

BRIEFING PAPER

Exeter Policy Research Programme Evidence Review Facility: September 2022

Seeking redress and reconciliation following a life-changing event: What do patients, families and carers think is a fair process?

Key stakeholders, including bereaved families and public figures, are calling for a process that investigates historically unresolved cases of suspected National Health Service (NHS) care failures,^{1,2} going back as far as 20 years or more. Creating a system to address unresolved historical patient safety cases in the NHS is a complex issue. These cases have often been subject to multiple reviews, but some families feel that justice has not yet been achieved and remain traumatised. To address this, it is important to first understand how the current investigation process is experienced and which features seem to lead to perceptions of “truth, justice and/or reconciliation” among those affected.

This review therefore focuses on two areas; aspects of the processes and outcomes of redress and reconciliation following a life-changing event that lead the individual and/or family or carers to feel that they were/were not treated fairly and appropriately and how these perceptions may vary over time following the initial event.

This is a systematic review which synthesizes evidence exploring the experience of individuals and/or family or carers regarding their experiences and/or views of redress and reconciliation processes following a life changing event.

The review was commissioned by the National Institute of Health Research Policy Research Programme.

The findings highlight:

- ◆ Three interdependent themes ‘Transparency’, ‘Person-centred’ and ‘Trustworthy’ represent what a redress-reconciliation process **looks like (procedural elements)** to support a fair and objective process.
- ◆ The final theme ‘Restorative justice’ encapsulates how a **fair process feels** to those who have experienced a life-changing event.
- ◆ A combination of what the redress-reconciliation process **looks like** and **feels like** influences whether the process & its outcomes are perceived as fair and appropriate.
- ◆ **Key elements** of what a fair process should look and feel like can be applied to historical medical cases where individuals and/or their families continue to pursue redress and/or reconciliation, to identify cases where further intervention may be indicated.

Historically unresolved cases gives rise to the following policy questions:

1) What are the issues for the NHS to consider on how to respond on a case-by-case basis to historical patient safety cases?

2) How can the way the NHS currently supports and responds to bereaved families, particularly those whose cases are historic (non-recent), be improved?

Why did we do this review?

To establish a system that addresses individual safety concerns and historical medical cases, it is essential to understand how the current processes are experienced and the features that lead to perceptions of “truth, justice and/or reconciliation” among those affected by a life-changing event.

We therefore sought to identify and synthesize primary qualitative studies regarding:

1. The aspects of the processes and outcomes of redress and reconciliation following a life changing event that lead individual and/or family to feel that they were/were not treated fairly and appropriately
2. How the perception vary over time following the initial event?

How did we do this review?

Finding the literature:

We searched six bibliographic databases to identify studies. We supplemented with forward citation searches, backwards citation chasing, targeted bibliographic database searches, searching Google Scholar and topically relevant websites.

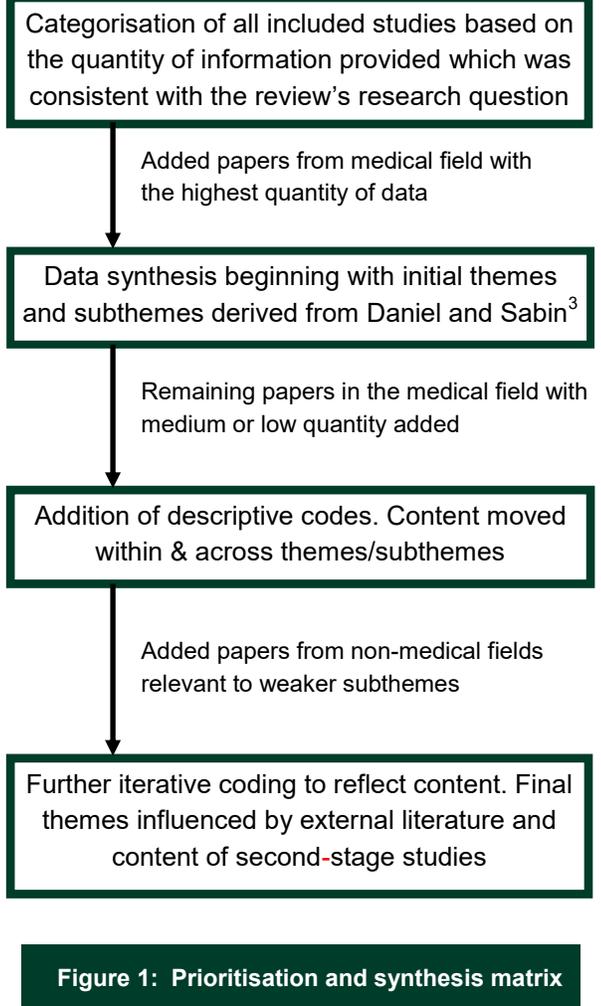
Eligibility criteria:

Primary qualitative studies on individuals and/or family or carers regarding their experiences and/or views of redress and reconciliation processes following a life changing event occurring within health/ social care systems, child protection or sudden death investigations, homicide reviews or any other service amenable to importing into the health care context.

Study selection, data extraction and quality appraisal:

Study selection was completed independently by two reviewers. Data extraction and quality appraisal were carried out by one reviewer and checked by a second, with consultation with a third reviewer to resolve disagreements.

To ensure the review remained deliverable within the timeframe available, we prioritised a sample of studies for best-fit framework synthesis (see Figure 1).



Overview of included studies

53 studies (61 papers) met our inclusion criteria. Of these, 41 studies (47 papers) were prioritised for full data extraction, quality appraisal and synthesis. The field of life-changing events represented in the studies are medical (n=31), homicide (n=3), child

sexual abuse (n=2), employment/work-related death (n=2), death in custody (n=1) and suicide (n=2). The majority of studies scored positively on at least 8 of the 14 items of the modified Wallace checklist used for quality appraisal.

What did we find?

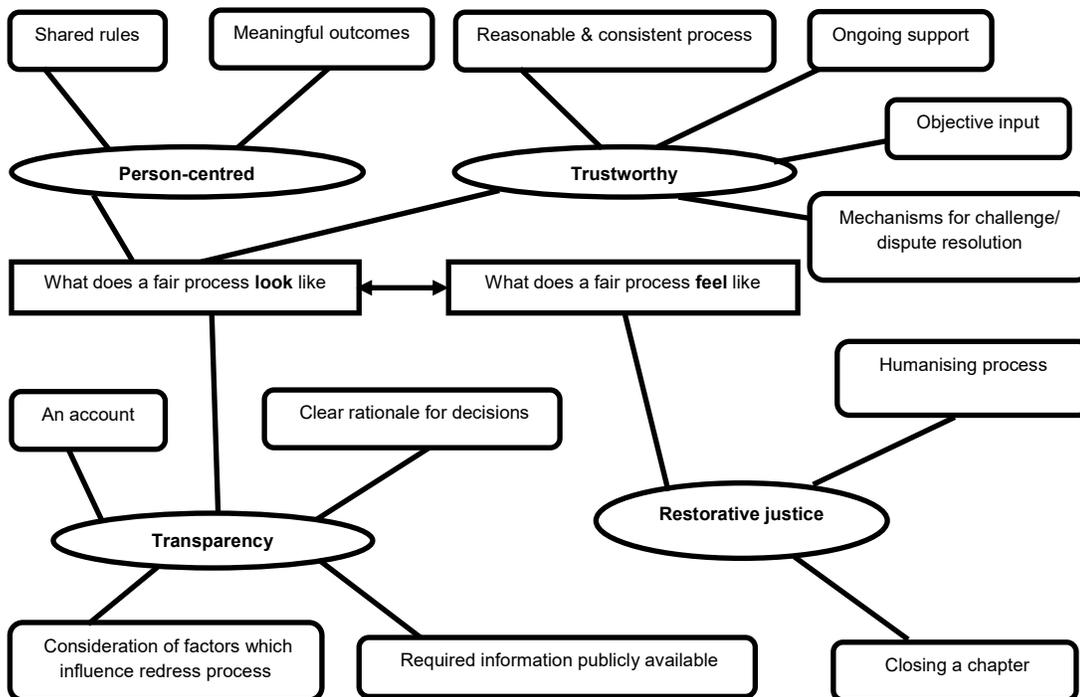


Figure 2: Relationship between themes and subthemes

Four themes were identified (see Figure 2).

Three interdependent themes 'Transparency', 'Person-centred' and 'Trustworthy' represent the procedural elements of redress-reconciliation which support a fair and objective process.

The theme, 'Restorative justice' encapsulates how a fair process feels to those who experienced the event. Themes, sub-themes & number of studies supporting them are highlighted below.

Theme—Transparency (n=38), subtheme:

- 1) A comprehensive account of the event, the circumstances leading up to it, what is being done to investigate & steps to prevent recurrence (n=31).
- 2) Information surrounding the event, how to access the redress-reconciliation process and rights within the process to be publicly available (n=32).
- 3) Consideration of systemic factors which may influence decision-making within the redress-reconciliation process (n=16).
- 4) Clear rationale for decisions made during the redress-reconciliation process (n=7).

Theme—Trustworthy (n=37), subtheme:

- 1) A reasonable and consistent process with a formal pathway, promoting timely, two-way dialogue between justice-seekers and professional stakeholders, including individuals responsible for the harm (n=30).
- 2) Ongoing support to maintain involvement (n=25).
- 3) Mechanisms to challenge or resolve disputes through opportunities to correct formal accounts of the life-changing events, or pursuing litigation (n=15).
- 4) Objective input and support from individuals or organisations who are independent of the formal redress-reconciliation process (n=12).

Theme—Person-centred (n=39), subtheme:

- 1) Process based on a shared understanding of the event and the needs and goals of justice-seekers, with a mutually-agreed end point (n=24).
- 2) Identify fair or meaningful outcomes, likely to be unique for each person. Such outcomes include but are not limited to: an apology (expressions of remorse & admission of responsibility), assurance that future health needs will be met and appropriate sanctions against those responsible (n=38).

Theme—Restorative justice (n=38), subtheme:

- 1) A humanising process encompassing principles of respect, empathy, and good communication and acknowledge the individuals who have experienced harm as equal participants in the redress process (n=30).
- 2) Supporting individuals with closing a chapter of their lives through developing a shared cathartic narrative of what has happened, validating their emotions, pursuing accountability and identifying learning points for organisations (n=34).

What are the implications of this review?

This systematic review synthesizes primary qualitative evidence on individuals and/or family or carers regarding their experiences and/or views of redress and reconciliation processes following a life changing event. Thirteen elements of a fair redress and reconciliation process which could be applied to historical patient safety cases were identified:

1. *Opportunity to develop a comprehensive account of the life-changing event and redress-reconciliation process.*
2. *Key information made available.*
3. *Joint reflection on systemic factors which may influence redress process.*
4. *Assessment of needs and provision of ongoing support.*
5. *An apology.*
6. *Identification and implementation of points of learning.*
7. *Achievement of other meaningful outcomes.*
8. *Access to a reasonable and consistent process.*
9. *Mechanisms in place to support the challenge of institutional accounts and/or decisions made.*
10. *Opportunity for objective oversight or input.*
11. *Opportunity to meet those perceived to be responsible for harm.*
12. *Validation of experiences.*
13. *Meaningful action for those who have experienced harm.*

These elements can support NHS systems or professionals involved with reviewing cases to establish if individuals seeking redress-reconciliation following a recent/historical medical life-changing event have experienced a fair process, or not and where further intervention might be needed.

Contact Us

Exeter PRP Evidence
Review Facility
South Cloisters
St Luke's Campus
University of Exeter
EX1 2LU

E.H.Shaw@exeter.ac.uk

Twitter: @Exeter_ERF

Blog:
planeterfexeter.wordpre
ss.com/



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We are one of two research groups in the UK commissioned by the National Institute of Health Research Policy Research Programme to conduct syntheses of evidence to inform policy development and evaluation across the full policy remit of the Department of Health and Social Care. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or the Department of Work and Pensions.

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