

Learn from patient safety events (LFPSE)

# Patient and family Discovery phase

Show and Tell

October 2023





# Agenda

- Introduction
- Background
- What were we testing? What did we find out?
- Future options
- Next steps
- Summary
- Questions – please submit your questions at any time for us to cover at the end of the session

# Introduction



# Introduction

## About this session

- In this session we will run through the main findings of our Patient and Family Discovery process.
- We will explain what we did, how we did it, and why, and what we have learned from our research.
- We are also publishing a report of this work (link here if available) which contains a Plain English summary, and full details of the research and findings.
- We are running this session as part of NHS England's [commitment to “Involve people and communities at every stage and feed back to them about how it has influenced activities and decisions”](#).
- There will be time for questions at the end, so please submit them using the “Ask a Question” function.
- The presenters are a mixture of NHS England staff from the National Patient Safety team, and colleagues from our delivery partner, Informed Solutions.



# Introduction

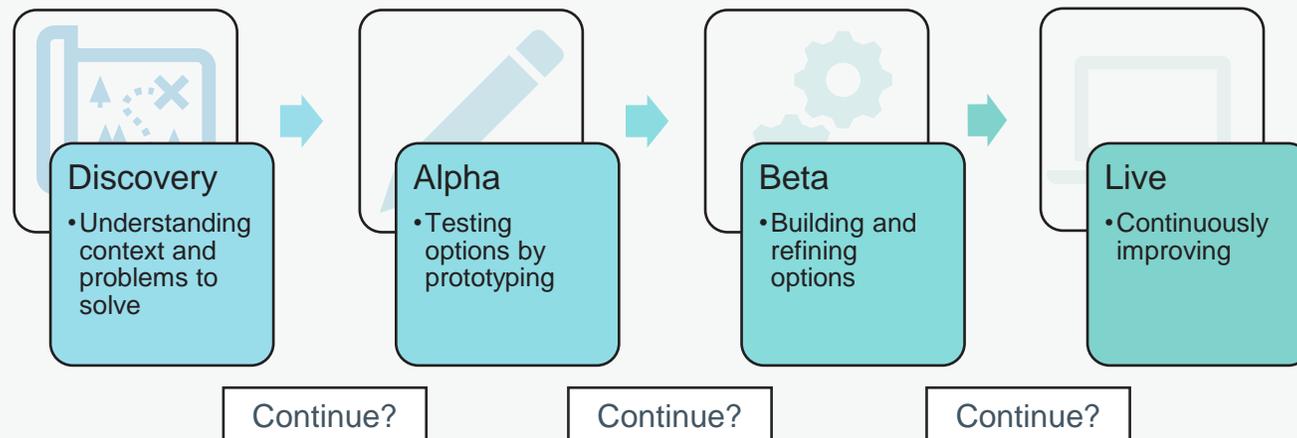
## What is LFPSE?

- Sometimes things go wrong in care and can make people more unwell. We call these problems “patient safety incidents”.
- [Patient Safety](#) is the science of trying to make care safer. It tries to understand how and why things sometimes go wrong, and how we can improve the way the NHS works to protect patients from harm. It is not about finding people to blame, but instead making sure we design health care, hospitals, and the work that NHS staff do to be as safe as possible.
- NHS England has a National Patient Safety team, who work with NHS staff and organisations of all kinds on this, and lead on finding out what the NHS can do differently to make it safer for patients. They [look at information from a lot of different places](#), and [work with many experts of different types to come up with ideas for improvement](#). They also work with [teams that test using these ideas in the NHS](#), and find out if they have helped to make patients safer, so they can suggest the best ideas for everyone to use.
- [The Learn from Patient Safety Events \(LFPSE\) service](#) launched in July 2021, to replace old systems. It is one single place where all information about patient safety events can go, and be used to help healthcare providers and the whole NHS learn, share, and improve safety for people who use their services. You can watch a short video about the LFPSE service here: [Introducing the Learn from Patient Safety Events service - YouTube](#).
- LFPSE is one part of the [NHS Patient Safety Strategy](#), NHS England’s plan to make the NHS as safe as possible.

# Introduction

## What is a Discovery Phase?

- The Discovery phase is the first step in deciding how to solve a problem. It is part of Agile Development, which NHS England uses to design new digital services.
- The whole Agile process is governed by a [Service Standard](#), set by the government. The most important rule is that you have to understand your users, and what they need.
- Discovery is the phase where you understand the problem that needs to be solved before you commit to building a service.





# Introduction

## Why did we do this Discovery Phase?

- There has always been [a way for patients to report safety problems](#), but not many people know about it.
- Very little research had been done before to understand the best ways to make sure patients, service users and their families can give their views on safety incidents, for the whole NHS to learn from.
- Learning from patients' experiences and how they feel about the care they have received is known to be a very good way to make healthcare services better.
- However, getting the right information from people in the right way, and making sure the right NHS staff see it and can act on it, is difficult to do.
- This research starts the process of working out how we can do this better.



# Introduction

## What does this LFPSE Patient and Family Discovery Phase cover?

The aim of this Discovery Phase was to think about how patients, service users and their families can share their experiences of patient safety events (things that go wrong in care) to help the NHS to learn and do better.

To find this out, we looked at:

- What the NHS needs out of this service, both within providers and in national teams
- How things work now, and what is good and bad about that
- Who are the most important people involved, and what do they need from this service
- Research findings from similar exercises by other organisations
- What our options are, and how well they will give users what they need
- What could we do next, and what else do we need to find out

# Background



# Background

## Aims

The aim of this research is to find out **the best way to include** patient and family feedback on safety incidents within the LFPSE.

## Approach

Desk research was carried out to understand the current landscape surrounding patient feedback processes.

User research sessions were then conducted with a variety of participants.

We also used survey responses to feed into our research.

## Participants

We held user research sessions with **9 Providers/ICBs, 3 LFPSE team members, 1 NHSE team member, and 21 patients.**

We spoke to **5 further patients** within their “voice of experience” patient group which is for disabled patients.

We also analysed **survey responses from 30 patients.**

# Key findings

Patients

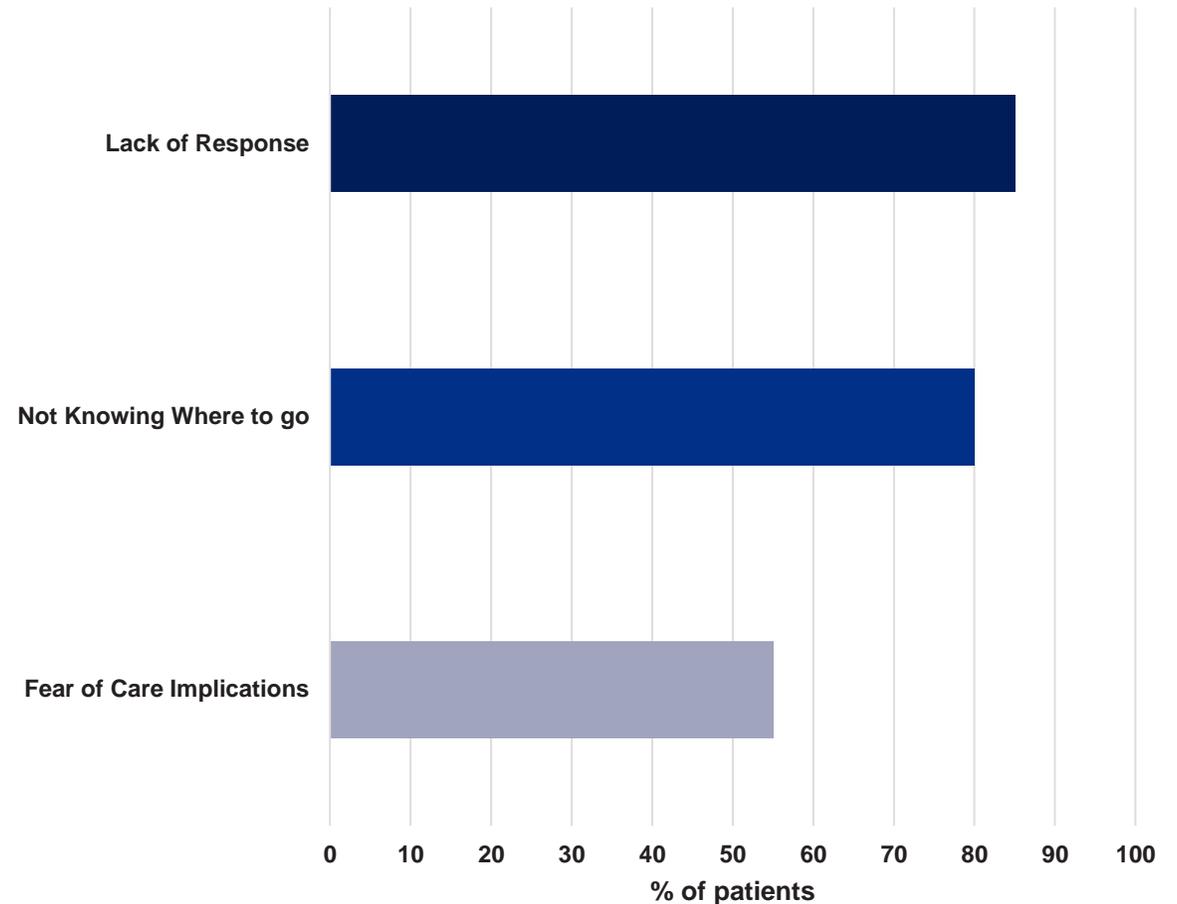
# Key Pain Points

**Fear of impact on care** - Patients have concerns that their care will be affected, and this prevents patients from recording any issues.

**Not knowing where to go** - Knowing where to go is not obvious as a lot of avenues are not clearly signposted, leaving patients feeling the only option is to record it on the ward in person.

**Lack of response** - The lack of response provided to patients after they raise a concern leaves them feeling as though they aren't being heard.

## Patients



# Patient Pain Points

*“The authentic story was ignored and rewritten with a bias to the services within the final report”*

*“It’s not clear, and not accessible especially to people with dementia and people who are neurodiverse.”*

## Account Lost

**The authentic account of patients are lost as they are rewritten by staff.**

## Reputation Management

**Reputation of the healthcare setting is often prioritised more than reaching out to the patient.**

## Lack of Response

**Lack of response frustrates patients as they feel that their concerns are being ‘sent into the ether’.**

## No clear recording method

**Patients do not know where to go or who to speak to regarding their concerns.**

# Patient Pain Points

*"You just felt like you were excluded from the care unless you actively went out and engaged."*

*"I've got a misguided sense of loyalty" - Does not want to cause a fuss*

## Care Implications

**Fear of being treated differently** after raising a concern.

## Long Experience

It is a **long experience** which can take several years to find any kind of resolution.

## Feel Ignored

**Patients do not feel heard** and feel that they are overlooked throughout the process.

## Do Not Want to Cause Trouble

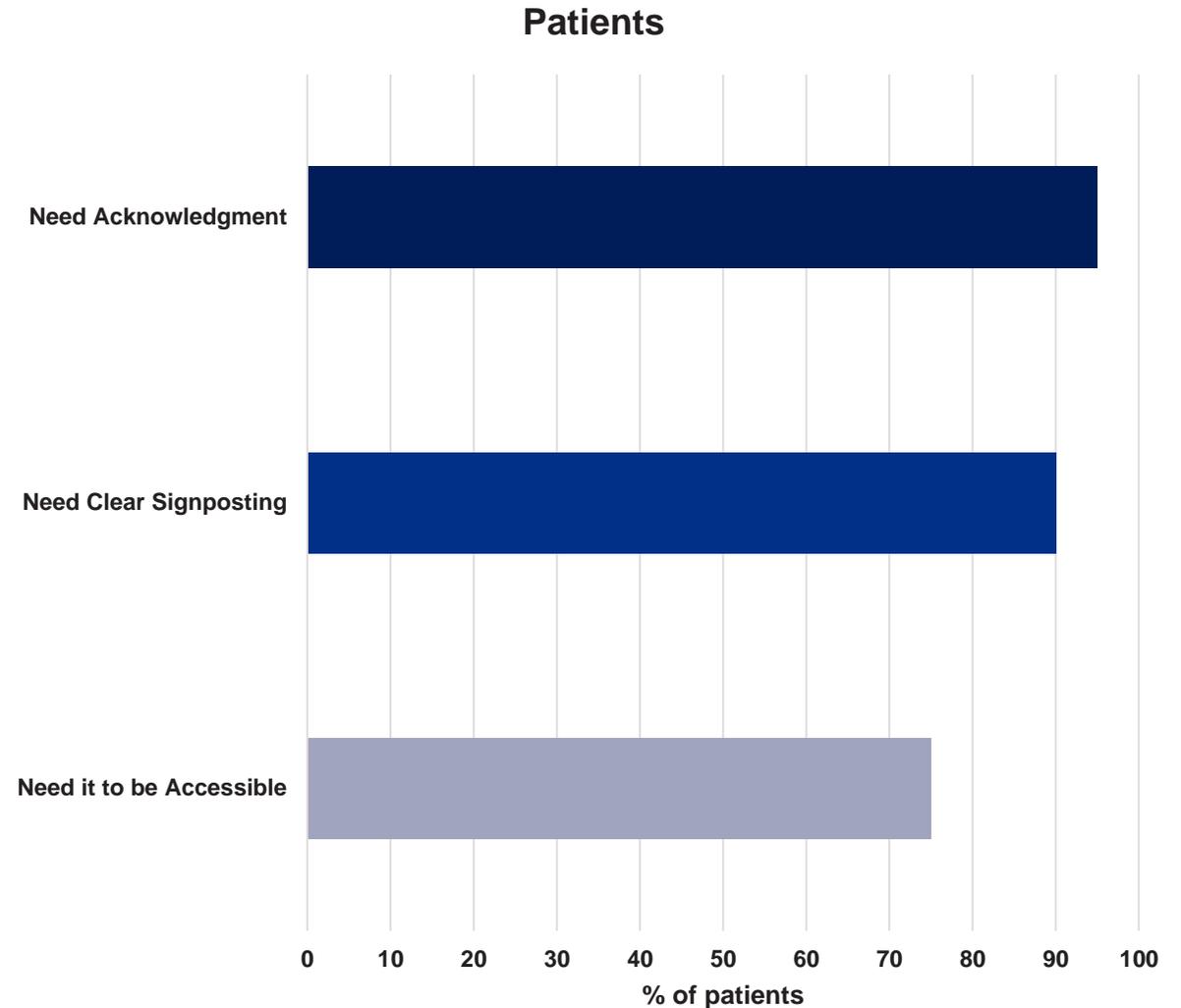
**Patients don't always want to cause a fuss** and feel that they are an inconvenience if they raise a safety concern.

# Key Needs

**Accessibility** - Patients need to be able to access a service which works for them and does not exclude them based on their capabilities.

**Clear Signposting** - Clear signposting of the correct avenues for recording is needed, as currently not all avenues are well-known.

**Acknowledgement** - Patients need confirmation from those receiving the complaint that it will be looked into and not ignored and therefore know that recording it is worth their time.



# Patient Needs

*“The only place you can go is on the ward where you've got the issue and you need somebody independent.”*

*“I think things like good sign posting sometimes, like good volunteers, support can be really helpful just to kind of access the right information.”*

## Independent Review

Patients need someone who is **unbiased and independent** from their care to review their concerns.

## Immediate Recording

Patients need to be able to **immediately raise a concern.**

## Clear Recording Avenue

Patients need **to know where to go.**

## Trust

Patients need to **trust in the process and be engaged with regularly.**

# Patient Needs

*“You want to know that it is getting to the right place and not just disappearing into the ether”*

*“We just want to be listened to.”*

## What Qualifies?

Patients need to **understand what exactly a safety incident is.**

## In Person Help

Patients need **in person help.**

## Feedback

Patients need **feedback.**

## Own Perspective

Patients need to be able to **provide their own perspective.**

# Patient Recording Motivations

**They want to prevent it from happening to others**

The most frequent motivation mentioned by patients was a desire to prevent similar events from happening to others in the future.

**To improve their own care**

Patients are often motivated to record an event to improve the quality of the care they are receiving.

**They want learning to occur from it**

A desire to ensure that NHSE learns from patient feedback is also mentioned.

# Patient Recording Barriers

## Fear

Most patients expressed that they would be fearful of their care being impacted by any complaints/concerns that they raise.

## Time

Several patients, particularly those who have actively engaged in the recording process previously, stated that the time-consuming nature of raising concerns would discourage them from recording an event.

## Futility

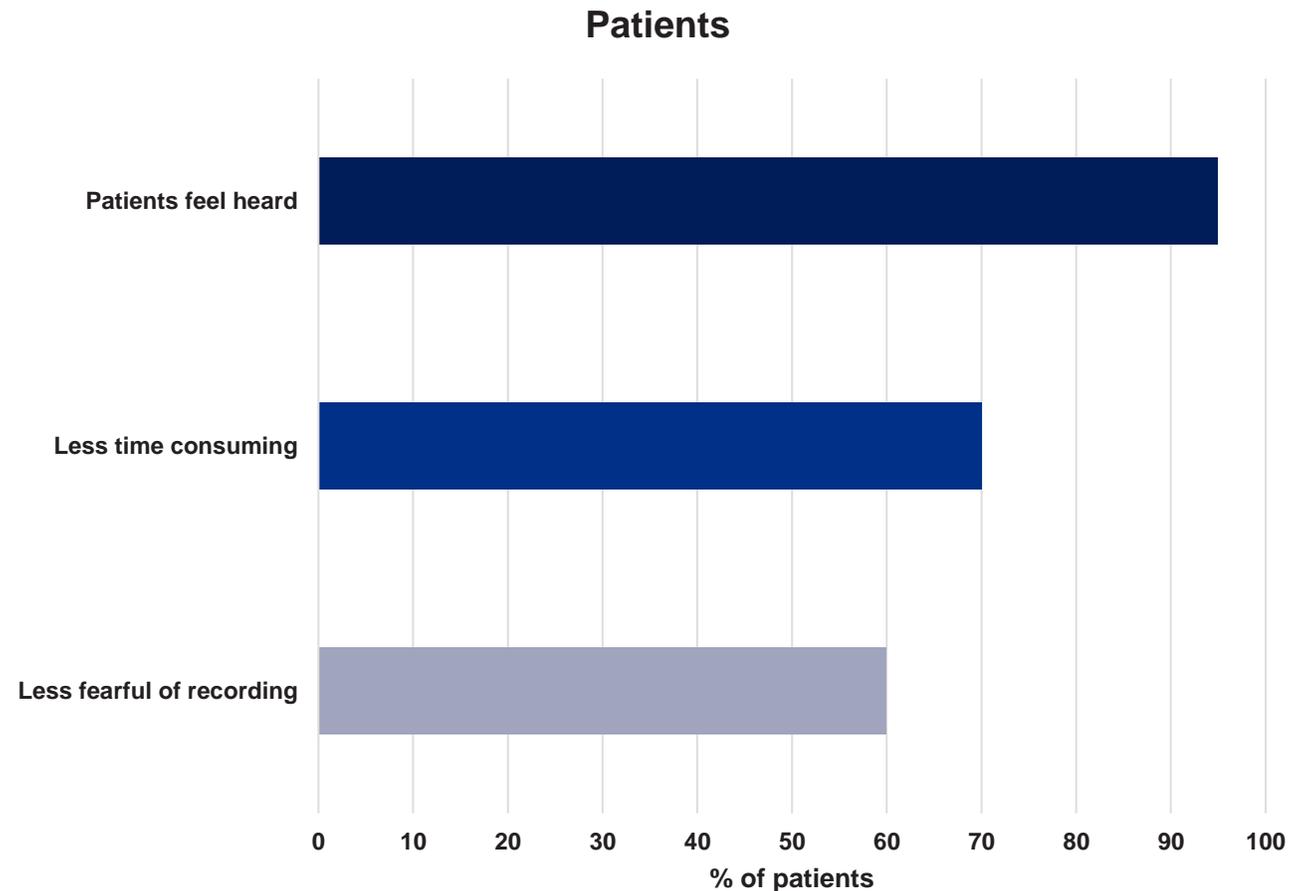
Some patients stated that they felt that raising a concern was futile, as they would not be listened to, and nothing would come of their recordings.

# Key Benefits

**Patients feel heard** – Through providing their perspective, patients feel that they are actively being engaged with and therefore are less likely to feel overlooked.

**Less fearful of recording** – By creating a culture which encourages recording, this will help to stop patients from feeling fearful that recording their concerns will impact their care.

**Less time consuming** – Providing an online service for patients would create a quicker, more efficient service which is more visible to patients and thus easier to find.



# Patients Recording Preferences

## In Person and Online

Most patients stated that they would be happy to use an online service but if it were a 'serious concern', they would like this to be alongside in person contact.

## Online Service

Most patients would be comfortable using an online service and would prefer it for its ease and flexibility.

## Recording vs Complaints

The most common recording method was complaints as it is the most obvious, however it was identified that patients feel it is "combative".

## Social Media

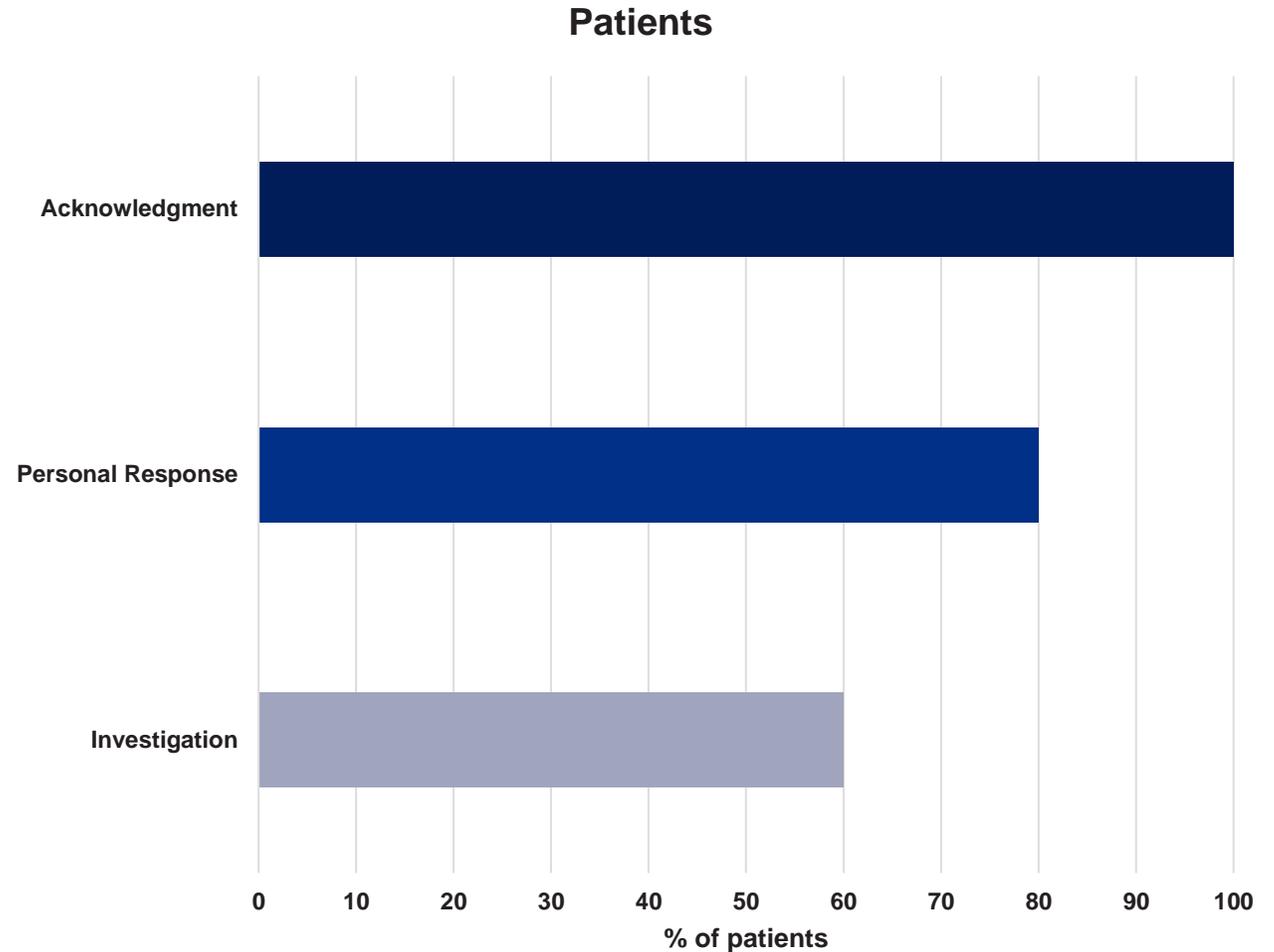
All interviewed patients stated that they would not want to use social media for recording safety events or concerns.

# Feedback

**Acknowledgment** – 100% of patients specified that they would expect at least an acknowledgment of their raised safety concern.

**Personal Response** – 80% of patients stated that they would expect a personal response which outlined what would be done with the information they provided.

**Investigation** – 60% of patients stated that they would expect an investigation into all of the concerns they raise.



# Key findings

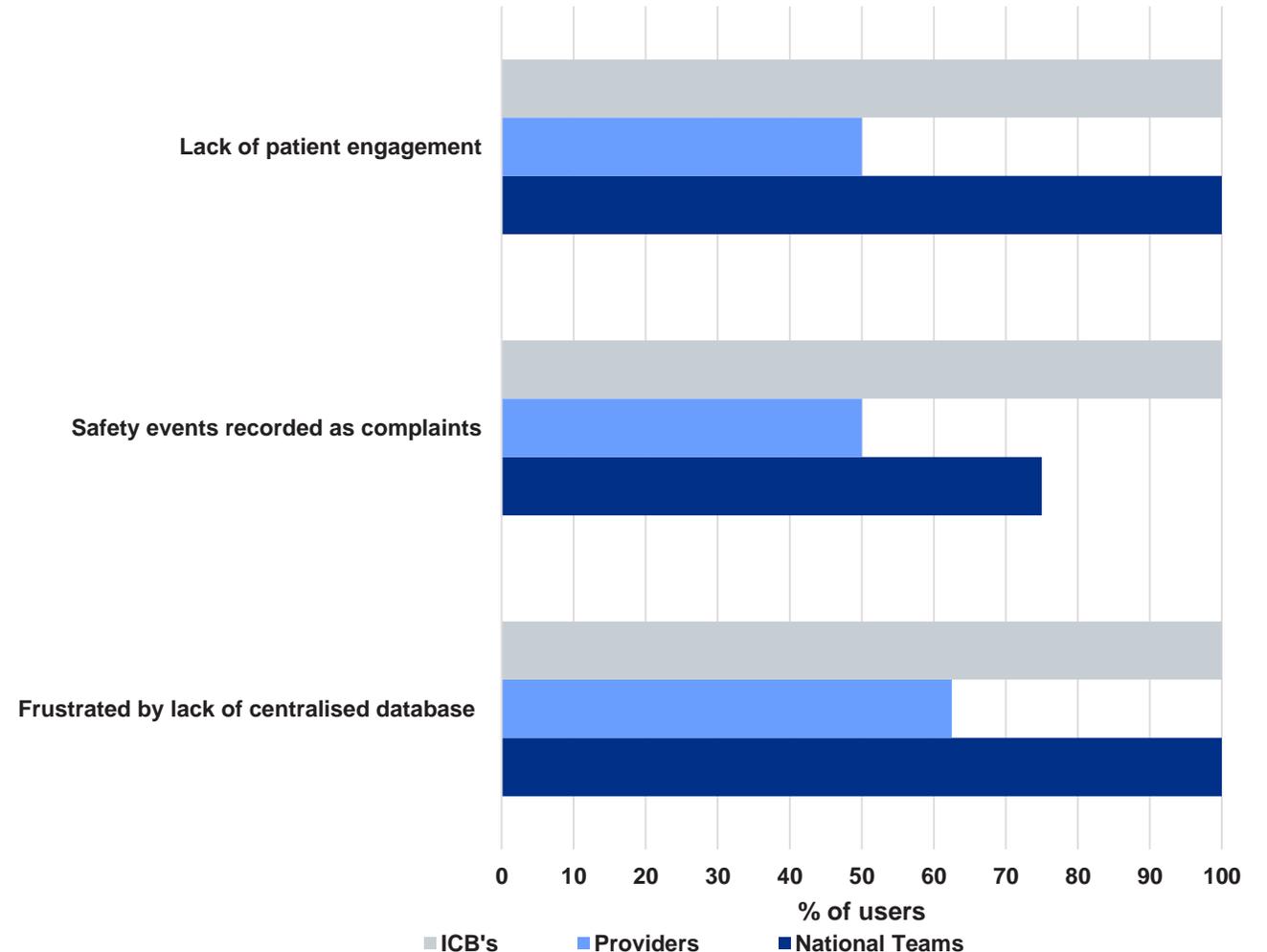
Internal stakeholders

# Key Pain Points

**Lack of Engagement** – Patients are not actively engaged with when carrying out investigations.

**Complaint vs Safety Event** – Patient's identify something going wrong rather than a distinction between safety and a complaint, leading to safety events being recorded as complaints.

**No centralised database** – Data comes in from several different places and is not easily accessible in one place in order to be analysed.



# Internal Stakeholders: Pain Points



Patient safety **feedback is not all kept in one place**



Complaints often **contain things which should have been recorded as safety events**



Patients **do not know where to go to record safety events**



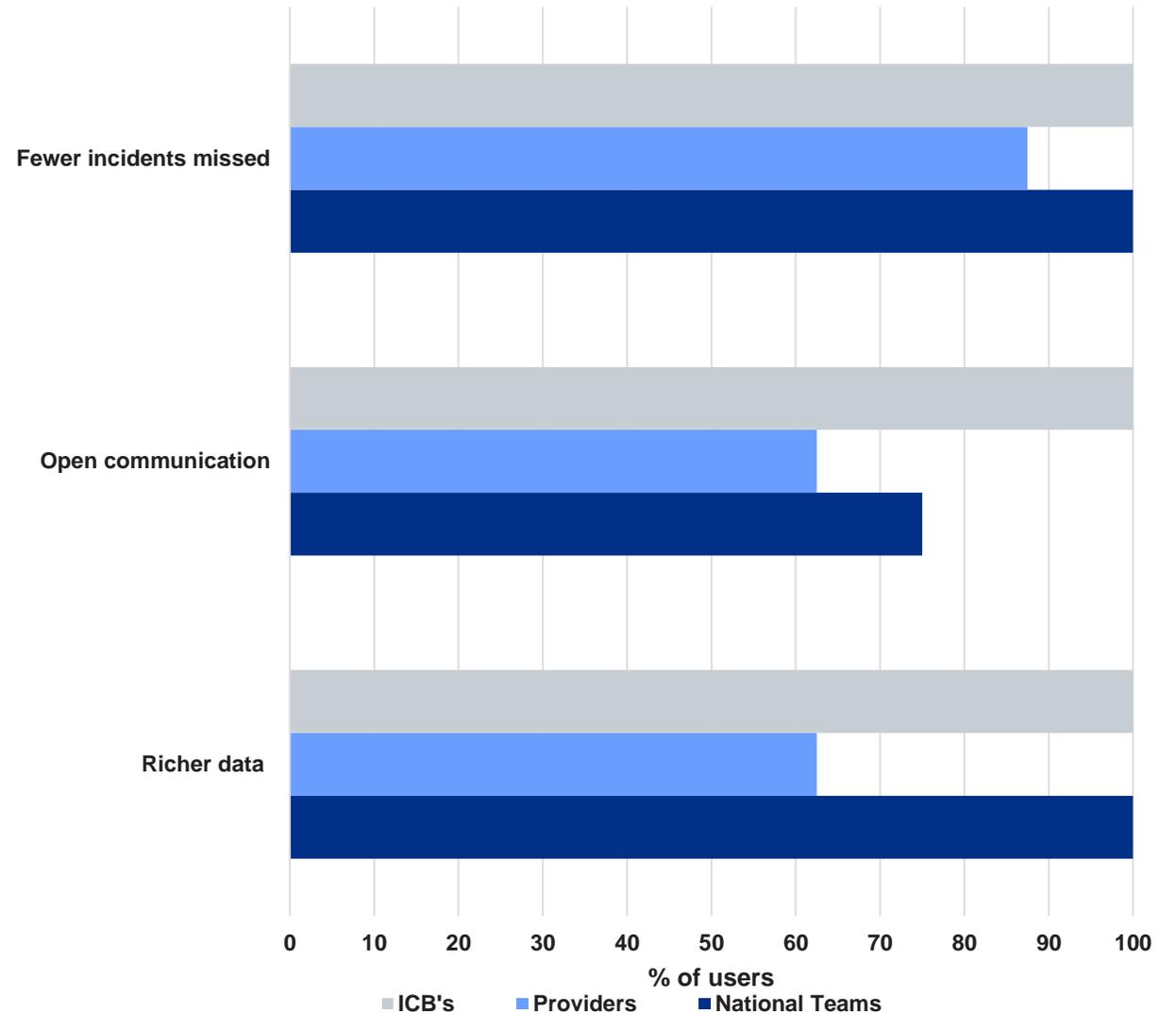
Data recordings **often contain information which is not relevant for learning**

# Key Benefits

**Fewer incidents missed** – Gaining direct feedback from patients would likely result in fewer safety incidents being mislabelled as complaints.

**Open communication** – Communicating more openly and providing a simple process for patients would reduce frustration and subsequent complaints stemming from miscommunication.

**Richer data** – The data provided would have more detail and would highlight additional areas of potential learning.



# Internal Stakeholders: Benefits of collecting patient perspective



**Richer data** with information on new topics



**Authentic account** direct from the patient



**More engagement** with the patient, in turn reducing complaints



**Systemic or cultural issues** could be identified

# Internal Stakeholders: Key Challenges

## Resource Constraints

**Resources constrain the ability of teams to review high quantities of data.** Increasing the number of recordings may result in learning opportunities being overlooked.

## Excess Information

**Patients may provide information which is potentially not beneficial to learning.** This could lead to issues being missed as they get lost within the details.

## Duplication

**There is potential for duplicated data** as patients may record events which have already been noted by clinicians.

## Limited Data Sharing

**Sharing data between organisations and departments** is limited which can lead to vital information being missed.

## Responsibility

**Who is going to oversee this data** and where will the responsibility lie for reviewing, managing, and responding to it sit?

## Recording Culture

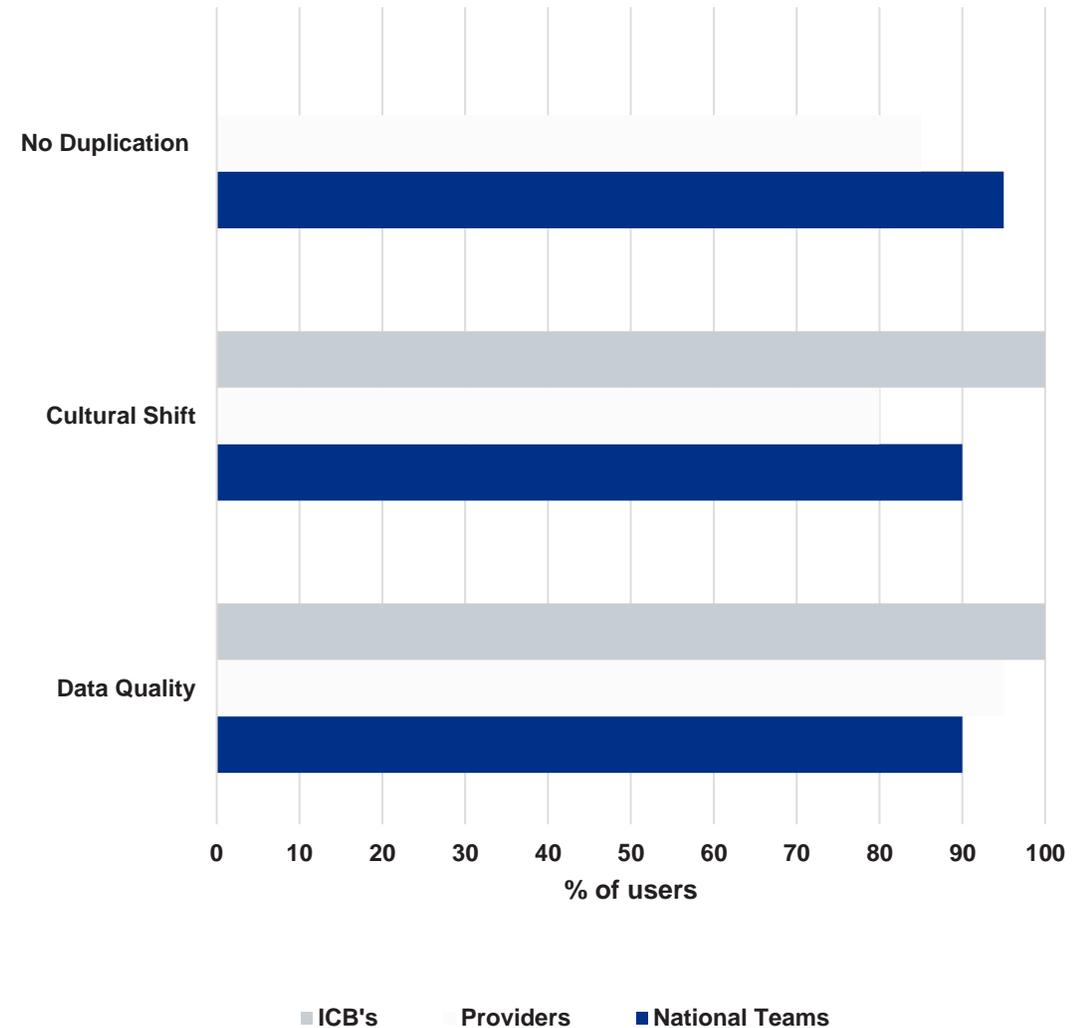
Organisations are **concerned that having a good recording culture reflects poorly upon themselves.** This leads to informal recordings being missed.

# Key Needs

**No duplication** – Data needs to be provided only once to ensure that it is not duplicated which could exaggerate the commonness of an issue.

**Cultural shift** - Recording needs to be seen as beneficial and not harmful so that it encourages people to record.

**Data quality** - Only the most relevant data is needed so that information that is key to learning is not missed.



# Internal Stakeholders: Needs

## Cultural Shift

**Need incident recordings to be viewed as beneficial** and not a threat to the trust or individuals, so that issues are not under-recorded.

## Priority Data

**Teams need users to understand what information is required** to make sure they only receive relevant information.

## No Duplication

**Need the data to not be duplicated** so that they do not review the same data twice.

## Patient Engagement

**Need patient's to be engaged with** throughout the process to prevent complaints being made due to miscommunication.

## Next Steps

**Need patients to understand what will be done with the data** provided nationally/locally in order to handle patient safety events in a satisfactory way for patients.

## Anonymity

**Need patient recordings to have the option for anonymity** to ensure that patients who may be afraid of any consequences can do so without fear.

# Key findings

Survey

# Survey Findings

**As well as interviews, we used the information from surveys filled in by patients, service users and their families to feed into our research.**

## Feedback Preferences

- 21 respondents stated that they would like someone to explain what happened to them and why.
- 20 respondents specified that they would like to know that their raised concern would contribute to national learning.

## Recording Preferences

- 21 respondents said they would use an online service.
- Most respondents said, in the past, they spoke to staff immediately or made a complaint when recording events.
- 20 respondents stated they would want the information to go to a team which stops mistakes nationally.

# Survey Findings

**As well as interviews, we used the information from surveys filled in by patients, service users and their families to feed into our research.**

## Safety Incident Understanding

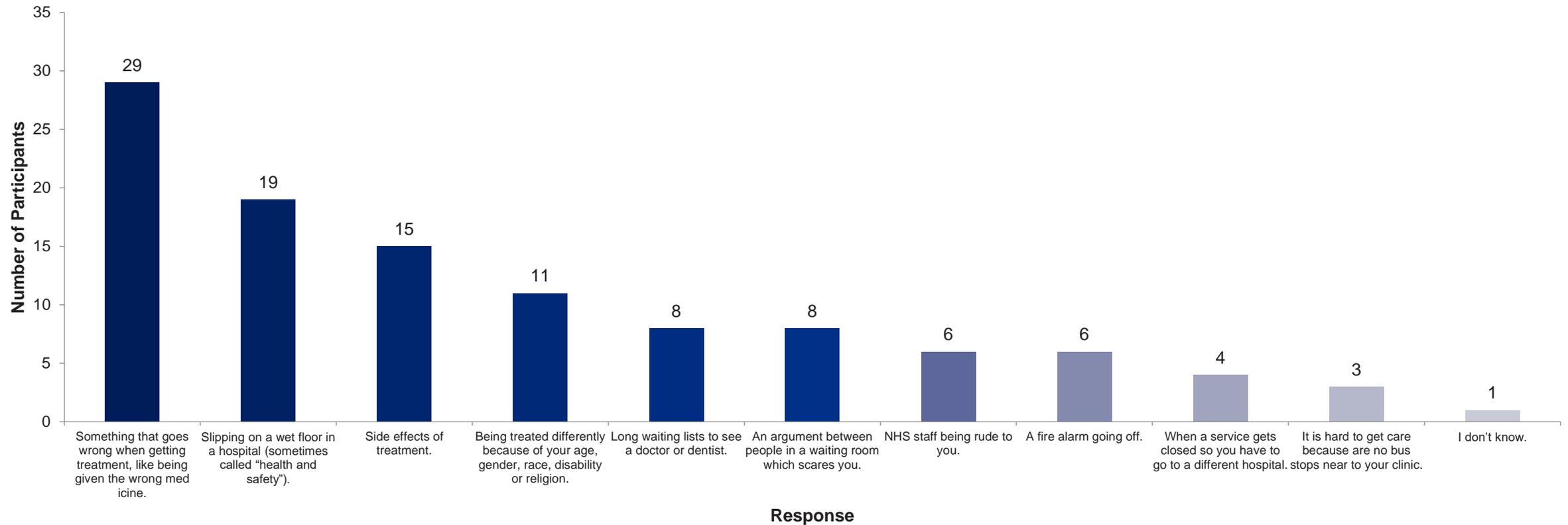
- 29 respondents identified a safety incident as “something that goes wrong when getting treatment, like being given the wrong medicine”.

## Service Recommendations

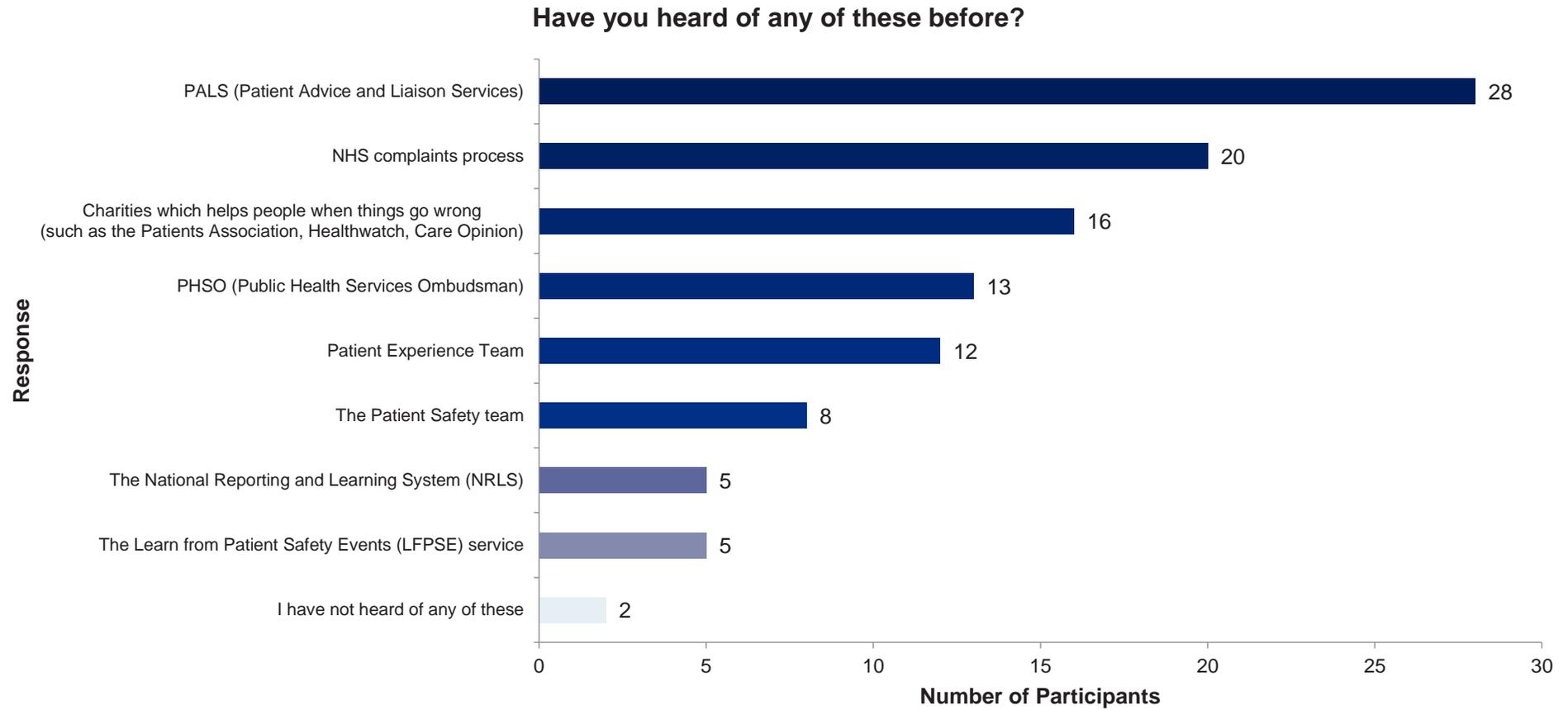
- 17 respondents want space to write ‘whatever they want’.
- 15 respondents stated that it would be useful if there were questions to help them decide what information they should provide.



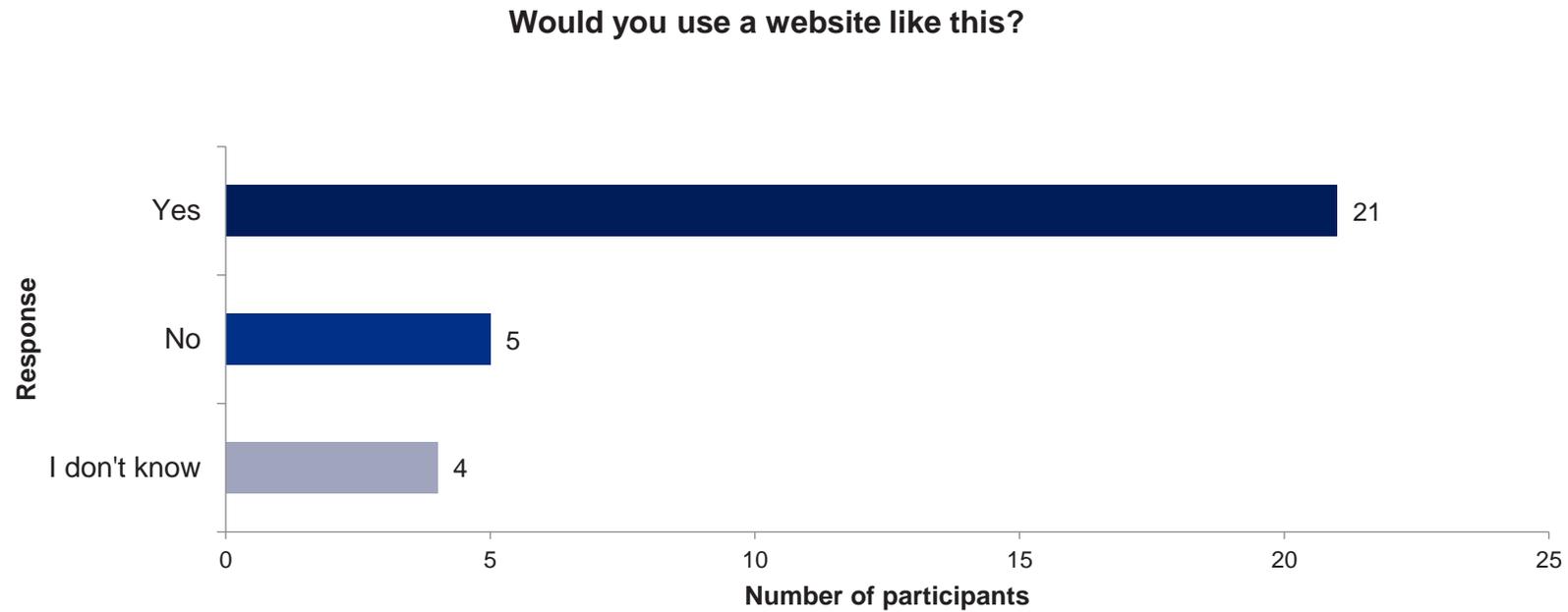
### What do you think a “patient safety incident” means?



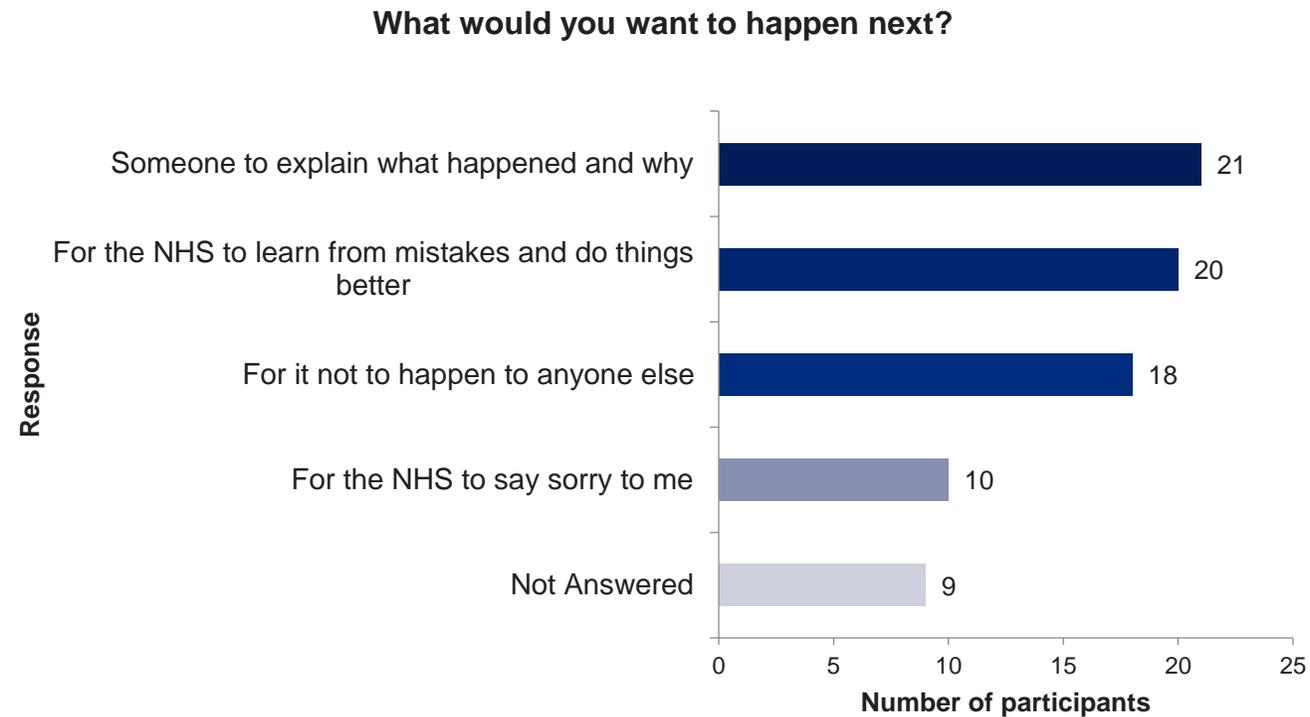
When asked which existing services they had heard of before, 28 out of 30 respondents reported they had heard of PALS.



Patients' feelings towards an online recording service show that the majority would be comfortable with using this type of platform, with 21 out of 30 respondents stating that they would use it.



When asked which types of feedback they would like in response to raising a concern, 21 participants stated that they would want “someone to explain what happened and why.”



# Other reports with similar findings

Research has been carried out by other organisations into patient safety recording, specifically within mental health inpatient settings. Their report outlines similar findings to our research in that it highlights the value of patient input and the existence of barriers to recording experienced by patients. Furthermore, it determined that there are concerns amongst staff that they do not receive useful data which could help to support them in their roles.



[Home](#) > [Health and social care](#) > [Public health](#) > [Mental health](#)  
> [Rapid review into data on mental health inpatient settings: final report and recommendations](#)

[Department  
of Health &  
Social Care](#)

Independent report

# **Rapid review into data on mental health inpatient settings: final report and recommendations**

Published 28 June 2023

# Future options

# Future options

## Local

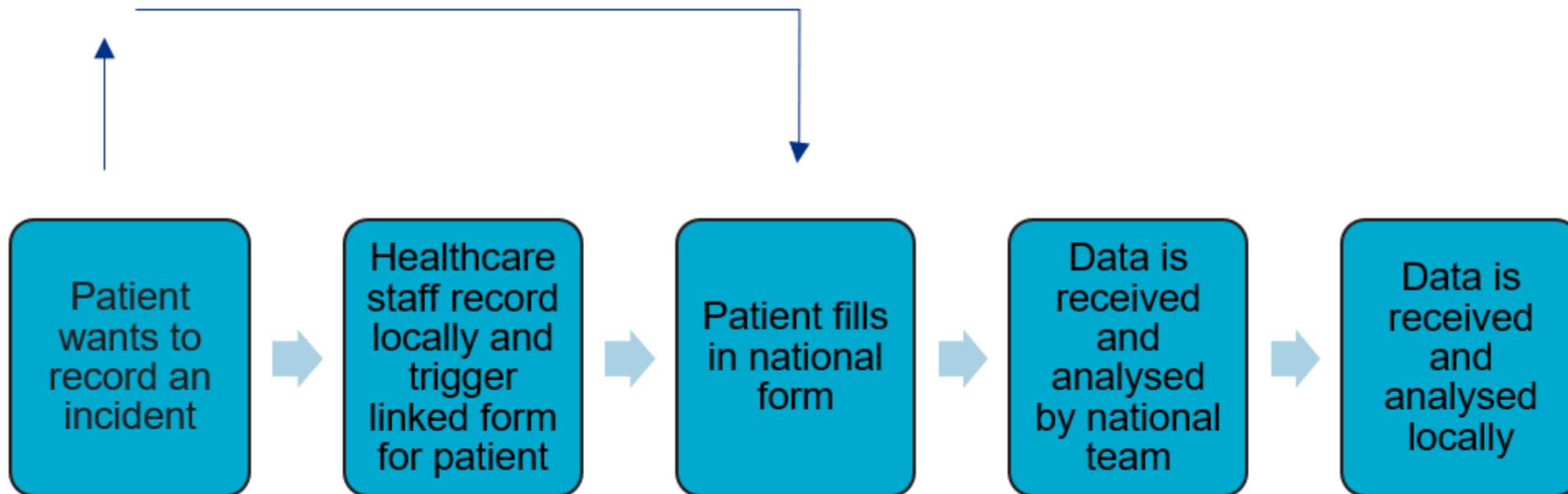
A local process where patients fill in a form for their provider.

## National

A national form (like the NRLS eForm) which patients complete and send to the national team.

## Hybrid

A form that is agreed nationally, which patients can fill in on their own or with their provider, and which is shared with the national team and then back to the provider.



# Next Steps and Summary





# Next steps

- We have published the [Patient and Family Discovery report](#), and will be making a recording of this Show and Tell session available.
- We are requesting approval and funding to move to [Alpha](#) and [Beta](#) phases for this work.
- If this is successful, we hope to start this within the next 12 months.
- In the meantime, the survey will remain open, so that by the time we start Alpha we have more data and can confirm our Discovery findings are still accurate.
- If you would like to be involved in the user research for Alpha, please send an email to [england.patientsafetyhelpdesk@nhs.net](mailto:england.patientsafetyhelpdesk@nhs.net) and we will keep your information on file and be in touch once we are ready to start this work.

# Summary

- Thank you to all participants who took part in the research, both in interviews and through completing the online survey.
- If you would like to provide any further feedback, please fill out our survey. This will feed into our ongoing research:



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## Thank You



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