

## A6: The principles of patient safety



International Forum on  
**QUALITY & SAFETY**  
in **HEALTHCARE**  
**COPENHAGEN**



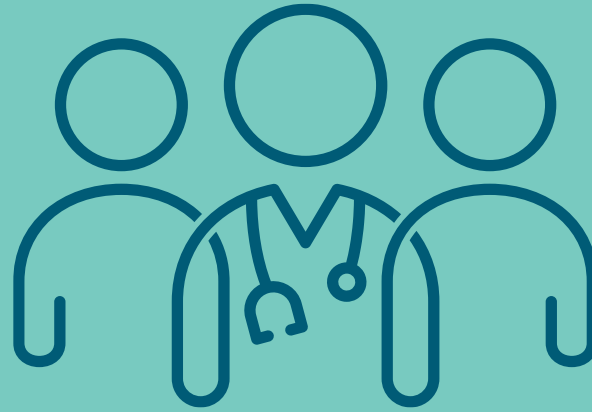
Adapting to a changing world: equity, sustainability  
and wellbeing for all



 @QualityForum #Quality2023

 Institute for  
Healthcare  
Improvement

**BMJ**



# The headache calendar

A digital way towards patient quality

**Mette Christensen**, System Architect and Nurse, Department of IT, Region Zealand  
& **Henrik Winther Schytz**, Associate Professor, Ph.d., DMSCi and Neurologist,  
Rigshospitalet Glostrup



Region  
Hovedstaden



# In 30 minutes, you will know



How a simple idea transformed the contact between patients and clinicians into a digital tool leading towards better treatment and patient quality when treating headache.



**Improved and trustworthy data**



**Better use of clinician's time and outcome of consultations**



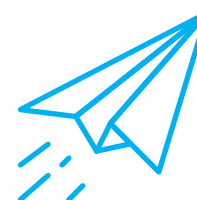
**Improved quality and patient empowerment**

# A tour of "Sundhedsplatformen"



## Health care information system for clinicians

- Patient records
- Medicine
- Documentation
- Rounds
- Operation booking
- Laboratory tests



Since 2016



45.000 users in the clinic



Capital Region of Denmark incl. Bornholm and Region Zealand

# A tour of "Min Sundhedsplatform"



## Digital platform and app for patients

- Test results
- Message the hospital
- Book appointments
- Questionnaires (patient-reported outcome)
- Access to medical record and notes
- Monitoring – e.g., blood pressure, saturation, pain management etc.



**600.000 downloads of the MinSP app**



**Collaboration between patient and clinician**



**5.8 mill. citizens** across Denmark. 1 million of them have logged on to Min Sundhedsplatform

# Help us: what does patients perceive as quality?

1. Take out your phone
2. Scan the QR code
3. Describe in one word: *what is quality according to patients?*



# Involvement contributes to quality



63%



- 2.000 users in a digital patient panel
- 8 personas
- A focus group of 20 patients and care takers



# Once upon a piece of paper

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**Hovedpinekalender**

**Vejledning:**  
Hovedpinekalenderen udfyldes hver aften som et gennemsnit af dagen.

**Ved migræne:**  
1 = let; 2 = middel; 3 = svær

**Ved hovedpine af spændingstypen:**  
x = let; xx = middel; xxx = svær

**Ved klyngehovedpine (Horton):**  
z = let; zz = middel; zzz = svær

**Ved trigemineusneuralgi:**  
o = let; oo = middel; ooo = svær

**Let:**  
Hæmmer ikke arbejde eller anden aktivitet.

**Middel:**  
Hæmmer, men forhindrer ikke, arbejde.

**Svær:**  
Forhindrer arbejde eller anden aktivitet.

Behandende læge:

Husk at medbringe hovedpinekalenderen ved ALLE lægekonsultationer

Egne noter:

# Who are we – The Danish Headache Centre and The It & Medico Technology Centre (CIMT)

- The Danish Headache Centre team initiated the idea of a digital headache calendar
- Doctors, nurses and secretaries involved from the start
- December 2021 collaboration with CIMT
- Headache calendar launched May 2022



# A digital headache calendar – why?

Manual input  
in the system



Difficult to  
manage treatment



# The headache calendar; the clinicians' view

**EpicCare** | Patientopslag | Altaler | Afmålingsoversigt | Telefonkontakt | Forskning | Påmind mig | Brugertips | Rapportering | Udveksl. hjælpesøgt | Best.Ord-historik | Opret/rediger henvisning | Print | Log af

Tilføjelse: Frost, Griet T...

POC LAEGE-RGH T. EpicCare

Vis journal | Journaloptagelse | Konsultation | XeroViewer | Resultatgennemgang | Vaccinationer | Apopleksi | MS-kontrol (neurologi) | Epilepsi (neurologi) | Bevægelseforstyrrelse | Synopsis | Notater | Status

**Vis journal**

Behandlingskontakter | Notater | Laboratoriesvar | Billeddiagn. us | Procedurer | Medicin | Medie | Udgående korrespondance | Helbredsforløb | Henvisninger | Øvrige best./ord. | LDA'er | Epikrise/Notat til prakt. læge

Neurologi VL Snapshot

**Personoplysninger**

Griet Tele Test Frost  
Kvinde, 50 år  
180373-9266  
Beh.niveau: Ej udfyldt  
Patient-FYL: Ingen  
Søg

Klemenservej 22  
3600 Frederikssund  
12 34 56 78 (H)

**Diagnoseliste - Markér som gennemgået**

Diagnoseliste under indlæggelse Dato for gennemgang: 02-05-2023  
Ingen

Ambulant diagnoseliste Dato for gennemgang: 02-05-2023  
SKS Prioritet Klasse

RH NGHC, DANSK HOVEDPINECENTER GLO 03-05-2023 11:47 - Aktuel

Spændingshovedpine (DG442) DG442

**Familiære dispositioner**

Ingen

**EKG (Seneste 10 resultater fra de seneste 365 dage)**

Ingen

**Hovedpinekalender (seneste 30 dage)**

Antal dage med migræne (total)	Antal dage med spændingshovedpine (total)	Antal dage med smertestillende
0	12	7
Antal dage med svær migræne	Antal dage med svær spændingshovedpine	
0	3	
Antal dage med moderat migræne	Antal dage med moderat spændingshovedpine	
0	6	
Antal dage med let migræne	Antal dage med let spændingshovedpine	
0	3	

**Specialekommentarer**

Ingen kommentarer vedrørende dit speciale

**Lægemidler**

Ingen Tidligere godkendelser

Aldrig gennemgået

**Livsstilsfaktorer**

Elementer: 4

Rygestatus Aldrig vurderet  
Status for røgfri tobak  
Alkoholforbrug Ikke spurgt  
Brug af stoffer Ikke spurgt

**Medicinsk historik**

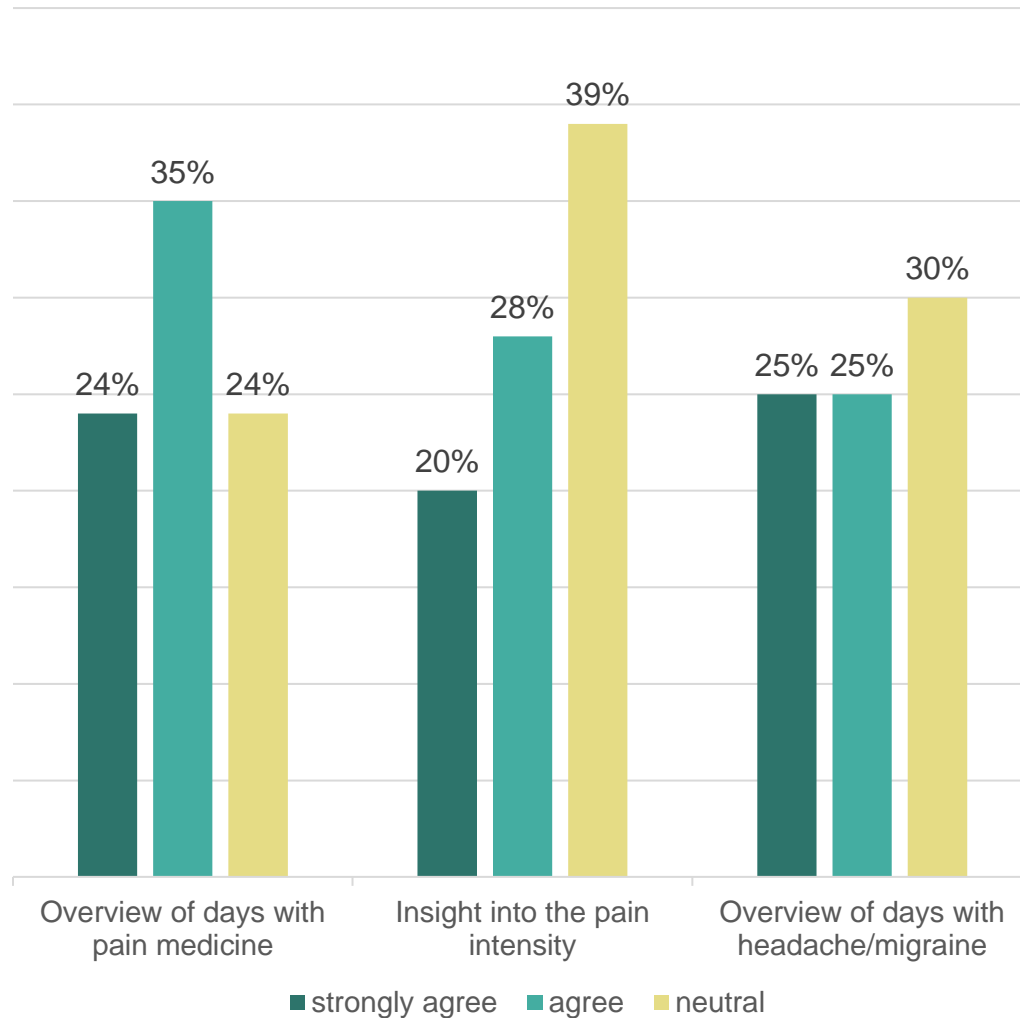
**Kirurgisk historik**

**MinSP Måling**

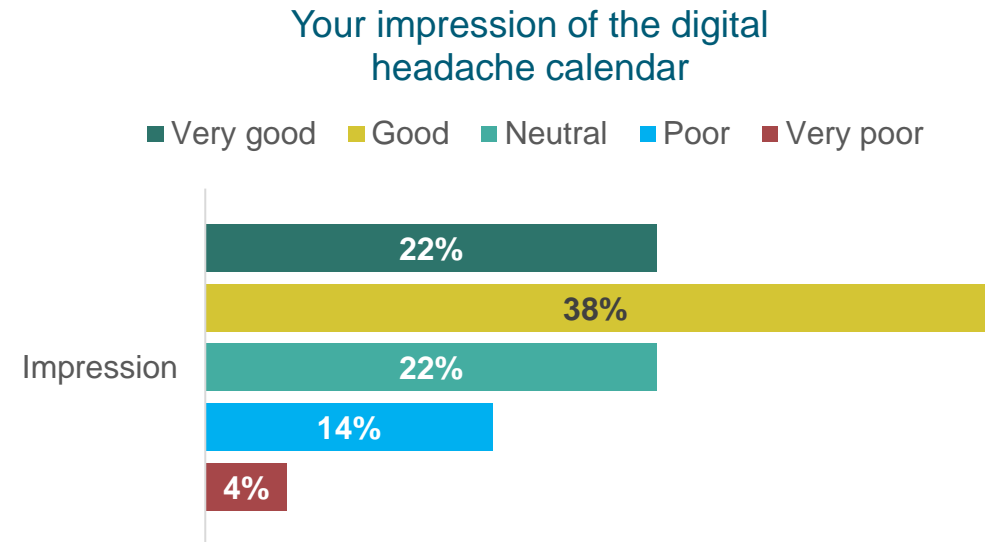
Gå til MinSP Måling

FMK + TILFØJ BEST./ORD. PRINT BES. SIGNER TILFØJELSE

# Patient's point of view – overview of pain medicine

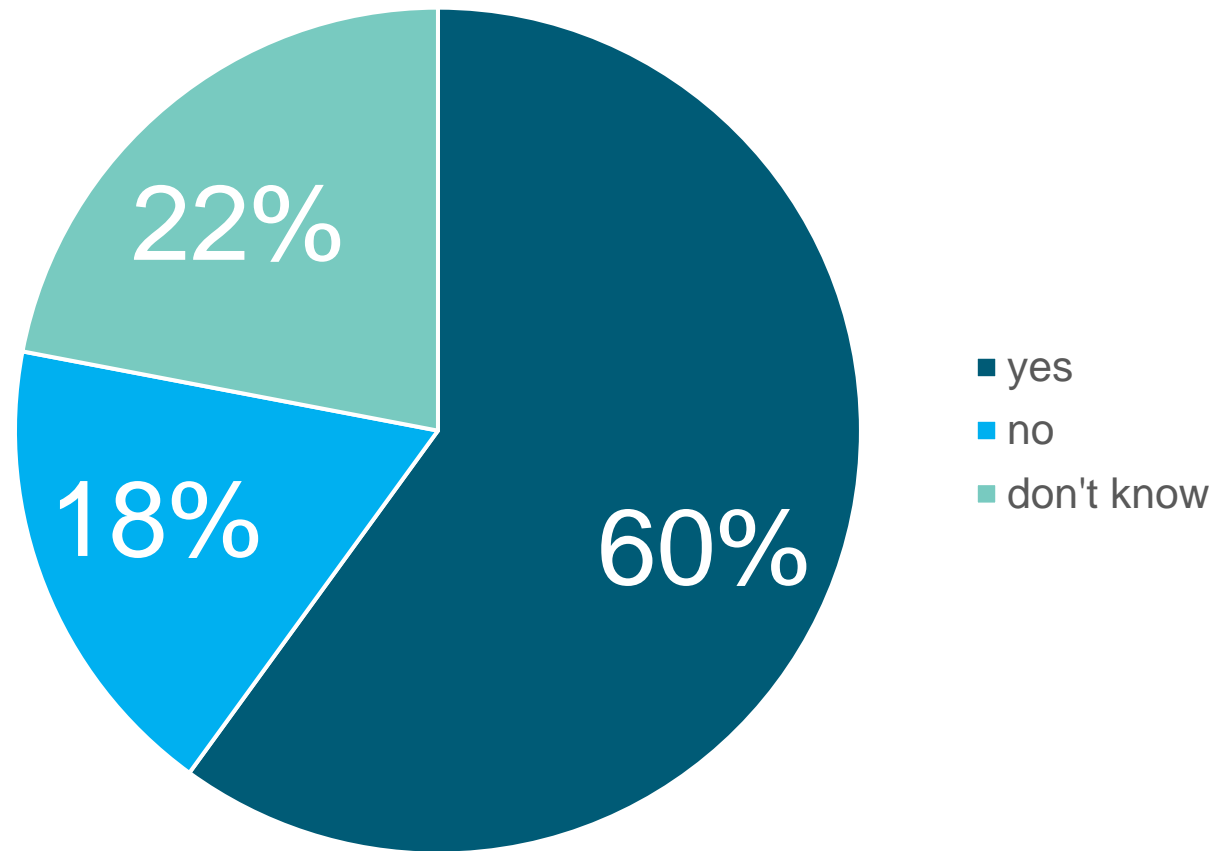


*The paper version didn't work well and sometimes got lost (...) I found an app myself and then transferred everything to paper straight away before meetings at CHPC. Now I always have it at hand and the doctor gets it (the data ed.) straight away. Definitely a fan.*



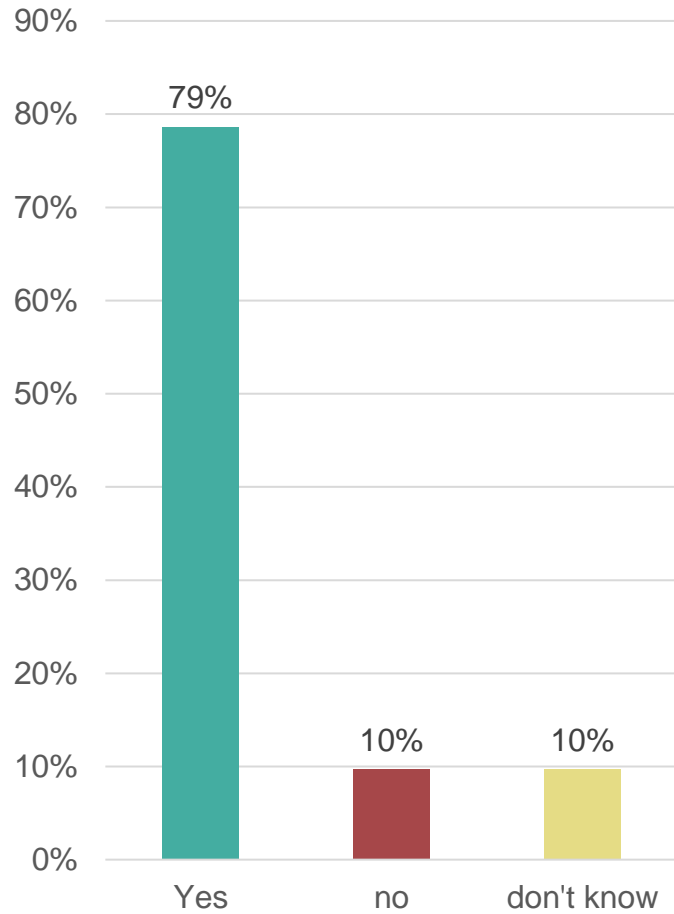
# The results – patient's point of view

Does the clinicians' acces to your data lead to a shared insight in your days with headache

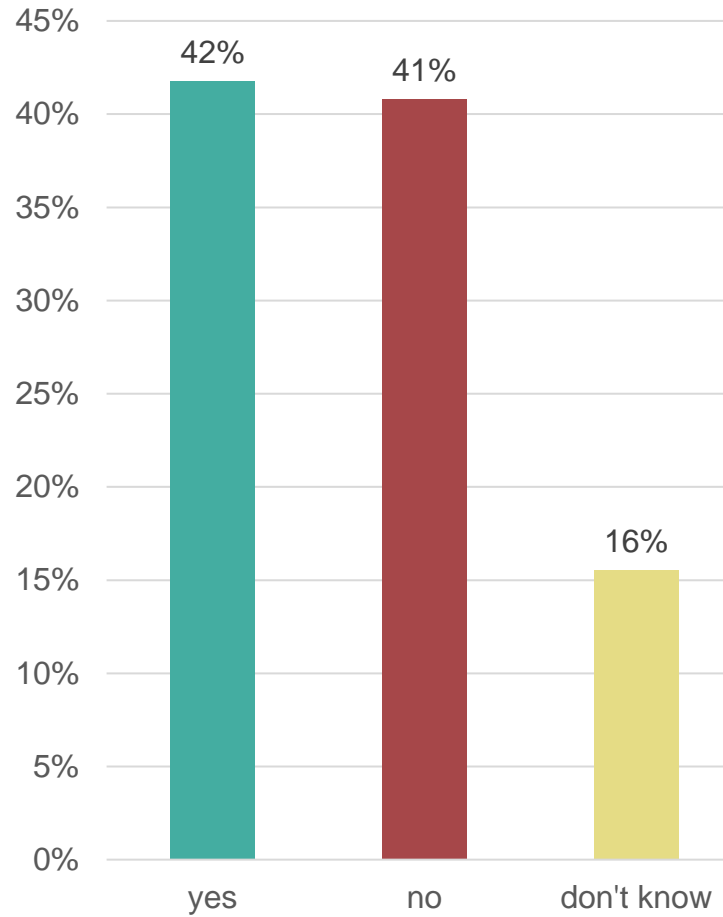


# The results – Patient's point of view

Easier to give knowledge to  
DHPC



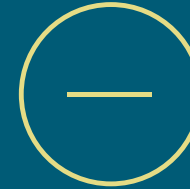
Easier to get insight into own  
illness



# Pro's and cons from the clinician's point of view



- Fast and **accurate data** presented to the clinicians before a consultation
- Data is **valid**: sensitivity of 84% and specificity of 88% in diagnosing the headache day correctly
- More **time to talk** with the headache patients
- **Easy to document** the headache data in the medical charts



- Patients and colleagues are used to the old headache diary – **changing old habits** is a lengthy process
- There is a need for **better visual presentation** of data for the patients



## What have we learned?

1. Implementation of a digital headache calendar takes time and effort
2. Education of colleagues and patients are of key importance
3. Ask the patients and clinicians what they want
4. Refine the product if possible
5. Harvest data that can document your success or failures



# What is the future for headache calendars?

Create other specific calendars for rare headaches and pain conditions such as e.g., cluster headache and trigeminal neuralgia



Use headache calendar data in clinical trials



Monitor and tailor treatment for each individual patient based on the headache calendar data



# Moral and epistemic principles of involvement in patient safety incident response

**Dr Siobhan McHugh**

Senior Researcher, University of Leeds



*On behalf of the Learn Together research project team*



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Yorkshire Quality and Safety  
Research Group

  
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## Core Research Team



Prof Jane O'Hara  
Principal Investigator



Dr Jenni Murray  
Programme Manager



Dr Lauren Ramsey  
Senior Research Fellow



Dr Siobhan McHugh  
Senior Researcher



Daisy Halligan  
Research Fellow



Dr Giorgia Previdoli  
PPIE Coordinator

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Lawton



Dr Gemma Louch



Professor Carl  
Macrae



Scott Morrish



Dr Laura Sheard



Dr Joe Langley



Professor Justin  
Waring



Professor John  
Baker

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# What did we do?



Scan  
me!



**1A** Literature  
Review



**1B** Documentary  
Analysis



**2A** Interviews



## Synthesis

What are the principles  
for meaningful  
involvement?

What approach or  
'programme theory'  
should underpin new  
involvement guidance?



## Co-design

of new involvement  
guidance



## Implementation & Evaluation

of co-designed  
guidance in live  
investigations



## Refine and share guidance

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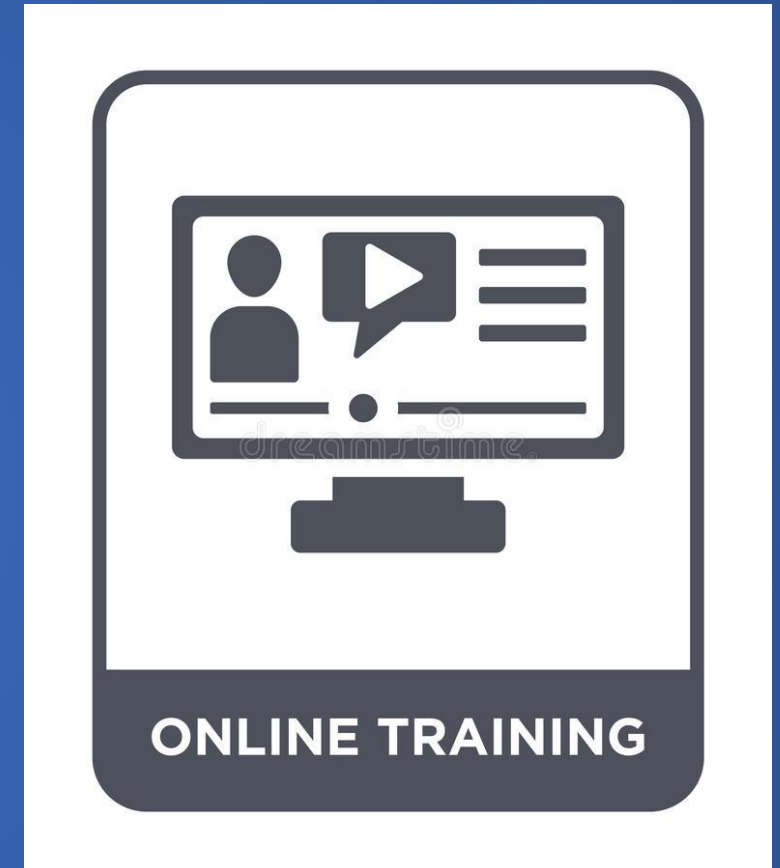
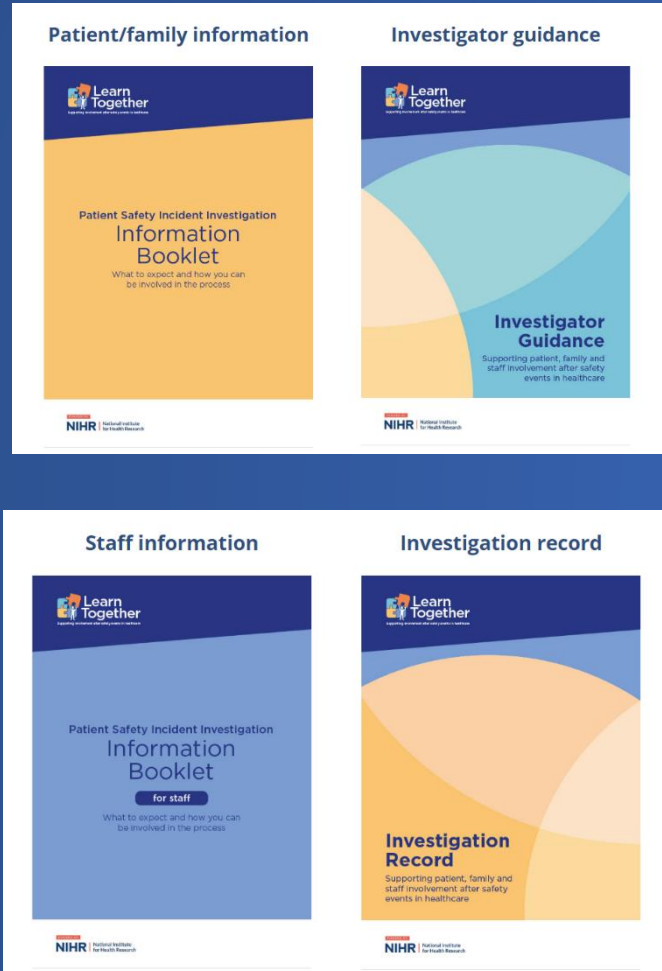
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# What did we do?



# What did we do?

The booklet is in two parts. A detailed overview of the beginning of each section.

## General Information

This section contains all of the key information about serious incidents and the serious incident investigation process. It gives you a good idea of what you might expect from an investigation you are involved in.

## Your Investigation

This section is specific to your investigation. It gives you to be as involved as you would like to be. It also records key information, any questions you have, and what you feel is important.

## Key words and phrases

You'll notice that we've highlighted certain words and phrases. These are words or phrases that might be used to collect the definitions in a list at the bottom of the page.

## Your investigation

This next section has been designed to support your investigation. It is divided into three sections: **continued contact** and **closing the investigation**.

At the end of this section you'll find spaces to write about the investigation so that you can keep it. It also contains information to support the different ways you might be involved if you would like to be.

The investigator might refer to this section of the investigation, and in ongoing communication with you, and in ongoing communication with you.

### Initial conversations

Investigator details

Incident details

### Continued contact

Terms of Reference

My experience

Draft investigation report

### Closing of the investigation

Final investigation report

Further involvement

Your support needs

### Question Log

People/ Organisations I've met

Timeline templates

Notes

## My experience

As outlined on [page 14](#), the investigator might ask you to be involved in the incident about their experience about what happened and why.

If you would like to share your experiences with them, you can use this space to note down the important information to share with them.

## Question log

Date	My question	Response

# What did we do?

## Contents

### Introduction

- Common principles for involvement
- What do people need during an investigation?
- Support resources

### Making It work in practice

#### Prepare yourself

#### Initial contact

- What to cover
- Clear introduction
- Discussing the incident
- Explaining the process
- Discussing support needs
- Scheduling continued contact
- Involvement preferences

#### Continued contact

- What to cover
- Terms of Reference
- Sharing experiences of the incident
- Draft report
- Discussing support needs
- Revisit involvement preferences

#### Closing contact

- What to cover
- Maintaining contact
- Final report
- Further investigations
- Opportunities for further involvement
- Formal end of the process
- Ongoing support
- Support for you

3



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## Initial contact

Ideally, you will make first contact with the patient or family member and the healthcare staff involved, at the beginning of the investigation. However, we know that this might not always be possible. The timing of making this first contact might be flexible, but of making the first contact with people who have experienced the incident are important to get right. Initial conversations who has experienced the incident will set the tone for the investigation.

Patients and family members will have had varied experiences of healthcare provision leading up to the incident, and differ from the Duty of Candour process. They might be recovering psychologically or emotionally from the incident, or the immediate healthcare staff will respond to involvement in an incident and will have received varied levels of support afterwards.

You are not expected to know in detail their experiences up to this point but your role at this point is to set a tone you are both comfortable moving forward. Enacting the common principles for involvement likely to make the experience of this initial communication and more meaningful, for you and them:

Respect humanity

Different people will respond differently to the same in initial conversations to determine the impact of the incident on the individual you involve. This will make it easier for you to connect with each person and to accommodate their involvement.

Treat people with compassion

Harm can be caused during the investigation and the way people are treated within it. By being respectful, compassionate and listening to these early conversations you can prevent this additional harm.

Strive for equity

Organisational learning is the main output of an investigation. Meaningful involvement of the people who experienced the incident is a key element of learning whilst making the process feel less daunting.

Make apologies meaningful

In your initial conversations you should give a meaningful apology where appropriate, and demonstrate your learning about what happened.

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## Clear introduction

You should introduce yourself clearly to anyone you involve in the investigation. To maintain equity of access to involvement in the investigation patients, family members and healthcare staff should be able to contact you as well as you being able to contact them.

- **Give the patient or family member your full name.**  
Check if they would like you to repeat it.
- **Tell them you are the lead investigator and where you work.**  
This might be the specific hospital name or the name of the Trust.
- **Tell them if you also have another role within the Trust.**  
You should make them aware if you are not a full time investigator as this will mean their expectations of your time will be different.
- **Give them your contact details and discuss your working hours.**  
You should make it clear how and when they should contact you and set clear expectations about when they should expect you to reply.



Can you have this conversation over the telephone, video call or face-to-face to make it more personal?



The Information Booklets have space on page 23 for people to record these details. You could use these pages to structure your introductory conversations with patients, family and staff.

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Supporting involvement after safety events in healthcare

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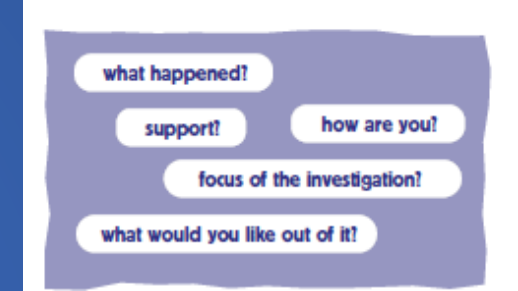
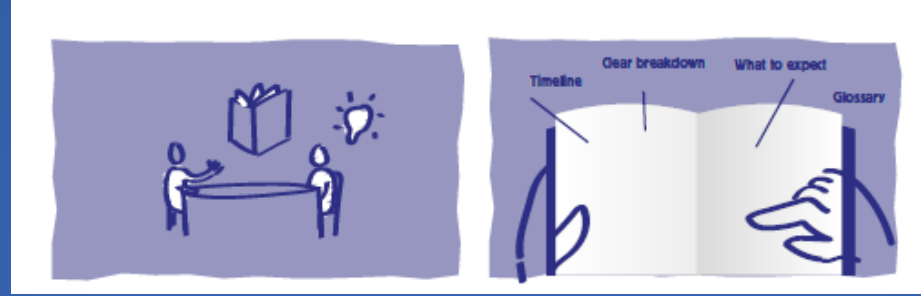
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# How do they work together?



# Central principles for involvement

**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/families/staff, the process can feel discriminatory.

**Provide guidance and clarity.** Patients, families and 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.

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# Minimise harm, maximise learning

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

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Reduce compounded harm

Epistemic motivation

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Thank  
You



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