



Extended Research Article

Co-designing and testing the learn together guidance to support patient and family involvement in patient safety investigations: a mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers. It also contains descriptions of bereavement and suicide.

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Plain language summary

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Plain language summary

Around 10,000 patient safety incidents resulting in severe harm or death happen every year within the English National Health Service. As well as the burden of harm for patients and families, the cost of legal claims is large. Involving patients and families in investigating incidents may help to clarify why something went wrong. It can also help make sure that investigations answer their questions. However, there was a lack of evidence to help people investigating incidents do this well. This research aimed to develop and test processes to guide the involvement of patients and families in incident investigations, to improve learning for organisations, and the experience of patients and families.

We spoke to patients and families, healthcare staff, and people who investigate incidents about their experience of investigations. We also looked at policies from National Health Service Trusts. We identified 10 'common principles' that could help people investigating incidents to involve patients and families meaningfully. Then, with over 50 people (patients/families, staff, investigators, managers) we developed new involvement guidance (<https://learn-together.org.uk/>). We tested this guidance over 15 months in 29 investigations. One further small study also looked at investigation effectiveness after a death by suicide, and who should be involved.

Everyone valued involvement and agreed it helped learning, but current guidance did not support it. Being part of an investigation was emotional and complicated, so information to help people understand and be involved was important. The testing of our guidance found that it supported investigators to involve patients and families, but the organisational systems they work in can make involvement difficult. Investigations after suicide are thought to be different to other incident investigations, and that support for bereaved families should be made available.

The Learn Together guides may support involvement of patients and families, but investigators need to be trained and supported properly to make it work.

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