Learn Together

Supporting involvement after safety events in healthcare

Investigation Guide

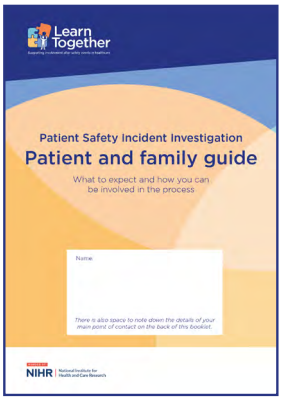
Supporting patient and family involvement in patient safety incident investigations

FUNDED BY

NIHR | National Institute for Health and Care Research

"When my mum died [in the Mid Staffordshire disaster, 2006], when I searched and looked for quite some time, there wasn't anything that I thought was supporting the families. There wasn't anywhere that the families had a voice. And it always seemed that it was a system doing something to you. It was a system, and an investigation that you weren't part of."

Debra (daughter of Ellen), involved in a patient safety incident.



This guide has been developed to support you to engage and meaningfully involve patients* and families in **patient safety incident investigations**. It is important that you familiarise yourself with the **Patient and Family Guide** which works together with this, and signpost patients and families to the relevant sections. You might find that they come to the investigation process with clearer expectations about how they will be involved if they have read the Patient and Family Guide or accessed the resources on the Learn Together website: **learn-together.org.uk**.

This approach is designed to be a supplement to training specific to engaging and involving patients and their families. It is highly recommended that you to attend training to consolidate your learning. The Patient Safety Incident Response Framework (PSIRF) suggests that staff should attend at least 6 hours of training as a minimum requirement. You can find examples of relevant training on the 'other resources' section of the Learn Together website.

The approach described in this guide is based on evidence generated from an independent research programme called Learn Together, funded by the National Institute for Health and Care Research. The guide has been co-designed by a community of stakeholders including patients and their families, patient safety managers, investigators, healthcare staff and legal representatives, and has been supported by **policy makers**.

This guide has been designed to meet the requirements of the Patient Safety Incident Response Framework (PSIRF), and provides practical steps to help you support people to be involved during an investigation. This guide will help you work flexibly, recognising that every investigation is different and that patients and families have different needs and preferences for involvement.

Contents

Words and phrases have been highlighted in **bold red text**.

*Please note, for the purposes of this guide, any reference to patients is inclusive of all people using healthcare services, including service users, as well as people who are no longer receiving care, but who were patients at the time of the patient safety incident.

Involving patients and families

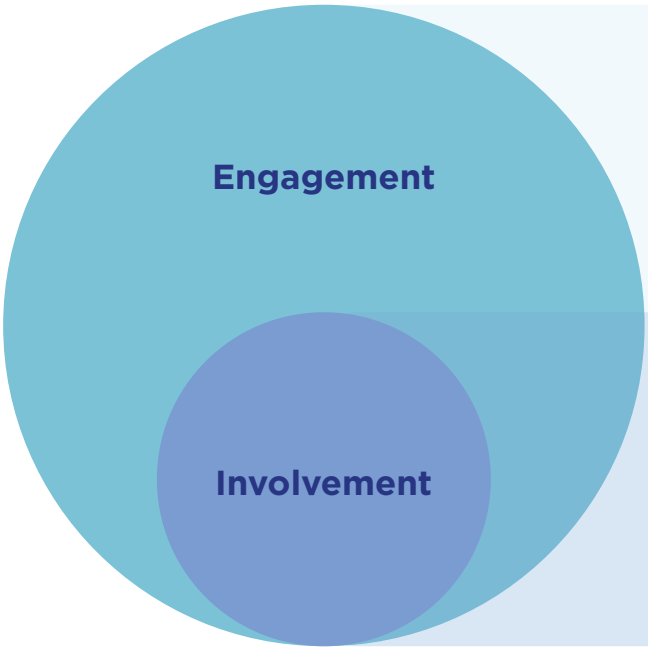
What involvement is (and what it isn't)

When supporting patients and families through investigation processes, **it is important to always seek to engage with them during the investigation, even if they choose not to be involved in the investigation itself.**

Engagement and involvement are terms that are often used interchangeably, and this can be confusing. In this guide, the terms are related, but different.

Engagement refers to everything organisations do to communicate and work with patients and their families, within the processes that follow a **patient safety incident**. This may include activity such as disclosing the incident to the patient and family through **Duty of Candour**. It might also include a range of activities that seek to actively involve patients and their families in the investigation.

Involvement refers to activity that is specific to the investigation, such as speaking to patients and families about the patient safety incident, and seeking their feedback on the draft report. Therefore, whilst the term engagement covers all activity to engage and communicate with patients and families following a patient safety incident, involvement relates to a smaller subset of engagement, and specifically to activity that directly supports the investigation.



- Disclosing the incident
- Providing a sincere apology
- Explaining what will happen

- Speaking to the patient and family about the incident
- Agreeing **terms of reference**
- Seeking feedback on the report

Why involve patients and families?

1. To support organisational learning

Research has shown that patients and families can reliably report patient safety incidents and provide accurate information about sources of risk in care settings. Because they are often the only people to be present throughout a whole care journey, they are able to provide information that helps join together different sources of evidence. This makes them an important source for providing evidence for investigations, as well as cross-checking evidence alongside clinical notes and the information provided by staff.

2. To support patient and family healing

The incident and how it is handled by the organisation, can lead patients and families to mistrust healthcare services and staff, which will need to be rebuilt over time. This will involve supporting patients and families to adjust to their new circumstances and come to terms with what has happened. Re-building trust is particularly important for those who need to use health services for ongoing physical or psychological care needs, and for those who need to use health services in the future. Whilst patient safety incidents are not always preventable, you can support those involved in ways that dignify and validate their experience of the event, and the impact it has had on their lives.

3. To reduce the risk of compounded harm

Compounded harm is the harm that can be created after a safety incident, due to the processes that follow.

An investigation may not be able to address all of the issues that arise for patients and their families due to a patient safety incident. However, supporting people in ways that address and acknowledge their human experience can help to reduce the risk of compounded harm.

Patient safety incidents will often result in some form of harm for patients and their families, and some will have profound physical and psychological impacts on their lives. Wherever possible, healthcare organisations should provide support and try to alleviate these impacts.

However, not all impacts result from the patient safety incident itself. Some are

created from the experience of processes that follow patient safety incidents.

One common misconception is that involvement in the investigation itself will re- traumatise patients and families. However, evidence from the Learn Together programme suggests that it is often the event itself that is traumatising. **The investigation can layer further trauma on top of that if patients and families are not informed and not involved in the way that they need.**

Compounded harm is not a trivial issue. For some patients and families, it can make an already difficult and emotional situation much worse.

> "We thought losing my mum was the worst thing. But we were wrong. The investigation was the worst thing. It just made everything so much worse."
>
> *Family member involved in a patient safety incident.*

Examples of compounded harm

Following a patient safety incident, patients and families describe expectations of an acknowledgement of the potentially profound and permanent impacts of what happened and a sincere expression of compassion. Where this does not happen, experiences jar with underlying assumptions of what caring organisations are setup to do, at a time when they potentially rely upon them most.

> "Nothing like, "we're really sorry that this is happening to you and we'll do our best to sort it". It wasn't like that at all. It felt very impersonal and it didn't feel like anyone was holding my hand through it."
>
> *Patient involved in a patient safety incident.*

During the early investigation stages, some patients and families describe feeling overwhelmed as they are managing the incident aftermath physically, emotionally and/or financially. Having never been through an investigation of a patient safety incident before, families may also feel unequipped and describe expectations of support to navigate what happens next. Without that, they may become involved when it is too late to meaningfully influence the investigation and outcomes, leaving them feeling that the investigation is done *to* them, rather than *with* them.

> “In terms of involving the family, it would be at the end of the report process. They might not have even known an investigation was going on, or the in’s and out’s of it. But once the report was ready we would then offer meetings… And I remember sitting in meetings offering this final report, and the family being very upset. We hadn’t achieved anything in terms of trying to answer their questions. We hadn’t even asked them what their questions were.”
>
> *Staff member leading an investigation.*

Some patients and families describe feeling forced to meet their needs elsewhere, via a complaints and litigation process, as the investigation did not listen to and meet their needs.

> “I felt like I got pushed towards the legal approach because I didn’t want money, like, you know, this wasn’t about that. This was about getting a proper investigation.”
>
> *Family member involved in a patient safety incident.*

The five-stage process **(page 16)** described in this guidance has been specifically designed to **reduce the risk of compounded harm** for patients and families. It does this by trying to balance the joint aims of improving learning and supporting healing within the investigation.

Working in this way may feel like a lot of additional work, but investing early in building trust and good relationships with patients and their families, may well reduce the demand on your time and resource as the investigation progresses.

The importance of working relationally

The research within the Learn Together programme demonstrates the significance of working relationally with patients and families. Patients and families describe how important it is for their experience of the incident – and the impacts on their lives – **to be heard, dignified and valued**. They also describe how important it is for organisations, and those leading the investigation, to try and understand what their needs are, even if they cannot always meet them.

Working relationally means **recognising the importance of your relationship** with patients and families, and conducting the investigation in ways that **try to meet their needs**. Working relationally means giving the time and space to patients and families to discuss what happened and what it means for them and their lives.

It means focusing not just on **what** you do, but also **how** you do it.

Scan the QR code or go to **learn-together.org.uk** to watch Sam, Julia and Andrew explain how they worked together relationally throughout their investigation.

You can share this video with patients and families. Alternatively, there is a transcript available on the Learn Together website.

What to do if patients and families do not want to be involved

Evidence from the Learn Together programme suggests that for some investigations, especially those that are particularly difficult or traumatic for patients and families, engaging or involving them might be problematic, or may not be possible during the official period of the investigation.

For some patients and families, this lack of engagement or involvement might reflect their preference and this should be respected. However, there are multiple reasons why people might choose not to be involved. For some of these reasons, there might be simple things that you can do to support their involvement.

It is important not to assume that all reasons for non-involvement are the same or that not wanting to be involved at the start of the investigation will continue throughout.

Some reasons for non-involvement:

- Missing, outdated or incomplete next of kin information.
- 'Opt in' rather than an 'opt out' approach to involvement from organisations.
- Lacking support to enable involvement.
- Investigation happening too soon, which doesn't allow for grieving or coming to terms with what happened.
- Feeling that the investigation is for the organisation, and not them.
- Mistrust in engaging with healthcare services generally.

Remember that how patients and families feel about being involved may change over time and you will need to check this periodically. Lack of interest in being involved early on does not mean that you should stop attempting to work relationally.

Across the five-stage process **(page 16)**, it is important to recognise that **involvement should be seen as an open door.** Patients and families can be involved at later stages, even if they indicated at the outset that they didn't want to be involved, or engage intially, but decide they would like no further involvement in the investigation.

Where you see this icon, you will find some suggestions for how to support **open-door involvement** across the five-stage process.

Preparation

Principles for working relationally

Due to the range of incidents that occur and the different levels of involvement that people might want or need, every investigation is different. It is therefore difficult to completely standardise the approach to involvement. Using the principles for working relationally (shown below) you will be able to work flexibly to meet the needs of patients and families. These principles are based on multiple sources of evidence which include interviews with patients, family members, healthcare staff, investigators and legal representatives, about their personal and varied, experiences of patient safety incident investigations.

Strive for equity.

Individualise your approach.

Be sensitive to timing.

Respect humanity.

Be collaborative and open.

Provide guidance and clarity.

Listen.

Accept subjectivity.

Make apologies meaningful.

Treat people with respect and compassion.

These principles are foundational for each of the five stages of the process **(page 16)**, and for working relationally with patients and families. Throughout this guide, wherever you see this lightbulb icon, you will find examples of how these principles can be used to work relationally.

What patients and families might need during an investigation

Whilst the principles provide the foundations for working relationally with patients and families, it is also important to understand what practical needs they might have.

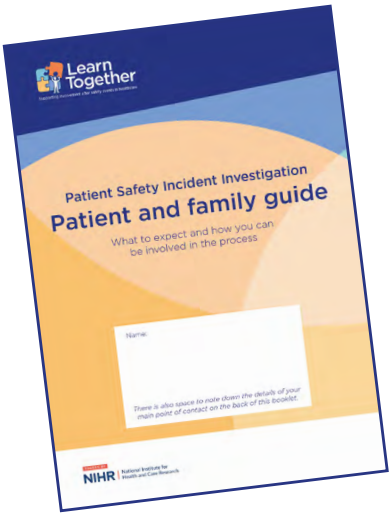
Patients and families involved in the investigation will have a unique set of needs, and these might fluctuate and change as the investigation progresses. You might not be able to address every need. However, it is important to be aware of these needs, and support people to access the relevant additional support wherever possible. This will reduce the risk of compounded harm.

Common needs described by patients and families:

- An acknowledgement that something has happened.
- A sincere apology for what has happened and an expression of compassion for the impacts they might be experiencing.
- An early opportunity to freely describe what has happened from their perspective and what it means for them.
- Support to understand the investigation process and other related processes.
- Input into the investigation scope.
- Flexibility in how and when they can become involved.
- A commitment to try and develop a coherent account of what happened and how, which is inclusive of things most important to them.
- An opportunity to read and discuss the draft report, and provide feedback.
- Reassurance that the organisation has listened and learned following the incident.
- Opportunity to read and discuss the final report which reflects the feedback provided where necessary.

Preparing yourself and your team

- Depending on your experience of responding to patient safety incidents, you might want to take time to prepare yourself for engaging with and involving patients and families within the five-stage process **(page 16)**. It might also be useful to make sure that the appropriate processes are in place within your team.



- Read through the **Patient and Family Guide**. This is designed to work in combination with the Investigation Guide. You should encourage patients and families to read their guide and make any notes in preparation for meeting with you. Familiarise yourself with ways of working according to your local **Trust policy** relating to patient safety incident investigations. It might also be useful to speak to colleagues about how this works in practice, and as a team, be open to challenging ways of doing things to help support you to better support patients and families.

- Make sure that your organisation has a clear process surrounding these guides i.e. Where are they kept? How will you share the guides with patients and families? When will you do this? Whose responsibility is this?

Who provides and manages access to these guides?

Organisations involved in the Learn Together programme of research found that the process of providing Patient and Family Guides was best managed by someone central, such as admin support. The Patient and Family Guides stand alone, and so can be sent via the post as soon as the team becomes aware that a patient safety incident investigation is going to take place. This could be on its own, or perhaps alongside other material being sent to patients and families such as the Being Open letter. As the **main point of contact**, you can then verbally introduce the Patient and Family Guide upon initial contact, and continue to signpost them to the relevant sections at each of the five stages.

- Familiarise yourself with the current version of the Patient Safety Incident Response Framework (PSIRF) **national level policy**. Given the changing landscape of patient safety policy and related processes (e.g. coronial processes and independent investigatory bodies), a regularly updated list of relevant policies and information about related processes can be accessed on the 'Other helpful resources' section of the Learn Together website.

- Explore, and have available, information about **additional processes connected with the investigation**, such as coronial processes, and the Parliamentary and Health Service Ombudsman. People in your team might have more experience you can learn from.

- Explore, and have available, **support resources locally and nationally**. As a team, you should compile a list of supportive resources you can draw upon for each investigation, depending on the circumstances of the patient and family.

- Familiarise yourself with the **terminology** used throughout the five-stage process, and the wider investigations process.

- Take one of the available **training courses** for engaging and involving patients and families in patient safety learning responses and incident investigations.

- **Don't forget to take care of yourself.** Make sure you know how to access support, formally and informally, within your organisation. Involving patients and families in investigations can be challenging and complex. As their main point of contact, your discussions might be the only opportunity for them to express their range of emotions. Remember that this is not personally aimed at you. The information within this guide will hopefully go some way to rebuilding trust, and make working together with patients and families easier for you.

Notes:

Notes:

The five-stage process

Stage 1.

Understanding you and your needs

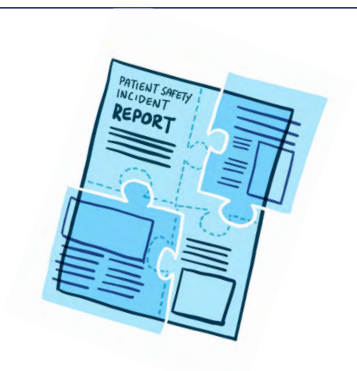
Stage 2.

Agreeing how you work together

Stage 3.

Giving and getting information

The five-stage process will help you to involve patients and families in ways that meet their needs, and reduce the likelihood of compounded harm. **Those who have read the Patient and Family Guide may also come to you prepared for being involved according to the five-stage process.**



Stage 4.

Checking and finalising the report

Stage 5.

Next steps

Key words and phrases

Words and phrases have been highlighted in **bold red text**. Definitions can be found on **pages 61-63**.

Stage 1. Understanding you and your needs

"When I found out that an investigation was being carried out into the circumstances leading up to my baby's death, I was devastated and full of so many conflicting emotions.

Investigations have the potential to cause enormous harm to already harmed families, so it is vital to give patients and families the space and time to discuss what is most important to them and what support needs they have at the very beginning of, and throughout, the investigation (without the organisational agenda in mind).

Whether the family choose to be involved or not, your job is to listen and communicate compassionately and to keep the person at the centre of your processes, recognising they can add valuable evidence from their unique viewpoint. In this way, you can begin to rebuild their trust in healthcare systems, keep those individuals from compounded harm and aim to prevent the same thing from happening again to others."

Sarah (mother of Thomas), involved in a patient safety incident.

One of the things that patients and families who have experienced a patient safety incident describe is the importance of having time and space to talk about what happened, in their own words. This might be an important step on the road to recovery and help them begin to make sense of what happened.

This first stage of the process supports you to work with patients and families to understand them and their needs following the incident.

If patients and families feel that they are treated compassionately from the outset, and that their experiences are dignified and valued, this can really help to reassure them, and might support their further involvement. **Reducing compounded harm starts from the first contact.**

Using the principles to work relationally

Individualise your approach.

Different people will respond differently to the same incident, and you will need to be flexible in your approach. See your initial conversations with patients and families as an opportunity for them to share what they know about what happened. **Listen and learn** about them, what they experienced and what they might need.

Make apologies meaningful.

Receiving a meaningful, sincere apology is an important part of recovering from a patient safety incident. Even if a patient or their family has received an apology before, when contacting them for the first time, it is important to reiterate this apology at the first contact.

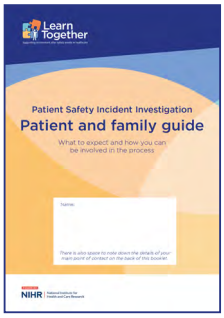
Treat people with compassion.

Treating people with compassion at what might be a difficult time for them, might help their initial recovery from the incident, and start to rebuild their trust in healthcare services and staff.

Initial contact with the patient and family

Initial contact should be approached sensitively and with compassion. Contact should be made with the patient or family as soon as possible following the decision to investigate, and ideally at the beginning of the investigation. Where this is not possible, you should make it clear to the patient or family what has happened already. Remember that the period after an incident can feel overwhelming and confusing. Patients and families will have had varied experiences of both healthcare provision leading up to the incident and of the **Duty of Candour** process. They might also be continuing to receive healthcare, or have additional things to attend to such as home adaptations, additional care arrangements or funeral planning. Patients and families might know less than you think about the incident, they might be eagerly waiting to share the information they have, or they might have a different view to others about what happened and the impacts. They might be recovering physically or emotionally from the incident and the impacts of it.

Everyone will bring different experiences, harm and needs and so with this initial contact, you will need to start working relationally from the outset.



Before moving into the procedural aspects of the investigation, you should invite the patient or family to a discussion to understand more about them, their experience and their needs. You should signpost patients and families to **page 10** which contains the 'Things to discuss' section, and ask them to think it through before you meet. It is important to get them involved in this if they would like to and feel able to.

This meeting has 3 three main purposes:

- **To ensure that patients and families have the time and space to share what happened, from their perspective and in their words**. It is important to provide this opportunity for patients and families at the start of an investigation, so that they feel listened to, and that their account of the incident is felt to be valued.
- To help everyone begin to make sense of what happened and its personal impacts.
- To provide an opportunity for them to ask questions about the investigation, and **start to rebuild trust in healthcare services and staff.**

Working relationally with patients and families in this way might be new to you, or it might feel a little daunting. This is understandable. To prepare, you might want to talk to colleagues first, to help you feel comfortable with how to guide and support the meeting.

In cases of severe harm or bereavement, or where patients or families are very distressed, it is important that you feel confident in having these conversations. It might be that in these situations, a more experienced colleague can provide support, or be the main point of contact for certain investigations. There may also be independent advocates or trained restorative practitioners that can support organisations conducting investigations where the patient or family might have experienced significant physical or psychological harm.

Initial contact

What to cover

- Make contact over the phone if you can, rather than more passive forms of communication such as letter or email.
- Briefly explain what you know about the incident that is being investigated.
- If the investigation has already started, explain what has happened already.
- Give a sincere apology for the incident and an expression of compassion for the impacts they might be experiencing.
- Explain that you will be the main point of contact for the investigation.
- Check that they have received the Patient and Family Guide. If they haven't, check their address.
- Encourage them to have a look at Stage 1 'Understanding you and your needs' and to think about the **'Things to discuss'** section on **page 10 in their guide** before you meet with them. They might find it useful to bring their guide to your meeting.
- Arrange a follow-up meeting, ideally in-person and in place where they are comfortable, such as their home. If people feel comfortable they might feel better able to say what they want to say and recall everything they remember. They might also want to have someone with them for support.

Meeting with the patient and family

Your main role in this meeting is to listen and learn about the patient and family, what they experienced, and what support they might need. Some of the things they raise with you will be covered in the investigation. For other things, you might need to help them to access relevant support. However, it is important that you provide them with the space to raise issues and ask questions that won't be covered in the investigation, and be upfront and honest about what won't be covered. Listening to what is most important to them will show the patient and their family that in the investigation, **even if you cannot always meet their needs or provide answers, you will treat them with respect and compassion.**

What to cover

Setting the tone

It is important to set the right tone for the meeting. Emphasise that this is an informal discussion, and there are no right or wrong things to discuss. Reassure them that there is no obligation to get further involved in the investigation if they don't want to, but that you will revisit this over time.

Start by reiterating the apology. **An apology is not always an admission of wrongdoing – it can be an expression of empathy for what happened and the impacts the patient and their family might be experiencing.**

Things to discuss

You might find it useful to structure your conversation around the following questions, which are provided in the Patient and Family Guide to think about ahead of this meeting:

- *How would you describe what happened?*
- *How has the patient safety incident affected you, and those around you?*
- *What do you need to support you and your family following what happened?*
- *What questions do you have about what happened?*
- *How would you, or the patient, like to be referred to within written communication such as the report?*
- *What would you like to see happen next?*

Closing the conversation

Following your discussion, you should thank them for sharing their experience with you. It is important to recognise that sharing their experience might be a difficult and emotional thing to do. To close the conversation you should:

- *Explain what happens next in the investigation process.*
- *Ask them to consider their preferences for involvement throughout the investigation on* **page 18 of their guide**.
- *Ask if there is anything else they would like to ask or share.*
- *Suggest that you will check in with them shortly, to see how they are and provide details of any relevant support if necessary.*

- **FOR YOU:** Identify a colleague to attend the meeting with you for support if you feel you need it.

- **FOR YOU:** When organising the meeting, allow sufficient time in your diary to prepare for, conduct and debrief from the meeting. If, on reflection, you think that working relationally will be a change for you, then remember to add more time onto this session.

Supporting the patient and family

Whilst you might be unable to provide support personally for everything that is raised, you can reassure the patient and family that you will use the information they have shared to try and advise them to access any support that they need. Support may be provided by your organisation, or you may need to signpost to external sources of support.

The investigation process might be emotionally challenging for the patient and family, and for you. You might want to follow up with the patient and family a few days after you meet, to check how they are, and provide details of relevant support services. You might also want to discuss the investigation with colleagues, as part of peer support.

Everyone will respond differently to incidents, and some people will be more aware of their support needs than others. Not everyone will need further support. It is likely, however, that support needs might change over the course of the investigation. It is important to understand these needs so that you can respond to them appropriately.

Do they need support? Patients and families might not be aware of what they need, especially if the incident has been particularly traumatic. Try and prompt them with examples of support, using your expertise from previous investigations, or your understanding of the incident. Give them time and space to answer if they need it.

If so, what type of support? Support needs can be *emotional* or *practical*. You should try and prompt people to think about these different types of support if they haven't already.

Sharing support resources. You should compile support resources you think might be useful to patients and families and share those relevant to their circumstances.

Supporting open-door involvement

You should ensure that from the very first communications with patients and families, the open-door nature of involvement is emphasised, and that they know they can get in contact at any time throughout the investigation even if they have not before.

Some patients and families might not want to have a meeting. Or, they might want a meeting, but not at the beginning of the investigation. When working relationally, it is important to be flexible in your approach. If they are experiencing physical or psychological trauma as a result of the incident, you could offer to meet with them later in the investigation.

If you have met with the patient and family but they do not want to be engaged further, you should inform them that the investigation will still need to proceed, but that you will work with them according to their preferences. You should continue to support open-door involvement, and check if their preferences change as the investigation progresses.

If you cannot make contact with the patient or family, try to find alternative sources of addresses or contact numbers. For situations where there is involvement of the **coroner**, you might be able to get information from that source.

Stage 1: Understanding you and your needs can be found on page 8 of the Patient and Family Guide

Notes:

Stage 2. Agreeing how you work together

"Helping patients and families to understand the processes involved in the investigation, and working together to plan how they can be involved, is such an important step in building trust. By encouraging curiosity and considering the perspective of patients and families early on in the investigation, it will be so much easier to see the whole picture. You will not only have created the strongest foundation for learning, but also for healing."

Penny (mother of Anna), involved in a patient safety incident.

This second stage of the process supports you to work with patients and families to develop a shared understanding of how the investigation will progress, and how you will work together based on the principles for working relationally. You should invite the patient and family to use the 'Preferences for involvement' section of their Guide to prepare their thoughts ahead of the meeting.

Using the principles to work relationally

Listen.	**Listening** and **working collaboratively** to develop a shared understanding of how the patient and their family will be engaged and involved, is a visible demonstration of openness which can be reassuring for them early in the investigation.
Be collaborative and open.	
Provide guidance and clarity.	Providing guidance helps patients and families to **be clear about what will happen, and how they can be involved.**
Be sensitive to timing.	Being sensitive to timing enables you to **be sensitive to certain dates or anniversaries** that might be important to the patient and their family, and to ensure their involvement can fit around their particular circumstances.
Accept subjectivity.	Supporting the patient and family to understand that **their account is an important part of a wider set of information sources**, can help prepare them for receiving the draft or final report.

It is unlikely that patients and families will have been involved in an incident investigation before. It is important to remember that **it is difficult for people to engage meaningfully with a process they are unfamiliar with**, particularly when they are experiencing harm as a result of an incident and the wider impacts, and have other interlinked processes happening at the same time.

Your role is to help them to understand what to expect. You can do this by developing a shared understanding of what an investigation involves, and also what it doesn't. Setting these expectations early helps to reduce the likelihood of compounded harm as the investigation progresses.

What an investigation involves (and what it doesn't)

What to cover

Be clear about the purpose of an investigation

An investigation is something that NHS Trusts do to learn about what happened, how it happened and how things can be improved to help reduce the risk of it happening again. The purpose is not to apportion blame. Patient safety incidents are very rarely caused by a single thing. Usually there are multiple contributing factors. It is important that patients and families are prepared for this as soon as possible and before they read the report.

Be clear in the way you communicate

Wherever possible, use plain non-technical language. If you use terms that are specific to the investigation process, explain what you mean. There is a 'key words and phrases' section at the back of their guide. You might want to start by explaining what a patient safety incident is.

NHS England defines a patient safety incident as: *an "unintended or unexpected incident which could have or did lead to harm for one or more patients receiving healthcare."*

They might also hear people using different terms to refer to a patient safety incident. For example:

Serious Incident	**Never Event**	**Adverse Event**
Patient Safety Event	**Serious Untoward Incident**	**Near Miss**

Be clear about timelines

Most investigations will be completed in around 3-6 months. However, this varies as there is no set time limit defined by the Patient Safety Incident Response Framework (PSIRF). Where possible, you should set timeframes in conjunction with the family. Use your experience and knowledge of the reasons that an investigation might take longer than usual, or be completed sooner than usual, to be as clear as you can about the likely timeframe of the investigation. It is also important that you are upfront about any expected delays as the investigation progresses.

Give a brief outline of the five-stage process

It is important to give patients and families as much information as they need to be able to engage meaningfully, without overwhelming them. A brief overview of the five-stage process might be helpful. However, they don't have to remember everything you say. There is more detailed information within their guide and you will signpost them to the section relevant to them at the time as the investigation progresses.

Agreeing what the investigation will cover

In order for patients and families to become involved in an investigation, they need to understand what an investigation can achieve, and what it can't (and is not designed to) achieve. The Patient and Family Guide provides them with information about this (**page 14**).

Together with the patient or family, you should agree the **Terms of Reference**. While there are specific things you will need to cover to meet the needs of the organisation (e.g. information relevant to organisational learning), the Terms of Reference should be flexible to also consider the needs of the patient and family, which may be different. It is important to involve the patient or family in agreeing the investigation scope if they would like to and feel able to, to ensure that the Terms of Reference respect their needs and aim to answer any questions they have.

Unfortunately, some of the questions they have may be unanswerable due to the complexity of the incident. It is important to prepare families for this. Some of the questions they have may also be better answered in other ways and fall outside of the Terms of Reference. If this is the case, you should advise the patient or family about getting answers to those questions in other ways e.g. signpost them to psychological support or relevant charities, provide them with Patient Advice and Liaison Services (PALS) details or information to raise a complaint or litigation, or explain other connected processes and how they differ (e.g. **inquest**).

Principles for working relationally

The 'preferences for working together' pages suggest some things to agree with the patient and family to guide involvement in the investigation. You will need to revisit this at each contact, as preferences for involvement may change. Patients and families are also provided with a copy of this in their guide so they know that this will be part of the conversation with you. This is underpinned by the principles for working relationally.

The process

- The investigation will try to clarify **what happened and how it happened**.
- It will be **flexible to the patient and family's needs and how they would like to be communicated with and when**, where possible.
- It will **provide updates** on what is happening and why at different stages of the investigation.
- It will make sure that the **patient and family's perspective is valued** alongside other information and evidence, in understanding what happened.

The people

- People that patients and family meet during the investigation will treat them, and their account of what happened with **respect and sensitivity**.
- They will **listen to patients and family** and make sure they have the space to share things most important to them.
- They will **work collaboratively with patients and family** to develop an understanding of what happened.
- They will understand that this might be a very difficult or distressing time for patients and family, and will **treat them with compassion.**

The investigation might not be able to provide all the answers that patients and families hope for. But by working together in the investigation based on these principles, it is hoped that patients and families will have confidence in the process and their valuable perspective will help to shape what conclusions are made.

Preferences for working together

This is a plan for how you will work together throughout the investigation. Where possible, you should accommodate the preferences of the patient and family. Preferences for involvement might change during the course of the investigation. You will need to revisit this at each contact.

1) How would they like to be involved in the investigation?

- [ ] Be updated as the investigation progresses.
- [ ] Share their experience of the patient safety incident and what is important to them.
- [ ] Ask questions that they would like to be looked into as part of the investigation.
- [ ] Provide a short summary from their perspective about what happened for the report.
- [ ] Check a copy of the report.
- [ ] Receive a copy of the final report.
- [ ] Be advised about additional support.
- [ ] All of the above.
- [ ] They do not want to be involved at this time.

If they do not want to be involved at this time, is there someone else affected by the patient safety incident who could be involved e.g. a family member?

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2) How will you contact them throughout the investigation?

The best times and ways to contact them are:

The specific dates and/or times that they do not want to be contacted are:

How they would like to be contacted:

- ☐ Not at all.
- ☐ Only at key points of the investigation e.g. when there is opportunity to provide or receive new information.
- ☐ Routinely throughout the investigation, regardless if there is opportunity to provide or receive new information.

If routinely, how often would that be?

3) Do they need any additional support?

3a) Do they need any additional support to be involved **in the investigation?** If so, how will that be provided?

3b) Do they need any additional support **outside of the investigation?** If so, how will that be provided?

4) How would they like the patient to be referred to within written communication such as the draft report? Are you able to accommodate this or will it be anonymised?

Other important things to note:

Supporting open-door involvement

Even if patients and families do not want to agree the specific ways of working, make sure you try to get as much information about their preferences for involvement as you can. Knowing things like specific dates to avoid contacting them, and the ways they like to be communicated with, will help to reduce the risk of compounded harm.

If patients and families do not respond in this stage, do not assume that they do not want to be involved. Get back in contact at a later date, to revisit their preferences for involvement.

Stage 2: Agreeing how you work together can be found on page 14 of the Patient and Family Guide

Stage 3. Getting and giving information

"An investigation tends to be performed by the organisation in which the incident occurred. Therefore, it is important that a balanced view is incorporated into that investigation. This includes listening to the perspective of those involved - the patient, family members, carer or service user, alongside clinical records and the views of healthcare professionals.

In our case, we as a family were fully aware of what had happened. We knew our child better than anyone else. We had been physically present and knew what had occurred prior to the catastrophic event.

We compiled a list of relevant questions. We asked that they be included within the report. Questions, that when answered could lead to organisational learning and minimise risk to others in the future.

Families should feel that the information they give holds equal weight. A jigsaw puzzle that when put together forms an accurate picture of events."

Mary (mother of Conall), involved in a patient safety incident.

By this stage, you will hopefully have met with the patient and family to discuss the incident from their perspective, what impacts it has had on their lives, and what their needs might be. You will also have agreed the Terms of Reference and how you will work together.

During this stage, you should work together in the way you agreed and be open and clear about how the investigation is progressing.

Using the principles to work relationally

Individualise your approach.

Although you might have agreed how you will work together, you **should be flexible and respond to potentially changing needs.** People might change their mind over time about their preferences for working together.

Be sensitive to timing.

Time can feel distorted for people during times of stress or anxiety, so patients and families might feel the investigation is moving too slowly, or too quickly. Be sensitive to this, as well as being aware of any potentially sensitive dates for them.

Be collaborative and open.

Openness and collaboration will make people feel involved in the investigation. When people feel they are being as involved as they want to be, they are more likely to feel positive about the process and the outcomes.

Accept subjectivity.

It is important to accept that **patients and families may have a different experience of the same incident than other sources,** but that there is no one 'objective truth' about what happened. All information is equally valuable.

Giving information

Long periods without contact can cause confusion or anxiety for patients and families. It can seem to them that the investigation has stalled, or that the silence is due to attempts to 'cover up' what has happened. Whilst you might not always have specific updates for the patient or family, it is important that you reliably maintain contact in the way that you agreed. This can really support patients and families to rebuild trust in healthcare services. It might also make them feel more comfortable to ask questions and seek advice about their support needs as the investigation progresses.

If for any reason you cannot maintain contact as agreed, you should let them know as soon as possible and make an alternative agreement that considers and accommodates their preferences where possible. Patients and families feeling excluded at this time can contribute to compounded harm. It can also lead to them feeling that the report does not resonate with their experience, or finding out unexpected information when reading the report for the first time.

Getting information

The investigation is a bit like a jigsaw. You will need to gather different pieces of information relating to the patient safety incident. A key part of the jigsaw is the experience of the patient or family. **They have a unique and valuable perspective on what happened and may have information others do not have access to.**

You might also gather information from healthcare staff, clinical notes and observe the relevant healthcare setting. Trying to fit these jigsaw pieces together is complex – and sometimes, no matter how hard you try, they won't fit.

Your role is to fit those pieces together where there are common themes, but also to **clearly highlight any points of disagreement** based on different people's experiences of what happened. It is important to be transparent about how you will use any information they share.

What to cover

- **Give an update on what has happened since you were last in contact.**
- **Give an update on what will happen next including being upfront about any delays.**
- **Share information that you are able to relating to any previously asked questions or raised concerns.**
- **Give an update about any unexpected information that is likely to be included in the report.**
- **Provide space to ask any additional questions or raise concerns.**
- **Thank them for sharing any information with you.**
- **Revisit their needs for support (page 25).**
- **Revisit their preferences for working together (page 33).**

Supporting open-door involvement

Time can feel distorted for people experiencing periods of trauma or where life has changed very suddenly and unexpectedly. This might mean that patients and families miss scheduled meetings, or stop responding to communications.

The most important thing in this phase is to reliably do what you have agreed in terms of involvement activity (e.g. speaking to them about the incident), or engagement activity (e.g. providing updates). This will reassure them that the investigation is proceeding, even if they cannot be involved, and help rebuild trust in services and staff. You can also remind them that they can come back into the process whenever they want, or feel able to.

Notes:

Notes:

Stage 3: Getting and giving information can be found on page 24 of the Patient and Family Guide

Stage 4. Checking and finalising the report

"Investigations such as these are part of staff's work life. But for patients and families at the centre of them, it can be their whole life. The family have already seen their loved one come to harm or lost them due to errors, and now the same Trust is about to tell them just how they got it wrong.

All anyone ever wants is the truth, what happened and why, and what will happen to change that going forward. The investigation will seem daunting to a family on top of their grief and harm.

So make it easier. Be open at every point. Explain what is happening. The more they are told during the process the less likely it is that the final report will come as a shock. And ask if families want the anonymised version of the report because something as simple as using theirs or their loved ones name can ease the pain. It stops it being so cold and clinical."

Faye (daughter of Sue), involved in a patient safety incident.

Sharing a draft of the investigation report, and inviting patients and families to feed back about the accuracy of their account of the incident and other important details, is a visible way of demonstrating openness and transparency. It ensures that the investigation has tried to address the questions that the patient and family asked to be addressed. It can also support you to ensure that the report is correct on important details.

This stage of the process has been designed to help to support you to share the draft report with patients and families in ways that support working relationally, and reduces the likelihood of compounded harm.

This is one of the most important stages of the five-stage process, which might require careful handling. The following section will provide some practical ideas and guidance to help you navigate this stage in ways that address everyone's needs.

Preparing to share the draft report

Using the principles to work relationally

Strive for equity.

Sharing a copy of the draft report with patients and families for accuracy checking, comment and feedback, is an important part of working relationally. It is an active demonstration that **the patient and family's experience is a valuable part of understanding what happened**, and that the organisation's needs are not prioritised over theirs.

Provide guidance and clarity.

Receiving the draft report can be traumatising for the patient and family, and you should try to prepare them in advance for how they might feel. Inaccuracies in important details – however small – can be distressing for patients and families, and also undermine their trust in the rest of the report. You need to be responsive to their feedback and take care to get these details right in the final version of the report.

Treat people with compassion.

Accept subjectivity.

Help the patient and family to understand that there is **likely to be points of disagreement** based on different people's experiences of what happened, and the different sources of information. Some of these disagreements might be distressing for the patient and family, so it is important that they are prepared.

How "draft" should the draft report be?

Evidence from the Learn Together programme suggests that for most organisations, a draft report will have been seen and agreed by the clinical teams before sharing with the patient and family. However, depending on the local procedures and timelines for governance approval processes, the report might be regarded as being in draft form either before, or after certain internal approvals. Before sharing the draft report, you should make sure you are aware of what your local policy or procedure is, and at what stage of approval the organisation is willing to share.

You will produce a report by bringing information gathered from different perspectives together. It is important that you **discuss the key findings of the investigation with the patient or family prior to sharing a copy of the draft report** with them. This includes sensitively preparing them for any information that might be unexpected, any points of disagreement and any questions that you were unable to answer. Understandably, some will be keen to receive the report as soon as possible and won't necessarily see the value in having a discussion at this time. But one thing that patients and their families describe with hindsight is that being ill-prepared for reading the report for the first time causes compounded harm, even when they have been involved throughout the investigation until this point.

What to cover

- **What does the report look and feel like?**

Most people won't have seen a report like this before and will be unprepared for what they receive. You might want to advise them to read it together with others who have been affected by the incident, such as their family, for support. It also might be useful to let them know that the report is written for different audiences which includes them, but also includes others such as healthcare staff and senior management. This shouldn't affect their ability to understand the information as all clinical terminology should be fully explained, but the factual tone it is written in might not be the way they are used to engaging with you. This may appear to lack compassion. You should explain that this is not the intention, but it is to make it accessible to all. Simple things, like telling them how long the report is, or providing any other information about the formatting, such as section headings, might also help to set their expectations. They don't have to read it all at once. They might find it useful to read it a section at a time and come back to other bits when they feel ready.

- **Will the report be anonymised?**

One thing that patients and families describe is that reading about them or their loved one in a way that has been anonymised feels cold and reads insensitively. You should work with the patient and family based on their preferences for how they would like to be referred to. If the patient or family does not want their report to be anonymised, this should be considered and accommodated where possible. If for any reason the report is anonymised, it is important that you prepare them for how they will be referred to, and why.

- **Does the report contain any unexpected information?**

It might be difficult to determine what information within the report might be unexpected for the patient or family. But it is important that they do not find out new things for the first time when reading it. Particularly, if those things are significant to the findings of the investigation or are related to aspects of the investigation that the family have told you are important them.

- **Does the report contain any points of disagreement?**

It is important to prepare the patient or family for any points of disagreement, reiterating that all sources of information are equally weighted. They should be sensitively reminded that is not always possible to get definite answers from an investigation, particularly if the incident was complex. They should also be encouraged to highlight any additional points of disagreement that aren't made clear in the report once they have had time to read it.

- **Was the report unable to answer any of the questions it looked into?**

Uncertainty can be one of the hardest emotions to deal with. It is important that the patient or family are prepared if the investigation was not able to get answers to any of the questions it looked into, and why. If necessary, you might need to signpost them to other services that may be able to get answers to these questions and/or relevant support.

- **What are the key learning points and recommendations?**

It is important that the patient or family understand the purpose of the investigation, which is to identify organisational learning to improve systems, and not to apportion blame or liability. You should reiterate this to them, and share any key learning points and recommendations. If there are no learning points or recommendations as a result of the investigation, patients and families might be understandably disappointed or angry. You should prepare them for what they will read in advance.

- **How long does the patient or family have to read the report and feedback?**

You should let the patient or family know that they will be asked to provide their feedback on the report after taking some time to read it. You should be clear about how long they have to do this. If they feel like they need more time, this should be considered and accommodated where possible.

- **Provide space to ask any additional questions or raise concerns.**
- **Revisit their needs for support (page 25).**
- **Revisit their preferences for working together (page 33).**

Getting feedback on the report

Once the report is ready to share with the patient or family, you might want to use:

A copy of the draft report cover letter

This sensitively reminds the patient or family of the purpose of the report, what to expect and lets them know that you are there for support and to answer any questions. It also suggests that they may want to discuss the report with other people affected by the incident e.g. their family.

'Checking the report' document

This provides some prompts to keep a note of any reflections, questions they have or areas they might want to see changed. They will also be provided with a copy of this in the Patient and Family Guide **(page 32)**.

*Both the cover letter and the checking the report document can be downloaded from the Learn Together website (**learn-together.org.uk**). The cover letter can be tailored where necessary.*

Avoid sending a copy of the draft report to patients and families immediately before weekends and holidays, or when they will not be able to contact you for a while, as they might need support or guidance upon receiving and reading it.

You should offer to meet with the patient or family again after they have had some time to read through it. You may want to encourage them to complete the 'checking the report' sheet in the Patient and Family Guide **(page 32)** and share it with you, or use it to prompt your conversation. It is important to be upfront if they only have one opportunity to provide their feedback to you.

How to manage feedback on the draft report

You will not always be able to change the report in light of the feedback, for example, if it contradicts multiple sources of evidence, or seeks to change what is written in the clinical notes or the perspective of healthcare staff.

Patient and family feedback shouldn't be about fundamental changes – the 'checking of the report' pages in their guide helps them think about what they should comment on. **However, it is really important to take account of this feedback where possible, make changes where necessary or appropriate, and highlight points of disagreement.**

What to cover

- **Does the patient or family have any questions about the information in the report?**
- **Does the patient or family disagree with anything in the report? If so, how would they like to see it changed?** It is important to remind them that it might not be possible to change information. For example, they cannot change what is written in the clinical notes or the perspective of healthcare staff. All information is equally valuable. However, where they do disagree with information that is not possible to change, points of disagreement can be recorded in the report.
- **Having read the report, is there anything else they would like to discuss?**
- **Explain how you will use their feedback.**
- **Explain what will happen next and when they are likely to receive the final report.**
- **Revisit their needs for support (page 25).**

Supporting open-door involvement

This stage of the process can feel difficult for both patients and their families, and for you. Even if you have prepared them for the draft report and the information the report contains, their responses can be unpredictable. This is a normal part of processing trauma and grief.

Remember that many of these responses are likely to be a reaction to the experience of receiving and going through the report. Be patient, and let people process the report, and provide feedback in a timeframe that meets their needs. They might need longer than they originally thought.

If people don't respond to your communications in this stage, try again at another time. You might get pressure from others in the organisation to move more quickly, but it is important that the organisation values working relationally with patients and families to support the best outcomes for everyone.

Notes:

Stage 4: Checking and finalising the report can be found on page 28 of the Patient and Family Guide

Stage 5. Next Steps

"Remember that for the patient or family, the investigation report is often only a step along a journey that could continue for some time to come. Being aware of this and passing on information about help and support available as the patient or family navigate future processes can make a real difference.

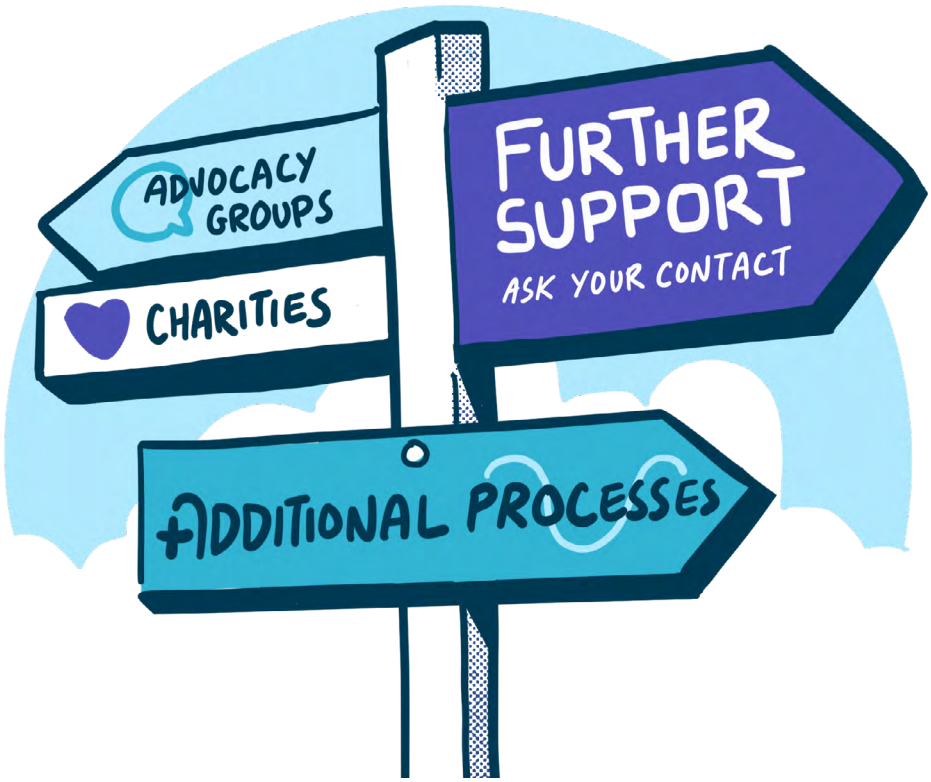
In some cases, patients or families might want to play an active part in helping to drive and embed learning from what has happened. If this is something a patient or family are interested in doing, exploring any opportunities there might be could be hugely beneficial for everyone.

Thinking about opportunities for involvement e.g. through your organisation's patient experience team, possible involvement as a **patient safety partner** or perhaps opportunities to help design training or learning lessons."

James (father of Joshua), involved in a patient safety incident.

The end of the investigation might be emotional for patients and families, regardless of how involved they have been in the investigation. It may mark the beginning of a new phase in their lives. Patients and families might have to learn to live with the impacts of the incident, whether that is physically or emotionally. They might have to navigate additional healthcare services, or process life-changing injuries or bereavement. The investigation might have provided structure and a sense of agency for people during a difficult and uncertain time.

This final stage of the process has been designed to help to support you to close the investigation in ways that dignify and reflect the potential impact on those involved.



Using the principles to work relationally

Respect humanity.

Different people will have different emotional responses to the end of the investigation process. **It is important to accommodate these different responses** when planning how to close the investigation. Patients and families might feel a range of different emotions at this time, and receiving the final report might make what happened suddenly feel very real.

Treat people with compassion.

It is important to **close the investigation with sensitivity and compassion**.

Individualise your approach.

You should be flexible and adapt to the different needs people may have as the investigation comes to a close.

Sharing the final report

It is important that the final report reflects the feedback that the patient or family have provided, or that it has been made clear to them why not. If the patient or family disagree with something in the report that cannot be changed, for example, what is written in the clinical notes, you should make it clear within the report that this is a point of disagreement.

Once the final report is ready, you should ask how they would like to receive a copy and provide them with it. You should thank them for their involvement in the investigation, and let them know how valuable it has been to you – and that you hope it has also been valuable for them.

If the patient and family have not been involved in shaping the draft report, receiving the final report might be a different experience. It might be that this is the first time they become engaged in the process. For people who haven't been involved in the investigation, it might feel more appropriate to send them an email or a letter to let them know, with an offer to speak to them in more detail if they wish. You might want to use an adapted version of the cover letter to accompany the draft report (available on the 'other resources' section of the Learn Together website), as this might help prepare those who have not been involved better for how to receive the final report.

Discussing any final thoughts and reflections

Some patients and families might not need further discussion or engagement. For others, they might welcome some discussion about the report, any points of disagreement, and what will happen next.

Some patients and families might also welcome further discussion about their support needs, and how to access support once the investigation is closed and their contact with you has finished.

What to cover

- **Explain what happens next for the NHS Trust.**

Be clear about the specific processes that the Trust follows to respond to reports and implement any learning. Where possible, give likely timeframes including setting expectations that the Trust might not be able to attend to some things immediately (e.g. increase the number of staff or change a particular working environment). Explain that their actions are monitored by the Integrated Care Board (ICB).

- **Explain what might happen next for the patient or family.**

For most people, receiving the final report marks the end of their involvement. However, in certain circumstances there may be additional processes they become involved in. These might happen at the same time as the investigation, or begin once the investigation is complete. If you know about any processes that they are likely to become involved in, you should advise and support them to find out more information. For example, will they become involved in an inquest led by the coroner? Is an independent body doing a separate investigation? Depending on your previous experience and how much information you have, you might only be able to provide basic details. Provide people with as much information as you can. But be honest. If you don't know something, tell them. You might be able to advise them on where else they can find more information. Or get back to them later when you have had some time to look into it.

- **Explore opportunities for the patient or family to become involved in ongoing learning at the Trust, if appropriate.**

Some patients and families might want to continue to be involved via wider improvement work related to the patient safety incident they were involved in. If this is possible, ask if this is something they might be interested in. In some cases, this can be very meaningful for both the patient and family, and the service, and can support their recovery from the trauma of the incident.

- **Revisit their needs for support (page 25).**

- **Explain what to do if they are unhappy with the investigation, there is information about this on page 39 of their guide.**

Closing the investigation

It is important to formally close the investigation. Different people will have had different levels of involvement in the investigation, so your formal closure might differ depending on this.

For people who have been involved during the investigation, you will be able to close communication during a regular point of contact. You should thank them for their involvement in the investigation.

For people who haven't been involved in the investigation, it is important that they are still made aware that the investigation has officially finished. You might want to send them an email or a letter.

When closing contact with anyone, regardless of their level of involvement in the investigation, you should recognise the impact of the incident and the investigation. Give another meaningful apology for the incident, and reassure them that the organisation is committed to responding to the outcome of the investigation to try and reduce the likelihood of similar incidents happening in future.

Supporting open-door involvement

For some patients and families that you have not been able to engage or involve across the five stages of this process, you might find that they get in contact upon receiving the final report, or once the investigation has been formally closed. People can respond to trauma in very different ways and with different emotions. Even if they have not engaged previously, receiving the final report might make what happened suddenly very real, and concrete.

If the patient or family has not been engaged before the final report but seeks engagement following the close of the investigation, it can feel difficult to know what to do. As part of supporting open-door involvement, you could:

- Invite them to a meeting to help them understand what has happened in the investigation, and support them to make sense of the incident **(page 8)**.
- Invite them to add their account, or information they might want to share about their family member to humanise the report, as an addendum to the final report.
- Explore opportunities for them to participate in futher service improvement activity if they would like to.
- Discuss their support needs and try to advise them on appropriate sources of support **(page 25)**.

Stage 5: Next steps can be found on page 36 of the Patient and Family Guide

Support for you

You might value some support to process details of the incident, what you have heard during the investigation, or support after sharing the emotional load of those involved in the investigation. Below are the details of some different organisations you can access for support and guidance.

Speak to your line manager, or trusted colleague in the first instance, if you require more specific or locally appropriate support. You can also speak to the Occupational Health team in your Trust confidentially or access support through membership of any professional organisation.

It is highly recommended to attend one of the available training courses for engaging and involving patients and families in patient safety learning responses and incident investigations. Details of some of these course can be found on the Learn Together website: **learn-together.org.uk**.

NHS staff support line is a confidential, free-phone line operated by the Samaritans. It is available to access between 7am and 11pm, seven days a week. You can call the dedicated staff support line if you would like to talk to someone confidentially if you have had a hard day, if you are worried about anything, or if you just feel you would like to talk to someone. The free-phone line number is **0800 069 6222**. Alternatively you can text **FRONTLINE** to **85258** for text support. Text support is available 24 hours a day, seven days a week.

The NHS staff wellbeing hubs have been set up to provide NHS staff access to local support and mental health services where needed. The hubs can help you access support such as talking therapy and counselling. You can self-refer to your local hub. There is more information about the Hubs and how to access them at **https://www.england.nhs.uk/supporting-our-nhs-people/support-now/staff-mental-health-and-wellbeing-hubs/**

Your local Integrated Care Board (ICB) is responsible for monitoring the patient safety incident investigations and reports from your organisation. The ICB might be able to provide you with support if you have queries or concerns about the outcome of the investigation, or how the actions and recommendations might be applied in your Trust.

Notes:

Notes:

Key words and phrases

Case note review: Use of case or medical notes to determine whether there were any problems with the care provided to a patient, identify the prevalence of issues, or when families/carers or staff raise concerns about care.

Clinical audit: Measurement of the effectiveness of specific elements of healthcare against agreed and proven standards for high quality, with the aim of then acting to bring practice into line with these standards to improve the quality of care and health outcomes.

Commissioner: Services are commissioned by **Integrated Care Boards (ICBs)** overseen by NHS England on a regional and national basis. Commissioners might include people who have been GPs, or other clinicians such as nurses and consultants.

Common themes: Common themes are recurring ideas, subjects or topics, relevant to the incident and the **Terms of Reference**, which the **investigator** identifies when they are reading all of the information they have collected about the incident.

Compounded harm: The harm that can be created after a safety incident, due to the processes that follow.

Department for Health and Social Care (DHSC): The government group responsible for health and social care across the UK.

Duty of Candour: A professional responsibility for healthcare staff and organisations to be honest with patients and families when things go wrong. The patient and/or family should be told when something has gone wrong, should be offered an apology and appropriate support, and the full effects of what has happened (if any) should be explained.

Family liason officer (FLO): A member of Trust staff whose primary role is to provide compassionate support and advice to patients and their families during a patient safety incident investigation.

General Data Protection Regulation (GDPR): A Regulation in EU law on data protection and privacy.

Governance team: Governance teams work in NHS organisations and are responsible for monitoring the quality of services and for safeguarding high standards of care.

His Majesty's Coroner: A coroner is a government official or member of the judicial system who carries out **inquests**.

Hot debrief: A post-incident review by the medical team used to collectively discuss and answer a series of questions.

Inquest: An inquest is a formal investigation conducted by a **coroner** to determine how someone died.

Integrated Care Board (ICB): An ICB is a statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the integrated care system (ICS) area.

Learning disabilities mortality review (LeDeR): A specialist review of the care of a person with a learning disability (recommended alongside a case note review).

Learning Response Lead, or Investigator: A member of staff, normally employed by the NHS Trust, who has been trained to conduct **patient safety incident investigations.**

Legal team: Most NHS Trusts have legal teams to manage a wide range of legal matters for the Trust including: claims brought against the Trust; **inquests**; any proceedings involving Trust witnesses; medical treatment applications to the High Court; medical records requests from solicitors.

Main point of contact: This will be the person from the NHS Trust assigned to engage with the patient and family throughout their investigation. They may be the **learning response lead, or investigator**, or they might be a **Family Liaison Officer (FLO)** or someone undertaking engagement and involvement as the main part of their role.

Mortality review: A review of a series of case records to identify any problems in care and draw learning or conclusions that inform action needed to improve care, within a setting or for a specific patient group, particularly in relation to deceased patients.

Near miss: An event that does not cause harm, but which has the potential to cause injury or ill health if it had not been caught in time.

Never event: Serious, largely preventable patient safety incidents that should not occur if the available preventative measures have been implemented.

Patient safety incident: Any unplanned or unintended event or circumstance which could have resulted or did result in harm to a patient.

Patient safety incident investigation: These are investigations conducted to identify how and why certain patient safety incidents happen. They are not inquiries into the cause of death or for apportioning blame. Investigations result in a set of recommendations and an improvement plan that is designed to effectively and sustainably address the underlying factors in the organisation that led to a patient safety incident, to help deliver safer care in the future.

Patient safety partner: This is a specific role undertaken by patients, carers and other lay people in supporting and contributing to an NHS Trust's governance and management processes for patient safety. Patient safety partners might be members of safety and quality committees, and have involvement in patient safety improvement projects, or work with organisation boards to consider how to improve safety.

Patient safety specialist: Individuals in NHS Trusts who have been designated to provide senior patient safety leadership.

Patient safety team: Most NHS Trusts will have a patient safety team dedicated to working within the service to minimise the risk and impact of incidents.

Perinatal mortality review: A specialist multidisciplinary audit and review to determine the circumstances and care leading up to and surrounding a stillbirth or neonatal death, and the deaths of babies in the post-neonatal period having received neonatal care.

Policy: An official document that includes a set of guidelines to guide decisions and achieve specific outcomes.

Policy makers: People working at NHS England who put together policies for NHS organisations to work according to.

Public inquiry: Public inquiries are independent, national level investigations ordered by a government department to deal with matters of public concern.

Terms of Reference: These are guidelines that define the scope and purpose of the investigation.

The approach described in this guide is based on evidence generated from an independent research programme (the Learn Together programme (learn-together.org.uk), funded by the National Institute for Health and Care Research. The guide has been co-designed by a community of stakeholders including patients and their families, patient safety managers, investigators, healthcare staff, legal representatives, and has been supported by policy makers.

FUNDED BY
NIHR | National Institute for Health and Care Research

This study is funded by the National Institute for Health and Care Research NIHR (Health Services and Delivery Research; NIHR Reference Number 18/10/02). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.