

Beyond disclosure:

How listening to, and learning with, patients and families during incident investigations can reduce further harm.

Professor Jane O'Hara

University of Leeds, UK



Some background...

ORIGINAL RESEARCH



OPEN ACCESS

What can patients tell us about the quality and safety of hospital care? Findings from a UK multicentre survey study

Jane K O'Hara,^{1,2} Caroline Reynolds,² Sally M Laura Sheard,⁴ Claire Marsh,² Ian Watt,⁵ John Rebecca Lawton^{2,7}

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjqs-2017-006974>).

¹Leeds Institute of Medical Education, University of Leeds,

ABSTRACT

Background Patient safety measurement remains a global challenge. Patients are an important but neglected source of learning; however, little is known about what patients can add to our understanding of safety. We sought to understand the incidence and nature of patient-reported safety concerns in hospital.

(PSI) published, including and measuring learning

HSR

Health Services Research

© Health Research and Educational Trust
DOI: 10.1111/1475-6773.12593
PATIENT SAFETY & MEDICAL LIABILITY

Patients as Partners in Learning from Unexpected Events

Jason M. Etchegaray, Madelene J. Ottosen, Aitebureme Aigbe, Emily Sedlock, William M. Sage, Sigall K. Bell, Thomas H. Gallagher, and Eric J. Thomas

Importance. Patient safety experts believe that patients/family members should be involved in adverse event review. However, it is unclear how aware patients/family members are about the causes of adverse events they experienced.



Serious Incident Framework

Supporting learning to prevent recurrence

BRIEFING

Learning from serious incidents in NHS acute hospitals

A review of the quality of investigation reports

June 2016

2. Routinely involving patients and families in investigations

Only nine (12%) of the reports in the sample included clear evidence that the patient or their family had been involved in the investigation.

'Organisational learning' is a key aim of investigations

Patients and families are not routinely involved in investigations

Missing a key perspective in understanding what went wrong

If we can involve patients and families, can we improve learning?


What did we do?

To *develop* and *test*
new processes and
guidance to support
the better *involvement*
of patients and
families in serious
incident investigations

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Incident/Serious Incident Report Policy

This policy describes the process for investigating and managing incidents and serious incidents.

Key Words:	RIDDOR Investigation
Version:	9
Adopted by:	Quality Assurance Committee
Date Adopted	25 July 2016

REVIEW ARTICLE

OPEN

Patient and Family Involvement in Serious Incident Investigations From the Perspectives of Key Stakeholders: A Review of the Qualitative Evidence

Lauren Ramsey, PhD, Siobhan McHugh, PhD,* Ruth Simms-Ellis, PhD,* Kayley Perfetto, MSc,† and Jane K. O'Hara, PhD*‡*

Objectives: Investigations of healthcare harm often overlook insights of patients and families. Our review aimed to explore perspectives of key stakeholders when patients and families were involved in serious incident investigations.

Methods: The authors searched three databases (Medline, CINAHL) and Connected Papers software for qualitative studies of patients and families involved in serious incident investigations. No new articles were found.

Results: Twenty-seven papers were eligible. The perspectives of patients and families, healthcare professionals, nonclinical staff, and sought across acute, mental health and maternity settings and families valued being involved; however, it was important to ensure involvement was meaningful and not just a box-ticking exercise.



PRINCIPLES FOR MEANINGFUL INVOLVEMENT

[VERSION 1.3]

Make apologies meaningful. Rather than offer excuses, demonstrate understanding and a commitment to learn what has happened and why.

Individualise your approach. Involvement should be flexible and adapt to changing needs. Set realistic expectations.

Be sensitive to timing. Investigations can feel like they're happening slowly, quickly or at insensitive times. Investigators need to manage time carefully.

Treat people with respect and compassion. Harm can happen through the experience of the investigation, and how people are treated within it.

Strive for equity. Investigations allow an organisation to learn, but if their agenda is prioritised over patients/staff, the process can feel discriminatory.

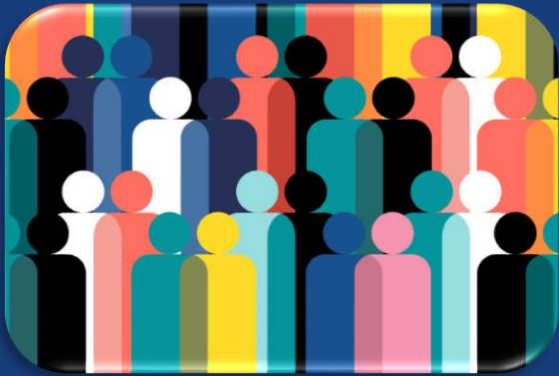
Provide guidance and clarity. Patients, families and even healthcare staff can all be confused by what an investigation actually entails.

Listen. If there is a true commitment to learning, then everyone involved should have the opportunity to share their experience.

Be collaborative and open. People who feel involved are less likely to need to seek other routes to be heard (e.g. complaints, litigation).

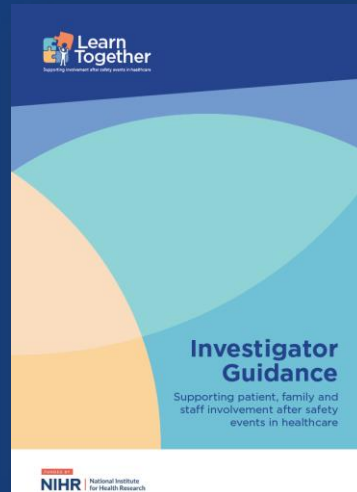
Respect humanity. Investigations should embrace and accommodate different human responses.

Accept subjectivity. Each individual will experience the same incident in different ways. No one truth should be prioritised over others.



50+

6m



x2

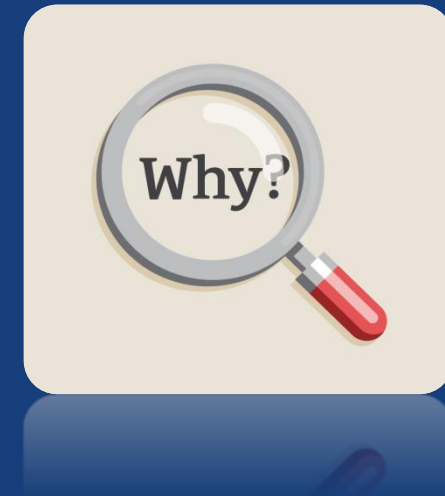


14m



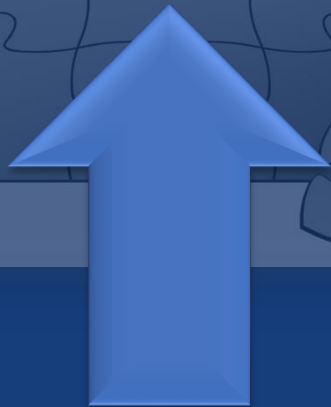
29

What did we learn?


$$> 1$$




For learning



For healing




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

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DOI: 10.1111/hex.13478

VIEWPOINT ARTICLE

WILEY

Humanizing harm: Using a restorative approach to heal and learn from adverse events

Jo Wailling MHR, RN, Senior Research Fellow¹  |

Allison Kooijman MA, Patient Advocate² | Joanne Hughes Patient Advocate³ |

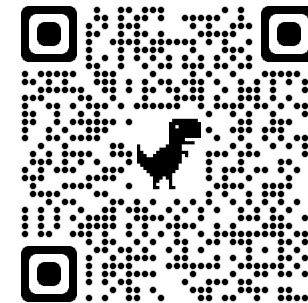
Jane K. O'Hara PhD, Professor⁴

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Abstract

Background: Healthcare is not without risk. Despite two decades of policy focus and improvement efforts, the global incidence of harm remains stubbornly persistent,



“I wrote a really carefully worded complaint letter. I put a lot of thought into it....I tried to make sure that the letter wasn't aggressive or pointing the finger... but when I got the response, I've often said that was the worst day of my life.”

“At one stage I was so upset by the whole thing I felt like taking legal action but I was very aware that the NHS is a very large organisation and, you know, it was little me against them.

I felt like I was in the boxing ring with my hands tied behind my back. And I felt desperate.”



Listening



Learning

Can it be done?

Learn Together

Home Patients and families Investigators Resources Contact us



Learn Together

Supporting involvement after safety events in healthcare

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After a safety event in healthcare, NHS Trusts may conduct a Patient Safety Incident Investigation. Listening to and valuing different

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Supporting involvement after safety events in healthcare

Investigation Guide

Supporting patient and family involvement in patient safety incident investigations

NIHR | National Institute for Health and Care Research

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.

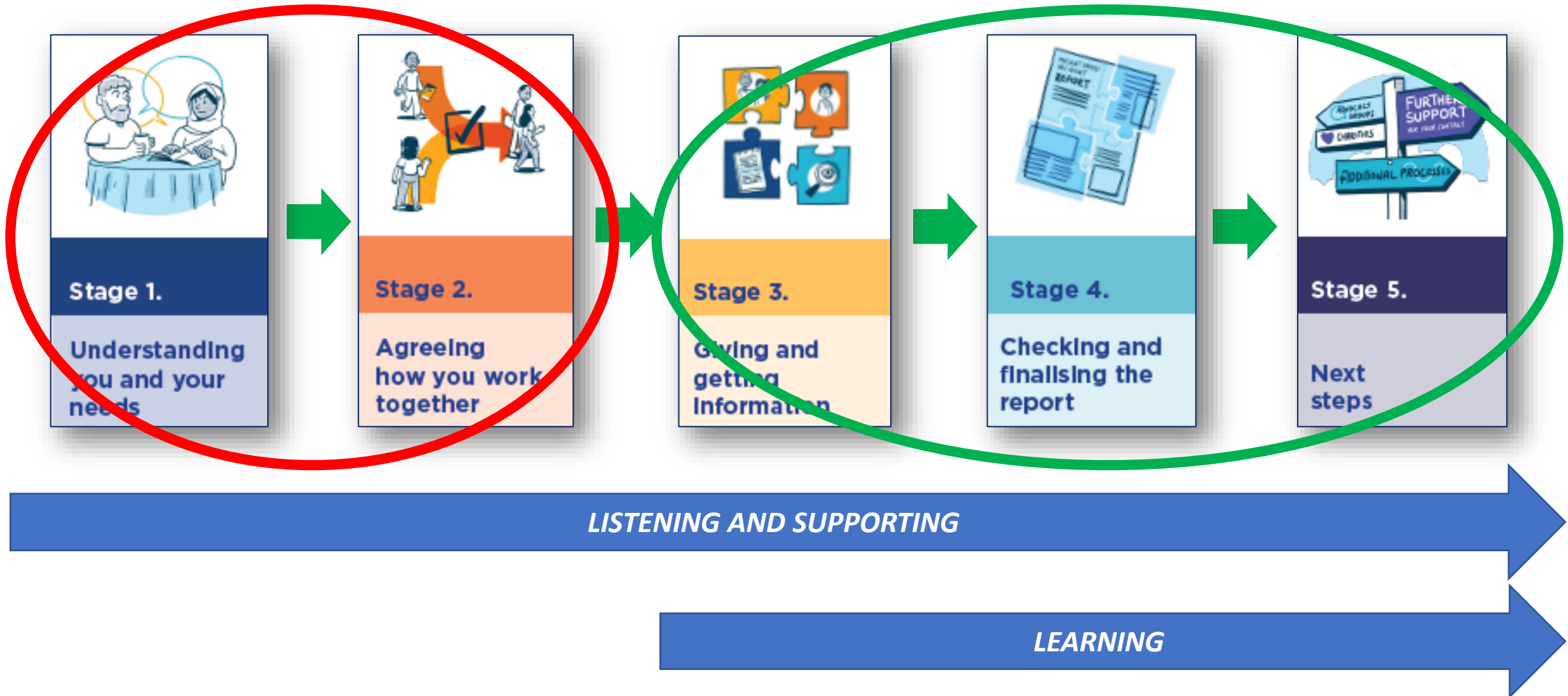
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Supporting involvement after safety events in healthcare







Classification: Official

Publication approval reference: PAR1465

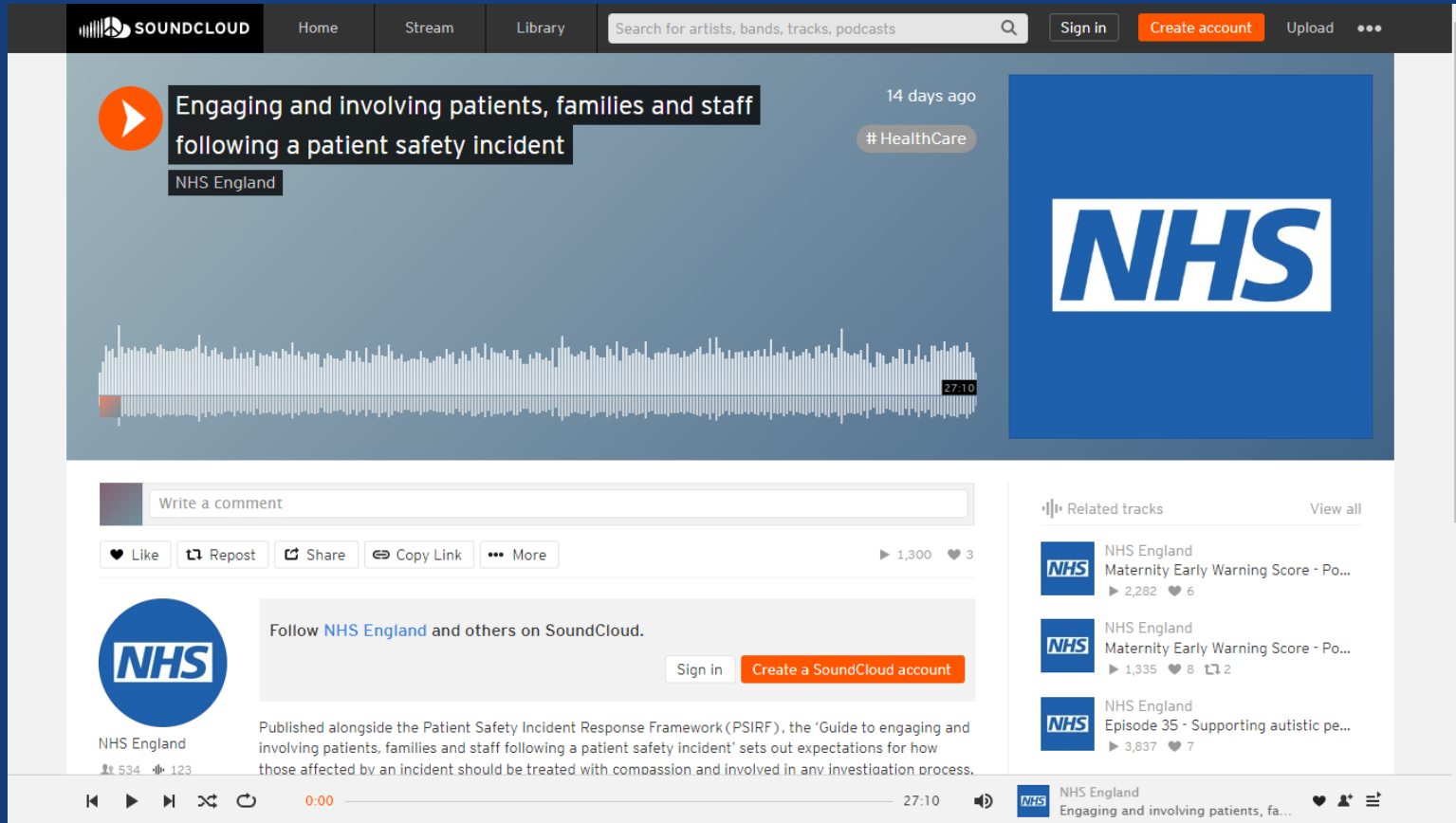


Patient Safety Incident Response
Framework supporting guidance

Engaging and involving
patients, families and staff
following a patient safety
incident

Version 1, August 2022

- National guidance
- Collaboration with NHSEI and HSIB
- Released August 2022
- *Revisions due 2024*



The image shows a SoundCloud player interface. At the top, there's a navigation bar with 'SOUNDCLOUD' logo, 'Home', 'Stream', 'Library', a search bar, and buttons for 'Sign in', 'Create account', and 'Upload'. The main content area features a track titled 'Engaging and involving patients, families and staff following a patient safety incident' by NHS England, posted 14 days ago. The track has a waveform and a duration of 27:10. Below the track, there's a comment section with a 'Write a comment' input field and buttons for 'Like', 'Repost', 'Share', 'Copy Link', and 'More'. To the right, there's a 'Related tracks' section with three tracks listed, each with a play button, a heart icon, and a share icon. At the bottom, there's a player control bar with play/pause, stop, previous, next, and volume buttons, along with a progress bar showing 0:00 / 27:10.

SOUNDCLOUD Home Stream Library Search for artists, bands, tracks, podcasts Sign in Create account Upload

Engaging and involving patients, families and staff following a patient safety incident NHS England 14 days ago #HealthCare

Write a comment

Like Repost Share Copy Link More 1,300 3

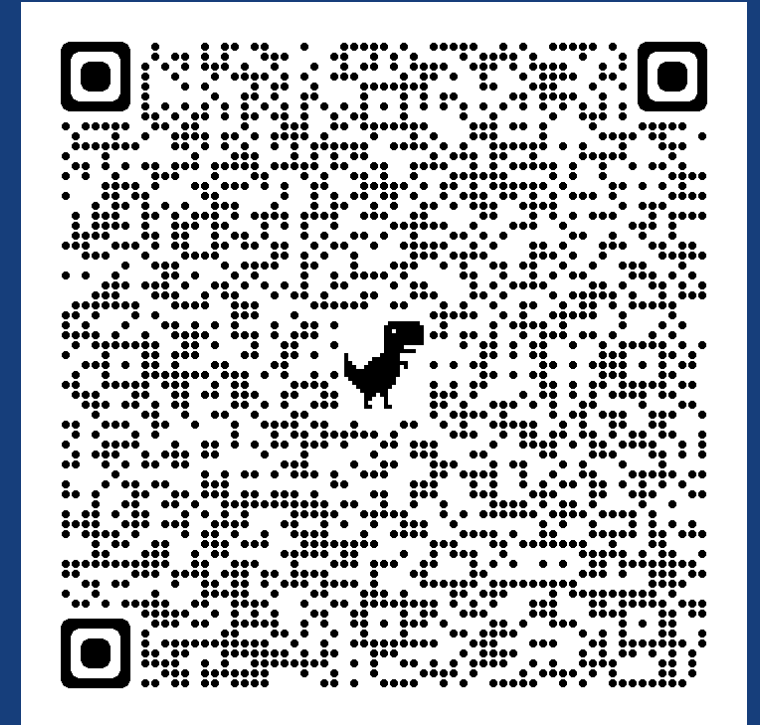
Follow NHS England and others on SoundCloud. Sign in Create a SoundCloud account

NHS England Published alongside the Patient Safety Incident Response Framework (PSIRF), the 'Guide to engaging and involving patients, families and staff following a patient safety incident' sets out expectations for how those affected by an incident should be treated with compassion and involved in any investigation process.

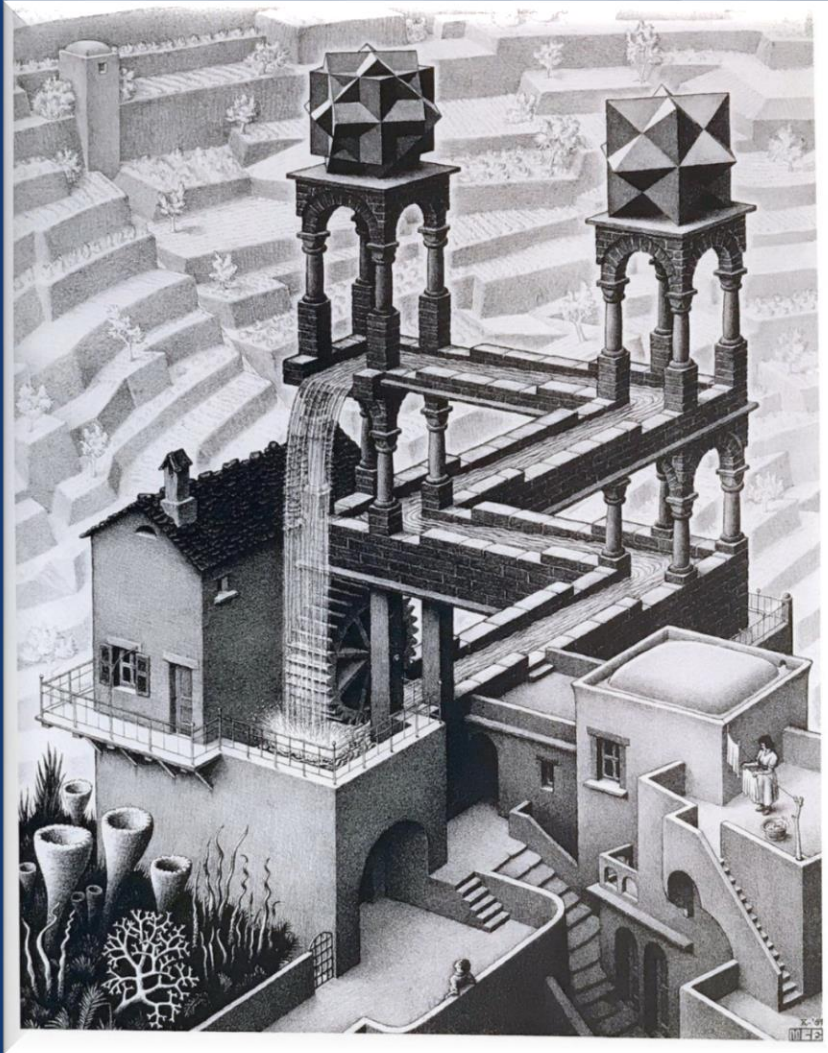
Related tracks View all

- NHS England Maternity Early Warning Score - Po... 2,282 6
- NHS England Maternity Early Warning Score - Po... 1,335 8 2
- NHS England Episode 35 - Supporting autistic pe... 3,837 7

NHS England Engaging and involving patients, fa... 27:10 0:00



https://soundcloud.com/nhsengland/engaging-and-involving-patients-families-and-staff-following-a-patient-safety-incident?utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing



Is reducing compounded
harm...

... deceptively simple?

A photograph of a cobblestone path leading into the distance. The path is made of dark, irregular stones and is flanked by green grass and a brick wall on the left. The text "Path to compounded harm may be paved with good intentions..." is overlaid in white, centered on the path.

Path to compounded harm may
be paved with good
intentions...

Focused on
incidents with
*greatest learning
potential*

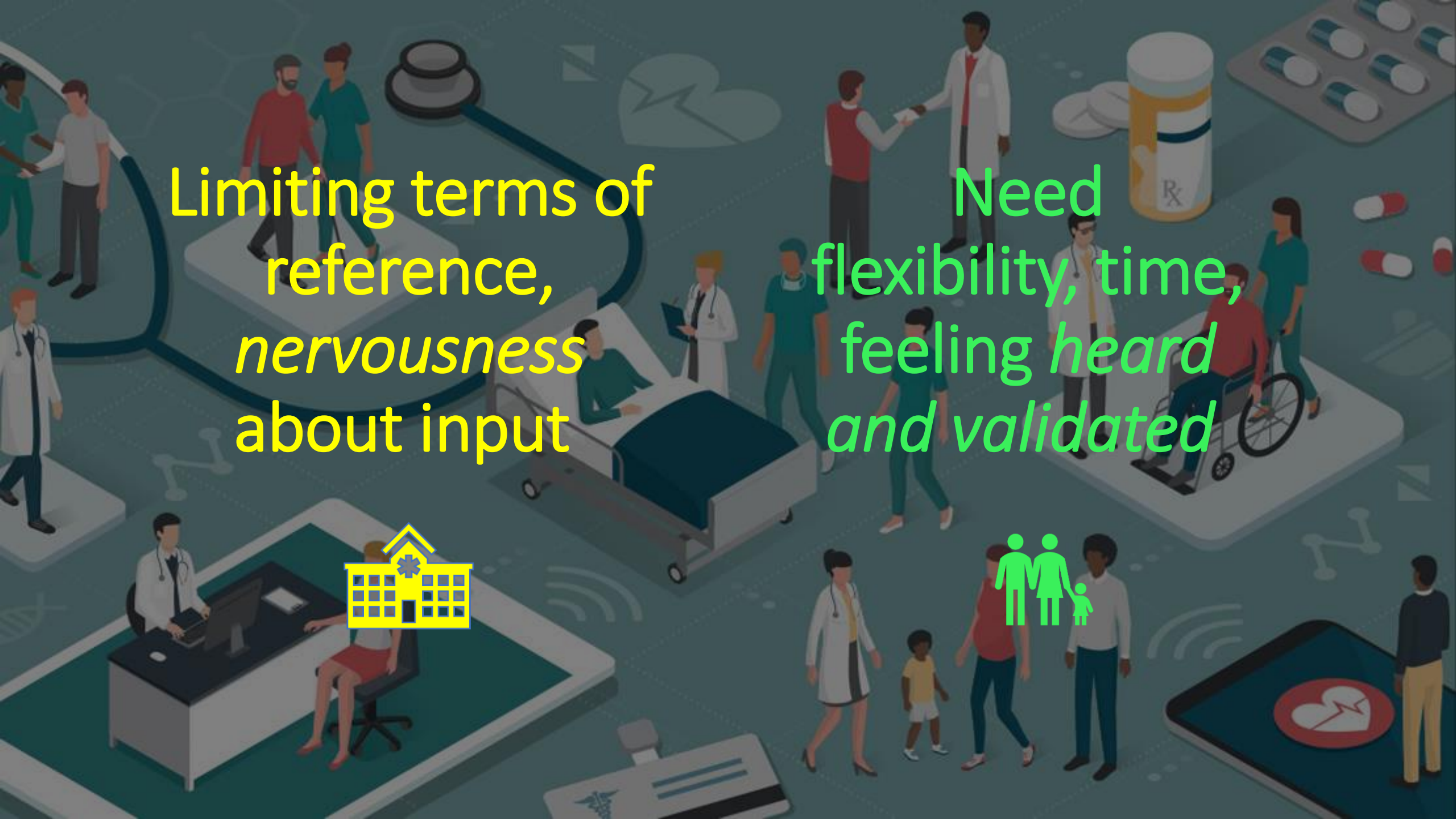


Want answers
about *their
experience*



An isometric illustration of a healthcare ecosystem. It features various medical professionals like doctors in white coats, nurses in teal scrubs, and a pharmacist in a red vest. Patients are shown in different states of care: an elderly couple with a cane, a man in a wheelchair, a family with a pregnant woman and child, and a doctor at a desk with a patient. Medical symbols like a stethoscope, pills, a pill bottle, a heart with an ECG line, and a DNA helix are scattered throughout. The background is a dark teal with faint geometric patterns. The text is centered in a large, white, sans-serif font.

Can rigid systems
accommodate family-centred
investigations?

An isometric illustration of a healthcare ecosystem. It features various medical professionals like doctors and nurses, patients in different settings (hospital bed, wheelchair, office), and medical equipment like a stethoscope, pills, and a heart rate monitor. The background is a dark teal with faint geometric patterns.

Limiting terms of
reference,
nervousness
about input

Need
flexibility, time,
feeling *heard*
and validated





Stage 4.

**Checking and
finalising the
report**





Stage 4.

**Checking and
finalising the
report**

- Critical point of process
- Welcomed in principle, but nervousness about the practice
- *Does it put the organisational processes above needs of patients and families?*



Stage 4.

Checking and finalising the report

- If investigations are to learn, patients and families *should* be able to see the report and amend inaccuracies
- But this can cause problems in terms of:
 - Timing in organisational processes
 - *Post clinical accuracy, pre governance sign off?*
 - The influence of competing pressures
 - *Reputational damage and the need to keep control of negative information?*

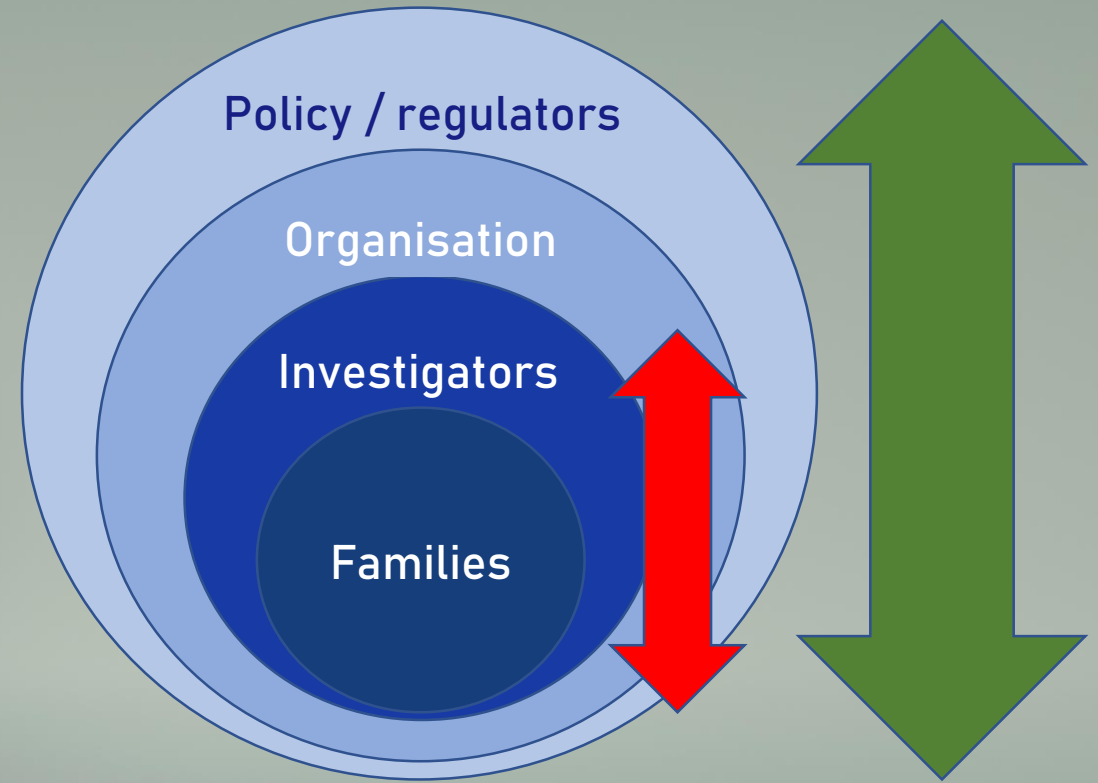


Stage 4.

Checking and
finalising the
report

What we learned

- *‘Put your money where your mouth is’ moment*
- It addresses ‘other needs’
 - Dignifying the person
 - Making sure details are accurate
 - Supporting a sense of transparency and working together
- Pivotal point that impacts further processes?
- Needs to be *demonstrably* a point where things can still be changed



Even if *everyone wants something*, getting it embedded can be difficult...



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*Patients and
families*

*Learn
Together
Research
Team*

THANK YOU

*Healthcare
staff*

*Our partner
NHS Trusts*

*NHS England
and HSIB*