NHS
North East and
North Cumbria

Family experiences of the Child Death Review in the North East and North Cumbria

Involvement findings report

July 2026

The Involvement Team

Better health
and wellbeing for all...

Contents

Plain English summary

Why this work was done

When a child dies, a Child Death Review (CDR) takes place. The review looks at what happened, whether anything could be learned, and how care can be improved for children and families in the future.

Parents should be told about the review and given the chance to ask questions or share information. However, families do not always experience the process in the same way. This project explored what the Child Death Review process was like for bereaved parents in North East and North Cumbria.

How we listened

Five parents whose child's death had already been reviewed shared their experiences.

Parents chose how they wanted to take part. They could complete a survey, provide written feedback or speak to us in a one-to-one conversation.

Taking part was voluntary and parents could stop at any time.

What parents told us

Parents said that emotional support after their child's death was very important. Many valued support from hospital staff, charities and counsellors. However, some felt support reduced too quickly, even though they were still grieving.

Parents also said practical help mattered. This included help with appointments, paperwork, funeral arrangements and understanding what would happen next. Without this support, families often felt overwhelmed.

Communication about the Child Death Review was not always clear. Some parents did not know that a review was taking place. Others found it difficult to understand how the review fitted alongside other meetings and investigations. Parents wanted clear information, regular updates and opportunities to ask questions.

Parents also told us that having one named person to contact would make the process easier. They wanted someone who could explain what was happening, provide updates and help coordinate support, so they did not have to repeat their story to different professionals.

One family described a positive experience of being involved in the review and valued seeing that learning had led to changes in practice. This helped reassure them that their child's death had contributed to improving care for other families.

What this means

Overall, parents wanted the Child Death Review process to be clear, compassionate and well-coordinated. They wanted to feel informed, listened to and supported throughout the process, and to understand how learning from their child's death was being used to improve care for other children and families.

Executive summary

Background

This report presents the findings of an involvement project exploring bereaved parents' experiences of the Child Death Review (CDR) process across North East and North Cumbria.

The Child Death Review is a statutory process that takes place following the death of a child to understand what happened, identify learning and improve care for children and families in the future. National guidance states that parents should be kept informed, given opportunities to share questions or concerns, and receive appropriate feedback about the review. However, evidence suggests that families' experiences of the process are not always consistent.

This project was undertaken to understand parents' experiences of the CDR process locally and identify opportunities to strengthen communication, support and family involvement.

Involvement methodology

Bereaved parents whose child's death had already been reviewed through the CDR process were invited to share their experiences. Families involved in an active review were not approached.

Five parents participated in the project. Two completed a survey and three took part in one-to-one interviews. Parents could choose the method that felt most comfortable for them. Feedback from surveys and interviews was analysed together to identify common themes, positive experiences and opportunities for improvement.

Key findings

Parents described a range of experiences of the Child Death Review process. While some experienced compassionate, coordinated support, others described gaps in communication, continuity and involvement.

Emotional support from hospital staff, charities and specialist bereavement services was highly valued, particularly where relationships continued over time. However, parents also described support reducing despite their ongoing need, highlighting the importance of longer-term bereavement support.

Practical support was equally important. Parents valued help with appointments, paperwork, funeral arrangements and understanding what would happen next. Where this support was not coordinated, families described feeling left to navigate complex systems during a period of acute grief.

Experiences of communication about the Child Death Review process varied considerably. Some parents were unaware that a review was taking place or found it difficult to understand how the review related to other investigations and meetings. Others described positive experiences of being actively involved, receiving clear explanations, having opportunities to ask questions, and seeing evidence that learning had led to changes in practice.

Parents consistently highlighted the value of having a named key worker or single point of contact to coordinate communication and reduce the need to repeat distressing information to multiple professionals. They also emphasised the importance of compassionate communication throughout all processes associated with the death of a child, including post-mortem procedures and wider investigations.

Overall, the findings highlight opportunities to create a more consistent, coordinated and family-centred Child Death Review pathway across North East and North Cumbria. This includes strengthening communication, improving coordination between services, ensuring families have access to a named contact, providing timely emotional and practical support, and embedding trauma-informed approaches throughout the review process.

Background

The death of a child has a profound and lasting impact on families and on the professionals who support them. After a child dies, services have a responsibility to understand what happened, identify learning and use that learning to improve care and help prevent future deaths. In England, this is set out in the Child Death Review (CDR) statutory and operational guidance.

The guidance is clear that families should be treated with compassion and kept informed. Parents do not attend review meetings, but they should be told that a review is taking place and given the chance to share questions, concerns or information they feel is important. This helps ensure that families are heard and that their child's story contributes to learning and improvement.

National guidance also describes several important parts of good family support. These include a named key worker or single point of contact, clear information about the process, opportunities for parents to contribute before the multi-agency review, sensitive feedback after the review, and signposting to bereavement support.

Although this national approach is in place, evidence shows that families' experiences of the CDR process have not always been consistent. Some parents have received clear information, compassionate support and feedback. Others have not known that a review was happening, have been unclear about how the review linked to other processes, or have had to repeat their story to different professionals. National learning also highlights the importance of plain English information, careful timing of communication, trauma-informed practice and regular updates when reviews are delayed.

Recent work has also strengthened understanding of what good parental involvement can look like. A CDR parental involvement toolkit was developed by researchers from the University of Birmingham and the University of Bristol with bereaved parents and professionals. The toolkit was designed to help key workers involve families in a sensitive and consistent way. The toolkit includes practical resources such as a pathway for when and how parents should be contacted, template letters, parent feedback forms, easy-read information and training materials for staff. These resources reflect the need for clear communication, sensitive conversations and a more structured approach to involving parents.

Parental involvement matters because parents know their child best and may hold information or questions that are important to understanding what happened. Being involved can also help some families understand the review process, ask questions and know how learning from their child's death has been used. For professionals and the wider system, family involvement can strengthen learning, improve transparency and support more compassionate care.

However, challenges remain. Access to key workers is not always consistent, staff may need more support and training to have difficult conversations, and information may need

to be available in different formats and languages. Families may also be involved in other processes, such as coronial investigations, complaints or internal reviews. Without clear coordination, this can add confusion and distress.

This local involvement project was developed in this context. It aimed to hear directly from bereaved parents across North East and North Cumbria about what the CDR process felt like for them, what support they received, what was difficult, and what could be improved.

Involvement Methodology

About this project

This project was carried out to understand bereaved parents' experiences of the CDR process and identify opportunities to improve support, communication and involvement for families across North East and North Cumbria.

The work was undertaken as a service improvement and involvement exercise rather than formal research. It was overseen through Integrated Care Board (ICB) governance processes and supported by the Child Death Review Expert Reference Group. Information materials and the approach were developed and refined with feedback from stakeholders before the project began.

Who could take part?

Parents were invited to take part if their child's death had already been reviewed through the CDR process and enough time (at least 18 months since review conclusion) had passed for families to reflect on their experiences. Families who were still involved in an active review were not approached, to avoid adding pressure or distress during an ongoing process.

The project aimed to hear from parents with a range of experiences from across North East and North Cumbria.

How parents were invited to take part

Parents were approached through professionals who were already known to them, such as key workers and members of the Expert Reference Group. This helped ensure that invitations were shared in a sensitive and supportive way.

Information about the project was provided to parents, giving them time to decide whether they wished to take part. Only parents who expressed an interest in participating were contacted by the involvement team.

Taking part was entirely voluntary.

Who took part?

In total, five parents shared their experiences. Two parents completed the survey and three took part in one-to-one interviews.

Method	Number
Survey	2
Interview	3
Total	5

Although the number of participants was small, parents shared detailed accounts of their experiences, providing rich qualitative insights into the Child Death Review process.

How parents could share their experiences

Parents were offered different ways to take part so they could choose the approach that felt most comfortable for them. These included:

- Completing a survey online or on paper
- Providing written feedback using a guided template
- Taking part in a one-to-one conversation in person, by telephone or online

Offering different options helped make participation accessible and allowed parents to choose the method that best suited their circumstances and preferences.

What we asked about

The survey and discussion topics were designed to explore parents' experiences of:

- Support provided immediately after their child's death
- Emotional and practical support in the weeks and months that followed
- Information and communication about the CDR process
- Awareness of key roles, including key workers and the Child Death Overview Panel (CDOP)
- Experiences of receiving feedback and outcomes from reviews
- What worked well and what could be improved

A trauma-informed approach

The project was designed to be sensitive to the experiences of bereaved parents. Parents were reminded that participation was voluntary and that they could choose not to answer any question, take a break, or stop taking part at any time.

For one-to-one conversations, parents were able to choose how and where discussions took place and could set the pace of the conversation. Where conversations were recorded, this was only done with consent and to ensure that parents' views were captured accurately.

Support and safeguarding

Several measures were put in place to support participants throughout the project. Parents were only approached through professionals who could ensure appropriate support was available if needed. Information materials included signposting to bereavement and wellbeing services. Materials and processes were reviewed and updated throughout the project to ensure language remained sensitive and appropriate.

Confidentiality

All information shared by participants was treated confidentially. Parents were informed that their responses would be anonymised in reporting and that personal information would be stored securely. Any recordings were used only to support analysis and were not retained once reporting was complete.

Analysis and reporting

Feedback gathered through surveys, written responses and conversations was reviewed together to identify common themes and experiences.

The analysis focused on:

- What was working well
- Areas where families felt unsupported
- Gaps or inconsistencies in communication and support
- Suggestions for improving the CDR process

All names of people, hospitals, and specific procedures have been removed to give families anonymity. All children have been given pseudonyms.

Limitations

This project involved a small sample of five parents who volunteered to share their experiences. All participants were from two geographical areas within North East and North Cumbria, and the findings therefore cannot be assumed to represent the experiences of all bereaved families across the region. The project also heard only from parents whose infants had died, rather than parents of older children. The findings should therefore be interpreted as rich qualitative insights intended to inform service improvement, rather than as evidence of how common particular experiences or views are across the wider Child Death Review pathway.

Key findings

Parents described a range of experiences following the death of their child. While some received compassionate, coordinated support, others encountered gaps in communication, continuity and involvement. Despite these differences, several consistent themes emerged across the survey responses and interviews. The following sections explore parents' experiences of emotional and practical support, understanding of the CDR process, challenges associated with navigating services and investigations, and their views on what could improve support for bereaved families.

Emotional support is valued but not sustained

Parents consistently described receiving emotional support following the death of their child, particularly from specialist services and charities.

> *Tiny Lives organised psychology input and put support in place for the whole family.*

In interviews, parents described the impact of sustained therapeutic relationships:

> *I saw her [bereavement counsellor] for about a year… every fortnight for bereavement counselling… and actually, within the space of a couple of weeks of talking to her, my temperament changed, my kind of behaviour changed because I wasn't angry, I wasn't snappy.*

However, parents consistently described support reducing over time, despite their ongoing need.

> *And people don't expect you to still need the support as time goes on.*

Some parents also highlighted the absence of peer support:

> *Support groups with other bereaved parents would have been useful.*

Early emotional support, particularly through specialist bereavement services, charities and sustained therapeutic relationships, was highly valued and often made a meaningful difference to families' wellbeing. However, parents also described support reducing over time despite the ongoing nature of grief. The findings suggest that bereavement pathways should include planned follow-up, opportunities for families to re-access support when needed, and access to different types of support at different stages of bereavement, including peer support with other bereaved parents.

Practical support is helpful but not always timely or coordinated

Parents described receiving practical support, particularly from individual staff members.

> *Support from nurse who was there during bereavement with appointments, getting baby photos etc and practical support with funeral.*

Help with arranging appointments e.g. sorting birth/death certificates. Directed to good funeral directors/help with the process.

However, parents also described practical support as being inconsistent, with coordination and timing varying across services.

In interviews, this was linked to the absence of a coordinating role:

That's something I really could have done with… [there] wasn't anyone ever professional…extra people always seem to ask, have you done that? And I was like, I don't know. Like, I didn't know [what I was supposed to do]? I could have done with the role of someone that handled the admin that just booked me the appointment and said, here you go...

These findings demonstrate that practical support can make a significant difference to bereaved families, particularly when it reduces the burden of appointments, paperwork and funeral arrangements. However, parents' experiences suggest that this support needs to be proactive, timely and well-coordinated, rather than relying on families to navigate complex systems during acute grief.

Communication about the CDR process is inconsistent

Parents' understanding of the CDR process varied considerably.

Some parents reported not being informed that there was a review or what that process entailed:

I was not informed. (Survey response)

Others described confusion and the need to actively seek information:

Am not sure if the CDR was discussed at our fetal medicine review… we didn't get a letter from this meeting… to get information about any follow up I had to chase the bereavement midwife which I think is awful.

I think we got confused because we had… there was an internal one from [hospital name removed]… and it was a separate investigation, the Health and Safety Investigation Branch… it did get confusing.

One family described a particularly positive experience of communication and involvement, providing an example of what good practice can look like.

The parents described being invited back to hospital to attend a formal review meeting with consultants, where their child's care and death were discussed in detail.

And we were invited to go in for a meeting. And the meeting was with two of the consultants that had looked after Oliver… we got taken into a room,

this meeting room had been booked… all of Oliver's… paper files were on the desk… and… they basically just took us through the nine weeks that Oliver spent there.

The meeting included a detailed walkthrough of care, identification of issues, and direct acknowledgement of errors.

There was a couple of things that had been discovered… a [procedure removed] hadn't been changed when it should have been changed… we were told who had been responsible for that… they apologised and said that it shouldn't have happened… they had explained that following the death of a child, this review has to happen… it was just a meeting basically where they just reviewed the nine weeks and the history… but at the end of it, they said they had noted discrepancies and things were being put into place.

The family also described being reassured that the review included independent scrutiny:

They had said that they had already shared Oliver's folder with a neighbouring hospital… to check that everything was… all above board… and now obviously this meeting… was to share… all the findings.

The parents explained that they had been encouraged to ask questions and contribute to the discussion.

We were told that… following the passing of any… child, there was a review meeting and that we were… invited to attend… and if there was any questions we wanted to ask… they would try their best to provide that for us.

The same family also described seeing tangible changes within the unit, which they perceived as evidence that learning had taken place following the review. These visible environmental and operational changes appeared to provide reassurance that concerns had been recognised and acted upon.

What they're now doing is… they've shut all that side of the unit down… doing a refurb… instead of four babies… they're now only going to put three babies in… reconfiguring the room so that there isn't a baby near the sink area.

I think it's probably got something to do with it… I remember them saying that they had tested pipes… and they were changing pipes… it's nice to see that these things are in place now and that things are improving.

Overall, communication about the CDR and CDOP processes was inconsistent, and parents did not always recall receiving or retaining information about the review. However, where families were actively involved, the process could feel meaningful and valuable.

For this family, the review meeting provided a structured opportunity for transparency, explanation and accountability. Parents valued having dedicated time with senior clinicians, the opportunity to review their child's care, ask questions and understand what had happened. Importantly, reassurance came not only from receiving explanations, but from seeing that concerns had been acknowledged and that learning had resulted in tangible improvements to practice and the care environment.

Lack of a named contact creates fragmentation and repetition

Parents did not consistently have a single point of contact to guide them through the process.

> *No, it was just the bereavement counsellor from the neonatal team… I think mainly she is there for parents of children on the neonatal unit so I just feel like maybe bereavement wasn't her specialty.*
>
> *A key worker? No, we didn't have that.*

Parents described having to repeat their story across multiple interactions:

> *I don't want to re-explain it… I've heard the outcomes… and now I'm going somewhere else and they don't know what's happened.*

Parents highlighted the importance of a named key worker or equivalent coordinating role. Without this, families may experience fragmented support, uncertainty and the distress of having to repeat their story to different professionals. A consistent contact could help join up communication, reduce emotional burden and ensure families are supported through the process in a more coordinated and compassionate way.

Trauma associated with external and internal processes

This theme highlights how interactions with wider systems and processes following a child's death can contribute to additional trauma when communication, language and service processes are not handled with sensitivity and compassion.

One parent described feeling overwhelmed by the number of decisions and consent processes they were expected to navigate immediately after their baby's death, at a time when they struggled to process information or recall events clearly.

The parent also described significant distress during the post-mortem process. Delays in the return of their baby's body, alongside changing explanations about the reasons for those delays, heightened their anxiety and grief.

> *[There] just kept being a delay [in returning the body]. All the pathologists off work, the pathologists are sick, there's no one else to look at him. And then I said, I just want him back now. I just, I want him back like you've had him for over a week and you said it would only be two days.*

When the parent asked for their baby to be returned, they described being told that this was not possible because organs removed as part of the post-mortem examination had not yet been replaced. The parent explained that they had not anticipated this aspect of the post-mortem process and found the information unexpected. They also described the explanation as being delivered in a direct and matter-of-fact way, without acknowledgement of the emotional impact the information might have at a time of acute grief.

This account highlights how bereaved parents may be unprepared for some aspects of post-mortem procedures and reinforces the importance of sensitive, compassionate communication when explaining these processes. While clear and honest information is essential, participants emphasised that the language, timing and delivery of difficult conversations can significantly influence how families experience an already traumatic period.

Another parent highlighted the impact of language used by staff and the physical environment they were in after the death of their child.

> *Better support from maternity services! Use of language 'at least you got 1'.*
>
> *Being put in a side room with 2 empty cots!*

These experiences underline the need for all parts of the pathway to be trauma-informed, with compassionate communication, sensitive environments and clear coordination to avoid compounding families' grief.

Taken together, the findings suggest that bereaved families need a more consistent, compassionate and family-centred CDR pathway. Across the themes, parents described the importance of clear information, a named contact, coordinated emotional and practical support, sensitive communication and timely feedback about outcomes and learning. Together, these changes would help create a more coordinated, compassionate and family-centred experience while ensuring parents' experiences continue to inform meaningful learning and improvement.

Discussion: Learning for the design of the CDR process

The findings point to a need to design the CDR process around family experience as well as statutory requirements. Parents' accounts show that the way information, support and involvement are offered can shape whether the process feels transparent, compassionate and useful, or fragmented and difficult to navigate. This discussion therefore focuses on what the findings mean for pathway design across North East and North Cumbria.

A key implication is that emotional and practical support should be planned as part of the pathway, rather than being dependent on individual staff members or services. Parents' needs change over time, and support may therefore be required at different points, including after key meetings, during delays, around anniversaries and when review outcomes are shared. A more structured approach would help ensure that families are not left without support once the immediate period after their child's death has passed.

The findings also suggest that practical support should be treated as a core element of bereavement care. Help with appointments, paperwork, funeral arrangements and next steps can reduce pressure at a point when families may be least able to manage complex systems. Embedding this support within the pathway would reduce reliance on parents having to ask for help or coordinate actions themselves.

The findings align with wider evidence that bereaved families may not be able to absorb or retain complex information during periods of acute trauma. This suggests communication should be viewed as an ongoing process rather than a single event. Families may benefit from receiving clear, plain English information at different stages, repeated opportunities to revisit questions, and clear explanations of how the CDR process relates to other reviews, investigations and meetings.

The findings also indicate that involvement should be offered flexibly. Some parents may want detailed feedback, opportunities to ask questions and reassurance that learning has led to change; others may want less contact or may not feel ready to engage at particular points. The pathway should therefore create opportunities for involvement without placing expectations on families, allowing parents to choose how and when they contribute.

A named key worker or single point of contact is central to making this approach work in practice. This role could help join up communication, explain the process, coordinate support, provide updates and reduce the need for parents to repeat distressing information. Consistency of contact would also help families know who to approach when questions arise or when they need support later in the process.

Finally, trauma-informed practice needs to extend across all organisations and processes connected to a child's death. This includes healthcare services, post-mortem processes, investigations, communication about delays, environments where families are supported, and the language used by staff. Strengthening the pathway therefore requires a whole-system approach, with shared expectations about compassionate communication, sensitivity and coordination.

Implications for the NENC CDR process

Taken together, the findings suggest that the greatest opportunity for improvement lies in creating a more consistent, coordinated and family-centred CDR pathway across North East and North Cumbria.

Key areas for consideration include:

- Ensuring all families have access to a named key worker or single point of contact throughout the review process.
- Providing clear, consistent and accessible information about the CDR process and what families can expect.
- Improving coordination between the CDR process and other investigations or reviews to reduce confusion and duplication.
- Offering flexible opportunities for parents to contribute their views and ask questions if they wish to do so.
- Providing timely feedback on review outcomes and sharing how learning has informed improvements in practice.
- Embedding trauma-informed approaches across all organisations involved in responding to the death of a child.
- Strengthening access to emotional and practical support throughout the bereavement journey, including at key milestones and at the conclusion of the review process.

Overall, parents consistently valued feeling informed, listened to, supported and involved. Designing the CDR process around these principles would help create a more compassionate and consistent experience for families while also strengthening the quality of learning and improvement across the system.

Conclusion

This project demonstrates that parents value being informed, listened to and treated as partners in learning following the death of their child. While many examples of compassionate care were identified, the findings also highlight opportunities to improve consistency, communication and coordination across the Child Death Review pathway. Strengthening these aspects of the process has the potential to improve both families' experiences and the quality of organisational learning across North East and North Cumbria.

Above all, the findings suggest that families should experience the Child Death Review process not simply as a statutory requirement, but as a compassionate partnership that supports families while enabling services to learn and improve