HSIB

HEALTHCARE SAFETY INVESTIGATION BRANCH

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National Learning Report

Giving families a voice: HSIB's approach to patient and family engagement during investigations

Independent report by the
Healthcare Safety Investigation Branch I2020/007

September 2020


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Providing feedback and comment on HSIB reports

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We aim to provide a response to all correspondence within five working days.

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About HSIB

The Healthcare Safety Investigation Branch (HSIB) conducts independent investigations of patient safety concerns in NHS-funded care across England. Most harm in healthcare results from problems within the systems and processes that determine how care is delivered. Our investigations identify the contributory factors that have led to harm or the potential for harm to patients. The recommendations we make aim to improve healthcare systems and processes, to reduce risk and improve safety. Our organisation values independence, transparency, objectivity, expertise and learning for improvement. We work closely with patients, families and healthcare staff affected by patient safety incidents, and we never attribute blame or liability to individuals.

Considerations in light of coronavirus (COVID-19)

A number of national learning reports were in progress when the COVID-19 pandemic significantly affected the UK. Much of the work associated with developing the reports necessarily ceased as HSIB's response was redirected. For this national learning report, while the learning described has not changed due to COVID-19, the processes by which HSIB engages with patients and families had to be adapted. These changes are acknowledged in this report and described further.

National learning reports

These reports offer insight and learning about patient safety subjects in NHS healthcare that have been explored by HSIB. These subjects include the highlighting of risks from recurring themes in investigated events, and exploration of HSIB's experiences in the management of investigations.

National learning reports can be used by healthcare leaders, policymakers, organisations and the public to aid their knowledge of systemic patient safety risks and the underlying contributory factors, and to inform decision making to improve local processes in the management of patient safety investigations.

A note of acknowledgement

We would like to thank the many families who have been involved in investigations and who have provided feedback. The feedback has helped HSIB to evaluate its processes and make improvements for the future.

Our investigations

Our team of investigators and analysts have diverse experience working in healthcare and other safety critical industries and are trained in human factors and safety science. We consult widely in England and internationally to ensure that our work is informed by appropriate clinical and other relevant expertise.

We undertake patient safety investigations through two programmes:

Maternity investigations

From 1 April 2018, we have been responsible for all NHS patient safety investigations of maternity incidents which meet criteria for the **Each Baby Counts programme** (Royal College of Obstetricians and Gynaecologists, 2015) and also maternal deaths (excluding suicide). The purpose of this programme is to achieve learning and improvement in maternity services, and to identify common themes that offer opportunity for system-wide change. For these incidents HSIB's investigation replaces the local investigation, although the Trust remains responsible for meeting the Duty of Candour and for referring the incident to us. We work closely with parents and families, healthcare staff and organisations during an investigation. Our reports are provided directly back to the families and to the trust. Our safety recommendations are based on the information derived from the investigations and other sources such as audit and safety studies, made with the intention of preventing future, similar events. These are for actions to be taken directly by the trust, local maternity network and national bodies.

Our reports also identify good practice and actions taken by the Trust to immediately improve patient safety.

Since 1 April 2019 we have been operating in all NHS Trusts in England.

We aim to make safety recommendations to local and national organisations for system-level improvements in maternity services. These are based on common themes arising from our trust-level investigations and where appropriate these themes will be put forward for investigation in the National

Programme. More information about our maternity investigations is available on our **website**.

National investigations

Our national investigations can encompass any patient safety concern that occurred within NHS-funded care in England after 1 April 2017. We consider potential incidents or issues for investigation based on wide sources of information including that provided by healthcare organisations and our own research and analysis of NHS patient safety systems.

We decide what to investigate based on the scale of risk and harm, the impact on individuals involved and on public confidence in the healthcare system, and the learning potential to prevent future harm. We welcome information about patient safety concerns from the public, but we do not replace local investigations and cannot investigate on behalf of families, staff, organisations or regulators.

Our investigation reports identify opportunities for relevant organisations with power to make appropriate improvements.

More information about our national investigations including in-depth explanations of our criteria, how we investigate, and how to refer a patient safety concern is available on our **website**.

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1 Introductory messages

1.1 Introduction from the Chief Investigator

HSIB's purpose is to conduct independent investigations of patient safety concerns in NHS-funded care across England. It does this via national and maternity investigation programmes. Central to this is the effective support of patients and families to engage with investigations to share their insights and participate fully from beginning to end. I am therefore pleased to introduce this national learning report exploring HSIB's approach to family engagement.

In the past decade, the healthcare sector has recognised the need to ensure it works with patients and families, highlighted by the many reports published nationally about patient safety investigation and learning from deaths. However, it is also recognised that undertaking family engagement of a high quality can be challenging, particularly when the guidance on how to do it is limited.

I welcome the opportunity to share HSIB's approach and process for family engagement in this report. It is informed by years of experience working within healthcare and non-healthcare organisations. The intention of this report is to share HSIB's experiences so organisations can, should they choose, understand and reflect on how HSIB's experience may be applicable to them.

Healthcare safety investigations are an opportunity to learn and improve systems and processes to reduce risk and improve safety. Including the family's voice in investigations is fundamental to bringing about these improvements.

Keith Conradi
Chief Investigator, HSIB

1.2 Message from one of our families

I first came across HSIB after the death of my younger daughter, Kaitlyn, at the very end of pregnancy and during early labour. Kaitlyn's circumstances met all HSIB's criteria and did therefore warrant further investigation.

We first met our HSIB investigator in our home a couple of weeks later, having already exchanged messages and phone calls. I will forever remember our investigator as one of the most wonderful people I have ever met. Her manner with us was completely professional and wonderfully compassionate. She listened to every word we said and explained everything thoroughly without ever making us feel patronised.

Our investigator was completely up front about how long the report would take to complete, so our expectations were set from the start. After every conversation she set a date and time to call me again and she never once missed

one of those appointments. After months of fighting alone, we finally felt that someone cared about our story and cared about trying to get to the bottom of what happened to our baby.

All I have wanted since Kaitlyn died was to know that lessons would be learned and improvements made. I will forever be grateful to HSIB for enabling that to happen. Nothing will ever ease the pain of losing our beloved daughter, but the way we were included, respected and cared for throughout the process allowed us to finally start finding some peace. I firmly believe that other organisations, both in healthcare and in other sectors, have a huge amount to learn from the way HSIB engages with families. I hope that these organisations take the time to reflect on the contents set out in this report and build it into the way they work with families following serious and catastrophic events.

Kaitlyn's Mum

2 Introducing HSIB's family engagement

2.1 Definitions

HSIB defines family engagement as **'the prompt, effective liaison between a family and an investigation to ensure the family is integral to the investigation and is treated professionally, respectfully and according to their individual needs'**. This definition is adapted from the historical National Policing Improvement Agency (NPIA) family liaison guidance (National Policing Improvement Agency, 2008), which is a proven family engagement process that has existed for many years.

To ensure HSIB's engagement approach is as unique to the individual as possible, **'family'** is defined in maternity and national investigations as including **'patients, mothers, partners, parents, siblings, children, guardians and others who had a direct and close relationship with the individual concerned'**. It refers to the person or patient (the individual) to whom the incident occurred, their family and close relationships. Within this report, patient and family engagement will simply be referred to as family engagement.

2.2 Overview

HSIB's family engagement is embedded throughout the entire investigation process, aiming to facilitate continuous involvement and support. For HSIB, support is the creation of an environment where a family can share their insights to inform an investigation, have their questions answered within the boundaries of an investigation, and be signposted to further help if required.

The HSIB approach has developed from listening to families who have experience of investigations within healthcare, and learning from other services such as policing. HSIB's view is that meaningful engagement with families throughout the investigation process can support the production of high-quality reports and an improved experience of the investigation for all involved.

2.3 Purpose of this report

This report aims to provide an overview of HSIB's approach to family engagement in the investigations it has undertaken to date, sharing what has worked well and what has been learned. HSIB recognises its unique investigating position compared with many other organisations. As an organisation undertaking independent investigations it can focus on learning without blame or consideration of liability.

HSIB is hopeful that by explaining what has worked well for its investigations, what has needed improvement, and how it has continually evaluated its processes, valuable insights can be shared for consideration by any healthcare

organisation that undertakes safety-related investigations. It is hoped that this report will help raise awareness of the difference that can be made when an effective process is used for family engagement.

In the long term, HSIB is developing formal family engagement guidance which will be shared externally for organisations to access and use if relevant. This guidance will consider the available evidence and recommendations in support of family engagement.

2.4 Scope

This report focuses on HSIB's approach to family engagement. The word 'family', as defined in section 2.1, is used to refer to the patient and their family in HSIB national investigations, and the woman/mother and their family in HSIB maternity investigations.

HSIB undertakes up to 30 national investigations and around 1,000 maternity investigations per year. There are differences between the investigation processes used in the national and maternity programmes. This is because national investigations focus on a patient safety concern, while maternity investigations follow defined criteria as described on the **HSIB website** (Healthcare Safety Investigation Branch, no date a) and focus on a specific case. Despite these differences, the principles of meaningful family engagement remain the same.

This report will highlight specific differences between processes in the national and maternity programmes.

HSIB recognises that there are specific expectations of individual healthcare organisations when undertaking investigations, including disclosure of the incident and Duty of Candour in line with national requirements. This report does not cover these specific aspects as they are expected to have been undertaken by the organisation/trust where the initial incident occurred.

2.5 COVID-19

This report was initially prepared prior to the restrictions implemented as a result of the COVID-19 situation. The authors acknowledge that the contents of this report are based on HSIB's experiences pre-COVID-19. In the context of COVID-19, HSIB has had to adapt elements of its approach to family engagement. This has meant that face-to-face meetings were unable to take place and therefore HSIB undertook virtual meetings with family agreement.

HSIB believes that face-to-face family engagement is important, but that the priority must be the safety of patients, families and staff. Even if face-to-face engagement is not possible, the principles within this report remain. As guidance changes in light of COVID-19, HSIB will constantly review its approach.

3 Background to HSIB's family engagement

3.1 Aims of family engagement

Effective family engagement should underpin every healthcare safety investigation. Family members may be the only people with insight into what has occurred at every stage of a person's journey through the healthcare system. Not obtaining those insights results in an incomplete investigation.

HSIB's aims for family engagement are to:

- work with families to sensitively gather all relevant information in the context of the defined investigation
- understand the needs, expectations and concerns of families to ensure appropriate information and advice is given, and, where HSIB cannot assist, signpost families to relevant agencies.

HSIB's objectives for family engagement are therefore to:

- secure the confidence and trust of the family members to ensure they are treated as integral to any investigation
- gather information from the family in a way that contributes to the investigation
- provide information and facilitate the required support for the family in a sensitive and compassionate way
- support the family to understand the findings of HSIB investigations and the recommendations
- inform the family of the reasons for ending the family engagement role at the completion of an investigation and ensure any signposting to other agencies is revisited.

3.2 The importance of family engagement

National reports from the past decade clearly articulate the importance of family engagement, highlighting that families often feel excluded from investigations. HSIB recognises that efforts are being made to provide meaningful family engagement, but this does not yet appear to be consistent across all healthcare organisations. Examples include the development of family liaison officer roles. Appendix 10.1, although not exhaustive, describes some of the key themes, recommendations and statements that have informed HSIB's family engagement approach.

Academic literature over the years has added value to what is known about family engagement, but at present there is relatively little academic evidence that underpins how it should best be undertaken in healthcare investigations.

While this report does not seek to provide an extensive literature review, HSIB has drawn principles from such examples as Vincent and Davis (2012) who described patients as 'privileged witnesses of health care in the sense that they are at the centre of the treatment process, and, unlike individual clinical staff, they observe almost the whole process of care'.

This report has also explored international practice, in particular through liaison with colleagues in Norway (Wiig et al., 2019; Wiig, et al., 2020) and Canada (Patient Engagement Action Team, 2017).

4 The HSIB approach to family engagement

Commentary over the last decade has described the requirements of families during investigations and the need for meaningful family engagement. However, there is yet to be a specific and detailed national framework or process to assist those working with families during investigations.

Failing to collaborate effectively with families excludes their experiences from investigations and perpetuates feelings that their voices are not heard. This is compounded when families are not informed of incidents and investigations, not updated on what is happening during investigations and not given the opportunity to influence improvements. Poor engagement may inflict further harm to families.

With this in mind, HSIB has developed a set of five fundamental principles (figure 1 and table 1) for effective family engagement. These principles were informed by the available literature, experience in other industries and consultation within HSIB.

Up to April 2020, the fundamental principles have been applied to more than 1,700 HSIB investigations and have evolved during this time based on feedback from families and staff.

HSIB's position as an investigating organisation with dedicated investigators allows the family engagement principles to be embedded and developed. It is recognised that HSIB's role in healthcare safety investigation is different to that of many other healthcare organisations and therefore putting into practice some of the family engagement principles described may be more straightforward. However, HSIB believes that the principles it follows for family engagement may be of interest to other healthcare organisations when reflecting on their own processes.

Fig 1 HSIB's fundamental principles for effective family engagement

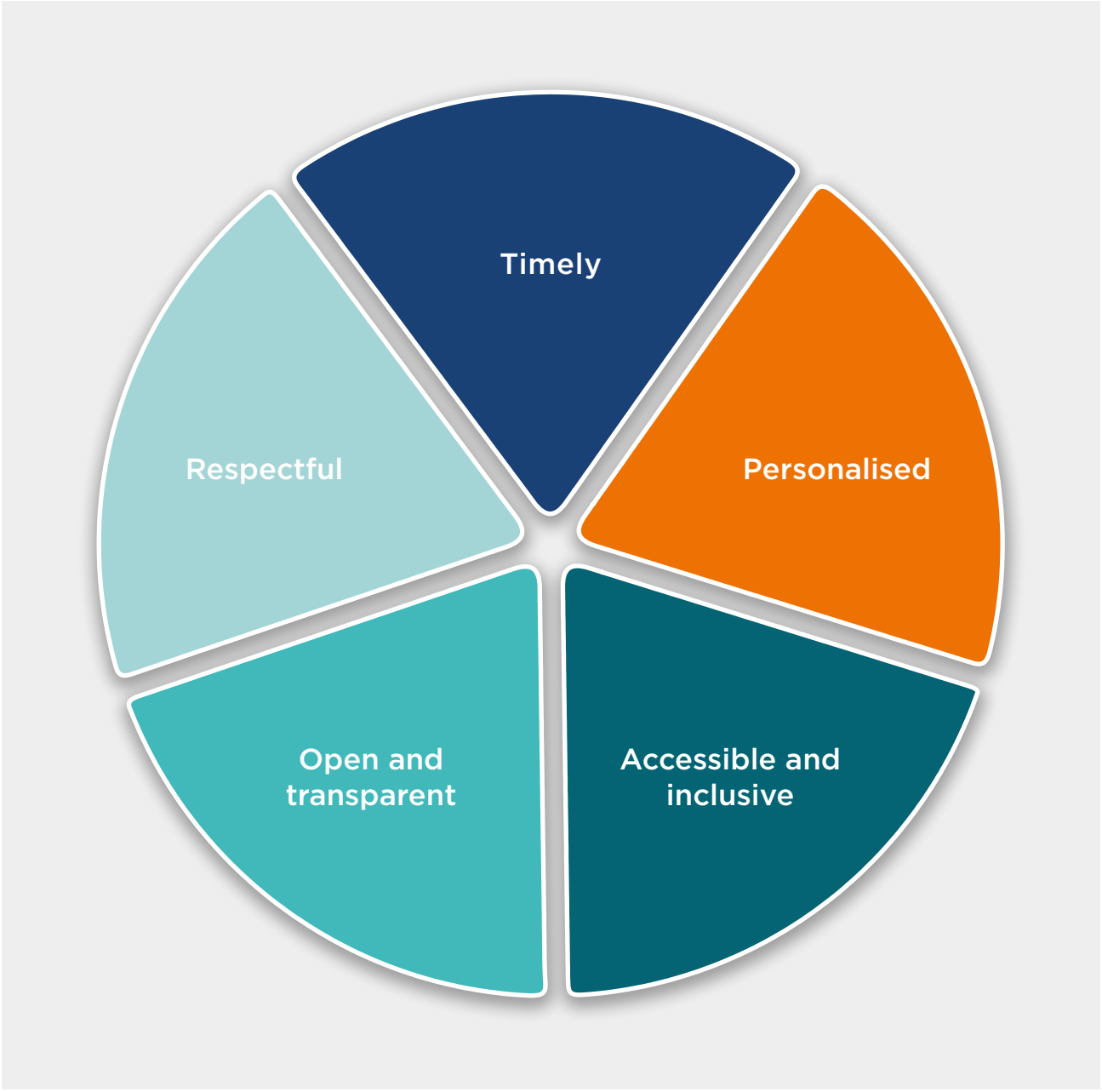


Table 1 HSIB's fundamental principles for effective family engagement

Principle	Descriptors
Personalised	• All families are given a choice about whether and how they wish to be involved in an investigation. • Families have a voice and are heard during investigations with opportunities to ask their questions.
Accessible and inclusive	• Families are integral to investigations by providing significant inputs. • Any family member is included, should this be appropriate and their wish. • Families are given a named contact within the investigation team and this continuity is kept wherever possible. • Staff are suitably trained and supported to undertake their family engagement activities.
Open and transparent	• Investigators are open and honest with families about what they have found.
Respectful	• Investigations are conducted compassionately. • The effects that incidents may have had on families are considered and support is provided or signposted to throughout.
Timely	• Investigations are undertaken efficiently. • Regular updates and feedback are provided to families with their agreement.

5 The HSIB process for family engagement

5.1 An overview of the approach

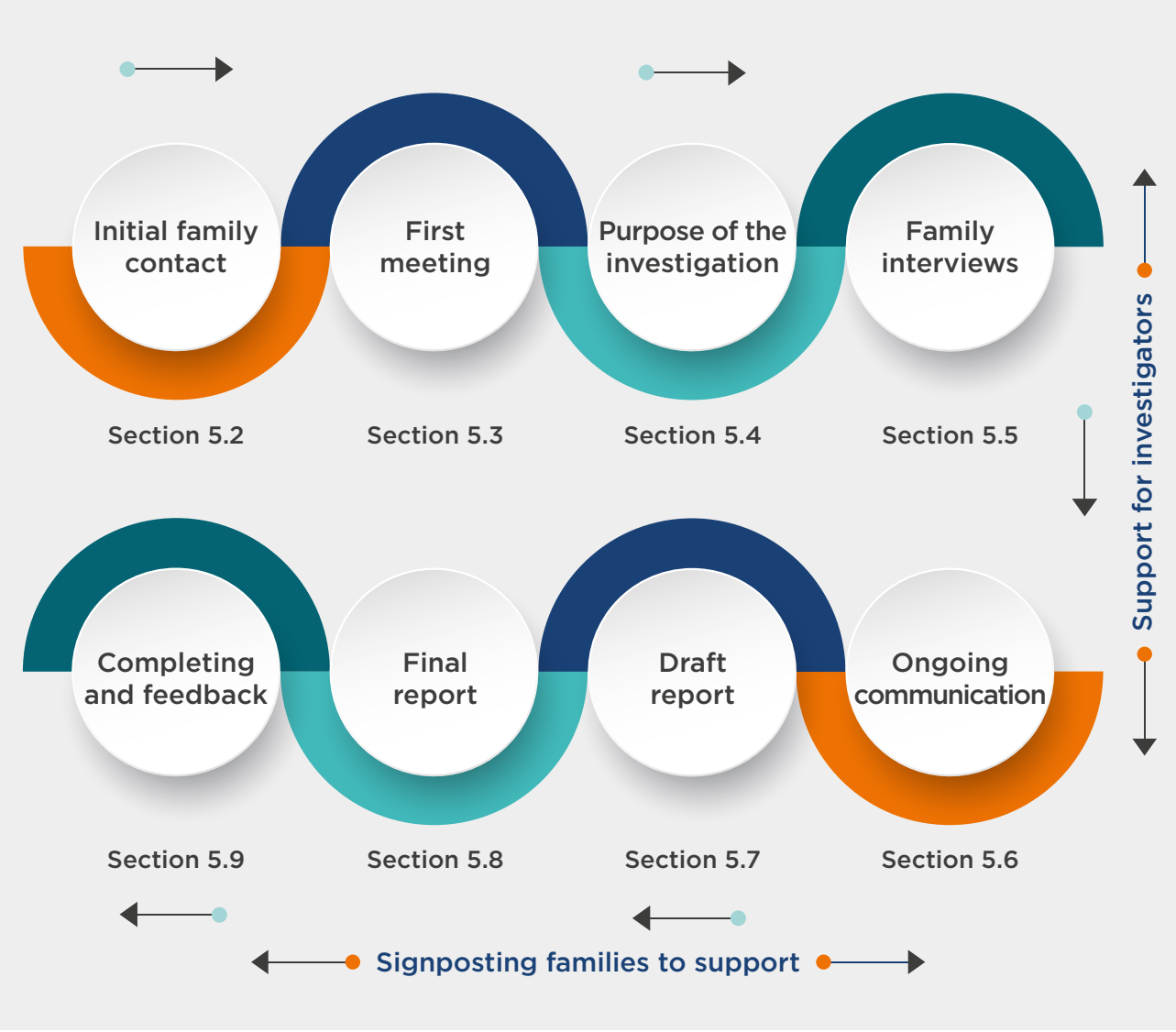
A general overview of HSIB's family engagement process is shown in figure 2. There are differences between the national and maternity programme investigation processes; these are described where relevant in the following sections.

5.2 Initial family contact

5.2.1 Preparing for the initial contact

HSIB believes that the most crucial component of family engagement is the initial contact with the family, as first impressions can greatly influence the subsequent success of any ongoing communications. The initial contact with the family is usually made by phone and should be timely, sensitive, honest and informative.

Fig 2 Overview of HSIB's family engagement process



Although there is a need for the initial contact to be prompt, care and consideration should be given to its planning. Any HSIB staff making the initial contact should ask themselves the following questions:

- What information is known about the family and the circumstances of the incident?
- What family contact details are available?
- Who is being contacted and what is their relationship to the person who was central to the incident under investigation?
- Does the family have any specific communication needs (see section 5.6)?
- Has any preferred method of contact been requested by the family?
- Are there any significant dates or times to contact, or not contact, the family (for example, birthday or day of a funeral)?
- What is the objective of the contact with the family and what are the family's priorities and objectives for any investigation?

HSIB recognises that the initial contact may occur at a time when a family is not ready to engage with an investigation. This may be because family members are grieving or unable to be involved. HSIB staff are flexible about when family members may wish to be involved and how they want to be involved.

5.2.2 Making the initial contact

For HSIB investigations the purpose of the initial contact is to introduce the family members to the investigation process and obtain their explicit consent to access medical records and take part in the investigation. This decision should be facilitated by providing appropriate information about how the investigation will take place and how the family could be involved. It should be an informed decision and investigators should take time to answer any questions, concerns or needs of the family while managing expectations to avoid raising false hopes.

HSIB investigators are mindful that the family member with whom initial contact is made may not be the only family member who has useful information about the incident under investigation. Engagement may be needed with a number of family members. Some families may wish to nominate one member as a central point of contact within their family to manage conversations with the investigation team; this should be discussed for each individual case. During these early discussions investigators should also find out how best to refer to

family members by name to help personalise their approach.

At the end of the initial contact, HSIB investigators agree a timescale with the family for when their next contact will be, how it will be made and who will be making it.

Every family contact should be documented, including this initial contact. This documentation provides investigators with a useful record of what was discussed. It can also be used to inform written communication with the family to confirm the conversations that have taken place. This type of follow-up communication can support family members who may be finding it hard to retain information due to the circumstances they are in.

5.3 First meeting

5.3.1 Preparing for the first meeting

HSIB believes that meeting the family in person is the best way to explain the investigation process and realistic timescales, and to answer immediate questions. Investigators' priorities and a family's priorities may not always be the same and therefore sensitive and honest conversations assist with understanding each other's perspectives. An in-person meeting also helps to highlight the importance HSIB places on family participation.

In preparing for the first meeting, the same principles apply as per preparing for the initial contact (see section 5.2.1). The timing and location of the meeting needs careful consideration in partnership with the family. In most cases, the investigators will meet the family at their home address. In cases where this is not suitable or when restrictions exist for safety reasons (for example, COVID-19 and the need for social distancing), alternative locations or communication methods will be considered. If meeting face to face, it is important to remember that the family may not wish to meet at the hospital where the events under investigation took place or any similar setting.

Prior to the meeting, investigators will try to estimate how long the meeting will last and explain this to the family. This will include any additional time for specific communication needs such as interpreters. It may be necessary to build breaks into the meeting, particularly if family members are finding conversations emotionally challenging or difficult.

Wherever possible, and before any meeting, investigators check that the day of the visit is not a significant date for the family. For example, the date may be a family birthday, anniversary, or religious festival. This may not exclude the meeting from taking place, but should be discussed with the family members to find out whether they feel it is still an appropriate day to meet.

HSIB recognises its responsibility for minimising any potential risk to family members and its investigators. During conversations it is possible that some family members may become distressed, angry, or present investigators with complex social situations. Before the first meeting, investigators should consider potential risks and prepare strategies to deal with them. They should also do this before any subsequent meetings, as circumstances may change.

5.3.2 Undertaking the first meeting

On the day of the first meeting, investigators ensure they give themselves enough time to arrive at the meeting. An investigator leads the meeting, which should not be rushed and should allow time for family members to ask any questions they might have.

At the meeting clear objectives for the meeting are set by investigators; this should be done for any family visit. Clear objectives ensure the family knows what to expect from the conversations. Investigators will then sensitively discuss the purpose of the investigation (this is covered in more detail in section 5.4). Towards the end of the meeting, investigators summarise what has been discussed and agreed, and ensure that the family understands the next steps. It is important that family members know when to expect the next contact from HSIB and how they can contact HSIB if they need to.

Investigators should always ensure that any promised contact takes place. The family will be expecting the next agreed contact and an update on the progress of the investigation. Therefore failing to make contact as promised, without letting the family know beforehand, would harm the relationship with the family and further engagement would be needed to re-develop trust.

5.3.3 Information for families

HSIB recognises the importance of written information for family members, who may find it difficult to retain detail in what is likely to be a new, unfamiliar and unwelcome situation. Any information provided should be accessible and available in plain language or a suitable format as agreed with the family; information should also contain details of their contact person at HSIB. HSIB considers that continuity of a named contact is extremely important to ensure that repetition is avoided and to highlight the family's value in the investigation.

HSIB has developed a library of literature to help families understand the investigation process and their role within it. A number of these documents have been produced with the assistance of families who were involved in early HSIB

investigations. As an example, a list of the literature for HSIB's maternity investigations is available in appendix 10.2.

5.4 Explaining the purpose of the investigation

Within a maternity investigation, terms of reference are developed outlining the purpose, approach and intended goal of the investigation. Within a national investigation, the purpose of the investigation depends on whether it is a preliminary or full investigation, and this will be discussed with the family.

The purpose of any investigation should be shared with the family for their awareness, input and understanding. Family members will often have unique and valuable information that they can contribute to an investigation and may also have their own questions and desired outcomes from any inquiry. These should be considered as part of the investigation.

HSIB investigators will discuss the purpose of the investigation openly with the family. It is important that the family understands the goal of an HSIB investigation, and what it can and cannot provide. For example, HSIB investigations aim to identify learning to prevent a similar incident happening again, but do not apportion blame. A family may sometimes need signposting to additional information or other organisations if their questions fall outside of the goal of the investigation.

Clarifying the purpose of an investigation is vital to set expectations and ensure that the family does not feel confused or unnecessarily disappointed about the outcome of the investigation. Investigators must be mindful of other inquiries that are being undertaken at the same time (for example, by Her Majesty's Coroner) and that these inquires may also involve family participation. It is important for all parties to remember the boundaries of the HSIB investigator role and the investigation itself in order to manage the family's expectations.

5.5 Family interviews

The family interview provides valuable insights for HSIB investigators and gives the family an opportunity to share their perspective and concerns.

The purpose of the family interview is to gather information from the family to inform the investigation. It also helps investigators to understand the context within which the incident happened and any questions the family might have.

The timing and method of gaining information from a family should be carefully planned by investigators. Flexibility is required to ensure family members understand the choices available to them for the interview and the purpose of the interview. Like the first

family visit, consideration will be given to the location for the interview and how family members want to share their information. The family needs to understand the rationale for interviewing and options for how their information will be used. Some family members may wish to have someone with them for support during phone calls or meetings, for example another family member, friend, or advocate, and this should be encouraged.

HSIB investigators are trained to conduct interviews. When conducting the interview, they will provide a clear introduction and use appropriate questioning techniques. Investigators will summarise the main points of the interview at the end, and explain the next steps of the investigation. HSIB interviews are recorded, with family members' agreement, and once the interview is complete, the family is able to access a recording of their interview. The family is then welcome to add further information to the investigation at any time during the process.

5.6 Ongoing communication

5.6.1 Communication skills

An HSIB investigator's communication style and skill is of paramount importance when communicating with a family. HSIB encourages its investigators to actively listen, show openness, demonstrate empathy and create a rapport with the family. The family will then be more comfortable about sharing their experience and will also feel supported throughout the investigation.

HSIB recognises that communication should be a two-way dialogue to allow the imparting and receipt of helpful and accurate information. The use of plain language and avoiding jargon or acronyms will ensure the family understands the investigator. Where appropriate, checking understanding and summarising can ensure the intended message was received and understood.

5.6.2 Effective ongoing communication

Investigators will agree with the family the frequency of future contacts and the preferred method of contact. A single point of contact within the family is useful to maintain ongoing communication between investigators and the family. However, HSIB recognises that this is not always possible and particular family circumstances might necessitate additional considerations.

A family in distress may need more regular contact and written guidance to help understand and retain information, particularly in the earlier stages of an investigation. In some cases written communication may be the preferred choice for the family.

As part of HSIB's family engagement approach, barriers to communication have been considered. These may include the need to communicate in alternative languages via interpretation or translation, or other language formats such as easy-read or audio. Specialist language services are available to ensure the family can fully participate and understand the final report, which can also be translated if necessary. Investigators can also access specialist knowledge to find out about relevant cultural or social factors.

Investigators keep written records of all contact made with the family. This provides evidence of the contact and discussions that have taken place. These records are kept securely and are subject to relevant HSIB information governance procedures.

HSIB has developed an explanatory document for maternity investigations that shows at a glance what the investigation process is and when families might expect certain aspects of the investigation to happen (see appendix 10.3). This helps families to understand when they might be contacted and how the investigation will progress.

5.7 Draft report

Once an investigation report has been drafted, the family is given the opportunity to review it for accuracy and to provide comments. The intention is that the report appropriately reflects the family's account of the incident. HSIB investigators try to prepare family members before they read this first draft as revisiting the incident, and the contents of the report itself, can be upsetting.

The style and presentation of HSIB reports will be discussed with the family, including the fact that the report may be anonymised to remove any identifiable information. HSIB's maternity investigators have a sample report to share with family members so they can see the format. HSIB's previous national investigations are available to view on the **HSIB website** (Healthcare Safety Investigation Branch, no date b).

When the draft report is shared with family members, they are informed about the timeframe for feeding back their comments and who else is being given an opportunity to view the report. The length of the consultation period will depend on the type of report and the family's circumstances. Investigators also provide additional information, such as the difference between findings and recommendations.

5.8 Final report

The final investigation report is shared with the family by HSIB investigators once the investigation is complete. This may be in the form of a translated or adapted version of the report if required. HSIB is able to provide

reports in alternative languages or more accessible formats such as large print.

The investigators let the family know who else has access to the final report. For maternity investigations this will include the healthcare trust where the incident took place. For national investigations the reports are publicly available and published on the **HSIB website** (Healthcare Safety Investigation Branch, no date b).

In the case of maternity investigations, a meeting between the family and the relevant healthcare trust is encouraged. This can allow family members to discuss their experience, the findings of the report and what actions have been taken following the investigation. Maternity investigators can attend all or part of this meeting.

5.9 Completing the investigation and feedback

When the investigation is complete, the process of family engagement also concludes. If the initial contacts were managed effectively, the family should be expecting and anticipating this. The investigators will have explained the timescales at the first meeting and at regular intervals throughout the investigation. When they conclude their contact with the family, investigators will revisit the need for any onward signposting for additional support or advice.

HSIB encourages and values feedback from families at any point during an investigation. At the end of an investigation family members will be asked directly whether they would provide HSIB with feedback about its process, either at that time or at any point in the future. There is also a link on the **HSIB website** that families can use to provide feedback (Healthcare Safety Investigation Branch, no date c).

5.10 Signposting families to support

HSIB recognises that all investigations are different and a family may have additional needs, questions or concerns outside the scope of the investigation. The investigators or family members themselves may identify these needs during their conversations. It is important for an HSIB investigator to understand the purpose of the investigation, their scope of practice and that they are not trained to deliver clinical advice or professional emotional support. They should be able to effectively signpost the family to other support as required. Signposting might include directing the family to support for emotional, practical, medical, legal or financial advice. HSIB investigators have access to information about national support and advocacy organisations, and can search for local services.

If required, HSIB investigators will liaise with the healthcare organisation/trust where the incident occurred to develop a collaborative plan for how to support the family.

5.11 Supporting investigators

HSIB recognises the challenges of the investigator role and therefore seeks to support its investigators, for example through direct line management, peer support, specialist assistance or debriefing. HSIB has developed a peer support programme that enables all staff to request a personal and confidential conversation with a trained facilitator. These facilitators also attend team meetings to discuss resilience strategies and the general challenges of the investigator role.

The support provided to HSIB staff recognises the need to look after them as individuals, and that staff who are well supported are much better placed to work effectively and sensitively with families.

In August 2018 HSIB appointed a Head of Family Engagement to develop the processes, training and ongoing structures to support investigators. The responsibilities of the Head of Family engagement include:

- supporting investigators to deliver family engagement, including providing advice on complex situations
- the management of internal and external processes for family engagement during HSIB investigations
- reviewing and learning from evaluation of the family engagement process
- supporting staff involved in family engagement to make improvements in their own practice and support their wellbeing
- identifying and sharing good practice
- delivering induction and ongoing training for HSIB investigators, and facilitating external training as required.

5.12 Training and education of investigators

HSIB aims to ensure its investigators have comprehensive initial training and regular development opportunities, enabling them to engage with families and conduct investigations effectively.

Staff learn about HSIB's approach to family engagement in their initial and ongoing training. Investigators are given opportunities to attend workshops and development days, both internally and externally. To date, these additional opportunities have covered subjects such as:

- how to work sensitively and effectively with patients and families
- diversity awareness
- enhanced bereavement training.

6 Evaluating the HSIB approach to family engagement

6.1 Approaching families and investigators for their feedback

To ensure HSIB's approach to family engagement is effective and to better develop it in the future, families and investigators are approached for their feedback. Feedback from families received up to the end of 2019 was explored to gather their insights into the process. HSIB investigators were also surveyed for their perceptions of the process.

Fifty families responded to a formal survey and their responses were analysed as part of this report. A copy of the survey is provided in appendix 10.4. Responses predominantly related to maternity investigations, but also included four responses in relation to national investigations. Sixteen HSIB investigators across the maternity and national programmes provided responses to the formal survey. A selection of comments are shared in this report, with the respondents' consent.

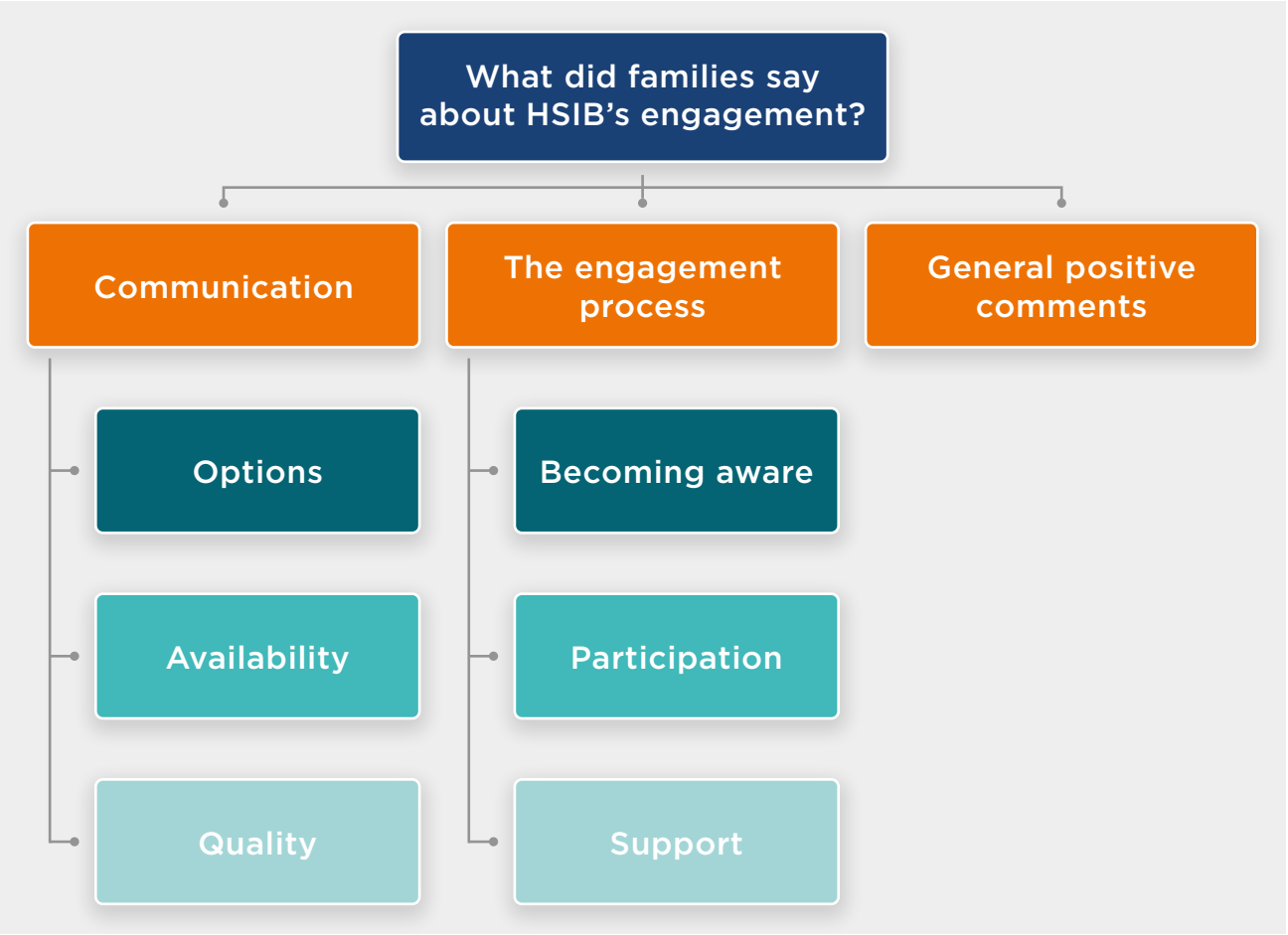
Subsequently, due to the delayed publication of this report as a result of COVID-19, a further six months of family feedback received up to the end of June 2020 was reviewed. During this period a further 88 families provided feedback, again mainly related to maternity investigations. This more recent feedback supports the themes identified in this report.

6.2 What did families say about HSIB's engagement?

Families were positive about HSIB's family engagement with the majority of respondents strongly agreeing or agreeing with statements in the survey. Families felt they were given options for how to communicate with HSIB; their investigators were flexible; HSIB worked to enable them to feel part of the investigations and their perspectives were considered; investigators kept them updated; and they were signposted to support when this was needed.

Feedback from free-text answers was reviewed and themes emerged to help identify what HSIB is doing well and where it can improve. Figure 3 provides a representation of the themes highlighted by families. The main themes related to the quality of communications, the engagement process and general positive thoughts.

Fig 3 Main themes from family engagement feedback



6.2.1 Communication

The feedback helped HSIB explore how it exchanges information with families as part of the investigation process, including options for communication, the availability of investigators and the quality of communications.

HSIB communicates with families using different methods and this flexibility, including the use of translation or interpretation services, was recognised. Families highlighted the importance of face-to-face meetings; these were missed by families during the COVID-19 period.

> 'As a family we had a face-to-face meeting to discuss the draft [report] and made significant suggestions and changes. This of everything was the most important part of the liaison process.'
> Family Member

Investigators were available, meaning that families could make contact with them when they wanted to ask questions. This ease of access also meant families were kept up to date with the progress of investigations at intervals decided by them; this highlights HSIB's individualised approach.

Depending on a family's wishes, contact should be maintained during an investigation to discuss any concerns the family might have. Even brief updates, particularly as the investigation progresses and while work is happening in the background, are important and asked for by families.

'There was one quite long period without any communication, so just a quick text even just to say process is still ongoing would be helpful.'
Family Member

When making contact, investigators should recognise that inappropriate timing can have a negative impact on a family. The time of day, day of the week, whether it is close to an important date and whether ongoing support is available should be considered.

One comment highlighted the importance of HSIB having disengagement strategies following completion of an investigation. While families may welcome remaining in contact with investigators, this is not a sustainable support mechanism and expectations should be clarified with signposting to further support.

Families described their feelings about the quality of HSIB's communications. They described investigators undertaking contacts with kindness, sensitivity and support. Families felt their questions were appropriately responded to.

'We felt extremely supported and cared for through the interview and further chats, I got the feeling they really cared for us and appreciated our situation.'
Family member

Feedback also highlighted that HSIB should ensure families are aware of the investigation role of HSIB versus the role of the organisation where the incident occurred, which may undertake its own investigations. This would help manage expectations, define boundaries and allow families to direct their questions appropriately.

6.2.2 The engagement process

Feedback allowed HSIB to understand how families felt they were engaged with during investigations. This included how they became aware of HSIB, how they participated in investigations and how they were supported.

Families described how they first became aware of HSIB and the purpose of its investigations. The feedback focused on the early stages of investigations and how information about HSIB was shared with them; in maternity investigations this is done by the hospital trust. There was evidence of variation in the level of information provided to families by trusts, which initially caused confusion.

‘We were initially informed about the involvement of HSIB by the consultants…and the message we received from them wasn’t particularly clear… This was allayed upon speaking to the HSIB investigator but I do wonder if there could be a more informed way of letting the families know about the involvement of HSIB.’
Family member

HSIB needs to engage further with trusts to ensure that initial information provided to families is correct and clear. The information should be clear about the role of the trust, the role of HSIB and the intended purpose of HSIB investigations.

It was evident that a family’s role in their investigation was important to them. Families felt encouraged to be part of HSIB investigations, ensuring their narratives were heard. The positive impact of this was evidenced by expressions of satisfaction and feeling reassured that they were an important part of the investigation.

‘We absolutely felt part of the investigation and that as the parents our concerns and feelings would form a key part of things.’
Family member

Families discussed their role in ensuring the accuracy of HSIB’s findings in reports. Families felt that, through their participation, they were able to support the writing of reports to ensure a high-quality output.

One comment confirmed the need for investigators to be sensitive to the impact of recent events on the accuracy of a family member’s memory and the need to revisit information regularly throughout an investigation.

‘…I felt like I remembered things a little better later on or that I was able to communicate them better later on but it was a bit too late by then as the report was pretty much complete and staff interviews already finished.’
Family member

Other comments highlighted the need for HSIB to ensure that family feedback on the content of reports is always listened to and that investigators work with families to ensure they understand the rationale for not including or changing information in a final report. Again, this relates to ensuring families are clear about the role of investigations. If expectations are not addressed early on, it can lead to the undermining of engagement and further distress for families who are trying to get answers about what has happened.

Support of families by HSIB was also considered. Families felt that the informal support received from investigators was positive and therapeutic.

'[The investigator] has supported me throughout the whole process and has actually helped me to come to terms with what happened.'
Family member

Some feedback did highlight a further need for HSIB to appropriately signpost to support and help families to access it; it was sometimes unclear to families what support services were available to them.

Reports can take a long time to complete, and HSIB should be aware of the impact this can have on the family, and therefore the potential need for further ongoing signposting.

6.2.3 General positive comments

The majority of family feedback on HSIB's approach and the experience of engaging with investigators was positive. Many families included thanks for the efforts to ensure they were engaged with throughout the investigations. This highlights the quality and consistency of the approach used by investigators.

6.2.4 Other feedback from families

While not the focus of this report, families also commented on their perceptions of HSIB's processes. Families generally felt that the reports produced by HSIB were of high quality and set out the facts that they were keen to understand to a good depth.

HSIB is modelled on similar investigation branches in the transport sector, and therefore comparison is expected. One comment suggested that the depth of investigation was not the same as that of an air accident investigation. A few comments highlighted that families wanted HSIB investigations to apportion blame and enforce recommendations, but this is not the purpose of an HSIB report.

Families also commented on impartiality with maternity reports. There was a challenge to HSIB about whether a report is truly impartial if the hospital trust involved has been allowed to comment on the contents of a draft report before the family has had the opportunity to comment.

Families described the positive impact HSIB investigations had in finding out the truth of what had happened, particularly with the knowledge that they were transparent and independent. The role of investigation reports in sharing learning with the healthcare community to prevent similar incidents happening to others was also recognised.

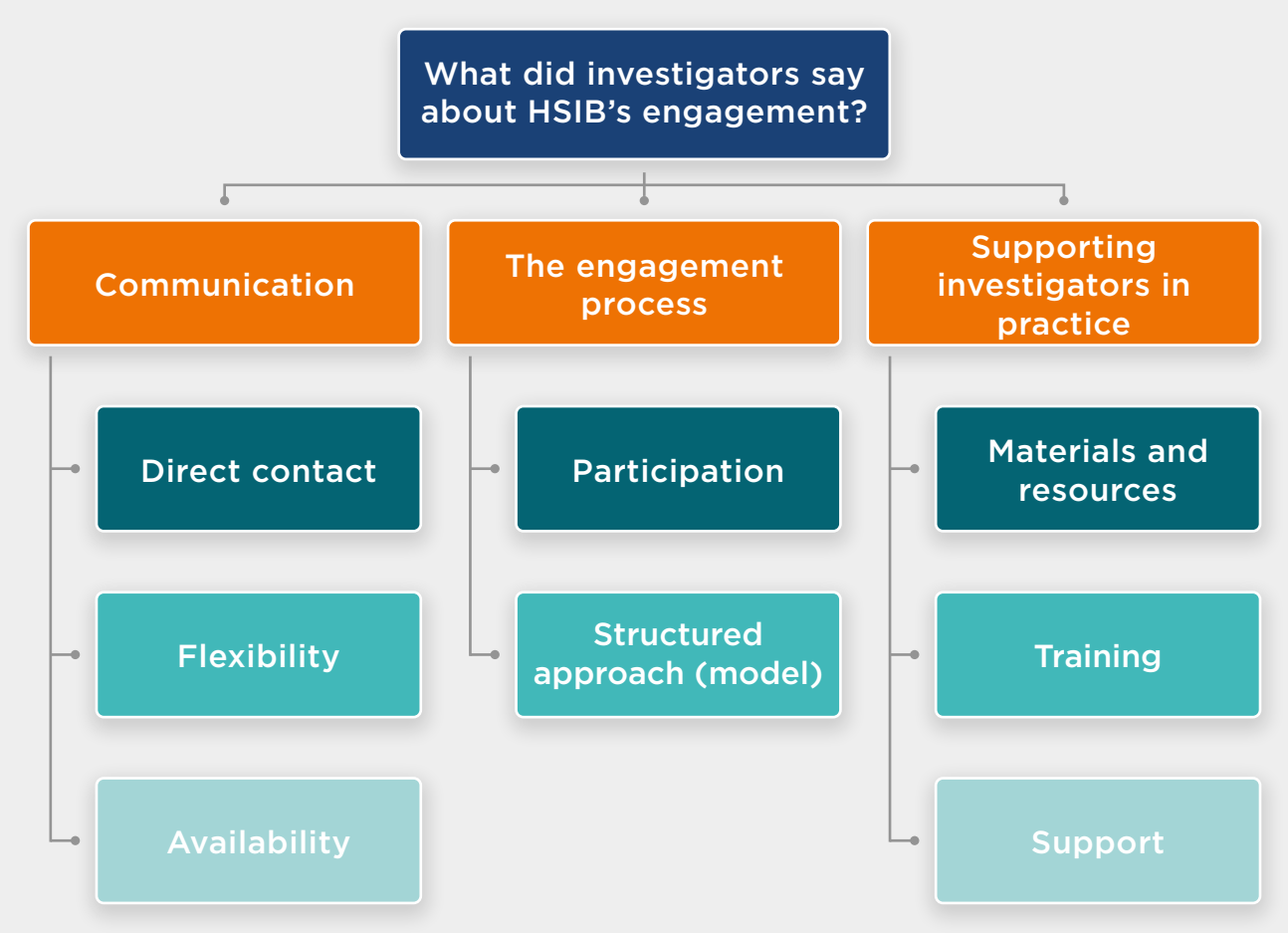
'Just knowing my Mum's death may not be in vain and may prevent similar incidents happening to other families. That is the best legacy I can think of in memory of my wonderful Mum and it is what she would've wanted.'
Family member

A final area of feedback from families highlighted the challenge HSIB faces in ensuring reports are completed within a reasonable timeframe. Families recognised the need for time extensions, and the importance of keeping families updated was again identified. However, the impact of the time it takes to complete reports should not be underestimated; for families, delays can affect future planning and the coming to terms with grief after an incident.

6.3 What did investigators say about HSIB's engagement?

Figure 4 represents the themes identified in the investigators' feedback. These related to communication, the engagement process, and individual aspects of the support provided for investigators. Investigators also provided insights into how HSIB's approach to family engagement differs from the approaches taken in other organisations they have worked in, and thoughts on what learning should be shared outside of HSIB.

Fig 4 Main themes from investigators' feedback



Feedback from investigators mainly related to maternity investigations, but also included four responses in relation to national investigations. There were no clear differences in the feedback from maternity versus national investigators.

6.3.1 Communication

HSIB investigators recognised the importance of making direct contact with families and meeting them in person. This makes the engagement more meaningful and personal. It also allows for sharing of more information and the answering of questions.

> 'Family are contacted first and meeting arranged at their convenience and location – normally occurs at their home where they will feel more comfortable so can relax and share their experiences. From my experience this works very well and the families have been very open with us and forthcoming.'
> HSIB investigator

It is important to be flexible during engagement with families, using the different methods of communication available. The method of communication should be decided upon with the family.

Investigators described the importance of ensuring enough time is spent with families throughout the investigation. There was particular emphasis on keeping families updated on their terms, and having check points to see how they were coping. However, there were challenges in providing new information if none was available.

Investigators also recognised that an investigation may be one of a number of priorities for the family, particularly when they may be dealing with recent grief.

> '...bereaved families want to meet us earlier than the families who are facing the prospect of caring for a baby with a potential serious brain injury, as their focus is on the baby's progress in the initial days and on taking their baby home and dealing with the baby's immediate needs.'
> HSIB investigator

6.3.2 The engagement process

Investigators shared their positive impressions of the HSIB engagement process. They described how family engagement was seen as a priority by HSIB and that it functioned well through a kind and caring approach.

The feedback described the challenge of ensuring early on in the engagement process that families are fully aware of HSIB's role. A number of investigators felt that this needed to be made clearer for families by providing more information to trusts for them to share with families and by making the investigation process more transparent.

Investigators recognised the importance of active family participation throughout investigations. They wanted to make sure that families felt heard and were involved in a collaborative way throughout. Active participation may also provide further information for trusts outside of the scope of HSIB investigations.

'HSIB allows me to care about my families and do whatever it takes to give them a voice, involve them, support them, signpost them, find the answers (or be open when the answers cannot be found).'
HSIB investigator

A few challenges to active participation were identified. These related to the timing of meetings in the face of HSIB deadlines, and when reports were shared with the family and trusts.

'We progress the investigation at the pace that suits the family. This flexibility is needed as some families need longer before they are ready to talk to us.'
HSIB investigator

HSIB investigators recognised that the HSIB approach to family engagement has allowed them to better support families and in doing so has developed them as investigators.

'The model of family engagement at HSIB...allows me to support patients and families, whilst being supported myself.'
HSIB investigator

One investigator did feel that more information on signposting to available support services would be useful to share directly with families.

6.3.3 Supporting investigators

Support for investigators included materials and resources, preparation and training, and support of the investigators themselves. HSIB provides investigators with a series of resources on family engagement. All investigators agreed that these were useful and met their needs. They also found it useful to be able to leave resources with families for them to refer to later.

Investigators provided thoughts on how resources could be improved. Suggestions included a sample report for families, clearer consent procedures around family data, clearer investigation process details, the addition of certain resources around bereavement, and an index of documents. HSIB now provides a sample report of a maternity investigation for families.

Investigators described feeling confident and well prepared to undertake family engagement. They recognised the importance of experience and their previous roles in helping to influence this. They also agreed that the family engagement training they had received was helpful. The training incorporated roleplay to practise handling different scenarios and included specific topics such as safeguarding, personal security and minimising risk to family members and investigators.

All investigators agreed that HSIB supported them to work with families. They spoke highly of HSIB's Head of Family Engagement and this role was felt to be fundamental to guide investigators and provide support. Investigators also felt supported by their team leaders and peers.

'Access to Head of Family Engagement for advice when needed – particularly in the more challenging cases e.g. maternal deaths. Great to have a discussion and strategy for the engagement.'
HSIB investigator

While investigators felt supported, some suggested there was a need for more opportunities to shadow colleagues for experience. The inclusion of formal debriefs for investigators within the investigation process was also suggested.

6.3.4 What does HSIB do differently?

Drawing on their own personal experiences, HSIB investigators shared their thoughts on how HSIB family engagement processes differ from those they have experienced before working for HSIB.

'I have a more emotionally honest approach and while remaining professional engage with families in a much more open way. I feel less worried about the discussions I have with families as I am there to listen.'
HSIB investigator

HSIB's process was felt to be independent, meaning that investigators could be completely open and honest with the families they were working with. This changes the dynamic with families, who may have negative emotions towards an organisation that has harmed them.

HSIB's process was felt to be more structured, allowing timely engagement with support, provision of face-to-face visits and disengagement at the appropriate time.

'...family is integral to the investigation and is treated professionally, respectfully and according to their individual needs. Family involvement is fundamental from the start, identifying a dedicated liaison person.'
HSIB investigator

However, it was also recognised that HSIB is in a unique position that allows time for family engagement and provides resource for it.

6.3.5 What learning should HSIB share?

Investigators shared their thoughts on key learning and principles for family engagement that they had observed while working at HSIB. These thoughts were reviewed and collated into categories relating to investigators themselves and the investigation process. These are shown in table 2.

Table 2 What should HSIB share as learning for family engagement?

Category	Descriptors
Investigators	• Should be approachable and actively listen. By being approachable, they should give time to families, individualise their approach and work in collaboration with them. This should be done in an open, kind and sensitive way. • Should acknowledge the impact an event has had on a family. They should identify the families' questions, prioritise them and ensure they are answered. • Should also look after themselves. Investigators should minimise risk to themselves when undertaking visits and contacts in unfamiliar places and situations.
Investigation process	• Should be clear, structured, family centred and provide support. It should also be seen to be independent, which is challenging for an organisation where an incident has **occurred***. • Should include a nominated contact person for each family, who can inform them about the process and its purpose. Even when structured, the process can still be tailored to a family. • Should be supported by someone in the role of a family liaison/engagement officer. • Should be family centred throughout. This ensures that families are involved throughout with consideration of their wishes. It includes regular updates and signposting to further support at every **opportunity****.

*

'The independence and external nature of the organisation provides us with an opportunity to see a holistic approach to all aspects from the family and trust perspective.'
HSIB Investigator

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'For me one of the very best things is that all our families and their experiences are treated in a level playing field: they receive the individual support they need to be as much a part of the process as they want. This is rare but so important.'
HSIB investigator

6.4 Summary of the feedback

The feedback provides insights into the effectiveness of HSIB's approach to family engagement. It highlights that a structured and tailored approach is welcomed, with families feeling that they are collaborated with effectively. Families appreciate the kindness of investigators and the support they provide. HSIB investigators feel prepared and resourced to undertake family engagement.

The feedback also highlights areas where HSIB can further improve its family engagement. The approach must be consistently applied across every investigation, ensuring families are given options to meet face to face and receive regular updates. The purpose of HSIB investigations may need to be clarified to ensure families know what questions HSIB is able to answer. For investigators, HSIB should ensure they are supported to undertake engagement and to disengage in an appropriate way at the right time. It must also be clear to investigators what support avenues are available to both families and themselves.

7 The future for HSIB's family engagement

7.1 Learning from feedback

The feedback detailed in section 6 has allowed HSIB to reflect on its family engagement process and has identified areas for further development. This approach of receiving and reviewing feedback will be undertaken regularly to inform continuous improvement. HSIB will also continue to work with other local, national, international and charitable organisations to learn from them.

HSIB acts on feedback as it is received and is paying particular attention to ensuring the family engagement process is consistently applied by all investigators. One example of an improvement was the amendment of the initial literature to include a message from a family, to help other families understand what to expect.

Work is needed to ensure organisations and families are clear about the role of HSIB investigations, what they can expect from the investigation reports and how HSIB will engage with them. HSIB will also continue to develop internal support processes for its investigators and make improvements to speed up the completion of reports.

It is important to ensure that processes are regularly reviewed to ensure their quality. HSIB is therefore working on a quality process to evaluate compliance with the family engagement process.

7.2 Broader family engagement developments

HSIB has appointed a Chair of the Citizens' Partnership. The Citizens' Partnership was established to support the work of HSIB by ensuring the public perspective is as integral as possible to HSIB's strategy and plans. HSIB's family engagement process is being revisited regularly and is evolving; the Citizen's Partnership will offer a critical eye on this work and add value to the engagement process.

Beyond HSIB, NHS England and NHS Improvement is currently developing a new Patient Safety Incident Response Framework (PSIRF) (NHS England and NHS Improvement, 2020a) and a framework for involving patients in patient safety (NHS England and NHS Improvement, 2020b). HSIB has seen an introductory version of the PSIRF, which is due to be introduced in 2021. It incorporates information about transparency and support of those affected by patient safety incidents, including setting expectations for informing, involving and supporting patients, families, carers and staff. The framework for involving patients in patient safety is under consultation and due to be published early in 2021; it was a key priority in the NHS Patient Safety Strategy published in 2019 (NHS Improvement, 2019). HSIB welcomes these publications

and will review its family engagement approach in light of their final contents.

HSIB is also pleased to be a collaborator in a project being undertaken by the Bradford Institute for Health Research and University of Leeds (2019) and funded by National Institute for Health Research. The project seeks to co-design processes and resources to support patients and families in patient safety investigations. It is due for completion in 2022 and will help address the gap in the evidence base around how to undertake effective family engagement in healthcare investigations.

8 Sharing learning from HSIB's family engagement

8.1 Summary

Families are integral to investigations and they should be supported to be part of investigations should they wish. The term 'family' is used in the broadest sense as anyone who can provide valuable insights into an investigation including the individual involved in the incident and those who have a close relationship with them.

This report has presented HSIB's experiences of developing a family engagement process and its perspective on how that process works in practice. HSIB's approach is based on five principles for effective family engagement: personalised, accessible and inclusive, open and transparent, respectful, and timely.

The steps of the process, and useful information about each step, have been shared with an overview of HSIB's supporting documentation for family engagement. Feedback has shown that HSIB's approach to family engagement is welcomed by families and HSIB investigators. The structured but tailored process is effective and HSIB's investigators feel able to support families through the process. HSIB recognises that there are further developments that could be made and these are being explored.

Through engagement with families, HSIB has witnessed the effectiveness of giving families informed choices, continuity of contact, meaningful involvement in investigations and open and honest communication. HSIB continues to believe that families are vital to investigations and an investigation is not complete without their voices being heard.

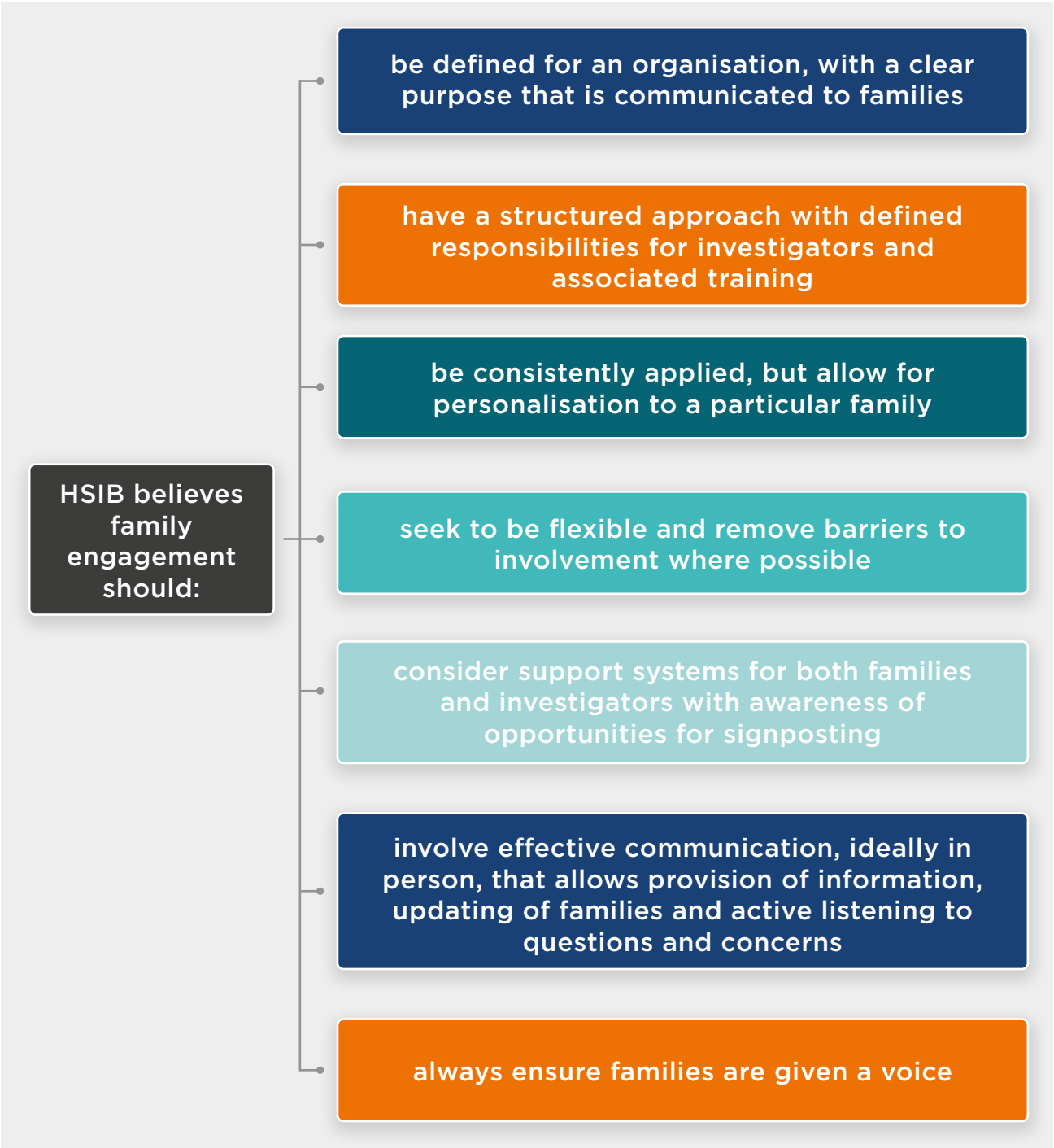
8.2 Sharing what HSIB has learned

The process of collating this report has prompted HSIB to reflect on its experiences of family engagement and what it has learned during the development of its processes. This learning, about what makes an effective family engagement process for HSIB, is shared in figure 5. It is shared as an offer to healthcare organisations that undertake safety investigations, and that might wish to reflect on or develop their local family engagement processes.

Feedback from families supports HSIB's belief that the principles described in this report create the right conditions for meaningful family engagement so families will be heard during investigations.

'Communication throughout was excellent and considerate of the situation. The investigator visiting me at home and giving me time to tell my side of events put me at ease and gave me a voice.'
Family member

Fig 5 Learning from HSIB's experiences of effective family engagement



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10 Appendices

10.1 Summary of nationally published documents describing the importance of family engagement

Document	Quotes and description
Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013)	**'The arrangements for public and patient involvement, and for local government scrutiny in Stafford, were a conspicuous failure.' 'The investigation demonstrates how powerful the combination of direct observation of practice, contact with patients, families, frontline staff and examination of real cases is...'**
The report of the Morecambe Bay Investigation (Kirkup, 2015)	Recommendation 23 states: **'We believe that there is a strong case to include a requirement that investigation of these [maternity] incidents be subject to a standardised process, which includes input from and feedback to families...'**
Independent review of deaths of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust April 2011 to March 2015 (Mazars LLP, 2015)	**'The involvement of families and carers in investigations of unexpected deaths has been very limited – 64% of investigations did not involve the family based on our review of the evidence in SIRI [Serious Incidents Requiring Investigation] reports. Not all families wish to be involved in investigations and, in a small number, it may not be possible or appropriate. When contacted only 4% of families declined any involvement.'**

Learning, candour and accountability **A review of the way NHS trusts review and investigate the deaths of patients in England** (Care Quality Commission, 2016)	**'Bereaved relatives and carers must always be treated as equal partners and receive an honest and caring response from health and social care providers. Families and carers should be supported to the extent that they wish to be involved, with particular importance and priority given to the first discussion and explanation of the processes that will follow, offering a full and accurate explanation of the reasons the person died and a response to all concerns they have raised about care provided.'** **'...families also reported being ignored by others and feeling that their questions were left unanswered.'** Recommendation 3 states: **'NHS Improvement and NHS England, with support from CQC** [the Care Quality Commission]**, should lead work to define what families and carers can expect from healthcare providers when they are involved in the investigation process.'**
National guidance on learning from deaths **A framework for NHS trusts and NHS foundation trusts on identifying, reporting, investigating and learning from deaths in care** (National Quality Board, 2017)	**'Providers should engage meaningfully and compassionately with bereaved families and carers in relation to all stages of responding to a death...'** **'...bereaved families and carers should receive timely, responsive contact and support in all aspects of an investigation process, with a single point of contact and liaison...'** **'...bereaved families and carers should be partners in an investigation...as they offer a unique and equally valid source of information and evidence that can better inform investigations...'**

Learning from deaths: case studies from trusts (NHS Improvement, 2017)	**'In December 2016 Southern Health recruited an experienced family liaison officer (FLO) to support the families and carers of those who die while in our care.'** **'It is not just bereaved families and carers who need support but those participating in any Serious Incident or complainant investigation.'** **'There is very limited support externally for bereaved people and this can be difficult to access. The FLO has worked with the third sector to develop contacts for ongoing support to the people who require it.'** **'Families and carers value the support and information, independent from the investigation process, that the FLO provides. Feedback has been overwhelmingly positive.'**
Learning from deaths Guidance for NHS trusts on working with bereaved families and carers (National Quality Board, 2018)	**'Developing a well-trained, supported and motivated family liaison service is an effective way to provide a compassionate service to bereaved families. This should be a distinct service within a trust, with dedicated staff time to provide effective family support.'**
Learning from suicide-related claims A thematic review of NHS Resolution data (NHS Resolution, 2018)	Recommendation 7 states: **'Family members and carers offer invaluable insight into the care their loved ones have received. Commissioners should take responsibility for ensuring that this is included in all SI** [Serious Incident] **investigations by not closing any SIs unless the family or carers have been actively involved throughout the investigation process.'**

The future of NHS patient safety investigation: engagement feedback (NHS Improvement, 2018)	Describes a people-focused principle where patients, families, carers and staff are active and supported participants. **'Respondents stressed the need for dedicated staff (with the right skills, seniority and resources) to support a two-way conversation that runs from the start of an investigation process to its end.'** **'Stated good practice requirements included: allowing patients and families to ask their questions at the outset; continuing to receive questions during the investigation process; making sure that views are recorded in the report – even if the trust disagrees with it – patients and families need to know that their views have been heard and considered.'**
Learning from deaths A review of the first year of NHS trusts implementing the national guidance (Care Quality Commission, 2019)	**'Inspection staff found that staff can sometimes be fearful of engaging with bereaved families and carers. Reasons for this could be linked to a lack of skills or confidence to contact bereaved families, a fear of adding to families' distress and grief...'** **'However, we have also seen some examples of positive engagement with families and carers, where trusts had clear pathways of contact, an open and transparent approach to engagement, and showed compassionate communication with families.'**
The NHS Patient Safety Strategy Safer culture, safer systems, safer patients (NHS Improvement, 2019)	**'The importance of the role of patients, their families and carers, and other lay people in improving the quality of NHS care is increasingly recognised, as is involving patients as partners in their own care.'** **'If harm occurs, patients must be supported to be as involved as they wish to be in the work to develop an understanding of what happened so that the contributory factors can be identified and learned from. They should also be able to access support to aid their recovery.'**
Each Baby Counts: 2019 progress report (Royal College of Obstetricians and Gynaecologists, 2020)	Recommendation: **'The Each Baby Counts project team encourages all trusts and health boards to always inform the parents of any local reviews taking place and invite them to contribute in accordance with their wishes.'**

10.2 List of the family literature for HSIB's maternity investigations

Document title	Purpose
Introductory card	An introductory card given by a trust to families when introducing HSIB and asking for agreement for HSIB to contact them.
Family information	Information leaflet intended to be given to the family at their first meeting with investigators following discussion. The leaflet explains the investigation process and gives a written version of what should be discussed.
Investigation process	A one-page guide explaining the 10 steps of an investigation. This gives a written explanation of the process which is described by investigators and allows families to understand the progress at each step of the investigation.
Feedback letter	A letter to give to families to welcome feedback and to provide an option for early feedback.
Feedback postcard	A card requesting feedback from families at the conclusion of the investigation and providing an online link and options for other formats.
Family feedback	Paper version of online survey that families are asked to complete at the conclusion of an investigation. An electronic version is also available.
Letter to family	When a referral is made, but the trust informs HSIB that the family does not wish to be contacted by HSIB, a letter is sent to the trust enclosing the 'letter to family' and the trust is asked to pass the letter on to the family on HSIB's behalf.
Sample report	A fictitious case and sample extracts of a report to help families understand what the final report will look like.
Note: these documents are available in alternative languages and can be provided in other formats.	

HSIB Maternity Investigation Process

An explanation for families

STEP 01

- The hospital refers your case to HSIB as required to by Department of Health & Social Care
- The hospital informs you about HSIB and asks for your agreement to pass your contact details to us
- The hospital gives you our HSIB introduction card

STEP 02

- An investigator contacts you and explains more about our investigation process
- We ask for your agreement to investigate and to look at your medical notes
- You discuss with the investigator how and to what extent you would like to be involved and contacted

STEP 03

- An initial visit by investigators is planned with your agreement
- The investigation process is explained further, and you ask any questions you have
- We provide you with a family information leaflet
- We ask for your written agreement to continue the investigation
- We can give you information about additional support you may require
- You can change your mind at any time

STEP 04

- We visit to interview you and other key family members about your experience
- We discuss with you the terms of reference of the investigation
- We revisit any support you may require
- (Steps 3 and 4 can happen at the same time if this is what you wish)

STEP 05

- Your Investigators will visit the hospital and interview key members of staff
- The investigators will seek expert clinical advice surrounding your experience
- Your Investigators will keep you updated of the progress of the investigation

STEP 06

- Investigators will analyse findings
- Further clinical advice will be sought to review the progress of the investigation
- Your investigators will keep you updated to their progress

STEP 07

- A draft report will be prepared detailing what happened, any finding and recommendations
- The report will be will go through a comprehensive quality assurance process

STEP 08

- The draft report will be shared with you and details explained
- Draft report will be shared with the hospital
- Any details that you believe are inaccurate are discussed

STEP 09

- You are given your copy of the final report
- The final report is also given to the hospital

STEP 10

- We ask you and your family for feedback on our investigation process
- We will discuss with you an optional meeting between you, HSIB and the hospital to discuss what will happen as a result of our report

10.4 HSIB's family feedback survey

10.4.1 Part 1 questions

Respondents are asked to rank the following statements on a scale of: strongly agree, agree, undecided, disagree, strongly disagree, and not relevant to my situation. A comment box is also provided for each question for free-text comments.

- I was initially informed about the involvement of the Healthcare Safety Investigation Branch (HSIB) and given a choice as to how to communicate with investigators.
- HSIB investigators' contact with me enabled me to feel part of the investigation.
- I was given details of a specific individual and how and when I could contact them.
- The investigator showed flexibility in their approach towards me.
- The investigator kept me informed throughout the investigation as much as I wished to be.
- I was given the opportunity to make comments on the draft report.
- The investigator gave me a realistic assessment of how long the investigation may take.
- I received a copy of the draft final report and was given the opportunity to make comments on it.
- Other family members were included in an appropriate way.
- I felt supported and was given helpful guidance and information regarding additional support I required.
- I/we had help with translation/interpreting, so we could engage with the investigation.
- I felt that my perspective on what happened was considered by the investigation team.

10.4.2 Part 2 questions

Respondents are asked for a free-text response to the following questions:

- Please tell us what was most helpful to you regarding our investigation process.
- Please tell us anything that we could have improved.
- Are there any other comments you wish to make?

WWW.HSIB.ORG.UK
@hsib_org

HSIB
HEALTHCARE SAFETY INVESTIGATION BRANCH

Further information

More information about HSIB – including its team, investigations and history – is available at **www.hsib.org.uk**

If you would like to request an investigation then please read our **guidance** before contacting us.

@hsib_org is our Twitter handle. We use this feed to raise awareness of our work and to direct followers to our publications, news and events.

Contact us

If you would like a response to a query or concern please contact us via email using **enquiries@hsib.org.uk**

We monitor this inbox during normal office hours - Monday to Fridays (not bank holidays) from 09:00hrs to 17:00hrs. We aim to respond to enquiries within five working days.

To access this document in a different format – including braille, large-print or easy-read – please contact **enquiries@hsib.org.uk**