like.

Findings from the PMRT's latest annual report suggests there has been an improvement in parent engagement since the launch of engagement resources in 2019. The number of bereaved parents who were told about the review process improved from 75%⁷ to 90%⁸ between the 2019 and 2021; 84% of parents are reported as now being offered the opportunity to share their perspectives and any questions about their care, although 40% of parents in the PMRT's latest report said they had no questions.⁹

Nevertheless, despite improvements to parents' engagement with review, reported by Trusts and Health Boards via the PMRT, Sands continues to hear a range of experiences from recently bereaved parents. These narratives reach us via our forums, helpline and social media platforms. While some parents describe a positive experience, others report poor and insensitive communications from hospital staff, delays and explanations about their baby's death which still lack clarity and compassion.

Survey Findings

We invited parents to tell us about their experience of the hospital review into their care. Because we wanted to capture parents' experiences since the PMRT was rolled out we limited the survey to parents whose baby had died after 22 weeks' gestation from January 2019 onwards¹⁰.

The questions were based on key aspects of care, such as giving information, opportunities to ask questions and be heard, and the quality of communications and support throughout the process. We offered space for parents to share further thoughts in free-text responses, which were analysed by Joanne Dickens, Specialist Bereavement midwife and Doctoral Candidate at The University of Leicester. The thematic report is available [here](#).

The survey was open for five weeks in April to May 2021. It was promoted widely through Sands professional networks, Sands support groups, Sands devolved nation representatives, regular bulletins, and via Sands social media accounts. We asked key charity partners to share the survey within their own networks of Black, Asian and minority ethnic parents.

314 parents responded to the survey, of which we were able to use 278 responses. Most (62%) were the parent of a baby who had been stillborn; 22% were the parent of a baby who had died shortly after birth, and 16% were the parent of a baby who had died between 22-24 weeks' pregnancy. The vast majority (95%) of parents who responded were bereaved mothers. Most (86%) described themselves as White British; a proportion (5%) identified as White non-British. Around 1 in 10 responses were from parents from Black, Asian, mixed or minority ethnic backgrounds.

Being informed about the hospital review and being given the opportunity to ask questions

The PMRT Third Annual Report 2021 suggests that around 9 out of 10 parents are now told a hospital review of their care will happen. In our survey, 6 out of 10 of parents whose baby had died between 2019 and 2021, said they were told a review would take place. For some parents who did not know about the hospital review and missed the opportunity to ask questions, there was a long-term impact:



We were not told about a review. There were so many questions we had about our care leading up to our baby's death. I never got the chance to ask, and still think about what happened to this day. I wonder if I could have done something differently to prevent what happened. I do not know what was discussed or looked at during the review.

Mother of a baby who was stillborn, England, 2019

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Parents whose baby had died between 22 and 24 weeks' pregnancy were less likely to be told about review (44%) compared to parents of a stillborn baby or a baby who'd died after birth (66%).

Not enough support after we lost our baby. I didn't receive a check-up had to chase post mortem results, self refer for counselling. Just felt abandoned.

Mother whose baby died between 22 and 24 weeks' pregnancy, England, 2019

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1 in 5

parents did not entirely understand what a hospital review entailed

Parents living in England were more likely to be told a review was taking place (2 in 3 were told) compared to parents in Scotland, where half of parents who responded to our survey were told, and Wales or Northern Ireland, where only 1 in 3 parents were told a review was taking place.

For those 174 parents who were told about the hospital review, 1 in 5 did not entirely understand what it entailed:

I wish there had been an initial meeting to discuss what we wanted to be looked at in the review. Just having a letter saying get in touch if you have anything you want to say did not seem like a real opportunity as we weren't really sure what the process was so didn't make contact but face-to-face we would have raised our concerns.

Mother of a baby who was stillborn, Wales, 2020

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Or did not engage because they were in the midst of overwhelming events:

The hospital asked whether we had any questions, but at the time it was all so overwhelming. Then the report came back and I wish they would break the questions down for the parents to give us a guide as to what the report will cover. That would have allowed us a chance to ask questions more specifically. Instead we just didn't ask anything at all.

Mother of a baby who died between 22 and 24 weeks' pregnancy, England, 2020

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The majority of parents who were told about review were also offered the opportunity to put forward questions they wanted the review to address and to share their views and thoughts about their care. While the 2021 PMRT annual report suggests 6 out of 10 parents have questions, 8 in 10 parents in our survey raised issues they wanted the review to address.

When this offer of engagement was flexible and extended beyond even the end of the review process, this felt meaningful to parents:

The hospital was brilliant and we were given lots of opportunities to ask questions. Even now, almost five whole months on we feel we could call them to talk about things again.

Mother of baby who died after birth, England, 2020

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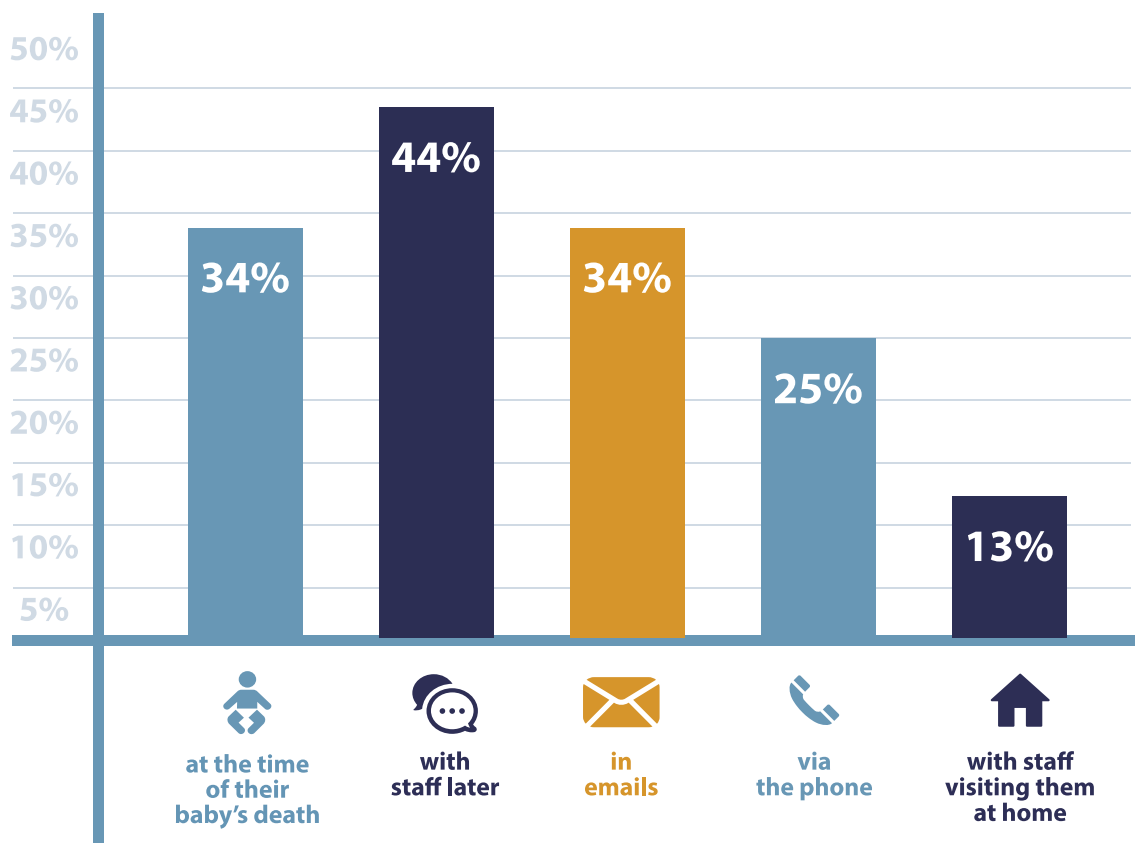
For the 32 parents in our survey who knew about the hospital review of their care but didn't get the opportunity to ask questions, all would have liked to have had this opportunity.

For 1 in 3 parents who were not told, or were not sure if they were told, whether a review would take place, the vast majority would like to have known more about the existence of hospital review, and had the opportunity to ask questions and share their views or concerns about their care.

Engaging with review and feeling informed

Parents who were able to ask questions and share their views or concerns about their care did this in several ways: with staff around the time when their baby died (34%) or with staff later (44%); in an email or series of emails (34%); over the phone (25%), or with staff in their homes (13%). Open-ended opportunities to ask questions were appreciated by parents.

Parents were able to ask questions in several ways:



Almost half of parents who were told about the review process said they were kept informed about the progress of the review and whether there were updates or delays:

The bereavement midwife was fantastic, she came to my home, made herself accessible and attended all meetings....I feel everything that could have been done for me and my son was done, I was kept fully informed throughout and cannot fault our hospital care at all.

Mother of a baby who died after birth, England, 2019

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The remaining 53% said they were only partially informed or not kept up to date at all, meaning in some cases that parents had to chase the hospital for information:

We were told the review process would take 12 weeks but we did not hear from the hospital and tried every week from the 12 week point to receive the information but did not hear anything until 8 months after.

Mother of a baby who was stillborn, England, 2019

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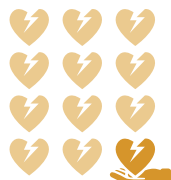
Learning about review findings and feeling listened to

The majority of parents who were told about the review process have received its findings. One in 6 parents had to wait between 4 and 6 months and 1 in 12 families waited more than 6 months.

Waiting times for review findings:



**3 in 12
parents
waited
4 months +**



**1 in 12
parents
waited
6 months +**

It took 9 months to have a review which is too long to wait when you want to start planning for more children.

Mother of a baby who died after birth, Scotland, 2020

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A proportion of parents responding to our survey were bereaved in late 2020 and early 2021 and given the timescale of the survey and the ongoing pandemic it may not be surprising that they have not had the results of the review, but 7 parents have waited more than 6 months and still not heard and 3 parents more than a year:

We had a post-mortem review, which we thought was the overall review. A quick 45 minute meeting which felt very rushed. In Jan 2020 my rainbow was born [a baby born to a family after the death of previous baby] I received a call from the director of midwifery to say my notes for the previous pregnancy were incomplete and therefore review was not complete. Review has now commenced, I was told it would be 12 weeks.

Mother of a baby who died after birth, England, 2019

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Parents who experienced long delays without being updated by hospital staff struggled get information:

Review process after my son passed away was very poor. I've had to chase it constantly and still not completed.

Mother of a baby who died after birth, Wales, 2020

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Parents appreciated being informed about the ongoing review and, knowing what to expect, improved the trust between them and those who had cared for them or were involved in the review.

I feel the bereavement midwife was key as she bridged the conversations between me and the hospital and ensured everything kept moving and I was updated throughout.

Mother of baby who died after birth, England, 2019

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Over 80% of parents had a meeting with a consultant to discuss the findings of the review into their care. Where parents commented on this meeting, their experiences were largely positive; where they weren't, issues were around lack of time, being given inaccurate information and feeling unsupported. Parents should receive a letter summarising the findings of the review clearly, but for 4 in 10 parents whose review was finalised this didn't happen, even in some cases when they were explicitly told it would:



never received a letter summarising the review and why their baby died

At the review the nurse said we will receive a letter about everything that has been mentioned that day, no letter was received.

Mother of a baby who was stillborn, England, 2020

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The clear, sensitive wording of these letters, summarising the review findings, were important to parents, and it was appreciated when healthcare professionals went the extra mile in communicating its contents:

The information I received was in the format of the PMRT report however it was brought to my house by my bereavement midwife and discussed sensitively, which I thought was better than just sending a letter. I had also met previously with my consultant and bereavement midwife and following further questions from myself my daughter's PMRT was re-opened.

Mother of baby who was stillborn, England, 2019

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For those parents who asked questions, half felt their questions were completely answered and half that only some of their questions were answered. This impacted their confidence in their care:

Didn't answer why I wasn't given additional support following two other pregnancy losses at various stages - it was acknowledged this should happen but nothing as to why it was missed. I don't feel confident falling pregnant again now.

Mother of a baby who was stillborn, England, 2019

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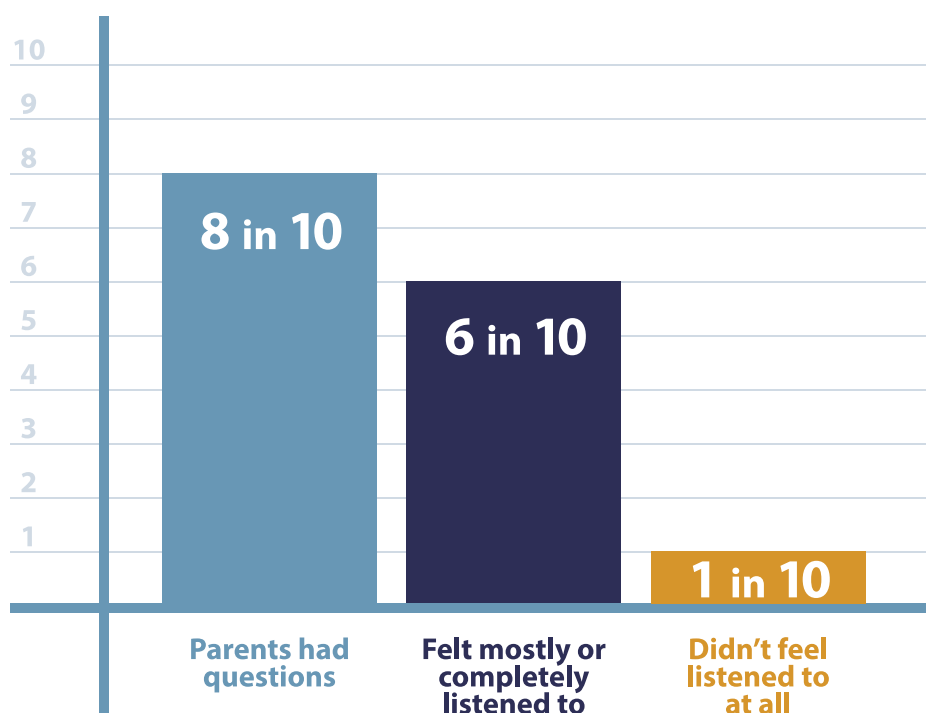
I had time to ask questions. In the meeting two months afterwards I wanted to discuss future pregnancy/prevention of another preterm birth too and was fully informed of future plans and have email contacts to get in touch with when this happens so they can put everything into place. This future reassurance really helped me.

Mum of a baby who died after birth, England, 2019

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Over half of parents (60%), who shared their views or thoughts about their or their baby's care, felt listened to but almost 1 in 3 felt only partially listened to and more than 1 in 10 not listened to at all.

Being listened to was strongly associated with parents' satisfaction with the review process:



Meeting was hurried and any questions dismissed

Mother of a baby who was stillborn, England, 2019

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Overall satisfaction with the review process

It was positive that the majority of parents - around 6 in 10 - who had received the findings of the review, said they were mostly or completely satisfied with the process. Being given the opportunity to ask questions and feeling listened to was strongly associated with parents' satisfaction.



parents said they were not or only quite satisfied with the review process



parents said they were mostly or completely satisfied with the review process

I feel like every care has been taken to ensure I have all the information needed about my baby. I still don't have an explanation as to why he was still born but have been assured that there will be more support available to me during a next pregnancy, if I'm lucky enough to have another baby.

Mother of a baby who was stillborn, Scotland, 2021

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Unresolved issues though remained for those parents who had experienced poor communication with the hospital such as delays, and inaccurate or lack of information.

In a letter describing the events chronologically it stated “you gave birth to a live baby boy” which I obviously did not. This was very upsetting.

Mother of a baby who was stillborn, Wales, 2020

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Very occasionally, this also resulted in an apparent break down in the relationship between parents and those involved in their care and/or a distrust in the objectivity of an internal hospital review.

These reviews MUST be independent moving forward. Allowing those directly involved or the same dept to 'investigate themselves' is an utter disgrace. Bereaved parents must have an impartial investigation in order to ensure they are getting the truth.

Mother of baby who died after birth, England, 2020

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I feel like it's all a ticking a box process and they don't realise the pain and tragedy that has actually occurred.

Mother of baby who was stillborn, England, 2021

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Conclusions and recommendations

While some parents in our survey have experienced clear, sensitive and timely communications around hospital review into their care, not all parents are either told that there will be a hospital review to understand why their baby died, or given an opportunity to share their questions or concerns about what happened in their care. The variation in parents' experiences, regardless of when or where the death occurred, is stark:

..was not kept informed as to when the review would take place or given details of the outcome.

Mother of baby who died after birth, England, 2020

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The bereavement midwife was fantastic, she came to my home, made herself accessible and attended all meetings.

Mother of baby who died after birth, England, 2019

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Parents who are not engaged in review, or who are given inaccurate information and have to chase hospitals for updates on the review's progress, are more likely to be left with unresolved issues and feelings of abandonment and distrust, not just in hospital staff but in the whole process itself. When the language staff used lacked compassion, it made everything worse:

The review actually caused myself huge anxiety and upset, I didn't want my baby's name brought up again in clinical circumstances as I wanted to remember her with love and not as a 'case review' or 'statistic'.

Mother of baby who died after birth, England, 2020

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Sands' survey has highlighted that despite a pathway and resources outlining meaningful parent engagement, it is not being universally delivered in the UK. Where it does work, the effort made to put families at the heart of review has the power to mitigate future harm to those parents still asking themselves years on exactly why their baby died. It can be summed up by this single comment from a mother whose baby was stillborn in 2019:

The review made us feel people cared and it wasn't just one of those things.

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There is no doubt, however, that timely, parent-centred, clear and sensitive parent engagement, as outlined by the PMRT and Sands, takes more time and resource for Trusts and Health Boards, where historically few parents were properly engaged at all in the review of their baby's death. Meaningful engagement for all families will require funding and staff training and will need to be monitored to ensure it genuinely is reaching all parents, equally.

Summary of survey conclusions

- All parents must be told a hospital review into their care is taking place and offered the opportunity to ask questions and share their views.
- Review panels must listen carefully to concerns expressed by parents and make every effort to respond to every question.
- Parents must be kept fully informed about the review process and updated on its progress and any delays.
- Communication with parents must be compassionate, sensitive, and accurate.
- Reviews must be flexible in the timing of parents' engagement, allowing parents to input when they are ready and feel able to. This may include enabling parents to engage after the review closes.
- Review panels should include a member who is independent of the Trust or Health Board, to improve parents' confidence in the process.

These conclusions are echoed in Sands' 6 Principles of Parent Engagement in Review.



Timely



Informed



Parent-centred



**Easy to access
and flexible**



**Compassionate
and gentle**



**Open and
honest**

Recommendations

To ensure the good parent engagement that families should have with the review of their baby's death, the following actions are needed:

Governments and the NHS

- Parent engagement in review should be mandatory for all local hospital review processes across the UK and should follow good practice as laid out in the PMRT Parent Engagement Pathway and Sands 6 Principles of Parent Engagement.
- Quality of parent engagement in review should be monitored and evaluated for all baby deaths, and improvement reviewed at Trust/Health Board governance level and by external inspections.
- There must be ring-fenced funding to secure staff time to support parents throughout the review and to release staff to participate in hospital reviews and in training.
- There must be additional funding to support the presence of an independent reviewer at every review meeting.

PMRT collaboration, maternity and neonatal professional bodies

- Evidence and best practice must be brought together to establish what constitutes truly independent 'external' review.

Sands actions

In the meantime, Sands continues to be committed to improving the experience of all parents in the hospital review of their care, as well as supporting healthcare professionals in delivering meaningful engagement, in the following ways:

- Sands is delivering 90-minute online training webinars in Parent Engagement in the PMRT and Sands 6 Principles of Parent Engagement, currently free until April 2022. We urge Trusts and Health Boards to take advantage of this opportunity. For more information go to: www.sands.org.uk/professionals/sands-training-and-education.
- Sands continues to support research around understanding what constitutes the best pathway to support all parents in engaging with the review of their baby's death. Further resources must be developed in co-production with parents, researchers and health professionals to ensure that all parents have an equal opportunity to engage in review no matter who they are, where they live, or the nature of their loss.

- As mortality reviews have improved in recent years with jurisdiction changing for some countries (all stillbirths are now referred to the coroner in Northern Ireland) and new systems for others (Healthcare Safety Investigation Branch – HSIB - in England now investigates a proportion of deaths), parents are at risk of being stranded in the middle of different review processes. We are working with bereaved parents, researchers and national bodies to improve information for parents around what these processes mean for them.
- To keep up to date with our work in this area go to: www.sands.org.uk/engagingparentsinreview where we will continue to develop materials to support healthcare professionals. These include an animation, podcasts and support tools for promoting an understanding of the value of parent engagement.

¹ MBRRACE-UK Perinatal Confidential Enquiries, 2015, 2017 and 2021. Available at: www.npeu.ox.ac.uk/mbrance-uk/reports/perinatal-mortality-and-morbidity-confidential-enquiries

² Each Baby Counts, 2015 report. Available at: <https://www.rcog.org.uk/en/guidelines-research-services/audit-quality-improvement/each-baby-counts/ebc-2015-report/>

³ Kirkup B. The Report of the Morecambe Bay Investigation. London: The Stationery Office; 2015. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/408480/47487_MBI_Accessible_v0.1.pdf

⁴ Ockenden Report: Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943011/Independent_review_of_maternity_services_at_Shrewsbury_and_Telford_Hospital_NHS_Trust.pdf

⁵ PARENTS study, University of Bristol Policy Statement. Available at: <https://www.nbt.nhs.uk/sites/default/files/attachments/Parents%20Study%20Policy%20Briefing%20Report.pdf>

⁶ Parent Engagement Materials. Available at: <https://www.npeu.ox.ac.uk/pmrt/parent-engagement-materials>

⁷ Learning from Standardised Reviews When Babies Die National Perinatal Mortality Review Tool First Annual Report 2019. Available at: www.npeu.ox.ac.uk/pmrt/reports

⁸ Learning from Standardised Reviews When Babies Die National Perinatal Mortality Review Tool Third Annual Report 2021. Available at: www.npeu.ox.ac.uk/pmrt/reports

⁹ Learning from Standardised Reviews When Babies Die National Perinatal Mortality Review Tool Second Annual Report 2020. Available at: www.npeu.ox.ac.uk/pmrt/reports

¹⁰ The PMRT is generally not used for babies born before 22 weeks

