Learn Together

Supporting involvement after safety events in healthcare

Patient Safety Incident Investigation

Patient and family guide

What to expect and how you can be involved in the process

Name:

There is also space to note down the details of your main point of contact on the back of this booklet.

FUNDED BY

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*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.

" We would like to start by saying we are sorry that you find yourself here.

Everyone is different and there is no right or wrong way to feel. But we understand that being involved in a patient safety incident investigation can be a very difficult time.

We are patients and family members who have experienced patient safety incidents and investigations ourselves. We know that the investigation cannot change what happened. But we want to make what happens next as easy and as meaningful for you as possible.

We would encourage you to be involved in the investigation as much as you would like to and feel able to. You can do this by asking questions and sharing information you have throughout the investigation.

This might help you to find answers to your questions and access support you need. It might also help to reduce the risk of the same thing happening to others in the future.

Together with a larger group of people who have experienced investigations before, we have developed this guide and the supporting website: learn-together.org.uk

This guide is yours to keep. You do not have to read it all at once. You can use the five-stage process on page 6 to help you find what you need easily. You can always come back to other information when you feel ready.

There is also space to make notes and write down your questions. We encourage you to use the information and anything you write in the guide, to prompt conversations with your main point of contact.

If you do not feel able or ready to be involved right now, you could pass this guide on to someone else who has been affected by the patient safety incident, such as a family member. You can always get involved later, if and when you do feel ready.

Most importantly, you should do what feels right for you and those affected by what happened."

A message from Debra, Faye, James, Joanne, Mary, Penny, Sarah and Scott. Patients and family members of people who have been involved in patient safety incidents and investigations.

Why be involved?

First and foremost, be kind to yourself. It's the most emotional time to go through... don't ever apologise for being emotional at a meeting. And if you don't understand something, ask and ask again. It's really important that you understand what is happening. And don't be afraid to ask for support.

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

Scan the QR code or go to **learn-together.org.uk** to access the full video. You can also request a copy of the video transcript from your contact. Debra discusses how you can use this guide and other information on the Learn Together website to help to make this process easier and more meaningful for you.

Patients and families really should get involved in investigations if they can and get the support they need... because this is actually **their** experience. This is their life that's being investigated.

Joanne (mother of Jasmine), involved in a patient safety incident.

We went through everything that happened in the pregnancy, during the labour and the birth - all from our perceptive, and they listened. And I think they were very aware that this was like, a tricky thing for us to have gone through, and they wanted to make sure that we felt comfortable. And we felt like they were getting a true picture, from our perspective, of what actually happened.

Sam and Julia (parents of Celeste), involved in a patient safety incident.

Scan the QR code or go to **learn-together.org.uk** to access the full videos. You can also request a copy of the video transcript from your contact. You can hear more from Joanne, Julia, Sam and Andrew talking about why it is important to get involved if you would like to and feel able to, drawing upon their own experiences.

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Words and phrases that might be unfamiliar to you have been highlighted in **bold red text**. Definitions can be found on **page 45-47**

Scan the QR code or go to **learn-together.org.uk** to access more information about how you can get involved in each stage of the investigation, including a video walkthrough of each stage.

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. There is no right or wrong way to feel. Your needs will take priority and the people leading the investigation will want to ensure that you are being well-looked after. Take your time to think about what you need and ask as many questions as you want to. The investigation may help you find out exactly what happened and help ensure that it doesn't happen to others. You may wish to be involved for these reasons. But whether you decide to be involved or not, the investigations team can help you access any ongoing support you may need."

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

Meeting your main point of contact

Your contact will aim to introduce themselves and have a discussion with you as soon as possible after the patient safety incident and at the start of the investigation. Sometimes, the investigation may have already started by the time you meet your contact.

Your contact might introduce themselves and have a meeting with you to discuss you and your needs at the same time, or this might be two separate meetings.

You will be given time and space to share what you know about what happened. Patients and families who have experienced a patient safety incident say that being involved at this stage might be an important step on the road to recovery and making sense of what happened. If you choose to be involved, you will be guided and supported through it.

It is important to know who your contact is throughout the investigation. You can make a note of their details on the back of this guide.

Preparing for the meeting

The following pages suggest some things you might like to think about ahead of meeting with your main point of contact. In this meeting, the key role of your contact is to **listen and learn about you and what you experienced.** You will be provided with space to discuss the things most important to you, even if they cannot be solved by the investigation.

Some of the things you raise might not be covered as part of the investigation as there are other, more suitable processes to look at these. If this is the case, your contact will discuss this with you in detail.

Sometimes investigations won't be able to provide answers to all your questions. This is because people's versions of events don't always align. Your contact will do their best to find answers, and if they can't they will tell you why.

Things to discuss

This meeting is about you. There are no right or wrong things to discuss. However, the following prompts might help you to prepare for this discussion, so that you can get the most from it and access any support you might need.

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?

What would you like to see happen next?

What to do once you have completed these pages

You can show your main point of contact what you have written here or you can keep it private, but use it to guide your conversation.

What you can do

If you haven't been offered a meeting, you can ask your main point of contact to arrange one. Don't worry if you don't cover everything you would like to during this meeting. You can get back in touch with additional information or questions at any time as the investigation progresses.

Why it's good to be involved

It will help both you and your contact understand what happened from your perspective. It will also help the investigation move forward in a way that respects the needs of you and your family, and what you would like to see happen next. You will be supported to get involved in this if you would like to and feel able to.

Your notes and questions

Stage 2. Agreeing how you work together

"It may feel as though there is a lot to take in at first, but please don't worry. As you are supported and guided through the different stages of the investigation, there will be an opportunity to work together with your main point of contact, to find the best way to answer your questions and to hear your valuable perspective. It may be a difficult time, but remember that you are such an important part of a team, whose members want to learn from you, and to connect with compassion, sensitivity and respect."

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

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

It is unlikely that you have been involved in something like this before. But it is important that you know what to expect from the process. If you have any questions, your main point of contact will do their best to help you.

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."

You might 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**

NHS Trusts are required to let patients and their families know that a patient safety incident has happened. This process is called **Duty of Candour**.

For some patient safety incidents, it will be appropriate to conduct what's called a **patient safety incident investigation**. This 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 of the investigation is to identify organisational learning to improve systems, and not to blame people. When things go wrong it's usually caused by many things rather than just one thing.

The time it takes to complete an investigation varies due to multiple factors, such as the complexity of the incidient and the number of people involved. Speak to your contact for an estimate of how long your investigation is likely to take. They will also update you if anything changes along the way.

A trained member of staff at the NHS Trust will be appointed to lead the patient safety incident investigation. Where possible and appropriate, they will be independent of the clinical area in which the patient safety incident happened.

As part of the investigation you will be given a **main point of contact**. Your main point of contact might also be the person leading the investigation, or they may work in a different role, such as a **Family Liaison Officer** (FLO) or a **Patient Safety Specialist**. There is space to note down their details at the back of this guide.

The investigation will gather information from different sources, including you and your family, to help understand what happened. You will also have your own views about what happened and it's important that you share these. There is more detail about the **giving and getting information stage** of the investigation on **page 24**.

Towards the end of the investigation, a report will be produced based on all of the gathered evidence. This will explain what is thought to have happened and how. It may also outline key learning points aiming to reduce the likelihood of it happening again, and what actions might need to be taken by the NHS Trust based on these points. You will be asked to check the report before the final version is produced. There is more detail about the **checking and finalising the report stage** of the investigation on **page 28**.

As well as the patient safety incident investigation, you may be involved in different processes. For example, following a patient safety incident that has led to an unexplained death, you might be involved in an **inquest** led by the **coroner**, or an independent body may carry out a separate investigation. Please speak to your contact about the purpose of these processes and how they differ from the investigation. There is more detail about the **next steps** on **page 36**.

Principles of working together

The Learn Together approach to investigations is based on a set of principles about how people should be treated after a patient safety incident, and in any investigation that follows. These principles were developed together with patients and family members of people who have experienced patient safety incidents and investigations, and are designed to support those involved to work together productively, and in ways that meet their needs.

The process

- The investigation will try to clarify **what happened and how it happened**.
- It will be **flexible to your needs and how you 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 **your perspective is valued** alongside other information and evidence, in understanding what happened.

The people

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

The investigation might not be able to answer all of your questions, but by developing a respectful, sensitive and honest working collaboration with your contact, you will hopefully have confidence in the outcome of the investigation.

Preferences for working together

The following pages provide space to outline your **preferences about how you and your main point of contact will work together** throughout the investigation. Where possible, these preferences will be considered and accommodated. Your preferences for involvement might change during the course of the investigation. You can revisit this and change your mind at any time.

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

Please indicate which aspects of the investigation you would like to be involved in by ticking the relevant boxes below. You will be supported to be involved in the investigation as much as you would like to and feel able to.

- ☐ Be updated as the investigation progresses.
- ☐ Share my experience of the patient safety incident and what is important to me.
- ☐ Ask questions that I would like to be looked into as part of the investigation.
- ☐ Provide a summary from my 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.
- ☐ I do not want to be involved.

*Please speak to your main point of contact to ask if this is possible. If so, they will give you more guidance about how long this should be and what it might include.

2) How would you like to be contacted throughout the investigation?

The best times and ways to contact me are:

.....

.....

.....

.....

.....

.....

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

.....

.....

.....

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.....

.....

Please indicate how often you would like to be contacted by ticking the relevant box:

☐ 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 of whether there is opportunity to provide or receive new information.

If you would like to be contacted routinely, ideally, how often would that be?

.....

.....

.....

3) What questions do you have?

4) What additional support might you need?

5) How would you, or the patient, like to be referred to within written communication such as the report? Please note, sometimes reports are anonymised.

6) Are there any other things that you would like your main point of contact to know?

What to do once you have completed these pages

You can show your main point of contact what you have written here or you can keep it private, but use it to guide your conversation. Your contact will try and meet your needs wherever possible.

Agreeing what the investigation will cover

The purpose of the investigation is to understand what happened and how. The scale of the investigation usually depends on how complex the patient safety incident was and whether a team are reviewing other incidents that are linked to this investigation. More complex investigations might have a team of people leading them, for example.

The scope of the investigation is often referred to as the **'Terms of Reference'**. These set out the questions that will aim to be answered. The NHS Trust will have a set of questions that they want to ask about what happened. But you might have other questions. These will be considered and included where possible. Together, you will agree what the investigation covers.

It may be that not all of your questions can be answered by the investigation. For example, some of the questions that you have may be better answered by other processes. If this is the case, your contact will discuss this with you and advise you about getting answers to these questions in other ways.

What you can do

If you haven't had a discussion yet about what will be included in your investigation, speak to your contact. Highlight questions that you would like answering at any time during their working hours. If they are unavailable, they will get back to you as soon as they can. If the terms of reference have already been agreed you can ask to see a copy of them.

Why it's good to be involved

It will help to ensure that what the investigation covers respects your needs and aims to answer any questions you have. You will be supported to get involved in this if you would like to and feel able to.

Your notes and questions

Stage 3. Getting and giving information

"Going through an investigation can be a daunting experience. You might be concerned with the standards of care recieved. You may have only recently become bereaved.

In our experience, and for many families, it is hugely important to recieve a factually accurate report. Please speak up if you have information to share and ask questions during this stage of the investigation. This will help to make sure that your voice is heard and the report resonates with your experience.

The investigation will listen to the perspective of those involved - including you as patients, family members, carers and service users, alongside clinical records and the view of healthcare professionals.

You should feel that the information you share 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.

The investigation is a bit like a jigsaw. There are different pieces of information relating to the patient safety incident. The investigation gathers the different information and tries to understand different people's experiences of what happened, as well as pulling together common themes and finding points of disagreement.

You are a key part of this jigsaw. You have a unique and valuable perspective on what happened and may have information others do not have access to.

The information you share will be brought together with information provided by staff and other relevant sources. For example, clinical notes might be reviewed to see what was written down at the time. Others who experienced the patient safety incident, such as healthcare staff, will also be asked to share their experience. Relevant healthcare settings might also be visited to observe clinical areas or procedures.

You will be informed about progress during the investigation. However, updates may not be as regular or there may be less information to share with you during this period. If you are unsure about anything, your contact will do their best to help you.

What you can do

Some people prefer to wait for their main point of contact to pass on information. But if you have questions, have information that you would like to share or would like a general update, you can get in touch with your main point of contact. They will be happy to answer any questions you have and let you know how the investigation is progressing.

Why it's good to be involved

It will help you to learn more about what happened and how, and help reduce the risk of it happening again to others in the future. You will be supported to get involved in this if you would like to and feel able to.

Your notes and questions

Stage 4. Checking and finalising the report

"Brace yourself for receiving the report because it can be difficult to read. It is facts with feeling removed and that can be really hard. It's ok not to read it all in one go. It's ok to cry. It's ok to be angry.

But please be kind to yourself. Give yourself time to digest it and then make a list of anything and everything you wish to raise and question. It is your right to do that. You might want to ask someone else to cast an eye over it too. Someone who is slightly more removed from what happened because they may spot something you didn't.

Lastly, I remember feeling really flat once I had the report. I guess in my head I thought receiving it would make me feel better. It didn't, and that took some getting my head around. There is no right or wrong way to feel."

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

What is the report?

All of the information gathered from different perspectives will be brought together to produce a report. This outlines what was thought to have happened and how. It may also outline key learning points aiming to reduce the likelihood of it happening again, and what actions might need to be taken by the NHS Trust based on these points.

Getting prepared for the report

Your main point of contact will discuss the key findings of the investigation with you. If you are unsure, it might be useful to ask the following questions to help to prepare you for receiving the report, and make a note of the answers:

What does the report look and feel like? e.g. How long is it?
What tone is it written in?

How will the patient be referred to in the report?
Will the report be anonymised?

Does the report contain any unexpected information?

Does the report contain any points of disagreement?

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

What are the key learning points and recommendations?

How long do I have to read the report and provide feedback?

After you've discussed the key findings

Your main point of contact will share a copy of the report with you and ask for your feedback. At this stage the report is still in draft. They will also work with you to meet any additional support needs you might have. For example, translating the report into another language, using a larger font size or using different coloured paper.

As well as asking for your feedback, the report may also be sent to teams in the NHS Trust such as **governance**, **patient safety** or **legal teams**.

One thing that patients and their families say, is that the report can be difficult to read. Here are some important things to think about, which may make it easier:

- The purpose of the investigation is to **identify organisational learning to improve systems, and not to blame people**. When things go wrong it is usually caused by many things, rather than just one thing.

- Everyone is different and there is no right or wrong way to feel. But **you might want to read the report together with others who have been affected by the patient safety incident, such as your family.** You might also want to meet with your main point of contact again after taking some time to read through it. Your contact will try to direct you to support that is specific to you and your needs if necessary.

- **You do not have to read it all at once.** You might find it useful to read it a section at a time. You can always come back to other sections when you feel ready.

- Any information you provided has been brought together with information from other relevant sources, such as healthcare staff and clinical notes. **All information is equally valuable. However, there may be points of disagreement. These should be clearly highlighted in the report.** You should speak to your main contact about these points of disagreement in more detail if you are unsure, and highlight any additional points of disagreement that aren't made clear.

- **The report is written for different audiences which includes you**, but also includes others such as healthcare staff and senior management. Because of this, reports are often written in non-technical language and use a factual tone. which might appear insensitive. This is not the intention. This is to make the report accessible to all. **However, if there is anything you do not fully understand (e.g. any medical terms) please speak to your main point of contact.** They will provide you with a detailed explanation.

- **Within the report, information may be anonymised.** For example, it may use terms like 'the patient', or 'the nurse', rather than giving their names. This may appear insensitive but that is not the intention. This may be due to various reasons such as **General Data Protection Regulation (GDPR)**.

Checking the report

Once you have taken some time to read through the report, you can provide feedback within the timeframe agreed with your main point of contact. If you feel like you need more time, let your main point of contact know. At this point in the investigation it is unlikely that fundamental changes to the report are required. However, the prompts below may provide a useful way of organising your questions, feedback and reflections.

What questions do you have about the information in the report?

Do you disagree with anything in the report? If so, please say how you would like to see it changed. *Please note that it may not be possible to change information in the report. For example, you cannot change what is written in the clinical notes or the perspective of healthcare staff. All information is equally valuable. However, where you disagree with information that it is not possible to change, points of disagreement can be recorded.*

Having read the report, is there anything else you would like to discuss?

What to do once you have completed these pages

You can show your main point of contact what you have written here or you can keep it private, but use it to guide your conversation.

What you can do

If you haven't discussed how you will check a draft version of the report and would like to know more, you can ask your main point of contact about it. You can get in touch with your main point of contact at any time during their working hours. If they are unavailable, they will get back to you as soon as they can.

Why it's good to be involved

It will help to make sure that the report captures your experience accurately and that you are able to raise any additional questions you may have. You will be supported to get involved in this if you would like to and feel able to.

Your notes and questions

Stage 5. Next Steps

Your involvement is hugely valuable - ensuring that your experience and perspective is at the heart of investigation. Hopefully, you will feel that this has made a difference to the report and that you have the answers and explanations you need to make sense of what happened and why. However, very often the investigation won't feel like a true 'end point'. Other processes might be ongoing and the emotional journey of coming to terms with what happened may have only just started. Being prepared for all of these feelings and having a plan in place to ensure you have as much help and support as you need is really important. Remember that strong emotions and complex feelings associated with trauma or grief are normal. Be kind to yourself. Talk to family members who might be feeling the same. Have conversations with work colleagues so that they are aware of what is happening and can provide support. Speak to the Trust about what support is available. Everyone's circumstances will be different. In my own case, I found speaking to other families who had experience of baby loss via the charity Sands, hugely helpful. Consider researching support forums or organisations that might help you.

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

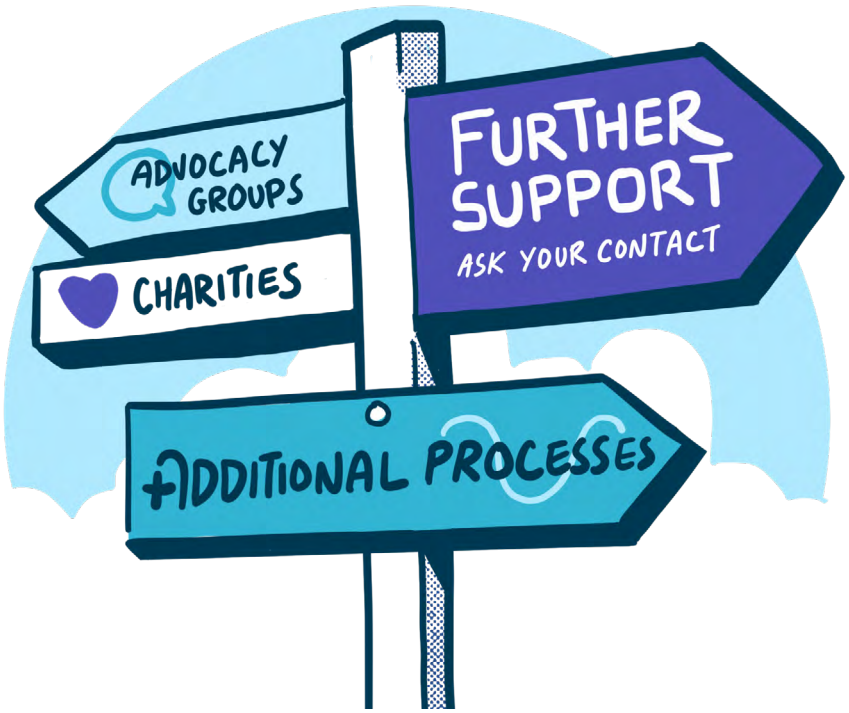
Receiving the final report

After making any necessary changes, your main point of contact will provide you with a copy of the final report. You might want to meet with them to discuss what has changed as a result of your feedback as well as your thoughts and reflections.

As the formal process comes to an end, hopefully, you will be able to move forwards feeling reassured by the investigation outcome. Your valuable involvement also hopefully helped to reduce the risk of the same thing happening again.

What happens next for the NHS Trust?

The NHS Trust has specific processes that they follow to respond to reports and implement any learning. There might be certain things that the Trust cannot attend to immediately (e.g. increase the number of staff or change a particular working environment). However, the Trust must respond to all learning set out in the report. This is monitored by what's called an **Integrated Care Board** (ICB). There may be some instances where you can continue to be involved in what the NHS Trust does next. For example, you might be invited into wider improvement work related to the patient safety incident you were involved in. If this is something you would be interested in, speak to your contact to understand if it might be possible.



What happens next for you?

Everyone is different, but you might find that the end of the investigation is a difficult and emotional time. If you still have outstanding questions or need further support, please speak to your main point of contact. They will do their best to help you, or be able to advise you on how to get the help that you need.

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 your main point of contact knows that there are other processes happening, they will tell you. They will also advise and support you to find out more information about these processes and the ways you can become involved. For example, following a patient safety incident that has led to an unexplained death, you might be involved in an inquest led by the coroner, or an independent body may carry out a separate investigation.

You may also find that you want to become involved more generally in supporting others who have experienced a patient safety incident or who are going through the investigation process. Speak to your main point of contact about any advocacy groups, support groups or charities.

Further Support

Speak to your main point of contact about accessing further support specific to your situation. However, here are some general support resources that might help you:

Citizens Advice can give high quality, independent advice about any problems or questions you might have. They can provide you with the knowledge and confidence to find a way forward. They have a network of national and local independent charities that can provide free and confidential advice. You can find out more at **https://www.citizensadvice.org.uk/**. You can also call an advisor on this free to dial number: **0800 144 8848**.

Mind is a registered charity that provides support and advice to anyone who is struggling with their mental health. If you have been affected emotionally following the incident you experienced or if you are finding the investigation process difficult, you can contact Mind. You can find general support resources and information about local services at **https://www.mind.org.uk/**. You can also email them on **info@mind.org.uk** or call their helpline on **0300 123 3393**.

Samaritans are a registered charity providing support to anyone in emotional distress or anyone who is struggling to cope. If you have been emotionally affected by the incident you were involved in, you can contact the Samaritans for free and there will always be someone there to listen to you and talk to you. You can find more information at **https://www.samaritans.org/**. You can email them on **jo@samaritans.org** or you can call free on **116 123**. Their support is available 24 hours a day, 7 days a week, 365 days of the year.

What if you are unhappy with the investigation?

If you are unhappy with the investigation speak to your main point of contact in the first instance, to see if the problem can be resolved. Alternatively, here are some services and organisations that might help you:

Action against Medical Accidents (AvMA) is an independent charity which provides free specialist advice to people who have been affected by patient safety incidents. They can advise you about your investigation as well as other processes that you may be faced with or be considering (for example inquests; complaints; fitness to practice/regulatory issues raised by the incident; or legal action). They can also give you details of other organisations providing different sorts of support. For further details, please visit: **www.avma.org.uk**

Patient Advice and Liaison Service (PALS) can be found in each NHS Trust. You can talk to a PALS member of staff about your incident and they will try to help you resolve any issues with the Trust informally. PALS can be particularly useful if you need action immediately, for example if the incident has been a problem with your care and you are still in hospital. You can ask a member of staff at the Trust for details of the local PALS service, or you can find more information at: **www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/**

If you want to make a formal complaint, you can contact the **NHS Complaints Service**. You can either make a complaint to the NHS Trust directly, or you can make a complaint to the local **Integrated Care Board (ICB)** who oversee hospital services.

The Parliamentary and Health Service Ombudsman (PHSO) respond to unresolved complaints. They can support you if you have made a complaint following your incident and the organisation has not responded to your complaint or you are dissatisfied with their response. You can find more information at **www.ombudsman.org.uk**.

Relevant documents and policies

The Patient Safety Incident Response Framework (PSIRF) is written to guide all NHS Trusts nationally across England in how to identify and respond to patient safety incidents. This includes Patient Safety Incident Investigations (PSII), but also other response types. If you would like to find out more about the Patient Safety Incident Response Framework (PSIRF) you can access it here: **https://www.england.nhs.uk/patient-safety/incident-response-framework/**

NHS Trust policy. Each NHS Trust will have their own policy, based on how they implement the Patient Safety Incident Response Framework (PSIRF) locally. If you would like to read the Trust policy, you can ask your main point of contact to provide you with a copy.

Duty of Candour. The Department of Health and Social Care mandates that each NHS Trust makes patients or their family aware that a patient safety incident has taken place via Duty of Candour. If you would like to read the Trust Duty of Candour policy, you can ask your main point of contact to provide you with a copy.

Your notes and questions

Notes

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.

Health Services Safety Investigations Body (HSSIB): HSSIB (formerly HSIB) is funded by the **Department for Health and Social Care**, and is responsible for carrying out independent investigations into NHS-funded care across England.

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.

It is important that you know who your main point of contact at the NHS Trust is. You can use the space below to record their details.

My main point of contact is:

Contact information:

(You might want to save phone numbers to your phone contacts)

Working hours:

Other important things to note:

You can get in touch with your main point of contact during the investigation using the contact details they provide. If they are unavailable, they will get back to you as soon as possible.

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