



Knowledge, understanding and  
learning to improve young lives

## **Engaging and communicating with parents in child death review**

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Charlotte Bevan, Joint Head Saving Babies' Lives Team, Sands

**Thursday 23<sup>rd</sup> June 2022**

10am to 11.30am

\*\*Presentation will start at 10.05am to allow participants time to join\*\*

[www.ncmd.info](http://www.ncmd.info)

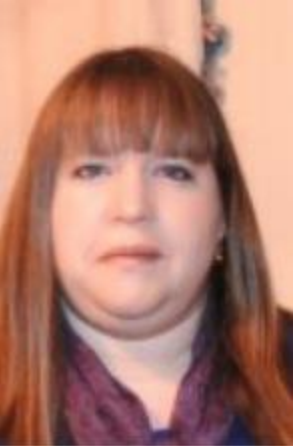
[@NCMD\\_England](https://twitter.com/NCMD_England)



# Who's presenting today



Charlotte Bevan – Joint Head, Saving Babies' Lives, Sands,  
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# Background and context

- ▶ This presentation has been adapted from a regular Sands training webinar that focuses on perinatal deaths, however many of the principles discussed are relevant to engaging with parents whose child dies at any age

# @SandsUK mission



To support anyone affected by the death of a baby.



To work in partnership with healthcare professionals to ensure that bereaved parents and families receive the best possible care.



To promote improvements in practice and support research to help reduce the number of babies dying.

# Covering in today's session



What is a Child Death Review Meeting (CDRM)



Why review is important?



Why meaningful communication with parents about their care and the review process is key



Parents' voices – are we getting it right?

# Polls

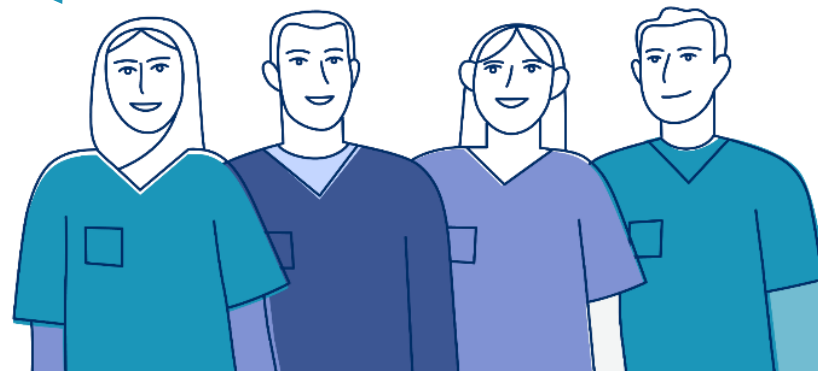
## barriers/facilitators and reflections

*Parents are dealing with a lot including post mortem. This is just one more thing*

*It will just take up a lot of time which we don't have*

*I can't answer parents' questions*

Make a note by writing down the thing you fear most in approaching parents about the review of their child's death. Does not have to be for sharing. We will return to it later



# Child Death Review Meeting (CDRM)

- ▶ The CDRM is a multi-professional meeting where all matters relating to an individual child's death are discussed by the professionals directly involved in the care of that child during life and their investigation after death.
- ▶ The nature of this meeting will vary according to the circumstances of the child's death and the practitioners involved. For example, it could take the form of a final case discussion; a perinatal mortality review group meeting or a hospital-based mortality meeting
- ▶ For the purposes of this session we will refer to the CDRM as “the review”

# Purpose of any review

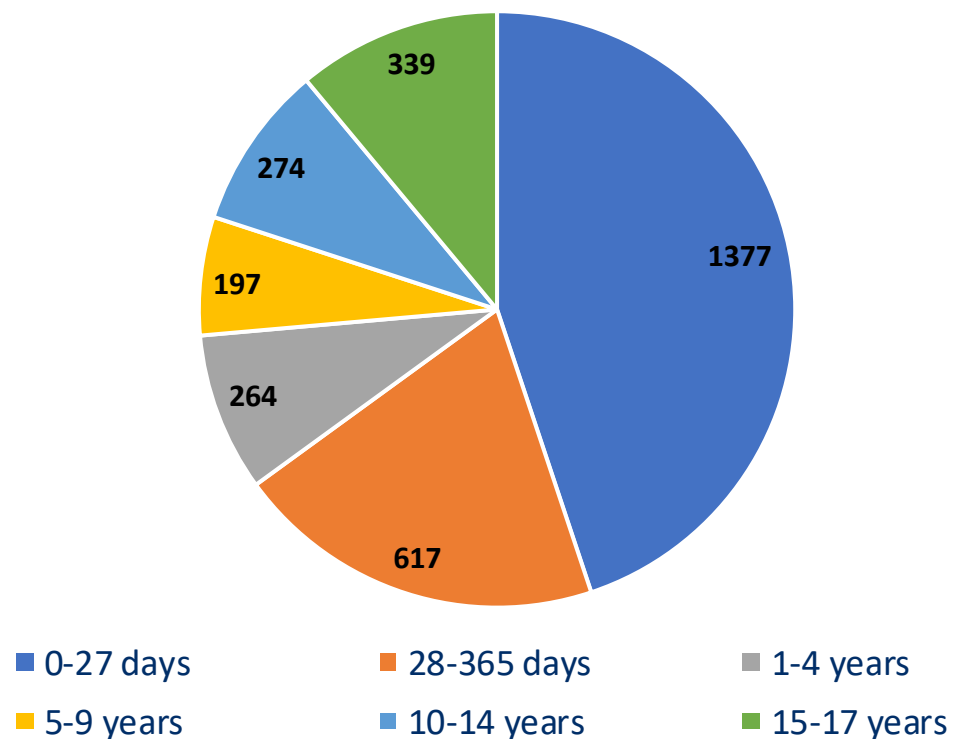
- **For parents:** to give parents as much information as possible about why their baby or child died so they can make sense of what happened
- **For services and systems:** to identify improvements in care for other families and save future children's lives





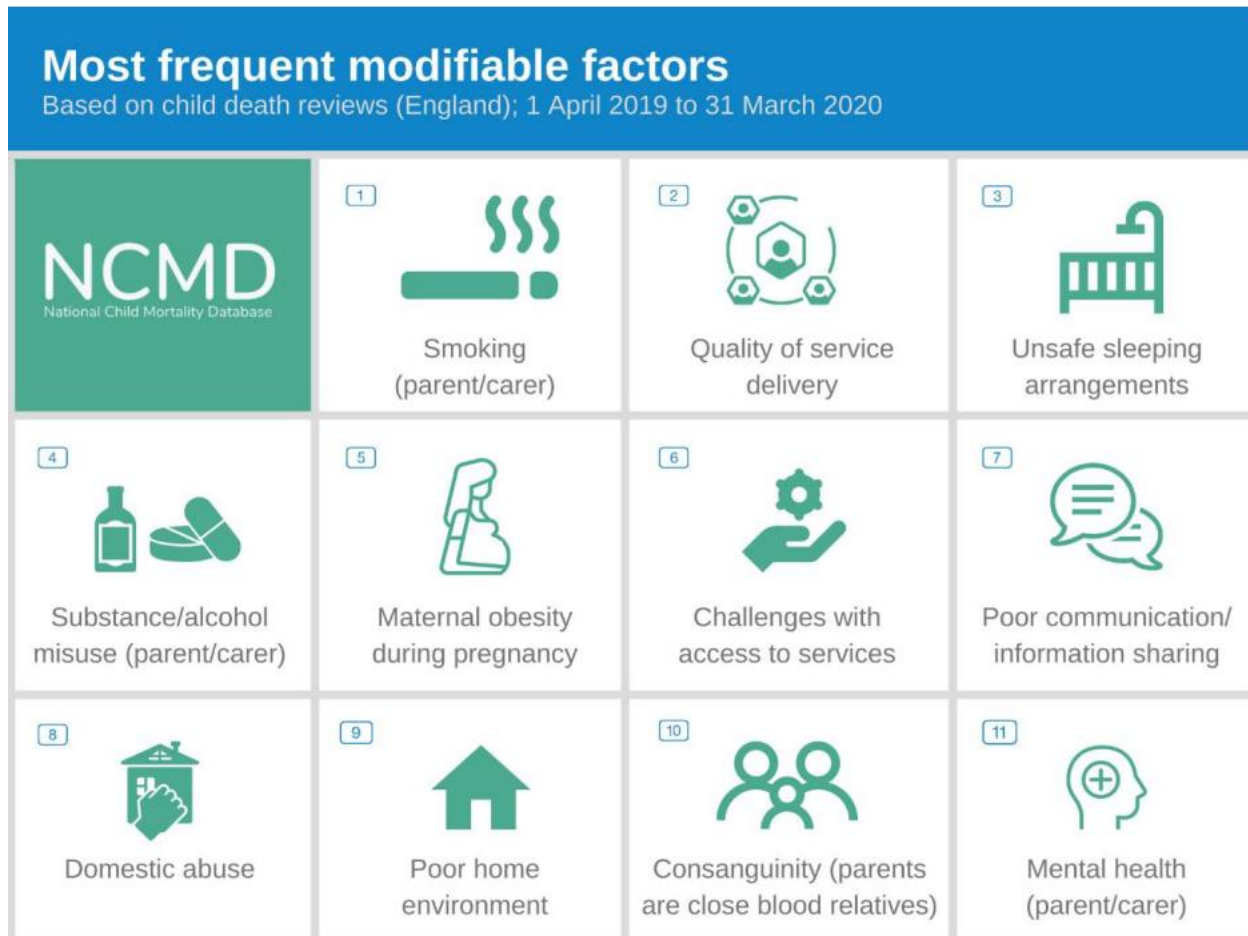
# Behind each number is a family, 2020/21

Deaths notified to NCMD between 1.04.20 and 31.03.21



- 3,068 children died
- 1,994 were under 1 year old
- Over 6,000 parents affected each year

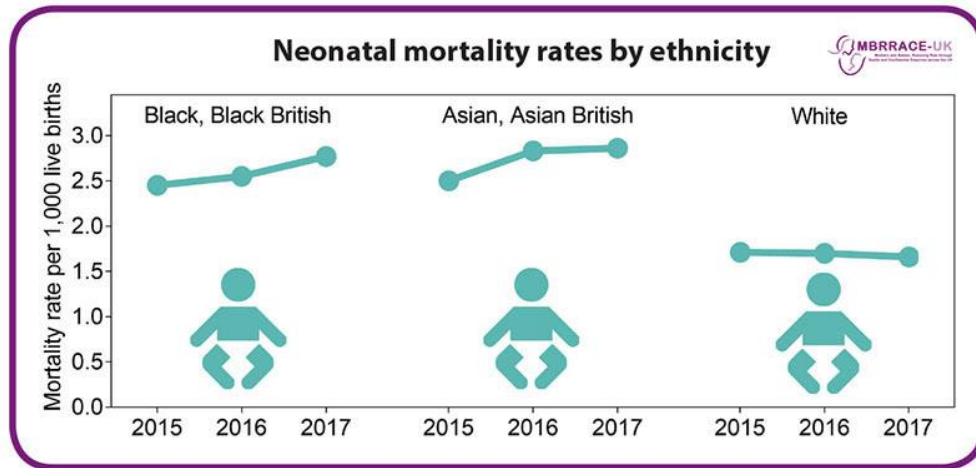
# What can we learn from NCMD about modifiable factors



- Around two thirds of child deaths occur under age of one
- Around 30% of all child deaths nationally have modifiable factors recorded by CDOPs

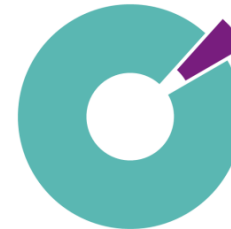
# What can we learn from MBRRACE-UK potentially 'avoidable' neonatal deaths every year

## Neonatal mortality rates remain high for babies of Black and Asian ethnicity

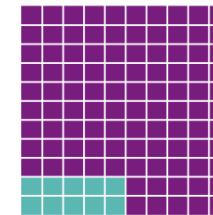


## When babies die at term as a result of something that happened during labour

1 in 20 stillbirths and deaths of babies within 4 weeks of birth is labour-related



In 80% of cases different care might have prevented the baby's death



In 1 in 4 deaths there were problems with adequate staffing and resources



[www.npeu.ox.ac.uk/mbrance-uk/reports](http://www.npeu.ox.ac.uk/mbrance-uk/reports)

# Poll One

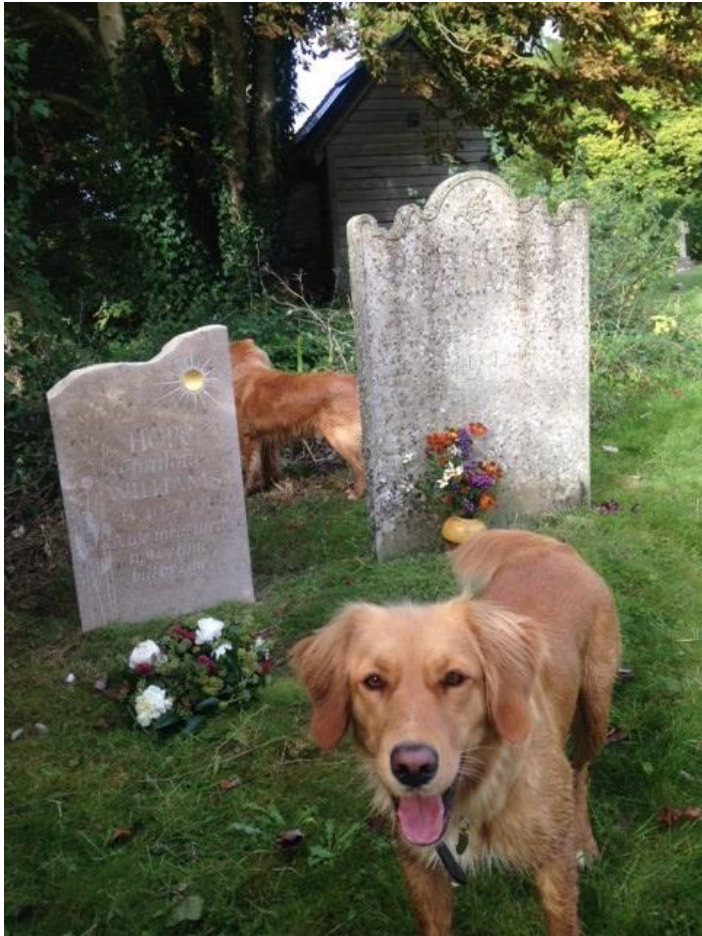
**Please mark the main barriers you face to engaging and communicating effectively with parents about the child death review process? (tick all that apply)**

- Lack of staff resource
- Lack of regular training to have confidence in engaging with parents
- Lack of time
- Concerns about what you can/can't say when investigation underway and there may be litigation
- Reaching parents who do not respond to communication attempts

**Which of the ones you marked do you think is the biggest barrier for you?**



# Hope Charlotte Williams 11th October 2001



# Why engage parents in the review?

Improves the quality and aim of review

- Parents are often at the centre of care – particularly if their child died as a newborn or had a complex or life-limiting condition, so parents' perspectives may add to the clinical narrative
- Research shows that parental engagement may focus the review meeting and promote an open, learning culture (PARENTS study Bristol\*) because it's as if the parent is 'in the room'

\*PARENTS study in Bristol

<https://www.bristol.ac.uk/policybristol/policy-briefings/engaging-parents-baby-loss/>

# Engaging parents: review is the narrative of their child's short life



- Guilt – ‘was it my fault?’
- Distrust – ‘was it someone else’s fault?’
- In case of newborn, planning future family
- Something good out of something bad
- Prevent long-term psychosocial harm to parents from not knowing



# The magnified moment

- Shock and disbelief
- Information about post mortem
- Information about tissue and organ donation
- Lactation for parents of neonates
- Physical postnatal recovery



- Precious moments to create memories
- Letting family, friends and work know
- Funeral arrangements
- Hospital parking
- Other children





# Role of the key worker

**First few days:** Face-to-face discussion with parents about the review should be with a senior member of staff, and NOT a junior staff member

**Week 2-3:** If parents cannot be reached after 3 phone/email attempts, sensitive template letters can be used to inform parents of the review process and inviting them to be in touch with key worker, if they wish. For neonatal deaths, template letters are available through the [PMRT website](#).

**Weeks 3-12:** Gain questions and perspectives on care from the parents by their preferred method (e.g. face to face, email etc) for discussion at CDRM

**After the review meeting:** Contact parents as soon as possible to arrange a time to meet with them to give feedback from the meeting and ensure their questions / concerns are addressed.

# Language can act as barrier or facilitator

The language you use will be remembered - possibly forever. It needs to be clear and compassionate.

- Provide face-to-face information and written information explaining the review's purpose, timescale etc.
- Be clear about what you mean by engagement – it's about whether parents have questions/concerns about the care of their baby/child?
- Keeping in touch/issue with delays [PMRT website](#) has template letters

# Top tips to involve parents in the review

<b>Tell</b>	the family, as soon as possible after the death, that a review will happen
<b>Ensure</b>	it is a senior person that talks to them about this
<b>Think</b>	about what additional support they might need to give their views
<b>Remember</b>	that, when this conversation happens, it may be some time since the death and the family might not be expecting to be asked about their thoughts so far after the event

# Top tips to involve parents in the review

<b>Give</b>	the family at least a week to think about and compile any questions and comments that they would like answered and support them to do this
<b>Decide</b>	at the review who will provide feedback to the family after the meeting. This should take place as soon as reasonably possible after the review.
<b>Ensure</b>	the right people are available to answer their questions at the feedback meeting. This might mean more than one professional needs to be at the feedback meeting
<b>NCMD</b>	has issued guidance on this which can be found on the website <a href="#">here</a>

# Sands 'Saying Sorry' is not a blame game..'

## Sands statement:

Parents consistently tell us that what they value hearing from a friend, a family member or health professional is the word 'sorry':

*I am sorry to hear about your baby*

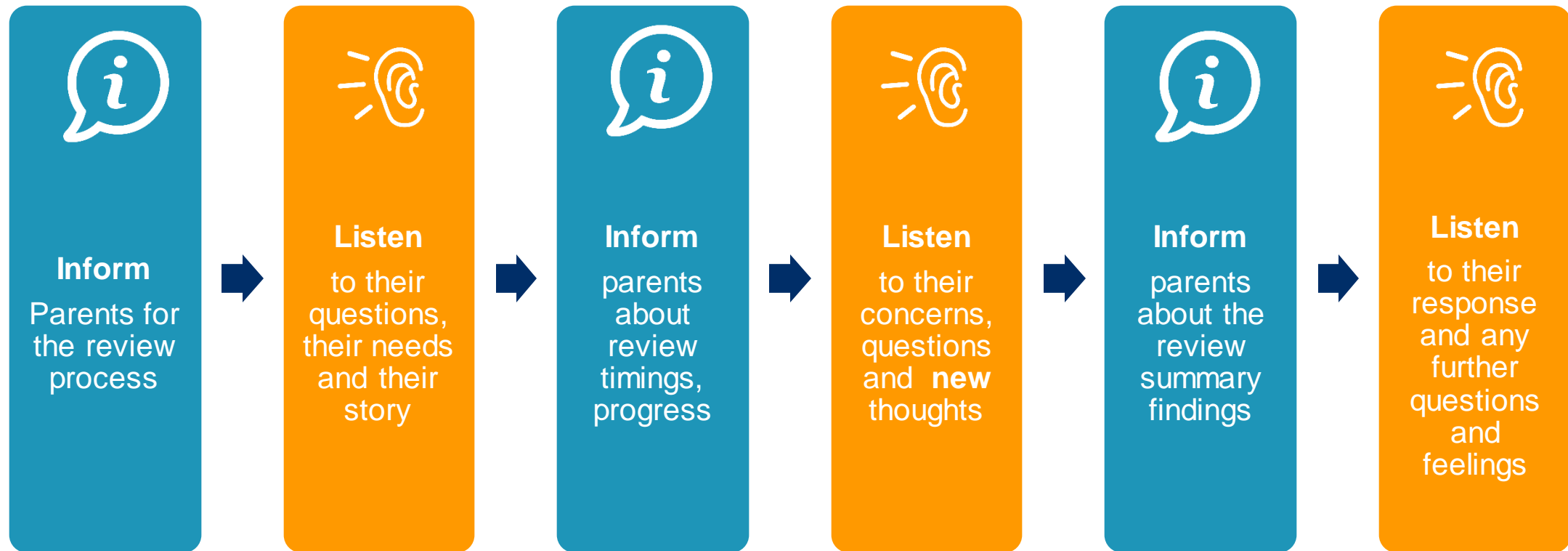
*I am sorry your baby has died*

## GMC and NMC guidance:

*Apologising to a patient does not mean that you are admitting legal liability for what has happened. This is set out in legislation in parts of the UK and the NHS Litigation Authority also advises that saying sorry is the right thing to do.*

...it is simply an expression of human empathy and compassion at a devastating time in a parent's life

# Parent engagement in review is a process of continually LISTENING and INFORMING



# Poll Two

**What extra resources would you need to more effectively engage with parents?**

- Staff to take lead on this role
- Greater time in delivering this role
- Training in what this looks like
- Better resources – tools, templates for communicating



# Poll Three

**Do you feel supported in parent engagement by your organisation?**

- Yes
- No
- Only partially



## Parents' voices

Has their understanding and experience of review improved?

Home made 'flags' by bereaved families

Joseph Little's photograph next to his living brother

# Hearing parents' voices

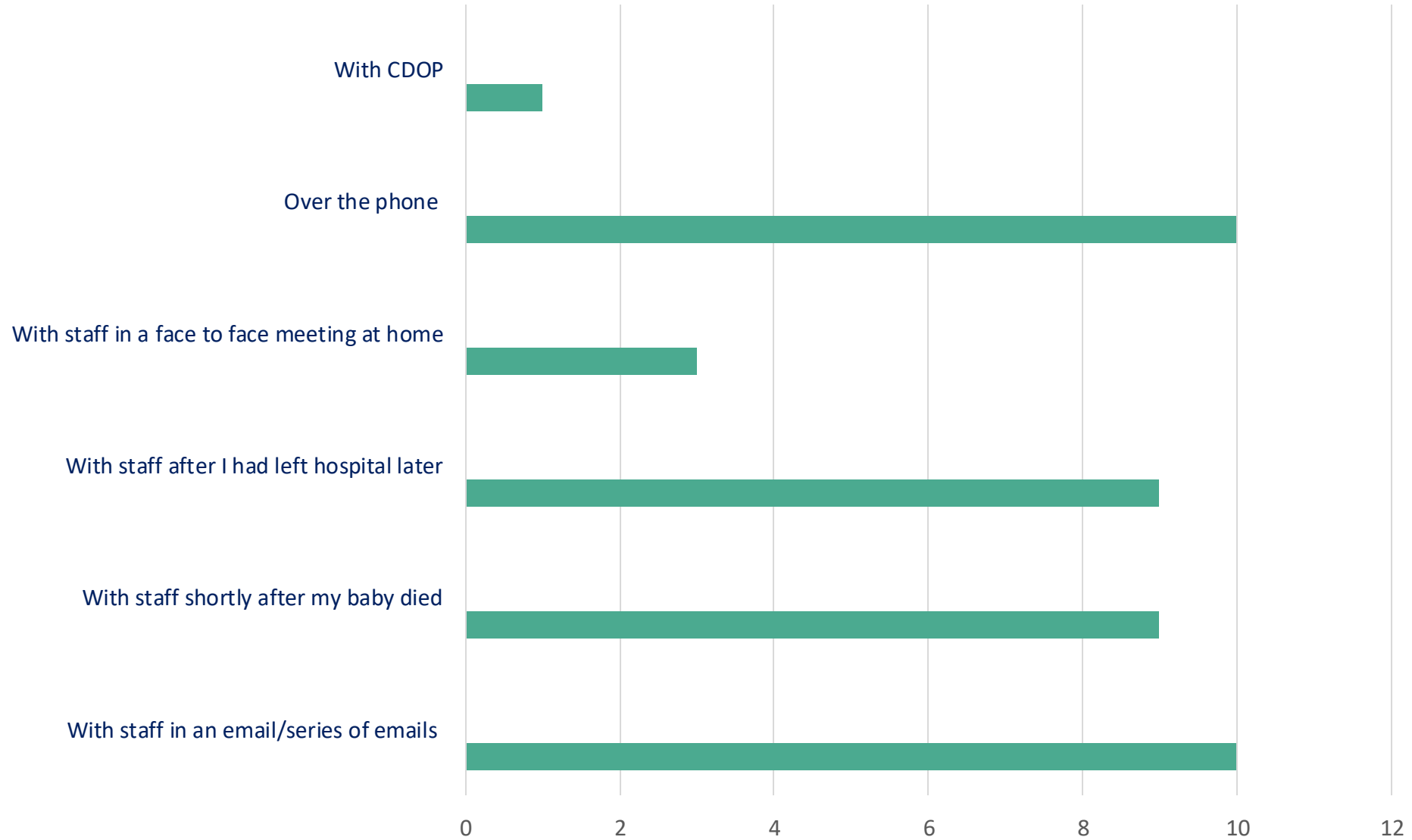
- [OASIS Study](#): Bereaved families interviewed about the events and asked to rate their satisfaction with the nature and quality of investigations and outcomes
- [In their Own Words](#), Sands survey of parents' experiences of review after their baby was stillborn or died as neonate, 2019-2021
- [PARENTS Study](#), Parents' Active Role and Engagement in Their Stillbirth / perinatal death review, 2018

# Parents' experience

- Sand survey shows that only around 68% of parents were told a review was happening and not all of those fully understood what the review was or its purpose
- 1 in 3 were not told, or were not sure if they were told there would be a review
- 1 in 5 said they only partially understood or didn't understand at all the purpose of the review
- While those who were told about review were mostly given an opportunity to share their views and ask questions, all of those who weren't would like to have had this opportunity.

Options for engaging with the review process – feeding back own perspectives of what happened, asking questions for panel to address

How did you ask questions for the review to answer and share your views or thoughts about your or your baby's care?  
Tick all that apply,  
28 responses



## In their own words

The junior doctor in A &E said that (mother)'s diabetes was the reason (baby)'s sugar was high – we found this very upsetting and blamed ourselves but did not find out it was not true for several months



## In their own words

*The review was held behind closed doors I was not invited to be involved or given the opportunity to express my views or tell mine or my daughter's story. My husband was barely acknowledged. We were simply invited to a reading of the review none of our questions have been answered to this day.*



## In their own words

*Fully satisfied with the summary of care. The only issue we had at the very end was that we never got to hold our baby until he died in our arms after 18 days. We told the Consultant about this and they have since put measures in place to ensure that parents can hold their babies as soon as possible. Covid also prevented any other family members meeting our son which was difficult, but we were able to take videos of him in the incubator to send to our family and friends.*



## In their own words

*It was sensitivity worded, it explained everything to me in terms I could understand but also included all the official documentation that went alongside this. We had an initial letter with a summary of care in a separate envelope inside, so we knew we could open it when we felt ready. The hospital were amazing and incredibly supportive.*

*The hospital were 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.*

# Sands 6 Principles of Parent Engagement



Timely



Informed



Parent-centred



Easy to access and flexible



Compassionate and gentle



Open and honest

# Being Open when things go wrong

- Good communication may reduce escalation/complaints
- Further research in this area:

DISCERN Study: [www.discernstudy.org](http://www.discernstudy.org) 2022

*"No follow up or update on changes they claimed they would make.. They refused to acknowledge their mistakes killed my son"*



# Poll Four

**Coming to the end of today's webinar, what are your thoughts about the personal barrier you identified at the beginning to engaging parents, tick all that apply**

- Feel more motivated to get it right
- Feel I have some more tools to get it right
- Feel I need to explore further training to meaningful engagement with colleagues
- No more informed than I was when webinar began

# Supporting you in engaging parents



## Resources:

meaningful engagement takes training and time



## Impact on staff:

Trusts should consider the additional impact parental engagement could have on staff, and support needs to be considered



## Sands helpline:

0808 164 3332 [helpline@sands.org.uk](mailto:helpline@sands.org.uk)

*Remember to take  
care of yourself.  
You can't pour from  
an empty cup*

# Further Resources

- [For professionals](#) pages on the NCMD website gives information on supporting families, participating in a CDRM and help with implementing the CDR guidance
- [How to hold an effective CDRM](#) guidance
- [For families](#) pages on the NCMD website gives information on NCMD, the CDR process and FAQa
- Sands [support for healthcare professionals around review](#)
- Sands [support for parents around review](#)
- [Sands training microsite](#) – Bereavement care and parent engagement in review
- [National Bereavement Care Pathway](#)
- [National Bereavement Care Pathway Online Learning Module](#)
- [Online training module](#) for obtaining perinatal post-mortem consent
- [When a child dies: Learning from the experiences of bereaved families and carers](#)
- SUDC UK explain the process of tissue sample collection, and provide advice to parents on making decisions, in [this video](#).





Thank you