

When a child dies: Learning from the experiences of bereaved families and carers

National Hub for Reviewing and Learning from
the Deaths of Children and Young People

June 2022



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“

Please take time to understand the fog the bereaved parents are existing in . . . losing a child is like learning to live in a foreign land, nothing makes sense and you have to take your time to understand things. What may seem straight forward to a professional is like talking a foreign language to a bereaved parent. No one should ever become complacent when dealing with bereaved families.

Quote from a bereaved family”

”

Foreword

The death of a child has a life-long impact on families and carers. The effect of such tragedies, out of synch with the natural order of life and death, ripples beyond immediate families - to siblings, grandparents and the wider family, as well as friends, work places, communities and society as a whole.

As charities supporting those who are impacted by the death of a child, we welcome this important survey of families' and carers' experiences of the review into the death of their child. Scotland has one of the highest rates of child deaths in Western Europe and 1 in 4 of those deaths are potentially avoidable, amounting to 75 lives every year. It is vital we learn from these deaths, wherever possible, and that the voices of families and carers are put at the very heart of understanding what happened and how care can be improved to change the future for other families and carers.

The views of families and carers are essential to any review to understand why a child dies and to learn whether anything could have prevented the death or changed the experience for the child, if the death was inevitable, as well as the family. Families and carers are experts in their own experiences, needs and wishes. Without their perspective of events leading up to the death of their child, any review can only be partial. Without a clear explanation of what happened and why their child died, alongside high-quality bereavement support, a family's recovery from such a devastating loss is likely to be, at best limited, and at worst, impacted by feelings of isolation and abandonment.

While the responses of families and carers reflected in this report cover a range of experiences over a broad period of time, the words they use echo the findings of other similar UK-wide reports highlighting how families can feel ill-informed and unsupported by agencies involved in the child death review process. However, it is important to note that some families and carers shared where they had exemplary experiences of support. The recommendations in this report highlight the process of engaging and supporting families needs to be family-centred, timely and flexible.

We commend its findings to you. We must implement and track progress on delivering responsive, meaningful pathways to family and carer engagement in the review of their child's death and ensure whenever a child dies, every family receives the support they need, wherever they live in Scotland.

Charlotte Bevan

Joint Head, Saving Babies' Lives
Sands, the stillbirth and neonatal
death charity



Rami Okasha

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Executive summary



Dr Alison Rennie, National Clinical Lead, National Hub

Scotland has a higher mortality rate for under 18s than most other Western European countries, with over 300 children and young people dying every year. Around a quarter of those deaths could be prevented. Every death of a child or young person deserves a review and, by reviewing and learning from these deaths, we may reduce the chances of future deaths.

Before 1 October 2021, Scotland had no national system to support reviewing and learning, or to share national learning from the deaths of children and young people, and not all deaths were reviewed. We also knew that the quality of reviews varied across services, and across Scotland. To address these issues, a National Hub was established in 2019, co-hosted by Healthcare Improvement Scotland (HIS) and the Care Inspectorate.

In August 2019, the National Hub conducted a [baseline scoping exercise](#) to investigate the different types of reviews being carried out, into the deaths of children and young people, across health and social care in Scotland. One of the questions asked was around engagement with families and carers in the review process and bereavement support. From this, we found that family and carer involvement in the review process was varied. We committed to making improvements in this area. The action from the baseline scoping exercise is outlined below:



Action: We will work with representatives from family and carer organisations, support organisations and voluntary organisations to understand what involvement families and carers would like in the review process. We will use this information to provide guidance to NHS boards and local authorities.

The National Hub produced a family and carer survey in collaboration with our third sector colleagues; Child Bereavement UK, Children's Hospices Across Scotland (CHAS) and Sands, the stillbirth and neonatal death charity. Our third sector colleagues distributed the survey to families and carers who had experienced a bereavement and asked them to share their experiences with us.

The aim of the survey was to learn from these experiences so that we could establish what is working well, understand the challenges families and carers have faced and assess where improvements need to be made. The survey was sent to families and carers in September 2021 and closed on 31 December 2021. We received 39 completed responses.

Summary of findings

Findings from the survey indicate that families and carers experiences of care and support following the loss of their child varied considerably. While some families spoke very positively about the compassionate care and practical and emotional support they received from a range of services and organisations, others faced more difficulties in accessing the help they needed.

Access to professionals who knew their child was, at times, difficult, particularly when a considerable period of time had passed since the child's death. Some families felt that it was only at this later point that they had questions they would like to ask to help them better understand why their child died.

Families and carers did not always understand the review process or how they could contribute to it, and not all felt they were kept informed about the progress of the review. The identification of a key contact was highlighted as being crucial in preventing families and carers having to repeat their story to different professionals, clarifying expectations and helping guide them through the review process. More information about the role of a key contact can be found in our [National Guidance](#).

Importantly, families talked about the significant emotional impact of their loss, and the need for professionals to recognise that their capacity to process information or ask questions at the time of the death was considerably affected.

Recommendations

NHS boards, local authorities and public protection committees*

1. NHS boards, local authorities and public protection committees should take account of the findings of this report when establishing local arrangements to review the deaths of children and young people.
2. NHS boards, local authorities and public protection committees with responsibility for conducting reviews into the deaths of children and young people should be sensitive, flexible and family-centred in their approach to engaging with and supporting bereaved families before, during and after the review process has concluded. The identification of a key contact for each bereaved family will be vital to guiding and supporting families during this time.
3. NHS boards, local authorities and public protection committees should take account of the [National Guidance](#) for reviewing the deaths of children and young people. This guidance sets out the processes services should follow when responding to, and reviewing, the death of a child or young person.
4. NHS boards, local authorities and public protection committees should develop systems to monitor the quality of reviews to ensure that the views of families and carers are sought and represented in review processes.

** or individual committees / partnerships with specific public responsibilities, such as child protection committees, adult protection committees etc.*

NHS boards, local authorities and third sector organisations

5. NHS boards and local authorities, in partnership with third sector organisations, should work together to plan, commission and deliver comprehensive and tailored bereavement support, as outlined in the [Bereavement Charter for Scotland](#) and the [National Bereavement Care Pathway](#).
6. NHS boards and local authorities, in partnership with third sector organisations, should ensure that staff have the necessary skills, knowledge and understanding of child bereavement to effectively support bereaved families and carers, the child's siblings, peers and where appropriate, the local community.

The National Hub

7. The National Hub should continue to work in partnership with third sector organisations and bereaved families and carers, to shape and inform the National Hub programme. Future work should include the development of an information leaflet for families and carers, outlining the child death review process and the rights of families and carers to have their views heard.
8. The National Hub should conduct a rolling programme of audit activity, including surveys and focus groups, to establish whether the experiences of bereaved families and carers improves over time.

Acknowledgements

We would like to thank all families and carers who took part in the survey. The information provided will be used to help develop a new, and more family and carer-centred process for organisations when they review the circumstances around the death of a child or young person. We would also like to thank our third sector colleagues - Child Bereavement UK, CHAS, Sands and Held in Our Hearts, for their input to the survey design, distribution of the survey and providing support to families and carers.

Introduction

Background

The Scottish Government requested a system be established for reviewing and learning from the deaths of all children and young people in Scotland, based on a National Hub, with an aim to co-ordinate all current review activity. Healthcare Improvement Scotland, in collaboration with the Care Inspectorate, are the co-hosts of the National Hub.

The programme will use a multidisciplinary and multi-agency approach, focused on using evidence to deliver change and ultimately aim to reduce deaths and harm to children and young people. We want to ensure the death of every child and young person is reviewed to an agreed minimum standard. Reviews will be conducted on the deaths of all live born children up to the date of their 18th birthday, or 26th birthday for care experienced young people who are in receipt of continuing care or aftercare provision at the time of their death.

National Hub

The National Hub will identify trends that could alert professionals of possible areas of risk, establish a minimum standard for carrying out reviews into the deaths of children and young people and ensure consistency is applied to all reviews. The National Hub will operate in the context of existing review arrangements. The key aims of the National Hub are to:

Ensure the death of every child in Scotland has a quality review

Improve support for families and carers in engaging with the review process, and understanding why their child died

Take learning from why children die across Scotland, through reviews, to prevent future deaths

This new approach means every family should have their child's death robustly and sensitively reviewed to understand the circumstances of the tragedy. Professionals should also support and involve families and carers at all stages in the review process. The National Hub has developed [National Guidance](#), which sets out good practice processes when reviewing the death of a child or young person. It also looks at how to keep families and carers are meaningfully involved in, and informed about, all parts of the review process, including bereavement support.

The National Hub have also developed a core review data set, to be used by NHS boards and local authorities when reviewing the deaths of children and young people. This contains a section on family and carer involvement in the review process. For the first time in Scotland, national data will be collected on the deaths of ALL children up to age 18, or 26 if receiving continuing care or aftercare, at the time of their death. New arrangements for reviewing child deaths became operational on **1 October 2021**.

Our approach

The National Hub established a third sector stakeholder group with representation from:

- CELCIS, Centre for Excellence for Children’s Care and Protection
- Child Bereavement UK
- Children’s Hospices Across Scotland (CHAS)
- Sands, the stillbirth and neonatal death charity.

The group developed an online survey, to be distributed and shared by our third sector stakeholders, asking families and carers to share their experiences following the death of their child. The survey aimed to find out more about bereavement support following their loss, their involvement in any review process and their knowledge of the outcome of the review.

We shared a draft version of the survey with a small number of bereaved families and carers to ensure the questions asked were appropriate, sensitive to the subject matter and easy for families and carers to understand. The feedback we received was valuable and helped inform the final survey (Appendix 1).

We acknowledged it could be difficult for families and carers to recall what happened at a traumatic time, and that completing the survey may trigger upsetting memories. Families and carers were offered the opportunity to skip questions they did not feel comfortable answering and could complete the survey over a number of sittings.

We shared the final survey with families and carers through our third sector colleagues. This approach was taken as these organisations already had established links with bereaved families and carers, or platforms where the information could be sensitively shared. This also ensured that support mechanisms were in place should the survey trigger any emotional distress. We also asked a further organisation (Held in Our Hearts) to distribute the survey, alongside organisations from our third sector group. The survey was shared with families and carers in September 2021 and a reminder email was sent in November 2021. The survey closed on 31 December 2021.

Terms used in this report and what they mean

- **‘Families’** – for the purposes of this report, we use the term ‘families’ or ‘family’ when referring to individuals who participated in our survey, which includes families and carers.
- **‘Child Death Review’** – this is a formal process which looks back at the circumstances surrounding the death of a child or young person, with the aim of understanding the reasons for it and preventing avoidable deaths in the future.
- **‘Bereavement support’** – care and support given to bereaved individuals to help them deal with the immediate and longer-term emotional and practical challenges following the loss of a child. For example, memory making when a child dies, information about what will happen next, support sessions and groups, counselling, reading materials, online support etc.

Responses

It is worth noting that, in total, **82 individuals** started to complete the survey but only 39 submitted their fully completed responses. Unfortunately, we did not have permission to use the information from the 43 partially completed responses for this report. We will consider the learning from this experience for our future work.

At the end of the survey, families were asked to provide information about themselves as part of an equality monitoring exercise. The purpose of this section was to allow us to ensure everyone had an equal opportunity to get involved with our work. By asking families to complete this section, we are able to understand who we have engaged with. As with all survey responses, the information provided was anonymous. An overview of families is outlined in Appendix 2.

Limitations

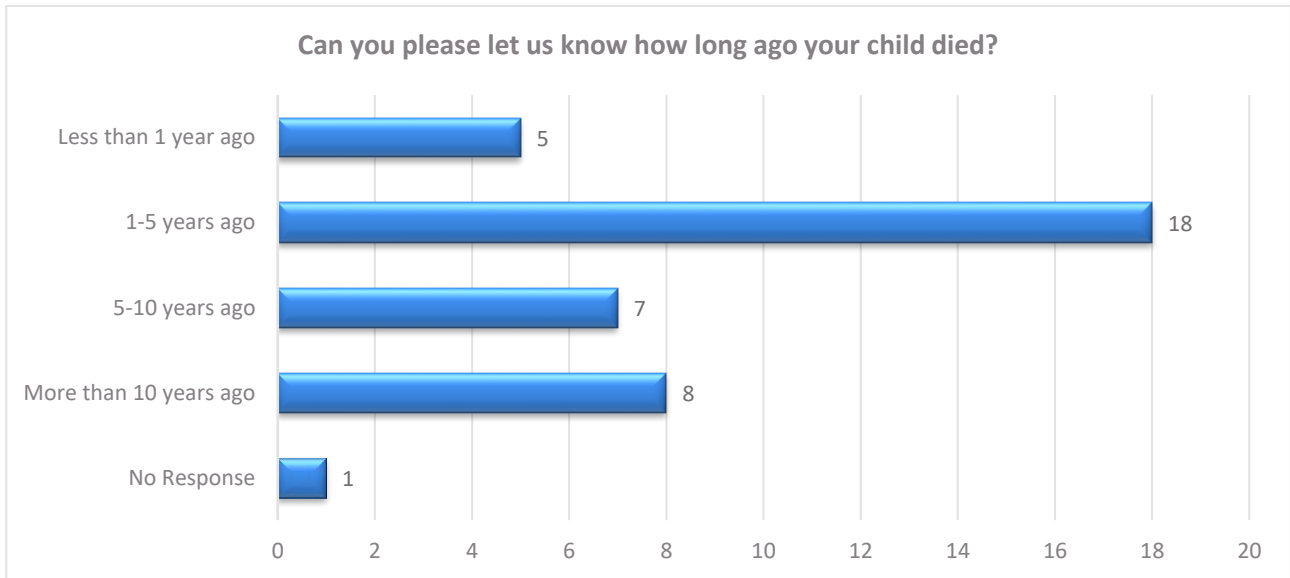
Limitations in the survey design meant that we did not identify the age of the child at the time of their death, or whether the death was expected or unexpected. Any future surveys of families experiences of a child death review process will take these factors into account during the survey design.

Findings from the survey

When reviewing the responses, some key themes were identified. These are outlined below.

We asked families to let us know how long ago their child died. The majority of families (61%) had lost a child in the last 5 years. Responses to this question are outlined below (Table 1).

Table 1:



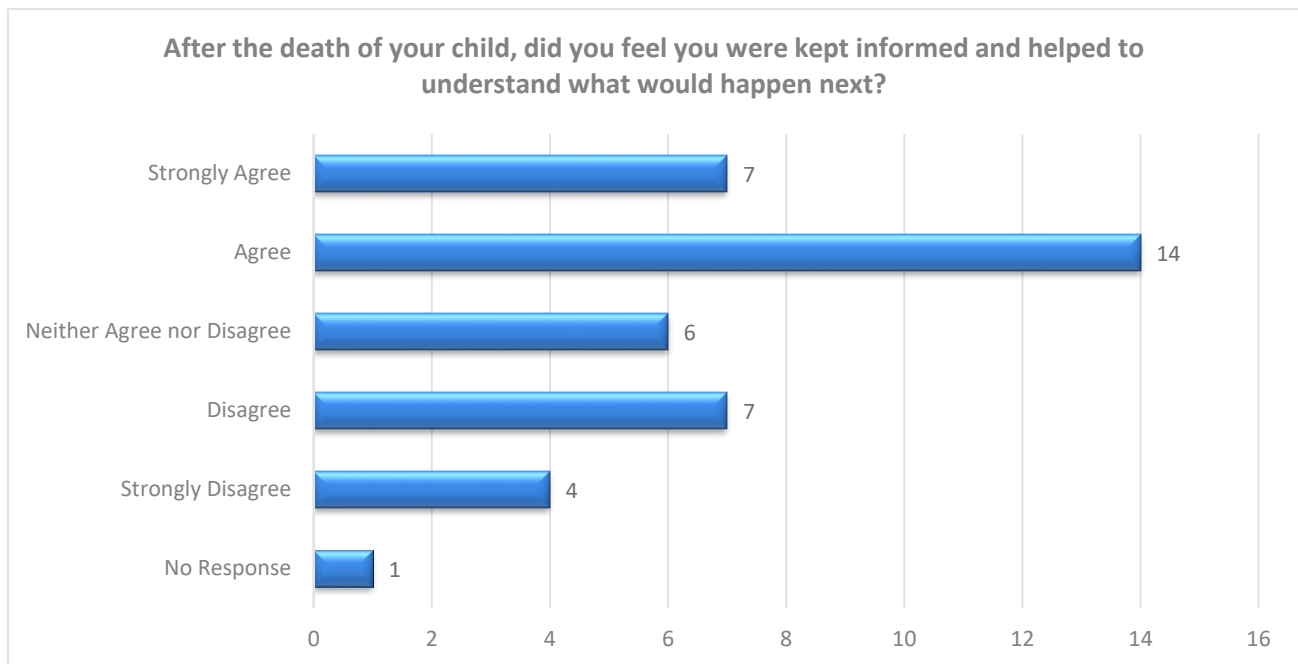
Engagement following the death of a child

The death of any child is a tragedy and every family should have their child’s death robustly and sensitively reviewed to understand what happened, identify learning and to, where possible, prevent future deaths.

[National Guidance](#) states that professionals have a duty to support and engage with families at all stages in the review process. In some cases, this will be to identify the cause of death and to ensure that lessons are learnt that may prevent further deaths of children and young people. When the death was anticipated and not preventable, it is important to ensure that the experiences of the child or young person were positively managed and that any wishes of the child, young person and family were met. Engaging in the review process must not make things worse for the family at this already extremely difficult time.

We wanted to know if families felt they were fully informed about what would happen following the death of their child. The majority of families (56%) agreed they had been kept informed and were helped to understand what would happen next. However, some felt their experience could have been better. A breakdown of responses is outlined below (Table 2).

Table 2:



We asked families to expand on this by telling us what worked well and/or helped, and what would have worked better or could have been done differently at the time. Due to the range of responses we received, this section has been put into the main themes that emerged.

Experiences of hospital involvement

Some families shared good experiences they had received from hospital services; where they felt well supported and were shown kindness during the difficult time:

“ The [hospital] doctor who was treating us at the time of [our child’s] death was very thorough and helped us to understand everything that would happen. ”

“ We were given great care and provided [with] information about what the next process would be. The care we received from the hospital was second to none. ”

However, not all families felt their experience with hospital services was positive. Some described communication as being poor and felt more could have been done to provide support following the death of their child:

“ Communication very poor from NHS side. A simple phone call or update at various time points would have really helped. Someone co-ordinating everything too . . . [I felt] let down on several occasions around timing of things, I had to constantly chase up. ”

“

Very badly let down . . . in relation to communication. When we left the hospital, we weren't contacted by anyone at the NHS until well over a year after [the] death.

”

One family also mentioned delays regarding the final approval of the child death review report. The final approval process had been delayed by several months, even though the review had been completed. They had also not been given the option to read the report before it was signed off.

Support from General Practitioners (GP)

There was very little reference in the survey responses to GP involvement. However, some families did state that they felt their GP could have been more supportive following the death of their child. One family commented that they had expected a call or follow-up appointment from their GP, particularly as they had indicated to an NHS out-of-hours service that they were struggling to cope with the loss, but this did not happen.

Involvement with Police Officers

Families offered a mixed response when describing their experiences of engagement with Police Officers. One family stated they had received good support from a Police Officer who was handling their case, and were given regular progress updates, which they found helpful.

“

We were given the number of the police officer who was handling our case. He would ring us and tell us what was happening and let us know where the process was up to.

”

However, others described less positive experiences. One family stated they had a Police Officer with them every time they visited the morgue to spend time with their child, but no one had explained why. This family said it made them “*feel like criminals*”.

Funeral directors

All families who had mentioned funeral directors stated they had positive experiences of the care they received. Funeral directors were described as being helpful and supportive in explaining the next steps following the death, and showed kindness to families.

“

Our funeral directors were incredibly helpful and supportive, and helped us navigate the process of registering our son's death and how the autopsy worked.

”

Support from charities and hospices

The vast majority of families described positive experiences of the care and support they received from charities and hospices. Staff had supported them emotionally and provided guidance on making funeral arrangements and sourcing further bereavement support. Families, whose children were receiving palliative care, said their wishes concerning their child's final days had been taken into consideration and they were able to talk openly about their feelings.



We were under palliative care and so we had everything mapped out for when the worst were to happen. We were luckily able to have clear heads knowing what would happen to our baby.



Asking questions following the death

Wherever possible, all staff should be open and honest with families and carers about the circumstances of a child's death and if anything could have been done to prevent the death. If questions have been raised about the quality of care provided, and whether the child's death might have been avoided, organisations have a responsibility to explain what has happened and to apologise if something went wrong. They should identify what lessons may be learnt to reduce the likelihood of the same, or similar, tragedies happening in the future.

We wanted to know whether families felt they had the opportunity to ask questions around the circumstances of their child's death with a staff member who was knowledgeable about their child. The majority (64%) felt they had been given this opportunity. A breakdown of responses is outlined below (Table 3).

Table 3:



We asked families to expand on their responses by asking what worked well and/or helped and what would have worked better or could have been done differently at the time. Some families gave examples of staff managing the situation in a positive way by being approachable, informative, and supportive and making themselves available to answer queries. We have put these responses under the main themes.

Responding to queries over time

Some families indicated that they would have liked the opportunity to ask questions about their child's death at any time, even if the death had occurred a number of years ago. Families described the initial period after the death as being "raw" and felt they were not in the right emotional space to discuss the death in detail. However, after some time, they would have appreciated information from medical staff about the death, without feeling as if it would be a problem.

“At the time, I was unable to speak, to go out, to think. Doctors etc. need to remember that and be willing to answer my questions years later without making me feel I am a pest.”

“It was only 2/3 years later that I had questions but didn't feel I could ask. I worried about them not remembering our family and forgetting details so didn't want to run the risk of becoming a problem.”

Delays in receiving answers

Some families stated they had experienced delays in getting answers following the death of their child. One family indicated they were not offered a meeting with medical staff, even though they had requested one. They were offered an explanation about what happened at the time of their child's death, around 3 years after the death occurred. However, they felt they would not have been given this information had they not requested it.

Another family described a series of delays following the death of their child. In this situation, a bereavement meeting did not happen at 6-8 weeks following death, as indicated by medical staff. The family had a number of questions and concerns, which were not followed up. The individual had to request a bereavement meeting more than 3 months after their child's death. The post-mortem then took over 5 months to be finalised; after they had chased it a number of times. They stated they would have benefited from realistic expectations about potential delays.

Difficulties having discussions with medical staff

Some families described problems they had faced when trying to have discussions with medical staff who had looked after their child. One family stated a meeting had been arranged with the consultant who was on-call at the time of their child's death. This consultant was the only person able to answer questions from the time of the death however on the day of the meeting, the family were told they were not allowed to ask any medical questions. The family stated they were "angry and frustrated" by this situation and felt they had no choice but to raise a complaint. Another family stated they had to "chase" medical staff for information following a misdiagnosis, as they did not feel they had received honest answers.

Helpful professions and agencies

We asked families to share which professions or agencies had been most helpful following the death of their child. Below is a list of the organisations that families told us about.



Bereavement support

In the event of the death of a child or young person, all families should be offered and provided with access to bereavement support that is appropriate to the needs of the individual family, the age of the child and the type of loss. The survey findings demonstrated that bereavement support, and how it is accessed, varies across Scotland.

We asked families to advise if they were offered, or directed to, bereavement support following the death of their child. We also asked if they had been able to access bereavement support when they needed it, or if they felt they needed it. 26% of families said they had not been directed to bereavement support and 16% said they had not been able to access support when they needed it. A small number (5%) advised that they did not feel they needed bereavement support. A breakdown of responses are outlined below (Tables 4 and 5).

Table 4:

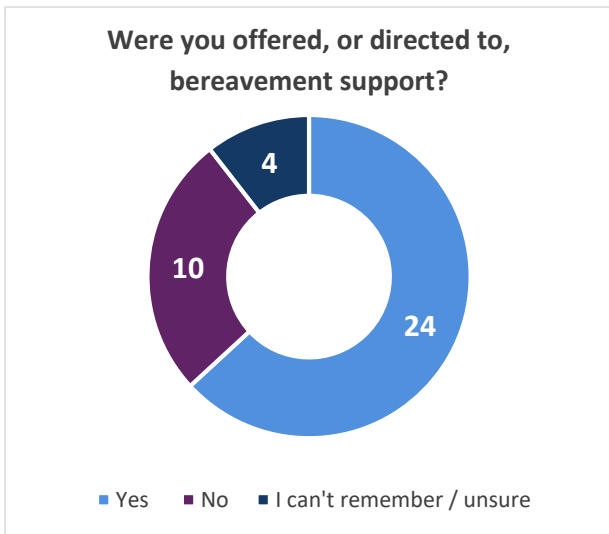
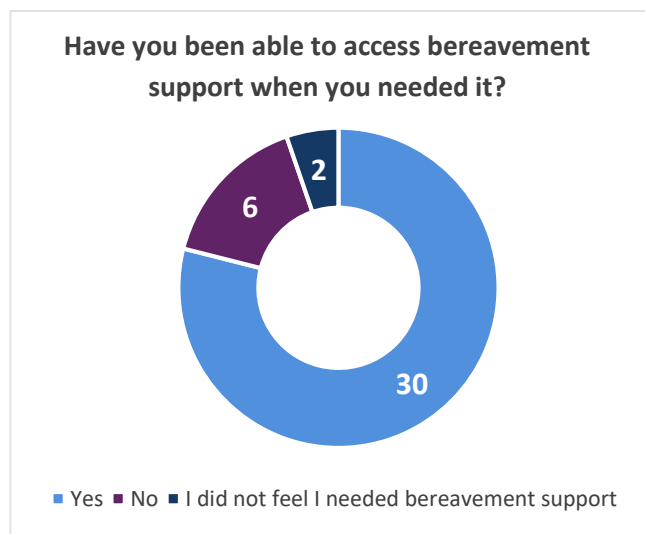


Table 5:



We asked families to tell us more about any bereavement or counselling support they had received following the death of their child. Examples are outlined below.

'Befriending Support' provided by Held in Our Hearts

Family bereavement support group provided by CHAS

Counselling support provided by Chaplaincy Team

Grief counselling provided by the Scottish Cot Death Trust

Telephone support provided by Rachel House

Online virtual support groups

Counselling provided by a Community Psychiatric Nurse

Social Media support groups

One family spoke positively about the ongoing support they received following their move away from Scotland. The charity supporting them was able to find support in their new location and had sent helpful resources.

“ [The charity] have always been there to support our family, even when we moved out of Scotland for a period of years. They helped us find support in the locations we moved to and were even willing to send us resources. ”

However, not all families were able to access bereavement support services so easily. A number of families described having to source services themselves with one family describing the process as “draining” and another stating they “always felt a bother” when trying to access ongoing support, or returning to a service after their child had died. Another family stated they found it difficult to navigate different bereavement supports and find the right one, as they had not been given information about the options available to them.

Bereavement support for siblings and other family members

The death of a child impacts an entire family and it is vital that bereavement support is made available to all family members. We asked families to provide feedback on whether bereavement support had been offered or provided to the child’s brothers, sisters and other family members.

A small number of families commented on the support provided by staff in schools. Families and bereaved brothers or sisters had benefited from the nurturing support provided through a range of individual and group activities.

Some families said that support had been provided to family members from charities and hospices. Families described the approaches used by the charities to support siblings who had lost their brother or sister including telephone support, interactions with play specialists, group support, one-to-one support and useful literature. The value of charities and hospices is clearly felt.

“
[The charity] offered help and support for us all and still do 11 years later after the death.”

“
The activities team [at the charity] have helped one of my daughters (age 9) through activity sessions online.”

“
Our eldest son was only 3 at the time of the accident. We were given some literature to help us understand his processes but the most helpful thing was the book *Rory's Star* as it directly showed him and was relevant to our situation.”

Where support was not offered

Whilst some families told us that support was provided to siblings and other family members, a significant number (27%) said that no support had been provided or offered. This resulted in some people having to seek support themselves and resort to privately funded services. Other families said that whilst some support was offered, they did not feel that the type of support was appropriate. Below are comments from the survey.

“ My other children were so young. Staff did not feel they needed support. It would've been good to revisit that as they grew older. ”

“ My daughter has been offered no support at all. If that support had started [at the time of the death], I think my daughter would have been more open to it. ”

“ Support was not readily available and too generic, and not in a child friendly space. ”

Contributing to the review process

In the second part of the survey, we wanted to hear views on how we can ensure families are at the centre of the process when reviewing the circumstances surrounding the death of their child. The review should provide an opportunity to meaningfully consider families and carers views and any concerns or queries they may have about the care they and their child, received. The review process will also help to identify practice that contributed positively to the care of the child or young person and help prevent the death of children and young people in the future.

We asked families what support, if any, they felt they needed to help them contribute to the review process. Due to the range of responses we received, this section has been themed into sections.

Key contact and access to support

Some families highlighted the importance of having a key contact available who is able to answer their queries directly and provide support to them throughout the review process. Families said this would be beneficial, so as to avoid having to provide the same information to different people which could cause unnecessary upset.

Other families outlined the importance of being referred to bereavement support immediately following the death, to build a support system ahead of the outcome of the review.

“ [Would be beneficial to have a] one to one case worker, so that you are not having to relive the trauma again and again by telling your story to everyone you meet. ”

Regular updates and realistic timescales

Some families, who had been involved in a review process previously, indicated they had been asked to put forward their concerns and questions prior to the review taking place. This gave them some confidence that their views were being taken into consideration. Some families emphasised the importance of receiving regular communication and updates regarding the progress of the review, to help ease anxieties and provide assurance that the review was moving forward.

A number of families also outlined their surprise at the length of time the post-mortem examination and review process took. Families said that it would be beneficial to have a clear outline of each stage of the review process and approximate timescales for completion.

Access to information

Some families stated it would be helpful to have access to information throughout the review process so they have a better understanding of what is being discussed. Some said it would be good to be able to meet with certain members of the review team prior to the review taking place and have these meetings noted. This would allow individuals to ask their own questions instead of having a representative ask them on their behalf. One family also stated that they would have liked to have seen a draft of the review report before it was finalised.

Some families stated they had no recollection of a review taking place, or whether they had been asked to contribute to a review. One family stated they had no official information from any organisation, other than the doctors and nurses immediately following the death.



Was not aware of any review process. My child died of cancer and no official from health or government agency engaged with me beyond her own doctor and nurses. Never got chance to speak to hospital, health board or any government agency.



While most families welcomed the review process, this was not universal. One family queried the purpose of having a review carried out, if the death was expected. They indicated that they would not have wished to be involved in a review process and would not have wanted to be contacted to contribute to the process.

Staff skills in supporting families and carers

All staff should support families following the death of a child or young person with kindness and compassion. We understand the type of support required can differ depending on the circumstances surrounding the death, and therefore the approach staff take to provide that support would also differ.

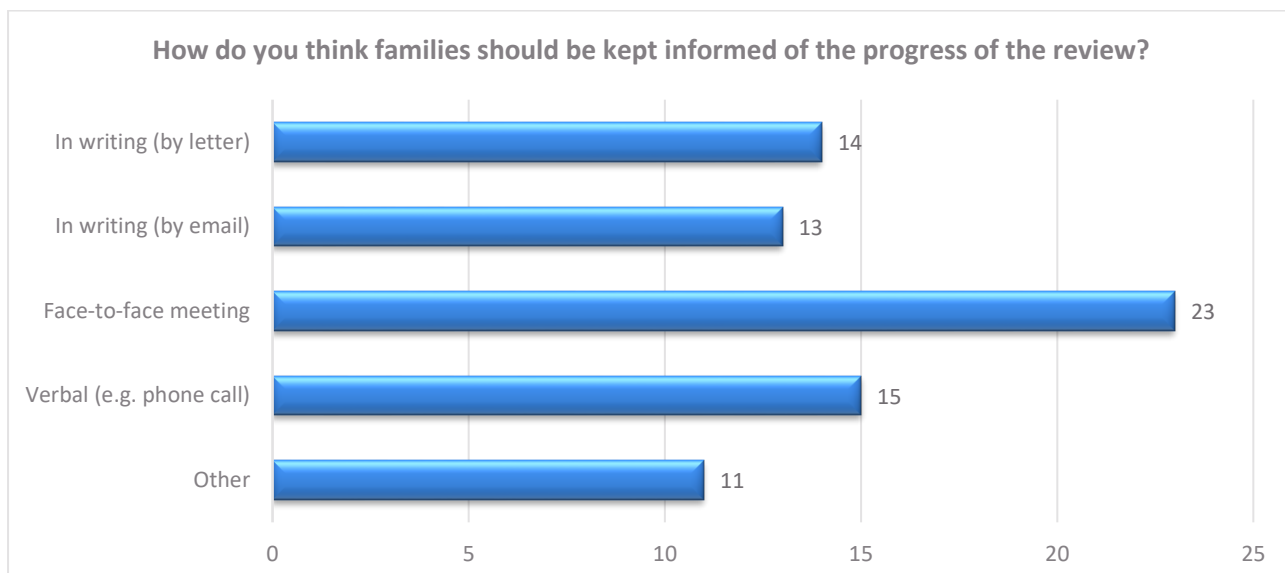
We asked families to outline the skills and qualities they felt professionals or agencies should demonstrate when supporting bereaved families through the review process. Responses included:

Treat all cases individually - every persons experience will be different	Avoid asking 'standard questions' and allow individuals to speak freely	Know the facts of the child's life, illness and cause of death
Understand the different forms, and complexities, of the grief process	Patient and Kind Caring and Compassionate Honest and Open-minded	Ensure adequate time for discussions with families and carers
Provide families and carers with a single point of contact for support	Provide advice on additional support for families and carers (particularly siblings)	Be available to answer questions and provide support when needed

Engagement during the review

We asked how families should be informed of the progress of the review. Families were able to select more than one answer to this question and provide further comment. The majority (30%) suggested that a face to face meeting would be the most beneficial. See responses below (Table 6).

Table 6:



A number of families felt the form of communication should be considered on an individual basis, as the circumstances surrounding the death may require a different approach.

Families also indicated that more than one method of communication would be beneficial to allow families the opportunity to have a personal conversation with someone but also have a written overview of the review progress.



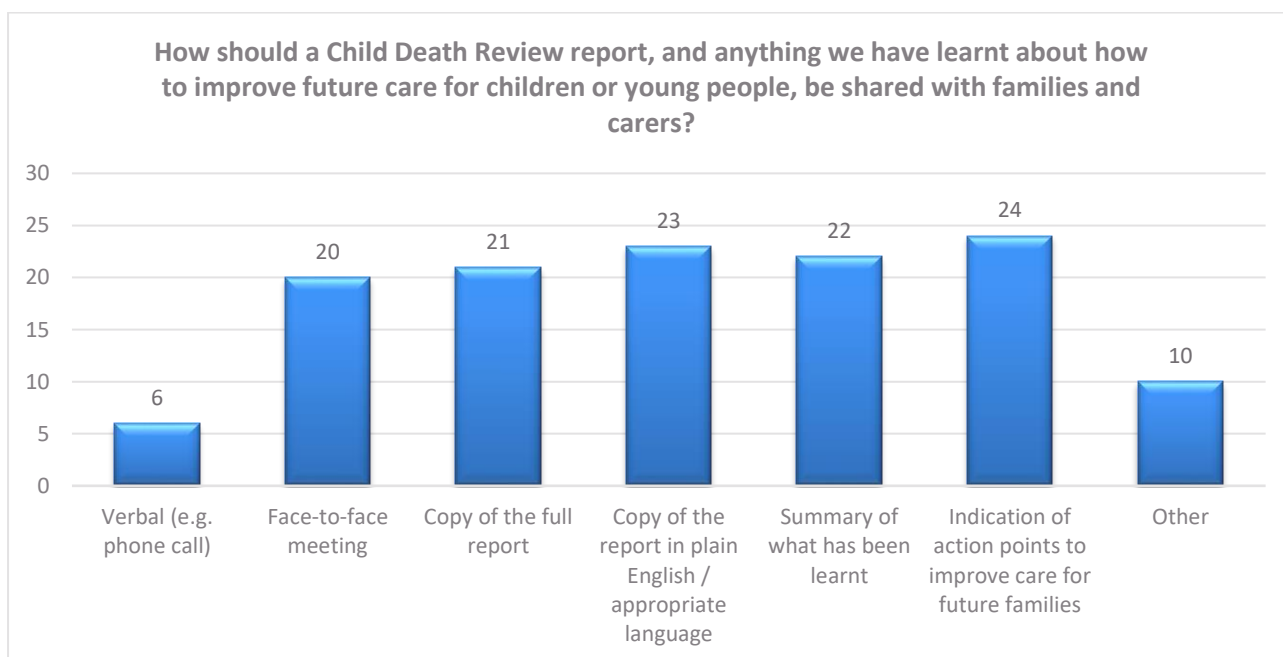
There needs to be an understanding that families aren't thinking straight and may not actually absorb the information. If a phone call happens, it should be followed up by a letter / email with all the information discussed in it so that families (or friends who are helping) can help them to understand / process the information they have been given.



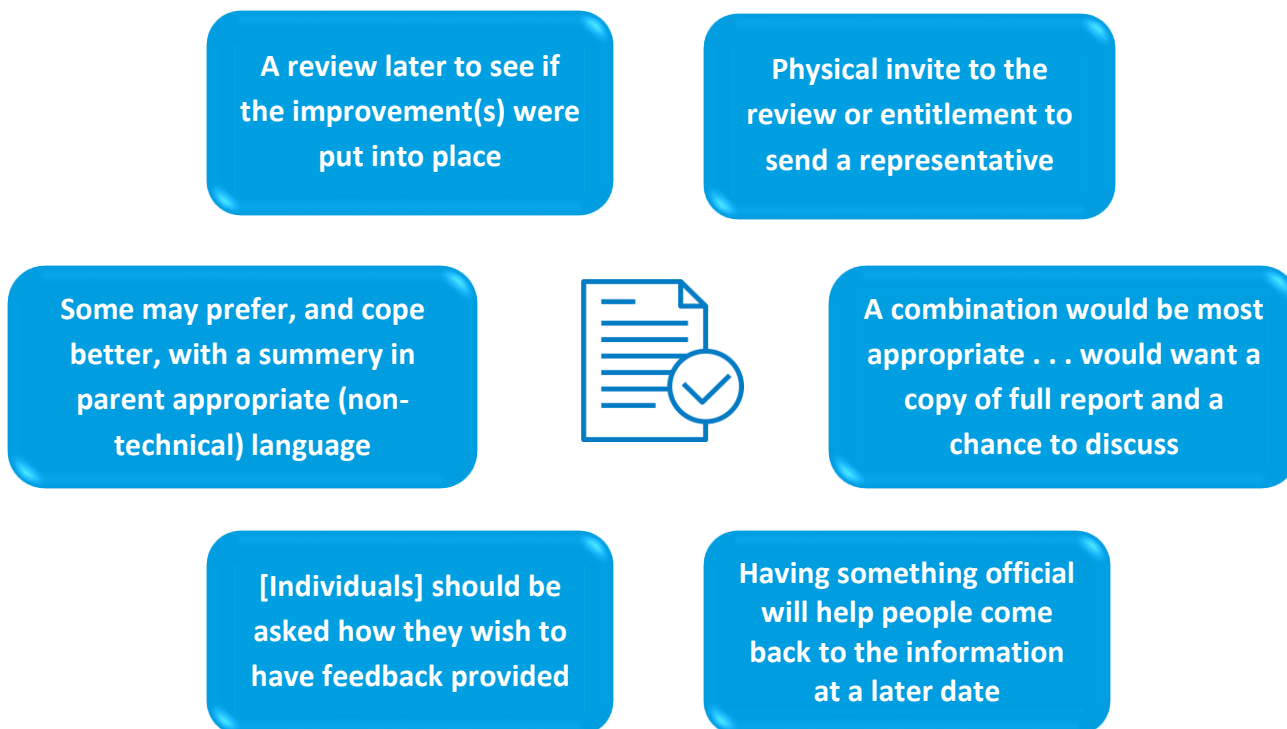
Engagement following completion of the review

We asked families to tell us how they thought a review report, and anything learned about how to improve future care for children or young people, should be shared with families. We provided options for this question and asked families to select all answers they thought should apply. Responses are outlined below (Table 7).

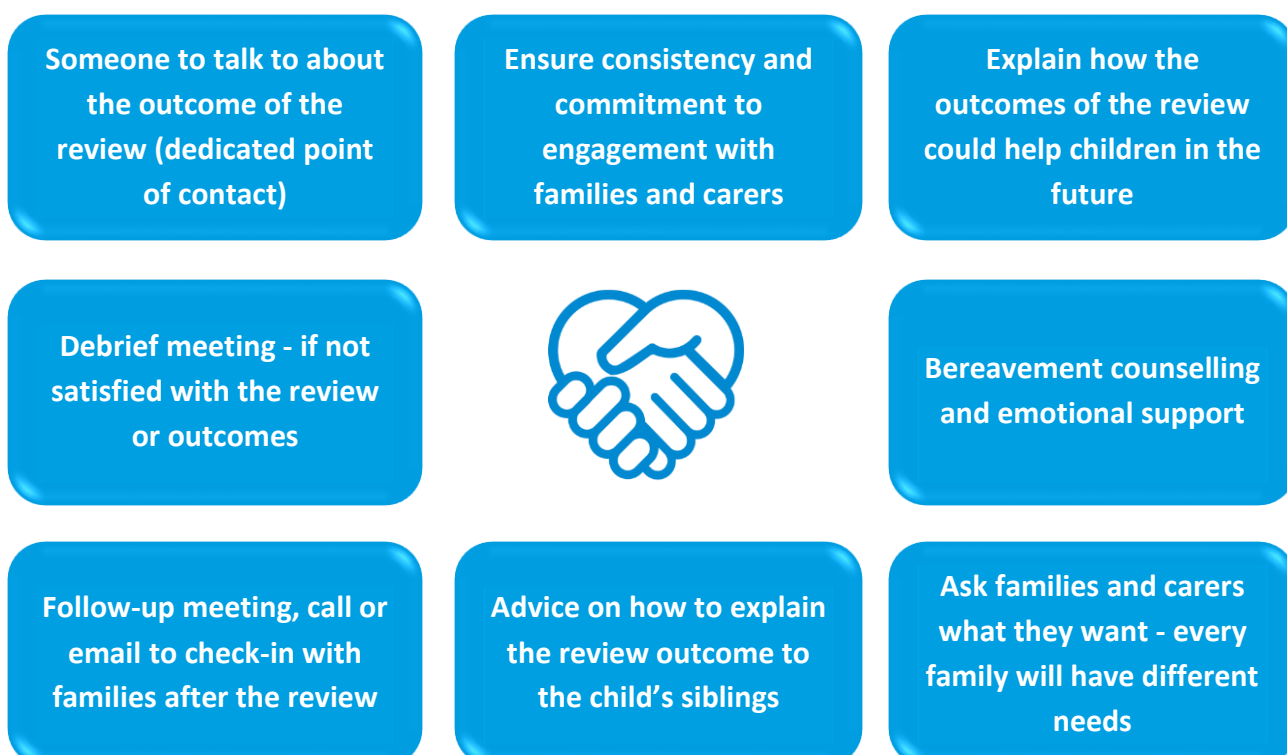
Table 7:



Again, a number of families advised that any learning from the review process should be shared in a format they feel most comfortable with, as not all circumstances will be the same. It was also reiterated that some families might not wish to be involved in the review process or be provided with information about the outcome of the review. We asked families to share their suggestions. Some responses include:



We understand the outcome of the review, and reliving the experience, could cause some upset. As such, we asked families what support they might need after the review has been completed. A number of families expressed the importance of the review being concluded in a timely matter to avoid unnecessary distress, the importance of having someone to talk to about the outcomes of the review and the benefit of support or counselling for all family members. These were the suggestions provided:



Conclusion

The findings from this survey have provided a valuable insight into the experiences of bereaved families following the death of their child. Families described the overwhelming emotional trauma they felt and how this considerably affected their capacity to process or retain new information or to ask questions at the time of their child's death.

Whilst the findings suggest that many families experienced compassionate care and support from a wide range of services and charities following their loss, for others, their experience was much less supportive. In particular, some families experienced difficulties in:

- accessing bereavement support, including support for the child's siblings to help them make sense of their loss
- accessing and engaging with professionals who knew their child well, to help them understand why their child died
- feeling fully informed about the progress of the review process
- understanding the review process and how they could contribute to it, and
- knowing who to ask and how to access the right person when they had questions about their child's death, especially when a considerable amount of time had passed since their child died.

The identification of a key contact was highlighted as being crucial in preventing families having to repeat their story to different professionals, in clarifying expectations and helping guide them through the review process. Importantly, families talked about the significant emotional impact of their loss, and the need for professionals to recognise that their capacity to process information at the time of the death can be considerably affected. This highlights the need for organisations, with the responsibility for conducting child death reviews, to be flexible in their approaches to engaging and supporting bereaved families prior to, during and after the review process has concluded.

Recommendations

NHS boards, local authorities and public protection committees

1. NHS boards, local authorities and public protection committees should take account of the findings of this report when establishing local arrangements to review the deaths of children and young people.
2. NHS boards, local authorities and public protection committees with responsibility for conducting reviews into the deaths of children and young people should be sensitive, flexible and family-centred in their approach to engaging with and supporting bereaved families before, during and after the review process has concluded. The identification of a key contact for each bereaved family will be vital to guiding and supporting families during this time.

3. NHS boards, local authorities and public protection committees should take account of the [National Guidance](#) for reviewing the deaths of children and young people. This guidance sets out the processes services should follow when responding to, and reviewing, the death of a child or young person.
4. NHS boards, local authorities and public protection committees should develop systems to monitor the quality of reviews to ensure that the views of families and carers are sought and represented in review processes.

NHS boards, local authorities and third sector organisations

5. NHS boards and local authorities, in partnership with third sector organisations, should work together to plan, commission and deliver comprehensive and tailored bereavement support, as outlined in the [Bereavement Charter for Scotland](#) and the [National Bereavement Care Pathway](#).
6. NHS boards and local authorities, in partnership with third sector organisations, should ensure that staff have the necessary skills, knowledge and understanding of child bereavement to effectively support bereaved families and carers, the child's siblings, peers and where appropriate, the local community.

The National Hub

7. The National Hub should continue to work in partnership with third sector organisations and bereaved families and carers, to shape and inform the National Hub programme. Future work should include the development of an information leaflet for families and carers, outlining the child death review process and the rights of families and carers to have their views heard.
8. The National Hub should conduct a rolling programme of audit activity, including surveys and focus groups, to establish whether the experiences of bereaved families and carers improves over time.

For further information about the National Hub, please visit our [website](#) or contact us at hcis.cdrnationalhub@nhs.net.

Useful resources

National Hub for Reviewing and Learning from the Deaths of Children and Young People – National guidance when a child or young person dies: January 2021.

https://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/deaths_of_children_reviews/national_guidance.aspx

National Hub for Reviewing and Learning from the Deaths of Children and Young People - Scoping exercise report: August 2020.

https://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/deaths_of_children_reviews/scoping_report_aug_20.aspx

In their own words - Parents' experiences of the hospital review of their care, Sands Survey: 2021.

https://sands.org.uk/sites/default/files/Intheirownwords_FullReport_0.pdf

In their own words - An analysis of bereaved parents' comments about their experiences of hospital review into their care, Sands Survey: 2021.

https://sands.org.uk/sites/default/files/Intheirownwords_FullReport_0.pdf

Sands 6 Principles of Parent Engagement in Review - Best Practice: September 2021.

https://sands.org.uk/sites/default/files/Sands_BestPractice_Sept21_Digital.pdf

National bereavement care pathway for pregnancy and baby loss – Self-assessment Tools: 2022.

<https://www.nbcpscotland.org.uk/self-assessment/>

Bereavement Charter for Children & Adults in Scotland – NHS Education for Scotland: 2020.

<https://www.sad.scot.nhs.uk/bereavement-charter/>

National Records of Scotland – Vital Events Reference Table: August 2021.

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2020>

National Records of Scotland – Avoidable Mortality: March 2022.

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/avoidable-mortality>

Appendix 1: Family and carer survey

Potential participants were sent a link to the family and carer survey via email. Below is the introductory information provided to families and carers, and the questions asked.

Introduction

Thank you for taking part in this survey. The death of a child or young person is a difficult thing for any family to go through and we are aware that each circumstance is different. Your input is valuable and will help us improve support and engagement with family members and carers following the death of their child, and throughout the review process. If you were unaware whether you had a review or not, it is still important we hear from you.

Please note, the survey does not have to be completed in one sitting. If you wish to save it and return to it at a later stage, you will be asked for your email address and a link will be sent to you to get back to your survey at a future point. The survey will remain open until 31 December 2021.

Terms used in this survey and what they mean

- **'Child'** – this means your child/children or any child or young person who you had caring responsibilities for. If you are completing this as the brother or sister of a deceased child, this means your brother or sister.
- **'Child Death Review'** – this is a formal process which looks back at the circumstances surrounding the death of a child or young person, with the aim of understanding the reasons for it and preventing avoidable deaths in the future.
- **'Bereavement support'** – care and support given to bereaved individuals to help them deal with the emotional and practical challenges following the loss of a child, for example, support sessions or support groups for families and carers, counselling, reading materials, online support etc.

What happens if I do not want to take part, or I start taking part and then change my mind?

We understand this can be difficult so there is no pressure on you to fill out this survey. If you change your mind about completing this survey, or want to skip some questions, you can still share your views in the comments section at the end of the survey (Question 17).

Your answers will only be submitted if you click 'Finish Survey'. Once this has been clicked, it will not be possible to remove your answers, as the survey is anonymous.

Information you provide

By completing this survey, you are consenting to Healthcare Improvement Scotland using the information you provide for the purposes stated in the survey introduction. Any information you give us will only be used for the reasons specified in this survey. We will not give your information to outside organisations (apart from organisations processing the information on our behalf).

The information we collect will be seen by the National Hub team and will then be anonymised; therefore, no one will know which answers are yours. In the interests of confidentiality, please do not include your name in this survey.

Consent

Having read the information above, I understand the survey is about improving family and carers' engagement in the Child Death Review process. I consent to take part in the survey on that basis. I have understood the information above, and I am happy to proceed with the survey.

When you have completed this survey to your satisfaction, please click 'Finish Survey' at the bottom of the final page.

Part 1: We would like to know a little bit more about your circumstances around the time your child died. This will include your understanding of the situation and what support, if any, you received during this time.

1. Can you please let us know how long ago your child died?

- Less than 1 year ago
- 1-5 years ago
- 5-10 years ago
- More than 10 years ago

2. After the death of your child, did you feel you were kept informed and helped to understand what would happen next?

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Prefer not to answer / Unsure / Can't Remember

3. Please use the box below to tell us about what worked well and/or helped and what would have worked better or could have been done differently at the time.

4. Were you offered the opportunity to ask questions or seek answers, to help you better understand the circumstances of your child’s death, with a staff member who was knowledgeable about your child?

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Prefer not to answer / Unsure / Can’t Remember

5. Please use the box below to tell us about what worked well and/or helped and what would have worked better or could have been done differently at the time.

6. Which professions or agencies were most helpful to you after the death of your child?

7. Were you offered, or directed to, bereavement support? (If yes, please go to question 9)

- Yes
- No
- I can’t remember / Unsure

8. Would you have liked to have been directed to bereavement support?

- Yes
- No
- I did not feel I needed bereavement support

9. Have you been able to access bereavement support when you needed it?

Yes

No

I did not feel I needed bereavement support

10. Please provide comment on any bereavement support you have received

11. Please provide comment on any bereavement support offered, or provided to, the child's brothers or sisters or other family members:

PART 2: We would like to hear your views on how we can ensure families and carers are at the centre of the process when reviewing the circumstances surrounding the death of their child. The Child Death Review should provide an opportunity to meaningfully consider families and carers views and any concerns or queries they may have about the care they, and their child, received. The review process will also help to identify practice that contributed positively to the care of the child or young person, and help prevent the death of children and young people in the future.

12. What support, if any, do you think you or your family would have needed to help you contribute to the review process?

13. What do you feel would be the most helpful skills and qualities that professionals or agencies should demonstrate when supporting bereaved families and carers through the review process? For example, being available to answer questions, being a good listener etc.

14. How do you think families should be kept informed of the progress of the review?

- Verbal (e.g. phone call)
- Face-to-Face meeting
- In writing (by email)
- In writing (by letter)
- Other – please state below:

15. How should a Child Death Review report, and anything we have learnt about how to improve future care for children or young people, be shared with families and carers? (Please tick all that apply)

- Verbal (e.g. phone call)
- Face-to-Face meeting
- Copy of the full report
- Copy of the report in plain English / appropriate language
- Summary of what has been learnt
- Indication of action points to improve care for future families
- Other – please state below:

16. What support might families and carers need after the review is completed?

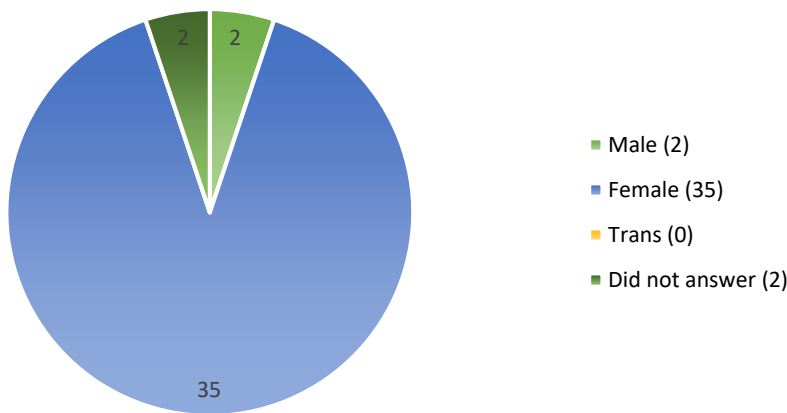
17. If you have any comments that would help us develop the Child Death Review process, please let us know:

Appendix 2: Equality monitoring

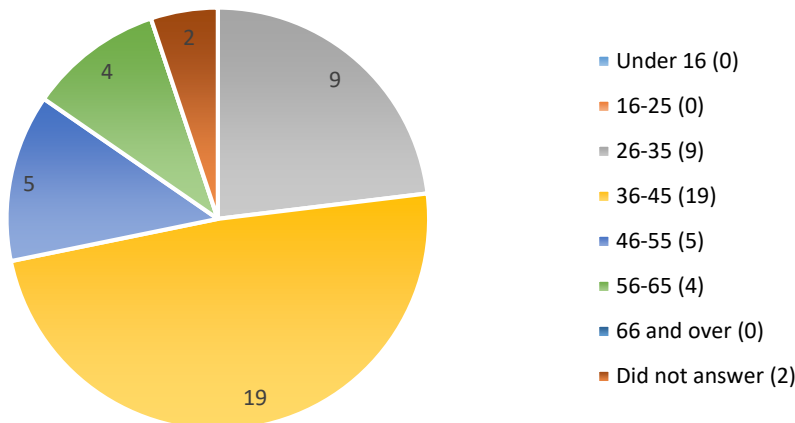
At the end of the survey, families were asked to provide information about themselves as part of an equality monitoring exercise. The purpose of this section was to allow the National Hub to ensure everyone had an equal opportunity to get involved with our work. By asking families to complete this section, we are able to understand whom we have engaged with.

As with all survey responses, the information provided was anonymous and families were able to skip this section if they preferred not to answer. Below is an illustration of the individuals who participated in our survey.

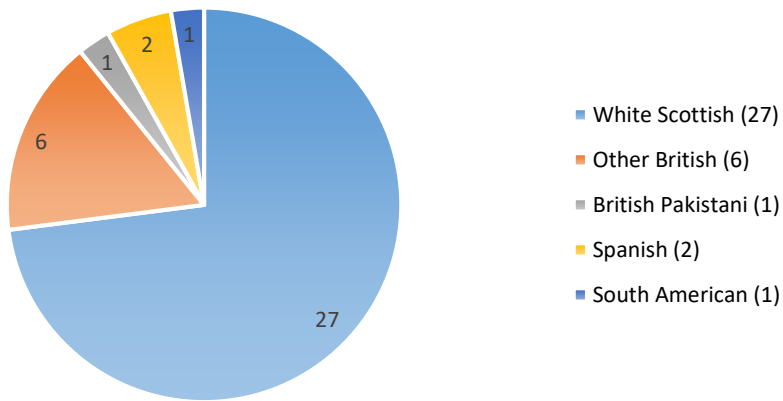
Which one of the following best describes your gender?



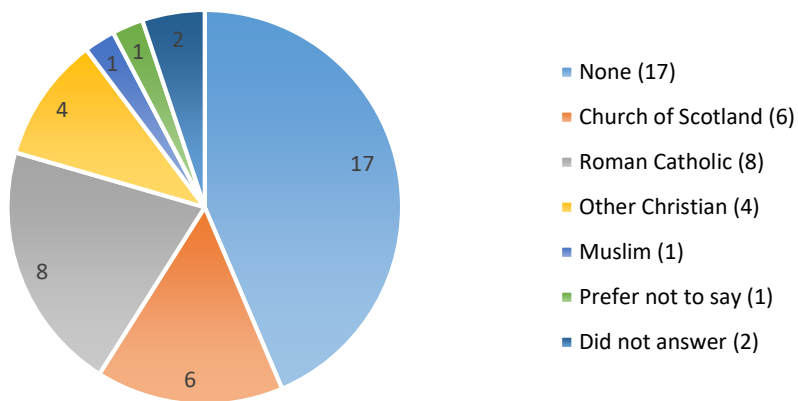
Which age group do you belong to?



What is your ethnicity?



What is your religion or belief?



You can read and download this document from our website.
We are happy to consider requests for other languages or formats.
Please contact our Equality and Diversity Advisor on 0141 225 6999
or email contactpublicinvolvement.his@nhs.net

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