



Sands

Stillbirth & neonatal death charity

**The role of parents in
reviews**

December 2018

The role of parents in reviews

- Why involve parents in reviews?
- What do parents want from reviews?
- Are parents involved in reviews currently?
- How can we include parents in reviews now and in the future?



Why involve parents in reviews?

For professionals - learning from review

- Parents are the only people 'there all the time' – they have a 360 degree view of care because they are at the centre of it
- Parents' perspectives may add to the clinical picture by providing details that aren't in the notes
- Their perspective could therefore drive improvements in care

For parents - making sense of what happened

- It's vital for parents to understand what happened
- If there's learning from a review, then 'good' will come out of a devastating event – so that another life might be saved
- Learning from a review may impact their own future pregnancies

Why involve parents in reviews?

Involving parents is also part of good bereavement care

Parents have the greatest stake in understanding what happened. It's their baby...and understanding what happened may impact their grieving and the narrative they share with family and friends for the rest of their lives



What parents tell us they want from reviews

Was something wrong with my baby?

What happened?

"...want desperately to know what happened, even when the truth is difficult. After all we've already experienced the worst"

Will care be improved?

"We want to know that things will be better for the next parents whose labour and birth are like ours"

It's a chance to ask questions



Are parents involved in reviews currently?

Each Baby Counts

Parents invited to be involved in 41% of Reviews (2018 Progress Report)



MBRRACE-UK

Perinatal Confidential Enquiries into term perinatal deaths, published in 2015 and 2016 found parents rarely invited to contribute to reviews









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Only 1 in 3 parents we surveyed were asked if they want to contribute to the review of their baby's death; of those who weren't asked, 66% would like to have been involved



Current reviews/investigations in UK

	Perinatal Mortality Review Tool (PMRT)	Healthcare Safety Investigation Branch (HSIB) Maternity Investigations	NHS Serious Incident Investigation (SII)	Child Death Overview Panel (CDOP)	Coroner or Procurator Fiscal (PF)	Each Baby Counts (EBC)
						
Which baby deaths does this review or investigation apply to?	All baby deaths before or after birth, from 22 weeks' gestation up to a year of life	Babies who die as a result of problems occurring during labour and birth at term ⁱ (ie after 37 weeks of pregnancy)	Death or harm to a baby where it is immediately thought something may have gone wrong with NHS care, that has caused the baby serious harm or death	All babies who are born alive and subsequently die, as well as children up to 18 years old	All stillbirths and deaths in Northern Ireland. Deaths of babies born alive only in the rest of the UK – but this may change in the near future (see below)	Babies who die or are harmed as a result of problems occurring during labour at the end of pregnancy (term ⁱ ie after 37 weeks gestation)
Review or Investigation?	Review	Investigation	Investigation	Investigation	May lead to an investigation	Looks at both
Are individual babies identified?	Yes	Yes	Yes	No	Yes	No
Which organisation is developing this review/investigation?	The PMRT collaborative run by MBRRACE-UK, and	HSIB - the maternity investigations will be run as a special	The Trust or Health Board where the baby was born	CDOPs sit within the Department of Health in England	Coroner's or PF's office which sits within the Department of Justice	Royal College of Obstetrics and Gynaecology (RCOG).

Parental engagement varies

Review / investigation	Parental involvement
Perinatal Mortality Review Tool (NEW 2018) – UK wide	Parents informed; offered opportunity to be engaged in review and informed of outcome
Health Safety Investigation Branch (NEW 2018) – England only	Parents invited to contribute; kept informed
NHS serious incident investigation – UK wide but may have different names	Parents should be told investigation is happening, offered opportunity to be involved and be given results – practice currently varies
Child Death Overview Panel – (guidance being updated) England only	Parents informed but due to anonymity they are not involved or given individual feedback
Coroner/Procurator Fiscal – UK wide	Parents may be invited to give evidence

What do we need now?

- There are clear benefits to involving parents in reviews and investigations
- The majority of parents would like to be involved in reviews
- There are a range of reviews that parents could be involved in

However

- Parents are not involved in reviews currently



What's needed now:

A shared understanding of how to engage parents in reviews, that's meaningful and sensitive and that works for both parents and professionals

Being open when things go wrong

- **MBRRACE-UK confidential enquiries** found 60% of antepartum term deaths and 80% of intrapartum-related perinatal deaths at term 'might have been prevented' with better care
- The vast majority of parents involved in these historic cases, are unlikely to have been told this
- Being open presents a new challenge

What's needed now?

A shared understanding of how to communicate to parents when things go wrong in the NHS and to answer their support needs



How to include parents: current work

Taking learning from:

- The PARENTS Study, Bristol
<http://bristol.ac.uk/policybristol/policy-briefings/engaging-parents-baby-loss/>
- Health Improvement Scotland, Being Open Pilot
- Perinatal Mortality Review Tool (PMRT) currently developing a pathway for engagement with evidence and learning from both these studies
<https://www.npeu.ox.ac.uk/pmrt/information-for-bereaved-parents> Sands is a collaborator on the PMRT and providing information to support parental engagement in review



Parental engagement process

Week 1

Bereavement midwife/nurse/key review contact informs parents about review before hospital discharge with written information to support; explains they will receive further information in the post

Week 2

Letter sent to parents about review process with written information as a trigger for parents to think about any questions and views they may want to share about their care; follow up call to ask if and how parents would like to give their questions and views about their care. Choices include: a face-to-face meeting with bereavement midwife/nurse/key review contact at home, or feedback via phone, email or post



Follow up letter and information

Letter reminds parents of the review process and offers them the opportunity to give their perspective or ask questions about any aspect of their care:

- from antenatal care, through care in delivery to bereavement care
- the good and the bad

Sands has created a template letter available here:

www.sands.org.uk/professionals/professional-resources/engagement-letters-parents-pmrt





Parental engagement process

Week
3 to 4

Parents feed back their questions and views about any aspect of their care in the way they wish

Weeks
4 to 12

Review takes place with parents' views fed into review panel by a parent advocate: the bereavement midwife/nurse/key review contact. Appointment made for follow-up consultant meeting and parents informed either by letter, phone, or email, depending on parents' preference

Weeks
12 to 16

Plain English summary of review explained in follow-up consultant appointment and communicated prior to meeting via email, phone call or letter if parents wish

Parents signposted to bereavement support when appropriate throughout the process

Principles of parental engagement process

Parents should have a say in:

How they would like to feedback their perspective of care or any questions they have: via a letter, email, or in a telephone call or face-to-face meeting with their key review contact and where the location of that meeting might be

When they would like to feedback - now or later, ensuring parents understand the review has a timeframe

What they would like to feedback on

Who they'd like to communicate their views in the perinatal mortality meeting

Some of the key learning points from Bristol

- For parents, a point of contact and ongoing support was essential through review process (bereavement midwife or nurse)
- Parents prefer to talk through experience and questions with midwife first rather than complete the feedback form alone
- Parental engagement helps to focus the perinatal mortality review meeting and adds clinical information where it's missing from the notes
- Feedback from parents on care is often positive and all aspects of care are commented on
- Trusts should consider the additional impact parental feedback could have on staff, and support should be considered
- The process required additional resource




Parental engagement and PMRT


Currently the tool triggers a question about parental engagement to ensure it's taking place. If parents have not been informed and invited to give their views then the tool will generate 'an issue' to be addressed by the service:

Parents' perspectives of their care

Have the parents been told that a review of their care and the care of their baby is taking place?

Please select an item 

Have the parents' perspectives and/or concerns about their care and the care of their baby been sought?

Please select an item 

Final word from parents about being involved in a review of their baby's death

"I think the lasting benefit is that I don't think about it any more"

"It helped us move on"

"Being involved in the process has been an invaluable experience for people in our devastating position"



#15babiesaday

15 too many

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- Text **BABY15 £10 to 70070** to donate

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